

# Data Access Advisory Group

## Minutes of meeting held 13 January 2015

**Members:** Alan Hassey (Acting Chair), Sean Kirwan, Eve Sariyannidou, Dawn Foster

**In attendance:** Alex Bell, Karen Myers, Frances Hancox, David Evans, Garry Coleman, Dickie Langley (application 2.2 onwards), Netta Hollings (application 2.3), Jennifer Donald (application 2.9)

**Apologies:** John Craven, Patrick Coyle

1	<p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 8 January 2015 meeting were reviewed, and it was agreed that the discussion of application 2.3 (Basildon and Brentwood CCG MedeAnalytics, NIC- 310899-B3N7T) would be amended. Other than this the minutes were agreed as an accurate record.</p> <p>Action updates were provided (see table on page 8).</p> <p><b>Out of committee recommendations</b></p> <p>No recommendations had been made out of committee since the previous meeting.</p>
2  2.1	<p><b>Data applications</b></p> <p><u>Leeds Teaching Hospitals NHS Trust (Presenter: Garry Coleman) NIC-230103-K0K3S</u></p> <p><b>Application summary:</b> This application for linked Hospital Episode Statistics (HES) data had previously been considered at the 30 July 2014 and 12 November 2014 meetings. Clarification had been requested about the data requested, and the applicant had now confirmed that postcode, consultant code and referrer code were not required. A query had also been raised regarding the flow of identifiable data, and the applicant had confirmed that once data linkage had taken place to produce pseudonymised data the original identifiable data would be deleted. The applicant had now also requested Office of National Statistics (ONS) data, and it was confirmed that they had Approved Researcher status.</p> <p><b>Discussion:</b> The Group queried the intended data flow, as it appeared from reference to identifiable data being deleted that the applicant would receive identifiable data and carry out data linkage, then delete the identifiable data. It was confirmed that this was not the case. The data would be linked within the HSCIC, and pseudonymised data would then be provided to the applicant. The applicant would then delete the identifiable data that they currently held. It was agreed that the application wording should be updated to clarify this.</p> <p>It was noted that the ONS data that would be shared was considered to be identifiable, and confirmation was sought that the section 251 approval from the Health Research Authority Confidentiality Advisory Group (HRA CAG) covered this. The HRA CAG final approval letter had not been provided, and the Group requested confirmation of the annual review date to ensure the section 251 approval was still in place. Information regarding any fair procession activities was also requested.</p> <p>A query was raised regarding the purpose of the application, and it was confirmed that the study had a clear medical purpose.</p> <p><b>Outcome:</b> Unable to recommend for approval. Clarification required regarding whether</p>

<p>2.4</p>	<p>section 251 approval covers the ONS data requested and confirmation of the CAG annual review date. Further information regarding fair processing activities and a clearer description of the data flow requested.</p> <p><u>University of Oxford - Internet Use and Health Outcomes (Presenter: Garry Coleman) NIC-255171-N8Y5L</u></p> <p><b>Application summary:</b> This application for HES data had previously been considered at the 12 November 2014 meeting. The applicant had been asked to provide a clear statement around the health benefits and medical purpose, and provide more detail about the research project.</p> <p><b>Discussion:</b> The need for data to be grouped by OACODE was queried, and it was confirmed that the applicant required this level of granularity in order to carry out the intended analysis. A query was raised regarding why small numbers would not be suppressed, and it was explained that this was due to the data granularity required.</p> <p>Some concerns remained around what the basis for disclosing this data would be, as it was not felt that the application had described any clear medical purpose for the use of data. It was noted that the applicant had stated that the results might be published and that it was hoped that the findings might influence the government's digital inclusion strategy, but the Group felt that this did not appear to constitute a medical purpose for the application as for example there were no references to communicating results to commissioners or to how the research could promote health.</p> <p>The Group queried the number of data years that had been requested, from 2003 to 2012. It was agreed that the applicant should be asked to justify why this amount of data was required. A reference to the dataset being stored by the University of Oxford was also queried and the Group asked for confirmation of how long the dataset would be retained for.</p> <p>There was a discussion around the fact that this application had only been brought to DAAG because the data requested was grouped by the sensitive field OACODE, as without this the data would have not been considered to be identifying. It was explained that due to the possibility that providing data grouped by OACODE could lead to data being potentially identifiable, it was therefore important to consider aspects such as the legal basis for disclosure and the need to ensure fair processing.</p> <p><b>Outcome:</b> Unable to recommend for approval. Applicant to be asked to provide a clear medical purpose for this use of data, justification for the number of data years requested, and confirmation of whether data will be retained by the University of Oxford solely for the duration of the study or for longer.</p> <p>2.3</p> <p><u>Res Consortium Ltd (Presenter: Garry Coleman and Netta Hollings) NIC-280016-T1G4D</u></p> <p><b>Application summary:</b> This had previously been considered at the 9 December and 23 December 2014 meetings and further information had been requested, particularly around the methodology and amount of data required and the involvement of Britannia Pharma. The applicant had confirmed that Britannia Pharma had funded the research but that they would not have any other role in the research, and that the report provided to Britannia Pharma would be made publicly available regardless of the outcomes of the research. The applicant had also reduced the amount of data requested by excluding any individuals under the age of 30 from the cohort. A reference to Parkinson's UK in the application had been clarified to confirm that this organisation would not be involved in the proposed data analysis.</p> <p><b>Discussion:</b> A query was raised regarding the data controller, and it was confirmed that Res Consortium would be both the data controller and processor for the data provided.</p>
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<p>2.5, 2.6, 2.7</p>	<p>The Group queried a reference within the application form to the intention to ‘link patients’ diagnoses with their packages of care both physical and mental health and outcomes’ as it was not clear whether this meant that the applicant intended to link the data provided with other datasets. In addition, it was noted that the Data Protection Act (DPA) registration wording provided did not appear to reflect the intended work, and it was agreed that this should be brought to the applicant’s attention.</p> <p><b>Outcome:</b> Recommendation to approve subject to assurance that the applicant’s DPA registration reflects the work taking place, and clarification of a reference to linking patients’ diagnoses with their packages of care and outcomes.</p> <p><u>Cheshire West &amp; Cheshire Council (Presenter: Garry Coleman) NIC-312924-D4G1J, Imperial College Healthcare NHS Trust NIC-275555-F8J3Z and Southampton City Council NIC-277336-P9Z4Z</u></p> <p><b>Application summary:</b> These three applications were for access to the HES Data Interrogation System (HDIS), which had replaced HES Business Objects.</p> <p><b>Discussion:</b> The Group queried what data could be accessed through HDIS, and it was confirmed that only pseudonymised, non-sensitive HES data was available. It was noted that one of the applications referred to sensitive data, and it was agreed that this was an error and should be corrected.</p> <p>The Group emphasised the need to ensure that data accessed through HDIS would only be used for medical purposes, as it was noted that the three applications were from local authorities where the DPA registration included the use of data for a variety of unrelated purposes such as marketing local tourism and crime prevention. It was agreed that applicants should be asked to confirm that data would only be used for specific healthcare purposes.</p> <p>Concerns were expressed about the facility for individuals accessing HDIS to download and store data, and although it was noted that the ability to download the entire database had been disabled it would still be possible for individuals to download a significant amount of data and store this locally. The Group suggested that the HSCIC should consider that it might be more appropriate if the facility to download data was removed, so that any individuals wishing to obtain a data extract after using HDIS would need to apply to the HSCIC as with all other applications for HES data. It was suggested that HDIS could potentially be treated as a form of ‘safe haven’, whereby data could be analysed and outputs stored within the secure system but without the option to download outputs to store locally unless these were anonymised, aggregated reports.</p> <p><b>Outcome:</b> Unable to recommend for approval. Members discussed the use of access to HDIS and recommended that HDIS could be treated as a ‘safe haven’ whereby customers could interrogate the data and store subsets of data within HDIS, but data could not be downloaded. HDIS should only be accessed for clearly medical purposes.</p> <p><b>Action:</b> Alan Hassey to write to Martin Severs, Rob Shaw and Chris Roebuck regarding HDIS.</p> <p><b>Action:</b> Garry Coleman to provide DAAG with a briefing paper on HDIS.</p> <p><b>Action:</b> Alex Bell to provide a summary of DAAG’s previous consideration of HDIS applications.</p> <p><u>NHS England – Improving Access to Psychological Therapies (Presenter: Garry Coleman)</u></p>
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2.8	<p><u>NIC-311505-X4K1P</u></p> <p><b>Application summary:</b> This was a new application for non-sensitive, pseudonymised HES data linked to Improving Access to Psychological Therapies (IAPT) data. The IAPT data would be sent to the HSCIC from 13 IAPT sites and then linked to create a pseudonymised dataset using HES-ID and study ID. This linked, pseudonymised data would then be provided to the University of Surrey who would act as a data processor on behalf of NHS England, who would be the data controller.</p> <p><b>Discussion:</b> It was noted that the data controller and processor had not been specified on the application form provided, and it was agreed that this should be updated.</p> <p>A query was raised regarding the IAPT data that would be provided to the HSCIC, and whether this was separate to the IAPT data that was already routinely collected by the HSCIC. It was noted that if this was a separate, bespoke flow of data then there would need to be a clear legal purpose for this specific use of data. Information about fair processing activities was also requested.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarification of whether the data provided by IAPT sites is the same as the IAPT data routinely collected by the HSCIC or if this is a bespoke data flow. If a bespoke data flow, confirmation required of the legal basis for this data flow and what fair processing activities have been undertaken.</p>
2.11	<p><u>Kings College London - Economic and Health Effects of Pollution Near Airports (Presenter: Garry Coleman) NIC-236594-T3Q6W</u></p> <p><b>Application summary:</b> This application had been considered previously at the 18 November and 23 December 2014 meetings. The Group had queried a reference to linking with other datasets, and the applicant had now confirmed that the data linked with would be at postcode district level and would not increase the risk of data being re-identified. Additional information had been provided regarding how data would be processed as well as what healthcare benefits could arise from this research. It was noted that the applicant intended to discuss the implications of the research with public health departments of local authorities in the relevant areas. The applicant had also clarified that data was required for the areas around all major airports in England as these would be considered simultaneously in comparison to Heathrow.</p> <p><b>Discussion:</b> The Group noted that an Information Governance (IG) Toolkit score had not been provided, although an IG Toolkit score for this organisation had been provided with a separate application. It was agreed that clarification should be sought as to why this had not been included with this application.</p> <p>It was suggested that the information provided on outputs and benefits was still somewhat unclear, although this had significantly improved since the application had previously been considered by DAAG. It was agreed that the relevant section of the application should be rewritten to clarify what the specific outputs of the work would be. It was also suggested that the reference to 'all major airports' should be clarified to specify which airports this included, and to be clear that data would only be provided for the surrounding areas of the 8 airports requested.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarification regarding why an IG Toolkit score was not provided, and further details regarding benefits and the intended specific outputs.</p>
2.14	<p><u>CHKS (Presenter: Garry Coleman) NIC-292296-Y2M2K</u></p>

	<p><b>Application summary:</b> This was an application from a commercial organisation for pseudonymised, non-sensitive HES data. It was noted that the applicant already held HES data under previous approvals, and this application was to renew their access to monthly updated HES data. This data would be used to provide a variety of services to the NHS including benchmarking, market share analysis, mortality profiling and consultant appraisal. It was noted that only non-sensitive data was requested so consultant code would not be provided; bespoke reports could be made available to individual organisations, but these would not include any record level data.</p> <p>It was noted that CHKS was part of the Capita Group but that the data provided would be used purely for the purposes outlined in the application, and would not be made available to any other organisations within the Capita Group.</p> <p><b>Discussion:</b> A query was raised regarding whether CHKS would be both the data controller and data processor for this work, as this had not been stated on the application form. It was confirmed that this was the case, and the application form would be updated.</p> <p>The Group queried why this application had been classed as an amendment and whether this meant that any additional data had been requested compared to previous applications. It was confirmed that the same monthly HES data was requested, but that the application had been classed as an amendment due to the updated description of the purposes for which data could be used.</p> <p><b>Outcome:</b> Recommendation to approve subject to updating the application form to state that CHKS are both the data controller and data processor.</p>
2.2	<p><u>City University London (Presenter: Dickie Langley) NIC-256929-M9C4B</u></p> <p><b>Application summary:</b> This application had previously been considered at the 18 November 2014 meeting, when the Group had been unable to recommend approval. Following this additional information had been provided by the applicant to answer the Group's queries about section 251 approval, the 'collaborators' for this work, and how patients had been informed of this use of data.</p> <p><b>Discussion:</b> The Group were content that the queries they had previously raised had been answered to their satisfaction.</p> <p>A query was raised regarding the amount of data requested, and whether data was only requested for patients within the specific cohorts or if data for patients without the specified conditions was also requested in order to create a control group for comparison. It was confirmed that data was only requested for individuals with the conditions listed.</p> <p>The Group emphasised the importance of ensuring that research results would be appropriately disseminated within the health service.</p> <p><b>Outcome:</b> Recommendation to approve.</p>
2.10	<p><u>University of Sheffield - Alcohol related hospital admission rates (Presenter: Dickie Langley) NIC-306894-H7B0N</u></p> <p><b>Application summary:</b> This was a new application for pseudonymised, non-sensitive HES inpatient data in order to study whether alcohol outlet density was associated with hospital admissions for alcohol related conditions.</p> <p><b>Discussion:</b> The Group queried a statement within the application that the customer 'has</p>

	<p>been approved' as it was not clear what this meant, and it was agreed that this would be clarified. A further query was raised regarding the statement that all researchers working on the project would be 'associated with' the School of Health and Related Research, and whether this meant that some individuals with access to the data would not be employed by the University of Sheffield. It was noted that this could be relevant in the context of the DPA requirement for confidentiality to be enforceable through staff contracts and disciplinary procedures.</p> <p>A query was raised about the role of Alcohol Research UK in this research. It was explained that Alcohol Research UK were an independent charity who had funded the research, and it was noted that Alcohol Research UK did not accept funding from the alcohol industry.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarification of the statement that 'all researchers working on this project will be associated with the School of Health and Related Research at the University of Sheffield'.</p>
2.12	<p><u>United Health UK (Presenter: Dickie Langley) UK NIC-277499-D3D0X</u></p> <p><b>Application summary:</b> This was an application for pseudonymised, non-sensitive HES data to be used in a risk stratification tool and the applicant's commissioning and contracting suite. The applicant had requested approval to hold 4 years of data, with the oldest year of data being deleted and replaced by a new data year annually.</p> <p><b>Discussion:</b> It was noted that the application form stated that the applicant's HSCIC framework contract had not yet been signed, but it was confirmed that since the application had been submitted this had been completed. The Group queried the customers for the tools described and it was confirmed that these tools were only made available to NHS organisations.</p> <p>It was noted that the application stated that data would be held within premises rented from SunGard Availability Services, but that no security assurance details had been provided for SunGard.</p> <p>A query was raised regarding the intention for this application to replace 4 separate data reuse agreements that had previously been in place between the HSCIC and the applicant organisation. It was confirmed that any data held under the previous agreements would be deleted by the applicant.</p> <p><b>Outcome:</b> Recommendation to approve subject to the provision of security assurance details for SunGard Availability Services.</p>
2.13	<p><u>NHS England (Presenter: Dickie Langley) NIC-275595-Q5W5Z</u></p> <p><b>Application summary:</b> This was an application for pseudonymised, non-sensitive HES and HES-Diagnostic Imaging Dataset (HES-DID) linked data.</p> <p><b>Discussion:</b> A query was raised regarding the involvement of Cancer Research UK in this work, and it was clarified that one analyst from Cancer Research UK would have access to the data but that this individual would be working on an honorary contract with NHS England for this project.</p> <p>The Group discussed the use of honorary contracts, and the potential impact of this due to the DPA requirement for confidentiality to be enforceable through staff contracts and disciplinary procedures. In this context a reference to accessing data remotely was queried, and it was agreed that further information should be requested around how data would be</p>

2.9	<p>accessed remotely.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarification of how data will be accessed remotely.</p> <p><u>King's College London - The Special Needs and Autism Project (Presenter: Jennifer Donald)</u> <u>NIC-269704-S8W6D</u></p> <p><b>Application summary:</b> This application was to receive address and fact of death for a small cohort of individuals on the autistic spectrum. This was to enable the applicant to re-contact the cohort members to follow up on previous studies, and to ensure that they would not cause families distress by attempting to make contact when an individual had died.</p> <p><b>Discussion:</b> The Group queried whether cohort members would be asked to re-consent to participation in the study, as they would have been children when the study originally began. It was confirmed that consent materials had been produced for this purpose, although copies of these had not been provided with the application.</p> <p>It was noted that section 251 approval was in place, but the Group noted that the approval letter from HRA CAG had not been included with the meeting papers and therefore the Group not aware if this approval had included any conditions.</p> <p><b>Outcome:</b> Recommendation to approve subject to DAAG members having sight of the relevant section 251 approval letter from HRA CAG.</p>
3	<p><b>Any other business</b></p> <p>It was noted that Jackie Gallagher would be retiring from the HSCIC, and Garry Coleman would take over her Information Asset Owner (IAO) role. Applications from this area would be brought to DAAG by Jennifer Donald on behalf of Garry Coleman.</p> <p>An update was given on the agenda for the training day taking place on 27 January.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
16/12/14	Diane Pryce to provide a briefing paper on home nations cross-border relationships and known issues.	Diane Pryce	23/12/14: Diane did not attend the meeting. Ongoing. 08/01/15: Ongoing – this will be brought to the training day. 13/01/15: This had been added to the agenda for the 27 January DAAG training day, and the action was closed.	Closed
16/12/14	Diane Pryce and Alex Bell to discuss self-assessed IG Toolkit scores with Marie Greenfield.	Diane Pryce	23/12/14: Ongoing 08/01/15: Ongoing - this will be brought to the DAAG training day. 13/01/15: This had been added to the agenda for the 27 January DAAG training day, and the action was closed.	Closed
09/12/14	Eve Sariyannidou and David Evans to provide bullet points on consent materials to assist discussions at DAAG training day.	David Evans	16/12/14: This action was ongoing. 23/12/14: Ongoing 08/01/15: Ongoing 13/01/15: A meeting was planned to discuss this, and an update would be provided at the training day.	Open
23/12/14	DF to ensure that Experian are added to the list of organisations to be audited, regardless of the decision of the outcome of this application.	Dawn Foster	08/01/15: 4 audits planned in first quarter of this year, DF has requested Experian are added to this list. 13/01/15: This action had been completed and was closed.	Closed
23/12/14	GC obtain some information on framework agreement for BMJ (NIC-292310-D7B7R) and DF to research to understand the criteria for applicants for framework agreement and see what implications are for them accessing the data.	Garry Coleman	08/01/15: GC updated that the BMJ and Kings College application is back with the customer for further information. Ongoing. 13/01/15: Ongoing.	Open
09/01/15	DAAG Secretariat to send round HSCIC Code of Practice to DAAG members	Alex Bell	13/01/15: This had been done and the action was closed.	Closed
09/01/15	DAAG Secretariat to send details of the pseudonymisation steering group to DAAG members.	Alex Bell	13/01/15: This had been done and the action was closed.	Closed



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.	Open
13/01/15	Alan Hassey to write to Martin Severs, Rob Shaw and Chris Roebuck regarding HDIS.	Alan Hassey		
13/01/15	Garry Coleman to provide DAAG with a briefing paper on HDIS.	Garry Coleman		
13/01/15	Alex Bell to provide a summary of DAAG's previous consideration of HDIS applications.	Alex Bell		