

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 24th August 2023

09:30 – 15:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser
Dr. Imran Khan (IK)	Specialist GP Adviser / Chair
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
Miranda Winram (MW)	Independent Lay Adviser (Observer – new AGD member)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Vicky Byrne-Watts	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: items 4.1 to 10)
Michael Chapman (MC)	Data and Analytics Representative (in attendance: items 1 to 3.3)
Garry Coleman (GC)	NHS England SIRO Representative (Presenter: item 10.1)
Dave Cronin (DC)	Data and Analytics Representative (Delegate for Michael Chapman) (in attendance: items 3.4 to 10)
Phil Koczan (PK)	NHS England Caldicott Guardian Team Representative (Delegate for Jonathan Osborn)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Heather Pinches (HP)	Head of Clinical Trials, Digi-Trials (Presenter: Item 4.1)
Andy Rees (AR)	Clinical Trials Operations Manager, Digi-Trials (Observer: Item 4.1)
Kimberley Watson	Data Access Request Service Senior Approval Team (DARS SAT) (item 10)

Harriet Wheeler (HW)	Project Manager, Digi-trials (Observer: Item 4.1)
Vicki Williams (VW)	AGD Secretariat Team
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Claire Delaney-Pope (CDP)	Independent Specialist Adviser (Observer – new independent adviser)
Prof Nicola Fear (NF)	Independent Specialist Academic Adviser
Dr. Robert French (RF)	Independent Specialist Academic / Statistician Adviser
Kirsty Irvine (Chair) (KI)	Independent Chair
Dr. Maurice Smith (MS)	Independent Specialist GP Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Jon Moore (JM)	NHS England Data Protection Office Representative
Dr Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative

1	<p>Welcome and Introductions</p> <p>The NHS England Senior Information Risk Owner (SIRO) Representative, noting the Advisory Group for Data (AGD) Terms of Reference (ToR) had not yet been agreed, proposed that:</p> <ul style="list-style-type: none"> • Dr Imran Khan (as an independent adviser) will be asked to Chair the AGD meeting; • 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. <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>
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	Dr Imran Khan 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 17 th August 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: There were no declarations of interest.
BRIEFING PAPER(S):	
4.1	<p>Title: Pilot NHS Digi-Trials Recruitment Support Services Directions 2021</p> <p>Presenter: Heather Pinches</p> <p>SAT Observer: Vicky Byrne-Watts</p> <p>Observers: Andy Rees, Harriet Wheeler</p> <p>The NHS DigiTrials Recruitment Service is currently in a pilot phase capped to four trials and time limited to 30th Sept 2023 by the Pilot NHS DigiTrials Recruitment Support Services Directions 2021.</p> <p>This Amendment to the Directions enables a further pilot and optimisation phase to onboard an additional eight studies (for a maximum of twelve) and time limited to 31st March 2025. This will use routinely collected NHS data to:</p> <ul style="list-style-type: none"> • widen the diversity of those given the opportunity to participate in clinical trials • enable faster, more efficient and effective trial set-up • increase overall recruitment to clinical trials <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. An amendment to the Pilot DigiTrials Recruitment Support Services Directions 2021 to increase the cap from four pilots to twelve pilots, 2. An amendment to extend the end date to 31st March 2025. <p>Outcome of discussion: The group welcomed the briefing paper and made the following observations / comments:</p> <p>4.1.1 In response to point 1 above, the independent advisers were supportive of the amendment to increase the cap from four pilots to twelve pilots, subject to current / future trial applications being presented to the group for advice, and the substantive points below being addressed.</p> <p>4.1.2 In response to point 2 above, the independent advisers were supportive of the amendment to extend the end date of the current direction to 31st March 2025 in order to continue the testing and development of the service.</p>

The group wished to draw to the attention of the SIRO the following substantive comments, which should be addressed as part of the next stage of service development:

4.1.3 Prior to the meeting, an independent adviser queried if an evaluation of the four pilot trials was available in order to judge whether an increase of another eight trials was justified. NHS England had provided an additional document providing some evaluation detail, however, the independent advisers were still unclear how success was being judged, for example by way of simple table which outlined the original pilot objectives with a description as to whether the objective(s) had been met, or not.

4.1.4 The independent advisers and the NHS England Data & Analytics Representative noted the use of the word 'pilot', and agreed the terminology may not fit with the next stage, which was to establish what trial types are suitable for the service.

4.1.5 The independent advisers noted concerns previously raised by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD), that thought should be given to a service specific opt-out, to allow citizens to opt out of receiving trial invitations, since currently to avoid receiving invitations a citizen would have to opt out of each individual study invitation or apply a National Data Opt-out (NDO). It was suggested that Digi-Trials discuss this with the service's patient and public involvement and engagement group (PPIE).

4.1.6 Concern was raised about the use of the NHS logo by the trials and the independent advisers suggested thought should be given to the reputation of the NHS and whether more citizens will apply an NDO.

4.1.7 The independent members suggested that NHS England explore whether the Mail Preference Service (MPS) needed to be applied, since contacting those that had registered with the MPS may lead to complaints and / or increased application of the NDO.

4.1.8 Noting that over 17.4 million invite letters had been sent out to the adult population of England since July 2021, the independent advisers noted that 37 complaints had been received during the period January 2022 to present, however that did not cover the period July 2021 to December 2021. NHS England noted verbally in meeting that 2 complaints / enquiries had been received prior to January 2022.

4.1.9 Noting that the Data Protection Impact Assessment (DPIA) provided as a supporting document had outlined a risk that "*data subjects believe there is unexpected or unfair processing of their personal / specific category data*" and that the mitigation outlined in the DPIA included scrutiny by AGD of communication materials, the independent advisers suggested that all communications with citizens be written in a language suitable for the lay reader and noted that if NHS England were requiring advice on communication materials, they should seek the view of the group whilst there was still an opportunity to make changes.

4.1.10 Noting that the cover note set out that NHS DigiTrials recommends that trials produce their materials for participants in line with HRA guidance, the group suggested that NHS England considered insisting that this high standard was met by any trial being given access to the NHS DigiTrials service.

	The group looked forward to receiving an update on the points raised by way of an updated briefing.	
4.2	<p>Title: Faster Data Flows for Integrated Care Boards (ICBs)</p> <p>Presenter: None</p> <p>SAT Observer: Vicky Byrne-Watts</p> <p>Previous Reviews: The Faster Data Flow Acute Patient Activity Briefing Paper was previously presented at the AGD meeting on the 17th August 2023 and 8th June 2023; and the IGARD meeting on the 18th August 2022.</p> <p>The application (NIC-616043-S9R4P) and relevant supporting documents were previously presented / discussed at the IGARD meeting on the 18th August 2022.</p> <p>The purpose of the original briefing paper was to request that the faster data flows product (Acute Activity Dataset) is permitted to be disseminated to the ICBs via the NHS England DARS process.</p> <p>The updated briefing paper provided details to address the points raised by AGD on the 8th June 2023.</p> <p>Outcome of discussion: The group welcomed the finalised briefing paper and confirmed that they had no further observations / comments.</p>	
EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	<p>Reference Number: NIC-343380-H5Q9K-v16.12</p> <p>Applicant: UK Health Security Agency (UKHSA)</p> <p>Application Title: D1.1 – UK Health Security Agenda (UKHSA) single data sharing agreement</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 3rd November 2022, 16th December 2021 and 3rd June 2021.</p> <p>A briefing paper in relation to this application was discussed at the IGARD meeting on the 23rd June 2022.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD-NHS Digital COVID-19 response meeting on the 27th July 2021</p> <p>Linked applications: NIC-359940-W1R7B and NIC-143888-H0W2N1</p> <p>Application: This was an amendment application.</p> <p>The purpose of the application and amendment is for a time-limited, parallel storage and receipt of data sets disseminated by NHS England under this data sharing</p>	

agreement (DSA), in separate UKHSA data management systems. The transition period for UKHSA's data management programme will require both the current data holdings and updated data extracts currently flowing from NHS England into the UKHSA Environment for Data Gathering and Engineering (EDGE) and the Data Lake Platforms to be run in parallel to the following two new services: the Enterprise Data and Analytics Platform (EDAP) and the Data Operations Service (DOS). EDAP is the long-term solution for consolidating the management of key data sets across UKHSA, including those disseminated by NHS England, DOS is being used in the short term to manage one data set that EDAP is not yet able to ingest. The time period is to end of March 2024.

NHS England were seeking advice on the following points:

1. The parallel running paper,
2. The changes to the data sharing agreement (DSA).

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 substantive comments:

5.1.1 The group noted that they had only been provided with limited documentation: '*UKHSA-NHSD-SingleDSA(NIC-343380)V16.12_proposed changes*' (tracked change data sharing agreement (DSA)), '*DARS-NIC-343380-H5Q9K-v16.12*' (current DSA), '*UKHSASingleDSA(NIC-343380)-ParallelProcessingProposal*' letter from UKHSA to NHS England; and '*NIC-343380 AGD Review request*' a note from DARS outlining the request; and noted that they would be providing observations based on these four documents only.

In response to points 1 and 2 above:

5.1.2 The SIRO Representative noted NHS England had been working with the UKHSA with regard to their improvement plan in relation to their DSPT. The group noted the verbal update from NHS England.

5.1.3 The group highlighted a significant risk to NHS England of flowing data under this amendment data sharing agreement (DSA), when the applicant appeared to be in breach of their current DSA, for example not publishing a 'Register of Dissemination' within three months of signing the DSA, which had previously been discussed at the Independent Group Advising (NHS Digital) On the Release of Data (IGARD) on the 23rd June 2022 and 3rd November 2023. The group noted their disappointment, particularly given the large volumes of patient data held and linkage being undertaken by UKHSA.

5.1.4 Concern was raised by the NHS England Data Protection Office (DPO) Representative and independent advisers with regard to the volume of data being processed and the processing arrangements of parallel running, and queried if this was proportionate and necessary; what alternatives had been considered and

	<p>discounted; and why it was deemed reasonable. In order for the group to be assured of the parallel running proposal, the group suggested that further detail be provided outlining the determinations made about how the parallel processing would be carried out, what processing was being undertaken in both environments, and how both processes were being undertaken from the outset.</p> <p>5.1.5 In addition, it was suggested that the NHS England DPO Representative contact the UKHSA's DPO to understand what was meant by parallel processing, discuss the considerations made, and review the documents and controls in place; after which the independent advisers suggested that this further detail could then be updated within the application.</p> <p>ACTION: NHS England DPO to discuss with UKHSA's DPO.</p> <p>5.1.6 The independent advisers suggested that this application could be considered a 'programme level agreement' for programmatic access, and advised, that as currently presented, it did not align with other similar applications. This includes, but is not limited to, the applicant having an internal advisory committee such as the one previously in place as part of Public Health England (PHE), Terms of Reference (ToR) for any governance committee, and a publicly accessible data release register. The group were clear that the applicant should have at least the same level of scrutiny with regard to programmatic access as its predecessor organisation (Public Health England).</p> <p>5.1.7 Separate to this application, the independent advisers reiterated the advice from the AGD meeting on the 10th August 2023, that NHS England considered having an NHS England DARS Standard for programmatic access; and how any programmatic access is aligned with the Department of Health and Social Care draft data access policy update that states <i>"Secure data environments (SDEs) will become the default route for accessing NHS data for research and external uses. Instances of disseminating NHS data outside of an SDE for research and external uses will be extremely limited"</i>.</p> <p>ACTION: NHS England to consider having an NHS England DARS Standard for programmatic access.</p> <p>5.1.8 Noting the large volume of data being processed, the independent advisers queried the number of analysts accessing the data (circa 2,000), and raised a number of queries, including but not limited to: were they all substantive employees; what oversight arrangements were in place; how they were accessing the data and if that was proportionate.</p> <p>5.1.9 The group were unclear why the Department of Health & Social Care (DHSC) Office for Health Improvement and Disparities (OHID) would continue to use the Data Lake Platform, when the applicant had determined the environment was not sufficiently secure for UKHSA, and suggested that more detail be provided within the</p>	
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	<p>application; in addition more detail should be provided with regard to what was happening with the Data Lake Platform in the future.</p> <p>5.1.10 Noting the data would be used as part of UKHSA's statutory functions, further clarity should be provided in section 5 (Purpose / Methods / Outputs) of how the distinction is made between the applicant using the data for its statutory functions and using the data for research.</p> <p>5.1.11 Concerns were raised with regard to the level of transparency available to the public, which appeared to be not to the same level standard as PHE, and suggested that further transparency materials be provided around the high levels of data being processed, types of processing being undertaken and the parallel running envisaged, in addition to the publication of the 'Register of Dissemination'.</p> <p>5.1.12 Prior to the meeting, an independent adviser had queried if the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) Professional Advisory Group (PAG) Chair had been consulted as to whether PAG advice was required with regard to the COVID-19 Therapeutics Eligible Population dataset, which is derived from the GDPPR data (and other datasets). NHS England confirmed that derived data would not form part of the finalised DSA. They advised that additional data may be disseminated via other NHS England teams. The group noted the verbal update but suggested that the PAG Chair be notified so that they could assure themselves that none of the datasets to be disseminated include GDPPR data.</p> <p>5.1.13 Noting this was national data for a national remit, the independent advisers queried if this aligned with the NHS England DARS Standard for Ethics, and that consideration should be given as to whether ethics should be part of any internal advisory committee's remit to check if ethics is required, and support is in place as appropriate for all uses of data.</p> <p>5.1.14 The independent advisers noted the possible change to processing for the NHS 111 data and suggested that section 5(a) (Purpose for Processing) be updated to clarify when identifiable data is used versus pseudonymised data, and that transparency materials for those using NHS 111 services on the phone and online NHS 111 data are reviewed and updated where necessary so that people have access to clear and accurate information about any secondary uses.</p> <p>5.1.15 In addition, the independent advisers suggested that the special condition in section 6 (Special Conditions) with regard to NHS 111 data, be updated to remove the COVID-19 use only restriction.</p>	
5.2	<p>Reference Number: NIC-727325-W4M7T-v0.3</p> <p>Applicant: NHS England and King's College London (KCL)</p> <p>Application Title: PRECISION: PREvent ductal Carcinoma In Situ Invasive Overtreatment Now</p>	

SAT Observer: Vicky Byrne-Watts

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 applications: NIC number not known

Application: This is a new application.

The purpose of the application is for the PRECISION: PREvent ductal Carcinoma In Situ Invasive Overtreatment Now study. PRECISION is an international collaboration building on multiple studies conducted in the UK, Europe and the US over the last two decades. It aims to reduce the burden of Ductal Carcinoma in situ (DCIS) overtreatment through the development of tests to support decision-making by clinicians, without compromising the excellent outcomes for DCIS presently achieved.

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:

5.2.1 The independent advisers noted within section 5 (Purpose / Methods / Outputs) and study protocol provided as a supporting document reference to “consortium” / “*Translational Research IT consortium*” and suggested that NHS England seek assurance from the applicant that the “consortium” do not have any data controllership responsibilities, in line with the [NHS England DARS Standard for Data Controllers](#).

5.2.2 In addition, the independent advisers noted within section 5, study protocol, ethics application and Health Research Authority (HRA) amendment document, reference to the “*Netherlands*” / “*Netherlands Cancer Institute*” and suggested that NHS England seek assurance from the applicant that the entity in the Netherlands do not have any data controllership responsibilities, in line with the [NHS England DARS Standard for Data Controllers](#).

5.2.3 Noting that the Netherlands organisation is also accessing data, it was suggested that section 5 be updated to clarify what NHS England data the Netherlands organisation is accessing.

5.2.4 Noting the King’s Health Partners is a partnership between King’s College London, King’s College Hospital, Guy’s & St Thomas’ Hospitals and South London & Maudsley Hospital, the independent advisers queried if any of the trusts were involved, and, if not, suggested a definitive statement be included in the internal application assessment form that the question had been asked of the applicant and that confirmation had been received.

5.2.5 Noting data from the screen-detected non-invasive breast cancer cases from the NHS England Screening Sloane Project would be requested from NHS England, alongside the screen-detected invasive breast cancer cases from the NDRS datasets, the independent advisers queried the HRA Confidential Advisory Group (CAG) s251 support in place for the Sloane Project and suggested that the applicant seek clarification from HRA CAG that the processing of data under this DSA was compatible with the s251 support.

5.2.6 Separate to the application: the independent advisers noted that it appeared that the Sloane project data had been gathered under s251 non-research approval. So, if the data was being linked, suggested that further detail be sought; noting that the [published guidance](#) appeared to show strict governance processes were in place.

5.2.7 In addition, further detail should be provided in section 5 around the relationship with the Sloane Project and if data used is to be linked to the screening data from the Sloane project or is being compared to the screening data from the Sloane project.

5.2.8 The independent advisers noted that it remained unclear why the applicant was requesting additional NHS England data, noting the data they already held, and suggested that further clarification be provided in section 5, and in line with the [NHS England DARS Standard for Data Minimisation](#).

5.2.9 The Independent advisers noted reference to the “*Royal College of Surgeons*” and suggested that NHS England assure itself that this was an error, or, if not, seek clarification from the applicant that the Royal College of Surgeons do not have any data controllership responsibilities, in line with the [NHS England DARS Standard for Data Controllers](#).

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

5.2.10 The group noted the valuable research being undertaken and its potential to benefit future patients.

5.2.11 The independent advisers queried the statement in section 5(b) (Processing Activities) “*employees or agents of KCL are permitted to access the pseudonymised data only*”; and suggested that further information was provided as to what was meant by “*agents*”, and that this aligned with the Data Sharing Framework Contract (DSFC).

5.2.12 The independent advisers noted technical language in section 5(a) (Objective for Processing) for example “*prophylactic*” and “*contralateral*” and suggested that this was updated to provide an explanation of the terms and written in a language suitable for a lay reader.

5.2.13 The independent advisers noted the potential benefits detailed in section 5(d) (Benefits) but suggested that this section could be written more simply, in a

	language suitable for a lay reader, noting section 5 forms NHS England's Data Uses Register .	
5.3	<p>Reference Number: NIC-705902-L2J0F-v0.4</p> <p>Applicant: King's College London (KCL)</p> <p>Application Title: Trends in the Prevalence and Complexity of Children with a Life-Limiting or Life-threatening Condition in England</p> <p>SAT Observer: Vicky Byrne-Watts</p> <p>Application: This is a new application.</p> <p>The purpose of the application is to assess trends in the prevalence and complexity of children with a life-limiting or life-threatening condition in England. The project aims 1) To assess the trends in the numbers of and prevalence of children and young adults with a life-limiting condition in England from 2003-2022, 2) To assess the complexity of children and young adults with a life-limiting condition and the trends over time in this complexity, 3) To describe the number and prevalence of children and young adults with a life-limiting condition at Integrated care board (ICB) level, 4) To model future national prevalence of children and young adults with an LLC utilising the ethnic specific population projections (2023/2035), and 5) To describe the population of children seen by consultants in Paediatric Palliative Medicine</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 comments:</p> <p>5.3.1 The independent advisers queried whether the purpose of the processing was for safety and effectiveness of medicines as per the Direction, since it was only mentioned in section 5 (Purpose / Method / Outputs); and suggested that NHS England clarify with the applicant whether the processing was in line with the current Direction.</p> <p>5.3.2 In addition, and noting that the NHS BSA data is only mentioned in the DSA, suggested that section 5(d) (Benefits) be updated to align the benefits with the Direction; and suggested that the study protocol be updated to outline how the study aligned with the Direction.</p> <p>5.3.3 Separate to the application, the SIRO Representative noted that following the NHS BSA presentation at AGD on the 20th July 2023, the Direction was being reviewed and would be presented back to the group in due course. The group thanked the SIRO Representative for the verbal update.</p>	

	<p>5.3.4 Noting that when the data is used in accordance with the controls set out in the DSA, individuals cannot be identified, the independent advisers suggested that further clarification be included in section 5 that individuals will not be re-identified.</p> <p>5.3.5 The independent advisers queried a statement in the internal application assessment form and section 5(b) (Processing Activities) that “...<i>the data will remain on the servers at KCL at all times...</i>”, and queried this statement, since the servers are not based at KCL. The independent advisers suggested that the statements be clarified and updated within the internal application assessment form and application, as appropriate.</p> <p>5.3.6 Noting the application is about life limiting / life threatening conditions in children, the SIRO Representative noted that data was being requested from 2003 to latest, and that the age range was 0 to 25, suggesting that data may be being disseminated for someone aged 45 if they joined the study at 25, back in 2003. The independent GP advisers noted that there was a justification provided, and that knowing someone was still alive now, who had previously been judged as having a life limiting illness, was valuable information, since it may show that with the advancement in medicines that people are living longer, for example the use of immunotherapies for cystic fibrosis.</p>	
5.4	<p>Reference Number: NIC-431736-X6C4F-v0.6</p> <p>Applicant: Kingston University</p> <p>Application Title: SkillMix-ED Study (Phase Two)</p> <p>SAT Observer: Vicky Byrne-Watts</p> <p>Application: This is a new application.</p> <p>The purpose of the application is to explore how non-medical practitioners, as part of the clinical workforce, are being deployed and the impact of different skill-mix including non-medical practitioners in emergency departments and urgent treatment centres on patient experience, quality of care, clinical outcomes, activity, staff experience and costs in acute NHS trusts in England, in order to inform workforce decisions of clinicians, managers and commissioners.</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 deferred the application as not all the necessary information was available to make a full assessment. The group wished to draw to the attention of the SIRO the following substantive points; and suggested that the application be brought back to a future meeting:</p> <p>5.4.1 The independent advisers noted within the internal application assessment form reference to two storage platforms (Computer Systems Integration Ltd (CSL) / Amazon Web Services (AWS)) and two cloud providers (AWS and Microsoft (MS) Azure) and asked that clarification be sought as to what processing was being</p>	

undertaken on which platform / cloud service provider to ensure that data minimisation / data handling had been considered, and in line with the [NHS England Data Minimisation Standard](#). The independent advisers suggested that once clarification had been sought that further detail be added to section 5(b) (Processing Activities) and updated in the internal application assessment form.

5.4.2 Noting that the research question to answer is “*what is the impact of different non-medical practitioner skill-mix in EDs* and UTCs** in NHS acute hospitals on patient and service processes and outcomes?*”, the group were unclear how the outcome of the project could be achieved using the data requested because of the many and varied variables, by, for example, creating the organisational level descriptors and linking to data, and suggested further clarity was provided in section 5(a) (Objective for Processing).

**Emergency Departments*

***Urgent Treatment Centres*

5.4.3 The group were also concerned that Mortality Data was not described within the project or requested by the applicant under this data sharing agreement (DSA), and noted this appeared to be an important metric with regard to the outcome of admissions.

5.4.4 Noting that sensitive ‘ethnic category’ data was being requested via the Emergency Care Data Set (ECDS), patient ethnicity was noted in the study protocol, and patient ethnicity was mentioned in the Integrated Research Application System (IRAS) form; the independent advisers queried why this particular sensitive category of data was being requested for patients, since the application was silent on patient ethnicity. Careful consideration should be undertaken by the applicant as to why ethnicity data was required, and they suggested a robust justification be provided in section 5 (Purpose / Methods / Outputs) of the application, which forms [NHS England’s Data Uses Register](#).

5.4.5 Noting that this was a National Institute for Health & Care Research (NIHR) funded project and the group would not usually comment on the benefits section of a DSA, the independent advisers suggested that the applicant may wish to consider the issue of ‘causality’ and suggested seeking further advice from their steering group / advisory panel on this point, and updating section 5(d) (Benefits) of the application, as appropriate.

5.4.6 The independent advisers queried the statement in section 5(b) “...Access is restricted to employees or agents of Kingston University who have authorisation from the study co Chief investigators...”; and suggested that further information was provided as to what was meant by “agents”, and that this aligned with the Data Sharing Framework Contract (DSFC).

5.4.7 The group noted that they had been unable to find a published privacy notice and advised that the applicant was required to have a UK General Data Protection

	<p>Regulation (UK GDPR) published privacy notice(s) prior to any data flowing from NHS England, in line with the contractual requirement in section 4 (Privacy Notice) of the DSA.</p> <p>5.4.8 The independent advisers noted in section 5(a) that a public involvement and engagement (PPIE) group had helped refine the purpose of the research and would receive selected excerpts of data analysis, and suggested that PPIE continues throughout the lifecycle of the project, noting that patient perspective may be different to the professional perspective in particular given the subject matter. The HRA guidance on Public Involvement is a useful guide.</p> <p>5.4.9 The independent advisers noted within the internal application assessment form that processing of the data under this DSA could be done remotely and “...<i>within the scope of the organisation’s DSPT*....</i>”, and that the special conditions highlighted in the ‘security assurance’ section highlighted the requirements of the DSPT, however the applicant does not have a DSPT, they have a System Level Security Policy (SLSP) which is currently under review by NHS England. The independent advisers suggested the relevant wording be updated as appropriate within the internal application assessment form and section 6 (Special Conditions).</p> <p><i>*Data Security and Protection Toolkit</i></p> <p>5.4.10 Separate to the application: NHS England to ensure that information within the internal application assessment form / application accurately reflects the facts, especially relevant when using templated wording.</p> <p>5.4.11 The internal application assessment form noted that the applicant was updating their internal security policy documents and since it was not clear if the System Level Security Policy (SLSP) had been approved by the NHS England Security Team, the independent advisers suggested that this be progressed as a matter of urgency.</p> <p>5.4.12 Separate to the application the group reiterated previous advice that NHS England needs a clear policy on remote access.</p> <p>ACTION: NHS England to provide its position to AGD on remote access (<i>as previously requested and agreed at the AGD meeting on the 2nd February 2023</i>).</p>	
AGD Operations		
6	<p>Statutory Guidance</p> <p>The independent advisers again noted the reference to reviewing materials in accordance with “<i>a clearly understood risk management framework</i>” within the published Statutory Guidance and advised that they were not aware of an agreed risk management framework, and requested that NHS England provide further information/ clarity on this, noting this topic had been raised by Lord Hunt in the House of Lords on the 26th June 2023, and was answered by Lord Markham on the 5th July 2023: Written questions, answers and statements - UK Parliament.</p>	

	<p>The NHS England SIRO Representative had provided further clarity on the risk management framework via email to the group, which confirmed that NHS England were asking the interim data advisory group to use the NHS England DARS Standards and Precedent model to assess the risk factors in relation to items presented to the interim data advisory group for advice; however the independent advisers noted that the wording in the in the statutory guidance “...using a clearly understood risk management framework, precedent approaches and standards that requests must meet...”, suggested that the risk management framework is separate to the DARS Standards and Precedents, and asked that this be clarified by NHS England.</p> <p>ACTION: NHS England SIRO Representative to provide a written response addressed to AGD with further clarity on the risk management framework.</p>	GC
7	<p>AGD Terms of Reference (ToR)</p> <p>Garry Coleman noted that NHS England were still considering comments from stakeholders on the AGD ToR.</p> <p>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 AGD ToR was scheduled to be considered by the NHS England Board / subcommittee of the Board.</p>	GC
8	<p>Standard operating procedures</p> <p>The ongoing forward plan of work for creating Standard Operating Procedures was discussed.</p>	To note
9	<p>‘No presenter pilot’ for external data applications 13th July to 24th July 2023</p> <p>It was agreed in-meeting following feedback received via email and in-meeting over the pilot period, that the pilot for external data applications having no ‘presenters’ to introduce the external data applications, thereby allowing the application to stand on its own with no in-meeting verbal updates / amendments, had been successful and that this would become business as usual (BAU) from the 7th September 2023 BAU meeting, with a review when the AGD Terms of Reference are finalised and published.</p> <p>The group agreed that should a colleague from NHS England’s Data & Analytics Team wish to attend to observe the external data applications to support any feedback discussions with applicants, they were welcome to attend.</p> <p>Briefing papers, internal data flows, AOB items etc, would continue to have a presenter when required and there was no change to this process.</p>	
10. Any Other Business		

<p>10.1</p>	<p>Special conditions and Standard Wording for Data Sharing Agreements (DSA)</p> <p>The SIRO Representative and Data & Analytics Representative provided the group with a draft of the usual standard special conditions inserted into section 6 of the data sharing agreement (DSA), to check that the wording was as agreed.</p> <p>The independent advisers provided a number of comments in-meeting and it was agreed that any further comments could be provided to the Data & Analytics Representative by the close of play on Friday 25th August so that the Data Access Request Service (DARS) could ensure that the team were updated with the correct version of all special conditions and all applications from the 7th September onwards could be updated to ensure they included the agreed wording, as discussed at today's meeting.</p> <p>It was agreed that the special condition wording would be reviewed in-meeting and updated quarterly by DARS Senior Approvals Team (SAT).</p> <p>ACTION: DARS SAT / Secretariat to put in place a forward plan of quarterly discussion items.</p>
<p>10.2</p>	<p>Secure Data Environment update</p> <p>The independent advisers asked for an update on the operation of the NHS England Secure Data Environment (SDE) at a future meeting.</p> <p>ACTION: NHS England Data and Analytics Representative and AGD Secretariat to schedule an SDE update for a future meeting.</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>	