

Data Access Advisory Group (DAAG)

Minutes of meeting held 27 May 2015

Members: Eve Sariyannidou, Dawn Foster, John Craven, Patrick Coyle

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

Apologies: Alan Hassey, Sean Kirwan

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 19 May 2015 meeting were reviewed and a correction was agreed to the recommendation wording for the East Riding of Yorkshire CCG application (NIC-344973-C1R6J). A query was raised regarding the recommendation for the Harvey Walsh application (NIC-346122-J2J0K) but it was confirmed that this was accurate. Subject to the previous correction the minutes were agreed as an accurate record.</p> <p>Action updates were provided (see table on page 7).</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-342891-K7W5K University of Nottingham• NIC-345510-Z5G7X Monitor Casemix
2 2.1	<p>Data applications</p> <p><u>NHS Great Yarmouth and Waveney Clinical Commissioning Group (CCG) (Presenter: Stuart Richardson) NIC-347785-T1V3Y</u></p> <p>Application summary: This application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised), covered by the section 251 support for stage one accredited safe havens to support the commissioning of health services. The CCG had achieved a satisfactory Information Governance (IG) Toolkit score and held an appropriate Data Protection Act 1998 (DPA) registration.</p> <p>Discussion: The intended data retention period was queried and it was confirmed that this would be a maximum of five years only if the section 251 support was renewed, as this was currently due for renewal in 2016. It was agreed that the application form would be updated to clarify this, and to provide additional details regarding fair processing if possible although it was acknowledged that work was underway within the HSCIC to provide additional fair processing information for CCG applications.</p> <p>DAAG queried whether any individual level data would be shared with providers, and it was confirmed that record level data would only be fed back to NHS providers in relation to the patients of that particular provider.</p> <p>Outcome: Recommendation to approve.</p>

2.2	<p>15 Health (Presenter: Dickie Langley) NIC-349877-M5P7D</p> <p>Application summary: This was an application to renew the provision of pseudonymised, non-sensitive Hospital Episode Statistics (HES) and Secondary Uses Service (SUS) data, which DAAG had previously recommended for approval on 18 November 2014. The purpose for requesting this data was for the applicant to evaluate non-medical prescribing on behalf of the Health Education Board and support CCGs in their decision making for commissioning purposes. It was noted that the applicant's DPA registration wording was in the process of being updated. In addition to extending the access to data previously approved, the application was for the applicant to also use data to support their work with voluntary sector organisations.</p> <p>Discussion: DAAG discussed the role of voluntary sector organisations in patient care, and it was felt that this work would be an appropriate use of data. However, it was agreed that confirmation should be sought that only voluntary sector organisations that were commissioned by the NHS would be able to access the outputs of this work. The specific outputs and measurable benefits were considered, and DAAG members felt that insufficient detail was provided. It was agreed that further details would be requested with specific examples of work planned.</p> <p>DAAG queried the applicant's updated DPA registration wording, as it was felt that a reference to the HSCIC within this wording was not necessary and it would be more appropriate for this to be removed.</p> <p>Outcome: Recommendation to approve subject to confirmation that only voluntary sector organisations that are commissioned by the NHS will be clients of this service, and subject to the provision of additional details of how benefits will be achieved, with examples of specific work planned. Also subject to the applicant's DPA registration wording being amended to remove reference to the HSCIC.</p>
2.3	<p>University of York – Centre for Health Economics (Presenter: Dave Cronin) NIC-324101-P4Y7Z</p> <p>Application summary: This application for pseudonymised, sensitive HES, Mental Health Minimum Dataset (MHMDs) and Patient Reported Outcome Measures (PROMS) data as well as Office for National Statistics (ONS) mortality data had previously been considered by DAAG at the 19 May 2015 meeting. Additional details had been requested about the purpose of each project and this had now been provided, along with a statement that each project could only use the data relevant to that particular project and that ONS data was provided on a project by project basis. Additional information had also been provided on the data access controls between projects, which had been reviewed within the HSCIC as part of the applicant's System Level Security Policy, and the applicant's DPA registration wording had been updated.</p> <p>It was noted that an additional project had now been included as part of this application so that there were eight projects in total, but the eighth project would not receive any access to ONS data.</p> <p>Discussion: DAAG considered the additional information provided, and agreed that the points previously raised had been addressed. The access controls between projects were discussed, and it was confirmed that there would be individual access controls in place on a project and personnel basis.</p> <p>A reference to a ninth project was queried, and it was confirmed that a request for data for the ninth project was being progressed separately and was not part of the current application.</p> <p>Outcome: Recommendation to approve</p>

2.4 University College London - National Institute for Cardiovascular Outcomes Research (NICOR) (Presenter: Dickie Langley) NIC-342590-T2B7L

Application summary: This application for HES data to support a number of audits had previously been considered on 3 February 2015, when DAAG had been unable to recommend approval. The application had subsequently been updated to list the Healthcare Quality Improvement Partnership (HQIP) as data controller, to clarify that no new data processing was requested in addition to the original application and to remove references to TAVI. The applicant's DPA registration wording had been updated, additional details had been provided about data flow, and the relevant section 251 support letter had been provided as part of the application papers.

Discussion: DAAG noted that HQIP would act as data controller for this application but had not completed the IG Toolkit. It was confirmed that HQIP themselves would not process or receive any data, but there remained some concerns about whether it was appropriate to accept a data processor's IG Toolkit score instead as the data controller remained ultimately responsible. It was thought that this was consistent with the approach taken by the Health Research Authority Confidentiality Advisory Group (CAG), and it was agreed that confirmation of this would be sought.

The anticipated benefits were discussed and it was noted that the application made no reference to NHS provider organisations who provided data for the audits being able to compare their own data in order to benchmark performance and potentially improve patient care. Given the potential importance of this use of data, it was agreed that the application should be amended to include a clear reference to this.

It was noted that the DPA registration wording for HQIP provided on this application differed from the DPA registration wording for HQIP on a separate application, and it was agreed that this should be amended for consistency.

Outcome: Recommendation to approve subject to updating the application form to include that individual NHS organisations will use this data for benchmarking purposes.

Action: Dawn Foster to contact CAG to discuss the approach to accepting IG Toolkit scores for data processors in instances when the data controller did not handle data.

2.5 University of Oxford – Missing data in PROMs DPhil project (Presenter: Dickie Langley) NIC-348831-P9J7C

Application summary: This application for pseudonymised, non-sensitive HES data and sensitive PROMs data had previously been considered on 28 April 2015, when DAAG had been unable to recommend approval. Additional information had now been provided about the controls in place between the University and the student in question in the event of a confidentiality break, along with a clearer explanation of the data retention period and confirmation that ethics approval was not required. Additional details of the expected benefits had also been provided.

Discussion: There remained concerns regarding the need to establish a clear benefit to health or social care, due to the requirements of the Care Act 2014. DAAG queried whether the outputs of this methodological study would be shared with the NHS provider organisations responsible for collecting PROMs data, in order to inform improvements to data collection, or shared with organisations such as NHS England to help guide future policy decisions regarding PROMs data.

Outcome: Unable to recommend for approval. Further information was required about the outputs and expected benefits with clarification of how the results of this research will be used to benefit healthcare, as per the requirements of the Care Act 2014, such as whether reports will be shared with NHS England or with NHS provider organisations.

2.6 Royal College of Surgeons – National Vascular Registry (Presenter: Dickie Langley) NIC-337091-P9S7M

Application summary: This was a request for non-sensitive HES data tabulated by trust with small numbers not suppressed, in order to compare the outcomes of major vascular surgery across England. This would help inform ongoing work around the reorganisation of vascular surgery in England, and the applicant would publish comparative information in order to help improve the quality of patient care.

Discussion: DAAG expressed their support for the work described but concerns were raised that the outputs and anticipated benefits described were not sufficiently specific, and it was not felt to be clear how the registry would be used and how the data provided would be used to benefit health as per the requirements of the Care Act 2014.

DAAG queried what was meant by a tabulation as it was not clear precisely what data would be provided to the applicant, and how this differed from aggregated or pseudonymised data. References to a 'HES server' at the Royal College of Surgeons were also queried as it was unclear whether this meant that the applicant already held a copy of the entire HES dataset. The DPA registration wording for HQIP was queried, and it was agreed that the application form should be amended so that this was consistent with the wording provided on the University College London application (NIC-342590-T2B7L).

The request for small numbers not to be suppressed in the tabulated data provided was discussed, and it was thought that this was due to the need to review instances where only a low number of operations took place at a particular organisation each year. It was agreed that this should be confirmed and explained more clearly in the application summary itself.

Outcome: Unable to recommend for approval. Further information was required about the outputs and anticipated benefits. Clarification was requested of the tabulated data that would be provided, as well as a clearer explanation of why small numbers are required not to be suppressed.

2.7 Health and Safety Laboratory (Presenter: Jen Donald) NIC-337801-K2N5Y

Application summary: This application was to renew an existing agreement for the applicant to receive ONS mortality, cancer registration and personal demographics service data in order to continue monitoring the long-term health of a cohort of asbestos workers. The outputs of the work would be published in peer-reviewed journals and made available online, as well as being used by the Health and Safety Executive to inform future policy decisions.

Given the long term nature of the study a combination of legal bases were in place, with section 251 support for the cohort prior to 2006 and participant consent in place for the cohort after that date. Approved researcher accreditation had been obtained for the use of ONS data. It was noted that the applicant had not yet signed a HSCIC data sharing framework contract, and no data would be provided until this had been completed. The applicant's DPA registration wording was in the process of being amended.

Discussion: DAAG considered the consent materials provided, and expressed their support for the study. There was a suggestion that it would be helpful if the information provided in the consent materials and in the fair processing materials could all be made available in one document or location, but the ongoing nature of the study was acknowledged.

Outcome: Recommendation to approve

<p>2.8</p>	<p><u>University of Leeds - Yorkshire Register of Diabetes in Children and Young Adults (Presenter: Jen Donald) NIC-300343-D5G8J</u></p> <p>Application summary: This renewal application was for the applicant to continue receiving ONS mortality data and personal demographics data for a cohort who had been diagnosed with diabetes as children or young people within the Yorkshire and Humber region. Outputs of research using this data had already been published in journals and presented at conferences, as well as being shared locally with parent and patient representatives, and outputs would continue to inform regional policy on the delivery of care to children with diabetes.</p> <p>DAAG were informed that this application only included the cohort members that had already previously been flagged. Recruitment to the study cohort was ongoing, but the applicant was in the process of updating the consent materials and a separate application to flag the new recruits who had used these updated materials would be made to DAAG at a later date.</p> <p>It was noted that although the application summary stated that the applicant had not yet signed a HSCIC data sharing framework contract, this had now been completed.</p> <p>Discussion: DAAG discussed the consent materials provided, and noted that the applicant would be updating these for use in ongoing recruitment.</p> <p>A reference to sharing data with the European Diabetes Consortium (EURODIAB) was queried, as details of the relevant EU project and funding had not been provided. It was agreed that this reference should be removed from the application and a separate application ought to be made to share data with EURODIAB.</p> <p>Outcome: Recommendation to approve subject to the removal of references to data sharing as part of the European Diabetes Consortium, as this would need to be subject to a separate application.</p>
<p>2.9</p>	<p><u>Imperial College London - Nottingham Study of Neurotic Disorder (Presenter: Jen Donald) NIC-311095-K1Q0B</u></p> <p>Application summary: This application, which was for latest demographic details and ONS mortality data (cause of death) for a small cohort of patients who had consented to participate in a study, had previously been considered by DAAG on 3 March 2015. The applicant had subsequently been granted section 251 support to obtain up to date demographic details.</p> <p>Discussion: The applicant's section 251 support was discussed, and it was noted that this would not cover the provision of ONS mortality data.</p> <p>DAAG queried references to cohort 'follow-up', as it was unclear whether this would include re-contacting members of the cohort and asking them to provide updated consent to participate. It was agreed that if this was the case, the consent materials provided were no longer considered appropriate and they would need to be updated prior to re-contacting the cohort. It was noted that updated consent wording had not yet been agreed between HSCIC and ONS, and although the wording used in the consent form had in the past been considered acceptable by ONS it was now likely to be considered too vague. DAAG suggested that rather than using the existing consent wording as the legal basis for the applicant to receive cause of death data, the applicant could be provided with demographic data and fact of death only to enable them to contact cohort members and obtain updated consent before any additional data was provided.</p> <p>A query was raised regarding the fair processing section of the application summary, as this contained a reference to the Care Act 2014 which was felt to be misleading. The legal basis for dissemination listed in the application summary was also queried, and it was agreed that this</p>

	<p>would be clarified.</p> <p>Outcome: Recommendation to approve the provision of demographic data and fact of death only, subject to clarification of whether the follow-up process will including seeking updated consent from participants and if so subject to consent materials being updated in line with current guidance. Application form to be updated to amend fair processing details and to correctly state the legal basis for dissemination.</p> <p>2.10 <u>University College London - Cancer Research UK and UCL Cancer Trials Centre (Presenter: Jen Donald) NIC-301539-W0C4H - for advice on consent</u></p> <p>Application summary: This application was brought to DAAG for advice only. It was intended that an application for ONS mortality data for the trial cohort would be brought to DAAG at a later date.</p> <p>Discussion: DAAG discussed the consent materials and agreed that by current standards these did not appear to be adequate.</p> <p>There was some uncertainty regarding whether the applicant intended to contact participants again, in which case it would be appropriate to update the consent materials and ask participants to re-consent, or whether data was requested for list cleaning purposes only in which case it might be more appropriate to make updated information available to participants through fair processing activities. It was agreed that this would need to be clarified before an application for data was brought back to DAAG for discussion.</p> <p>Outcome: DAAG advised that further information was required about whether the applicant intended to re-contact participants, or if data was requested for list cleaning purposes only.</p>
<p>3</p>	<p>Any other business</p> <p>A query was raised for DAAG to consider regarding the University of Leicester application (NIC-346273-J5L3M) that had been considered on 19 May 2015. DAAG had recommended that the applicant should send updated fair processing materials to individuals who had already undergone screening in order to provide them with an opportunity to opt out. The applicant had raised concerns regarding the practicality of this, given the sheer size of the cohort of individuals who had already undergone screening and the expected cost of a mail-out to this number of people. DAAG expressed sympathy with the practical concerns raised, and agreed that the applicant should be asked to determine what steps could feasibly be taken to inform individuals and to give them the opportunity to opt out. In addition, given the potential difficulties in informing individuals who had already undergone screening, DAAG agreed that the applicant should confirm how soon consent processes could be updated for individuals attending screening in future.</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>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>	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>	Open
12/05/15	Dawn Foster to contact CAG Secretariat regarding their role in considering consent.	Dawn Foster	<p>19/05/15: Ongoing.</p> <p>27/05/15: This had been raised, and CAG Secretariat had provided assurances that CAG did not consider consent and that the specific reference in the letter in question would not be considered appropriate today.</p>	Closed
19/05/15	Dawn Foster to contact CAG to discuss the	Dawn Foster		Open

	approach to accepting IG Toolkit scores for data processors in instances when the data controller did not handle data.			
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