

# Data Access Advisory Group (DAAG)

## Minutes of meeting held 7 April 2015

**Members:** Alan Hassey, Eve Sariyannidou, John Craven, Dawn Foster

**In attendance:** Frances Hancox, Catherine Nicholson, Dickie Langley, Jennifer Donald, Diane Pryce, Louise Dunn, Stuart Richardson, Netta Hollings

**Apologies:** Sean Kirwan, Patrick Coyle

1	<p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 31 March 2015 meeting were reviewed and agreed as an accurate record. Action updates were provided (see table on page 9).</p> <p><b>Out of committee recommendations</b></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 fulfilled:</p> <ul style="list-style-type: none"><li>• Liverpool clinical commissioning group (CCG), NIC-284440-M4G0Q</li><li>• University of Sheffield, NIC-310132-K3Z8B</li><li>• NHS England, NIC-324251-J9T5N</li></ul>
2	<p><b>Data applications</b></p> <p><b>2.1</b> <u>University of Cambridge - European Prospective Investigation into Cancer (Presenter: Jen Donald) NIC-330892-Q5J3T</u></p> <p><b>Application summary:</b> This application was to renew an existing agreement for the applicant to receive identifiable Patient Demographic Service data, Office for National Statistics (ONS) mortality data and ONS cancer registration data for a long-term study cohort. It was noted that the cohort had originally been recruited a number of years previously via general practices and had consented to participate in the study, but as this consent was no longer considered sufficient for the data processing requested the application had been covered initially by class action and then by section 251. DAAG were informed that the section 251 renewal application was currently undergoing review by the Health Research Authority Confidentiality Advisory Group (CAG), but that CAG had confirmed support would continue to be in place while this review was underway. The applicant had also obtained Approved Researcher accreditation to receive ONS data. Regular contact had been made with the study participants, and they would be informed of the continued use of data and given the opportunity to withdraw from the study.</p> <p><b>Discussion:</b> A query was raised regarding whether the data requested was sensitive or non-sensitive, as the application summary stated both in different sections of the form. It was clarified that the ONS mortality data was considered to be sensitive, but that the other data requested was identifiable non-sensitive data and this had not been made sufficiently clear on the application form.</p> <p>While the application summary referred to the significant benefits that had already been realised through this study, it was felt that insufficient information had been provided about how the data provided would be used to produce additional benefits in future. It was agreed that the applicant should be asked to clarify this, and in particular demonstrate how future study outputs would be disseminated to promote benefits to the health and social care system.</p>

The approvals required for the provision of ONS data were queried, and it was noted that the applicant had been granted Approved Researcher accreditation by ONS. DAAG suggested that it would be helpful if the process for ONS approvals could be discussed at a future DAAG training day. It was noted that the applicant's Data Protection Act (DPA) registration would shortly expire and that the section 251 renewal process was underway, and it was confirmed that if either of these things were not renewed then data would cease to flow.

**Outcome:** Recommendation to approve subject to satisfactory evidence being provided to specifically address future plans for dissemination, and subject to confirmation that the applicant's DPA registration has been extended and that the relevant section 251 support has been renewed.

**2.2** Healthcare Quality Improvement Partnership (HQIP) - National Oesophago-Gastric Cancer Audit NIC-303776-B2X1W

It was noted that this application had been withdrawn as it had not been confirmed whether the commissioning letter provided met the requirements to provide a legal basis for access to ONS data.

DAAG members expressed some concerns regarding the application, and it was agreed that comments would be sent by email. An updated application could then be considered at the next available DAAG meeting agenda slot.

**Outcome:** Application withdrawn.

**Action:** DAAG members to provide feedback on this application by email.

**2.4** University College London on behalf of University College NHS Hospitals Foundation Trust (Presenter: Dickie Langley) NIC-310876-D4S7B

**Application summary:** It was explained that this application had been made by University College London on behalf of University College NHS Hospitals Foundation Trust, who would be the data controller for this work with University College London acting as data processor. Pseudonymised, non-sensitive Hospital Episode Statistics (HES) data linked to identifiable, sensitive ONS data had been requested for a project funded by the National Institute for Health Research (NIHR) to examine whether clinical outcomes were impacted by day and time of admission.

**Discussion:** The legal basis for the applicant to receive ONS data was queried. It was stated that this would be section 42(4) of the Statistics and Registration Service Act 2007, as evidence by a funding letter from NIHR, but DAAG noted that this letter had not been shared with the relevant HSCIC team to confirm whether this met the requirements for ONS.

The applicant's fair processing materials were discussed, and there were concerns that these did not appear to state how individuals could object. Moreover it was felt that the fair processing materials did not provided sufficient information about how data would be used for this specific project.

The application summary referred to using ICD-10 codes to filter data in an effort to minimise the amount of data required, but it was not specified what codes would be used or how much of an impact this would have on the data requested. In addition it was noted that the application summary stated that work was underway to update the applicant's DPA registration, but the updated wording had not been provided. A reference to outputs being produced by June 2015 was queried, as it was noted that the project had been delayed and it was not clear if this target date was still accurate.

The anticipated benefits were discussed, and further information was requested about how the applicant intended to disseminate the outputs of this work in order to realise benefits to the health and social care system. It was noted that the application summary referred to accessible summaries that would be produced 'for wider dissemination', and it was suggested that the applicant should clarify what was meant by this.

**Outcome:** Unable to recommend for approval. Evidence was required to support the release of ONS data, with this to be confirmed by the HSCIC DAIS team. Further information was requested about how the outputs of this work will be disseminated to ensure a benefit to health and social care as required by the Care Act 2014. Further information was also requested about data minimisation efforts, and what specific ICD-10 codes were used to filter data. Fair processing materials should be updated to include specific information about this project, and clarify how individuals can opt out. Applicant's updated DPA registration wording to be provided.

## 2.5 Competition and Markets Authority (Presenter: Dickie Langley) NIC-330916-S9Q1W

**Application summary:** This application had previously been considered at the 17 March 2015 meeting, when DAAG had been unable to recommend approval. A query had been raised regarding the applicant organisation's DPA registration, which the applicant had now responded to. In addition DAAG had suggested that the application should be amended to request data for specific mergers only, and it was confirmed that the request for data had now been restricted to a number of CCGs in the relevant area that might be affected by the merger.

**Discussion:** DAAG agreed that the concerns they had raised during the previous consideration of this application had now been addressed.

A reference to the applicant potentially providing access to the data to third parties was queried, as it was not clear on what grounds the data could be shared and it was noted that this had not been referred to in the application previously considered by DAAG. It was agreed that the applicant would need to confirm that any third parties accessing data would be subject to appropriate data sharing agreements or sublicenses, and that no record level data could be taken away from the secure 'data room' where data would be accessed.

**Outcome:** Recommendation to approve subject to confirmation that no third parties will be given access to the data without an appropriate data sharing agreement or sub license in place, as well as confirmation that no record level data will be taken away from the data room and that any data taken away will be aggregated with small numbers suppressed.

## 2.3 HQIP - National Pregnancy in Diabetes Audit (NPID) (Presenter: Louise Dunn) NIC-318151-W1G2R

**Application summary:** This application was for linked HES data for the study participants, who had given their consent to participate in the NPID audit commissioned by HQIP. It was noted that the consent materials for this audit had previously been reviewed by DAAG in January 2013.

**Discussion:** Concerns were raised that the consent materials did not adequately describe the requested data processing, and in particular that the details given in the patient information leaflet were not reflected in the wording of the actual consent form. It was noted that the consent materials did not appear to state how individuals could withdraw their consent, and there were concerns about the fact that the consent form referred to 'anonymised information' when identifiable data based on NHS number was requested.

DAAG noted that a significant number of participants had already given their consent to participate in this study. It was agreed that while it would be disproportionate to ask the applicant to ask each

	<p>participant to provide updated consent it would be appropriate for the applicant to undertake fair processing activities to ensure these individuals would be informed of the use of identifiable data.</p> <p><b>Outcome:</b> Unable to recommend for approval. The patient information materials and consent form need to be updated to be better aligned and to follow current DAAG guidance. Fair processing activities should be undertaken to provide immediate information to participants who have already given consent.</p>
2.6	<p><u>University of Birmingham - School of Health and Population Sciences (Presenter: Dickie Langley) NIC-295451-Y2K3H</u></p> <p><b>Application summary:</b> This application was to renew and extend an existing agreement so that the applicant could receive additional pseudonymised, non-sensitive HES data. This data would be used to undertake research funded by NIHR as well as work funded by the National Institute for Health and Care Excellence (NICE).</p> <p><b>Discussion:</b> Overall it was felt that this application did not provide sufficient clarity on how precisely the data would be used and what specific data was required for which purposes, and it was agreed that a clearer justification should be provided for why this amount of data was required. In addition further clarification was requested regarding the research outputs and how the dissemination of these would be targeted to ensure benefits to the health and care sector. A reference to the applicant planning to produce a report by December 2014 was queried, and it was suggested that the anticipated output dates should be updated.</p> <p>It was noted that the application summary referred to ethics review letters as well as the study protocol, but that these papers had not been provided to DAAG. In addition the applicant's DPA registration wording was queried, as it appeared that this was the standard wording for academic organisations and did not cover the work described.</p> <p>DAAG members noted that this application made use of a number of acronyms, which were not consistently explained. The importance of ensuring that application summaries could be understood by a lay audience was emphasised.</p> <p><b>Outcome:</b> Unable to recommend for approval. Clarification was requested of how data will be used and why this amount of data is required, as well as clarification of the outputs and how these will be targeted. Copies of the study protocol and ethics approval letter were requested by DAAG. The applicant's DPA registration wording did not seem to cover the work described, and would need to be updated.</p>
2.7	<p><u>National Institute of Economic and Social Research (NIESR) (Presenter: Dickie Langley) NIC-289602-C2N5W</u></p> <p><b>Application summary:</b> This application had previously been considered at the 10 February 2015 DAAG meeting, when DAAG had been unable to recommend approval. Further information had been requested about what 'intangibles' specifically would be studied, as well as how this use of data would be compliant with the relevant provisions of the Care Act 2014. The application summary had now been updated to provide additional information about the planned work and the potential benefits.</p> <p><b>Discussion:</b> There remained concerns regarding the possible benefits described, as it was felt that these were not sufficiently specific and did not appear to meet the requirement for the HSCIC to only disseminate data either for the promotion of health or for the benefit of health and adult social care. Moreover, based on the description of the wider project it was DAAG's view that it was unlikely the applicant would be able to demonstrate compliance with the Care Act 2014 as benefits to health and social care were not the primary focus of this work. It was suggested that the</p>

applicant could consider making use of data already available in the public domain, such as workforce data published by the HSCIC or other sources of tabulated data.

**Outcome:** Unable to recommend for approval. On the basis of the evidence provided it did not appear possible for the applicant to demonstrate compliance with the Care Act 2014. DAAG suggested that the applicant should consider using data already published by the HSCIC and other sources of tabulated data for this research project.

**2.8** NHS Northern Eastern and Western Devon CCG Invoice Validation (Presenter: Stuart Richardson) NIC-322858-Y3C2T

**Application summary:** This was a new application for the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) into the applicant's Controlled Environment for Finance for the purpose of invoice validation, supported by section 251. The applicant organisation had achieved a satisfactory Information Governance (IG) Toolkit score and held a relevant DPA registration.

**Discussion:** No significant concerns were raised regarding this application. However it was noted that the DPA registration wording listed in the application summary included an extraneous sentence that had been copied into the summary in error, and it was agreed that this would be removed. It was also agreed that in the list of data already held by the applicant, the section 251 reference number would be corrected.

**Outcome:** Recommendation to approve

**2.9** Central Southern Commissioning Support Unit (CSU) Invoice Validation (Presenter: Stuart Richardson) NIC-330324-W2W8S

**Application summary:** This application was also for the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) into the applicant's Controlled Environment for Finance under the section 251 support for invoice validation. The applicant CSU would act as a data processor, with the CCGs that had a legitimate relationship with the CSU each acting as data controller for their own data. A list of the CCGs that currently had a legitimate relationship with this CSU had been provided. No data would be released to CCGs unless they held satisfactory IG Toolkit scores, appropriate DPA registrations and a signed framework contract with the HSCIC.

**Discussion:** A query was raised regarding the list of DPA registrations, as it was noted that one organisation did not have a registration listed and some others were shortly due to expire. Confirmation was requested that this list was complete and up to date.

There were some concerns that the application summary did not clearly explain what data would be shared with the CCGs, and it was explained that the data identifiable at the level of NHS number would not be shared outside the CSU Controlled Environment for Finance. It was agreed that the application summary would be updated to clarify that identifiable data would not be shared with the CCGs.

It was noted that the dataset period had been incorrectly listed as ending in 2015 rather than 2016, and this would also be amended.

**Outcome:** Recommendation to approve subject to clarification that the list of CCG DPA registration details is complete and up to date, and confirmation that no CCG either without a satisfactory IG Toolkit score and DPA registration or whose DPA registration has expired will receive any data.

2.10	<p><u>North West CSU risk stratification (Presenter: Stuart Richardson) NIC-295761-Q3S6C</u></p> <p><b>Application summary:</b> This application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) for use in risk stratification. This was covered by the section 251 support for the disclosure of commissioning datasets for risk stratification. The applicant CSU would act as a data processor, with the CCGs that had a legitimate relationship with the CSU each acting as data controller for their own data, and a list of the CCGs that currently had a legitimate relationship with this CSU had been provided. No data would be released to CCGs unless they held satisfactory IG Toolkit scores, appropriate DPA registrations and a signed framework contract with the HSCIC. It was noted that the applicant CSU held an appropriate DPA registration, and although the CSU had undergone a merger it was confirmed that the two former organisations had both achieved a satisfactory IG Toolkit score.</p> <p><b>Discussion:</b> No concerns were raised regarding this group application.</p> <p><b>Outcome:</b> Recommendation to approve</p>
2.11	<p><u>CCG Group stage 1 ASH renewal<sup>1</sup> (Presenter: Stuart Richardson)</u></p> <p><b>Application summary:</b> This group application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) to 3 CCGs under the section 251 support for stage 1 ASH. Data would flow directly to the CCGs from the relevant Data Services for Commissioners Regional Office (DSCRO), with no other organisation acting as data processor. All the CCGs had achieved satisfactory IG Toolkit scores. It was noted that the DPA registration for one CCG was due to expire, but the renewal process was already underway and no data would be released until this had been renewed.</p> <p><b>Discussion:</b> DAAG noted that a diagram in the Surrey Downs CCG application referred to CCGs with a legitimate relationship with Surrey Downs CCG; it was agreed that this was an error and the diagram would be amended. In addition the DPA registration wording listed in the application summary included an extraneous sentence that had been copied into the summary in error, and it was agreed that this would be removed. Furthermore the dataset period had been incorrectly listed as ending in 2015 rather than 2016, and this would also be amended.</p> <p>Other than these minor corrections, no concerns were raised regarding this group application.</p> <p><b>Outcome:</b> Recommendation to approve</p>
2.12	<p><u>CCG Group stage 1 ASH renewal<sup>2</sup> (Presenter: Stuart Richardson)</u></p> <p><b>Application summary:</b> This group application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) to 2 CCGs via a data processor under the section 251 support for stage 1 ASH. NHS North of England CSU would act as data processor for both CCGs. It was noted that all the organisations held appropriate DPA registrations and satisfactory IG Toolkit scores.</p> <p><b>Discussion:</b> A DAAG member queried why NHS North of England CSU were acting as data processor given that both CCGs were located in a different part of the country, but it was explained</p>

<sup>1</sup> NHS Surrey Downs CCG NIC- 297139-Z5L9N, NHS Cambridge and Peterborough CCG NIC-322238- S0R5F, NHS Northern Eastern and Western CCG NIC-316067-J2P6R

<sup>2</sup> NHS West Suffolk CCG NIC-301873-Y8P9M, NHS Ipswich and East Suffolk CCG NIC-301841-M9K4K

	<p>that each CCG could form a legitimate relationship with any CSU, as managed by NHS England, without this being restricted by geography.</p> <p>A query was raised regarding what format of data would be shared from the CSU to each CCG, as it was not specified whether this would include the single identifier (NHS number) or if only pseudonymised or aggregated data would be shared.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarifying the format in which data will flow from the CSU to the CCGs.</p>
2.13	<p><u>CSU stage 1 accredited safe haven (ASH) group application<sup>3</sup> (Presenter: Stuart Richardson)</u></p> <p><b>Application summary:</b> This application was to renew the provision of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) to 2 CSUs under the section 251 support for stage 1 ASH. The CSUs would act as data processors for CCGs with a legitimate relationship with the CSU, as authorised by NHS England, and each CCG would be data controller for their own data. It was noted that each CCG would only receive data if a signed framework contract was in place between them and the HSCIC, and if they had achieved a satisfactory IG Toolkit score and held an appropriate DPA registration. It was noted that both CSUs held satisfactory IG Toolkit scores and were covered by the NHS England DPA registration.</p> <p><b>Discussion:</b> The Group noted that the application form stated that any CCGs who were not a stage 1 ASH would not receive identifiable data, but in fact none of the CCGs listed appeared to be a stage 1 ASH. It was explained that as the list of CCGs with a legitimate relationship with these CSUs was liable to change, this statement was intended to cover any future changes.</p> <p>It was noted that the dataset period had been incorrectly listed as ending in 2015 rather than 2016, and this would be amended.</p> <p>It was noted that the DPA registrations for some of the CCGs were shortly due to expire, and it was agreed that these would need to be renewed for data to continue to flow. It was also noted that one CCG did not have a DPA registration listed, and clarification of this was requested.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarification that the list of CCG DPA registration details is complete and up to date, and confirmation that no CCG either without a satisfactory IG Toolkit score and DPA registration or whose DPA registration has expired will receive any data.</p>
2.14	<p><u>NHS England (Presenter: Netta Hollings) NIC-331739-Y7B7X</u></p> <p><b>Application summary:</b> This application was for the receipt of pseudonymised Mental Health and Learning Disabilities Data Set (MHLDDS) data including sensitive items. It was noted that the applicant had previously been given approval to receive this data without sensitive items for a period of 6 months, and an extension was now requested. DAAG were informed that sensitive items were required in order to examine compulsory admissions under the Mental Health Act 1983.</p> <p><b>Discussion:</b> Given the inclusion of sensitive data, there was a query regarding whether small numbers would be suppressed. It was explained that the data provided to NHS England would be at record level and pseudonymised, and that the standard controls around small number suppression would be in place.</p> <p>A reference to HSCIC as data controller was queried, and it was confirmed that NHS England</p>

<sup>3</sup> NHS South CSU NIC-327763-Y5X9R, NHS North England CSU NIC-301891-K7N9Q

	<p>would act as data controller for this application. It was agreed that this would be corrected on the application form.</p> <p>A query was raised regarding a reference in the application summary to the applicant intending to 'incorporate' this data into other datasets, and it was agreed that further clarity regarding this would be helpful. DAAG agreed that it would also have been helpful if further information had been provided on the intended dissemination of outputs and how this would benefit health and care. It was recommended that approval for a period of 6 months could be given, with the requirement for additional information on what benefits had been achieved to be provided when a renewal application was made.</p> <p><b>Outcome:</b> Recommendation to approve for a period of 6 months. The renewal application should include improved clarity on dissemination and evidence of benefit to health and care, as well as clarification of the proposed 'incorporation' of the data with any other datasets held by NHS England.</p>
3	<p><b>Any other business</b></p> <p>The Acting DAAG Chair confirmed that he had written to Professor Sir Simon Wessely regarding an application from the King's Fund (NIC-313785-P0H7C) which DAAG had considered on 31 March 2015.</p> <p>A query was raised regarding applications where a previous application for the same data had been approved for a specific period of time, with a request that the renewal application should fulfil certain caveats. It was not clear how this type of application should best be tracked, and it was agreed that the DAAG Secretariat would discuss this with the Data Access and Request Service team.</p> <p>Members' availability for upcoming meetings was raised, and it was agreed that the DAAG Secretariat would confirm whether any scheduled meetings would not be quorate.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
20/01/15	Alex Bell to discuss the application form template with DARS team and consider adding a section asking applicants to demonstrate how their intended use of data and dissemination of results would be compliant with the Care Act 2014.	Alex Bell	<p>27/01/15: This discussion had been scheduled, and details would be fed back to DAAG.</p> <p>03/02/15: It was agreed that this should be discussed with Garry Coleman in the context of the papers on data sharing drafted following the recent DAAG training day.</p> <p>10/02/15: Discussions had taken place about making changes to how information would be added to application forms.</p> <p>17/02/15: Ongoing.</p> <p>24/02/15: Ongoing.</p> <p>03/03/15: Ongoing.</p> <p>10/03/15: Ongoing.</p> <p>17/03/15: An update was requested on when the next planned update of the application form was scheduled to take place.</p> <p>25/03/15: Ongoing.</p> <p>31/03/15: Ongoing.</p> <p>07/04/15: Ongoing.</p>	Open
24/02/15	DAIS team to discuss the approach to local patient identifiers (LOPATID) with HRA CAG.	Diane Pryce	<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.</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>	Open
24/02/15	DAIS team 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	Diane Pryce	<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</p>	Open

	postcode.		and discussions were ongoing. 17/03/15: Ongoing. 25/03/15: Ongoing. 31/03/15: Ongoing. 07/04/15: Ongoing.	
25/03/15	Dawn Foster and Eve Sariyiannidou to update the recommended consent wording following discussions at 25 March training day.	Dawn Foster	31/03/15: Ongoing. 07/04/15: Ongoing.	Open
25/03/15	Once care.data pathfinder fair processing materials have been signed off by the care.data programme board and the National Data Guardian, Richard Irvine to share materials with DAAG for review ahead of any applications for access to data.	Richard Irvine	31/03/15: Ongoing. 07/04/15 This action was closed.	Closed
25/03/15	DAAG dashboard to be updated to include recommendation themes, the number of times applications are considered by DAAG and a breakdown of recommendations by applicant type (academic, NHS trust, commissioning organisation, commercial organisation).	Alex Bell	31/03/15: Ongoing. 07/04/15: Ongoing.	Open
31/03/15	Eve Sariyiannidou to share comments by email on the query that had been raised regarding pseudonymisation.	Eve Sariyiannidou	07/04/15: This had been sent, and it was agreed that the DAAG Secretariat would forward comments to DAAG members.	Closed
07/04/15	DAAG Secretariat to include discussion of ONS approval process on a future DAAG training day agenda.	DAAG Secretariat		Open
07/04/15	DAAG members to provide feedback on National OG Cancer Audit application (NIC-303776) by email.	Acting DAAG Chair		Open