

Data Access Advisory Group (DAAG)

Minutes of meeting held 9 June 2015

Members: Alan Hassey (Acting Chair), Sean Kirwan, Eve Sariyannidou, Patrick Coyle, Joanne Bailey

In attendance: Frances Hancox, Victoria Williams, Diane Pryce, Steve Hudson, Gaynor Dalton, Dickie Langley, Stuart Richardson, Jennifer Donald

Apologies: Dawn Foster, John Craven

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 2 June 2015 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 5).</p> <p>Out of committee recommendations</p> <p>The following application had previously been recommended for approval subject to caveats, and it had been confirmed out of committee that the caveats had now been fulfilled:</p> <ul style="list-style-type: none">• NIC-349877 i5 Health• NIC-345991 Imperial College London• NIC-318704 University of Edinburgh• NIC-346122 Harvey Walsh Ltd• NIC-309284 Northgate Information Solutions• NIC-319693 HSCIC/HMRC
2	<p>Data applications</p>
2.1	<p><u>UK Biobank (Presenter: Garry Coleman) NIC-356143-V5D7L</u></p> <p>Application: This application had previously been brought to DAAG for advice on 28 April 2015. The applicant requested Hospital Episode Statistics (HES), Mental Health Minimum Dataset (MHMDS), Diagnostic Imaging Dataset (DIDs) and Personal Demographics Service (PDS) data for members of the UK Biobank cohort, who had previously consented to the use of their data. Following discussions at the 28 April 2015 DAAG meeting, additional information had been provided regarding controls around the onward sharing of data and how information was provided to cohort members.</p> <p>Discussion: DAAG queried whether recruitment of participants was still underway. It was confirmed that recruitment of UK Biobank participants had ceased, but that existing participants could be contacted to ask whether they wished to participate in further assessments.</p> <p>The information made available to participants was discussed, and it was noted that while UK Biobank provided information on the projects that made use of UK Biobank data this did not seem to include details of what participant data was used for each project. DAAG advised that the applicant should consider publishing details at a more granular level of what participant data had been used for what particular projects, in addition to clarifying what data had been provided to UK Biobank by the HSCIC.</p> <p>DAAG queried how researchers using UK Biobank data would handle requests from participants for their data to no longer be used, if an individual chose to withdraw their consent. The potential</p>

difficulty of removing an individual's data from a pseudonymised dataset after this had been provided to a researcher was noted, and it was suggested that the UK Biobank website should clearly state that requests for 'no further use' of data can only apply prospectively rather than retrospectively.

A query was raised regarding a reference to researchers 'rendering data inaccessible' after a certain time period, and it was agreed that this wording would be amended to clarify that data would be destroyed. A reference to 'pseudo-anonymised' data was also queried, and it was confirmed that this should instead say pseudonymised.

DAAG highlighted the need for UK Biobank to ensure that customers would not use the data for any commercial purpose, in order to comply with the requirement of the Care Act 2014 for the HSCIC to only share data for the purposes of health and social care or the promotion of health. It was agreed that a statement to this effect should be included in the application summary and the data sharing agreement.

Outcome: Recommendation to approve subject to the applicant demonstrating compliance with the relevant requirements of the Care Act 2014 in terms of commercial uses. Advice was given that the applicant should review their fair processing materials published online and attempt to be as granular as possible in terms of how an individual's data is used.

2.2 University of Glasgow (Presenter: Jennifer Donald) NIC-332128-W2J9F

Application: This application was presented for advice only. The applicant had requested bespoke linkage of identifiable Office for National Statistics (ONS) mortality data for a specific cohort using the patient tracking service. This data would be used as part of a study of adjuvant chemotherapy, and the cohort members had given consent to participate. However, queries had been raised within the HSCIC as to whether the consent was appropriate for the use of identifiable data requested.

Discussion: DAAG noted the potentially significant benefits for patient care that could arise from this study.

The consent materials provided were discussed, and in particular there were concerns about a statement in the patient information sheet that '*Any information used outside of the hospital/SCOT Trial Offices will have your name and address removed so that you cannot be recognised from it.*' It was felt that participants would not understand from this that identifiable data would be shared with the HSCIC, and therefore could not be considered to have consented to that processing of identifiable data. DAAG agreed that participants should be provided with updated fair processing materials and given the opportunity to opt out, and that if this was not feasible then the applicant should consider applying for support under section 251 as well as seeking Approved Researcher status for access to ONS data.

A reference in the application summary to data being shared outside Europe was queried, and it was agreed that clarification would be needed of whether this would include anything other than anonymised aggregate data.

Outcome: DAAG's view was that the consent materials were not adequate to be able to recommend approval of an application for the processing of identifiable data. If it was not practical for the applicant to re-contact participants with updated fair processing materials and given them the opportunity to opt out, then the applicant should consider applying for support under section 251 as well as Approved Researcher accreditation for access to ONS data. Clarification was also requested of a reference to disseminating outputs outside of Europe, and whether this would include any identifying or pseudonymised data.

2.3	<p><u>East Riding of Yorkshire Clinical Commissioning Group (CCG) (Presenter: Stuart Richardson) NIC-344973-C1R6J</u></p> <p>Application: This application to renew the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised), which was covered by the section 251 support for the disclosure of commissioning datasets for risk stratification, had previously been considered at the 19 May 2015 meeting when DAAG had been unable to recommend approval. The application had now been amended to clarify that Optum Health Solutions (UK) and United Health UK had been incorporated into a single organisation, United Health (Optum), as well as to clarify the data retention period and provide additional detail regarding fair processing.</p> <p>Discussion: It was agreed that the majority of the concerns previously raised by DAAG had now been addressed, but there remained some concerns regarding fair processing. DAAG agreed that the applicant should publish an appropriate fair processing notice on their website within two months in order to continue making use of this data. It was suggested that advice regarding fair processing notices should also be shared with similar CCGs.</p> <p>DAAG queried the description of the data retention period. It was agreed that this should be amended to state that data would be retained until 30 April 2016 in line with the relevant section 251 support, but that this would be extended up to a maximum of five years if the section 251 support were extended.</p> <p>Outcome: Recommendation to approve subject to the inclusion in the data sharing agreement of a requirement for the applicant to publish a fair processing notice on their website within two months, in line with the advice DAAG had previously provided.</p> <p>Action: Stuart Richardson to inform DAAG in August 2015 whether East Riding of Yorkshire CCG have published fair processing information in line with DAAG's recommendation (NIC-344973-C1R6J).</p>
2.4	<p><u>Salford Royal NHS Foundation Trust (AQuA) (Presenter: Dickie Langley) NIC-330478</u></p> <p>Application: This application had previously been considered at the 5 May 2015 meeting, when DAAG had recommended approval for the provision of HES data but had been unable to recommend approval for the provision of ONS data. The application had now been amended to request HES data only, as well as to clarify that the Advancing Quality Alliance (AQuA) was part of Salford Royal NHS Foundation Trust and to confirm that only Salford Royal staff would have access to the data provided.</p> <p>Discussion: Some points of accuracy were raised regarding this application: a typo would be corrected, and it was agreed that a box referring to ONS data should not be ticked, and a reference to deleting ONS data would be clarified to state that data would be securely destroyed in line with the requirements of the data sharing agreement. In addition it was agreed that a reference to AQuA being hosted by Salford Royal NHS Foundation Trust would be clarified to stated that AQuA was part of this organisation.</p> <p>Outcome: Recommendation to approve.</p>
3	<p>Any other business</p> <p><u>HSCIC Clinical Audit Support Unit – Chronic Obstructive Pulmonary Disease (COPD) Audit NIC-349273-T3L4K</u></p>

This application had been considered at the 2 June 2015 DAAG meeting and evidence had been requested that the applicant's section 251 support covered the data sharing with Wales described in the application. In addition clarification had been requested of when fair processing materials will be made available to the public, and it had now been confirmed that materials would be published within the following few days.

Two options for the data flow to Wales had previously been outlined, and confirmation had now been provided that the section 251 support would cover Option B (whereby identifiable data for only the cohort members who attended hospital in Wales would be provided for linkage). DAAG confirmed that based on the evidence provided, they were content to recommend approval for Option B.

A query was raised regarding whether DAAG had considered a request for primary care data for this audit, and it was noted that although this had been considered by the General Practice Extraction Service Independent Advisory Group (GPES IAG) an application to link primary care and secondary care data for the purpose of the audit had not yet been considered by DAAG.

Outcome: Recommendation to approve.

Imperial College London – Dr Foster Unit NIC-345991-H2F5N

This application had been considered at the 12 May 2015 DAAG meeting and recommended for approval subject to caveats; it had subsequently been confirmed out of committee that these caveats had been met. The application had therefore been approved for a period of approximately two months, to the end of July 2015. However, DAAG were now asked to consider whether this approval should be extended until April 2016 in line with the applicant's section 251 support. No other changes had been made to the application. DAAG noted that the applicant was due to report to the HRA Confidentiality Advisory Group (CAG) in September 2015 regarding progress, and it was agreed that the approval extension should be subject to the satisfactory completion of this review in September.

Outcome: Recommendation to extend the current approval to 22 April 2016 in line with current section 251 support, subject to satisfactory review by CAG in September 2015.

It was noted that the current DAAG membership would be extended until October 2015.

Action: Alan Hassey to contact DAAG members regarding extending DAAG membership.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
24/02/15	Dawn Foster to raise with HRA CAG the possibility of stage 1 accredited safe havens receiving both data that is identifiable by NHS number and data that is identifiable by postcode.	Dawn Foster	<p>03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting.</p> <p>10/03/15: An initial response had been received and this would be shared with DAAG members for information. A further query had been raised and discussions were ongoing.</p> <p>17/03/15: Ongoing.</p> <p>25/03/15: Ongoing.</p> <p>31/03/15: Ongoing.</p> <p>07/04/15: Ongoing.</p> <p>13/04/15: Ongoing.</p> <p>21/04/15: Ongoing.</p> <p>28/04/15: Ongoing.</p> <p>05/05/15: It was agreed that Dawn Foster would raise this separately with CAG.</p> <p>12/05/15: Clarification had been requested from NHS England regarding a particular request for both identifiers.</p> <p>19/05/15: Ongoing.</p> <p>27/05/15: Ongoing.</p> <p>02/06/15: Ongoing.</p> <p>09/06/15: Ongoing.</p>	Open
12/05/15	DAAG Secretariat to invite the HSCIC Statistics Head of Profession to attend a future DAAG training session regarding sampling techniques.	DAAG Secretariat	<p>19/05/15: An invitation had been issued, but it had not yet been agreed what date the Head of Profession might be able to attend a DAAG training session.</p> <p>27/05/15: Ongoing.</p> <p>02/06/15: Ongoing.</p> <p>09/06/15: An invitation to the DAAG training session in July had been issued.</p>	Closed
02/06/15	Acting DAAG Chair to discuss benefits and	Acting DAAG	09/06/15: This discussion had been scheduled for 11 June.	Closed

	feeding research outputs back to the NHS with Chris Roebuck and with the Health Research Authority Confidentiality Advisory Group (CAG).	Chair		
02/06/15	DAAG Secretariat to schedule a training session to discuss mechanisms to feed research outputs back to the NHS.	DAAG Secretariat	09/06/15: A training session would be scheduled following the outcome of discussions with Chris Roebuck on 11 June.	Open
02/06/15	Acting Chair to notify the SIRO and Caldicott Guardian that this data release (HSCIC and HMRC workforce data) should be added to the data release register, and that DAAG's view was that other such releases should also be reflected on the register.	Acting DAAG Chair	09/06/15: Ongoing.	Open
02/06/15	DAAG Secretariat to circulate dates for DAAG training sessions.	DAAG Secretariat	09/06/15: Dates had been circulated.	Closed