

# Data Access Advisory Group

## Minutes of meeting held 2 December 2014

**Members:** Sean Kirwan, Dawn Foster, Eve Sariyannidou, John Craven

**In attendance:** Alex Bell, Diane Pryce, Frances Hancox, Karen Myers, Garry Coleman, Dickie Langley (applications 2.1 – 2.3)

**Apologies:** Alan Hassey, Patrick Coyle

1	<p><b>Review of previous minutes and actions</b></p> <p>It was noted that Alan Hassey had sent apologies, and Sean Kirwan acted as Chair for this meeting.</p> <p>The minutes of the 25 November 2014 meeting were reviewed and approved 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><u>Barts Health NHS Trust NIC-226652-NIG2N</u></p> <p>This application had been considered at the 25 November 2014 meeting and DAAG had recommended approval subject to caveats. The applicant had responded to the points raised by DAAG, and the Acting Chair had confirmed that the caveats had been addressed to his satisfaction.</p> <p><u>i5 Health NIC- 249530-Q5J8H</u></p> <p>This application had been considered by DAAG at the 18 November 2014 meeting, and received a recommendation for approval subject to caveats. The Acting Chair had confirmed out of committee that the caveats had been addressed to his satisfaction.</p>
2  2.1	<p><b>Data applications</b></p> <p><u>University of Manchester (Presenter: Garry Coleman) NIC-261676-P6W8V</u></p> <p><b>Application summary:</b> This was an application for pseudonymised, non-sensitive Hospital Episode Statistics (HES) data for use in five research projects with the purpose of evaluating the impact of financial and organisational reforms of the NHS. It was noted that the data requested would be held by the applicant in two separate locations. A data retention period of three years was requested, subject to moving to the new data sharing contract and agreement by the end of February 2015.</p> <p><b>Discussion:</b> The Group noted that a brief summary of each of the five projects had been provided, but it was felt that additional information was required. It was not thought to be clear whether the five projects were connected or which projects required what data. In particular queried were raised regarding project 3, as this referred to evaluating a payment scheme that was 'to be introduced in England in October 2008' and it was not clear if this was a date error, or if the summary provided had been taken from an old document without being updated to specify whether this work was still ongoing or what changes had taken place since 2008.</p>

	<p>The Group also emphasised the importance of ensuring that the applicant understood that the data requested could only be used for the five projects listed in the application summary, and not for any additional projects without submitting a further application.</p> <p>A query was raised regarding the security of the two data storage locations, as the application summary stated that the System Level Security Policy (SLSP) for the University of Manchester had been reviewed but there was no reference to review of the SLSP for the second location. A further query was raised regarding a reference to the fact that the work was funded by other organisations, as it was not stated clearly whether these organisations would also require access to the data requested.</p> <p><b>Outcome:</b> Unable to recommend for approval. Further details requested about each project and its data requirements, and in particular clarification sought about project 3 and whether this is still ongoing, as well as whether any of the 5 projects are linked. Confirmation requested that the SLSP for the second location has been reviewed and approved. Confirmation required that the data provided will only be used by the 5 projects listed and not for any additional projects, and that only the University of Manchester will have access to the data provided.</p>
2.2	<p><u>University of Oxford (Presenter: Dickie Langley) NIC-257796-H0P0C</u></p> <p><b>Application summary:</b> This application was for pseudonymised, non-sensitive HES data relating to maternal outcomes in childbirth, with the stated purpose of investigating a method for monitoring the trend of adverse maternal outcomes during childbirth. It was stated that Research Ethics Committee (REC) approval was not required for this work. It was noted that all a broader range of HES data had originally been requested, but this request had been focussed to HES data relating to maternal outcomes and childbirth only due to the principle of data minimisation.</p> <p><b>Discussion:</b> The Group felt that the application summary provided did not clearly explain the cohort for the data requested, and for example whether data on all women in England within the age ranges stated would be provided or if data for a smaller cohort of individuals would be provided. It was agreed that this would be clarified. In addition references to 'this method' in the application summary were queried, as it was not clearly explained what this method would be.</p> <p>Overall the Group were largely content with the application, but it was agreed that the applicant should be asked to clarify these two points for consideration out of committee.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarification of the methodology and anticipated outputs, in addition to clarification of the cohort.</p>
2.3	<p><u>Clinical Practice Research Datalink (CPRD) (Presenter: Dickie Langley) NIC-243369-D0Q2H</u></p> <p><b>Application summary:</b> This application was for an amendment to the existing agreement with CPRD in order for them to receive Diagnostic Imaging Dataset (DID) data in addition to the HES and Office of National Statistics (ONS) data already provided. It was stated that Section 251 approval from the Health Research Authority Confidentiality Advisory Group (HRA CAG) was in place for CPRD to receive this data.</p> <p><b>Discussion:</b> A query was raised regarding the section 251 approval granted by HRA CAG, as it was noted that the annual review letter provided did not refer to the additional provision of DID data requested. It was agreed that this should be confirmed.</p> <p>It was noted that the application summary described the data requested as identifiable,</p>

<p>2.4</p>	<p>sensitive data. It was explained that this description was due to the inclusion of ONS data, but it was confirmed that CPRD only received pseudonymised HES and primary care and only pseudonymised DID data was requested.</p> <p>There was a discussion of the need to address fair processing by ensuring that information about this use of data was available to the general public. It was noted that the HRA CAG annual review letter provided stated that the section 251 approval was subject to a number of conditions, which included the need for the patient information letter to be reviewed by the appropriate Research Ethics Committee. It was not known whether this review had taken place, and the Group agreed that confirmation of this should be sought. The Group agreed that it would be helpful if a clearer description of the data flows involved could be included with future applications.</p> <p>Some concerns were raised regarding the wording used in the application, and it was agreed that this would be clarified.</p> <p><b>Outcome:</b> Unable to recommend for approval. Confirmation requested whether the patient information leaflet has received REC approval, as this was a condition of the section 251 approval from HRA CAG, and confirmation of whether the DID data requested is included in the section 251 approval. Application wording to be clarified.</p> <p><u>RAND Europe (Presenter: Garry Coleman) NIC-255450-G2Z6F</u></p> <p><b>Application summary:</b> This was an application from a commercial organisation (RAND Europe) commissioned by Guy's and St Thomas' NHS Foundation Trust to carry out data analysis for the evaluation of Southwark and Lambeth Integrated Care. The application was for pseudonymised, non-sensitive HES data and it was confirmed that the data requested would only be used to support this evaluation and not for any additional purposes.</p> <p><b>Discussion:</b> The Group noted that while only HES data was requested, the application summary listed a number of other datasets and did not clearly state that these were not required. It was agreed that this should be clarified on the application form.</p> <p>A query was raised regarding the wording of the data retention period and it was clarified that data would be retained for three years from when the data sharing agreement with the applicant began, with the understanding that the new format data sharing contract and agreement would need to be in place before the end of February 2015. It was agreed that this should be clarified on the form.</p> <p>There was a further query regarding the comparison of data at general practice level within certain age groups, and whether this could result in data becoming identifiable due to small numbers. It was confirmed that only pseudonymised data would be supplied to the applicant, and that any data made publically available would be aggregated with small numbers suppressed.</p> <p>The Group requested further clarification of the relationship between the different organisations listed in the application form and whether any other organisations would have access to the data provided, and in particular what controls would be in place for staff from the University of Cambridge working in collaboration with RAND Europe. Additional information was also requested about the anticipated measurable benefits of this work, as it was felt that the outcomes described were not sufficiently specific or clear.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarification of the relationship between RAND Europe, University of Cambridge and LSE, and particularly staff from University of Cambridge carrying out work for RAND Europe. Application form to be updated to specify that only HES data is requested, and data retention period wording to be clarified. Further detail</p>
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<p>2.5</p>	<p>requested on outputs and benefits.</p> <p><u>University of East Anglia (Presenter: Garry Coleman) NIC-308892-P2H0Y</u></p> <p><b>Application summary:</b> This application for identifiable HES and DID data for study participants had previously been discussed at the 16 September 2014 DAAG meeting, and additional information had been requested regarding the applicant's SLSP. It had now been confirmed that the SLSP had been reviewed and was acceptable. Data retention until the end of February 2015 was now requested. It was acknowledged that due to delays, the application summary template used for this application was in an older format than the template used for current applications.</p> <p><b>Discussion:</b> Some concerns were raised regarding the consent form provided, as it was noted that the role of the HSCIC was not described and the Group felt that a statement that 'health care records may be looked at' did not appropriately describe this use of data. It was agreed that the applicant should be asked to provide an action plan for how they would make study participants aware of this use of data, which could involve writing to participants and giving them the opportunity to opt out. Other than this point the Group agreed that they were content with the application.</p> <p><b>Outcome:</b> Recommendation to approve subject to the provision of an action plan for how participants will be informed of the role of the HSCIC in the processing of their data.</p> <p>2.6</p> <p><u>University of Sheffield (Presenter: Garry Coleman) NIC-204484-N8H5N</u></p> <p><b>Application summary:</b> This application had initially been considered at the 19 October 2014 DAAG meeting, when DAAG had been unable to recommend approval. A number of queries had been raised, and it was noted that there had been delays due to the applicant not responding to the DAAG outcome letter. The applicant had now responded to the points raised and this response was provided for the Group's consideration.</p> <p><b>Discussion:</b> It was noted that due to the delays, the application submitted was in an old application summary format and this did not include all the information required from current applications, such as DPA registration details. In addition, the Group did not feel that the applicant had appropriately responded to the queries raised. In particular the response stated that personal data would not be shared with any third parties and so the consent materials used were not required to cover this, but the Group noted that personal data would need to be shared with the HSCIC to enable linkage and the study cohort should therefore be made aware of this.</p> <p><b>Outcome:</b> Unable to recommend for approval. Application to be updated to use the current application summary template. As had previously advised, the applicant should accompany their consent form with the appropriate consent material prior to re-submitting an application.</p>
<p>3</p>	<p><b>Any other business</b></p> <p><u>Updated DARS application form</u></p> <p>It was noted that this had been updated following the comments made by DAAG members. The updated application form would be circulated by email and agreed out of committee.</p> <p><b>Action:</b> Dickie Langley to circulate the updated DARS application form by email, and DAAG members to provide comments.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
02/12/2014	Dickie Langley to circulate the updated DARS application form by email, and DAAG members to provide comments.	Dickie Langley		Open
25/11/2014	Dickie Langley to bring updated draft application summary template to next DAAG meeting for approval.	Dickie Langley	02/12/14: Agenda item scheduled for discussion of updated draft template. Action closed.	Closed
12/11/2014	Dawn Foster to discuss DPA registration concerns with the ICO.	Dawn Foster	18/11/14: This had been raised with the ICO and a response was awaited. 25/11/14: No update available. 02/12/14: A response had been received from the ICO explaining the change in process, and it was agreed that applicants should be made aware of the potential need to update their DPA registration wording if required.	Closed
12/11/2014	Dawn Foster to discuss with HRA CAG Secretariat whether the addition of the data item Place of Death to the requested dataset could affect identifiability (CASU National Oesophago-Gastric Cancer Audit NIC-292440-R9G8P).	Garry Coleman	18/11/14: This had been raised with HRA CAG Secretariat, who had noted that place of death could in some cases mean a home address. It was agreed that the applicant should be asked to confirm whether they required full addresses for this, and if so to provide justification for why this was needed. 25/11/14: No update available. 02/12/14: Garry Coleman agreed to confirm whether the applicant had addressed this.	Open