

# Data Access Advisory Group (DAAG)

## Minutes of meeting held 3 February 2015

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

**In attendance:** Alex Bell, Karen Myers, Frances Hancox, David Evans, Joanne Bailey, Garry Coleman (applications 2.2 and 2.4), Stuart Richardson (applications 2.1 and 2.3), Paula Moss (applications 2.1 and 2.3)

**Apologies:** Sean Kirwan

1	<p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 27 January 2015 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 5).</p> <p><b>Out of committee recommendations</b></p> <p>The following application had previously been recommended for approval with caveats, and it was confirmed that the relevant caveats had now been fulfilled:</p> <ul style="list-style-type: none"><li>• University of Oxford, NIC-317612-V1Q3X</li></ul>
2  2.1	<p><b>Data applications</b></p> <p><u>Doncaster Clinical Commissioning Group (CCG) (Presenter: Stuart Richardson) NIC-309763</u></p> <p><b>Application summary:</b> This was an application from a Stage One Accredited Safe Haven for weakly pseudonymised Secondary Uses Service (SUS) data under the section 251 approval from the Health Research Authority Confidentiality Advisory Group (HRA CAG). The applicant had previously received approval to receive data until the end of November 2014, and an extension was now requested until the end of April 2015. The data provided would be used to support local healthcare and social care commissioning. It was noted that the applicant had a satisfactory Information Governance (IG) Toolkit score, and that information was available on the CCG website regarding the use of patient data. The applicant had requested to retain data for the shorter of either the section 251 approval period or 5 years.</p> <p><b>Discussion:</b> It was noted that the application form stated that non-identifiable data would be shared with the Local Authority in order to support initiatives such as the Better Care Fund. The Group requested confirmation that NHS number would not be shared with the Local Authority. In addition a query was raised regarding whether there would be any other organisation acting as data processor for the CCG; it was thought that the CCG would process data itself, but it was agreed that this would be confirmed.</p> <p>Some concerns were raised regarding the continued use of the term ‘weakly pseudonymised’ as it was not thought to be clear what was meant by this. It was noted that the term had been used in the section 251 application for Stage 1 Accredited Safe Havens, and it was agreed that it would be helpful if Stage 1 Accredited Safe Haven applications to DAAG could specify what level of data was requested with the term weakly pseudonymised in parentheses.</p> <p>The geographical extent of the data requested was queried, as the application form referred</p>

2.2	<p>to national priorities and to requiring data on CCG of registration and residence. It was confirmed that the data requested would be for the Doncaster CCG area only, and it was agreed that the application form would be updated to clarify this.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarification that only data for the Doncaster CCG area is requested rather than national data, confirmation that NHS number will not be shared with Local Authorities as part of the Better Care Fund work, and subject to updating the application form to specify what is meant by weakly pseudonymised data.</p> <p><u>University College London (Presenter: Garry Coleman) NIC-291217-K6M8H</u></p> <p><b>Application summary:</b> The applicant had previously been given approval to receive Hospital Episode Statistics (HES) data to support 6 audits, but due to delays data had only been provided for 2 of these audits and the agreement had now expired. This application was to extend the previous agreement to August 2015 so that the applicant could provide cohort identifiers for the remaining 4 audits, enabling this data to be tracked by the Medical Research Information Service (MRIS) and then linked to HES data, with the linked HES data provided back to the applicant. It was noted that section 251 approval had been in place for this work, and HRA CAG had confirmed verbally that this approval had been extended although written confirmation would also be sought. It was also noted that the applicant had not yet signed the new data sharing framework contract, and no data would be shared until this had been completed.</p> <p><b>Discussion:</b> A query was raised regarding how the results of the audit would be disseminated within the health service, and it was noted that in addition to publishing an annual report the results of the adult cardiac surgery audit would be shared with all participating cardiac units. The Group noted that the audits had been commissioned by the Healthcare Quality Improvement Partnership (HQIP), and confirmation was requested of whether HQIP would therefore be the data controller. If this was the case the application would need to be updated to include DPA registration details and an IG Toolkit score or equivalent for HQIP.</p> <p>The importance of fair processing was discussed, and it was noted that this could be an issue for a number of audits that had been running for many years as there was now a greater emphasis on fair processing than there had been in previous years. It was agreed that David Evans would raise this with HQIP as that organisation commissioned a large number of audits. The Group noted that information for patients about these particular clinical audits was available on the University College London website.</p> <p>It was felt that the data processing involved in this application was not clearly described, and it was not sufficiently clear from the application form provided which organisation would carry out data linkage. It was agreed that the application form would be updated to provide additional detail regarding how the data would flow. In addition, a number of amendments to the application form were suggested to clarify that only HES data was requested, that no new data processing was intended in addition to that described in the original application, and to remove a reference to trans-catheter aortic valve implantation (TAVI) as that was not relevant to the audits listed. It was also noted that the original section 251 approval letter had not been included with the application papers, and the Group requested sight of this.</p> <p><b>Outcome:</b> Unable to recommend for approval. Confirmation sought of whether HQIP are the data controller for this application, and if so their IG Toolkit score and DPA registration details should be provided. Application to be updated to clarify that no new data processing is requested in addition to the original application, that only HES data is requested, and to remove reference to TAVI. Applicant to be informed that DPA registration wording does not appear to cover the data processing requested. Additional detail requested about data flow and what organisation will carry out what processing, and in particular clarification requested</p>
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	<p>of references to linkage. Section 251 approval letter from HRA CAG to be circulated to DAAG members.</p> <p><b>Action:</b> David Evans to raise the importance of fair processing in ongoing audits with HQIP.</p> <p><b>Action:</b> Karen Myers to provide David Evans with a copy of the outcome letter for this application once sent.</p>
2.3	<p><u>RSR Consultants Ltd (Presenter: Stuart Richardson) NIC-253076-Q5S6S</u></p> <p><b>Application summary:</b> This was a new application for pseudonymised, non-sensitive SUS data in order for the applicant to create aggregated analysis outputs for NHS customers on a commercial basis. The intended purpose was to compare local provider casemix against the national average within Health Research Groups (HRGs), with CCGs being able to use this information to potentially negotiate reductions in tariff prices and thereby free up funding to reinvest in other services for the benefit of patients. It was noted that the applicant's DPA registration wording did not appear to cover the work described, but that the applicant had requested an amendment to their registration wording. It was also noted that the data provided would be stored on a single laptop within encrypted folders.</p> <p><b>Discussion:</b> Some concerns were raised regarding the purpose described, and whether the commercial aspects of the application could be considered to be compatible with the requirements of the Care Act 2014. It was suggested that a clearer explanation could be provided of how this work would benefit patients.</p> <p>The requested data retention period was queried, as the application form stated that the aggregated report would be produced within 3 months of receiving data but the requested data retention period was until the end of February 2016. There were some concerns raised that the applicant might intend to use the retained data for additional purposes or additional customers once the report had been completed, and it was suggested that the application form should be updated to clarify that data could only be used for the specified purposes.</p> <p>The reference to data being stored within encrypted folders within a laptop was queried, and confirmation was requested of whether the laptop itself was encrypted and if so to what level of encryption. In addition there was a query regarding whether the applicant's CCG customers in question should be considered the data controllers for the work described.</p> <p>Clarification was requested regarding the amount of data requested, and why national data was required in order to benchmark local organisations as opposed to using data from a smaller number of comparable areas. It was agreed that the applicant should provide a clearer justification for the need for national data in order to ensure proportionality.</p> <p><b>Outcome:</b> Unable to recommend for approval. Applicant asked to 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. Clarification requested whether the laptop where data will be stored is encrypted, and if so what level of encryption is used. Confirmation requested of whether the CCGs should be considered the data controllers for this data.</p>
2.4	<p><u>Imperial College London – IMPROVE trial (Presenter: Garry Coleman) NIC-287804-H1T1R</u></p> <p><b>Application summary:</b> This application was for an extension and an amendment to an existing study which compared the mortality rates of keyhole and open surgery for emergency endovascular aneurysm repair. Identifiable, sensitive Office of National Statistics (ONS) mortality data was requested for the study cohort, who following surgery had provided their</p>

	<p>consent for the use of their data. It was noted that the trial had commenced in 2010 and this data had previously been provided to the applicant, but that the provision of data had been suspended in 2014. The applicant had now applied to continue receiving ONS mortality data until the trial ended in December 2016.</p> <p>It was noted that a researcher from the University of Cambridge would analyse the data received, but that he would be working under a sub-contract to Imperial College London. It was also noted that the applicant had not yet signed the new data sharing framework contract and no data would be provided until this had been completed.</p> <p><b>Discussion:</b> The Group discussed the method of obtaining consent from patients following surgery, and it was agreed that it would be inappropriate to attempt to obtain consent prior to surgery due to the emergency nature of the procedure. There were some concerns regarding whether consent materials provided were appropriate, but it was agreed that they would have been considered appropriate at the time when the trial began. It was agreed that the applicant should be made aware that for any new trials, more up to date consent materials should be used.</p> <p>There was some confusion regarding references in the application form to a 'researcher' or 'researchers'. It was agreed that this should be updated to clarify that this referred to either the researcher from the University of Cambridge or the two Imperial College London researchers named, and not any additional researchers. In addition a query was raised regarding the contract in place for the University of Cambridge researcher, and whether this was an honorary contract. A reference to the University of Cambridge only receiving pseudonymised data was also queried, as it was stated that this would include date of death which was considered to be identifiable.</p> <p><b>Outcome:</b> Recommendation to approve subject to confirmation of whether the University of Cambridge researcher is employed on an honorary contract or a sub-contract, and subject to updating the application form to clarify which researchers are referred to.</p>
3	<p><b>Any other business</b></p> <p>It was noted that a response had been received from the Nuffield Trust regarding the recommendation DAAG had made for their application (NIC-283419-T9H7X). The Group discussed the possibility of providing applicants with additional guidance on consent materials and it was agreed that the Acting DAAG Chair would draft a response to the Nuffield Trust, enclosing a copy of the paper on consent materials discussed at the DAAG training day on 27 January 2015.</p> <p><b>Action:</b> Alan Hassey to draft a response to the Nuffield Trust regarding their application (NIC-283419-T9H7X).</p> <p>The Group further discussed the papers that had been produced to support the recent DAAG training day, and agreed that it would be potentially helpful to applicants if these papers could be published as an indication of the issues considered by DAAG. It was agreed that the papers would be redrafted to ensure they would be appropriate for publication.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
09/01/15	DF to look into lower super output areas (LSOA) and if they have previously been discussed at the Small Numbers Panel.	David Evans	13/01/15: This action had been passed to David Evans to provide an update from the Small Numbers Panel. 20/01/15: This would be raised with the Small Numbers Panel the following week. 27/01/15: A response from the Small Numbers Panel had been received, and David Evans would circulate this to DAAG members. 03/02/15: The response from the Small Numbers Panel had been circulated and it was suggested that any more detailed queries could also be raised with the Panel in future.	Closed
13/01/15	Garry Coleman to provide DAAG with a briefing paper on HDIS.	Garry Coleman	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. 27/01/15: Ongoing. 03/02/15: A briefing paper had been drafted and would be shared by email following clarification regarding HDIS extracts.	Open
13/01/15	Alex Bell to provide a summary of DAAG's previous consideration of HDIS applications.	Alex Bell	20/01/15: This would be circulated by email. 27/01/15: Ongoing. 03/02/15: This action had been completed and was closed.	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	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.	Open
20/01/15	Diane Pryce to speak to HRA CAG Secretariat regarding the use of terminology such as 'anonymised' and 'pseudonymised'.	Diane Pryce	27/01/15: A phone call had been scheduled to discuss this. 03/02/15: This discussion had taken place, and the following explanation had been provided: <i>'CAG view pseudonymisation as a process, the process generates a</i>	Closed

			<i>pseudonym/code which identifies the record but not the individual the information relates to. If the data is released with the pseudonym but no key or way for the recipient to link back to the identity of the individual then the release is considered to be anonymised. Therefore following this example the HES extracts without identifiable fields are referred to as anonymised. If the recipient holds the key/code or has access to it which enables them to re link the data then this is identifiable any would need s251 or other legal basis. Any identifiable field will of course need a legal basis for the flow of data.'</i>	
27/01/15	John Craven to draft guidelines for applicants requesting data as part of PhD studies.	John Craven	03/02/15: This action had been completed and was closed.	Closed
03/02/15	David Evans to raise the importance of fair processing in ongoing audits with HQIP.	David Evans		Open
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		Open
03/02/15	Alan Hassey to draft a response to the Nuffield Trust regarding their application (NIC-283419-T9H7X).	Alan Hassey		Open