# Advisory Group for Data (AGD) - Meeting Minutes

Thursday, 16<sup>th</sup> March 2023 09:30 – 16:15

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:							
Name:	Role:						
Paul Affleck (PA)	Specialist Ethics Adviser (not in attendance for part of item 9)						
Maria Clark (MC)	Lay Member Adviser						
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser						
Kirsty Irvine (KI)	Chair (not in attendance for item for item 5.2)						
Dr. Imran Khan (IK)	Specialist GP Adviser (Chair for item 5.2)						
Jenny Westaway (JW)	Lay Adviser						
NHS ENGLAND STAFF IN ATTEN	IDANCE:						
Name:	Role / Area:						
Michael Ball (MB)	Data Access Request Service (DARS) (Presenter: item 5.3)						
Michael Chapman (MCh)	Data and Analytics representative						
Garry Coleman (GC)	Senior Information Risk Owner (SIRO) representative ( <b>Presenter</b> : item 8.1)						
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 5.4) (Observer: item 5.2)						
Cath Day (CD)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 5.1)						
Louise Dunn (LD)	Data Access Request Service Senior Approval Team (DARS SAT) (Presenter: item 4.1) (SAT Observer: item 5.1 to 5.2)						
Duncan Easton (DE)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 5.3)						
Mujiba Ejaz (ME)	Data Access Request Service (DARS) (Presenter: item 5.1)						
Kim Fell (KF)	National Cancer Programme of Care (Observer: item 2.1)						
Liz Gaffney (LG)	Head of Data Access, Data Access Request Service (DARS) (Presenter: item 9)						

Dickie Langley (DL)	Data Protection Officer (DPO) representative (Delegate for Jon Moore)					
Sarah Lawton (SL)	National Disease Registration Service (NDRS) ( <b>Observer</b> : item 2.1)					
Susan Main (SM)	Data Access Request Service (DARS) (Presenter: item 9)					
Karen Myers (KM)	Secretariat Team					
Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative					
Frances Perry (FP)	Digi-Trials ( <b>Presenter</b> : item 5.2)					
Andy Rees (AR)	Digi-Trials ( <b>Observer</b> : item 9)					
Gemma Walker (GW)	Data Access Request Service (DARS) (Observer: item 4.1)					
Vicki Williams (VW)	Secretariat Team					
INDEPENDENT ADVISERS NOT IN ATTENDANCE:						
Prof. Nicola Fear (NF)	Specialist Academic Adviser					
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser					
Dr. Maurice Smith (MS)	Specialist GP Adviser					
NHS ENGLAND STAFF NOT IN ATTENDANCE:						
Dr Arjun Dhillon (AD)	Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)					
Jon Moore (JM)	Data Protection Officer (interim)					

#### 1 Welcome and Introductions

The NHS England Senior Information Risk Owner (SIRO) Representative advised attendees that, noting the statutory guidance and the AGD Terms of Reference (ToR) had not yet been agreed, the meeting could not be held under the draft ToR, until they have been approved, and recognised that the draft ToR may change as the statutory guidance evolves. As NHS England would like to seek advice on a number of areas, the NHS England SIRO Representative therefore proposed that:

- 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); Privacy, Transparency, Ethics and Legal (PTEL); the Caldicott Guardian; and the SIRO.
- Attendees would not be listed as "members" in minutes during the transitional period;

- NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting;
- It was agreed to use the Data Access Request Service (DARS) Standards / Precedents in relation to applications for external data sharing.

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 9<sup>th</sup> March 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.

#### 3 Declaration of interests:

Paul Affleck noted professional links to the University of Leeds (NIC-636167-D4F5F) but noted no specific connections with the application or staff involved and it was agreed that this was not a conflict of interest.

Paul Affleck noted a personal connection to one of the cohort studies in NIC-420168-K4N1F-v4.3 (University of Bristol). It was agreed this did not preclude Paul from taking part in the discussions about this application.

Michael Chapman noted a professional link to the Longitudinal Linkage Consortium in NIC-420168-K4N1F (University of Bristol) due to reviewing materials relating to the consortium as a member of the UK Statistics Authority Research Accreditation Panel. It was agreed that this was not a conflict of interest.

Dr Robert French noted a professional link to the staff involved with NIC-420168-K4N1F (University of Bristol), but noted no specific connection with this application and it was agreed this was not a conflict of interest.

Kirsty Irvine noted a professional link to one of the organisations involved with NIC-383356-N8J6Z - Cambridge University Hospitals NHS FT. It was agreed that Kirsty would not remain in the 'room' for the discussion of that application.

Dr. Imran Khan noted a previous working relationship with a member of staff involved with NIC-616967-H6Z6L (NHS Dorset ICB) application. It was agreed this did not represent a substantive conflict of interest.

Dr. Imran Khan noted a previous working relationship with a member of staff involved with NIC-175120-W5G2X (Office for National Statistics (ONS)) application. It was agreed this did not represent a substantive conflict of interest.

#### 4. INTERNAL DATA DISSEMINATION REQUESTS:

4.1 | Reference Number: NIC-661891-S1S9Q-v0.4

**Applicant:** NHS England (Quarry House)

Application Title: National radiotherapy demand and capacity modelling

Presenter: Louise Dunn

Observers: Sarah Lawton, Kim Fell, Gemma Walker

**Application:** This was a new application.

The purpose of the application is to access pseudonymised National Disease Registration Service (NDRS) data; to support a project, to inform future radiotherapy provision and capital investment by forecasting future demand for linear accelerators and the capacity required to meet this demand.

Should the application proceed, further details would be made available within the relevant 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 significant points:

- **4.1.1** The independent advisers queried whether the processing outlined in the application was referenced within NHS England's published <u>privacy notice</u>; and advised that, if not, this was a significant risk to NHS England in respect of UK General Data Protection Regulation (UK GDPR) transparency obligations; and that the generic published privacy notice may not be fit for purpose, for example, if the involvement of the Data Processor Edge Health Ltd was not listed.
- **4.1.2** The independent advisers acknowledged the logistics and resource implication to NHS England in terms of the drafting and uplifting their privacy notice, and highlighted the importance of publishing an internal data uses register which may mitigate this issue.
- **4.1.3** The independent advisers noted the statements in section 3(b) (Additional Data Access Requested) "The data requested is the minimum amount necessary..."; and asked that ,for transparency, section 5(b) (Processing Activities) was updated with further information of the data minimisation efforts undertaken in line with <a href="NHS Digital DARS standard for data">NHS Digital DARS standard for data</a> minimisation, since this was currently unclear.
- **4.1.4** In addition, NHS England advised the group of some additional dataset fields that would be disseminated, including, but not limited to, the first part of the postcode and ethnicity; and it was suggested by the independent advisers that this information was also added to section 5(b) for transparency, in line with the <a href="NHS Digital DARS Standard for processing activities.">NHS Digital DARS Standard for processing activities.</a>

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

- **4.1.5** The group noted that this was the first NHS England application reviewed by AGD.
- **4.1.6** The independent advisers noted the importance of the service evaluation work being undertaken as part of this application and supported the processing.
- **4.1.7** The presenter noted to the group that there were incorrect references within the application to "research"; and advised that these would be removed and updated to ensure it was clear that the purpose of the application was for "service evaluation".
- **4.1.8** The group noted that the application would not become a 'contract', because the applicant was NHS England and that the application had been reviewed by the group in line with the same process as all other DARS applications on the understanding that it would form part of a published internal data uses register. The group noted that the process for internal

flows of data applications was still being discussed within NHS England, and that the process would be brought to AGD before being finalised.

- **4.1.9** The independent advisers confirmed that they would be very supportive of a published data uses register for the internal flows of data, containing the information within section 5 (Purpose / Methods / Outputs) of the application; that outlines the details of the objective for processing, processing activities, specific outputs expected and the benefits.
- **4.1.10** The independent advisers noted that section 2.1 (Category) of the internal application assessment form stated that ethics approval was **not** required, as the application was not for the purpose of 'research'; however, advised that this was updated further, to make it clear that this assessment was undertaken in line with NHS Digital DARS Standard for Ethical Approval.
- **4.1.11** The independent advisers queried the statement in section 5(a) (Objective for Processing) "A data processing agreement is in place with Edge Health Ltd, this Agreement sits outside the scope of DARS and is not DARS' responsibility to put it in place"; and suggested that this was not necessary to include this statement in the application, and that this should be moved to the internal application assessment form, provided as a supporting document.
- **4.1.12** In addition, the independent advisers suggested that section 5(a) was updated to be clear that the appropriate Data Protection Impact Assessment (DPIA) process for Edge Health Ltd had been followed.
- **4.1.13** It was also suggested by the independent advisers that, for transparency, section 5(a) was updated to be clear that Edge Health Ltd had been recruited by the appropriate NHS England tendering process; and that they were considered to be the most appropriate service provider for the processing outlined.
- **4.1.14** The Senior Information Risk Owner (SIRO) representative noted to the group that section 5(b) stated "The data will be stored on secure servers based in the UK"; and suggested that this should be updated to state "...secure data centres at specific centres throughout the UK", or similar. The independent advisers noted and were supportive of the proposed update to section 5(b).
- **4.1.15** The independent advisers noted the reference in section 5(c) (Specific Outputs Expected) to two reports being produced following analysis, however queried the statement *"The results of the analysis will not be made publicly available"*; and queried if the reports could be made public.
- **4.1.16** Noting that section 5(e) (Is the Purpose of this Application in Anyway Commercial) stated that there was **no** commercial purpose of the application, the independent advisers noted that Edge Health Ltd were providing a service beyond just hosting the data, and queried if the <a href="NHS Digital DARS Standard for Commercial Purpose">NHS Digital DARS Standard for Commercial Purpose</a> needed updating to also anticipate the processing under this type of application (or to carve out such processing from the application of the Standard for Commercial Purpose); and / or if section 5(e) needed updating to reflect that there was a commercial purpose to the application.
- **4.1.17** The independent advisers queried why the analysts could not be 'brought to the data' (rather than disseminating the data) to minimise data flows. They also suggested this should be the default position when undertaking such evaluations.

# 5. EXTERNAL DATA DISSEMINATION REQUESTS:

**5.1** Reference Number: NIC-420168-K4N1F-v4.3

**Applicant:** University of Bristol

**Application Title:** University of Bristol - Longitudinal Linkage Collaboration

Presenter: Mujiba Ejaz

SAT Observers: Louise Dunn / Cath Day

**Previous Reviews:** The application and relevant supporting documents were previously presented at the IGARD meetings on the 21<sup>st</sup> January 2021, 4<sup>th</sup> February 2021, 4<sup>th</sup> March 2021, 5<sup>th</sup> May 2022, 23<sup>rd</sup> June 2022 and the 7<sup>th</sup> July 2022.

It was also previously discussed at the IGARD – NHS Digital COVID-19 response meetings on the 8<sup>th</sup> December 2020,15<sup>th</sup> December 2020, 12<sup>th</sup> January 2021, 26<sup>th</sup> January 2021, 2<sup>nd</sup> February 2021, 16<sup>th</sup> March 2021, 30<sup>th</sup> March 2021, 27<sup>th</sup> April 2021 and the 5<sup>th</sup> October 2021.

The application was presented to the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 10<sup>th</sup> March 2021 and the 16<sup>th</sup> December 2021.

**Application:** This was a renewal, extension and amendment application.

The amendment is to change the lawful basis to address the common law duty of confidentiality from Health Service (Control of Patient Information) Regulations 2002 (COPI) to consent.

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

NHS England were seeking advice on the following points:

- Whether the consent material is acceptable (and if so, does it follow therefore that for the studies listed, the consent covers the ability to link to NHS England data and use for general research as listed).
- 2. The approach to long-running research projects where there is opportunity to considerably broaden the scope beyond that originally envisaged "in the public interest".

**Outcome of discussion:** The Group made the following observation on the application and / or supporting documentation provided as part of the review.

In response to points 1 and 2 above:

- **5.1.1** The independent advisers noted and thanked the efforts undertaken by DARS colleagues in assessing the various consent materials for each study.
- **5.1.2** The independent advisers noted however, that communications such as privacy notices and newsletters were being cited as a way of meeting the common law duty of confidentiality. It was suggested that the consent analysis should hone in on any potentially conflicting statements in the original consent forms/participant information sheets, since whilst privacy notices and newsletters can clarify what the consent was intended to cover, they cannot reverse any restrictions in the original materials to where data will be stored, what research it will support and who will analyse it.
- **5.1.3** The independent advisers also suggested that a further column should be added to the consent review table, for a Caldicott Guardian view.

- **5.1.4** It was agreed that any specific comments, from the independent advisers on individual studies / consent materials, that form part of this application, would be sent to the presenter via the AGD Secretariat following the meeting, if available; noting time was limited in-meeting to discuss every aspect of each consent for each individual study.
- **5.1.5** The independent advisers advised that they would encourage and be supportive of further engagement by NHS England with the Health Research Authority Confidentiality Advisory Group (HRA CAG); noting that HRA CAG is an independent body which provides expert advice on the use of confidential patient information).
- **5.1.6** Some independent advisers queried whether there were any updates / changes in respect of the status of the data, for example, was this now 'anonymised in context' as per the draft Information Commissioner's Office (ICO) <u>guidance</u>; noting that this may provide a further gateway for linkage, depending on the exact wording of the consent in each case.
- **5.1.7** When the application was reviewed on the 4<sup>th</sup> March 2021, the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) had suggested that the applicant engaged with a sample of members from each cohort to see if the processing is encompassed by their original consent. The independent advisers reiterated that they were still supportive of this approach, with carefully worded questions for the cohort members, and as previously advised that the outcomes of such engagement would be compelling evidence in reaching a view on the breadth of the consent.

**5.2** | Reference Number: NIC-383356-N8J6Z-v0.6

Applicant: Cambridge University Hospitals NHS FT

Application Title: Prophylaxis for patients at risk of COVID-19 infection (PROTECT-V)

Presenter: Frances Perry

SAT Observer: Louise Dunn

**Observer:** Dave Cronin

**Application:** This was a new application.

The purpose of this application is for a trial on prevention of COVID-19, rather than treatment once disease occurs. This will be measured by comparing if COVID-19 develops in people who take the trial treatment against those who receive a placebo ("dummy") treatment.

Should the 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 comments:

- **5.2.1** The independent advisers noted and commended NHS England on the information provided within the application and internal application assessment form, which supported the review of the application.
- **5.2.2** The independent advisers queried the statement in section 3(b) (Additional Data Access Requested) and section 5(a) (Objective for Processing) that "GDPR does not apply to data solely relating to deceased individuals", however, noting that the status of those patients that are still alive could be inferred, suggested that these statements were updated to include a UK General Data Protection Regulation (UK GDPR) legal basis.

	<b>5.2.3</b> In addition, it was noted by the independent advisers that a query had previously been raised on the point raised above (5.2.2) by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD), with Privacy, Transparency, Ethics and Legal (PTEL). The group advised that they would welcome an update from NHS England in due course.	NHSE		
	<b>5.2.4</b> The independent advisers noted that section 5(e) provided details of the commercial purpose of the application; however, suggested that section 5(a) <b>and</b> section 5(e) were updated further to include details of any indirect commercial benefits, in line with <a href="NHS Digital">NHS Digital DARS Standard for Commercial Purpose</a> .  Purpose.			
	<b>5.2.5</b> Noting the statement in section 5(b) (Processing Activities) "Statistical data analysis will be carried out either directly in person or remotely"; the independent advisers asked that this was updated to align with NHS England's policy on remote access.			
	<b>ACTION:</b> NHS England to provide its position to AGD on remote access in relation to the listed territory of use (as agreed at the AGD meeting on the 2 <sup>nd</sup> February 2023).	NHSE		
5.3	Reference Number: NIC-616967-H6Z6L-v0.3			
	Applicant: NHS Dorset ICB			
	Application Title: DSfC - NHS Dorset ICB - Comm / IV			
	Presenter: Michael Ball			
	SAT Observer: Duncan Easton			
	Application: This was a new application.			
	The purpose of the application is for Invoice Validation, which is part of a process by which providers of care or services get paid for the work they do; and to support the commissioning of health services.			
	Should the application be approved by NHS England, further details would be made available within the <a href="Data Uses Register">Data Uses Register</a> .			
	<b>Outcome of discussion:</b> The group were supportive of the application and wished to draw to the attention of the SIRO the following comments:			
	<b>5.3.1</b> The independent advisers noted that the applicant's published privacy notice contained information in respect of the opt-out arrangements, that did not align with the opt-out information within the application; and suggested that this was reviewed, and the privacy notice and / or application were updated as necessary to align and reflect the correct information.			
	<b>5.2.2</b> The independent advisers queried the reference in section 6 (Special Conditions) to a release register in "April 2023"; and advised that this date was reviewed and updated if it was now deemed to be incorrect.			
5.4	Reference Number: NIC-636167-D4F5F-v0.4			
	Applicant: Leeds Institute of Health Sciences			
	<b>Application Title:</b> The Yorkshire Lung Screening Trial – Identifying smoking cessation service users			
	Presenter: Dave Cronin			

Application: This was a new application.

The purpose of the application is for a research project, which aims to assess the effect of colocating lung cancer screening units with smoking cessation services on smoking rates.

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

NHS England were seeking advice on the following points:

- 1. The specific data request noting that the advice would inform its wider data minimisation policy.
- 2. Subject to point 1, whether independent advisers would be supportive of this application.

**Outcome of discussion:** The group made the following observations on the application and / or supporting documentation provided as part of the review:

In response to points 1 and 2 above:

- **5.4.1** It was the view of some of the independent advisers that the processing was reasonable, i.e. to undertake the linkage as presented in the application; in line with the Caldicott Principles, UK General Data Protection Regulation (UK GDPR) etc; and they could see the value of this research.
- **5.4.2** The independent advisers advised that they had located a published <u>privacy notice</u> for 'One You Leeds' on a website, which seemed to rule out the proposed linkage method. They also noted that they had not seen the consent materials One You Leeds used and therefore could not ascertain if they were compatible with the proposed linkage/data use.
- **5.4.3** The independent advisers noted the information within section 2.3 (Benefits Evaluation) of the internal application assessment, that noted the applicant had concerns that some of the cohort members may be apprehensive about attending a lung check if their invitation emphasised that smoking cessation services would also be offered, due to concern that they may feel pressured to stop smoking. Noting this, the independent advisers queried if the lung screening cohort had sufficient information on the study and the opt-out arrangements / options and how transparent this was; and suggested that this was clarified with the applicant.
- **5.4.4** The independent advisers noted that it was not clear if Reed Wellbeing Ltd were a Data Processor or a Data Controller and suggested that further work was undertaken to determine their status in line with NHS Digital DARS Standard for Data Controllers.
- **5.4.5** The group discussed a Data Processor Agreement, and noted that in line with current practice, there was not a separate Data Processor Agreement in place; and suggested that there should be some documentation of agreement(s), to ensure all the correct parties were adhering to a written contract of agreement.
- **5.4.6** The independent advisers queried if there was actually a need for NHS England to carry out the linkage and whether the Yorkshire Lung Screening Trial had sufficient identifiers for Reed Wellbeing Ltd to identity those who were also in the One You Leeds dataset, thus minimising the flows of data.

#### EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL

**6.1** | Reference Number: NIC-175120-W5G2X-v10.2

**Applicant:** Office for National Statistics (ONS)

**Application Title:** D5 - Office for National Statistics requirements for NHS-Digital data, for the purposes of Statistics and Statistical Research, under section 45 of the Statistics and Registration Services Act 2007 as amended by the Digital Economy Act 2017

**Application:** The purpose of the application is to use data previously disseminated under this data sharing agreement (DSA) for the PSS CQUIN project, for this new project the Social Network Research Study.

**Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided:

- **6.1.1** It was noted that the SIRO approval form stated that independent oversight of the application had **not** been sought for this application, due to a legal notice mandating the provision of the requested datasets. The independent advisers suggested that this was updated to more accurately reflect that there was no independent oversight due to an NHS England policy decision.
- **6.1.2** In addition, the independent advisers suggested that where there was a legal notice mandating the provision of datasets, this provided a stronger rationale for NHS England to seek independent oversight, for example, to review the yielded benefits and ethical approval etc.

The NHS England SIRO representative thanked the group for their time.

6.2 Reference Number: NIC-157211-T8B2M-v1.5

**Applicant:** University College London (UCL)

**Application Title:** The role of IAPT in the prevention of dementia and the amelioration of its impact on service use and co-morbidities (the MODIFY project)

**Previous Reviews:** The application and relevant supporting documents had previously been presented at the IGARD business as usual (BAU) meeting on the 17<sup>th</sup> October 2019 and the 8<sup>th</sup> December 2022.

**Application:** The purpose of the application is for a study, originally aimed to only look at dementia incidences, but has now expanded its scope to cover other mental health conditions.

**Outcome of discussion:** The group appreciated that the NHS England SIRO representative was seeking advice on interpretation of a precedent, and seeking to ensure that NHS England acted transparently and in accordance with agreed process.

**6.2.1** The group confirmed that they were supportive of the application proceeding via precedent.

The NHS England SIRO representative thanked the group for their time.

6.3 Reference Number: NIC-72064-V5V2X-v5.8

**Applicant:** London School of Hygiene and Tropical Medicine

Application Title: Liver transplantation as treatment for patients with hepatocellular

carcinoma; a study using existing electronic data.

**Previous Reviews:** The application and relevant supporting documents had previously been presented at the IGARD business as usual (BAU) meeting on the 10<sup>th</sup> August 2017, 21<sup>st</sup> September 2017 and the 7<sup>th</sup> April 2022.

**Application:** The purpose of the application is to maximise the benefit of liver transplantation as a treatment option for patients with liver cancer.

**Outcome of discussion:** The independent advisers noted that at the request of NHS England, any applications previously reviewed by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) that had outstanding conditions over three-months old; would be submitted to the AGD Secretariat for review in-meeting by AGD independent advisers, in line with IGARD's previous out of committee policy.

The AGD independent advisers would only review if the conditions have been met or not, and not the whole application.

The conditions from the IGARD meeting on the 7<sup>th</sup> April 2022 were as follows:

- 1. In respect of the s251 support:
  - a) The applicant to liaise with HRA CAG to clarify if s251 support is still required for this application.
  - b) If the s251 support is **not** required, to provide written confirmation from HRA CAG; or,
  - If the s251 support is required, to provide written confirmation that the applicant has continued to meet the HRA conditions of support, by way of annual reports; and.
  - d) To provide written confirmation that HRA CAG continue to support the application.
  - e) To upload all the written confirmation to NHS Digital's CRM system for future reference.

A quorum of independent advisers in-meeting were content that the multi-limbed condition had been met.

#### **AGD Operations**

## 7 Standard operating procedures

The ongoing forward plan of work for creating Standard Operating Procedures was discussed.

To note

# 8 New Operational Actions & those carried forward from previous meetings of AGD:

# 8.1 Inside Scope of IR35

Garry Coleman provided a further verbal update in respect of IR35 and the impact on independent advisers who were previously on IGARD, noting that they would fall inside scope of IR35 from the 1<sup>st</sup> April 2023.

Garry Coleman noted that there was urgent work ongoing within NHS England to clarify the impact on the independent advisers of falling in scope of IR35, and the options available to NHS England to mitigate the impact / risks on independent advisers, AGD and NHS England as a result of this.

The independent advisers noted the verbal update from NHS England, and reiterated previous concerns in respect of the impact both to the current group of advisers, and future recruitment to the group.

The independent advisers also confirmed that they were still in the process of considering their individual circumstances due to the impact of the IR35 change.

NHS England noted the urgency of this ongoing issue and advised that they would provide an update as soon as possible, either out of committee or in-meeting.

Both independent advisers and NHS England again re-iterated a significant risk to AGD, noting that independent advisers would be inside scope of IR35 from the 1<sup>st</sup> April 2023; and therefore individual decisions on whether to continue, on this basis, would need to be confirmed by the 31<sup>st</sup> March 2023 to the AGD Secretariat.

# 8.2 AGD Terms of Reference (ToR) and statutory guidance

Colleagues at the Department for Health and Social Care (DHSC) provided a copy of the draft statutory guidance to the AGD Chair on the 14<sup>th</sup> March 2023, which was shared with the group on the 15<sup>th</sup> March 2023 by the AGD Secretariat.

The independent advisers thanked the DHSC for sharing the latest draft and noted that comments would need to be provided back to DHSC by 17:00 on Tuesday 21st March 2023.

# 8.3 Policy position: no confidentiality issues for the receipt of pseudo data for those that hold the means to re-identify

The IGARD meeting minutes from the 26th January 2023 stated the following:

IGARD members noted the outstanding action following their meeting on the 15<sup>th</sup> September 2022, which reiterated an action from the 28<sup>th</sup> July 2022 that following SAT 'touching base' with HRA CAG to confirm their previous position that there are still no confidentiality issues for the receipt of pseudo data for those that hold the means to re-identify, that a file note be provided of the meeting and be recirculated to HRA CAG, NHS Digital and the IGARD Chair to ensure that everyone had a formal output of the meeting, since it was a key policy change which needed to be kept on file as an "artefact" for future use.

**ACTION:** IGARD asked that a copy of the correspondence as noted above be circulated to IGARD's successor group to keep on file.

The group noted that NHS England had provided a written update on this action following further correspondence from HRA CAG; that was provided in advance of the meeting.

The group thanked NHS England for sharing the update and noted the content of the response; and confirmed that they had no further comments to make, and the action was therefore closed.

# **Any Other Business**

## 9 [Draft] Annual Confirmation Report

Liz Gaffney and Susan Main attended the meeting to provide the group with an update on the draft Annual Confirmation Report; and to receive any further advice on the draft provided to the group in advance of the meeting.

The independent advisers noted, that the Independent Group Advising (NHS Digital) on the Release of Data (IGARD), had sent comments / feedback on the draft Annual Confirmation Report to colleagues in DARS in March 2022 and September 2022.

Michael Chapman advised the group that comments previously received from IGARD had been noted and the relevant updates had been made to the latest version of the draft Annual Confirmation Report shared with the group, to reflect the IGARD feedback.

The independent advisers and DARS colleagues spent time in-meeting going through each individual aspect of the draft Annual Confirmation Report and previous IGARD comments; and discussed suggested amendments and updates. AGD queried what the specific feedback was from the user group so that they could take that into consideration, but this was not available in written form. The independent advisers were keen to understand how the form was received by users.

The independent advisers asked that the next iteration of the Annual Confirmation Report template be shared with the group at a future AGD meeting.

**ACTION:** DARS to share a copy of the next iteration / finalised draft Annual Confirmation Report with AGD. DARS/project team to provide a copy of user feedback, if available.

NHS England thanked independent advisers for their comments / feedback.

# **Meeting Closure**

As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.

# Independent Group Advising on Releases of Data (IGARD): Out of committee report 10/03/23

These applications were previously recommended for approval with conditions by IGARD, and since the previous Out of Committee Report the conditions have been agreed as met out of committee.

NIC Reference	Applicant	IGARD meeting date	Recommendation conditions as set at IGARD meeting	IGARD minutes stated that conditions should be agreed by:	Conditions agreed as being met in the updated application by:	Notes of out of committee review (inc. any changes)
NIC-58999- K6P8B-v5	IQVIA IES UK Limited	01/12/2022	<ol> <li>In respect of the retention / deletions of the data:         <ul> <li>a) To provide written justification, in section 1 and section 5, for retaining the data; and,</li> <li>b) To provide written confirmation in section 1 and section 5 outlining the plan for deleting the data in terms of an organisational data retention and destruction policy.</li> </ul> </li> </ol>	IGARD Chair	IGARD Chair	N/A