

Advisory Group for Data (AGD) – Meeting Minutes

Thursday 9th February 2023

09:30 – 17:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser
Maria Clark (MC)	Lay Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Michael Ball (MB)	Data Access Request Service (DARS) (Presenter: item 4.4 & 4.5)
Michael Chapman (MCh)	Data and Analytics representative (not in attendance for part of items 6 and 7)
Garry Coleman (GC)	Senior Information Risk Owner (SIRO) representative
Louise Dunn (LD)	Data Access Request Service Senior Approval Team (DARS SAT) (Observer: items 4.1, 4.2 & 4.3)
Duncan Easton (DE)	Data Access Request Service Senior Approval Team (DARS SAT) (Observer: items 4.4 & 4.5)
Dan Goodwin (DG)	Data Access Request Service (DARS) (Presenter: item 4.1)
Dickie Langley (DL)	Data Protection Officer (DPO) and Information Governance (IG) representative (Delegate for Jon Moore) (Presenter: item 5)
Jon Moore (JM)	Data Protection Officer (interim) (in attendance for item 5)
Karen Myers (KM)	Secretariat Team
Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative

James Watts (JW)	Data Access Request Service (DARS) (Presenter: item 4.2)
Anna Weaver (AW)	Data Access Request Service (DARS) (Presenter: item 4.3)
Vicki Williams (VW)	Secretariat Team
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic 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)

1	<p>Welcome and Introductions</p> <p>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:</p> <ul style="list-style-type: none"> • 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. <p>The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis.</p> <p>Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.</p>
2	<p>Review of previous AGD minutes:</p>

	<p>The minutes of the 2nd February 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.</p>
<p>3</p>	<p>Declaration of interests:</p> <p>Maria Clark noted professional links as part of her role as an external member of the University of Sheffield Research Ethics Committee. However, she noted no specific connections with the application (NIC-347209-L2Q4S-v0.7 St. George’s Hospital Medical School), or the staff involved, and it was agreed that this was not a conflict of interest.</p> <p>Maria Clark noted that as part of her role as officer of the BMA, she had a professional link with NIC-172334-W0G2L-v4.12 Imperial College London. However, she noted no specific connections with the application, or the staff involved, and it was agreed that this was not a conflict of interest.</p>
<p>EXTERNAL DATA DISSEMINATION REQUESTS</p>	
<p>4.1</p>	<p>Reference Number: NIC-347209-L2Q4S-v0.7</p> <p>Applicant: St. George’s Hospital Medical School (Data Controller)</p> <p>Application Title: A randomised controlled trial of Specialist Physiotherapy for Functional Motor Disorder (Physio4FMD)</p> <p>Presenter: Dan Goodwin</p> <p>SAT Observer: Louise Dunn</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study to evaluate the clinical and cost-effectiveness of the specialist physiotherapy intervention compared to ‘treatment as usual’ for participants with Functional motor disorder, over 12 months.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none"> 1. Compatibility of consent. <p>Outcome of discussion: The Group were broadly supportive of the application if the following significant / high level comments were addressed, and wished to draw to the attention of the SIRO the following significant comments:</p> <p>In response to point 1:</p> <p>4.1.1 The cohort may be surprised about the nature and breadth of data being requested, for example, the v4.0 of the Patient Information Sheet (PIS) dated 11/05/21 states participants “<i>will be in the study for 12 months</i>”, whereas the application is requesting data for each participant over a 6-year timeframe.</p> <p>4.1.2 Noting Caldicott Guardian Principle 8 “<i>...A range of steps should be taken to ensure no surprises for patient and service users...</i>”, the independent advisers suggested that the applicant take proactive steps, such as engaging with the Patient & Public Involvement & Engagement (PPIE) Group to check their understanding.</p>

	<p>4.1.3 Based on the engagement with the PPIE group, next steps could include updating the Privacy Notice, and given the long term follow up in place, the independent advisers also suggested the applicant proactively contact the cohort in relation to point 3.1.1 above.</p> <p>In addition, the Group made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>4.1.4 The independent advisers asked that section 1 (Abstract) be updated to include a brief summary of the work undertaken by DARS with regard to data controllership questions asked around the University College London, and suggested that a clear statement be included in section 5 (purpose / methods / outputs) as to why the co-investigator was not considered a joint data controller.</p> <p>4.1.5 The independent advisers queried the extent of the activities carried out in parallel in Scotland, and if the Scottish activity was done in collaboration with, or complementary to, this application. The independent advisers suggested further information was included in section 5, including but not limited to, when referring to the hospitals in England to also include the Scotland activity, and to consider if the nature of the activity in Scotland meant there were any joint data controllership questions with the University of Edinburgh. The independent advisers noted they were unable to provide a view on the data controllership, because no information had been provided for them to consider this aspect.</p> <p>4.1.6 The independent advisers suggested the following amendments to the application:</p> <ul style="list-style-type: none"> 4.1.6.1 Section 5(a) (Objective for Processing) be updated to include a description of the data minimisation carried out. 4.1.6.2 Section 3 (Data Sets Held / Requested) be updated to include details of the minimisation of the fields in HES. 4.1.6.3 To ensure acronyms be defined upon first use in section 5. 4.1.6.4 Section 5(c) (Specific Outputs Expected) be updated to temper the language to avoid any suggestion that changes will happen. 	
<p>4.2</p>	<p>Reference Number: NIC-671672-G6R6W-v0.4</p> <p>Applicant: London School of Hygiene and Tropical Medicine (Data Controller)</p> <p>Application Title: Identifying Cancer Recurrence within Patient Care Pathways across Linked National Clinical Datasets</p> <p>Presenter: James Watts</p> <p>SAT Observer: Louise Dunn</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research study to develop and validate methods to phenotype cancer recurrence after curative treatment for bowel cancer in linked national clinical datasets and to assess how well the methods extend to other cancer sites.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The Group were supportive of the application and wished to draw to the attention of the SIRO the following high-level comment:</p>	

<p>(IGARD) last saw the application in September 2022, they had been “unable to recommend for approval” and asked that this be updated.</p> <p>4.3.2 Although the independent advisers and NHS England attendees were supportive of the application, the independent advisers suggested that the applicant address the previous comments made by IGARD on the 29th September 2022 and 6th February 2020, including but not limited to a wider discussion with the British Medical Council (BMA) Consultants Committee UK.</p> <p>4.3.3 The Independent advisers noted the concerns raised by IGARD previously that there are potential significant ethical implications and impact, for example, on medical schools, which needed to be carefully explored. The independent advisers suggested the applicant may wish to also engage with the BMA ethics committee.</p> <p>4.3.4 Separate to the application, the independent advisers noted reference to “remote access” and asked that NHS England provide its position on remote access, noting that IGARD had previously raised this query several times with NHS Digital, and this was to ensure that any policy position was being applied consistently. In addition, the independent advisers queried if applicants were aware of the remote access policy. The independent advisers noted, Privacy, Transparency, Ethics & Legal (PTEL) were advising that when an applicant listed “EEA”* in the Territory of Use section of the DSA, that the EEA countries be specifically named in section 6 (Special Conditions).</p> <p>*European Economic Area</p> <p>ACTION: NHS England to provide its position to AGD on remote access in relation to the listed territory of use.</p> <p>In addition, the Group made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>4.3.5 Noting that DARS had not been in contact with the applicant since December 2022, the independent advisers suggested that section 5(d)(iii) (Yielded Benefits) be updated if any other recommendations had been taken on board since last reviewed and the section be edited to highlight the impact of the yielded benefit included.</p> <p>4.3.6 The independent advisers noted that the funding ended in March 2023.</p>	DARS
<p>4.4 Reference Number: NIC-627124-V8Z6Z-v0.3</p> <p>Applicant: Bradford Teaching Hospitals NHS Foundation Trust (Data Controller)</p> <p>Application Title: DSfC - Bradford Teaching Hospitals NHS Foundation Trust - Comm</p> <p>Presenter: Michael Ball</p> <p>SAT Observer: Duncan Easton</p> <p>Application: This was a new application.</p> <p>The purpose of the application is to provide intelligence to support the commissioning of health service.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented at the IGARD meetings on the 28th July 2022.</p>	

	<p>Outcome of discussion: The Group were not supportive of the commissioning application and wished to draw to the attention of the SIRO the following significant / high-level comments, and suggested that the application be brought back to a future meeting:</p> <p>4.4.1 The Group were unable to support the commissioning application based on previous points raised by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) and based on the evidence provided in-meeting. However, the Group were supportive if the application was recast as a 'research' application.</p> <p>4.4.2 The independent advisers noted that the letter provided by the Bradford District & Craven Health & Care Partnership, as a standalone document, did not provide confirmation that the application was supporting commissioning.</p> <p>4.4.3 The independent advisers suggested that the applicant address the previous comments made at IGARD on the 28th July 2022, including but not limited to, confirming why this was a 'commissioning' application, not a 'research' application.</p> <p>4.4.4 Noting that the Health Research Authority Confidential Advisory Group (HRA CAG) supported aspects of the processing for medical 'research', and noting that applicant maintained the application was for 'commissioning', to confirm how the use of data is in line with HRA CAG support.</p> <p>4.4.5 Noting that a member of the business intelligence team in the hospital has the ability to pseudonymise hospital datasets and therefore requires access to the SALT key, the attendees noted issues with regard to transparency, since the applicant was stating that data subjects could not be identified whilst also holding the SALT key.</p> <p>4.4.6 At each stage of the process, the independent advisers suggested that the data flows and the nature of the data be more clearly explained at each point.</p> <p>4.4.7 The attendees noted that the National Child Measurement Programme Data is governed by the Local Authority Regulations 2013, and has strict parameters with regard to how the data can be processed for the purpose of surveillance, research, monitoring, audit or the planning of health services (Regulation 15); and onward processing (Regulation 16) which is subject to the condition that no individual child can be identified.</p> <p>In addition, the Group made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>4.4.8 The independent advisers suggested the following amendments to the application:</p> <p style="padding-left: 40px;">4.4.8.1 To update section 2(c) (Territory of Use) to correctly reflect that the territory of use was "<i>England and Wales</i>" and not "<i>UK</i>".</p> <p style="padding-left: 40px;">4.4.8.2 To provide confirmation that the appropriate data destruction procedure has been adhered to and a certification of destruction will be provided to NHS England.</p>	
<p>4.5</p>	<p>Reference Number: NIC-617743-X0M9Z-v0.3</p> <p>Applicant: NHS Coventry and Warwickshire Integrated Care Board (ICB) (Data Controller)</p> <p>Application Title: Integrated Care Board Pseudonymised National HES Extract Service</p> <p>Presenter: Michael Ball</p> <p>SAT Observer: Duncan Easton</p> <p>Application: This was a new application.</p>	

The purpose of the application is to allow the ICB to compare / benchmark services commissioned by other ICBs with their own, to show their effectiveness and adjust their future commissioning decisions.

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. Seeking advice on an application with a view to the wording being templated across other ICBs.

Previous Reviews: The application and relevant supporting documents were previously presented at the IGARD meetings on the 28th July 2022.

Outcome of discussion: The Group were supportive of the application and wished to draw to the attention of the SIRO the following high-level comments:

In response to point 1:

4.5.1 The independent advisers noted that there was an inherent risk for NHS England of relying on multiple Data Security and Protection Toolkits (DSPT).

4.5.2 The Independent advisers suggested that where referencing legislative extracts that these be edited to only those relevant to commissioning and that they be correctly cited, including the relevant section number of the Statute.

4.5.3 The independent advisers queried the approach of using data dissemination, and suggested that a templated wording approach would not be appropriate, each application needing to justify why an NHS England Trusted Research Environment (TRE) / Data Access Environment (DAE) could not be used.

4.5.4 The independent advisers suggested that section 5(a) (Objective for Processing) be updated to provide a clear justification as to why an NHS England Trusted Research Environment / Data Access Environment could not be used.

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

4.5.5 The independent advisers suggested the following amendments to the application:

4.5.5.1 To update section 5(c) (Specific Outputs Expected) to include narrative of shared learning or outputs will be shared more widely with other ICBs.

4.5.5.2 To update section 2(c) (Territory of Use) to correctly reflect that the territory of use was "*England and Wales*" and not "*UK*".

4.5.5.3 To provide confirmation that the appropriate data destruction procedure has been adhered to and a certification of destruction will be provided to NHS England.

4.5.5.4 To correct the plethora of typo and grammatical errors in the templated wording.

4.5.5.5 To update the citation wording in section 6 to the correct version and remove reference to "*NHS Digital*" (Special Conditions) .

ACTION: The independent advisers asked DARS that the citation special condition be harmonised to reflect the merger and to ensure that the most recent version was being used in section 6 of the data sharing agreements (DSA).

		DARS
5	Confidential Advice Session	
AGD Operations		
6	Standard operating procedures	
6.1	The ongoing forward plan of work for creating Standard Operating Procedures was discussed and it was agreed to create a priority list ahead of the finalisation of the AGD Terms of Reference.	VW
7	Operational Actions carried forward from 2nd February 2023 AGD meeting:	
7.1	ACTION: The NHS England representatives noted that NHS England was still considering the issue of IR35 and the impact on independent advisers who were previously on IGARD, and would provide an update at the 23 rd February meeting.	DL
7.2	ACTION: Draft text for the new AGD landing page for the group on the NHS Digital website was considered and corrections fed back to the NHS England Web Team.	VW
7.3	ACTION: AGD Secretariat were liaising with NHS England web team colleagues to arrange publication of AGD ratified minutes on the newly created AGD landing page on the NHS Digital website (an interim measure until AGD is added to the NHS England website).	VW/KM
7.4	ACTION: AGD Secretariat to liaise with NHS England IT colleagues to create a new “AGD” mailbox (once the name of the group is finalised), until that time, the IGARD@NHS.net mailbox would continue for an interim period. An update on the new mailbox would be provided at the next meeting (provisional date: 23 rd February 2023)	VW/KM
7.5	In addition, AGD discussed outstanding actions from the Independent Group Advising on the Release of Data (IGARD), as outlined in the final IGARD minutes from the 26th January 2023 . It was agreed that this would be discussed at today’s AGD meeting to determine an agreed process for reviewing outstanding actions, and how this could be made transparent to the public, however the relevant NHS England representative was not present and it was agreed to carry this action forward, with the exception of the IGARD action: National Disease Registry Service Congenital Anomalies Data Set Briefing. The finalised briefing had been received by the AGD Secretariat and would be received by AGD on the 23 rd February and appended to those minutes. ACTION: the NHS England representatives agreed to discuss the outstanding IGARD actions outside of the meeting, and bring the proposed way forward at the AGD meeting on the 23 rd February 2023.	MC
8	Operational Actions from 9th February AGD meeting:	
8.1	It was agreed that in the absence of the finalised AGD Terms of Reference (TOR) and underpinning standard operating procedures, that today’s minutes would be ratified at the next meeting of AGD on the 23 rd February 2023.	
Any Other Business		
9.1	NHS England Annual Confirmation Report	

<p>9.2</p> <p>9.3</p>	<p>Michael Chapman agreed to provide an update to AGD on the NHS England Annual Confirmation Report, with a draft copy of the report circulated in advance (provisional date: 2nd March 2023).</p> <p>Privacy Notice</p> <p>Michael Chapman agreed to discuss with NHS England colleagues the suggestion that applicants provide a link to their privacy notice in section 4 of data sharing agreements (DSA). It was agreed that this could form part of a wider transparency discussion for a future meeting (provisional date: 9th March 2023).</p> <p>ACTION: Michael Chapman to provide a verbal update at the next AGD meeting (provisional date: 23rd February 2023).</p> <p>ACTION: NHS England to have a wider transparency discussion with AGD to discuss applicant privacy notices, the data uses register, internal data use register, process etc (provisional date: 9th March 2023).</p> <p>AGD work programme</p> <p>It was agreed that once the AGD Terms of Reference (TOR) were finalised and the remit of the work programme was agreed, that a workshop session be set up to prioritise the work programme.</p> <p>ACTION: The AGD Secretariat Team to work with AGD to find a suitable date in diaries.</p>	<p>MC</p> <p>MC</p> <p>AGD</p> <p>ALL</p> <p>VW/KM</p>
<p>10</p>	<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>	