

Data Access Advisory Group (DAAG)

Minutes of meeting held 13 August 2015

Members: Alan Hassey (Acting Chair), Eve Sariyannidou, John Craven, Joanne Bailey

In attendance: Frances Hancox, Victoria Williams, Garry Coleman, Chris Dew, Terry Hill, Stuart Richardson, Jack Wheeldon, Steve Hudson, Dickie Langley, Sophie Fletcher

Apologies: Sean Kirwan, Patrick Coyle, Dawn Foster

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 4 August 2015 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 8).</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 met:</p> <ul style="list-style-type: none">• NIC-321968 University of Cambridge
2 2.1	<p>Data applications</p> <p><u>Public Health England - Local Authority public health application template (Presenter: Garry Coleman)</u></p> <p>Application: This template application had previously been considered at the 30 June 2015 and 28 July 2015 DAAG meetings. It was intended that this template would be used for Local Authorities to apply for pseudonymised, non-sensitive Hospital Episode Statistics (HES) data for use in fulfilling their public health responsibilities. Following previous DAAG discussions, the template application had been amended to clarify that data could only be used by Local Authorities in fulfilment of their public health duties, to clarify the Director of Public Health's accountability to the Local Authority, and to specify that Local Authorities would need to clearly state any instances where their local arrangements differentiated from the generic description in the application template. The fair processing section of the template had also been updated to state that if Local Authorities had not yet published an appropriate privacy notice, they would need to commit to doing so within eight weeks; DAAG were informed that this approach had the support of Public Health England. In addition, the benefits section had been amended to indicate that Local Authorities would commit to providing evidence of the benefits achieved over the next year as part of a renewal application, and would in particular provide details of benefits from any uses of data that were in addition to the generic purposes outlined.</p> <p>Discussion: DAAG discussed the possible risk of Local Authorities sharing data with other organisations, particularly in instances where certain public health functions had been subcontracted to third parties. Although it was noted that the generic template stated that data will not be transferred or otherwise made available to any third party', given the possibility for public health functions to include supporting health research it was agreed that this wording should be amended to state 'including to any organisation for the purpose of health research'. Local Authorities' rights to share data with other organisations were discussed, but it was emphasised that the contract in place between Local Authorities and the HSCIC would prohibit further data sharing unless the Local Authority specifically applied to share data with another organisation. Concerns were expressed regarding recent media reports of data breaches within Local</p>

Authorities, and it was suggested that the HSCIC should undertake audits of a number of Local Authorities and their use of data for public health functions.

A point was raised that given the broad definition of public health, Local Authorities might be required to share data with the police for purposes such as to prevent serious crimes. However it was noted that the HSCIC could also be required to share data, for example if under a court order to do so. A query was raised regarding why a particular section of the Health and Social Care Act 2012 had been cited as the legal basis, and DAAG were informed that this had been specified by Public Health England in relation to the requested data flow. A reference to 'upper tier' Local Authorities was also queried, and it was clarified that this referred to the tier of Local Authorities with public health functions.

DAAG discussed the statement that the Director of Public Health was 'a permanent employee of the Local Authority', and suggested that this wording should be altered to accommodate other employment arrangements such individuals on a fixed term contract. It was agreed that this would be amended to 'a contracted employee to the permanent role within the Local Authority'.

A query was raised regarding whether DAAG would still be asked to review Local Authority applications that did not differ substantively from this generic template, and it was confirmed that DAAG would be asked to review these applications.

DAAG expressed some reservations about the broad definition of public health purposes, and in particular the statement in the application form that the list of functions provided was 'not exhaustive'. It was noted that the definition of public health purposes would be expected to develop over the following year, particularly in light of the integration of public health functions, and this would need to be considered when renewal applications were submitted. Any Local Authority making use of data for any public health purposes outside of the specified list would be expected to provide specific details of this use and of what benefits this had resulted in as part of the renewal process.

Outcome: Recommendation to approve. DAAG expressed the following concerns:

It was highlighted that the definition of public health purposes will need to be reviewed by DAAG or its successor body in light of the integration of public health functions into other mainstream local government functions and this should be considered as part of renewal applications. DAAG noted the recent reports around LAs and data breaches and expressed some concerns in relation to this, and suggested that the HSCIC should prioritise the audit of local authorities' use of data in support of their public health functions.

It was agreed that the generic template application would be amended to include the wording that data 'will not be transferred or otherwise made available to any third party, including to any organisation for the purposes of health research,' and also to state that the Director of Public Health 'is a contracted employee to the permanent role within the Local Authority'.

2.2 Local Authority public health – Leeds City Council (Presenter: Garry Coleman)

Application: This was a Local Authority public health application based on the template discussed above. It was noted that Leeds City Council did not currently have a data sharing framework contract and that no data would be provided until a signed contract was in place. Leeds City Council had a privacy notice in place, and had committed to updating this to include the use of healthcare data for public health functions. It was noted that the applicant had achieved a satisfactory Information Governance (IG) Toolkit score and held an appropriate registration under the Data Protection Act 1998 (DPA).

Discussion: DAAG queried the statement that the privacy notice would be updated within eight weeks, and precisely when this period began. It was confirmed that this referred to eight weeks from when the Data Sharing Agreement was signed, and the application template wording would

	<p>be amended to clarify this. In addition DAAG queried how it would be confirmed whether privacy notices had been updated within this time period, and it was agreed that Garry Coleman would update DAAG on this.</p> <p>Outcome: Recommendation to approve. The application summary would be amended in line with the changes agreed to the generic application template, and the wording on page nine would be amended as agreed. DAAG reiterated the concerns raised during the discussion of the generic application above.</p> <p>It was agreed that the minutes of DAAG's consideration of future Local Authority applications should also refer back to the concerns raised during the discussion of the generic template application, and the DAAG Secretariat would explore how best to do this.</p> <p>Action: DAAG Secretariat to explore how the minutes of future DAAG discussions of Local Authority applications can best refer back to the generic template application discussion.</p>
2.3	<p><u>Local Authority public health – Lincolnshire County Council (Presenter: Garry Coleman)</u></p> <p>Application: This was also a Local Authority public health application based on the template discussed above. DAAG were informed that the applicant held an appropriate DPA registration and had achieved a satisfactory IG Toolkit score. The applicant had committed to update their privacy notice within eight weeks to encapsulate public health functions.</p> <p>Discussion: No additional concerns were raised regarding this application.</p> <p>Outcome: Recommendation to approve. The application summary would be amended in line with the changes agreed to the generic application, and the wording on page nine would be amended as agreed. DAAG reiterated the concerns raised during the discussion of the generic application above.</p>
2.4	<p><u>Local Authority public health – Norfolk County Council (Presenter: Garry Coleman)</u></p> <p>Application: This was also a Local Authority public health application based on the template discussed above. DAAG were informed that the applicant held an appropriate DPA registration and had achieved a satisfactory IG Toolkit score. The applicant had committed to update their privacy notice within eight weeks to encapsulate public health functions.</p> <p>Discussion: No additional concerns were raised regarding this application.</p> <p>Outcome: Recommendation to approve. The application summary would be amended in line with the changes agreed to the generic application, and the wording on page nine would be amended as agreed. DAAG reiterated the concerns raised during the discussion of the generic application above.</p> <p>Action: Garry Coleman to confirm within eight weeks whether the privacy notices for Leeds City Council, Lincolnshire County Council and Norfolk County Council have been appropriately updated.</p>
2.5	<p><u>Castle Point and Rochford CCG Invoice Validation (Presenter: Stuart Richardson) NIC-347878-N1D5Y</u></p> <p>Application: This application was for the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) into the applicant's</p>

Controlled Environment for Finance for the purpose of invoice validation, supported by section 251. This had been considered by DAAG at the 4 August 2015 meeting as part of an invoice validation group application, but DAAG had deferred a recommendation as the applicant's fair processing information had been unavailable.

Discussion: DAAG noted that the applicant's fair processing notice was now available online, but that the PDF document on their website was inaccessible from certain browsers. It was agreed that the applicant should ensure this notice was accessible from all common browser versions.

Some concerns were raised regarding the fair processing notice, as it was felt that statements that patient data would not be shared with any third parties without patient consent could be misleading. It was agreed that the description of the use of data for invoice validation was accurate, but that the CCG should amend the notice before any further applications were made to DAAG for uses such as risk stratification.

Outcome: Recommendation to approve. The applicant's privacy notice must be made available and accessible to all common browser versions, and DAAG raised a number of specific concerns regarding the privacy notice.

Action: Stuart Richardson to ensure that the privacy notice for Castle Point and Rochford CCG is appropriately updated.

2.6

NIC-370843 Imperial College London – COSMOS (Presenter: Garry Coleman) NIC-370843-R6V8T

Application: DAAG had previously considered this application at the 21 July 2015 meeting for advice on consent only and had advised that there were concerns regarding the consent form and patient information leaflet, as these did not explicitly state that record level data would be shared overseas.

DAAG were now asked to consider the application itself, which was for identifiable, linked HES and Office for National Statistics (ONS) mortality and cancer data to be provided to the applicant. This data would be linked by the applicant to other data including mobile phone usage data and used as part of a study into the health impact of mobile phone use. DAAG were informed that this was part of an international collaboration with five other academic institutions within Europe, and that the applicant had requested to share pseudonymised data with these other European organisations. It was noted that individuals had consented to participate in the study, but that concerns had been raised about whether or not this consent could be considered to cover international data sharing. Participant recruitment to the study had ended in 2012, and participants were provided with updates via a study website and regular newsletters that included details of how individuals could withdraw their consent.

Discussion: A query was raised regarding whether the data shared internationally could be linked with other datasets that could increase the risk of data being re-identified. It was clarified that while the international collaborators wished to combine the UK dataset with data from their own countries, this would not increase the amount of data held about each individual and would not be expected to increase the risk of individuals being re-identified from the data.

DAAG discussed the applicant's consent materials, and as previously it was noted that the consent form itself did not refer to sharing data outside the UK and that applicants consenting online would have had to click a separate link in order to be informed about this. In addition, the information leaflet stated that international researchers would '*only have access to anonymised information that does not identify [participants]*', whereas the application referred to sharing pseudonymised data. DAAG therefore did not consider that participants could be considered to have given informed consent for their data to be shared internationally. However, it was noted that

if data was fully anonymised in line with the Information Commissioner's Office (ICO) Anonymisation Code of Practice then participant consent would not be required to share the anonymised data.

The planned data retention period was queried, as it was noted that the previous application summary had listed this as three years whereas the current application summary stated 30 years. It was confirmed that 30 years was the correct retention period based on the applicant organisation's requirements to retain trial data. DAAG noted the importance of making sure that the results of this work would be disseminated appropriately, in order to maximise impact.

Outcome: Recommendation to approve, subject to confirmation that record level data will only be shared internationally if de-identified in line with the ICO Anonymisation Code of Practice.

2.7 Midlands and Lancashire CSU (Presenter: Steve Hudson) NIC-363897-P5D9L

Application: This application to amend an existing agreement had previously been considered by DAAG at the 21 July 2015 and 4 August 2015 meetings. DAAG had requested confirmation that NHS England were content for this type of agreement to sit under the existing data sharing framework contract, and NHS England had now provided reassurance that they were content with this. In addition, clarification had been requested about the statement that a Data Services for Commissioners Regional Office (DSCRO) would act as a data processor; it was now confirmed that this had been an error on the application summary, and the DSCRO would not act as data processor.

Discussion: DAAG noted that the application summary provided stated that confirmation from NHS England had been requested, but not that this had been provided. It was agreed that the application summary should be updated to specify that NHS England had confirmed that this agreement could sit under the existing data sharing framework contract.

Outcome: Recommendation to approve, subject to the application summary to be updated to reflect that NHS England have provided the required reassurances.

2.8 University of Warwick - Prevention of Fall Injury Trial (Presenter: Garry Coleman) NIC- 302792-X4T6B

Application: This application was to extend and renew an existing data sharing agreement for the provision of identifiable, non-sensitive HES data for a specific cohort of individuals aged over 70. The University of Leeds would act as a data processor to analyse the data, and it was confirmed that both organisations held satisfactory IG Toolkit scores and appropriate DPA registrations. Some concerns had been raised regarding the study consent materials, as these contained wording that would not now be considered appropriate, but it was noted that recruitment to the study was no longer taking place. DAAG were informed that study participants had been provided with details of how to opt out of the study if they wished to do so.

Discussion: DAAG queried the legal basis for the HSCIC to receive patient identifiers, and whether this was covered by the participant consent as it was noted that the consent form and patient information leaflet did not explicitly refer to identifiers being provided to the HSCIC. This was acknowledged, but it was also noted that the consent materials did state that '*information held by the NHS and records maintained by The NHS Information Centre and the NHS Central Register may be used to help contact me and provide information about my health status*' and this wording would have been considered appropriate at the time when the consent materials were written.

It was considered that while the consent materials did not explicitly refer to providing identifiers to the HSCIC, it could be implied that individuals would need to be identified to the HSCIC in order for their health status to be tracked. However, it was agreed that this should have been explained

more clearly to participants and DAAG recommended that the applicant should undertake appropriate fair processing activities to ensure participants were made aware of the flow of identifiers to the HSCIC. The potential difficulties of contacting an elderly cohort were noted.

The planned data retention period was queried, and it was explained that data would be retained for five years following the end of the research in case of queries or challenges that might arise regarding the analysis of the data. It was agreed that a clearer explanation of this in the application summary would have been helpful.

Outcome: Recommendation to approve, subject to the applicant undertaking fair processing activities that are appropriate to this cohort – including both web based information and a newsletter or other direct communication where this is feasible.

2.9 Northgate Public Services (UK) Limited – National Joint Registry Annual Report 2014 (Presenter: Steve Hudson) NIC-309284-N4T2H

Application: DAAG had previously considered an application for this purpose at the 2 June 2015 meeting (NIC-309284-N4T2H) and had recommended approval. A renewal application was now submitted as an additional data year was requested to cover 2014-15 data. In addition the applicant's legal name had changed, the data processor University of Bristol's DPA registration wording had been updated to include health research, and the address for the data controller HQIP had been updated.

Discussion: DAAG queried whether any other substantive changes had been made to the application in addition to the changes outlined above, and it was confirmed that no other changes had been made.

Outcome: Recommendation to approve.

2.10 University College London - Healthcare transitions for young people (Presenter: Dickie Langley) NIC-330769-C9Y8Y

Application: This was a new application for HES data linked with ONS mortality data in order to study the effect of transitioning from paediatric to adult healthcare. Confirmation was provided that the study was funded by the Department of Health, and ONS mortality data could therefore be provided under section 42(4) of the Statistics and Registration Service Act 2007.

Discussion: DAAG queried whether the applicant required full date of death or if month of death would be sufficient, but it was suggested that using date of death would increase accuracy given the nature of the transition being studied. A query was raised regarding why data for individuals aged 10 to 18 was requested, given that the study focused on ages 15 to 24, and it was clarified that as healthcare transition could happen at a range of ages, this range of data would be required for the applicant to examine health outcomes over time.

References in the application summary to evidence of poor transitions were queried, as it was also stated elsewhere that data on transitional care was not routinely collected. It was clarified that there had been evidence that poor transitions negatively impacted health outcomes, and one specific national report was cited, but routine data on transitions was not available.

It was noted that the planned target date for the expected benefits was December 2016, and DAAG queried whether this was realistic. DAAG discussed the expected outputs and benefits, and noted that submission to peer reviewed publications. It was suggested that the applicant should be encouraged to also disseminate outputs more widely and target relevant professional groups and organisations, rather than relying solely on publications, as it was felt that this could increase the impact of the study.

	<p>Outcome: Recommendation to approve. DAAG strongly encouraged the applicant to ensure that outputs would be appropriately disseminated to relevant professionals and organisations in order to increase the impact and potential benefits of this work.</p>
3	<p>Any other business</p> <p>The Acting Chair gave his apologies for the 18 August 2015 DAAG meeting, and it was agreed that Eve Sariyannidou would chair that meeting in his absence.</p> <p>There was a discussion of the process for applications to be brought back to DAAG with minor changes or to request more of the same data, and it was noted that this process should be clarified in the draft HSCIC Data Dissemination Policy.</p> <p>The Acting Chair informed the group of a large number of upcoming applications relating to long term studies, and there was a brief discussion of how these applications should be approached. It was agreed that an additional session should be scheduled to take place a DAAG meeting specifically to consider examples of these applications.</p>

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>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>30/06/15: No response had yet been received from NHS England, and a further reminder would be sent.</p> <p>07/07/15: It was agreed that if no response was received within a week then this application should be closed.</p> <p>21/07/15: A response from NHS England had been received, and this would be discussed with the HRA CAG Secretariat.</p> <p>28/07/15: Discussions with the HRA CAG Secretariat had taken place, and copies of the documents provided by NHS England had been shared with the Secretariat for their review.</p> <p>04/08/15: This action was ongoing pending feedback from HRA CAG.</p> <p>13/08/15: HRA CAG had confirmed that the section 251 support did not include the use of more than one identifier and it was their expectation that if more than one identifier is required, a further application would be made to them; they had not received any such application.</p>	Closed
04/08/15	DAAG Secretariat to send DAAG members a copy of the HSCIC Board minutes that covered the discussion of changes to HSCIC Executive Director team and Caldicott Guardian arrangements.	DAAG Secretariat	13/08/15: The relevant Board minutes had not yet been published.	Open

04/08/15	Steve Hudson to provide a diagram of current DARS team setup.	Steve Hudson	13/08/15: It was agreed that Terry Hill would pick up this action.	Open
04/08/15	Dawn Foster and Steve Hudson to discuss data disseminations process.	Dawn Foster	13/08/15: Ongoing.	Open
13/08/15	Garry Coleman to confirm within eight weeks whether the privacy notices for Leeds City Council, Lincolnshire County Council and Norfolk County Council have been appropriately updated.	Garry Coleman		Open
13/08/15	Stuart Richardson to ensure that the privacy notice for Castle Point and Rochford CCG is appropriately updated.			Open