Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 30th April 2026

09:00 – 16:05

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	**Role:**
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative)
Dr. Jon Fistein (JF)	AGD independent member (Chair)
Prof. Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser)
Andrew Martin (AM)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Dr. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
Kimberley Watson (KW)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative (not in attendance for items 4.4, 5.3 to 5.4, 9.1 to 10.1)
Dave Cronin (DC)	Applications Service Owner, Data Access and Partnerships, Transformation Directorate (**Presenter**: item 4.1)
Louise Dunn (LD)	Principal Operational Delivery Manager, Data Access and Partnerships, Data Portfolio Management, Transformation Directorate (**Presenter**: item 4.2)
Laura Evans (LE)	Data Operations Management Officer, NHS DigiTrials, Data and Analytics, Transformation Directorate (**Observer**: item 4.3)
Suzanne Hartley (SH)	Data Applications Service (DAS) - Senior Manager, Data Access and Partnerships, Transformation Directorate (**Observer**: item 5.1)

Maddie Laughton (ML)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.3)
Sara Lubbock (SL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.2)
Jorge Marin (JM)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.2)
Harry Millard (HM)	Information Governance Officer, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Technology, Digital and Data (**Observer:** item 4.4)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: items 5.6 and 5.7)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
Sara Petitjean (SP)	Screening Service Office, Transformation Directorate (**Observer**: item 5.5)
Paul Sadler (PS)	Screening Service Office, Transformation Directorate (**Observer**: item 5.4)
Gemma Walker (GW)	Information Governance Specialist, IG Risk and Assurance, Privacy, Transparency, and Trust (PTT), Technology, Digital and Data (**Presenter**: item 4.4)
James Watts (JWa)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (**Observer**: item 5.4 and 5.5)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	**Role / Area:**
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician Adviser)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)

Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)
NORTH OF ENGLAND COMMISSIONING SUPPORT UNIT STAFF IN ATTENDANCE:	
Rick McLeod (RMc)	Chief Technology Officer, North of England Commissioning Support Unit (**Presenter**: item 4.2)

1	**Welcome and Introductions:** The AGD Chair welcomed attendees to the meeting. AGD noted that, due to unforeseen circumstances, there would be no NHS England SIRO Representative or delegate in attendance for items 4.4, 5.3 to 5.4, 9.1 to 10.1. Noting that the AGD Terms of Reference (ToR) state that: *"…a representative of the SIRO must also be in attendance for any meetings of the Group or a Sub-Group…"*, the Group were advised that, prior to the meeting, the NHS England SIRO Representative had confirmed contentment for these items to be discussed in their absence.	
2	**Review of previous AGD minutes:** The minutes of the AGD meeting on the 23rd April 2026 were reviewed and, after minor amendments, were agreed as an accurate record of the meeting.	
3	**Declaration of interests:** Dr. Jon Fistein noted a professional link to the University of Oxford but noted no specific connections with the application (NIC-800347-F4P5X), and it was agreed that this was not a conflict of interest. Dr. Jon Fistein noted a professional link to the University of Leeds but noted no specific connections with the application (NIC-801643-G1K4H), or staff involved, and it was agreed that this was not a conflict of interest.	
4 BRIEFING PAPER(S) / DIRECTIONS:		
4.1	**Title:** Data Access Models **Presenter:** Dave Cronin AGD were provided with an overview, of the proposed 'Data Access Models' programme of work within NHS England's Data and Analytics; which included an overview of the aims of this programme of work, which is to **1)** formally recognise the proposed five data access models with each one having a clear governance and eligibility criteria; **2)** to enhance understanding of the available data access models, for example, within NHS England and for applicants; **3)** reduce lead time for complex data access models by clearly defining requirements and standards; and **4)** will reduce / resolve inconsistencies and disparities across DSAs.	

	Within the briefing paper provided, was a request for the involvement of some AGD independent members to form a 'working group', to consider a number of points in three phases which are as follows: **Phase One** to consider **1)** whether the proposed five data access models are sufficiently defined; **2**) whether applications reviewed by AGD fall into one of the five data access models; **3)** whether there should be additional data access models; **4)** any filters / factors that should be applied to the data access models; and **5)** any key risks and concerns. **Phase Two** to review and advise on the recommended requirements per the data access model. **Phase Three** to review current applications and existing data sharing agreements (DSA) against the data access models and recommendations to test the theory and advise on the specific applications / DSAs. **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **4.1.1** AGD noted and supported the proposed 'Data Access Models' programme of work outlined. **4.1.2** AGD advised that they were supportive of the involvement of some AGD independent members on the proposed 'working group' to support phase one and phase two; however, advised that phase three could be discussed as part of an AGD business as usual meeting. The Group were advised by the AGD Secretariat that as per process, expressions of interest would be sought from AGD independent members in due course.	
4.2	**Title:** Commissioning Support Unit (CSU) closure and Data Services for Commissioners Regional Offices (DSCRO) Management **Presenters:** Rick McLeod and Louise Dunn NHS England is moving towards a more consistent, nationally enabled approach to data management, aligned to a National Data Service and the Federated Data Platform (FDP), while continuing to support local system priorities and flexibility. This transition forms part of NHS England's wider work to ensure data is managed once, securely and efficiently, and reused across the system where there is a legal basis and appropriate purpose AGD were provided with an overview for information, of the programme of work in respect of CSU closure and DSCRO management; including, but not limited to, the background, current position, key design principles, interim position, and what this means for NHS England / CSUs / Integrated Care Boards. **Outcome of discussion:** AGD welcomed the briefing and made the following observations / comments: **4.2.1** The Group noted the content of the briefing, and advised that they would welcome any further updates in due course.	
4.3	**Title:** NHS DigiTrials Recruitment Service - Calming Minds Study - Invitation letters review **Presenter:** Laura Evans	

	At the AGD meeting on the 13th November 2025, as part of the 'DigiTrials Recruitment Service - Invitation Letter Standards' review / discussion, AGD had agreed that the first three instances of the finalised standard (which will form part of the NHS DigiTrials Precedent) used to assess an NHS DigiTrials invitation letter would come to AGD for review. AGD advised at the AGD meeting on the 16th April 2026, that the Group would encourage and support any further letters being brought to a future AGD meeting; and therefore, this was the **fourth** instance of where the finalised standard had been used to assess NHS DigiTrials invitation letters. NHS England were seeking advice on the following points: 1. Provide advice on the points raised in the template review document. 2. Confirm if this letter was correctly brought to AGD for advice based on the points identified in the review document. 3. Confirm that AGD are content for the letters to be used, subject to any advice provided, and subject to relevant Research Ethics Committee (REC) approval. **Outcome of discussion:** AGD welcomed the briefing paper / letter templates and made the following observations / comments: **4.3.1** AGD queried the cohort size for this study; and were advised by NHS England that the study was hoping to recruit approximately 500 participants, and therefore this would equate to approximately six to twelve thousand letters being sent out. **In response to point 1 above:** **4.3.2** The Group advised that they had significant concerns that a telephone number was not included in the letter templates, and were not supportive of the applicants' position on this, i.e. that the study team had limited resources to manage any calls. Noting the sensitive nature of the study, the Group advised that the letters should not be distributed until this point had been addressed. **4.3.3** AGD discussed whether the content of the letter was broadly suitable and advised that it was, noting the sensitive nature, however advised that the applicant should do the following (or explain why this is not to be done) **4.3.3.1** review the structure and tone of the letter, taking into account any potential surprise or distress to recipients; **4.3.3.2** reorder the letter to better meet the potential needs of recipients, for example, having information about 'support available' further up the letter so that it appears clearly highlighted on the first page; **4.3.3.3** make it clearer what the eligibility is for the study, including, but not limited to, online access; and **4.3.3.4** link to the NHS DigiTrials Directions were included in the letters. **4.3.4** AGD discussed whether the incentive (shopping vouchers) being offered to study participants were appropriate and proportionate; and advised that whilst the potential maximum incentive as a whole was higher than previous incentives they have seen, it was material that they were provided on a staged basis to participants as they completed	

	different parts of the study, and that each stage incentive was broadly in line with the National Institute for Health and Care Research guidance. The Group advised that: **4.3.4.1** the applicant provides a clear justification as to how the incentives are at a level representing a "thank you" to participants as opposed to an inducement; and **4.3.4.2** the applicant discuss the incentives with the REC when an opinion is sought. **In response to point 2 above:** **4.3.5** AGD advised that they were supportive of the letters being brought to AGD for advice based on the sensitive nature of the study; and thanked NHS England for highlighting specific points of advice required in the internal NHS DigiTrials template review document. **In response to point 3 above:** **4.3.6** AGD advised that they were content for the letters to be used, subject to the advice provided by the Group; and subject to relevant REC approval.	
4.4	**Title:** Organisational Change Reusable Decision Package **Presenter:** Gemma Walker **Observer(s):** Harry Millard The NHS England Data Access Request Service (DARS) occasionally receive requests to amend a Data Sharing Agreement (DSA), for example, legal name changes, closures, mergers and takeovers. There are currently no reusable decisions that permit DARS to progress amendment requests that arise from organisational change. This purpose of this briefing paper is to present suggested reusable decisions regarding organisational change. NHS England were seeking advice on the following points: 1. Are AGD content with the proposal to establish a series of reusable decisions around organisational changes? 2. Do AGD agree that the reusable decisions can now be made live on the Knowledgebase? 3. Are AGD supportive of the NHS England exploring potential mechanisms for detecting Data Sharing Framework Contract (DSFC) non-conformities arising from unreported organisational changes? **Outcome of discussion:** AGD welcomed the briefing paper and made the following observations / comments: **In response to point 1 above:** **4.4.1** AGD advised that they were content with the proposal to establish a series of reusable decisions around organisational changes. **In response to point 2 above:** **4.4.2** AGD advised that it was reasonable to have the reusable decision for the purpose of organisational closures.	

	4.4.3 AGD advised that a reusable decision for the purpose of legal names changes would be appropriate if NHS England can satisfy itself that it is purely for the purpose of a name change, and that other related issues such as the ICO Register etc were updated in conjunction. **4.4.4** AGD advised that in respect of takeovers and mergers, NHS England should give this further thought, for example, to ensure that the original object for processing does not change, and to ensure that the relevant organisation(s) are aware of their responsibilities in respect of NHS England data. **4.4.5** AGD advised that for the more complex areas, some parallel running between the reusable decisions and AGD review was undertaken, before this goes live. **In response to point 3 above:** **4.4.6** AGD advised that they were supportive of NHS England exploring potential mechanisms for detecting DSFC non-conformities arising from unreported organisational changes. **4.4.7** AGD looked forward to a further update on this programme of work in due course.	
5 EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-744993-Z8K2K-v2.1 **Applicant and Data Controller:** Methods Business and Digital Technology Limited (MBDT) **Application Title:** "Triple Negative Breast Cancer Study" **Observer:** Suzanne Hartley **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 5th March 2026 and the 10th October 2024. **Application:** This was an amendment application. NHS England were seeking advice on the following points: 1. Whether AGD feels that the data sharing agreement (DSA) is now sufficiently clear on the role of Methods Business and Digital Technology Limited. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD supported the action that NHS England has taken over the breach outlined, and recommend that no further access (dissemination / release) of data should be permitted until the following points are addressed. **In response to point 1:** **5.1.1** AGD noted that the internal form / application had been submitted to the Group for review, following a breach of the data sharing agreement (DSA), whereby following a business transfer from Methods Analytics to its parent company MBDT, an analyst who had transferred to MBDT had been accessing the data in NHS England's Secure Data Environment (SDE) without the agreement naming that company. The Group noted that Methods Analytics Limited (the existing applicant / Data Controller) transferred business into	

	MBDT (the parent company) on the 31st December 2025. The Group noted that the NHS England SIRO Representative had engaged with the MBDT on actions subsequent to the breach and this application was to amend the applicant / data controllership under this DSA to reflect the new organisational changes. **5.1.2** AGD noted that whilst data access by the new entity (Methods Business and Digital Technology Limited) may be acceptable, advised that NHS England ensure that the following points are fully addressed **prior** to any data access: **5.1.2.1** that the applicant ensure **all** transparency materials are updated to ensure that they **i)** reflect the updated organisational structure; **ii)** outline the data access proposed; and iii) were in line with UK General Data Protection Regulation (UK GDPR); and **5.1.2.2** the commercial aspects are reviewed and updated in line with NHS England DARS Standard for Commercial Purpose, including, but not limited to, the balance between public and commercial benefits. **5.1.3** AGD supported NHS England passing on additional charges to the applicant to cover the cost incurred by NHS England in investigating / addressing the breach. **5.1.4** AGD advised that NHS England should consider undertaking an audit of the access arrangements for Methods Business and Digital Technology Limited. **5.1.5** AGD noted that the purpose of the data access had not changed following the recent organisational change. **5.1.6** AGD noted and commended the work undertaken by NHS England to address the breach outlined. In addition to their advice on the specific points raised by NHS England, AGD made the following observations **separate** to the application: **5.1.7** AGD advised that NHS England considers how it manages potential organisational changes, in particular noting that NHS England may naturally be more aware of public sector organisational changes than those in the commercial sector. AGD advised that this issue is addressed by: **5.1.7.1** ensuring there is an explicit question in the annual compliance report (ACR); **5.1.7.2** ensuring organisations are aware of their responsibilities due to any wider organisational changes; and **5.1.7.3** considering how NHS England are made aware of organisational changes outside of any standard discussions with the applicant, for example, outside of the ACR discussions.	
5.2	**Reference Number:** NIC-800347-F4P5X **Applicant and Data Controller:** University of Oxford **Application Title:** "Investigating the risks and outcomes of surgery for fracture-related infection and bone infection after fracture fixation" **Observers:** Sara Lubbock and Jorge Marin **Application:** This was a new application.	

NHS England were seeking advice on the following point:

1. Whether the data minimisation is sufficiently clear and appropriate.

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

Outcome of discussion: AGD advised that significant concerns had been identified within this point and that further consideration should be given before the access (dissemination / release) of data proceeds.

In response to point 1:

5.2.1 AGD noted that the justification in the internal form / application for the applicant receiving access to 25 years of data was not sufficient / clear; and queried why a shorter period of time, for example, 10 or 15 years would not be adequate; and advised that NHS England seek further clarification from the applicant on this point, for example, giving some quantitative indication of the potential impact on the study if a shorter period of data was provided.

5.2.2 AGD advised that the timing of the data in respect of each data subject was unclear in the internal form / application, for example, if the 25 years referred to is correct, does this commence at the point of surgery or a different point; and advised that NHS England seek further clarification from the applicant on this point.

5.2.3 AGD noted concern that it was unclear in the internal form / application what data would be accessed in NHS England's secure data environment (SDE), for example, would this be **all** of the Hospital Episode Statistics (HES) data for all of the eligible cohort, or only those where specific ICD-10 diagnoses codes and OPCS-4 procedure codes have been applied; and advised that NHS England seek further clarification from the applicant on this point.

5.2.4 AGD noted that there would be a lower risk for NHS England if:

5.2.4.1 as much data minimisation was undertaken by NHS England as possible **prior** to the data being accessed, rather than allowing access to all of the data (with subsequent minimisation by the applicant); and

5.2.4.2 the level of data minimisation was clearly justified.

5.2.5 Noting that the applicant is requesting data for patients aged 16 years and above, AGD advised that clarification was provided as to whether this includes data from patients after they turn 16 who had previously had an operation prior to the age of 16, or just applies to those who had an operation after turning 16.

In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review, which should be addressed before the access (dissemination / release) of data proceeds:

5.2.6 AGD noted that one of the outputs referred to the development of a *"risk stratification"* tool and advised that the objective for processing is updated to reflect this, in line with NHS England DARS Standard for Objective for Processing, noting there may be further implications relating to the development of a risk stratification tool, separate to any research outputs, for example, commercial implications and / or the use of AI to develop of this tool.

5.3	**Reference Number:** NIC-802555-L3Y2K **Applicant:** Royal College of Psychiatrists **Data Controllers:** Healthcare Quality Improvement Partnership (HQIP) and NHS England **Application Title:** "RCPsych National Clinical Audits Combined Data (NCAP, NAED, NAD)" **Observer:** Maddie Laughton **Application:** This was a new application. NHS England were seeking advice on the following points: 1. Whether there are any unmitigated risks in relation to the provision of a single data flow for three audits to Royal College of Psychiatrists (for HQIP). 2. Whether the data minimisation that applies is adequately explained. 3. Whether there are specific risks that need to be considered given that the application does not yet have s251. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD advised that significant concerns had been identified within those points and that further consideration should be given before the access (dissemination / release) of data proceeds. **In response to point 1:** **5.3.1** AGD discussed the provision of a single data flow for three audits to Royal College of Psychiatrists; and noted that whilst they commend the ambition and there were benefits to having a single data flow for the three (possibly similar) audits however, advised that there may be significant risks in respect of potential overprocessing of the data, and / or possible re-identification. The Group advised that NHS England explore these potential risks further. **In response to point 2:** **5.3.2** AGD noted that for the three audits proposed, there may be an over provision of data as currently requested. **5.3.3** AGD advised that a clear justification for the proposed level of data minimisation outlined in the internal form / application had not been provided, for example, in respect of the numerous patient identifiers, noting the only consistent patient identifier appears to be the local patient identifier; and advised that NHS England further engage with the applicant on this point to justify the data being requested or to minimise the data further. **5.3.4** AGD also noted that there was not a clear justification for the size of the cohort, and queried whether they could be minimised by ages or codes; and advised that NHS England explore this further with the applicant on this. **In response to point 3:** **5.3.5** AGD noted the intention to submit a s251 application to Health Research Authority Confidentiality Advisory Group (HRA CAG), and advised that a clear rationale was provided for this, noting that HRA CAG would not provide s251 support for data that was not identifiable.	

	In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review, which should be addressed before the access (dissemination / release) of data proceeds: **5.3.6** AGD queried whether other options could be explored, instead of a single data flow for three audits, for example, could NHS England consider undertaking the data minimisation prior to the data flowing to the Royal College of Psychiatrists; and noted that the offer from the AGD NHS England Caldicott Guardian Team Representative, to discuss with the relevant parties, i.e. NHS England, HRA CAG, HQIP and the applicant, to discuss whether this was the best model, or whether there was an alternative option to meet the objective for processing.	CG Rep
5.4	**Reference Number:** NIC-801642-B0K2B **Applicant and Data Controller:** University of Southampton **Application Title:** "Exploring inequalities in bowel cancer screening uptake" **Observers:** James Watts and Paul Sadler **Application:** This was a new application. NHS England were seeking advice on the following points: 1. Whether it is clear why the work cannot be undertaken within the Secure Data Environment (SDE) 2. Whether the data minimisation to be undertaken is sufficiently clear and appropriate 3. Whether there is sufficient detail on the approach to transparency. 4. Whether it is helpful to amend the wording on remote access, such that it is consistent with a different part of data sharing agreement (DSA) that doesn't permit remote access. 5. Whether there are specific risks in relation to "the project's anonymised IDs". 6. Whether there are any specific risks that necessitate such applications requiring ethics before being considered for advice by AGD. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD advised that significant concerns had been identified within those points and that further consideration should be given before the access (dissemination / release) of data proceeds. **In response to point 1:** **5.4.1** AGD noted that NHS Bowel Cancer Screening Data requested under this application was not currently available in the NHS SDE, therefore were supportive of a data extract until such time the data was available in the NHS SDE. **In response to point 2:** **5.4.2** AGD discussed the proposed data minimisation to be undertaken, which is based on age and the date of invite for routine bowel cancer screening; and advised that the eligibility criteria for bowel cancer screening changed over the period outlined, and that the data	

provided should align with the age ranges per year, and not as collective for the cohort as a whole.

In response to point 3:

5.4.3 AGD raised a concern about the lack of transparency available on this study; and advised that NHS England engage with the applicant on this, to ensure transparency materials were available and were in line with UK General Data Protection Regulation (UK GDPR); and that no data should flow until this has been addressed.

5.4.4 In addition, AGD noted the excellent patient and public involvement and engagement (PPIE) undertaken, and advised that views could be sought via PPIE on the transparency materials prior to being published.

In response to point 4:

5.4.5 AGD noted an inconsistency within the internal form / application on remote access; and advised this was reviewed to:

5.4.5.1 clarify whether data access would be limited to being on the premises of the University of Southampton **only**; and if so any reference to "remote access" is removed; or

5.4.5.2 if the data access is on the premises of the University of Southampton and also via remote access, then this should be accurately reflected in the internal form / application.

In response to point 5:

5.4.6 AGD discussed the references in the internal form / application to "the project's anonymised IDs", and advised that this was most likely referring to pseudonyms that won't be further linked / retained; and advised that if this was correct, then they were broadly comfortable with this, however, advised that NHS England satisfy itself that this was accurate.

In response to point 6:

5.4.7 AGD noted that this particular study was a retrospective analysis, and advised that they did not identify any additional ethical issues other than what is already outlined in the internal form / application.

In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review, which should be addressed before the access (dissemination / release) of data proceeds:

5.4.8 AGD noted that it was unclear if the PhD student undertaking the work was doing this under an honorary contract; and if this was the case, then the Group advised that NHS England clarify this with the applicant, noting that an honorary contract may not be the most appropriate arrangement, noting this would usually be done via a more direct relationship with their University.

5.4.9 AGD noted that whilst there was value in the work outlined, advised that NHS England satisfy itself that there was no duplication of existing work being undertaken by the NHS England screening team, to ensure there is appropriate value added.

	5.4.10 In addition, AGD noted that the Group had seen similar work being commissioned by NHS England, and in which case NHS England had also being considered to be a joint Data Controller. **5.4.11** AGD advised that NHS England add a special condition in the internal form / application in respect of the data destruction certificate for the mapping key. **5.4.12** AGD noted that the screening team apply the National Data Opt-out (NDO) to the data, notwithstanding the fact the data is pseudonymised; and advised that: **5.4.12.1** NHS England satisfy itself that this is in line with the NDO policy; and **5.4.12.2** further clarification on this point is provided to the Group at a future AGD meeting to support the Group's understanding / learning.	
5.5	**Reference Number:** NIC-801643-G1K4H **Applicant and Data Controller:** University of Leeds **Application Title:** "BENE-FIT Trial" **Observers:** James Watts and Sara Petitjean **Application:** This was a new application. NHS England were seeking advice on the following points: 1. Whether there is sufficient clarity on the various roles in relation to the dataflow, and whether they are captured correctly within the internal form / application. 2. Based on advice point 1, whether the appropriate model is correctly described in the rest of the application, for example, in relation to National Data Opt-outs (NDO). Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD noted that it was responding to NHS England's request for advice on specific points, and did not identify any major concerns in those areas. **In response to point 1:** **5.5.1** AGD noted the information provided in the data flow diagram and the internal form / application, and based on this, that NHS England would not be considered a joint Data Controller noting they are acting on the instructions of the applicant. The Group advised that the data flow diagram could be clearer on this point, for example, adding the study arm and building randomisation was not being initiated by NHS England. **In response to point 2:** **5.5.2** AGD noted in the internal form / application stated that those lacking in capacity would not be contacted; and advised that this was reviewed and updated to recognise that although there is no direct intention to contact participants lacking in capacity, they may be contacted incidentally, and the applicant should be clear how they would proceed if someone lacking in capacity was incidentally contacted. **5.5.3** AGD noted that the screening team apply the National Data Opt-out (NDO) to the data, notwithstanding the fact the data is pseudonymised; and advised that: **5.5.3.1** NHS England satisfy itself that this is in line with the NDO policy; and	

	5.5.3.2 further clarification on this point is provided to the Group at a future AGD meeting to support the Group's understanding / learning.	
5.6	**Reference Number:** NIC-764486-G2T0J **Applicant:** University of Aberdeen **Data Controllers:** Imperial College London and London School of Hygiene and Tropical Medicine (LSHTM) **Application Title:** "The FOLLOW UP study - a natural experiment estimating the clinical and cost-effectiveness of follow up strategies after curative treatment for prostate cancer" **Observers:** Joe Lawson **Linked applications:** This application is linked to NIC-784559-L4H8L (item 5.7) **Application:** This was a new application. NHS England were seeking advice on the following points: 1. Whether the data minimisation of the data is sufficient, and adequately expressed within the internal form / application? 2. Whether the interaction between this and NIC-784559-L4H8L is adequately and accurately explained? 3. Whether any implications of the re-identification of pseudonymised data are adequately addressed? 4. Whether the requirement for LSHTM having the entirety of data for the cohort is sufficiently clear? 5. Whether the data controllership arrangement is adequately justified? 6. Whether the classification of the data should be identifiable (due to date of death), identifiable (due to re-id) or pseudonymised? Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** AGD advised that significant concerns had been identified within those points and that further consideration should be given before the access (dissemination / release) of data proceeds. **In response to point 1:** **5.6.1** AGD advised that in respect of the data minimisation, there was an inadequate justification as to why data not relating to the primary conditions being studied were being requested, for example, medication data; and advised that: **5.6.1.1** clarification was provided as to whether further data minimisation can be undertaken; or **5.6.1.2** a clear justification was provided for the data requested if no further data minimisation can be undertaken. **In response to point 2:** **5.6.2** AGD noted the complex arrangements outlined in both of the internal forms / applications; and advised that further updates were made to be clear on the relationship between the two, noting that different processing environments may be used.	

	In response to point 3: **5.6.3** AGD noted concerns with the provision and then removal of date of death data once a period had been derived from this data; and advised that further clarity was provided as to why this process was being used, as opposed to the applicant only being provided with the derived data. The Group advised that NHS England explore this further with the applicant. **In response to point 4:** **5.6.4** AGD noted that there was not a clear justification for LSHTM having the entirety of data for the cohort; and advised that NHS England engage with the applicant on this point. **In response to point 5:** **5.6.5** AGD noted in the internal form / application that there is a Project Management Group, in which the co-applicants (not listed as Data Controllers) will be part of; and whilst it does state that the organisations of the co-applicants will not be influencing the purpose and means of the study, the Group advised that NHS England explore this with the applicant in line with NHS England DARS Standard for Data Controller(s), noting that it was their view, that they may be influencing the purpose and means. **In response to point 6:** **5.6.6** AGD noted that this point had been discussed under point 3. In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review, which should be addressed before the access (dissemination / release) of data proceeds: **5.6.7** AGD queried why the data could not be accessed in NHS England's Secure Data Environment (SDE); and advised that NHS England explore this with the applicant. **5.6.8** AGD noted that the study website stated on its landing page that the study would not receive any data from individuals that had a National Data Opt-out (NDO); and that notwithstanding that the data requested would be pseudonymised and therefore not normally subject to the NDO. The Group advised that NHS England should address this point with the applicant to ensure that assurances to participants are honoured.	
5.7	**Reference Number:** NIC-784559-L4H8L **Applicant:** University of Aberdeen **Data Controllers:** Imperial College London and London School of Hygiene and Tropical Medicine (LSHTM) **Application Title:** "The FOLLOW UP study - a natural experiment estimating the clinical and cost-effectiveness of follow up strategies after curative treatment for prostate cancer" **Observer:** Joe Lawson **Linked applications:** This application is linked to NIC-764486-G2T0J (item 5.6) **Application:** This was a new application. NHS England were seeking advice on the following points:	

1. Whether the interaction between this and NIC-764486-G2T0J is adequately and accurately explained within the internal form / application?
2. Whether the length of the data sharing agreement (DSA) is appropriate, given the time limited nature of the use of the data (for sending invites)?
3. Whether the data controllership arrangement is adequately justified?
4. Whether it is clear as to what demographics data is being provided?
5. Whether AGD agree with the consent assessment in relation to the questionnaire; and whether it is correct to state that the Common Law Duty of Confidentiality is not being met by consent in any flow?

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

Outcome of discussion: AGD advised that significant concerns had been identified within those points and that further consideration should be given before the access (dissemination / release) of data proceeds.

In response to point 1:

5.7.1 AGD noted the complex arrangements outlined in both of the internal forms / applications; and advised that further updates were made to be clear on the relationship between the two, noting that different processing environments may be used.

In response to point 2:

5.7.2 AGD advised that the length of the DSA is reviewed and updated as may be appropriate, noting the time limited nature of the use of the data for sending invites.

5.7.3 AGD noted the statements in respect of archiving the data for a period of ten years; and advised that this was reviewed and updated as may be necessary prior to any data access.

In response to point 3:

5.7.4 AGD noted in the internal form / application that there is a Project Management Group, in which the co-applicants (not listed as Data Controllers) will be part of; and whilst it does state that the organisations of the co-applicants will not be influencing the purpose and means of the study, the Group advised that NHS England explore this with the applicant in line with NHS England DARS Standard for Data Controller(s), noting that it was their view, that they may be influencing the purpose and means.

In response to point 4:

5.7.5 AGD noted that it was unclear what demographics data is being requested, and it was the understanding of the Group that this may be name and address data; however, advised that NHS England clarify with the applicant and update the internal form application as may be necessary.

In response to point 5:

5.7.6 AGD noted the information in the questionnaire that implies consent for data sharing will be taken to have been provided by participants by the completion of the questionnaire; and noting that did not align with usual practice when obtaining consent for research purposes or some aspects of the information in the patient information sheet (for instance

	the statement that other researchers would access questionnaire data 'with your consent'); and advised that NHS England satisfy itself that the consent process is: **5.7.6.1** in line with the Common Law Duty of Confidentiality; **5.7.6.2** in line with UK General Data Protection Regulation (UK GDPR); and **5.7.6.3** is auditable In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review, which should be addressed before the access (dissemination / release) of data proceeds: **5.7.7** AGD advised that the DSA should be clear, for instance via a special condition, that any onward sharing of data does not include NHS England data as the Participant Information Sheet states that other researchers would have access to 'questionnaire data' (not NHS England or other data) with participant consent. **5.7.8** AGD queried why the data could not be accessed in NHS England's Secure Data Environment (SDE); and advised that NHS England explore this with the applicant.	

6 INTERNAL DATA DISSEMINATION REQUESTS:	
There were no items discussed	
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL	
There were no items discussed	
8 OVERSIGHT AND ASSURANCE	
There were no items discussed	
9 AGD OPERATIONS	
9.1	**AGD ways of working** *There were no items discussed*
9.2	**AGD Stakeholder Engagement** The AGD Chair noted he had met with Prof, Lorna Fraser, the Chair of the Health Research Authority Confidentiality Advisory Group (HRA CAG), and Dr. Nicola Byrne, the National Data Guardian for health and adult social care in England, on the 28th April 2026, as part of their regular engagement.
9.3	**AGD Project Work** **NIC-762279 Project work request** The AGD Secretariat advised the Group that as discussed at the AGD meeting on the 16th April 2026, expressions of interest had been received from AGD independent members to provide additional support on NIC-762279-Q6S6T (University of Newcastle Upon Tyne) out of committee; and was awaiting feedback from NHS England SIRO Representative.

	Data Access Models AGD noted that as discussed under item 4.1, expressions of interest would be sought from AGD independent members in due course, to provide support out of committee, as part of the data access models working group.
10 Any Other Business	
10.1	**NHS England Data Access Request Service (DARS) internal form / application form** AGD noted that following the presentation to the Group on the 26th February 2026 to discuss the NHS England DARS internal form / application form, the Group had now started to receive revised forms for discussion in-meeting. As agreed on the 26th February 2026, the Group noted some additional suggestions for updates / amendments to the forms, and noted that this would be fed back to DARS for consideration, including but not limited to the purpose of the application being more prominent at the start of the form, to help set the context; all sections of the form to be completed, or to be clear why any sections are incomplete; and the size / scale of the cohorts to be clear.
10.2	**UK Biobank** The NHS England SIRO Representative drew the Group's attention to the statement made in the House of Commons, by the Rt Hon Ian Murray MP, Minister of State (Minister for Creative Industries, Media and Arts) and Minister of State (Minister for Digital Government and Data) and subsequently the statement made in the House of Lords; in respect of the UK Biobank data incident. The Group were advised that they would be kept informed of updates as appropriate. AGD noted and thanked the NHS England SIRO Representative for the update. The Group welcomed the approach that NHS England had taken to informing its independent advisory group, and appreciated the complexity of the issues involved. AGD noted the potential for broader discussions on data access, and emphasised that it would be willing to provide independent advice and assurance to NHS England, either in relation to specific queries or more broad policy discussions. The Group looked forward to being involved at appropriate points, whether in committee or separately.
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.	