

Data Access Advisory Group (DAAG)

Minutes of meeting held 24 November 2015

Members: Joanne Bailey, John Craven, Eve Sariyannidou

In attendance: Dave Cronin, Gaynor Dalton, Frances Hancox, Steve Hudson, Dickie Langley, Stuart Richardson, Netta Hollings

Apologies: Dawn Foster, Alan Hassey (Acting Chair), Sean Kirwan, James Wilson

1	<p>It was agreed that John Craven would chair the meeting in the absence of the Acting Chair.</p> <p>Declaration of interests</p> <p>No conflicts of interests relevant to this meeting were declared.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 17 November 2015 meeting were reviewed.</p> <p>DAAG noted that after the discussion under Matters Arising at that meeting about the application from Imperial College London's Small Area Health Statistics Unit (SAHSU) NIC-204903-P1J7Q, queries had been raised outside the meeting about the actions that the HSCIC was taking regarding this application. Terry Hill had been asked to provide a written report on the actions taken regarding this, in order to ensure transparency and clarity, but that report was not yet available.</p> <p>Some changes to the Matters Arising section of the minutes were therefore agreed, and subject to those changes the minutes were agreed as an accurate record.</p> <p>Action updates were provided (see table on page 7). It was agreed that actions that were not yet due would be removed from the summary of ongoing actions, and added back once they were due.</p> <p>Out of committee recommendations</p> <p>The following applications 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-380680-T6F4D Newcastle University• NIC-371243-H1P5T North and East London CSU• NIC-366216-Z9H9Q University of Sheffield• NIC-381638-T2R0V North East Essex CCG• NIC-381572-Z7ROV Mid Essex CCG
2	<p>Data applications</p> <p>2.1 <u>University of Leeds - Prospective comparative evaluation of alternative vascular service models in the UK NHS (Presenter: Dave Cronin) NIC-293277-R3Z1V</u></p> <p>Application: This application was to extend an existing data sharing agreement in order for the applicant to retain linked Hospital Episode Statistics (HES) and Office for National Statistics (ONS)</p>

mortality data. The applicant wished to retain this data for longer in order to address any queries that may arise following publication, as well as to carry out further analysis with the aim of developing further grant applications to support future research.

DAAG were informed that ONS data had initially been released under section 42(4) of the Statistics and Registration Service Act 2007 as the research project had been commissioned by NIHR, but as that project had now come to an end section 42(4) no longer applied. The applicant had therefore obtained Approved Researcher accreditation and Microdata Release Panel approval in order to continue to hold ONS data. It was proposed that the data sharing agreement for this application should last until March 2016, as by this time the applicant should have carried out further analysis to determine the possibilities for future research, and at that point the applicant would need to re-apply to retain the data for any longer.

It was noted that the applicant used data storage provided by the University of York and by Iron Mountain as an off-site backup, but that those two organisations were unable to access the encrypted data stored within their facilities. The HSCIC had confirmed they were content with the security arrangements for these two sites.

Discussion: DAAG were informed of a typographical error in the application summary and in the ONS email provided as evidence of support, as this stated that accreditation would expire in 2015; ONS had confirmed that this should in fact read 2016. It was agreed that this would be corrected within the application summary.

The potential clinical importance of this work was noted, but DAAG felt that the expected benefits of the work could have been more clearly described within the application summary. It was suggested that if the applicant did apply to use data for additional future research, more information regarding benefits would be expected.

DAAG discussed the gap in time between when the applicant's NIHR funding had ended, and section 42(4) support for use of ONS had no longer applied, and when they had obtained Approved Researcher and Microdata Release Panel approval. It was confirmed that ONS had been aware of this, and that the applicant had continued to store data but had not accessed it for any purpose during that time.

DAAG noted the security assurance provided for Iron Mountain and the University of York, and there was a discussion around whether it was appropriate to review details such as Data Protection Act (DPA) registration entries for these two organisations given that they did not have access to the encrypted data stored within their facilities. It was agreed that this should be discussed further outside the meeting, given the importance of agreeing a standard approach for all similar applications.

Action: DAAG Secretariat to ask Dawn Foster to provide advice on the security aspects of encrypted data storage used solely for disaster recovery purposes, and the implications this has for DPA registration.

DAAG discussed the applicant's request to use the data for further analysis to determine the possibility of additional future research, and whether this should be considered a separate new purpose or an extension of the original project's purpose. On balance it was agreed that this should be considered part of the original project's broader purpose, and it was therefore felt to be appropriate to amend the existing agreement to incorporate this use of data.

A reference to publishing aggregated data was queried, and DAAG asked for the application summary to be updated to include the statement that small numbers were suppressed in publications. In addition DAAG asked for the first section of the application summary to be updated to include organisation addresses.

DAAG noted that one of the documents provided referred to handling identifiable data, and queried

whether this would be linked with the HES and ONS data. It was confirmed that no linkage would take place, and the application summary included a statement that it was not possible to re-identify individuals through data linkage with National Vascular Databases data.

Outcome: Recommendation to approve.

- Application summary to be amended to include organisation addresses in section one and to include the correct ONS approval expiry date.
- Application summary also to be updated to include a statement that aggregated publications will apply small number suppression in line with the HES Analysis Guide.

2.2 Imperial College London – Patient Experience Study (Presenter: Dave Cronin) NIC-392358-J2H2D

Application: This application for pseudonymised HES data had previously been considered at the 29 September 2015 meeting, when DAAG had been unable to recommend approval. A clearer explanation of the expected healthcare benefits had been requested along with further information about funding, justification for the amount of data requested, and information about other data sources used by the applicant. The additional information had now been requested, with confirmation that only provider level scores would be combined with the data requested as well as confirmation that the applicant's funding did not include any conditions regarding data sharing.

Discussion: DAAG queried the statement that this study was not considered to be research, and it was confirmed that this was based on the Health Research Authority (HRA) tool that had been completed and had confirmed that the study was not considered to be research by the NHS. It was noted that the data requested would be filtered to 'specific fields' and DAAG asked for the application summary to be updated to include a list of the applicable fields.

References to data at practice level, trust level or provider level were queried, and DAAG requested confirmation of the level of data requested. DAAG noted a possible ambiguity in the statement that the data requested would 'only be accessed by employees of Imperial College London for the purpose of this project', and suggested that this should be combined with the separate statement that only employees would have access to the data.

DAAG briefly discussed the applicant's DPA registration wording, but noted that the applicant had only requested pseudonymised data and this was therefore felt to be less relevant than for applications requesting identifiable data.

DAAG noted the additional information that had been provided regarding expected outputs and benefits, but there remained some concerns that these were not sufficiently specific. The justification for using national data was discussed, and DAAG questioned whether the expected benefits described could justify providing this amount of data. The applicant had previously indicated that they could instead make use of data for London and the South East region only if it was felt that national data would be excessive, and DAAG agreed that this would be more appropriate.

Outcome: Recommendation to approve subject to the following caveats:

- Confirmation that only data for London and the South East region will be provided, rather than national data.
- Clarification of the level of data requested.
- Provision of a list of the specific fields of data requested.
- Confirmation that small numbers will be suppressed in any publication.
- Clarification of the statement that access to data will only be granted to individuals for the purpose of this project, and only to employees of Imperial College London.

2.3 NHS England – Temporary National Repository (Presenter: Stuart Richardson) NIC-365714-P5P1J

Application: This application was for pseudonymised Secondary Uses Service (SUS) data for use in the Temporary National Repository hosted by Arden and GEM CSU on behalf of NHS England. It was noted that NHS England had previously had a Data Sharing Agreement in place for this data flow, but that this had not previously been reviewed by DAAG. Data would be used to support the work of NHS England in managing commissioned services as well as supporting QIPP programme activities and carrying out data quality management.

Discussion: DAAG noted that Arden CSU and GEM CSU had achieved satisfactory IG Toolkit scores separately, and since the two CSUs had merged an improvement plan had been in place. It was confirmed that the HSCIC had reviewed the improvement plan and were content that it was satisfactory.

It was noted that the NHS England DPA registration entry had been duplicated within the application summary, as CSUs were covered by the same DPA registration entry given that they were not separate legal entities. It was agreed the application summary would be updated to remove this duplication.

DAAG discussed the expected benefits for this application, and noted that the description of benefits was very brief. It was agreed that when a renewal application was made for this use of data, the applicant would be expected to provide a more clearer explanation of outputs and benefits with specific examples of what had been achieved using the data.

Outcome: Recommendation to approve.

- Application summary to be updated to remove the duplicated DPA registration entries.
- DAAG noted that when a renewal application was submitted, clearer examples would need to be provided of the outputs that had been delivered and the benefits that had been achieved.

2.4 Northumberland, Tyne & Wear NHS Foundation Trust - Use of Mental Health currency data to predict prognosis (Presenter: Netta Hollings) NIC-393388-Y4J4G

Application: This application for pseudonymised Mental Health & Learning Disabilities Data Set (MHLDDS) data had previously been considered at the 27 October 2015 meeting. DAAG had been unable to recommend approval and had suggested that the Care Pathways and Packages Consortium should be listed as a co-applicant and had requested a clearer justification for the amount of data requested and why a sample could not be used instead. The application had now been updated to remove all references to Care Pathways and Packages, as it had been confirmed that this programme had ended and therefore had no involvement in this use of data.

Discussion: DAAG noted that the updated application summary did still refer to the Care Pathways and Packages programme at one point, and it was agreed that this would be corrected.

The applicant's explanation that random sampling would not be appropriate for this study was discussed, and DAAG agreed that this seemed an appropriate justification for the amount of data requested.

Outcome: Recommendation to approve, subject to the following caveat:

- Updating the application summary to remove references to the Care Pathways and Packages Programme.

2.5 University of Leeds - The Paediatric Intensive Care Audit Network (Presenter: Gaynor Dalton) NIC-376211-Y8B6R

Application: This application for HES data had previously been discussed at the 20 October 2015

DAAG meeting, but had been withdrawn pending clarification regarding the applicant's section 251 support. It had now been clarified that the applicant had submitted an annual review application to HRA CAG, and CAG had indicated that the section 251 support would continue while the review was taking place. A query had been raised regarding whether their section 251 support covered providing ordnance survey grid reference, and it was confirmed that this was the case.

Following queries raised by DAAG, the applicant had indicated that the 'legal category' and 'legal group' fields were no longer required and these had been removed. In addition, it had been confirmed that the applicant was now content to receive pseudonymised data rather than requiring identifiable data. The applicant had also provided a justification for the number of data years requested given the need to follow long term patient outcomes and had provided additional information about the involvement of HCA International, who sent hospital data to the applicant but who would not receive any data back. Furthermore the applicant had provided a draft update to the patient information about opting out, which now provided a phone number that individuals could use to contact the study team if they wished to opt out after their child had left hospital.

Discussion: DAAG noted that the applicant had now requested pseudonymised rather than identifiable data, but also noted that section 3 of the application summary still listed identifiers such as date of birth. It was agreed that this would be corrected.

DAAG discussed the applicant's upcoming section 251 annual review, and it was noted that there had been some uncertainty in the past regarding DAAG reviewing applications prior to an applicant's annual review being completed. However it was acknowledged that section 251 supports often underwent annual review during the life of a yearly data sharing agreement, and that applicants should not be unnecessarily delayed if their annual review date happened to fall at a similar time to the DAAG review. DAAG were assured that the HSCIC had processes in place for if an applicant's section 251 support came to an end while a data sharing agreement was in place, and that the data sharing agreement would lapse if that legal basis was no longer in place. DAAG agreed that the Acting Chair should discuss this with HRA CAG to agree an approach for applications in future.

Action: Alan Hassey to contact HRA CAG regarding the process for DAAG to consider applications when a section 251 annual review date is pending.

DAAG discussed the updated wording regarding opting out, and there was a suggestion that in some instances parents might prefer to opt out via the telephone number provided while their child was still in hospital. It was suggested that the applicant could update the wording to be clear that this alternative was not only available after leaving hospital. In addition, DAAG requested confirmation of when the opt out wording would be updated.

Outcome: Recommendation to approve.

The application summary would be updated to remove references to identifiers within the HES data requested in section 3. DAAG suggested that the applicant should consider amending the opt out wording to be clear that opting out via the telephone number provided is an available alternative rather than that individuals can only use this method after leaving hospital. Confirmation was requested of the timescales for the applicant to amend the opt out wording. DAAG noted the need for the applicant's section 251 support to be renewed, and that if there were any change to the legal basis then an updated application would need to be brought back to DAAG.

2.6 University Hospitals of Leicester NHS Trust - PHD Study: How does deprivation affect wrist fracture treatment in England? (Presenter: Dickie Langley) NIC-374630-G7W3K

Application: This was a new application for pseudonymised HES data. The data would be used to evaluate treatments of wrist fractures, and to investigate a possible link between deprivation and the risk of fracture. It was noted that a local audit previously undertaken by the Trust had indicated

	<p>this possible link, but that the data requested would not be linked with that previous audit data.</p> <p>Discussion: DAAG queried whether the applicant's University PhD supervisor would have access to the data, and it was confirmed that this would not be the case as data would not be shared outside the applicant organisation.</p> <p>The planned data retention period was queried, as the application summary stated that data would be retained until 2018 whereas the data flow diagram provided referred to destroying data in 2016. It was confirmed that the application summary was correct and that the applicant wished to retain data until 2018.</p> <p>There was a discussion of a reference in the application summary to influencing policy decisions to improve fracture prevention rates. It was not considered clear how policy would be influence, and DAAG asked for this statement to either be removed or to be more clearly explained.</p> <p>A reference to publishing data with small numbers suppressed was queried, and it was agreed that the application summary would be amended to clarify that this referred to publishing aggregated data only. In addition DAAG queried a reference to future studies, and DAAG asked for a statement to be added to the application summary that any use of data for a future study would require a new application to DAAG.</p> <p>Outcome: Recommendation to approve, subject to the following caveat:</p> <ul style="list-style-type: none"> • The application summary should be updated to either remove a reference to influencing policy, or providing an explanation of how this influence will be achieved. <p>It was agreed that the application summary would be updated to include a statement that published outputs would only include aggregated data, and to add a statement that any use of data for a future study would be subject to a future application to DAAG.</p>
3	<p>Any other business</p> <p>No other business was raised.</p>

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
20/10/15	Paula Moss to provide an updated paper on DSCRO local data flows.	Paula Moss	10/11/15: A draft paper had been provided to the DAAG Chair by email but had not yet been circulated to the group. 24/11/15: Ongoing.	Open
03/11/15	Information Governance team to liaise with MedeAnalytics regarding their DPA registration to ensure that it reflects recent applications.	Dawn Foster	24/11/15: Ongoing.	Open
10/11/15	Dawn Foster and Alan Hassey to contact NHS England Director for Data and Information Management Systems regarding the need for more formal evidence that NHS England support certain applications from CSUs, and invite her to attend a future DAAG training session.	Alan Hassey	24/11/15: Ongoing.	Open
10/11/15	Dawn Foster to contact HRA CAG regarding lack of clarity in section 251 support letters.	Dawn Foster	24/11/15: Ongoing.	Open
10/11/15	Gaynor Dalton to inform DAAG once Imperial College London (SAHSU) have published information for patients and the public as per their implementation timeline.	Gaynor Dalton	24/11/15: Ongoing.	Open
17/11/15	Terry Hill to provide a written report on the SIGGAR/SOCCER application (NIC-291981-Y7J2F Imperial College London)	Terry Hill	24/11/15: Ongoing.	Open
22/11/15	Terry Hill to provide a written report on the Imperial College London (SAHSU NIC-204903-P1J7Q) application.	Terry Hill	24/11/15: Ongoing.	Open
24/11/15	DAAG Secretariat to ask Dawn Foster to provide advice on the security aspects of encrypted data storage used solely for disaster recovery purposes, and the implications this has for DPA	DAAG Secretariat		Open

	registration.			
24/11/15	Alan Hassey to contact HRA CAG regarding the process for DAAG to consider applications when a section 251 annual review date is pending.	Alan Hassey		Open