

Data Access Advisory Group (DAAG)

Minutes of meeting held 31 January 2017

Members: Joanne Bailey, Chris Carrigan (Chair), Dawn Foster, Eve Sariyannidou, James Wilson

In attendance: Anomika Bedi (observer), Gaynor Dalton, Jen Donald, Louise Dunn, Frances Hancox, Terry Hill (observer), Alan Hassey (observer), Kirsty Irvine (observer), Dickie Langley, Stuart Richardson, Vicki Williams

Apologies: John Craven

1	Declaration of interests James Wilson declared a potential conflict of interest for two applications (NIC-64572 NICOR and NIC-51342 Centre for Longitudinal Studies) due to his employment by University College London. Review of previous minutes and actions The minutes of the 24 January 2017 meeting were reviewed and subject to minor changes were agreed as an accurate record. Action updates were provided (see Appendix A). It was agreed that the open actions would be migrated to the IGARD action log. Out of committee recommendations An out of committee report was received (see Appendix B).
2 2.1	Data applications <u>Halton Borough Council (Presenter: Jen Donald) NIC-79018-W9T1D</u> Application: This new application requested access to pseudonymised Hospital Episode Statistics (HES) data via the HES Data Interrogation Service (HDIS) for public health purposes. Discussion: DAAG queried whether this organisation currently held any extracts of HES data in addition to the HDIS access requested. DAAG noted that there was currently an open action regarding the application template wording around the Licensing Act, and it was raised that references to 'the Act' should also be amended to be clear which Act was referred to. There was a discussion of the applicant organisation's privacy notice and DAAG raised that it seemed difficult to locate this notice on the Council website. It was agreed that this feedback would be shared with the applicant, and it was confirmed that this applicant contained the standard privacy notice advice wording as a special condition. Outcome: Recommendation to approve, subject to: • Updating section five to be clear that the applicant does not currently hold any HES extracts. DAAG noted that the template wording should be updated to clarify references to 'the Act' and

	to quote the correct section of the Licensing Act. It was agreed these caveats would be reviewed out of committee by the Director for Data Dissemination. 2.2 <u>Imperial College London - The Power Of Connections: Mapping the Behaviour of Health Care Networks (Presenter: Jen Donald) NIC-67398-K2Y3T</u> Application: This application requested pseudonymised HES data for the purpose of research, including the production of a PhD thesis and outputs to be shared with NHS Improvement and NHS England. DAAG were informed that a technical error meant that the application showed an incorrect start and end date, and in fact the data sharing agreement start date should be listed as 31 January 2017 with an end date of 31 January 2020. Discussion: DAAG noted a statement within the application that only individuals ‘associated with’ the project would have access to data, and asked for this wording to be amended to clarify that this would only be individuals employed by the applicant organisation wording on the project. The planned outputs were discussed and DAAG suggested that the applicant should consider making these more widely available. There was a discussion of the amount of data requested and on balance it was agreed that this seemed appropriate for the purpose described. DAAG noted the use of technical or academic language within this application and raised that in general, applicants should endeavour to write applications in a way that would be easily understandable to a lay audience. There was a discussion about the application renewal process and the controls in place when a data sharing agreement reached its end date; DAAG suggested that this should be discussed at a future IGARD training session. A query was raised about the PhD student referred to in the application and whether this individual was a substantive employee of the applicant organisation; it was agreed this would be confirmed. In addition it was agreed the application wording would be updated to state that the applicant would not link this data with any other record level data. Outcome: Recommendation to approve, subject to: • Amend a reference to data being available to individuals ‘associated with’ the project. • Including a commitment that the applicant must not link this data to any other datasets. • Confirmation that the PhD student is a substantive employee of Imperial College London. DAAG advised that the applicant should consider making the outputs of this work more widely and publicly available. DAAG noted that NHS Digital had advised the applicant to update the Imperial College London website to include details of this study and the data being used for transparency. DAAG suggested that applicants should try to ensure that applications are written in a way that can be more easily understood by a lay audience. It was agreed these caveats would be reviewed out of committee by the Director for Data Dissemination.
2.3	<u>NICOR University College London - Myocardial Ischaemia National Audit Project (Presenter: Jen Donald) NIC-64572-X0Q4D</u> Application: This application requested tabulated HES data, including small numbers, for use in the Myocardial Ischaemia National Audit Project (MINAP). Discussion: DAAG queried whether the applicant currently held any other data for this purpose and it was confirmed that while data may have been requested for other unrelated audits, data had not previously been requested for this purpose. There was a discussion of the

	justification for providing small numbers and it was agreed this seemed appropriate. DAAG reiterated their previous queries regarding security assurances for the data controller HQIP and it was noted that there was an open action relating to this. Outcome: Recommendation to approve. DAAG noted that for future applications where HQIP acts as data controller, an update would be expected regarding security assurances for HQIP.
2.4	<u>Centre for Longitudinal Studies (University College London) – Next Steps (Presenter: Jen Donald) NIC-51342-V1M5W</u> Application: This application requested pseudonymised HES data for the Next Steps study cohort who had given consent to the requested data sharing. DAAG were informed that in future the applicant wished to apply to share data with other researchers, potentially via the UK Data Service, but that this was not part of the current application. It was noted that the application included a special condition requiring the applicant not to link the data with other identifiable data held for this cohort, and it was also noted that due to a technical error the application listed a contract expiry date that had now passed. Discussion: DAAG noted the value of this study and the potential healthcare benefits. There was a discussion of the consent and patient information materials and DAAG commented that these were informative and well-written. A typographical error was noted and DAAG requested clarification of a statement that research would be 'of direct benefit' to the health service. Some reservations were expressed about the future intention to share data with researchers as it was unclear whether this would be covered by the participant consent, and what controls would be in place to ensure the data could still be considered anonymised in context when accessed by multiple researchers. DAAG noted that this additional data sharing was not part of the current application, but also noted references to the UK Data Service in section five of the application. Clarification was requested of whether the UK Data Service was relevant to this current application, and if not then DAAG asked for these references to be removed. It was agreed the application wording should be updated to include a commitment that data would not be shared with third parties under this particular data sharing agreement. Outcome: Recommendation to approve, subject to: • Updating a typographical error in section five, and amending a statement that research will be of direct benefit to the NHS. • Clarification of whether UK Data Service is relevant to this current application, and removing references from section five if these are not relevant. • Including a commitment that data will not be shared with third parties as a result of this data sharing agreement. DAAG suggested that the applicant's DPA registration should be amended to clarify a reference to providing healthcare services for patients. It was agreed these caveats would be reviewed out of committee by the DAAG Chair.
2.5	<u>KPMG - National Cancer Vanguard baseline and contract modelling project (Presenter: Dickie Langley) NIC-69707-G0Q7Z</u> Application: This application was for access to pseudonymised HES data via the HDIS, in addition to an extract of pseudonymised Secondary Uses Service (SUS) data. The Christie NHS Foundation Trust and Royal Marsden Hospital NHS Foundation Trust would act as data controllers and processors. The application had been discussed at the 17 January 2017 meeting, when DAAG had deferred making a recommendation. The updated application now more clearly explained the role of KPMG as a data processor only, and confirmed that the

	security assurances for KPMG had been accepted by NHS Digital. Discussion: DAAG agreed that the points raised at the previous meeting had largely been addressed. There remained some outstanding queries regarding the indicative data retention period, and it was agreed that when a renewal or amendment application was next submitted this would be expected to include an updated justification for why data would need to be retained for this period of time. In addition DAAG noted the assurances that the data retention related to the two data controllers, rather than to the data processor KPMG, and confirmation was requested of when KPMG would be expected to destroy the data to be clear that this would not be retained longer than necessary. There was a brief discussion of establishing a process to review the reasons some applications were reviewed multiple times before reaching a recommendation to approved and it was agreed NHS Digital would consider this further. Outcome: Recommendation to approve, subject to: • Clarification of at what point KPMG will securely destroy data. DAAG noted that when a renewal or amendment application was next submitted, a clearer justification would be expected for the indicative data retention period as well as further information about any continued support from KPMG at that point. It was agreed these caveats would be reviewed out of committee by the DAAG Chair.
2.6	<u>Monitor – Carter and GIRFT (Presenter: Louise Dunn) NIC-15814-C6W9R</u> Application: This application to amend an existing data sharing agreement had previously been considered at the 17 January 2017 meeting, when DAAG had deferred making a recommendation. Clarification had now been provided about the potential need for third parties to receive aggregated data with small numbers unsuppressed, although it was confirmed that this would be subject to further applications to NHS Digital. Discussion: DAAG agreed that the previously raised queries had largely been addressed but that the answer regarding the legal basis had left some ambiguity regarding which section of the Health and Social Care Act 2012 was applicable. A reference to sub-contractors was noted and in light of recent queries regarding the security assurances for contractors, DAAG suggested that NHS Digital should consider whether appropriate security assurances had been provided for these arrangements. In addition DAAG noted the references to data sharing with the NHS Trust Development Authority or NHS England and suggested that for future applications, it should be made clearly whether this related to specific teams within those organisations or how else the data sharing would be managed. Outcome: Recommendation to approve, subject to: • Providing a clearer explanation of which section of the Health and Social Care Act 2012 is applicable. DAAG noted a reference to sub-contractors working for and on behalf of Monitor, and suggested that NHS Digital should consider whether appropriate security assurances had been provided to cover this. It was noted that for future renewal or amendment applications, a clearer explanation would be expected of how data sharing would be limited within NHS TDA and NHS England. It was agreed these caveats would be reviewed out of committee by the Director for Data Dissemination.
2.7	<u>SVM Pharma (Presenter: Gaynor Dalton) NIC-28771-W5Z2Q</u>

2.8	Application: This new application requested monthly receipt of pseudonymised national HES data, which would be used to populate the organisation's HALO tools and generate three reports that would be made available free of charge to NHS organisations. Discussion: DAAG discussed the planned output and expected benefits and it was not felt that sufficient information had been provided to justify how this would meet the requirements of the Care Act 2014 regarding benefits to health or social care. Concerns were raised that the reports described might be used primarily to promote the services of the applicant organisation, rather than being principally intended to achieve healthcare benefits, and that this could therefore be considered a commercial purpose. DAAG noted the market research provided as a supporting document and reflected that this did not appear to offer appropriate assurances that NHS organisations would make use of the proposed outputs in a way that would generate benefits to the service. DAAG acknowledged the importance of innovation and not creating barriers to market entry, and noted that commercial organisations could experience difficulty in establishing a customer base prior to receiving healthcare data. However DAAG emphasised that a request for this amount of national data must provide a clear justification for why the data was required, how outputs would be disseminated to ensure benefits and what health or social care benefits were expected through the use of the data, and it was considered that the current application did not provide this justification. DAAG queried the history of the HALO tool, as it was thought that this may have previously been under development by a different company and it was unclear whether HES data had previously been requested for the development of this tool. Further information was requested about this with clarification of whether the named applicant had previously been in receipt of HES data, for this or other purposes, as well as clarifying whether the HALO tool was still in development. DAAG suggested that NHS Digital might wish to further consider how applications took into account whether applicants had a track record of making appropriate and efficient use of data in the past, in addition to considering the issue of data availability for new companies. A query was raised about how the HALO tool would function, particularly in relation to small number suppression. A further query was raised about a possible fourth purpose referred to in the application, relating to coronary thrombosis, and it was suggested this should either be updated or removed. In addition DAAG queried the statement that reports would be made available to NHS organisations free of charge for eight months, as it was unclear whether charges would apply at the end of that period. Outcome: Unable to recommend for approval. • The purpose of this application did not appear to meet the requirements of the Care Act 2014 with relation to solely commercial purposes and benefits to health or social care. • Further information was required regarding the history of the HALO tool, and whether this tool was completed or was still in development. • Clarification of whether the named applicant had previously held data from NHS Digital. DAAG noted that the discussion of this application had been wide-ranging and that if an updated application was submitted, further points could be raised. Action: To consider the NHS Digital process for new applicant organisations, such as due diligence and data availability for new start-ups. <u>University of Manchester - The Norfolk Arthritis Register (NOAR) longitudinal observational study (Presenter: Gaynor Dalton) NIC-333021-B6W2C</u> Application: This application was to renew an expired agreement for pseudonymised HES data for a long-term cohort study. It was noted that participants had originally given consent to
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	participate in the study, but that as time had passed and the consent materials were no longer considered adequate the applicant had also obtained section 251 support for the requested data processing. The applicant had provided their draft fair processing wording to inform participants about this data sharing, and NHS Digital had noted that this should be updated to more clearly state how participants could opt out. Discussion: DAAG queried the involvement of the University of East Anglia in this application, as it was noted that the study website referred to sponsorship of the project transferring between the two organisations. The proposed fair processing wording was discussed and DAAG agreed that this should be updated to more clearly explain how to opt out. DAAG requested confirmation that the updated wording would be agreed with NHS Digital and made available to participants for an appropriate period of time to allow individuals the opportunity to opt out before data sharing took place. There was a discussion of the planned data processing and it was confirmed that while NHS Digital would process identifiers, only pseudonymised data including a study ID would be provided to the applicant. It was agreed a special condition would be added that the applicant must not link this data with any other record level data other than the linkage described in the application. DAAG queried a reference to 'all personal data' being removed following linkage, as it was thought that this should instead refer to removing identifying data fields. A reference in the application to this as a 'sub study' was queried and DAAG requested clarification of whether this was part of a larger study. A query was raised about the frequency of patient forums, as this appeared to be referred to inconsistently. Outcome: Recommendation to approve, subject to: • Clarification of the role of University of East Anglia. • Clarification of the frequency of patient forums. • A commitment from the applicant to update their draft fair processing wording to include information about how individuals can opt out, with this wording to be agreed with NHS Digital, and to publish this fair processing information an appropriate amount of time prior to receiving data. • Correcting a statement that all personal data will be removed following linkage to instead state that all identifying data will be removed. • Including a special condition that data must not be linked to any other record level data other than the data linkage described within the application. • Clarification of a reference to this as a 'sub study' and whether this is part of a larger study. It was agreed these caveats would be reviewed out of committee by the DAAG members.
3	Any other business <u>Group application for 4 CCGs (GA01-CON-SW – change of storage address)</u> This application had been considered at the 19 July 2016 meeting, and DAAG were informed that the applicant had since requested to store the data at two additional storage locations. It was confirmed that appropriate security assurances were in place to cover both new locations. Outcome: Recommendation to approve It was noted that a DAAG Closure Report was currently in draft form and it was anticipated that this would be shared with IGARD and with NHS Digital colleagues shortly. DAAG members were thanked for their service over the previous years.

Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
15/11/16	To update DAAG on the feasibility of providing random samples of data to applicants, and to ask the Production Team to provide DAAG with further information about the options for data minimisation	Garry Coleman / Alan Hassey	06/12/16: This action was ongoing and it was anticipated an update would be available in mid-January. There had also been a discussion during the training session about data minimisation, with a suggestion for Peter Short to contact the Production Team for further information, and it was agreed that would be incorporated into this action. 20/12/16: It was anticipated an update would be available in mid-January. 10/01/17: Ongoing. It was agreed that this action would be taken forward by Alan Hassey rather than Peter Short. 17/01/17: A number of internal discussions had taken place and it was anticipated an update would be brought to DAAG within the next few weeks. 31/01/17: Ongoing. It was agreed the IGARD Chair would request an update on progress of this action.	Open
06/12/16	To query the privacy notice review process within NHS Digital.	Dawn Foster	13/12/16: This had been discussed with the Caldicott Guardian but further clarification was needed. 20/12/16: This action was ongoing in light of developments in other areas, including the drafting of minimum criteria. It was agreed that the action would be taken forward by Dawn Foster and Noela Almeida. 10/01/17: Ongoing, pending updated criteria. 17/01/17: DAAG were given a brief verbal update on the work taking place. 24/01/17: Work was ongoing following receipt of the final DAAG comments on the minimum review criteria. 31/01/17: A meeting was scheduled to discuss this later in the week.	Open

10/01/17	To speak to NHS Digital colleagues regarding security assurance for HQIP.	Chris Carrigan	24/01/17: This had been raised with NHS Digital. 31/01/17: This had been raised with HQIP and it was thought that work was underway to provide assurances.	Open
17/01/17	To provide an update on the security assurances that NHS Digital would seek for applicants using contractors.	Garry Coleman	24/01/17: It was anticipated this update would be provided to a meeting within the next few weeks. 31/01/17: Ongoing.	Open
24/01/17	To clarify the Local Authority Public Health application template wording regarding the Licensing Act.	Garry Coleman	31/01/17: Ongoing.	Open
31/01/17	To consider the NHS Digital process for new applicant organisations, such as due diligence and data availability for new start-ups.	Alan Hassey / Gaynor Dalton		Open

Appendix B: Out of committee report (as of 26/01/17)

These applications were previously recommended for approval with caveats by DAAG, and the caveats have subsequently been agreed as met out of committee.

The following application caveats have been signed off by DAAG:

- NIC-05217-T0Z0B Woodward Associates (*considered at 04/10/16 DAAG meeting*)
- NIC-63161-C6S8V Rotherham CCG (*considered at 20/12/16 DAAG meeting*)
- NIC-73678-Y1T0Y London Borough of Redbridge Council (LAPH/HDIS) (*considered at 10/01/17 DAAG meeting*)

The following application caveats have been signed off by the DAAG Chair:

- NIC-29785-Q4Y2T Leicestershire County Council (*considered at 17/01/17 DAAG meeting*)
- Group application for 2 Local Authorities¹ (PCMD) (*considered at 17/01/17 DAAG meeting*)

IAO and Director approvals

The following applications were not considered by DAAG but have been progressed for IAO and Director extension/renewal only:

- NIC-392358-J2H2D Imperial College London

¹ NIC-54589 London Borough of Havering; NIC-74145 East Riding Of Yorkshire Council
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