

Data Access Advisory Group (DAAG)

Minutes of meeting held 25 March 2015

Members: Alan Hassey, Eve Sariyannidou, John Craven, Patrick Coyle, Dawn Foster

In attendance: Alex Bell, Frances Hancox, Susan Milner, Dickie Langley, Dave Roberts, Netta Hollings, Stuart Richardson, Joanne Bailey, Richard Irvine, Rachel Lintott

Apologies: Sean Kirwan

1	<p>Care.data update (secure data facility)</p> <p>During the morning training session, Rachel Lintott and Richard Irvine provided an update on the care.data programme and in particular the Secure Data Facility (SDF) developed as part of the pathfinder stage. It was explained that this facility would provide approved users with a way to access and interrogate data without that data ever leaving the HSCIC on the day of the SDF session, with the hope that this would reduce the volume of extracts required in future.</p> <p>The approvals process map for the Secure Data Facility was discussed, and it was noted that during the pathfinder stage only approved users from the HSCIC, NHS England, CQC and Public Health England would be able to access data within the facility. It was proposed that applications for each of these 4 organisations to access the data would be submitted to DAAG, and that these applications would include the potential for approved users to request an output file in aggregated tabulated, non-sensitive anonymised form with small-numbers suppressed. The Group agreed to this approvals process.</p> <p>Given that applications to access the Secure Data Facility would be made to DAAG it was agreed that DAAG could review the draft fair processing materials for the care.data pathfinder stage at an appropriate time, in advance of receiving any applications.</p> <p>Action: 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.</p>
2	<p>Review of previous minutes and actions</p> <p>The minutes of the 17 March 2015 meeting were reviewed and a correction was agreed to the outcome for one application (North West Commissioning Support Unit NIC-301934-W2M5X). Subject to this change, the minutes were agreed as an accurate record. Action updates were provided (see table on page 7).</p> <p>Joanne Bailey, chair of the General Practice Extraction Service Independent Advisory Group (GPES IAG) was welcomed to the meeting as an observer.</p> <p>Out of committee recommendations</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">• Newcastle upon Tyne NHS Foundation Trust NIC-292948-H6S2Q• Department of Health NIC-314521-S8M1Q

<p>3</p> <p>3.3</p> <p>3.4</p>	<p>Data applications</p> <p><u>Cegedim (Presenter: Dave Roberts) NIC-329835-B9R0X</u></p> <p>Application summary: This application was for advice from DAAG only, and a recommendation was not sought at this stage. The applicant requested an extension to an existing agreement for pseudonymised, non-sensitive data which would be linked by an organisation named Sapior to data the applicant collected from a number of general practices. The linked data was then provided on to the applicant's customers for purposes such as epidemiological studies, public health research and health economic research. It was noted that previous applications for this use of data had not been reviewed by DAAG.</p> <p>Discussion: The possibility of data being shared with organisations within the European Economic Area and the USA was discussed, and some concerns were expressed regarding the reference to the EU – USA Safe Harbour agreement. The Group noted that all uses of data would need to be compatible with the relevant provisions of the Care Act 2014 in terms of benefit to the UK health and social care sector, and it was emphasised that this would apply to any applications where the applicant intended to share data outside the UK.</p> <p>The role of Sapior in linking the data provided was discussed, and the Group queried whether this was a UK organisation or potentially a subsidiary of a USA company. A statement in the application form that the pseudonymisation technique had been reviewed by the National Information Governance Board (NIGB) was queried, as it was noted that a section 251 application to test the pseudonymisation process had previously been made but not approved. The security assurance for Sapior was also queried, as it was noted that a System Level Security Policy (SLSP) for Cegedim had been approved by the HSCIC security team but it was not stated whether an SLSP or similar assurance had been provided for Sapior.</p> <p>There were some concerns about the potential commercial uses for this data, and it was agreed that clarification should be sought regarding this.</p> <p>Outcome: DAAG offered advice on the content of a future application for this use of data. Confirmation was requested that the data processor Sapior's security arrangements had been reviewed by the relevant HSCIC team, as well as clarification of whether Sapior was a UK organisation or a subsidiary of a US company. Confirmation was also requested that the approved uses will be compatible with the Care Act 2014 in terms of benefit to the UK health and social care sector. Clarification was requested about the potential use of data for commercial purposes.</p> <p>It was requested that future meeting agendas should clearly state whether applications had been considered by DAAG.</p> <p>Action: Alex Bell to ensure future meeting agendas specify whether applications have previously been considered by DAAG, and if so provide the relevant meeting date.</p> <p><u>Clinical Practice Research Datalink (CPRD) (Presenter: Dave Roberts) NIC-326073-Z0M3Q</u></p> <p>Application summary: This application to receive Diagnostic Imaging Dataset (DID) data in addition to the data already held had previously been considered by DAAG at the 10 March 2015 meeting, when the Group had been unable to recommend approval. Further information had been requested about the transparency of the CPRD approvals process, CPRD customers, compliance with the Care Act 2014, fair processing and how objections were handled. It was noted that section 251 support from the Health Research Authority Confidentiality Advisory Group (CAG) was in place.</p>
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	<p>Discussion: The Group were content that the majority of the queries they had previously raised had been addressed. It was suggested that additional detail about CPRD customers and how data was used would have been helpful, although it was noted that some examples had been given of customers and publications that had been produced. It was suggested that future applications should include a more comprehensive list of projects that had made use of CPRD data.</p> <p>A reference to Office for National Statistics (ONS) data was queried, and it was noted that the applicant received data directly from ONS rather than via the HSCIC. The Group agreed that confirmation should be sought that ONS were aware of the intention to link with this additional data. In addition it was noted that there were restrictions on the sharing of ONS data outside the UK and confirmation was also requested that ONS were aware of the intention to share data worldwide.</p> <p>The potential for data to be shared with customers worldwide was noted, and it was noted that any uses of data would need to be compatible with the relevant provisions of the Care Act 2014 in terms of benefit to health and social care within the UK.</p> <p>Outcome: Recommendation to approve subject to confirmation that ONS are aware that this will give the applicant the facility to link ONS data, and that ONS are aware of the intention to share data worldwide. Also subject to confirmation that the approved uses will be compatible with the Care Act 2014 in terms of benefit to the UK health and social care sector.</p>
3.1	<p><u>NHS England - Comparison of 2014 LD Census and Sept 2014 Assuring Transformation (Presenter: Netta Hollings) NIC-322767-F8V3X</u></p> <p>Application summary: This application was for a one-off comparison of Learning Disability Census and Assuring Transformation data in order to identify instances where commissioners were under-reporting in the Assuring Transformation dataset. It was noted that a query had been raised regarding the applicant's Data Protection Act (DPA) registration wording, and this had subsequently been clarified.</p> <p>Discussion: The legal basis for the application was discussed, and it was explained that while the flow of identifiable data to the HSCIC was covered by section 254 of the Health and Social Care Act 2012 there was also support in place under section 251 of the NHS Act 2006 for the identifiable data to flow to NHS England. The Group noted that the application summary referred to section 254 without specifying the relevant Act, and requested that this should be clarified in future applications.</p> <p>A reference in the application summary to a 'section 251 agreement' was queried, as it was not clear if this referred to the section 251 support or to a separate agreement which the Group had not had sight of. It was agreed that this would be clarified.</p> <p>Outcome: Recommendation to approve subject to clarification of the phrase 'section 251 agreement' referred to in the application.</p>
3.2	<p><u>NHS England - Assuring Transformation monthly data (Presenter: Netta Hollings) NIC-314187-M1D8Y</u></p> <p>Application summary: This application was for NHS England to receive the full, identifiable Assuring Transformation dataset each month. This was required to derive performance and quality indicators for learning disability services, to identify instances of good or poor practice and drive improvements, and to monitor care and discharge planning.</p> <p>Discussion: As with the previous application, the reference to a 'section 251 agreement' was queried and it was agreed that this would be clarified.</p>

Outcome: Recommendation to approve subject to clarification of the phrase 'section 251 agreement' referred to in the application.

3.5 BMJ Publishing Group (Presenter: Dickie Langley) NIC-332038-N4Z8R

Application summary: This application had previously been considered at the 10 March 2015 DAAG meeting. Further information had been requested about the applicant's security arrangements and customers, and concerns had been raised about the applicant's DPA registration wording. It was noted that the applicant had now requested an updated to their DPA registration wording, the security arrangements had been reviewed and approved, and further information had been provided about the applicant's customer base.

Discussion: It was noted that the Acting DAAG Chair had participated in a meeting with the applicant regarding this application, along with other senior HSCIC employees.

The Group discussed the need to ensure proportionality, as it was noted that national data had been requested for a very small list of customers. It was noted that the customer organisations were based in different areas of the country and that once data had been received the applicant expected to gain additional customers across the country, but there remained some concerns. The Group acknowledged the need to avoid restricting competition, and it was recommended that national data should be provided for a period of 6 months with the expectation that the applicant would be able to establish a wider customer base within that period. However it was emphasised that when a renewal application was made after 6 months the applicant would need to provide evidence of a wider geographic base of customers in order to justify the need for national data. It would also be important to ensure that the applicant could demonstrate compliance with the Care Act 2014 in terms of benefits to health and social care within the UK.

Outcome: Recommendation to approve for a period of 6 months. DAAG's anxiety was noted about the relatively small customer base given the request for national data, and there was an expectation that when the applicant submitted a renewal application in 6 months' time this would need to include evidence of the national distribution of customers. This would also be subject to demonstrating compliance with the relevant provisions of the Care Act 2014.

3.6 University of Oxford - Unit of Healthcare Epidemiology (Presenter: Dickie Langley) NIC- 315419-F3W7K

Application summary: This application was to renew an agreement for the provision of pseudonymised, non-sensitive Hospital Episode Statistics (HES) data in order to support epidemiological and health services research. The HES data previously provided to the applicant had been used to support a range of studies, and the data requested would be used for work packages including studying trends in admission rates, geographical variation in admissions and mortality rates.

It was noted that the applicant organisation did not have a signed framework contract with the HSCIC in place, and no data would be released until this had been completed. It was also noted that the application mentioned ONS data, but that this was not requested as part of the current application as the applicant was currently seeking Approved Researcher status.

Discussion: The Group noted that the data flows described in this application had been initially difficult to follow, and it was suggested that the inclusion of a data flow diagram would have been helpful. The possibility of linking to ONS data was queried, but it was noted that once the applicant had been granted Approved Researcher status then a separate application would need to be made at a later date for the linkage of ONS data.

	<p>A reference to the data provided being ‘anonymised in context’ was queried. It was clarified that pseudonymised data would be provided, but that the applicant had referred to this data as being anonymised in context as they would not have access to the encryption key to reverse the pseudonymisation. The importance of using terminology consistently was emphasised, and in particular it was noted that if the pseudonymised HES data was in future linked to ONS data then it would likely become potentially identifiable.</p> <p>Outcome: Recommendation to approve. It was suggested that the applicant should carefully consider their use of the term ‘anonymised in context’, particular if datasets are subsequently to be linked. It was also suggested that a data flow diagram would have been helpful.</p>
3.7	<p><u>Solihull Group ASH¹ (Presenter: Stuart Richardson)</u></p> <p>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) to support the commissioning of health services and improve patient pathways. This was under the section 251 support for stage one accredited safe havens, which had recently been renewed and was now in place until to the end of April 2016. Midlands and Lancashire Commissioning Support Unit (CSU) would act as a data processor for the 3 CCGs.</p> <p>All 4 organisations had achieved satisfactory Information Governance (IG) Toolkit scores, and their DPA registration wording included the use of personal data to support health services. It was noted that work was underway to renew the framework contracts between the CCGs and the HSCIC, and no data would be shared until this had been renewed.</p> <p>Discussion: No concerns were raised regarding this application.</p> <p>Outcome: Recommendation to approve.</p>
3.8	<p><u>ASH Group Application²</u></p> <p>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) to support the commissioning of health services and improve patient pathways. This was under the section 251 support for stage one accredited safe havens, which had recently been renewed and was now in place until to the end of April 2016. It was noted that there would be no separate organisation acting as a data processor for these 4 CCGs. All 4 CCGs had achieved a satisfactory IG Toolkit score. It was noted that the DPA registration wording for 3 of the CCGs did not refer to the organisations as CCGs, but that this was in the process of being corrected.</p> <p>Discussion: The DPA registration wording for the CCGs was queried, as it was noted that while two referred to the use of personal data to support health services the other two did not. It was confirmed that this had been a clerical error, and the application would be updated to confirm that all 4 DPA registrations included this use of data.</p> <p>Outcome: Recommendation to approve subject to clarifying the DPA registration wording for all 4 organisations.</p>

¹ Wolverhampton CCG NIC-296883-F4W6F, Solihull CCG NIC-296833, Birmingham Cross City CCG NIC-296852-M4M0V

² 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

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Any other business

The Group were asked to consider whether a particular application could be considered out of committee due to an approaching Service Level Agreement (SLA) deadline. On this occasion the Group agreed to consider the application and make a recommendation out of committee if this was felt to be appropriate, but it was emphasised that this would not be an option for any applications approaching SLA deadlines in future.

At the 17 March 2015 meeting it had been noted that an applicant had requested clarification of DAAG's recommendation for their application, and the Group were reminded to provide any comments on this by email.

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> <p>03/03/15: Ongoing.</p> <p>10/03/15: Ongoing. Alex Bell to request an updated from Garry.</p> <p>17/03/15: Ongoing.</p> <p>25/03/15: Acting DAAG Chair to request an update and report back to DAAG at an appropriate time. Action closed.</p>	Closed
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>	Open

24/02/15	DAIS team to discuss 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.	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. 25/03/15: Ongoing.	Open
03/03/15	DAAG members to discuss the current recommended consent wording.	Alan Hassey	10/03/15: Ongoing. 17/03/15: It was agreed that this would be discussed at the DAAG training day on 25 March 2015. 25/03/15: Discussion held at 25 March training day.	Closed
25/03/15	Dawn Foster and Eve Sariyiannidou to update the recommended consent wording following discussions at 25 March training day.	Dawn Foster		
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		
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,	Alex Bell		

	commissioning organisation, commercial organisation).			
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		