# Data Access Advisory Group

## Minutes of meeting held 25 November 2014

**Members:** Alan Hassey, Eve Sariyiannidou, John Craven, Sean Kirwan, Patrick Coyle

**In attendance:** Alex Bell, Diane Pryce, Frances Hancox, Karen Myers, Jennifer Donald (application 2.1), Alyson Whitmarsh (application 2.2), Garry Coleman (applications 2.3 – 2.5), Dickie Langley (applications 2.3 – 2.5)

**Apologies:** Dawn Foster

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| **1** | **Review of previous minutes and actions**<br><br>The minutes of the 18 November 2014 meeting were reviewed and approved as an accurate record.<br><br>Action updates were provided (see table on page 5).<br><br>**Out of committee recommendations**<br><br>NHS England - Casemix NIC-302643-R3R2H<br><br>This application had been considered at the 18 November 2014 DAAG meeting and further information had been requested from the applicant. The applicant's response had been circulated to members, and the application was recommended for approval out of committee. |
| **2** | **Data applications** |
| **2.1** | Barts Health NHS Trust (Presenter: Jennifer Donald) NIC-226652-NIG2N<br><br>**Application summary:** This application, which was for patient status to determine whether any women within a cohort had been inappropriately ceased from breast cancer screening, had previously been considered at the 4 June and 16 September 2014 DAAG meetings. The applicant had been asked to provide additional information about what data would be shared with the third party organisation PHAST and how the applicant had met their fair processing responsibilities under the Data Protection Act 1998 (DPA). The applicant had confirmed that patient identifiers would be removed before data was shared with PHAST.<br><br>**Discussion:** The Group queried the statement that the data provided to PHAST would be anonymised as it was thought that this would not enable the applicant to identify any individuals who had been inappropriately ceased from screening. It was suggested that the data provided might instead be pseudonymised, and it was agreed that the applicant should be asked to confirm whether this was the case and if so how data would be pseudonymised. |
| **2.2** | A query was raised regarding whether cause of death data would include whether an individual had had breast cancer if this was not the primary cause of death, and it was confirmed that cause of death data would be expected to include significant contributing factors.<br><br>A further query was raised regarding how data would be disposed of, as it was not felt that this was described clearly in the information provided.<br><br>The Group discussed the need to ensure fair processing, and it was noted that the women within the cohort had previously attended breast screening and would have been informed |

about the use of their data at that point. Further details were requested regarding what information had been given and whether any further fair processing activities would be taking place.

**2.3** There was a suggestion that the applicant should consider contacting all surviving women within the cohort and asking them to re-consent to this use of data. However, it was noted that this would significantly delay the proposed work and in addition it was not currently known for certain which women within the cohort were still alive. It was noted that this application followed the identification of a Serious Untoward Incident (SUI) and the Group acknowledged the importance of this work. It was agreed that if the applicant could clarify the three points raised, then DAAG could consider the response out of committee prior to the following meeting.

**Outcome:** Recommendation to approve subject to caveats. Clarification requested on whether the data shared with PHAST will be anonymised or pseudonymised and how this will be done, and clarification on how data will be disposed of appropriately. Further details also requested on how the applicant has met fair processing requirements.

HSCIC - Chronic Obstructive Pulmonary Disease (COPD) consent review (Presenter: Alyson Whitmarsh) NIC-303251-X4Y7M

**Application summary:** This was a request for DAAG to review the proposed patient information leaflet and patient consent form to be distributed by the British Thoracic Society for the COPD audit, with the intention to bring a further application to DAAG at a later date to request data to support the audit.

**Discussion:** The Group confirmed that they were satisfied with the content of the consent materials provided, although overall it was felt that the language used could have been clearer and could have made more use of plain English in order to be more easily understood by a lay audience.

**2.4** Advice was given that the consent leaflet could potentially be improved and made easier to read by reducing the amount of text, and potentially re-ordering paragraphs to avoid patients being put off from reading further by the first paragraph. In addition, the Group advised that point 4 on the consent form could be clarified by removing the statement 'if this is allowed by law' as it was felt that this could be confusing to members of the public. It was also suggested that providing an example of a central UK NHS body would help to clarify this point.

**Outcome:** Recommendation to approve

University of Warwick Clinical Trials Unit - PARAMEDIC (IAO: Garry Coleman) NIC-237151-V4Z5

**Application summary:** This application was for pseudonymised, non-sensitive Hospital Episode Statistics (HES) data for a cohort of patients participating in the Pre-hospital Randomised Assessment of a Mechanical Compression Device in Cardiac Arrest (PARAMEDIC) trial. It was explained that Section 251 approval had been obtained for the cohort members who were now deceased, and the surviving members of the cohort had provided their consent. Data was requested until November 2015, subject to the renewal of Section 251 approval and subject to moving to use the new data sharing contract by February 2015.

**Discussion:** The Group noted that the majority of members of the cohort were deceased and that Section 251 approval had been obtained to process their data, but that consent would be used as the legal basis for processing the data of surviving members of the cohort. It was

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| **2.5** | thought that the consent materials provided did not explain the role of the HSCIC in processing data. Therefore it was suggested that the applicant to contact the surviving members of the cohort and inform them of the intended disclosure of data to and from the HSCIC, and give them the opportunity to opt out if they wished to do so.<br><br>It was noted that the applicant could potentially provide justification for why this was not felt to be appropriate or practical, although it was also noted that the number of surviving cohort members was thought to be relatively small. The Group stated that they were content to recommend approval for the provision of data for deceased members of the cohort as this was covered by the Section 251 approval, and it was suggested that if there were difficulties regarding informing surviving members of the cohort then it might be helpful to treat the two cohorts as two separate applications.<br><br>**Outcome:** Recommendation to approve subject to surviving members of cohort being informed of HSCIC involvement in processing information and being given the opportunity to opt out.<br><br><u>City University London – Office of National Statistics (ONS) (IAO: Garry Coleman) NIC-273840-N0N0N</u><br><br>**Application summary:** This application for identifiable, non-sensitive HES data had previously been considered at the 18 November 2014 DAAG meeting, and the applicant had responded to the queries raised by DAAG. It was confirmed that the data controller would be ONS, and that the Section 251 approval for this work had been obtained by City University London on behalf of a collaborative group, which included City University London, ONS and Rob Gibson Associates.<br><br>It was explained that ONS intended to link the identifiable data provided with birth and mortality data, and then data clean this linked dataset to remove identifiers and store it within a secure ONS environment. City University London would then be able to access the data within this secure environment. DAAG were also asked to consider the possibility of this data being made available to other researchers for other research projects.<br><br>**Discussion:** The Group agreed that the majority of the queries they had previously raised had been addressed by the response provided, and it was agreed that the application summary should be updated to include the information provided in this response. It was also agreed that the application summary should be updated to include the Data Protection Act (DPA) registration details of City University London as well as ONS, and to clearly state that ONS would be the data controller.<br><br>A query was raised regarding whether the Section 251 approval was felt to appropriately cover the work described, and it was confirmed that this was the case.<br><br>The Group discussed the importance of fair processing, and it was noted that this had been considered by HRA CAG as part of the Section 251 approval process. It was agreed that HRA CAG should be asked to confirm that the Section 251 approval in place did not have any outstanding conditions of support relating to fair processing.<br><br>It was noted that a response had not yet been received regarding whether the Section 251 approval covered Patient Episode Database for Wales (PEDW) data, but it was confirmed that this was not pertinent to the HES data requested from the HSCIC.<br><br>The Group discussed research intermediaries, where an applicant requested data that would then be made available to other organisations or researchers for use in different projects. The Clinical Practice Research Datalink (CPRD) was cited as one example of this model. It was suggested that this topic could be discussed in more detail at a future DAAG training day. At |

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| | this stage it was not felt to be appropriate to recommend approval of the reuse of the data requested for other purposes.<br><br>**Outcome:** Recommendation to approve the use of data by City University for this specific purpose only. Subject to confirmation by HRA CAG that section 251 approval has no outstanding conditions of support related to fair processing, and subject to inclusion of City University DPA registration and security assurance in application form. Also subject to updating application form with response provided by email. Reuse of data for other purposes not recommended for approval.<br><br>Alder Hey Children's Hospital NHS Foundation Trust (IAO: Garry Coleman) NIC-243726-F1K2N<br><br>**Application summary:** This application was for a bespoke extraction of pseudonymised, non-sensitive HES data for a cohort of patients within a specific age range who had undergone certain surgical procedures. The data would be used to analyse the long term outcomes of key conditions treated in paediatric surgery.<br><br>**Discussion:** The Group queried a reference in the application summary to this research being funded by charitable funds; it was confirmed that the data provided would not be used for any commercial purposes. A further query was raised regarding whether patient consent should be required, but it was confirmed that no identifiable data would be provided to the applicant. DAAG expressed their support for this work.<br><br>**Outcome:** Recommendation to approve |
| **3** | **Any other business**<br><br>The Group noted that Alan Hassey would be unable to attend the 2 December 2014 DAAG meeting, and it was agreed that Sean Kirwan would chair that meeting.<br><br>There was a discussion of the draft updated application summary template. Several comments were made, including that the application form should state who the data controller(s) and data processor(s) were, that the difference between requests for extension, renewal and amendments should be more clearly explained, that applicants could be asked to demonstrate compliance with the ICO code of practice on privacy notices, and that applicants should be able to list multiple organisations in the 'security assurances' section. It was agreed that a further updated draft would be brought to the following DAAG meeting, and following approval applicants would be required to use this updated form from January 2015.<br><br>**Action:** Dickie Langley to bring updated draft application summary template to next DAAG meeting for approval. |

**Summary of Open Actions**

| Date raised | Action | Owner | Updates | Status |
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| 25/11/2014 | Dickie Langley to bring updated draft application summary template to next DAAG meeting for approval. | Dickie Langley | | Open |
| 18/11/2014 | DAAG Chair to circulate the response received for the Monitor CHKS application (NIC-281120-P8S3P). | Alan Hassey | 25/11/14: This had been circulated and the action was closed. | Closed |
| 18/11/2014 | Alex Bell to provide a report on applications considered out of committee. | Alex Bell | 25/11/14: This had been circulated and the action was closed. | Closed |
| 18/11/2014 | DAAG Chair to circulate the response received about PHE retaining data derived from HES. | Alan Hassey | 25/11/14: This had been circulated and the action was 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.<br>25/11/14: No update available. | Open |
| 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). | Dawn Foster | 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.<br>25/11/14: No update available. | Open |
| 28/10/2014 | Garry Coleman to speak to Stuart Richardson regarding whether the Local Patient ID field is used in SUS. | Garry Coleman | 04/11/14: Ongoing.<br>12/11/14: Formal confirmation requested that LOPATID is not included in SUS.<br>18/11/14: No update available. | Closed |

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| | | | 25/11/14: This action had been completed, and confirmation received that LOPATID was not included in SUS. Response to be circulated to DAAG members for information, and action closed. | |
| 22/10/2014 | Diane Pryce to circulate questions regarding fair processing and consider including this in the application summary template. | Diane Pryce | 28/10/14: Ongoing. DP has raised this with colleagues who are drafting application summary template.<br>04/11/14: Ongoing.<br>12/11/14: Ongoing.<br>18/11/14: A meeting had been scheduled to discuss this, and an update would be provided at the next DAAG meeting.<br>25/11/14: An updated application summary template was provided for discussion. Action closed. | Closed |