Data Access Advisory Group (DAAG)

Minutes of meeting held 31 March 2015

Members: Alan Hassey, Eve Sariyiannidou, John Craven, Dawn Foster

In attendance: Frances Hancox, Susan Milner, Catherine Nicholson, Stuart Richardson, Dickie Langley, Alex Bell

Apologies: Sean Kirwan, Patrick Coyle

1	**Review of previous minutes and actions** The minutes of the 25 March 2015 meeting were reviewed and agreed as an accurate record. Action updates were provided (see table on page 9). **Out of committee recommendations** 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: • University of Sheffield (NIC-310132-K3Z8B) • ASH group application[1] • NHS England (NIC-324251-J9T5N) • University College London (NIC-180665-GJMW5) One application for pseudonymised, non-sensitive Hospital Episode Statistics (HES) data had been considered out of committee and recommended for approval: • NIC-313605-H1H4S Transport Research Laboratory (TRL)
2 **2.1**	**Data applications** <u>Redbridge Clinical Commissioning Group (CCG) stage 1 ASH renewal (Presenter: Stuart Richardson) NIC-311092-B2P3H</u> **Application summary:** This application was to renew the flow of non-sensitive Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) to a stage 1 accredited safe haven (ASH). This was under the section 251 support for stage 1 ASH, which was now in place until the end of April 2016. The data would be used to support the commissioning of health services and improve patient pathways. It was noted that data would be transferred to the applicant via North East London Commissioning Support Unit (CSU). Both organisations had achieved satisfactory Information Governance (IG) Toolkit scores and had appropriate Data Protection Act (DPA) registrations. **Discussion:** The role of the CSU was queried, and it was explained that due to local arrangements it would not be feasible to transfer data directly to the applicant. North East London CSU would therefore act as a data processor and transfer data onwards to the CCG. The Group noted that scores for version 12 of the IG Toolkit should shortly become available as

[1] Rotherham CCG NIC-276337-L4F1W, Chiltern CCG NIC-276320-W1N9M, South Devon and Torbay CCG NIC-301119-Y5R0B, Horsham and Mid Sussex CCG NIC-308784-Y5Q1J

	part of the annual renewal process, and that this would supersede version 11 scores. **Outcome:** Recommendation to approve.
2.2	Redbridge CCG Risk Stratification (Presenter: Stuart Richardson) NIC-276358-G5Q2Y **Application summary:** 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 had achieved a satisfactory IG Toolkit score and held an appropriate DPA registration. It was noted that aggregated reports would be made available to the CCG, but that general practices would be able to identify patients registered at their practice who had been classed as at risk. **Discussion:** The Group noted that data would flow via North East London CSU, but that the application summary did not currently reflect this. It was agreed that the data flow diagram should be updated to include the role of the CSU as data processor. A query was raised regarding how general practice access to data would be restricted to ensure that each practice could only access the data relevant to their own practice population, and it was thought that this would be controlled through the use of smartcards. **Outcome:** Recommendation to approve subject to amending the data flow diagram to include the role of the CSU.
2.3	Redbridge CCG group risk stratification[2] (Presenter: Stuart Richardson) **Application summary:** This was a group application to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) with Redbridge CCG acting as data processor for 3 other CCGs, who would use the data for risk stratification. This was covered by the section 251 support for the disclosure of commissioning datasets for risk stratification. All 4 CCGs had achieved satisfactory IG Toolkit scores and held appropriate DPA registrations. **Discussion:** As with the previous application, the Group noted that data would flow via North East London CSU but that the application summary did not currently reflect this. It was agreed that the data flow diagram should be updated to include the role of the CSU as data processor. **Outcome:** Recommendation to approve subject to amending the data flow diagram to include the role of the CSU.
2.4	Redbridge CCG group stage 1 ASH renewal[3] (Presenter: Stuart Richardson) **Application summary:** This was a group application to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised). Redbridge CCG would act as data processor for 3 other CCGs, who would use the data to support the commissioning of health services and improve patient pathways. Data would flow via North East London CSU, and their role as data processor had been included in the data flow diagram within the application summary.

[2] NHS Waltham Forest CCG NIC-325971-X4W2P, NHS Barking and Dagenham CCG NIC-276365-H2T0Z, NHS Havering CCG NIC-276362-P0Q3X

[3] NHS Waltham Forest CCG NIC-310845-T9M5Y, NHS Barking and Dagenham CCG NIC-311057-H3G2G, NHS Havering CCG NIC-311056-B9B1Z

	This flow of data was covered by the section 251 support for stage 1 ASH, which was in place until the end of April 2016. All organisations involved had achieved satisfactory IG Toolkit scores and held appropriate DPA registrations. **Discussion:** No concerns were raised regarding this application. **Outcome:** Recommendation to approve.
2.5	<u>Liverpool CCG invoice validation (Presenter: Stuart Richardson) NIC-284440-M4G0Q</u> **Application summary:** This was a new application 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 for the purpose of invoice validation. The applicant had achieved a satisfactory IG Toolkit score and held a relevant DPA registration. It was noted that a framework contract between the applicant and the HSCIC was currently in the process of being renewed, and no data would be released until that process had completed. **Discussion:** The Group discussed the invoice validation process; a query was raised regarding whether all CCGs would need to request data for the purpose of invoice validation, but it was noted that some organisations instead made use of local flows of data. A query was raised regarding whether the data provided could potentially be accessed by other organisations, such as if external auditors were asked to review invoicing processes. It was stated that data received into a Controlled Environment for Finance would be tightly controlled. It was noted that the application summary listed the datasets that were already held by the applicant, and it was agreed that the application should be updated to clearly state that these datasets were held for a different purpose to the purpose outlined in this application. It was also agreed that the appropriate section 251 support under which these datasets were held should be listed. **Outcome:** Recommendation to approve subject to updating the list of data already held by the applicant to clarify the purpose for which these datasets are held and subject to specifying the appropriate section 251 support.
2.6	<u>Arden CSU stage 1 ASH renewal (Presenter: Stuart Richardson) NIC-330375-H8C9C</u> **Application summary:** This application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised) under the section 251 support for stage 1 ASH. It was noted that the application summary did not list the specific section 251 support as a legal basis, and this would need to be updated. The CSU had achieved a satisfactory IG Toolkit score and held an appropriate DPA registration. The Group were informed that the CSU would act as data processors on behalf of a number of CCGs with a legitimate relationship with the CSU as authorised by NHS England, with each CCG being data controller for their own data. Each CCG would therefore need to have a signed framework contract in place with the HSCIC before data could be shared. It was noted that the CCGs that were stage 1 ASHs would receive data identifiable at the level of NHS number, but that the CCGs that were not would only receive aggregated outputs. **Discussion:** The application summary did not specify which CCGs were stage 1 ASHs, and the Group requested clarification of this as this would determine which organisations could receive data that would be identifiable at the level of NHS number. It was also noted that the IG Toolkit scores and DPA registration details for these organisations had not been provided.

	A query was raised regarding the dataset period requested, and it was confirmed that this incorrectly referred to 2015 when it should instead have stated 2016. **Outcome:** Recommendation to approve subject to clarifying which of the CCGs are stage one accredited safe havens, and the confirmation of satisfactory IG Toolkit scores and DPA registration details for those organisations. Application form to be updated to clarifying that the dataset period is to 2016 not 2015, and to specify the appropriate section 251 support.
2.7	University of Nottingham (Presenter: Dickie Langley) NIC-225800-Y2P5F **Application summary:** This application was to extend a current agreement for the receipt of pseudonymised, non-sensitive HES data and Office for National Statistics (ONS) mortality data. The data would be used as part of a PhD project looking at the use of surgical lung biopsy in patients with interstitial lung disease. **Discussion:** The Group expressed their support for this project, as there was felt to be a clear public interest in the outputs. However it was felt that the application summary did not provide sufficient justification for why this amount of data was required, and why for example a smaller number of data years would not be sufficient. It was also not felt to be clear what impact the data minimisation filters referred to would have on the dataset, and how much this would limit the amount of data provided. It was not felt to be clear whether the HES data provided would be accessed by any other individuals within the PhD project in addition to the two individuals listed who held ONS Approved Researcher accreditation, and it was agreed that this should be clarified. Queries were raised regarding the applicant's dissemination plan, as it was suggested that given the potential public interest in the outcome of the project it might be appropriate for aggregated outputs to be made more widely available rather than relying solely on publication in peer-reviewed journals. **Outcome:** Unable to recommend for approval. DAAG expressed their support for this work but further information was required on proportionality – in particular why this amount of data is required, and what effects the data minimisation filters applied will have on the dataset. Further information also requested on how outputs will be disseminated, as well as clarification of what individuals are involved in the PhD work described.
2.8	Rod Gibson Associates Ltd (Presenter: Dickie Langley) NIC-325256-V6L1S **Application summary:** This application was for an extract of pseudonymised, non-sensitive HES data in order for the applicant to provide aggregate indicators for both the Which Birth Choice website and the BirthChoiceUK website. **Discussion:** There was some uncertainty regarding the legal status of the two organisations involved; the application summary stated that BirthChoiceUK were unable to enter into a contract, and Rod Gibson Associates would therefore act as data controller, but also stated that BirthChoiceUK's data security policy would be used. It was agreed that a clearer explanation was required regarding these two organisations and their responsibilities in relation to data handling. In addition queries were raised regarding the data security policy, as it was felt that in some places this was not sufficiently detailed. The Group queried the IG Toolkit score that had been listed for Rod Gibson Associates, and it was explained that this was a self-assessed score but that this had been reviewed by the HSCIC IG delivery team. The DPA registration wording for Rod Gibson Associates was also queried, as this stated that the personal information handled was 'about survey respondents' and it was not felt

	that this appropriately described this work. Some concerns were raised regarding the potential for the data provided to be used for other purposes, as the application summary made reference to 'other potential work for NHS supporting organisations'. It was agreed that the application summary should be updated to clarify that the data could not be used for any additional purpose other than those specified. In addition further information was requested about the outputs and expected benefits of the work in order to ensure that this would comply with the relevant provisions of the Care Act 2014. **Outcome:** Unable to recommend for approval. A clearer explanation was requested of what organisations were involved in the work and their legal status, as well as their responsibilities regarding the handling of data and in particular which organisation would act as data controller and which as data processor. Further information was requested about the relevant security arrangements. A clear statement was required that the data requested will not be used for any other purposes. Further evidence of the expected benefits was requested to ensure compliance with the Care Act 2014, as well as clarification of the applicant's DPA registration wording.
2.9	University of Cambridge (Presenter: Dickie Langley) NIC-321397-T0Q1R **Application summary:** This application was for a bespoke extract of pseudonymised, non-sensitive HES data that would include maternity and cardiovascular data only from 1989/90 onwards. This would be used to support academic research, funded by the British Heart Foundation, into the relationship between gestational hypertension and cardiovascular outcomes. **Discussion:** The EU funded project referred to in the application summary was queried, as additional details of this project had not been provided. A grant letter was referred to, but a copy of this had not been provided as part of the application papers. Some concerns were raised regarding the number of data years that had been requested, as it was not felt that the application summary provided a justification for why this amount of data was required. It was noted that the applicant had stated that this would allow risk over time to be assessed, but it was not clear whether this could also be achieved with a smaller sample of data. The Group agreed the potential importance of this research, but it was not clear how the outputs of the research would be disseminated either to NICE and the British Heart Foundation as particularly interested parties or to the wider healthcare sector in order to ensure benefits could be realised. It was agreed that the application should be updated to clarify this. **Outcome:** Unable to recommend for approval. Further information requested about the EU funded project, as well as a clearer justification of why 25 years of data are required. Clarification requested of the applicant's dissemination plan, including a statement on how outputs will be disseminated to NICE and the British Heart Foundation.
2.10	University of Manchester (Presenter: Dickie Langley) NIC-252254-F6T9V **Application summary:** This application was to extend the applicant's existing agreement to receive HES data and ONS mortality data, as well as to amend the list of accredited ONS users. The data would be used to support research into the impact of waiting time targets. It was noted that the applicant was in the process of updating their DPA registration wording. **Discussion:** The Group discussed the expected outputs and benefits of the work described, and it was felt that the application summary could have more clearly explained how the use of data would comply with the relevant provisions of the Care Act 2014. It was agreed that this could be covered if the applicant could provide further evidence of how the study would have an impact on commissioning activities. In particular, it was suggested that evidence should be provided of how

	the outputs of the study would be disseminated to NHS commissioners. A query was raised regarding the expiry dates for the ONS approved researcher accreditation, and it was noted that this accreditation was renewed annually. If the accreditation was not renewed for any reason and lapsed, data would cease to be made available to the relevant individuals. **Outcome:** Recommendation to approve subject to evidence being provided of how the applicant intends to disseminate the outputs of this work to support commissioning, in compliance with the provisions of the Care Act 2014.
2.11	Harvey Walsh (Presenter: Dickie Langley) NIC-325103-L4S4T **Application summary:** This application was to renew the applicant's subscription to the HES extract service, receiving pseudonymised non-sensitive data. It was noted that the data retention period field on the application summary had not been appropriately completed, and this would need to be amended. **Discussion:** It was noted that the applicant intended to use these data for commercial purposes, by using the HES data to provide services to the NHS as well as to companies including the pharmaceutical and the medical device industries. The Group felt that it was unclear what proportion of customers for the services provided by the applicant would be NHS organisations, or whether the customers were predominantly other commercial organisations. There were significant concerns regarding whether this could be considered compatible with the relevant provisions of the Care Act 2014, which specified that data should not be disseminated by the HSCIC for solely commercial purposes. A reference to the applicant providing services to 'other healthcare related areas' in addition to the NHS was queried, as it was not clear what other organisations this might include. It was agreed that the applicant should be asked to provide further information on what specific purposes data would be used for and by what types of organisations, with evidence of the outputs produced and how this would benefit health and social care. **Outcome:** Unable to recommend for approval. Additional supporting evidence required about the purpose and the nature of outputs from this work, as well as evidence of compliance with the relevant provisions of the Care Act 2014.
2.12	Royal Brompton and Harefield NHS FT (Presenter: Dickie Langley) NIC-311441-M7W3G **Application summary:** This applicant had requested HES and HES-ONS linked mortality data in order to support research into morbidity in patients with congenital disorders and patients with pulmonary hypertension. It was noted that a large number of data years had been requested, partly due to the low prevalence of the conditions involved. **Discussion:** The Group discussed the expected outputs of this work, and it was suggested that the application should consider disseminating the research outputs more directly to clinicians. It was noted that a letter had been provided as evidence that ONS data could be provided under Section 42(4) of Statistics and Registration Services Act 2007. However, the Group noted that this letter would not be considered sufficient by ONS as it did not specify what data was required or for what purpose. It was also thought that the letter would need to be signed by a senior staff member who was not part of the centre where the research was taking place. **Outcome:** Unable to recommend for approval, as the evidence provided was insufficient to meet the requirements of Section 42(4) of the Statistics and Registration Services Act 2007.

2.13 University of East Anglia – SCOOP (Presenter: Dickie Langley) NIC-332842-D7L9S

Application summary: An application from this applicant had previously been considered at the 2 December 2014 DAAG meeting and recommended for approval, subject to the provision of an action plan for how participants would be informed about data processing (application reference NIC-308892-P2H0Y). This application was to extend the agreement to receive HES and Diagnostic Imaging Dataset (DID) data by 1 year, and to receive additional data years as due to an error the previous application had not covered all the data years required. It was noted that the legal basis for data to be provided was patient consent, and following DAAG's recommendation made on 2 December 2014 the applicant had provided information on how participants were kept informed.

Discussion: The Group noted that the purpose of this work had not changed since the previous application was considered. The expected benefits were discussed, and the involvement of the Medical Research Council as well as the Department of Health were noted.

Outcome: Recommendation to approve.

2.14 King's College London (Presenter: Dickie Langley) NIC-313785-P0H7C

John Craven declared a potential conflict of interests with this application, and did not contribute to the recommendation made.

Application summary: This application proposed that identifiers for a consented cohort would be provided to the HSCIC, then linked to HES data with the linked, pseudonymised dataset to be provided back to the applicant. This would be used for research funded by the Economic and Social Research Council (ESRC) into alcohol misuse in serving and ex-serving military personnel. The applicant had indicated that participant consent was in place.

Discussion: The Group noted the importance of this study, and the potential for significant benefits to be realised.

However, it was agreed that the consent materials provided did not provide an appropriate legal basis for the proposed use of data as these did not refer to identifiers being shared outside of the research team, the linkage of data, or the use of data held by the HSCIC. In addition the Group noted that the consent materials stated that the study would monitor health but did not specifically refer to research into alcohol misuse, and that this would likely be considered to be a sensitive topic for many individuals. It was also noted that the consent materials stated that the research was funded by the Ministry of Defence, and did not refer to funding from ESRC.

It was felt that given these consent materials, the participants could not be considered to have consented to the data processing described in the application summary. In addition, concerns were raised regarding fair processing, as although the applicant had indicated that participants were made aware of uses of data via newsletters it was thought that participants should instead be made aware of proposed uses of data prior to this work taking place, rather than being informed after the fact.

It was suggested that as the consent materials provided did not provide an appropriate legal basis the applicant should explore other potential legal bases, such as pursuing the option of section 251 support with HRA CAG.

Outcome: Unable to recommend for approval. DAAG recognise the importance of this research; however DAAG support the comments made by the IAO and feel that the consent and fair processing materials are inadequate for the proposed purposes. There is currently no legal basis for the HSCIC to receive, link or disseminate these data and the applicant may wish to consider

	pursuing the option of section 251 support with HRA CAG.
3	**Any other business** The Group discussed a query that had been raised regarding the HSCIC pseudonymisation review steering group. It was agreed that comments would be shared by email. **Action:** Eve Sariyiannidou to share comments by email on the query that had been raised regarding pseudonymisation.

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	27/01/15: This discussion had been scheduled, and details would be fed back to DAAG. 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. 10/02/15: Discussions had taken place about making changes to how information would be added to application forms. 17/02/15: Ongoing. 24/02/15: Ongoing. 03/03/15: Ongoing. 10/03/15: Ongoing. 17/03/15: An update was requested on when the next planned update of the application form was scheduled to take place. 25/03/15: Ongoing. 31/03/15: Ongoing.	Open
24/02/15	DAIS team to dis**c**uss the approach to local patient identifiers (LOPATID) with HRA CAG.	Diane Pryce	03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting. 10/03/15: An initial response had been received and this would be shared with DAAG members for information. 17/03/15: Ongoing. 25/03/15: Ongoing. 31/03/15: Ongoing.	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 postcode.	Diane Pryce	03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting. 10/03/15: An initial response had been received and this would be shared with DAAG members for information. A further query had been raised and discussions were ongoing. 17/03/15: Ongoing.	Open

			25/03/15: Ongoing. 31/03/15: 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.	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.	Open
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.	Open
25/03/15	DAAG Secretariat to ensure future meeting agendas specify whether applications have previously been considered by DAAG, and if so provide the relevant meeting date.	Alex Bell	31/03/15: This action had been completed and was closed.	Closed
31/03/15	Eve Sariyiannidou to share comments by email on the query that had been raised regarding pseudonymisation.	Eve Sariyiannidou		Open