Data Access Advisory Group (DAAG)

Minutes of meeting held 16 June 2015

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

In attendance: Frances Hancox, Victoria Williams, Diane Pryce, Steve Hudson, Dickie Langley, Garry Coleman, Dave Cronin, Stuart Richardson, Paula Moss, Julia King, Jennifer Donald

Apologies: Dawn Foster

1	**Review of previous minutes and actions** The minutes of the 9 June 2015 meeting were reviewed and agreed as an accurate record. Action updates were provided (see table on page 7). **Out of committee recommendations** 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: • NIC-340660-Z7B8Y Rod Gibson Associates • NIC-348988-V6G1J HSCIC Clinical Audit Support Unit (CASU) National Pregnancy in Diabetes Audit
2 **2.1 and 2.2**	**Data applications** Luton Clinical Commissioning Group (CCG) (Presenter: Stuart Richardson) NIC-350559-G1X9N and Bedfordshire CCG NIC-348765-P2K6T **Application:** These two applications, which were presented together with a table of differences, were to renew the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) as covered by the support granted under section 251 of the NHS Act 2006 for stage one accredited safe havens. Data would flow through North East London Commissioning Support Unit (CSU) and then through the commercial organisation MedeAnalytics, who would act as data processor for both CCGs. All organisations involved had achieved satisfactory Information Governance (IG) Toolkit scores, and held appropriate Data Protection Act 1998 (DPA) registrations. However it was noted that due to an administrative error, the IG Toolkit score for MedeAnalytics had not been listed in the application summary. A draft fair processing statement from each CCG had been provided. **Discussion:** DAAG requested that for similar applications in future, a copy of the relevant section 251 support letter should be provided. A query was raised regarding the outputs that would be shared, and it was confirmed that the outputs would be summaries in an anonymised form. DAAG suggested that further work could be done to improve the applicants' fair processing materials, and it was suggested that the applicant should review these in line with the Information Commissioner's Office (ICO) code of practice for privacy notices. In particular members highlighted the potential benefits of taking a layered approach to providing information, ensuring that members of the public could read a summary of key points about the use of data before

	including further details. In addition it was suggested that the applicants should consider how these materials were presented online. However it was agreed that while further improvements could be done, the materials provided were adequate for DAAG to recommend approval. **Outcome:** Recommendation to approve. It was agreed that the application summary would be amended to include the MedeAnalytics IG Toolkit score, and DAAG requested sight of the most recent section 251 support letter for stage one ASH applications in future. DAAG advised that the applicant should develop their fair processing materials in line with the Privacy Notices Code of Practice published by the ICO, and in particular the applicant should consider a layered approach.
2.4	University Hospitals Bristol NHS Foundation Trust - Benefit of CMR after PPCI pathway activation (Presenter: Dave Cronin) NIC-319738-F3W3L **Application:** This application, which had previously been considered on 10 March 2015 (NIC-319284-X1J5S), was for data linkage to a bespoke extract of pseudonymised, non-sensitive Hospital Episode Statistics (HES) and identifiable, sensitive HES-Office for National Statistics (ONS) mortality data for a cohort of participants based on their consent. This data would be used to identify co-morbidities within the cohort as part of a feasibility study for work funded by the National Institute for Health Research. DAAG had previously been unable to recommend approval and had agreed that the consent materials should be updated, in addition to requesting additional details regarding benefits and the arrangements for an individual on an honorary contract. The applicant had provided additional information, and clarified that recruitment to the study had completed. It was noted that there had been no patient involvement in the development of the consent materials. **Discussion:** DAAG noted the additional information that had been provided, and agreed that the study had the potential to benefit health and social care. It was felt that further details were still required regarding the individual with an honorary contract, as while a copy of the Staff Conduct Policy for the Trust had been provided it was unclear whether an agreement was in place between the Trust and the University of Bristol to ensure that appropriate action could be taken in the event of a data confidentiality breach, and in particular whether the individual's employment could ultimately be terminated. It was also noted that the Staff Conduct Policy provided appeared to be out of date. Queries were raised about the planned data retention period, as the reason given implied that data could be used for additional purposes subject to a future application. DAAG agreed that this could be considered misleading, as the data requested could only be used for the specified purpose and the reason given for a planned data retention period should refer to that purpose alone. The consent materials were discussed, and there were some concerns regarding whether these could be considered to provide a legal basis for the data processing requested. For example, it was noted that the materials used out of date terms such as NHS Information Centre rather than HSCIC and no details were given of how participants could later withdraw consent if they wished to do so, as well as not providing sufficient details of the data that would be accessed. However, it was noted that the participant information leaflet did state that participant identifiers would be shared with the Information Centre in order to track patients' health status, and the consent materials did not contain any contradictory statements (such as that no identifiable data would be shared outside the study team) as had been seen with some similar applications in the past. On that basis, it was agreed that on balance it seemed appropriate for participant consent to be used as the legal basis for data processing. However it was agreed that the applicant would need to produce fair processing materials in line with the ICO privacy notices code of practice, which should include details of the data that would be accessed and how participants could withdraw their consent if they no longer wished to participate, and reasonable steps should be taken to

	make these available. In addition, while DAAG noted that the consent materials did not refer directly to the use of ONS data, it was acknowledged that the wording used would have been considered appropriate by ONS at the time. Moreover the applicant had provided evidence that section 42(4) of the Statistics and Registration Service Act 2007 applied, and so this rather than patient consent could provide a legal basis for the provision of ONS mortality data. It was noted that a meeting between HSCIC and ONS representatives was planned to discuss consent wording. DAAG agreed to defer a recommendation, as it was felt that additional information was required before a recommendation could be reached. **Outcome:** Recommendation deferred. Further information was required about how fair processing materials would be updated in line with the ICO privacy notices code of practice, and about what reasonable steps would be taken to make these materials available to participants as well as how requests from participants to withdraw their consent would be handled. A copy of the updated Staff Conduct Policy was requested, as well as confirmation of whether the Trust and the University have an agreement in place that should a confidentiality breach take place, appropriate action could be taken against an individual with an honorary contract and ultimately their employment could be terminated. It was agreed that an update on this application should be provided at the 30 June 2015 meeting.
2.5	<u>Imperial College London Healthcare NHS Trust – Late aneurysm related mortality (Presenter: Steve Hudson) NIC-325964-L1W7R</u> **Application:** This was a new application for linkage of a specific study cohort to pseudonymised, non-sensitive HES data. This data would be used to support research into aneurysm related mortality, which had been funded by the National Institute for Health Research (NIHR) with Imperial College London acting as the trial sponsor. DAAG were informed that all Imperial College London staff working on the project held honorary contracts with the NHS Trust, and it was noted that section 251 support was in place. **Discussion:** DAAG noted the potential importance of this study and expressed their support. The use of honorary contracts was discussed, and as with the previous application (NIC-319738-F3W3L) queries were raised regarding the controls in place should a clinician working under an honorary contract be involved in a data confidentiality breach. An example of an honorary contract had been provided, and it was thought based on this document that honorary employees would be required to follow the relevant policies of Imperial College London. It was noted that the Imperial College London had published the core terms and conditions applicable to clinical academics, and it was thought that these included information about the governance arrangements for honorary employees. It was agreed that a link to these terms and conditions would be circulated to DAAG members. DAAG discussed the fair processing statement wording provided and agreed that this wording should be amended to clarify how individuals could opt out if they wished to do so. In addition a query was raised about when the updated wording would made available on the applicant's website. **Outcome:** Recommendation to approve subject to fair processing materials being updated to include details of how participants can opt out. DAAG should be informed of when the updated materials will be published online.

2.6 University of Leeds - Cancer Epidemiology Group (Presenter: Garry Coleman) NIC-352291-Y7B1S

It was noted that Garry Coleman, who presented this application, held an honorary contract with the University of Leeds.

Application: This was an application for pseudonymised non-sensitive HES data, which would be linked to Public Health England cancer data to identify a cohort of individuals who had undergone bariatric surgery as well as a control cohort of individuals who were obese but had not undergone this surgery. Additionally data on the time elapsed between hospital admission and death, which would be derived from ONS mortality data, would also be linked. It was noted that section 251 support was in place, and the only output to the applicant would be pseudonymised, non-sensitive data.

Discussion: The applicant's DPA registration wording was queried, although it was noted that this did refer to health research involving the use of patient data. The expected outputs were discussed and it was noted that the applicant intended to share results with a bariatric support group in addition to publication in peer-reviewed journals and presentations at conferences.

A query was raised regarding the use of HES data to study bariatric surgery, as it was noted that the majority of this surgery was carried out in the private sector. It was suggested that there would be a risk that individuals included in the control group as not having undergone surgery might in fact have undergone surgery privately that was not reflected within HES, and this could therefore impact data quality.

DAAG queried the approach Public Health England took to fair processing, and it was suggested that this should be raised with Public Health England to ensure this was handled consistently.

Outcome: Recommendation to approve.
DAAG commented that the application did not acknowledge that during the period of the dataset, a significant proportion of bariatric surgery was conducted in the private sector rather than the NHS and this would therefore not be captured within HES data, which could lead to the potential misidentification of a control group.

Action: Garry Coleman to speak to Chris Roebuck regarding Public Health England's approach to fair processing.

2.7 King's College London - King's Centre for Military Health Research (Presenter: Dickie Langley) NIC-352310-L8R7H

John Craven declared an interest in this application and did not participate in the discussion.

Application: This was an application for linkage of pseudonymised, non-sensitive HES data for a specific study cohort in order to inform research into the health of serving and ex-serving military personnel. The application had previously been considered on 31 March 2015 (NIC-313785-P0H7C) when DAAG had been unable to recommend approval due to concerns that the participant consent materials used did not provide an appropriate legal basis for the data processing described. The applicant had subsequently applied for and been granted section 251 support, and had provided additional information on steps that would be taken to ensure fair processing which included issuing an updated newsletter to participants outlining data flow processes.

Discussion: DAAG agreed that the concerns previously raised regarding legal basis and fair processing had now been addressed.

	The planned data retention period of 20 years was queried, as while it was stated that this period was in line with Medical Research Council guidelines no further detail was provided of how these guidelines applied to the specific data requested. It was noted that the current application was for an agreement end date in June 2016, meaning that data retention past that point would be subject to further HSCIC approvals, but it was also noted that as per the published HSCIC Data Dissemination Approvals Policy an extension application to retain data for longer would not usually be brought to DAAG for further scrutiny. It was agreed that the HSCIC Data Disseminations Approvals Policy should be discussed at a future DAAG training session. DAAG queried how soon the newsletter informing participants of the proposed use of data would be issued, and it was agreed that the applicant should be asked to confirm this. **Outcome:** Recommendation to approve subject to clarification of the data retention period, and confirmation of when the updated newsletter will be issued. **Action:** DAAG Secretariat to include HSCIC Data Disseminations Approvals Policy and ongoing work with HRA CAG as topics for a future DAAG training session.
2.8	<u>NHS North of England CSU (Presenter: Dave Cronin) NIC-342238-W8H3M</u> **Application:** This application was for pseudonymised, non-sensitive HES data, which the applicant would use to produce aggregated data, in order to inform a dashboard analysis and reporting tool for NHS commissioners named RAIDR. DAAG were informed that RAIDR was made available on a commercial basis to NHS organisations only on a subscription basis, and would enable organisations to carry out benchmarking against national information. **Discussion:** A reference within the application summary to a diagram was queried, as it was noted that this diagram had not been included with the application papers. DAAG queried what data was currently being used by the RAIDR tool, as it was unclear whether this included general practice data or if the applicant intended to link the data currently used to the HES data requested in order to benchmark general practices. In particular, it was agreed that the applicant should clarify whether the data currently used included any identifying data. Further details were requested regarding the customer base for the RAIDR tool, and whether this only included CCGs or other organisations as well. In addition DAAG queried the geographic base of the customer organisations, as if these were only located in a particular area then national data might not be required. Furthermore, DAAG requested specific examples of measurable benefits that had been achieved through the use of this tool so far in order to ensure that data provided would be used for the benefit of health or social care, in line with the requirements of the Care Act 2014. **Outcome:** Unable to recommend for approval. Clarification was requested about the customers for this tool and their geographic base. Specific examples were requested of the benefits to health and care that had already been achieved through the use of this tool. In addition further details were requested about the data already used for the tool, whether these data were identifiable, and whether the data would be linked with the HES data requested.
3	**Any other business** <u>Imperial College London - Mortality outcome in the London COPD cohort NIC-340676-D5P9K</u> DAAG were informed that since this application had been considered and recommended for approval at the 13 April 2015 DAAG meeting, the project had moved from University College London to Imperial College London. The applicant had applied for an amendment to their section

	251 support, which had been approved. DAAG queried whether members of the study cohort had been informed of this change, as it was thought that previous consent materials had only referred to data being used by University College London. It was agreed that an amendment application should be brought back to a future DAAG meeting so that this could be considered in more detail. DAAG members were informed that the consultation on the proposed Independent Group Advising on Releases of Data (IGARD) had been launched and was now open online to the general public.

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	03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting. 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. 17/03/15: Ongoing. 25/03/15: Ongoing. 31/03/15: Ongoing. 07/04/15: Ongoing. 13/04/15: Ongoing. 21/04/15: Ongoing. 28/04/15: Ongoing. 05/05/15: It was agreed that Dawn Foster would raise this separately with CAG. 12/05/15: Clarification had been requested from NHS England regarding a particular request for both identifiers. 19/05/15: Ongoing. 27/05/15: Ongoing. 02/06/15: Ongoing. 09/06/15: Ongoing.	Open
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. 16/06/15: Garry Coleman and Chris Roebuck had met with Alan Hassey and would confirm whether one of them would present a future training day session.	Closed
02/06/15	Acting Chair to notify the SIRO and Caldicott	Acting DAAG	09/06/15: Ongoing.	Closed

	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.	Chair	16/06/15: This action had been completed. It was suggested that a session on the data release register should be included in a future DAAG training session.	
16/06/15	Garry Coleman to speak to Chris Roebuck regarding Public Health England's approach to fair processing.	Garry Coleman		Open
16/06/15	DAAG Secretariat to include HSCIC Data Disseminations Approvals Policy and ongoing work with HRA CAG as topics for a future DAAG training session.	DAAG Secretariat		Open