

Data Access Advisory Group (DAAG)

Minutes of meeting held 29 September 2015

Members: Alan Hassey (Acting Chair, item 2.4 onwards), James Wilson, John Craven, Eve Sariyannidou, Dawn Foster, Patrick Coyle

In attendance: Susan Milner, Frances Hancox, Steve Hudson, Dave Cronin, Gaynor Dalton, Dan Goodwin, Katharine Robbins, Peter Broughton, Netta Hollings

Apologies: Sean Kirwan, Joanne Bailey

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| 1 | <p>Declaration of interests</p> <p>It was noted that John Craven had been employed by one of the applicant organisations (University of Kent) almost two decades previously, but it was agreed that this should not prevent him from participating in the discussion of that application.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 22 September 2015 meeting were reviewed and 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 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-324360-T8R3T IMS Health Technology Services• NIC-354497 London School of Economics• NIC-367272 North East Lincolnshire CCG <p>It was agreed that in future, the DAAG Secretariat would ensure that applications where caveats had been agreed out of committee were listed on meeting agendas.</p> <p>Action: DAAG Secretariat to list out of committee recommendations on DAAG meeting agendas.</p> |
| 2 2.1 | <p>Data applications</p> <p><u>University of York (Presenter: Dave Cronin) NIC-376184-B2F2K</u></p> <p>Application: This application had previously been considered by DAAG on 30 June 2015 and was recommended for approval. A Data Sharing Agreement had not, however, been put in place and no data had been shared.</p> <p>The original application had sought permission to access a dataset held at University of York by the Centre for Health Economics. Due to a change in policy at the University, access is no longer permitted to other departments. Hence the Department of Economics and Related Studies at Alcuin College now requested a separate extract of data for this project. In addition, the applicant had requested an additional year of HES Admitted Patient Care data for 1998/1999. DAAG members were advised that there were no other changes to the access and processing of data from the original application previously approved.</p> |

Discussion: DAAG members were advised that the caveats raised previously had all been met and relevant evidence had been provided to the DAAG Secretariat.

DAAG members queried whether the change of policy by University of York affected the security checks which had been undertaken when this application had previously been recommended for approval. It was confirmed that a security check had been undertaken of the System Level Security Policy (SLSP) for the Department of Economics and Related Studies. Members were reassured that appropriate security measures were in place but requested that the application summary should be amended to reflect that the SLSP approved by the HSCIC was for Department of Economics and Related Studies.

DAAG members also requested that details of the University of York's change of policy should be provided and include clarification on their change of policy for providing access to data. This should set out clearly that data will not move between departments and how access will be restricted.

A query was raised on the date of retention provided on the application summary and it was requested that this should state the date when the data will be destroyed.

DAAG members recommended that a statement should be included in the Data Sharing Agreement for this application that only the Department of Economics and Related Studies, Alcuin College will access the data requested in this application.

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

- Clarification should be provided that only the Department of Economics and Related Studies, Alcuin College will access the requested data.
- The application summary should state that the System Level Security Policy approved by the HSCIC was for the Department of Economics and Related Studies, Alcuin College.
- A statement should be included in the Data Sharing Agreement to confirm that access to the data applies explicitly to the Department of Economics and Related Studies, Alcuin College.
- The reason for the data retention period should be amended to show the date of destruction of the data.

It was agreed that the University of York would be asked to provide clarification on their change of policy for providing access to data. This should set out clearly that data will not move between departments and how access will be restricted.

Action: University of York to be asked for clarification on their change of policy for providing access to data.

2.3 Public Health England – Learning disability census data (Presenter: Netta Hollings) NIC-364403-N2R6Y

Application: This application was for pseudonymised, sensitive learning disability census data from 2013 (which the applicant had previously received, and now destroyed) as well as 2014 and 2015 data once this was available. The different data years would be linked within the HSCIC using NHS number, then pseudonymised before this was provided to the applicant. This census data would be used by the applicant for detailed secondary analysis into predictors of patient movement between years, characterisation of why individuals are in hospital, and predictors of adverse experiences in hospital.

Discussion: DAAG noted that the application summary referred to the applicant's planned office move, and queried the timescales for this move. They were informed that the move had been delayed, but that once the move was confirmed the applicant would need to submit an updated

application with information security details for the new office location.

A query was raised regarding the use of NHS number for data linkage, and it was confirmed that the HSCIC would different HES data years requested using NHS number, with additional checks carried out using gender, date of birth and name. It was agreed that the application summary would be updated to include a clearer explanation of this linkage process. A statement that data would be accessed by 'only individuals associated with PHE' was queried, and it was agreed that this would be amended to clarify that only individuals associated with this particular project would have access to data.

Outcome: Recommendation to approve. Application summary to be updated to include a clearer explanation of how data is linked, and to correct the statement that 'only individuals associated with PHE' would have access to data to instead state only individuals associated with this project will have access.

2.4 Northumberland Tyne and Wear NHS Foundation Trust - Use of mental health currency data to predict prognosis (Presenter: Netta Hollings) NIC-360866-Z6N9K

Application: This application was for pseudonymised Mental Health and Learning Disabilities Data Set (MHLDDS) data, including sensitive data items relating to detentions under the Mental Health Act 1983. The applicant intended to analyse this data to ascertain any relationships between the Health of the Nation Outcome Scales (HoNOS) assessment tool and patient prognosis. DAAG were informed that this work had been funded by the Care Pathways and Packages Consortium's legacy funds.

Discussion: Some concerns were raised regarding the anticipated benefits of this work as it was felt that a clearer explanation was needed of how this work and its outputs would result in benefits to health and social care as per the requirements of the Care Act 2014. The amount of data requested was discussed, and DAAG asked for a clearer justification for this amount of data as well as confirmation that the applicant could not instead use a sample of national data.

Clarification was requested of the stated justification for requesting sensitive data items. It was confirmed that the applicant required data on detentions under the Mental Health Act in order to consider this within their analysis, as other published research indicated that this was a crucial factor. A reference to 'cluster 10' was queried, and it was suggested that a clearer explanation of this within the application summary would have been helpful. In addition, a reference to publishing summarised results was noted and DAAG asked for confirmation that this only included aggregated data with small numbers suppressed.

DAAG noted the lack of information about fair processing, and asked for confirmation that the applicant organisation was undertaking appropriate fair processing activities to meet their responsibilities as a data controller.

A reference to the applicant being employed as clinical lead by the Care Pathways and Packages Consortium was queried, and given that this research would form part of an MSc dissertation the involvement of the University was also queried. DAAG requested clarification of the role of these different organisations, and confirmation of which organisation was the applicant.

Outcome: Unable to recommend for approval.

- Further details were requested regarding outputs and anticipated patient benefits.
- Information was requested about how the applicant undertakes fair processing activities.
- A reference to publishing summarised results should be clarified and specify whether this will only include aggregated data with small numbers suppressed.
- Clarify the role of the University and confirm who is acting as the applicant, with clarification of what data will be shared with other organisations.
- The applicant should provide a justification for the amount of data requested, and whether

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| | <p>a sample of data could instead be used.</p> <p>DAAG discussed whether fair processing information should be provided in instances where an applicant had requested pseudonymised data under the Health and Social Care Act 2012. It was agreed that while this would not usually be a factor in DAAG's recommendations, it would be helpful if application summaries could include an indication that fair processing had been discussed with the applicant and that they were aware of their responsibilities as a data controller.</p> |
| 2.7 | <p>Imperial College London - Patient Experience Study (Presenter: Dave Cronin) NIC-368820-Y6F0Q</p> <p>Application: On 30 June 2015, DAAG considered an application from this applicant (NIC-315716-L0F4M) for pseudonymised Hospital Episode Statistics (HES) data for six separate projects within the Department of Surgery and Cancer. DAAG had recommended approval for five of the projects, but had been unable to recommend approval for one (project 3, patient experience study). This updated application had now been submitted, requesting to use the data HES Admitted Patient Care data already received under the previous application for this patient experience study project. Following DAAG's previous comments, additional information had been provided regarding how outputs would be disseminated.</p> <p>Discussion: Some confusion arose from the fact that the previously named project 3 was now referred to as project 6 within the application summary. It was clarified that this application was for HES Admitted Patient Care data only, and that the other HES datasets referred to had been only for use in the other projects previously recommended for approval.</p> <p>The amount of data requested was discussed, as the application summary did not include details of any data minimisation efforts. DAAG were informed that this data was required for analysis at national level and provider level, and it was agreed that a clearer explanation of this should be added to the application summary.</p> <p>DAAG felt that a clearer explanation of anticipated healthcare benefits was still required, to clearly state how these benefits could be realised. The number of trusts involved in this work was queried.</p> <p>It was noted that DAAG had previously queried the disciplinary code that would apply to PhD students, and that it had been stated this would feed into the next update of the HSCIC Data Sharing Framework Contract. DAAG were informed that work would shortly commence to review the Data Sharing Framework Contract.</p> <p>A query was raised regarding the statement that the applicant would use a range of data sources comparatively, and DAAG requested clarification of whether the use of additional data could potentially lead to individuals being re-identified.</p> <p>DAAG noted that this study formed the basis of a PhD project, and while the funding organisation for this PhD had been noted no other funding information was provided. Clarification was requested of whether this funding included any conditions regarding data sharing.</p> <p>Outcome: Unable to recommend for approval.</p> <ul style="list-style-type: none"> • A clearer explanation was required of how healthcare benefits will be delivered. • Funding information should be provided, with clarification of whether this funding includes any conditions regarding data sharing. • Justification is requested for why this amount of data is required. • Further information is required regarding the other data sources used by the applicant, and whether using other data could lead to individuals being re-identified. |
| 2.6 | <p>University of Kent - Personal Social Services Research Unit (Presenter: Katharine Robbins) NIC-328464-Y5Y8F</p> |

Application: This application was for pseudonymised, sensitive Adult Social Care Survey and Personal Social Services User Experience Survey for Carers data. DAAG were informed that the University of Kent had been commissioned to carry out work relating to these surveys by the Department of Health. The applicant had previously received survey data from the HSCIC, and the HSCIC currently held survey data on behalf of the applicant under a Data Depositor Agreement with the applicant organisation remaining the data controller. This application was for that survey data to be supplied back to the applicant, as well as providing the most recent data years of survey data.

Discussion: The roles of the different organisations involved in this work were discussed. It was confirmed that the Department of Health had commissioned the University of Kent Personal Social Services Research Unit (PSSRU) to carry out work relating to the adult social care survey, but that the HSCIC and the University of Kent would act as data controllers.

There was a discussion of the controls in place for published data; it was stated that this included the removal of records where one or two records within a council had a unique combination of variables that could help identify an individual, but these records would not be removed from the data provided to the applicant as they were necessary for the work commissioned by the Department of Health.

A query was raised regarding how outputs would be disseminated or published by the University of Kent or by the Department of Health, as this was not reflected in the data flow diagram provided.

Some concerns were initially expressed regarding the publication of record level data by the HSCIC, but it was confirmed that this did not include sensitive fields such as sexual orientation and that the publication was consistent with the ICO Anonymisation Standard. Confirmation was requested that any outputs published by the University of Kent or the Department of Health applied similar disclosure controls.

It was noted that the University of Kent had not completed the IG Toolkit and also did not have ISO 27001 certification, but a System Level Security Policy had been provided and signed off following review by the HSCIC security team.

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

- Clarification of any planned publication or dissemination of outputs, and confirmation that any outputs published by either the University of Kent or the Department of Health will apply appropriate disclosure controls in line with the ICO Anonymisation Code of Practice, the NHS Anonymisation Standard and the HSCIC Code of Practice for Confidential Information.

2.8 British Society of Gastroenterology – IBD Registry (Presenter: Gaynor Dalton) NIC-344511-H6N5B

Application: This was a new application for pseudonymised HES data, linked to the Inflammatory Bowel Disease (IBD) Registry data. This dataset would only include individuals identified as having IBD, and it was noted that section 251 support was in place for this release of data but that the applicant intended to move to a participant consent model in future. Draft consent materials were provided alongside the application for DAAG's advice. DAAG were informed that the University of Liverpool would act as data controllers on behalf of the British Society of Gastroenterology, and that the British Society of Gastroenterology would only receive aggregated outputs.

An error in the application summary was noted, as this referred to consent materials previously being reviewed at the 25 November 2014 DAAG meeting. In fact the consent materials had been considered at the 9 September 2014 meeting and recommended for approval subject to caveats; it had subsequently been confirmed out of committee on 27 November 2014 that these caveats had been met.

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| | <p>Discussion: It was noted that the applicant's registration under the Data Protection Act 1998 (DPA) was due to expire later in 2015, and that this would need to be renewed in order for the applicant to continue receiving data.</p> <p>The use of Chameleon Information Services Limited as a data processor for the British Society of Gastroenterology was discussed, and DAAG asked for this organisation to be listed as a data process on the application summary with their IG Toolkit score and DPA registration details provided.</p> <p>Some concerns were raised regarding the expected outputs, as it was not felt to be clearly explained how these would be used to ensure patient benefits. It was agreed that the applicant should be asked to provide a clearer description of the anticipated healthcare benefits and how these would be realised.</p> <p>Outcome: Recommendation to approve, subject the following caveats:</p> <ul style="list-style-type: none"> • Additional information is required regarding the anticipated benefits to patients, and to health and social care. • A clearer explanation is needed of which organisations act as data controllers and processors, with appropriate security information provided for Chameleon Information Services. <p>DAAG also reviewed the draft consent materials, and commended the efforts made by the applicant in terms of moving towards a consent basis for this application. DAAG offered further advice that the applicant should include additional clarity around data linkage and who would contact patients.</p> |
| 2.9 | <p><u>Picker Institute (Presenter: Gaynor Dalton) NIC-367152-K6Y1D</u></p> <p>Application: This application for identifiable Personal Demographics (PDS) data for the purpose of list cleaning had previously been considered at the 15 September 2015 DAAG meeting, when DAAG had been unable to recommend approval. An updated application summary had now been provided, which included confirmation from HRA CAG that the applicant's section 251 support provided a legal basis for the HSCIC to process identifiable data, clarified data flows and the proposed agreement end date, and provided a copy of the patient information sheet that had been requested.</p> <p>Discussion: DAAG were content that the previously raised queries had now been addressed.</p> <p>Outcome: Recommendation to approve.</p> |
| 3 | <p>Any other business</p> <p>No other business was raised.</p> |

Summary of Open Actions

| Date raised | Action | Owner | Updates | Status |
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| 22/09/15 | To provide DAAG with additional information regarding local data flows through DSCROs, and a proposal for what governance should be in place for changes to these flows. | Kemi Adenubi | 29/09/15: Ongoing. | Open |
| 29/09/15 | University of York to be asked for clarification on their change of policy for providing access to data. | Steve Hudson | | Open |