Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 28th September 2023

09:30 – 15:45

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	Specialist Ethics Adviser
Prof. Nicola Fear (NF)	Specialist Academic Adviser (items 1 – 4.1 and 5.1 – 5.5)
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Vicky Byrne-Watts (VBW)	Data Access Request Service Senior Approval Team (DARS SAT) (**Observer**: item 4.1)
Michael Chapman (MC)	Data and Analytics representative (item 4.1 only)
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for part of item 2.1 and 5.1)
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (**Observer**: item 5.2)
Louise Dunn (LD)	Data Access Request Service Senior Approval Team (DARS SAT) (**Observer**: item 5.4)
Prof. Ben Goldacre (BG)	NHS England (**Observer**: item 4.1)
Dan Goodwin (DG)	Data Access Request Service (DARS) (**Observer**: item 5.2 to 5.3)
James Gray (JG)	DigiTrials (**Observer:** item 5.1)
Dickie Langley (DL)	Head of Information Governance, Privacy, Transparency, Ethics, and Legal, Delivery Directorate (**Presenter**: item 2.1) NHS England SIRO Representative (Item 5.1 only)

Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Dr. Amir Mehrkar (AMe)	NHS England (**Observer**: item 4.1)
Karen Myers (KM)	AGD Secretariat Team
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Frances Perry (FP)	DigiTrials (**Observer:** item 5.1)
Narinder Sandhu (NS)	NHS England (**Observer**: item 4.1)
Ming Tang (MT)	Chief Data and Analytics Officer, Data & Analytics Directorate (**Observer**: item 4.1)
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
Tom Wright (TW)	Data and Analytics representative (**Observer**: item 4.1) (Delegate for Michael Chapman: items 1 and 4.2 - 8)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Claire Delaney-Pope (CDP)	Independent Specialist Information Governance Adviser **(Observer – new AGD member)**
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
Miranda Winram (MW)	Independent Lay Adviser **(Observer – new AGD member)**
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
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 21st September 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:** Dr. Imran Khan noted a potential conflict with the '*OpenSAFELY: all research analyses and participants who have consented for studies – Briefing Paper'*, as part of his roles as Deputy Chair of the Health Informatics Group at the RCGP, Co-deputy Chair of the Joint GP IT Committee and his role on the OpenSAFELY Oversight Board. It was agreed this did not preclude Dr. Khan from taking part in the discussion on this briefing paper, however it was agreed that he would not form part of the group's advice to the NHS England SIRO Representative.
BRIEFING PAPER(S):	
4.1	**Title:** OpenSAFELY: all research analyses and participants who have consented for studies – Briefing Paper **Presenter:** Dickie Langley

Observers: Ming Tang**,** Prof. Ben Goldacre, Dr. Amir Mehrkar, Narinder Sandhu, Vicky Byrne-Watts

Previous Reviews: OpenSAFELY has previously been discussed at the AGD BAU meetings on the 11th May 2023 and the 4th May 2023.

The NHS England OpenSAFELY Covid-19 Service (the Service) is operating under the COVID-19 Public Health Directions 2020 (COVID-19 Directions), having transitioned from a COPI Regulation 3(4) legal basis in June 2023. The Service is currently permissioned for Covid-19 research purposes (including service evaluation, clinical audit and health surveillance).

This purpose of the briefing paper is to seek the view of AGD regarding two new OpenSAFELY purposes:

1) The expansion of scope to include all research analyses (including service evaluation, clinical audit and health surveillance); and
2) The sharing of summary patient-level GP data of participants who have consented for their health data to be used in research: the summary patient-level dataset needed for the study will be created inside OpenSAFELY and only shared with another Trusted Research Environment accredited and approved by NHS England and the GP Profession (BMA/RCGP).

NHS England were seeking advice on the following points:

1. Is the group broadly supportive of these two purposes?
2. What further advice does the group have to help progress this plan? Including advice on public and stakeholder engagement to help with developing the new Direction would be particularly welcome.
3. In revising the OpenSAFELY project approval process, are there any key elements that should be considered? Known factors include: public transparency of approved projects, involvement of GP Profession for projects involving GP Data, HRA/sponsor support for projects.
4. What are the likely challenges/differences in approval considerations between the research projects and the consented cohort projects?

Outcome of discussion: The group welcomed the briefing paper and made the following observations / comments:

In response to points 1 to 4:

4.1.1 The group advised that they were broadly supportive of the two new OpenSAFELY purposes.

4.1.2 Noting the already crowded landscape, the group did however query how the new purposes differed from the work already being undertaken by other organisations / databases; and suggested that this was clarified and made transparent from the perspective of citizens whose data was being used. The group suggested that in respect of stakeholder engagement, the steps taken so far in respect of OpenSAFELY were consolidated and there was ongoing communication with the GP profession, including the GP Data Protection Officers (DPO).

	4.1.3 The DPO representative suggested that further stakeholder engagement could be undertaken via already established networks within NHS England, for example, the DPO webinars with GP DPOs. **4.1.4** The group noted the Direction has not yet been drafted, but suggested that it be carefully worded to ensure that it was clear on the dissemination powers, since some published Directions were often silent on this point. In addition, the group suggested that NHS England engage with the group in respect of the draft Direction at the appropriate time, and before the Direction is finalised. **4.1.5** The group queried why there appeared to be a different route / access for OpenSAFELY as opposed to the usual governance route via DARS; and suggested that NHS England should consider similar checks and balances to those given for programmatic access of data. **4.1.6** The group were minded to take a risk-based approach to governance, focusing attention on the uses of data and identifiability of data handled, rather than the system itself. **4.1.7** The group suggested that NHS England considered applying to the Health Research Authority Research Ethics Committee (HRA REC) for research database support for OpenSAFELY. **4.1.8** Noting that the AGD Terms of Reference (ToR) have not yet been finalised, the independent advisers suggested that there may be an opportunity in respect of providing ethical support, for example, by updating the AGD ToR, to reflect that where a project does **not** qualify for a HRA REC review, AGD may be able to offer a view. **4.1.9** In addition, the independent advisers noted a potential risk to NHS England, that AGD has been cited as a safeguard for the OpenSAFELY remit of work, when there are no finalised AGD ToR as yet, noting that nearly four months had passed since the Statutory Guidance had been published. **4.1.10** The group suggested that in respect of governance, the additional considerations should go beyond ethics; and the public benefits assessment should also be considered in line with the National Data Guardian (NDG) guidance on benefits. **4.1.11** In addition, public trust and confidence in the NHS should also be considered, noting that this would not usually be considered as part of an ethics review; and that this should be undertaken as appropriate and in accordance with the type of data being processed, for example, pseudonymised versus identifiable data. **4.1.12** The group noted the reference in the briefing paper to Health Data Research UK (HDR UK) working on their governance approach; and suggested that NHS England should have confidence in its own approvals process that were best suited to NHS England's unique role as the Data Safe Haven, while at the same time aligning with wider governance processes and others in this space. **4.1.13** The group queried whether Type 1 objections should be applied, and, noting that the National Data Guardian had been consulted on this, suggested that the rationale for applying them was made transparent to the public.

	4.1.14 In respect of the second 'new' purpose outlined, it was suggested by the group, that it may be helpful if this purpose was branded separately to OpenSAFELY (for example with a distinct and different name), to ensure transparency to the public and the medical profession about the different approaches and services being offered. **4.1.15** The group advised that they would welcome further engagement / discussions on OpenSAFELY at a future meeting.
4.2	**Title:** Updates to the National Diabetes Audit Core dataset: prisons and monogenic data Briefing Paper **Presenter:** None **Previous Reviews:** The briefing paper was previously discussed at the IGARD BAU meeting on the 20th July 2023. The purpose of the briefing paper was to provide details of a proposal to use data already collected by NHS England via the GP Extraction Service (GPES) relating to individuals in adult and young offender prisons in England with a diagnosis of diabetes for the National Diabetes Audit Core Audit (NDA Core Audit). Prison data is identified in the GPES extract by the organisation site code so that Healthcare Professionals can review service levels so that diabetes care and outcomes in this setting can be assessed. The proposal is also to collect monogenic diabetes data from the Royal Devon University Healthcare NHS Foundation Trust and analyse/link this data to the NDA Core Audit to allow care processes and treatment outcomes from the audit to be used to assess the care of people with monogenic diabetes. **Outcome:** The group welcomed the updated briefing paper and made the following observations / comments: **4.2.1** The group noted and commended NHS England on the majority of the updates / responses following the review of the briefing paper by the group on the 20th July 2023. **4.2.2** The group noted that point 4.1.2 in the minutes of the 20th July 2023 had **not** been addressed, and reiterated the point that: the briefing paper stated that those individuals who had submitted a National Data Opt-out (NDO), would still have their data shared with NHS England as part of the legal obligation to collect the data under the NDA Directions; however advised that the transparency materials were **not** clear on this point. Independent advisers suggested that the transparency materials were updated to clarify this, in line with Caldicott Principle 8, *"…A range of steps should be taken to ensure no surprises for patients and service users…"*. **4.2.3** The group noted that point 4.1.3 in the minutes of the 20th July 2023 had **not** been addressed, noting the updated response from NHS England that they were **still** seeking clarification as to where the Royal Devon University Healthcare NHS Foundation Trust collect the data, what the legal basis was for collecting the data and what information was given to patients about the collection and what (if any) opt outs there are from that provision.

	4.2.4 The independent advisers suggested that the briefing paper was updated to reflect that the collection of data was **not** for the purpose of direct care. **4.2.5** The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.	
4.3	**Title:** COVID Therapeutics Blueteq Briefing Paper **Presenter:** None **Previous Reviews:** The COVID Therapeutics Blueteq Briefing Paper was previously presented at the AGD meeting on the 10th August 2023 and the 7th September 2023. The purpose of the original briefing paper was to inform the group about this shell onboarded product to support an urgent application by Imperial College London and NHS Blood and Transplant requesting COVID-19 Therapeutics data, for the 'Mass evaluation of lateral flow immunoassays for the detection of SARS-CoV-2 antibody responses in immunosuppressed people' (MELODY Study). This request has support from the Secretary of State for Health and Social Care. **Outcome:** The group welcomed the updated briefing paper and made the following observations / comments: **4.3.1** The group noted that point 4.1.2 in the minutes from the 10th August 2023 had **not** been addressed and suggested that NHS England confirm whether type one opt outs should apply to the Blueteq data. **4.3.2** The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.	
EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-414067-K8R6J-v4.2 **Applicant:** Our Future Health **Application Title:** Our Future Health Recruitment Programme **Presenter:** None **SAT Observer:** Kimberley Watson **Observers:** James Gray / Frances Perry **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 10th August 2023, 13th July 2023, 29th June 2023, 11th May 2023, 20th March 2023 and the 2nd March 2023. The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 1st December 2022, 17th November 2022, 26th May 2022 and the 5th May 2022. **Linked applications:** This application is linked to NIC-411795-X5N2V	

Application: The purpose of the application is to help people live healthier lives for longer through better prevention, earlier detection and improved treatment of diseases. The Our Future Health research programme will aim to speed up the discovery of new methods of early disease detection, and the evaluation of new diagnostic tools, to help identify and treat diseases early when outcomes are usually better.

This version of the data sharing agreement (DSA) sees the total maximum number of mail-outs increase from approximately 16 million invitation mail-outs to approximately 20 million invitation mail-outs. This is an incremental increase, with the first two million invitations provided at the commencement of this DSA and the following two million invitations provided once NHS England are satisfied that Our Future Health have made substantive progress to address points raised through previous advice from NHS England.

NHS England were seeking advice on the following points:

1. Would AGD advise NHS England that sufficient progress is being made in relation to the details outlined within the letter from NHS England to enable the release of the additional two million invites? If not, in what areas is the progress deficient, and what advice would be offered in order to meet the requirement on Our Future Health?
2. Has AGD any advice to NHS England that may be passed on to Our Future Health that might help with the on-going work in the invitation space, noting the broader intention in the longer-term to go beyond 20m invitations?

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

Outcome of discussion: The group welcomed the application and noted the importance of the programme, which potentially may bring substantial benefits to patients.

The **majority** of the group were supportive of the additional data (two million mailouts) flowing; however, in light of the findings to date from the pilots, suggested that rigorous research was undertaken following the flow of the additional data, including, but not limited to, comparing a generic *"Dear Householder"* approach, with invitations to named individuals.

The **minority** of the group felt that additional work first needed to be undertaken, to understand the outcomes of the pilots, **before** the additional data (two million mailouts) should flow.

In response to points 1 and 2:

5.1.1 The group noted that following the suggestion by the group at the meeting on the 13th July 2023 a letter had been sent from NHS England to Our Future Health on the 8th August 2023 (published in the AGD minutes from the 10th August 2023). As part of this review a progress report had been provided that outlined updates / actions following

	receipt of this letter. The group noted the contents of the progress report and advised that they were supportive of the progress to date. **5.1.2** It was noted in the progress report that OFH have initiated two further pilots in other geographic areas to establish if initial findings from the original pilot were replicated, and also to establish greater information regarding the impact on ethnicity. It was noted that one of the findings of the pilot was a significant increase in response to the DigiTrials invitations compared with generic letters for participants under age 40 years; however the independent advisers advised that they **did not** necessarily agree with this outcome following some further analysis of the information provided. **5.1.3** It was also noted in the progress report that there had been a significant increase in response to DigiTrials invitations compared with generic letters for participants in the lowest two Indices of multiple deprivation (IMD) quintiles; which the independent advisers advised that they **did** agree with, following further analysis of the information provided. **5.1.4** It was suggested by the independent advisers that NHS England should investigate the capability / capacity to filter flows of data by IMD quintiles (and possibly other fields such as ethnicity) to target named invitations. **5.1.5** It was noted by the independent advisers that there were references in the progress report and the application to the *"partnership"* with the NHS; and suggested that this was further clarified / defined. **5.1.6** The group noted the information in the transparency materials in respect of the funding arrangements; however, suggested that for ease of reference, this was updated to ensure that **all** funding information was grouped together to ensure equal footing. **5.1.7** The independent advisers noted that the patient information sheet was still **not** explicitly clear on the commercial involvement; and suggested that this was updated to ensure it was clear. **5.1.8** With reference to the outcomes of participants' health screening appointments (and the positive benefit flowing to those participants), the independent advisers suggested the applicant did not average men and women together, for example statistics on cholesterol and blood pressure data, to ensure that significant percentages (and differences between the sexes) are not masked. It was an opportunity for the applicant to show the potentially significant positive impact of the screening process by signposting noteworthy numbers of participants to important health interventions.	
5.2	**Reference Number:** NIC-373563-N8Z9J-v11.8 **Applicant:** IQVIA Ltd **Application Title:** Analytical Services **Presenter:** None	

SAT Observer: Kimberley Watson

Observers: Dave Cronin, Dan Goodwin

Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 18th May 2023.

The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 24th November 2022, 28th January 2021, 6th February 2020 and the 7th February 2019.

The application and relevant supporting documents were previously presented / discussed at the DAAG meetings on the 10th January 2017, 18th October 2016, 27th September 2016 and the 13th September 2016.

Linked applications: This application is linked to NIC-315134-L9Z6B and NIC-210151-K9C7G.

Application: This was an 'advice' application.

The purpose of the application is for IQVIA Ltd to provide commercial services to clients in the health sector or clients that support the Health Sector.

NHS England were seeking advice on the following point:

1. The updates / responses to the previous AGD feedback on the 18th May 2023, including, but not limited to, whether the commercial benefit accruing to the commercial organisation is proportionate to the benefit to health and social care.

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 not offering support on the application as requested by NHS England, and made the following observations on the documentation provided as part of the review:

In response to point 1:

5.2.1 The group noted that the minor updates to the application were satisfactory, and had not provided comments on those aspects.

5.2.2 The independent advisers reiterated a previous point from the review on the 18th May 2023, that there were concerns that there was **not** an express proposition put forward by the applicant that the commercial benefit accruing to the commercial organisation is proportionate to the benefit to health and social care; and suggested again that these were reviewed and updated in line with NHS England's DARS Standard for Commercial Purpose and NHS England's DARS Standard for Expected Measurable Benefits; and that these are aligned with the recently published National Data Guardian guidance on benefits.

5.2.3 Noting that a Data Protection Impact Assessment (DPIA) extract had been provided as a supporting document, it was noted by the independent advisers that there **did not** appear to be a robust framework in place for assessing the public benefit

	versus the commercial benefit accruing to the commercial organisation, either now and / or in the future. In addition, it was advised that the National Data Guardian guidance on benefits had been misconstrued when referring to *"risks"* in the DPIA extract. **5.2.4** The independent advisers queried what / where the gap was in the marketplace, for example, in respect of Visualise Healthcare Data (VHD) and what can IQVIA Ltd provide that is not already available from other databases and work undertaken by public health sector analysts; and suggested that this clarification might be a helpful pathway to establishing the public vs. commercial benefit analysis (and could be a model for assessing other projects). **5.2.5** In addition, it was queried by the independent advisers, what the specific benefit(s) were to the NHS Trusts and whether further examples of this could be provided. **5.2.6** It was suggested that IQVIA Ltd engage with a clinical professional to further discuss projects and seek support to clarify what they are trying to achieve and what they can offer that is not already available elsewhere in the public health sector.	
5.3	**Reference Number:** NIC-663093-K1B0K-v0.5 **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)* **Presenter:** None **SAT Observer:** Kimberley Watson **Observers:** Dan Goodwin / Jodie Taylor-Brown **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 3rd August 2023. **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. 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 reiterated the points made at the AGD meeting on the 3rd August 2023 that remained outstanding and should be addressed, namely:

5.3.1.1 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 projects are relying on s251 support.

5.3.1.2 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.

5.3.1.3 Noting that under 16s were being excluded from the study, section 5 (Purpose / Methods / Outputs) should be updated to explain why (those aged under 16 are included in other similar research activities).

5.3.2 Notwithstanding any advice from the Health Research Authority Confidentiality Advisory Group (HRA CAG), it was advised by the group that (unless in some way deficient) consent should be relied on for any subsequent contact with the cohort, or the processing of data to ascertain any deaths; which was consistent with processing for other cohort studies. In addition, it was noted that relying on consent would mean that the National Data Opt-out would **not** be applied, which will ensure the fullest data flow possible which is essential to ascertain any deaths (and consequently reduce the incidence of contact with, and causing distress to, bereaved families: which was the primary aim of the exercise).

5.3.3 The group noted that at the review on the 3rd August 2023 the Privacy and Electronic Communications Regulations (PECR) had been discussed, and they had advised that they would expect a clear statement in the application and / or internal application assessment form that PECR had been considered. As part of this review, the group noted that the applicant appeared to have provided a response on this point, and queried if NHS England's Privacy, Transparency, Ethics and Legal (PTEL) had been engaged with in respect of PECR; and satisfied that nothing was going out in the communication that could possibly be classed as *"marketing"* (for example a click through to the applicant's website with information about taking part in paid-for surveys).

5.3.4 The independent advisers queried the processing as outlined in section 5(a) (Objective for Processing); and suggested that this was updated to provide a further

	rationale for the flow of data to select those to be invited rather than NHS England applying the selection criteria. In addition, NHS England should undertake a risk assessment and document the rationale for one approach of processing over another. **5.3.5** The independent advisers queried whether the ethnicity fields in the National Disease Registration Service (NDRS) were sufficient in terms of quality of data; and suggested that this was explored by NHS England. If the data was not of a sufficient standard, the group advised that they would be supportive of the addition of an alternate dataset to the data sharing agreement (DSA) that provides the most relevant ethnicity information. **5.3.6** The NHS England SIRO Representative suggested that the application be updated to be clear with regard to where the data was being processed, since the application and supporting documents were inconsistent.	
5.4	**Reference Number:** NIC-709865-W9X6H-v0.8 **Applicant:** The Royal College of Surgeons of England **Application Title:** National Cancer Audit Collaborating Centre (NATCAN) **Presenter:** None **SAT Observer:** Kimberley Watson **Observer:** Louise Dunn **Application:** This was a new application. The purpose of the application is for the Healthcare Quality Improvement Partnership (HQIP) and NHS England for the National Audit Centre: The National Cancer Audit Collaborating Centre (NATCAN). NATCAN will deliver six clinical audits of care delivered by NHS Providers, the audits are as follows: National Audit of Primary Breast cancer (NaoPri); National Audit of Metastatic Breast cancer (NaoMe); National Ovarian Cancer Audit (NOCA); National Pancreatic Cancer Audit (NPaCA); National Non-Hodgkin Lymphoma Audit (NNHLA) and the National Kidney Cancer Audit (NKCA). 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: **5.4.1** The group noted that NHS England's DARS had made efforts to understand the different roles of the parties involved; however, advised that in the public facing transparency materials NATCAN is described as a collaboration between The Royal College of Surgeons of England **and** the London School of Hygiene and Tropical Medicine (LSHTM). It was therefore suggested that this was explored further, to determine the role of LSHTM.	

	5.4.2 Noting that there were seven honorary contract holders the independent advisers suggested that NHS England queried this further, for example, in respect of the proportion of the team: were there only seven individuals within the team, or are the seven part of a much wider team. The independent advisers suggested that it may be appropriate for LSHTM to be added as a Data Processor in line with NHS England's DARS Standard for Data Processors. **5.4.3** In addition, it was suggested by the independent advisers that NHS England review the information within the application, in respect of where the data will be processed, noting that it is currently very prescriptive and only refers to the data being held on the servers at The Royal College of Surgeons of England. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.4.4 Separate to this application:** The independent advisers noted and applauded the questions asked by NHS England's DARS in respect of how many honorary contract holders there were for this application; however, suggested that for future applications, further follow up questions are asked in respect of the proportion of the honorary contract holders within the wider team. **ACTION:** DARS to seek further clarity from applicants in respect of the honorary contract holders and the number / proportions involved. **5.4.5** The group noted that the purpose of the application is for "*service evaluation and audit"*, however advised that there was information in the public domain, for example on the NATCAN website that refers to "*research*" being undertaken; and suggested that NHS England remind the applicant that research is **not** permitted under this data sharing agreement (DSA), and that processing for the purpose of research would be subject to an amendment or separate application. **5.4.6** The group queried why the Local Patient ID, consultant code and general medical practitioner data fields are required; and stated these need to be justified in section 5(a) (Objective for Processing) of the application.	DARS
6	**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. 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. **ACTION:** NHS England SIRO representative to provide a written response addressed to AGD with further clarity on the risk management framework.	GC
7	**AGD Terms of Reference (ToR)** The independent advisers noted that nearly four months had passed since the Statutory Guidance had been published, and queried whether there was any further update on the progress of the AGD 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 AGD ToR was scheduled to be considered by the NHS England Board / subcommittee of the Board.	GC
8	**Standard operating procedures** The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that this could not progress further without sight of the final draft of the ToR.	To Note
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		