

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 12 October 2017

Members: Sarah Baalham, Joanne Bailey, Nicola Fear, Jon Fistein, Kirsty Irvine (Acting Chair), Eve Sariyannidou

In attendance: Louise Dunn, Frances Hancox, Stuart Richardson, Vicki Williams

Apologies: Anomika Bedi, Chris Carrigan

1	<p>It was confirmed that Kirsty Irvine would act as Chair for this meeting.</p> <p>Declaration of interests</p> <p>No relevant interests were declared.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 5 October 2017 IGARD meeting were reviewed and agreed as an accurate record of the meeting. IGARD noted a comment on the minutes received from an NHS Digital member of staff but did not feel any change to the draft minutes was necessary.</p> <p>Action updates were provided (see Appendix A).</p> <p>Out of committee recommendations</p> <p>An out of committee report was provided (see Appendix B).</p>
2	<p>Data applications</p>
2.1	<p><u>NHS Blood & Transplant – Outcomes in the NIHR-funded ATTOM study (Presenter: Louise Dunn) NIC-14342-Q8W0X</u></p> <p>Application: This application for pseudonymised Hospital Episode Statistics (HES) data had previously been considered on 21 September 2017 when IGARD had deferred making a recommendation. The application had now been updated to remove references to a doctorate, as the applicant had indicated that this had come to an end and the study would be taken forward as part of the wider ATTOM study work.</p> <p>Discussion: IGARD noted the update provided but agreed that the amended application had raised some new questions in addition to the points raised during the previous discussion of the application.</p> <p>IGARD considered that one of the key reasons for deferral, that the link between this particular work and the wider ATTOM study was not clearly explained, had still not been sufficiently addressed. It was noted that while the application largely described the wider ATTOM study, a clearer explanation was needed of how the previous PhD study had been integrated into that work and what the specific outputs or benefits of this use of data would be beyond those of the wider ATTOM study. Concerns were raised that if the PhD study had ended, the applicant's section 251 support might no longer be applicable to this use of data as the section 251 approval letter explicitly stated that the activity would be to support a doctorate.</p> <p>An error in the abstract was noted and IGARD asked for this to be amended to list the correct date of previous IGARD review. The study cohort size was queried, as this was not described</p>

	<p>consistently across the application, and IGARD also queried a reference to the Scottish Renal Register. In addition IGARD asked for a reference within the application to ‘the above two individuals’ to be clarified and for references elsewhere to data being processed by ‘substantive employees’ to be amended to be clear this referred to the same two individuals.</p> <p>Furthermore IGARD queried a reference within the application to ‘a mechanism to respect any patient objection’ as it was noted that NHS Digital would not apply type two objections to the data disseminated. In relation to this some concerns were raised about the apparent lack of fair processing information for patients that would enable them to consider whether they wished to object; IGARD noted that the applicant’s section 251 support referred to a requirement to publish information online to notify participants, and confirmation was requested of whether this had taken place as the website link provided within the application was broken. IGARD noted that the website linked to provided information about a number of different studies but not about the ATTOM study specifically, and it was agreed that the applicant should publish an appropriate privacy notice that would meet NHS Digital’s nine minimum criteria.</p> <p>IGARD requested sight of the updated research protocol, as it was noted that the version provided as a supporting document seemed older than the version that had been reviewed and approved by a research ethics committee. IGARD welcomed the updated explanation of health literacy within the application and suggested that section five should be amended to incorporate a brief summary of some of the additional information currently provided in the fair processing section.</p> <p>Outcome: Not recommended for approval.</p> <ul style="list-style-type: none"> • Confirmation was requested that the applicant’s section 251 support is still applicable to this use of data given that this is no longer in relation to a PhD study. • Confirmation of whether the applicant has published information for patients as required by HRA CAG, as the link provided within the application was broken. • The applicant should publish an appropriate privacy notice with information about the use of data for the ATTOM study, and this should be reviewed by NHS Digital against the nine minimum criteria. • Providing further information about this specific research study and how this fits within the wider work of ATTOM. • Providing the most recent version of the study protocol as approved by ethics committee. • Updating the abstract to reflect the correct date when the application was last considered by IGARD. • Clarifying the cohort size to ensure this is described consistently throughout the application. • References to the Scottish Renal Register should be clarified to be clear this data will not be provided by NHS Digital. • Amending the application to clarify references to patient objections. • A reference to data analysis by ‘only the above two individuals’ should be amended for clarity, and statements that data will only be accessed by substantive employees should also reflect that this refers to the same two individuals. • Amending section 5 to briefly reflect some of the additional information provided within the fair processing section of the application.
3	<p>Privacy notices update</p> <p>Stuart Richardson joined the meeting to provide an update on the approach being taken by NHS Digital to the review of CCG privacy notices in relation to applications for data. It was noted that work was underway within NHS Digital to ensure more consistent interpretation of the privacy notice review criteria, with this work involving the IG Advisor to IGARD and the Deputy Caldicott Guardian. The intention was that following internal review and consultation</p>

	<p>with IGARD, revised guidance could then be issued to CCGs to assist them in appropriately updating their privacy notices.</p> <p>IGARD suggested that ICO guidance regarding privacy notices should be used to clarify any concerns about how the criteria should be interpreted, and requested sight of the draft NHS Digital guidance at an early stage if possible.</p>
4	<p>Any other business</p> <p>No other business was raised.</p>

Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
20/04/17	IGARD Chair to contact key stakeholder organisations regarding the benefits of uses of data to feed into the IGARD annual report.	IGARD Chair	14/09/17: Ongoing. It was agreed this would be discussed during the educational session. 05/10/17: It was agreed that the first draft would be discussed at December's education session. 12/10/17: ongoing	Open
27/04/17	IGARD Chair to contact the NHS Digital Caldicott Guardian regarding GPs' data controller responsibilities for fair processing around risk stratification.	Arjun Dhillon	18/05/17: Ongoing. It was agreed this would be discussed with the Deputy Caldicott Guardian. 22/06/17: Ongoing; it was suggested the Deputy Caldicott Guardian should discuss this in more detail with Joanne Bailey. 29/06/17: It was noted this action would be taken forward by the Deputy Caldicott Guardian, and the action owner was updated. 20/07/17: It was agreed the Deputy Caldicott Guardian would provide an update on the current status of this. 10/08/17: An update from NHS England had been requested. 12/10/17: Ongoing.	Open
18/05/17	Garry Coleman to provide information about different arrangements for data storage and backup locations, for consideration of whether the organisations involved would be considered to be processing data.	Garry Coleman	15/06/17: IGARD had been advised by email that a paper about this would be submitted to an upcoming IGARD meeting. 22/06/17: It was anticipated that this would be discussed at the 6 July 2017 IGARD meeting. IGARD asked for some information to be circulated by email prior to the meeting in order to inform members who would not be present at that particular meeting. 27/07/17: An email had been circulated requesting further information from IGARD members. 03/08/17: Two IGARD members had responded by email and the action remained ongoing. 10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks. 24/08/17: The paper was in the process of being updated based on	Open

			<p>recently published ICO guidance.</p> <p>14/09/17: Ongoing. IGARD noted that given the amount of time that had passed, they would consider starting to note this on relevant applications where a data storage location was not listed as a data processor.</p> <p>21/09/17: Ongoing. IGARD asked for Dickie Langley to provide an update on Garry Coleman's open actions at the next meeting to help ensure timely progression.</p> <p>12/10/17: ongoing</p>	
15/06/17	Data Services for Commissioners to work with NHS Digital IG staff to check the privacy notices for these 4 CCGs (South Kent Coast CCG; Ashford CCG; Thanet CCG; Canterbury & Coastal CCG) as part of the ongoing training, and provide a copy of the outcome of this check to IGARD for information.	Stuart Richardson	<p>29/06/17: Ongoing. It was suggested it would be helpful to discuss this at an upcoming educational session.</p> <p>05/10/17: It was confirmed this would be discussed at the October education session</p> <p>12/10/17: Stuart Richardson attended IGARD</p>	Open
06/07/17	Stuart Richardson to ensure that privacy notice checklists are provided for all DSfC applications for a trial period of three months from 13 July IGARD meeting.	Stuart Richardson	<p>05/10/17: It was confirmed this would be discussed at the October education session</p> <p>12/10/17: Stuart Richardson attended IGARD</p>	Open
20/07/17	Garry Coleman to provide an update within two weeks on how NHS Digital manage the risk involved in CCGs using South Central and West CSU as a data processor in light of data sharing breaches and recent audits.	Garry Coleman	<p>10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.</p> <p>24/08/17: IGARD received a verbal update on the work that had taken place following both audits and verbal assurances that NHS Digital were content with the level of risk involved in this organisation continuing to act as a data processor. IGARD welcomed this update and requested written confirmation.</p> <p>31/08/17: IGARD were notified that the requested written confirmation should be provided within one day.</p> <p>14/09/17: An email response had been circulated on 31 August, and IGARD noted that they were awaiting receipt of the post-audit report.</p> <p>12/10/17: ongoing</p>	Open
20/07/17	Garry Coleman to categorise different standard lengths of indicative data retention periods for	Garry Coleman	12/10/17: ongoing	Open

	general research and clinical trials, with appropriate justification.			
27/07/17	Arjun Dhillon to provide information for IGARD about the robustness of different funding processes and how this might affect the level of scrutiny applied to or information included in applications provided to IGARD.	Arjun Dhillon	10/08/17: Ongoing. It was thought that this action might be addressed within the context of a forthcoming paper on a risk-based approach to application, which it was anticipated would be brought to IGARD for discussion soon. 24/08/17: Ongoing, pending wider work on a risk-based approach. 12/10/17: Ongoing	Open
31/08/17	Garry Coleman to report back on how cancer registration data was previously described as pseudonymised PDS data within older versions of applications, and present to a future education session on changes to how MRIS reports are now shown within applications.	Garry Coleman	12/10/17: Ongoing	Open
14/09/17	Stuart Richardson to provide IGARD with a copy of the Directions relating to the Emergency Care Data Set (ECDS) with confirmation of the date this was approved by the NHS Digital Board.	Stuart Richardson	21/09/17: The Directions had been provided by email. IGARD members were asked to provide any comments by email, ahead of potentially closing the action at the next meeting. It was noted that confirmation would still be required of NHS Digital Board approval. 12/10/17: Ongoing	Open
14/09/17	Stuart Richardson to provide IGARD with a copy of the Directions relating to Social Care Data with confirmation of the date this was approved by the NHS Digital Board.	Stuart Richardson	21/09/17: The Directions had been provided by email. IGARD members were asked to provide any comments by email, ahead of potentially closing the action at the next meeting. It was noted that confirmation would still be required of NHS Digital Board approval. 12/10/17: Ongoing	Open
21/09/17	Dickie Langley to provide a briefing paper (with relevant supporting documents) regarding the legal basis for receipt of data from Department for Education, and for this to be reviewed by the IG Advisor prior to circulation to IGARD.	Dickie Langley	12/10/17: Ongoing	Open
21/09/17	Dickie Langley to provide IGARD with a copy of the new standard DSA terms and conditions.	Dickie Langley	12/10/17: Ongoing	Open

Appendix B: Out of committee report (as of 06/10/17)

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-63347	Royal College of Anaesthetists	28/09/17	<ul style="list-style-type: none">Providing additional details of the telephone calls made to inform participants of the updated fair processing information, such as what percentage of participants have now been spoken to in order to inform them of the change	IGARD Chair	IGARD Chair	N/A

In addition the following applications were not considered by IGARD but have been progressed for IAO and Director extension/renewal:

- None