## **Data Access Advisory Group (DAAG)**

## Minutes of meeting held 17 January 2017

Members: Joanne Bailey, John Craven, Dawn Foster, Eve Sariyiannidou

In attendance: Nicola Bootland (observer), Gaynor Dalton, Jen Donald, Louise Dunn, Nicola Fear (observer), Frances Hancox, Alan Hassey (observer), Louise Hill, Kirsty Irvine (observer), Stuart Richardson, Martin Severs (observer) Vicki Williams

Apologies: Chris Carrigan (Chair), James Wilson

## 1 Welcome and introductions

It was agreed that as Chris Carrigan had given apologies, Joanne Bailey would act as chair for this meeting.

## **Declaration of interests**

John Craven declared a conflict of interest in the King's College London application (NIC-25051-V0K1X) due to being a student with that organisation. Nicola Fear also declared an interest in that application due to being an employee of King's College London.

## Review of previous minutes and actions

The minutes of the 10 January 2017 meeting were reviewed and subject to some changes were agreed as an accurate record.

Action updates were provided (see Appendix A).

#### Out of committee recommendations

An out of committee report was received (see Appendix B).

A query was raised about instances where applications had been progressed by the IAO and Director and it was confirmed that this was part of normal process. The DAAG Secretariat confirmed that any instances where normal process was not followed would be highlighted within the out of committee report.

## 2 Data applications

2.1 Group application for two Local Authorities<sup>1</sup> – PCMD (Presenter: Robyn Wilson)

**Application:** This was an application for access to Office for National Statistics (ONS) births and deaths data via the Primary Care Mortality Database (PCMD). The application was based on a previously agreed template, which had most recently been considered at the 13 December DAAG meeting as part of a group application for five Local Authorities.

A brief verbal update was given on the agreed process for Local Authority privacy notices, and it was confirmed that all applicant Local Authorities would be expected to make appropriate improvements to their privacy notice to cover this use of data within 12 weeks of the DSA commencing.

<sup>&</sup>lt;sup>1</sup> London Borough of Havering NIC-54589-L9F2C; East Riding of Yorkshire Council NIC-74145-

**Discussion:** DAAG noted the use of red text within the template and suggested that for future applications this should be changed to black, with red text only used to note any specific changes to the template. In addition it was noted that the template included a footnote with a list of Local Authorities, but as this had been taken from a previous application those Local Authorities were not included within the current application. It was agreed the footnote should be removed to avoid confusion.

There was a brief discussion about patient objections and the reason that these would not be applied, and it was confirmed that objections were not applicable to data that NHS Digital disseminated on behalf of ONS. It was agreed the application wording should be updated to more clearly explain the reason patient objections did not apply.

**Outcome:** Recommendation to approve, subject to:

- Removing a footnote from the application that lists a large number of Local Authorities.
- Correcting a statement that patient objections will not apply as the data is not considered confidential personal data, to provide the correct reason, and also amending the wording to be clear that this refers to the data disseminated by NHS Digital rather than data received.

It was agreed these caveats would be reviewed out of committee by the DAAG chair.

# 2.2 King's College London - Identifying Genetic and Environmental Interactions in Psychosis (Presenter: Gaynor Dalton) NIC-25051-V0K1X

**Application:** This application requested list cleaning for a small cohort of individuals who had previously consented to participate in a study, but who had been lost to further contact, so that the applicant could contact individuals and ask them to re-join the study. The application had previously been discussed at the 13 December 2016 DAAG meeting, when DAAG had deferred making a recommendation pending clarification of queries including the status of the EU funded project. It had now been confirmed that the original study had ended and the EU funding had ceased, and information was provided to DAAG about the current funding in place. A special condition had also been added to the application regarding the deletion of data about non-responders or individuals who chose not to re-consent, and it had been confirmed that when individuals were contacted this would include information about the data processing that had been carried out by NHS Digital.

**Discussion:** DAAG noted that while the application abstract had been updated to indicate that the original study had now ended, section five of the application still referred to this study as ongoing. It was agreed that section should be updated to ensure that the data sharing agreement would accurately reflect the status of the original study.

It was noted that the applicant's section 251 support included a requirement for patient notification, separately to the broader requirement for fair processing. DAAG noted the applicant's commitment to directly provide information about the data processing that had taken place when they re-contacted individuals, and it was proposed that the applicant should work with IG ISA staff within NHS Digital to agree appropriate wording to describe NHS Digital's data processing.

The requirement for the applicant to destroy data held for non-responders was queried and it was confirmed this only applied to data provided by NHS Digital under this application, rather than referring to any study data the applicant already held.

**Outcome:** Recommendation to approve, subject to:

- Amending section five to clearly state that the original project has ceased, and remove any references to this project as ongoing.
- Updating a reference to the information that will be provided to participants to be clear

that IG ISA will work with the applicant to agree appropriate wording about the data processing carried out by NHS Digital.

It was agreed these caveats would be reviewed out of committee by DAAG.

# 2.3 <u>KPMG – National Cancer Vanguard baseline and contract modelling project (Presenter: Gaynor Dalton) NIC-69707-G0Q7Z</u>

**Application:** This was a new application for access to pseudonymised Hospital Episode Statistics (HES) data via the HES Data Interrogation Service (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.

DAAG were informed that the security assurances for KPMG were currently under review by NHS Digital and that confirmation would be required that these were satisfactory before data could be released. In addition it was noted that the application listed the two Trusts as joint data controllers but that this would need to be amended to data controllers in common.

**Discussion:** DAAG queried the role of KPMG in the proposed data flow and whether this organisation was also acting as a data controller in common for the SUS data. It was considered to be unclear from the application which organisation would be processing what data (SUS extract or HDIS download) in what ways and DAAG asked for this to be clarified.

The planned data retention period was queried and DAAG requested a clearer justification for why data would need to be retained for 15 years; it was suggested that it might be helpful to refer to the indicative data retention periods for similar applications. A query was also raised about the proposed data minimisation as it was agreed that a clearer justification was needed for why this particular amount of data was required.

DAAG discussed the expected outputs and benefits. It was agreed that a clearer explanation was needed of how the outputs would be disseminated and used in order to achieve the expected healthcare benefits.

The DPA registrations for the three organisations were discussed; DAAG suggested some particular improvements but also suggested that the organisations should review their DPA registrations to ensure that they adequately reflect the proposed data processing.

DAAG queried the access controls that would be in place, both at KPMG and at the two Trusts, as the data was described as anonymised in context. It was noted that this should include consideration of the other data held by the organisations, as for example NHS staff would be expected to have ready access to NHS numbers.

Outcome: Unable to recommend for approval.

- Confirmation is required that the ISO 27001 security assurance for KPMG has been fully signed off.
- The two Trusts should be listed as data controllers in common rather than joint data controllers
- Clarification of the proposed data flows and processing carried out by each organisation, with confirmation of whether KPMG should be listed as an additional data controller in common.
- Providing a clearer justification for the indicative data retention period, potentially with reference to the indicative data retention period for similar applications.
- Providing a clearer explanation of the data minimisation efforts with clarification of why
  this particular amount of information is required.
- Providing further information about the expected outputs and how these will be disseminated and used to realise healthcare benefits.

• Updating section five of the application to include additional detail about the access controls in place.

DAAG noted that the DPA registrations for the two Trusts should be updated to refer to patients more widely rather than 'our patients'. In general DAAG advised that the applicants should consider whether their DPA registrations adequately reflect this type of data processing.

## 2.4 Monitor - Carter and GIRFT (Presenter: Louise Dunn) NIC-15814-C6W9R

**Application:** This application requested an amendment to an existing agreement, which had been considered at the 9 August 2016 DAAG meeting. No additional data was requested, but the applicant wished to use the data already held for two additional purposes – namely to develop the Carter Model Hospital dashboard and the 'Get It Right First Time' (GIRFT) programme. A data processing location had also been updated.

**Discussion:** A question was raised about the current legal status of Monitor and the NHS Trust Development Authority, and whether these were still considered separate organisations or a single entity under the NHS Improvement umbrella. It was thought that they remained separate legal entities and it was agreed that section five of the application should be updated to more clearly explain this. A reference to the PLICS data collection having ceased was queried and it was agreed this wording would be amended for clarity.

DAAG noted that the original purpose of the previous application had been to provide Monitor with the data needed to fulfil its statutory functions. DAAG queried whether the two additional purposes were part of the organisation's statutory functions and it was agreed this would be clarified. Some concerns were raised that there was not sufficient detail about the expected benefits of the two new purposes.

There was a discussion about the proposal to share data with third party organisations (where a separate DSA was in place with NHS Digital) and DAAG queried why these organisations would require aggregated data with small numbers unsuppressed, rather than applying small number suppression before sharing data. In addition DAAG noted that the application elsewhere stated that Monitor would not share data with any third parties and that this statement would need to be amended as it now appeared to be incorrect.

It was noted that the previous application had raised some queries regarding a future system and that at that stage it had been agreed references to the future system would be removed from the application. DAAG queried whether the additional purposes in this updated application related to that same future system, and if so what the legal basis was for this.

DAAG noted that the application abstract referred to possible future access to data by the improvement team and it was agreed the wording would be amended to clarify that this would be subject to a future application.

Outcome: Recommendation deferred, pending:

- Including appropriate wording in section five to clarify the legal status of Monitor and NHS Trust Development Authority in relation to NHS Improvement.
- Clarifying a reference to PLICS data collection having ceased.
- Clarifying whether the two additional programmes referred to are part of Monitor's statutory functions.
- Clarifying the statement that data will not be shared with third parties.
- Providing an explanation of why it will be necessary to share aggregated data with small numbers unsuppressed rather than applying suppression prior to sharing.
- Confirming whether the additional purposes are part of a planned future system and if

so what the legal basis is for this system.

 Clarifying within the abstract that a reference to future access would be subject to a further application.

## 2.5 <u>Leicestershire County Council – Public Health (Presenter: Jen Donald) NIC-29785-Q4Y2T</u>

**Application:** This application used the standard template for Local Authority Public Health applications for pseudonymised HES data. It was noted that this applicant organisation would use the Arden and GEM CSU data centre to host the HES data, but that Arden and GEM CSU staff would not have access to the data.

**Discussion:** DAAG queried the statement that the Local Authority was a joint data controller; it was confirmed this was an error and the application would be amended to list them as sole data controller.

The role of Arden and GEM CSU was queried and DAAG suggested that a special condition should be included in the application to confirm that the CSU staff must not access the data stored on behalf of the Local Authority. It was confirmed that Local Authority staff would remotely process the data held by Arden and GEM CSU, rather than a copy of the record level data being held by the Local Authority.

There was a brief discussion of the applicant's privacy notice and DAAG noted that this referred to processing healthcare data for public health purposes.

It was agreed that a reference to the Licensing Act should be clarified, as it was unclear how this was relevant, and DAAG asked for references to 'health duties' to be amended to be clear that data could only be used specifically for public health purposes.

Outcome: Recommendation to approve, subject to:

- Including appropriate special condition wording that Arden & GEM CSU staff must not access the data stored on their premises on behalf of the Local Authority.
- Amending a reference to health duties to be clear that this data can only be used for public health purposes, not wider health purposes.
- Clarifying a reference to the Licensing Act and how this is applicable to this application.
   As a result of this application DAAG would like to draw the applicant's attention to the

importance of the accessibility and clarity of their Privacy Notice. The applicant is advised to review their notice against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice standards. They will be expected to demonstrate progress against this recommendation in any audit undertaken and completion of the requirement for any renewal / new application for data.

It was agreed these caveats would be reviewed out of committee by the DAAG chair.

## 2.6 Oliver Wyman - New Models of Care Analytics (Presenter: Jen Donald) NIC-291736-N6J7Z

**Application:** This application requested to renew and amend a previous data sharing agreement, which had not previously been considered by DAAG. Pseudonymised HES and mental health (MHMDS) data were requested in addition to SUS data, in order to continue to provide services to NHS clients.

**Discussion:** DAAG noted that the application offered examples of recent clients, such as the Cabinet Office, Foundation Trusts and Cancer Alliance, but it was unclear whether how many of these were current clients or if they were past clients, how recently this work had taken place. DAAG asked for further information about existing and future clients as well as clarification about any commercial clients. Given the potential commercial aspects DAAG suggested that a special condition should be added that data must not be used for sales or

marketing purposes.

DAAG noted that a statement that data access would be restricted to 'substantive employees' should be amended to clarify that this only referred to substantive employees of Oliver Wyman. In addition DAAG noted a statement that Sysadmins would be instructed by policy not to access the data, and it was suggested that this restriction should also be reflected as a special condition within the application. It was agreed that wording should also be added to section five of the application to specify that the applicant must not make any attempts to reidentify the data and must not link with any other record level data.

The amount of data requested was queried and DAAG requested a clearer justification for why this number of data years would be required, with reference to current or upcoming projects. Fair processing was discussed and DAAG suggested that although only pseudonymised data was requested, in the interests of openness and transparency the applicant should consider making information about this use of data available to the general public.

It was noted that the application seemed to contain a large amount of background information about new models of care; there was a suggestion that in future the applicant might wish to provide this detail as a separate supporting document, and provide more information within the application about the specific areas of work that this data would be used to support.

Outcome: Recommendation deferred, pending:

- Providing further information about the applicant's past and current clients, with clarification of whether this includes any commercial organisations.
- Including a special condition that Sysadmins must not access data held on the servers
- Providing a clearer justification for the number of data years requested, with reference to current projects.
- Including a special condition that data cannot be used for any sales or marketing purposes.
- Adding wording to section five that the applicant cannot link this data to any other record level datasets and that no attempt must be made to re-identify the data.
- Correcting a reference to data only being accessed by substantive employees to be clear this refers to Oliver Wyman employees.

DAAG wished to draw the applicant's attention to the importance of openness and transparency and suggested that they consider making information about this use of data available to the general public.

DAAG suggested that in future the applicant should consider providing information about new models of care within a supporting document, and reducing the amount of detail about this included within the application to instead provide more information about the specific outputs and benefits expected from this work.

## NHS Salford CCG (Presenter: Stuart Richardson) NIC-76770-F0J5W

This application was withdrawn by the applicant prior to the start of the meeting.

## 3 Any other business

### NIC-32833 Competition & Markets Authority

DAAG received a verbal update on this application as requested at the previous meeting. It was confirmed that in December NHS Digital had taken the decision to progress with the application before DAAG were content that the recommendation caveats had been met, due to the urgency of the customer's requirements and the fact that NHS Digital were content with the assurances provided by the applicant.

There was a discussion about the potential difficulties that could arise when DAAG requested assurance about an area that could be deemed commercially sensitive or confidential. DAAG suggested that it would be helpful to discuss possible approaches to this at a future training session.

## DSCRO and CSU mergers

DAAG were notified of the impending merger of North East London DSCRO and South London DSCRO, as well as the merger of the associated CSUs. This would impact a number of previous applications where data had been described as flowing through South London CSU or DSCRO. It was proposed that in future applications should not name specific DSCROs but should instead refer to data flowing from 'a DSCRO', and DAAG were supportive either of this approach or of referring to the data as simply flowing from NHS Digital (as the responsible legal entity). However it was noted that any differences between DSCROs, such as when a DSCRO required a particular CSU to be used as a landing stage to disseminate data, would still need to be highlighted within the applications.

DAAG queried the timescales for CCG applications to be migrated to DARS Online, as it was suggested that this would have enabled the previous applications to be updated more easily, and they were informed that discussions about this were ongoing. DAAG agreed that NHS Digital should determine the most appropriate method to amend the existing applications that referred to South London CSU or South London DSCRO.

### Invoice validation

DAAG were notified that following an amendment to the section 251 support for CCG invoice validation data flows (CAG 7-07(a-c/ 2013 amendment), the ability to share data between Controlled Environments for Finance (CEfF) was required to validate NHS to NHS invoice payments. At present the invoice validation applications and therefore Data Sharing Agreements contained wording that prevented data sharing with any third parties not listed within the application, which would prohibit this sharing with other CEfFs.

There was a brief discussion about how the change to allow this data sharing would be implemented and it was agreed that this should be discussed further by the relevant teams within NHS Digital. It was agreed that DAAG (or IGARD) would be provided with a copy of the proposed amendment wording.

## Contractors

A query was raised about security assurances where contractors would have access to data, as it was thought that a different approach would be required to where honorary contracts were used. It was agreed that NHS Digital would provide an update on the appropriate security assurances, and that for a current application where the use of contractors was referred to the application should be amended to restrict data access to only substantive staff or those on an appropriate honorary contract.

**Action:** To provide an update on the security assurances that NHS Digital would seek for applicants using contractors.

## 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.	Open
06/12/16	To provide feedback to the NHS Digital Caldicott Guardian on the minimum criteria for privacy notices and to suggest any necessary additional criteria.	DAAG Chair	20/12/16: A draft document had been circulated amongst DAAG members for comments.  10/01/17: A number of comments had been received and an updated draft would be urgently circulated.  17/01/17: Further comments had been received on the updated draft; the agreed changes would be made and a final version circulated as soon as possible.	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	Open

			taking place.	
20/12/16	Garry Coleman to provide an update on his previously closed action on Local Authorities and their requirement for national HES data.	Garry Coleman	17/01/17: It was confirmed that Local Authorities currently believed that national level data was required to fulfil their statutory public health functions, but some organisations had raised concerns about the size of the dataset and difficulties with storage and processing. Some Local Authorities were now opting to request access to HDIS, rather than receiving an extract of the full national dataset, and downloads of HES data via HDIS would be limited by a maximum number of records. DAAG asked for Local Authority HDIS applications to clearly reflect the current position regarding download of record level data.	Closed
10/01/17	To speak to NHS Digital colleagues regarding security assurance for HQIP.	Chris Carrigan	17/01/17: Ongoing.	Open
17/01/17	To provide an update on the security assurances that NHS Digital would seek for applicants using contractors.	Garry Coleman		Open

## **Appendix B: Out of committee report**

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-55950 Queen Mary University of London (considered at DAAG meeting 13/12/16)
- NIC-36826 NHS Hartlepool & Stockton on Tees CCG GA01-CON-NoE (considered at DAAG meeting 20/12/16)

The following application caveats have been signed off by the Director for Data Dissemination:

 Group application for 5 Local Authorities (PCMD) (considered at DAAG meeting 13/12/16)

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

- NIC-344511 British Society of Gastroenterology
- NIC-29554-L0P4F University College London
- NIC-366216-Z9H9Q University of Sheffield