

Data Access Advisory Group

Minutes of meeting held 22 October 2014

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

In attendance: Garry Coleman, Diane Pryce, Frances Hancox, Terry Hill

Apologies: Sean Kirwan, Patrick Coyle

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 14 October 2014 meeting were reviewed. It was agreed that a reference to accredited safe havens should be updated to clarify that this meant stage one accredited safe havens; other than this the minutes were agreed as an accurate record.</p> <p>Action updates were provided and recorded in the applications tracker.</p>
2	<p>Data applications</p>
2.1	<p><u>Nine Health CIC (IAO: Garry Coleman) NIC-240038-C6G3N</u></p> <p>This application was for pseudonymised Hospital Episode Statistics (HES) data linked to Diagnostic Imaging Dataset (DIDS) data for use in a research project into cerebral aneurysm. It was explained that record level data would be provided to the applicant, who were a not-for-profit social enterprise, and that the applicant would subsequently share aggregated data with small numbers suppressed with the University of Sheffield and the Instituto Ortopedico Rizzoli in Italy.</p> <p>A query was raised regarding the EU funding for this project, and whether Nine Health CIC were formally part of the research project consortium. A further query was raised regarding who would be the data controller for the data provided, and it was confirmed that Nine Health CIC would be the only organisation to hold record level data and they would therefore be the data controller.</p> <p>It was agreed that further information should be requested regarding the involvement of the University of Sheffield and the Instituto Ortopedico Rizzoli and the purpose for sharing data with these two organisations. It was noted that the applicant had stated that none of these organisations would use the data provided for commercial purposes, although a query was raised regarding how this would align with the requirements of the project's EU funding.</p> <p>Outcome: Unable to recommend for approval. Further clarification was required around: whether the data would be used for any commercial activities; what the exact role was of Nine Health in the research project; what data years were requested for HES and DIDS; and clarification around the data processing activities and what information was available to patients.</p>
2.2	<p><u>University of Sheffield (IAO: Garry Coleman) NIC-239402-S1P5Q</u></p> <p>This application was for pseudonymised HES data with linked ONS mortality data for research into the treatment of acute lymphoblastic leukaemia. It was noted that the research was sponsored by a commercial company, Amgen Ltd, who would receive a final report containing aggregated analysis with small numbers suppressed in addition to the research results being submitted for publication in a peer reviewed journal.</p>

	<p>The Group discussed whether providing research results to a commercial organisation should be considered a commercial use of data, and it was suggested that the applicant should be asked to provide further details regarding how the final report provided to Amgen Ltd would be used and what the anticipated benefits and outcomes of this would be for the healthcare system. It was also suggested that confirmation should be sought that the aggregated data provided to Amgen Ltd would be made publically available.</p> <p>Outcome: Recommendation to approve subject to the provision of further details regarding the anticipated healthcare benefits, with the response to be passed to a DAAG member for recommendation to the DAAG Chair out of committee. DAAG Chair to report back to members at the following meeting.</p>
2.3	<p><u>South London Commissioning Support Unit (IAO: Garry Coleman) NIC- 246288-B1S0R</u></p> <p>This application requested pseudonymised HES data in order to benchmark the performance of local acute providers.</p> <p>It was noted that as commissioning support units were part of NHS England rather than being legal entities in their own right, NHS England should have been listed as the licensee on the application form. It was agreed that this would be corrected.</p> <p>Outcome: Recommendation to approve – subject to NHS E being the licensee</p>
2.4	<p><u>Midlands and Lancashire Commissioning Support Unit (IAO: Garry Coleman) NIC-277269-G9Q3P</u></p> <p>This was an application for pseudonymised linked HES and DIDS data in order to support contractual and strategic benchmarking across the Midlands and Lancashire. In addition an extension was requested for the applicant to continue to hold the HES data that the HSCIC had previously supplied to the Central Midlands Commissioning Support Unit (CSU) prior to that organisation merging with Lancashire and Staffordshire CSU to form the Midlands and Lancashire CSU.</p> <p>The application format was discussed, and the Group agreed that it was helpful that this used the agreed generic template for CSU applications with the specific elements for this particular application, such as specific processing activities, clearly noted.</p> <p>It was noted that although two organisations had merged to form the current CSU, an Information Governance Toolkit score had only been provided for the former Central Midlands CSU and not the former Lancashire and Staffordshire CSU. It was agreed that as these two organisations had now merged, Information Governance Toolkit scores for both former organisations should be supplied.</p> <p>The Group queried how the DIDS data requested would be used, as the stated purpose in the application form only referred to HES data. It was agreed that the applicant should be asked to confirm this.</p> <p>Outcome: Recommendation to approve subject to satisfactory Information Governance Toolkit score, and confirmation of why DIDS data is required. The response to be passed to a DAAG member for recommendation to the DAAG Chair out of committee. DAAG Chair to report back to members at the following meeting.</p>

2.5	<p><u>Public Health England – Diagnostic Imaging Dataset (IAO: Garry Coleman) NIC-297344-D6J1W</u></p> <p>This application was for identifiable diagnostic imaging dataset (DIDS) data to support activities related to cancer registration and access to diagnostic tests, cancer staging and care pathway monitoring, and it was stated that this was a renewal of an application that had previously been approved by DAAG at the 26 June 2014 meeting. The Information Governance Toolkit score for the applicant was discussed, and it was noted that this had been raised when the previous application was considered by DAAG in June 2014.</p> <p>It was noted that the application provided had referred to both a Section 251 approval and Regulation 2 of the Health Service (Control of Patient Information) Regulations 2002 as the legal basis for the application, and it was agreed that clarification should be sought regarding how these both applied.</p> <p>A query was raised regarding how the applicant had met fair processing requirements under the Data Protection Act 2008, and it was noted that HRA CAG had considered this when reviewing the Section 251 application. It was agreed that the relevant letter from HRA CAG would be shared with DAAG members.</p> <p>Outcome: Unable to recommend for approval. Further clarification required around the Section 251 support. GC will circulate CAG letter to members for a decision; if acceptable this can be actioned out of committee and if not this will need to be resubmitted to DAAG.</p> <p><u>HSCIC Clinical Audit Support Unit applications</u></p> <p>The Group discussed whether it was appropriate to review the two Clinical Audit Support Unit applications, as it was noted that in both cases data were not being supplied outside the HSCIC but was requested for use by teams within the HSCIC. It was noted that in both cases the team was acting as a data processor under contract with an external organisation, and it was therefore felt to be appropriate for DAAG to review these applications.</p>
2.6	<p><u>HSCIC Clinical Audit Support Unit – National Diabetes Audit (IAO: Garry Coleman) NIC-296674-W4C6H</u></p> <p>This application was for pseudonymised HES data in order to monitor continuing preventive care key processes and treatment target achievements plus most long term complications for people with diabetes, with the HSCIC Clinical Audit Support Unit acting as data processor for the Healthcare Quality Improvement Partnership (HQIP).</p> <p>The Group discussed fair processing requirements under the Data Protection Act 2008, and it was noted that the HRA CAG approval letter provided had referred to the fair processing activities undertaken by the applicant. It was thought that the audit was generally well known within the general practice profession.</p> <p>Outcome: Recommendation to approve</p> <p>The need for applications to include details about how fair processing requirements had been met was raised, and it was agreed that IAOs should be reminded of this. It was also suggested that the application summary template could be updated to include a section on fair processing.</p> <p>Action: Terry Hill to remind IAOs of the need to state how applicants have met fair processing requirements.</p>

2.7	<p>Action: Diane Pryce to circulate questions regarding fair processing and consider including this in the application summary template.</p> <p><u>HSCIC Clinical Audit Support Unit – National Bowel Cancer Audit (IAO: Garry Coleman) NIC-297435-X6L2N</u></p> <p>Pseudonymised HES data is requested by the Clinical Audit Support Unit, who were acting as data processor for HQIP to produce an annual National Bowel Cancer Audit report.</p> <p>A point of accuracy was raised regarding the application form as at one point it referred to the Data Linkage and Extract Service, when this should have been the Data Access Request Service.</p> <p>Outcome: Recommendation to approve</p>
4	<p>Any other business</p> <p>The potential need for full day DAAG meetings in November was raised, and it was agreed that the timings for the November meetings would be agreed as soon as possible.</p>