

Data Access Advisory Group (DAAG)

Minutes of meeting held 24 February 2015

Members: Alan Hassey (Acting Chair), Eve Sariyiannidou, Dawn Foster, John Craven, Patrick Coyle, Sean Kirwan

In attendance: Alex Bell, Frances Hancox, Diane Pryce, Susan Milner, Dickie Langley, Stuart Richardson, Paula Moss, Dave Roberts

Apologies: None

1 Review of previous minutes and actions

The minutes of the 17 February 2015 meeting were reviewed and agreed as an accurate record.

Action updates were provided (see table on page 6).

Out of committee recommendations

The following applications had previously been considered by DAAG and recommended for approval subject to caveats, and it had been confirmed out of committee that the caveats had now been completed:

- Public Health England, NIC-323580-X3H8M
- McKinsey and Co, NIC- 292306-S7Y2V

Matters arising

The Group discussed the possibility of DAAG members providing assistance to Information Asset Owners (IAOs) with certain applications, and the need to ensure that the Group's consideration of an application would not be unduly influenced was emphasised. It was agreed that any requests for specific input should be made via the DAAG Secretariat and Chair, rather than IAOs approaching DAAG members directly, and that it would likely be more appropriate for members to provide written feedback or guidance rather than being involved in face to face meetings with applicants. It was also agreed that queried regarding legal or information governance advice should be directed to the DAIS team in the first instance, and then escalated via the DAAG Secretariat and Chair if necessary.

National Audit Office (NAO), NIC-307558-L7P8M

This application had been discussed at the 17 February 2015 meeting and the Group had sought clarification regarding the legal basis, the applicant's DPA registration wording and a clearer justification for why Hospital Episode Statistics (HES) extract data was required in addition to access to the HES Data Interrogation Service (HDIS). It was noted that the applicant had provided an additional sentence that would be added to their DPA registration wording.

The Group noted that HSCIC had signed a Memorandum of Understanding with the NAO regarding data sharing, with the intention that this would replace the need for a data sharing framework contract.

The legal basis for the requested disclosure of data was discussed, and it was noted that the applicant could lawfully receive this data from the relevant NHS bodies based on its powers under the National Audit Act 1983. The Group discussed whether the provisions of the Care Act 2014 would therefore apply, and they acknowledged the vital role of the NAO in holding public bodies to account. However there remained some concerns regarding whether the data

requested was proportional to the purposes for which it would be used, and it was suggested that as the NAO had previously received similar data it should be possible to provide more detailed examples of how this had been used for the benefit of health or social care. It was suggested that DAAG could in future seek advice from the Health Research Authority Confidentiality Advisory Group (HRA CAG) regarding this type of application.

It was agreed that the Acting DAAG Chair would write to the HSCIC Senior Information Risk Owner (SIRO) regarding this application, and state that the Group were uncertain about their role in relation to this application given the legal basis that may exist for this dissemination of data and the special position the NAO has, as well as its unique relationship with the HSCIC. The Group stated that for any similar application not in this unique position they would have been unable to recommend approval due to concerns in particular around the proportionality of the data requested, but also the need for applicants to be accountable for how data will be used as well as uncertainty regarding the benefits to health and social care.

Action: Acting DAAG Chair to write to HSCIC SIRO regarding NAO application.

2 Data applications

2.1 University Hospitals Birmingham (Presenter: Dave Roberts) NIC-325819-D6V9H

Application summary: This application was for pseudonymised, sensitive HES data as well as Office for National Statistics (HES-ONS) data. This was to extend and renew an existing agreement, the application for which had most recently been considered by DAAG on 12 November 2015 (NIC-292303-L4B0Z). The purpose and processing were unchanged since the previous application, but the data had now been requested for a longer period of time.

Discussion: A few corrections were raised regarding the application form. In particular, at one point the application form indicated that identifiable data was requested; it was clarified that this referred to the ONS data requested, and other than that data only pseudonymised HES data was requested. In addition it was noted that the organisation type had been listed as 'Other health and social care system public body' whereas it would be more accurate to describe the applicant as a CQC-registered health provider. It was agreed that these points would be corrected. There were some concerns as DAAG members felt that these errors had also been noted when the application had previously been considered, and confirmation was requested that the caveats to the Group's previous recommendation had been met.

The Group queried the proportionality data, and whether HES data for the whole of England was required rather than data for the specific organisations that would be customers of the applicant. It was confirmed that data for the whole country was required in order to benchmark organisations against national averages as well as against similar NHS trusts. A reference to the need to recoup costs 'in some instances' was queried, and it was suggested it would have been helpful if further details on this had been provided. The Data Protection Act (DPA) registration wording was also queried. In addition a statement that types of organisations who would have access to the tool 'include' was queried, and it was agreed that this should be amended to 'are limited to' to ensure that the list was not considered to be open-ended.

The provision of the sensitive field local patient identifier (LOPATID) was discussed, and it was noted that this was requested as it would be necessary in some instances for NHS trusts to be able to re-identify patients within their trust. However there were concerns about the potentially identifiable nature of this field, and it was agreed that this should be raised with HRA CAG.

Outcome: Recommendation to approve subject to confirmation that the previous caveats were met, as well as subject to updating the application form to clarify the organisation type and to clarify that sensitive identifiable data is not requested.

Action: DAIS team to discuss the approach to local patient identifiers (LOPATID) with HRA CAG.

2.2 NHS England - National Elective Revascularisation PROMs Pilot (Presenter: Dave Roberts) NIC-324251-J9T5N

Application summary: This application was for the linkage of patient data held by the National Institute for Cardiovascular Outcomes Research (NICOR) to Patient Reported Outcome Measures (PROMs) linked HES data and ONS data for the purpose of service evaluation. The pseudonymised, sensitive linked data would be provided to Miles-Green Associates Ltd and to Liverpool Heart and Chest Hospital NHS Foundation Trust for processing, and it was noted that this work was funded by NHS England.

Discussion: It was noted that the NHS England DPA registration listed on the application form had now expired. However the applicant had confirmed that this had been renewed, and the application form would be amended to list the new expiry date. Liverpool Heart and Chest Hospital NHS Foundation Trust had achieved an unsatisfactory Information Governance (IG) Toolkit score, but it had been confirmed that an improvement plan was in place.

A reference within the application to post-operative questionnaires was queried, as only the pre-operative questionnaires had been included with the application papers. It was agreed that these should be made available to the Group.

The Group expressed their support for the work proposed. The need to share the results of this work within the NHS was raised, and it was suggested that the applicant should be encouraged to report back to practicing cardiologists through appropriate channels.

Section 251 support was in place for NICOR to share patient identifiable data with the HSCIC, but it was stated that the legal basis for these patients' PROMS data to be linked with HES data was patient consent. ONS data would be provided to the applicant under Section 42(4) of the Statistics and Registration Service Act 2007 (SRSA). Concerns were raised regarding this, as the consent form did not state that ONS data would be used and it was felt that referring to 'other NHS databases' would not cover the use of ONS data. Furthermore there were concerns that the consent forms were inadequate to provide a sufficient legal basis for the dissemination of data, and although it was noted that the applicant intended to update the consent forms it was not clear how soon this would occur.

Outcome: Unable to recommend for approval. There was a lack of a clear legal basis for the use of ONS data; while section 42(4) of the SRSA appeared to be engaged, there was a lack of inclusion of the use of ONS data in the patient consent materials. There were also concerns that the current consent materials were not adequate.

2.3 Experian Ltd (Presenter: Dave Roberts) NIC-325151-R5W7B

Application summary: This application for pseudonymised, non-sensitive HES data had previously been considered by DAAG on 23 December 2014, when the Group had been unable to recommend approval. The applicant's response to the queries raised had been provided along with an updated application form.

Discussion: There remained some concerns regarding the points previously raised, as it was felt that the response provided by the applicant had not given sufficiently clear answers. There were particular concerns regarding the onward use of data and whether this would be under sublicense to restrict further sharing, as the applicant had not provided sufficient assurances regarding this. It was proposed that the applicant should be asked to provide more specific details regarding key points such as the protocols for how commercial organisations could use the HES data provided.

A reference to limiting access to public sector organisations was queried, as it was noted that this could potentially include a large number of organisations and bodies outside the health and social care sector. In addition a statement that the applicant would only receive anonymised data was also queried, as it was noted that pseudonymised data had been requested rather than anonymised data.

Outcome: Unable to recommend for approval; the Group felt that the queries raised when this application was previously considered had not been answered in sufficient detail to provide reassurance.

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South West Commissioning Support Unit (CSU) (Presenter: Stuart Richardson) NIC-322557-V3Q8Y and NIC-317972-H0R6R

Application summary: Two applications were considered together; the first was for the applicant to continue to receive Secondary Uses Service (SUS) data that was identifiable at the level of NHS number (weakly pseudonymised), while the second was to continue to receive SUS data that was identifiable at postcode level. The applicant was a stage 1 accredited safe haven, and both applications were based on the section 251 approval granted by HRA CAG for stage 1 accredited safe havens, and data was requested until either the end of April 2015 or in line with any extension to this section 251 approval. It was stated that the applicant would use role based access controls to ensure that staff members would only have access to either the data identifiable at NHS number level or to the data identifiable at postcode level at any one time, not to both simultaneously, and it was noted that the applicant had been externally audited to confirm that those arrangements were in place. The relevant clinical commissioning groups (CCGs) would act as data controllers, and it was noted that the applicant had achieved a satisfactory IG Toolkit score.

Discussion: The applicant's DPA registration wording was discussed, and it was noted that this included a large number of purposes for processing data outside the scope of this application. It was suggested that only the relevant section of the registration wording should be included on the application form. The Group noted that the application form did not list the data controllers for the data requested, and also did not include the application reference number (NIC number). It was agreed that these details should be added. In addition it was noted that DPA registration details or IG Toolkit scores had not been provided for the data controllers. It was also noted that the application for postcode data included a reference to identifying at risk children, which was not thought to be possible using postcode data and it was suggested that this might have been included in error.

A query was raised regarding whether it could be specified which staff would have access to which identifiable dataset, to avoid crossover, but the Group were informed that this would not be practical as staff might move between teams and have access to different datasets at different times. A reference to pseudonymised data was also queried, as the data requested would be identifiable at either postcode or NHS number level, and it was agreed that this would be corrected. Some concerns were raised regarding the wording of the expected benefits, and it was noted that the section 251 review date was missing from section 6 of the application form.

There were significant concerns regarding the request for the applicant to receive both data that was identifiable by NHS number as well as data that was identifiable by postcode, rather than receiving either one or the other, as it was not thought that this was in keeping with the spirit of the section 251 approval that had been granted. It was agreed that this should be discussed with HRA CAG.

Outcome: Recommendation to approve the provision of one identifier only (either NHS number or postcode), subject to the application form being updated to reflect the corrections raised during the meeting.

Action: DAIS team to raise with HRA CAG the possibility of stage 1 accredited safe havens

<p>2.6, 2.7</p>	<p>receiving both data that is identifiable by NHS number and data that is identifiable by postcode.</p> <p>Sean Kirwan left the meeting at this point.</p> <p><u>North East Essex CCG and Mid Essex CCG (Presenter: Stuart Richardson) NIC-324680-P1Z1W and NIC-324840-B2B2S</u></p> <p>Application summary: These two applications were to extend access to SUS data that was identifiable at the level of NHS number (weakly pseudonymised) under the section 251 approval for stage 1 accredited safe havens. Both CCGs had achieved an IG Toolkit score of 65%, but it was noted that an improvement plan was in place for each organisation.</p> <p>Discussion: As with the previous two applications it was noted that there was an erroneous reference to pseudonymised data instead of identifiable data, and that the DPA registration wording included sections that were not relevant to these applications. Both applications were also missing the section 251 review date from section 6 of the form.</p> <p>There was some uncertainty regarding how the data would be processed by each organisation, and why the DSCRO had been listed as data processor rather than the CSU. It was noted that the CSU had been listed in the security assurance section of the application form, but that no IG Toolkit score had been provided for the CSU. There was a suggestion that the use of a data flow diagram would help clarify the data flows involved and the role of each of the three organisations.</p> <p>Outcome: Unable to recommend for approval. Clarification requested (potentially through the use of a data flow diagram) about how data will flow, and in particular how data will be processed by the data processor.</p>
<p>2.4</p>	<p><u>RSR Consultants Ltd (Presenter: Stuart Richardson) NIC-253076-Q5S6S</u></p> <p>Application summary: This application had previously been considered by DAAG at the 3 February 2015 meeting.</p> <p>The Group had requested that the applicant should demonstrate that the data requested is proportionate to the described purpose, provide evidence of compliance with the relevant provisions of the Care Act 2014, and provide an explanation of the requested data retention period. The applicant had subsequently confirmed that national data was required as the relevant national guidance stated that casemix must be compared to the national average, rather than using any smaller samples, and additional detail had been provided regarding how this use of data complied with the Care Act 2014. The Group had also requested further detail regarding the encryption of a laptop, and additional details had been provided. It had also been confirmed that the applicant would be considered data controllers for the data provided.</p> <p>Discussion: The Group considered the clarification that had been provided, and confirmed that they were satisfied with the response given.</p> <p>Outcome: Recommendation to approve.</p> <p>Due to time restraints one application (Yorkshire and Humber CSU, NIC-301908-K6H2W) was deferred to the following meeting.</p>
<p>3</p>	<p>Any other business</p> <p>No other business was raised.</p>

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
13/01/15	Garry Coleman to provide DAAG with a briefing paper on HDIS.	Garry Coleman	<p>20/01/15: It was agreed that a briefing paper would be circulated, but it was noted that no further HDIS applications would be brought to DAAG at this stage while internal discussions were ongoing.</p> <p>27/01/15: Ongoing.</p> <p>03/02/15: A briefing paper had been drafted and would be shared by email following clarification regarding HDIS extracts.</p> <p>10/02/15: Clarification had not yet been received.</p> <p>17/02/15: Ongoing.</p> <p>24/02/15: Ongoing.</p>	Open
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>	Open
03/02/15	David Evans to raise the importance of fair processing in ongoing audits with HQIP.	David Evans	<p>10/02/15: Ongoing.</p> <p>17/02/15: Ongoing.</p> <p>24/02/15: This had been raised, and a response was awaited. The action was closed.</p>	Closed
03/02/15	Karen Myers to provide David Evans with a copy of the outcome letter for this application (University College London, NIC-291217-K6M8H) once sent.	Karen Myers	<p>10/02/15: Ongoing.</p> <p>17/02/15: This letter had not yet been sent to the applicant.</p> <p>24/02/15: This had been completed.</p>	Closed
17/02/15	Alex Bell to schedule a discussion of the applications process for a future DAAG	Alex Bell	<p>24/02/15: This action had been completed and was closed.</p>	Closed

	training session, and specify on meeting agendas which applications have gone through the pre-DAAG review process.			
17/02/15	Alex Bell to invite HRA CAG representatives to attend a future DAAG training session.	Alex Bell	24/02/15: This action had been completed and was closed.	Closed
17/02/15	Alex Bell to provide Garry Coleman with a copy of DAAG's advice on consent materials.	Alex Bell	24/02/15: This action had been completed and was closed.	Closed
24/02/15	Acting DAAG Chair to write to HSCIC SIRO regarding NAO application.	Alan Hassey		Open
24/02/15	DAIS team to discuss the approach to local patient identifiers (LOPATID) with HRA CAG.	Diane Pryce		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		Open