

Data Access Advisory Group (DAAG)

Minutes of meeting held 1 September 2015

Members: Alan Hassey (Acting Chair), Joanne Bailey, Patrick Coyle, Dawn Foster, John Craven (item 1 and morning training session)

In attendance: Frances Hancox, Diane Pryce, Garry Coleman, Dickie Langley, Dave Cronin, Jennifer Donald

Apologies: Sean Kirwan, Eve Sariyiannidou

1	<p>Declaration of interests</p> <p>DAAG members declared their various interests, and it was agreed that the Register of Interests would be updated appropriately. No potential conflicts of interest that would be relevant to the applications scheduled for discussion at this meeting were declared.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 25 August 2015 meeting were reviewed and, subject to some minor corrections, agreed as an accurate record.</p> <p>Action updates were provided (see table on page 6).</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-370843-R6V8T Imperial College London (COSMOS)• NIC-352414-W9M3F CHKS Ltd
2 2.1	<p>Data applications</p> <p><u>Lightfoot Solutions Ltd (Presenter: Garry Coleman) NIC-359692-Q4X1C</u></p> <p>Application: This application was to renew and amend an existing agreement for the applicant to receive and retain pseudonymised, non-sensitive Hospital Episode Statistics (HES) data. Data would be used to inform the Signals from Noise (SFN) tool which provides statistical analysis to NHS Trusts, commissioning organisations and Ambulance Trusts. DAAG had previously considered an application for this purpose at the 23 December 2014 meeting and had recommended approval subject to caveats, which had subsequently been addressed. It was confirmed that the purpose for the application had not substantively changed since the previous DAAG review.</p> <p>Discussion: The proposed data retention period was queried, and it was agreed that this should be amended to state that the proposed retention would be ongoing in line with the services that the applicant provided to customers.</p> <p>DAAG queried the applicant's customer base, as the application summary referred to NHS Trusts and Ambulance Trusts but also elsewhere referred to 'public sector organisations' as well as an organisation named PenCHORD. DAAG were informed that PenCHORD was a collaboration</p>

working with local NHS Trusts that made use of the Lightfoot tool, and it was agreed that this should be clarified in the application summary.

The expected benefits were discussed, and DAAG agreed that examples should be provided of benefits realised with the data already provided to the applicant.

Outcome: Recommendation to approve subject to:

- Clarification of the applicant's customer base, in particular references to 'public sector bodies'.
- Provision of specific examples of benefits realised with the data already provided.
- Amending the proposed data retention period in the application summary to state that this is ongoing in line with the services provided to customers.

2.2

University of Swansea - FARR Institute of Health Informatics Research (Presenter: Dickie Langley) NIC-324116-W0K9R

Application: This was an application for Hospital Episode Statistics (HES) data with linked, identifiable Office for National Statistics (ONS) mortality data. The data would be used to support the Joint Action on Monitoring Injuries in Europe (JAMIE) project, to develop a trauma mortality prediction model, and to support the UK burden of falls project.

Discussion: The use of record level data was queried and DAAG were informed that while record level data would be analysed within the SAIL Gateway, only aggregated data would be shared outside this secure platform. The applicant's Data Protection Act 1998 (DPA) registration wording was also queried, as this did not specifically refer to the use of health data, but it was noted that the use of data for health research was included and on balance this was considered appropriate.

DAAG discussed the amount of data requested, and whether further data minimisation might be feasible. It was suggested that the applicant might consider the use of sampling techniques to reduce the amount of data required in future, although it was noted that the attribution of a large number of fall related deaths to 'bucket codes' could mean that a large amount of data would still be needed for appropriate analysis.

DAAG noted that the applicant had requested a re-supply of some data they had previously received from the HSCIC, and it was explained that this was due to historic data quality issues that had now been addressed within the data in question.

The applicant had received European funding for this work, and DAAG noted that this grant offer referred to commercial exploitation of the results of work funded by the grant. DAAG were informed that the data sharing agreement with the applicant would include wording to specifically exclude commercial exploitation and to be clear that data could only be used for the benefit of health and social care within the UK, in line with the requirements of the Care Act 2014. DAAG requested confirmation from the applicant that they would abide by this data sharing agreement and that any uses of data would be compatible with the Care Act 2014 as relating to commercial purposes. In addition, DAAG requested clarification of the legal status of the FARR Institute and whether the requested data sharing would be covered under the data sharing framework contract between the HSCIC and Swansea University.

Outcome: Recommendation to approve subject to:

- Confirmation by the applicant that they will abide by the new Data Sharing Agreement and that their uses of data will be compatible with the requirements of the Care Act 2014 relating to commercial purposes.
- Clarification of the legal status of the FARR Institute and whether this work would be covered by the Swansea University data sharing framework contract.

2.3	<p>Methods Analytics (Presenter: Dickie Langley) NIC-363259-M1X8F</p> <p>Application: This application was for an amendment, following a renewal application for HES and Secondary Uses Service (SUS) data that had been considered at the 17 March 2015 DAAG meeting and recommended for approval. The applicant had now also requested linked HES-ONS mortality data, as ONS had now approved the provision of mortality data for the applicant's stated purpose. An updated application summary was provided which included an additional sixth purpose for using the data, which involved using ONS mortality data to analyse published Summary Hospital Mortality Indicator (SHMI) outputs, and it was confirmed that the applicant would also use ONS mortality data to support the five purposes previously listed.</p> <p>Discussion: A query was raised regarding the planned data retention period, and it was confirmed that this period was consistent with the previous application made to DAAG. DAAG noted the potential healthcare benefits of the work described.</p> <p>The applicant's DPA registration wording was queried, as this did not refer to the use of health data. However it was clarified that the applicant's full DPA registration wording did state that they processed health and social care data received from HSCIC, and that this had not been included in the application due to an administrative error.</p> <p>Outcome: Recommendation to approve. Application summary to be amended to include additional DPA registration wording.</p>
2.4	<p>University of York - National Audit of Cardiac Rehabilitation (Presenter: Dave Cronin) NIC-362236-V8R5S</p> <p>Application: This application was for pseudonymised, non-sensitive HES data relating to specific cardiac conditions. This data would be used to support the National Audit of Cardiac Rehabilitation. DAAG were informed that the applicant would request annual data on an ongoing basis, but that data more than two years old would be destroyed on a rolling annual basis so that no more than two data years were held at any one time.</p> <p>Discussion: DAAG queried whether this audit was sponsored by any other organisations, and it was confirmed that the British Heart Foundation had provided funding. The expected healthcare benefits were noted.</p> <p>The dataset period requested was queried, as the application summary stated that data was destroyed after a period of two years but only one data year was requested. It was confirmed that this was correct.</p> <p>A reference in the application summary to reporting against performance at 'local clinical research programme level' was queried, as it was unclear what was meant by this statement. It was agreed that clarification would be requested.</p> <p>Outcome: Recommendation to approve. Application summary to be updated to clarify references to local clinical research programme level.</p>
2.5	<p>University of Manchester - The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (Presenter: Garry Coleman) NIC-345760-Q0M2Z</p> <p>Application: This application was to extend, renew and amend an existing data sharing agreement for the receipt of identifiable, sensitive HES data relating to certain mental illnesses. Data would be used to examine the characteristics and clinical care of people with schizophrenia who commit homicide compared with control cases with schizophrenia who do not commit homicide. The application had previously been discussed by DAAG on 27 January 2015, when</p>

DAAG had been unable to recommend approval as the process to renew the applicant's Section 251 support had not yet been completed. It was confirmed that renewed Section 251 support for this use of identifiable data was now in place.

DAAG were informed that the sensitive fields Local Patient Identifier (LOPATID) had been requested, and that this field was considered sensitive as the free text field could sometimes contain identifiable information. However as other identifiers were also requested, the receipt of this sensitive field was not considered to pose any additional risk.

Discussion: The potential benefits of this work were noted, but given the sensitive subject matter there was felt to be a risk that the publication of results could potentially result in increased stigmatisation of mental illness if not carefully handled. It was noted that the application summary stated that the existing sample size was not large enough to guarantee a satisfactory level of statistical power, and DAAG queried what number of cases would be required to guarantee this.

DAAG noted from the additional information provided that this work was part of a PhD, and asked for this to be made clearer in the application summary. Clarification was also requested about the PhD funding.

A copy of the applicant's research protocol had been provided, and it was noted that in Scotland case matching to determine controls appeared to have been carried out by National Services Scotland before data was provided to the applicant, rather than providing the applicant with a wide range of mental health data for the applicant to then carry out case matching. DAAG queried whether it would be possible for the HSCIC to carry out case matching before data was provided, to reduce the amount of data that would need to be provided to the applicant.

The statement that the research database would be fully anonymised was queried, and it was confirmed that researchers would be able to see an individual's Study ID but that all other identifiers would be removed from this data and held separately. Confirmation was requested of whether identifiable data would still be retained once responses from consultants had been received, or if identifiers would be deleted at that point. In addition it was not felt to be clear how data would be processed once responses from consultants had been received.

DAAG discussed the importance of ensuring fair processing, and while it was acknowledged that directly approaching the control cases might not be appropriate it was agreed that an accessible fair processing notice should be made available online.

Outcome: Recommendation to approve subject to:

- The applicant undertaking to provide an accessible fair processing notice in line with the Information Commissioner's Office (ICO) Privacy Notice Code of Practice, within eight weeks.
- Confirmation of how the PhD is funded, with the application summary to be updated to clarify that this work is part of a PhD.
- Confirmation of whether the control cohort could be identified before data is provided to the applicant, as was the case in Scotland.
- Confirmation that identifiable data provided to the applicant will be deleted following responses from consultants.
- Confirmation of the number of cases that will be required for the study to have a satisfactory level of statistical power.

2.6 PCMD test case applications – ONS births and deaths data (Presenter: Sharon Thandi)

Application: DAAG were asked to provide advice on a generic template application for access to the Primary Care Mortality Data (PCMD) system ONS births and deaths data. It was noted that the Local Authorities applying for access had previously received data directly from ONS, and that the HSCIC had taken responsibility for access to this data in the previous year. The template

	<p>application had previously been discussed at the 12 May 2015 and 2 June 2015 DAAG meetings and had now been updated based on the feedback received.</p> <p>Discussion: DAAG provided feedback on the updated generic template application. Overall members were positive about the changes that had been made, but it was suggested that it should be clearer how each of the three different datasets would be used and for what purpose. DAAG felt that the example application provided for Stockport was less clearly written, and suggested that this should be more closely aligned to the generic template.</p> <p>DAAG members agreed to review the updated generic application out of committee. It was agreed that once the generic template application had been updated and agreed out of committee, PCMD applications should be submitted as groups of similar application with a table of differences. It was noted that these applications could potentially be considered via a Fast Track process in future, which was currently under development.</p> <p>Outcome: Recommendation to approve the provision of data for a further period of three months to allow updated applications to be submitted to DAAG.</p> <p>DAAG gave advice on the content of the generic application summary template, and it was agreed that an updated generic template would be reviewed out of committee.</p>
2.7	<p><u>NHS England - Management Information for Assuring Transformation (Presenter: Netta Hollings) NIC-358253-S5N7T</u></p> <p>Application: This application was for Assuring Transformation data to be released weekly to NHS England without small numbers suppressed in order to monitor the transition of individuals with a learning disability from inpatient to community settings. DAAG were informed that NHS England currently received this data with small number suppression applied, but that due to the very small number of individual transitions each week the data would be significantly more useful if small number suppression could be removed.</p> <p>Discussion: DAAG supported the aims of this work, although it was felt that the expected benefits could have been described more explicitly in the application summary.</p> <p>DAAG noted the aim to increase the frequency of reporting to daily and raised some concerns regarding this, as the increased risk to privacy this would cause was not considered to be outweighed by an increase in benefit.</p> <p>Outcome: Recommendation to approve subject to removal of the reference to 'potentially daily' reporting from the application summary. DAAG were unconvinced of the benefits of daily reporting, given the increased risk to privacy, and would want to see a further application from NHS England if this were requested.</p>
3	<p>Any other business</p> <p>No other business was raised.</p>

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
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. 18/08/15: The next meeting of the Board is on the 23 September after which the draft minutes will be agreed. DAAG secretariat to circulate following publication 25/08/15: Ongoing – DAAG secretariat to circulate following ratification at the 23 September 2015 Board meeting. 01/09/15: Ongoing, pending publication.	Open
13/08/15	Stuart Richardson to ensure that the privacy notice for Castle Point and Rochford CCG is appropriately updated.	Stuart Richardson	18/08/15: Stuart Richardson to continue to work with applicants and feedback update at future DAAG. 25/8/15: Stuart Richardson to update members on the 8 September with regard to fair processing notices in general and progress to date – Secretariat to add to agenda as discussion item 01/09/15: An update would be provided at the 22 September meeting.	Open