# Data Access Advisory Group (DAAG)

## Minutes of meeting held 6 October 2015

**Members:** Joanne Bailey, John Craven, Eve Sariyiannidou

**In attendance:** Frances Hancox, Vicki Williams, David Evans, Susan Milner, Diane Pryce, Jen Donald, Gaynor Dalton, Dave Cronin, Stuart Richardson, Paula Moss

**Apologies:** Alan Hassey, James Wilson, Dawn Foster, Patrick Coyle, Sean Kirwan

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| **1** | In the absence of the Acting Chair it was agreed that Joanne Bailey would chair the meeting.<br><br>**Declaration of interests**<br><br>No conflicts of interest relevant to this meeting's agenda were declared.<br><br>**Review of previous minutes and actions**<br><br>The minutes of the 29 September 2015 meeting were reviewed and agreed as an accurate record.<br><br>Action updates were provided (see table on page 7).<br><br>**Out of committee recommendations**<br><br>No recommendations had been made out of committee since the 29 September 2015 meeting. |
| **2**<br><br>**2.1** | **Data applications**<br><br><u>Institute of Occupational Medicine - Hard Metals (Presenter: Jen Donald) NIC-335133-K2Y2S</u><br><br>**Application:** This application for identifiable Office for National Statistics (ONS) mortality data as well as Personal Demographics Service data had previously been presented to DAAG for advice at the 7 July 2015 meeting. Clarification had been requested regarding the different phases of the study, alignment with the applicant's section 251 support, the anticipated health benefits, why demographic data was required, how outputs would be disseminated and what fair processing activities had been undertaken. Additional information about these points had now been provided, and DAAG were informed that demographic data would be required in order to improve data quality and increase the number of participants that could be traced in future. It was noted that the applicant intended to share de-identified mortality data with the University of Pittsburgh in the USA, and the HSCIC had produced an information governance (IG) risk assessment regarding this.<br><br>**Discussion:** DAAG were informed that the flow of de-identified data to the University of Pittsburgh had been approved by the Office for National Statistics (ONS) during the Approved Researcher and Microdata Release Panel application process. A query was raised regarding the use of the term 'de-identified' rather than describing the data shared with the University of Pittsburgh as either anonymised or pseudonymised. DAAG were informed that the HSCIC would classify the data shared as pseudonymised, but that the pseudonymisation key would not be shared and the IG risk assessment stated that the risk in sharing this data was either low or very low. This risk assessment also noted that only data about deceased individuals would be shared. A reference to linking this pseudonymised data was queried, as it was unclear whether this could increase the |

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| | risk of reidentification, but it was clarified that this referred to combining data with similar datasets from different countries rather than linking additional data for individual records.<br><br>DAAG noted the applicant's efforts to inform workers about this use of data, but suggested that it would be helpful if the applicant also made information about the study available online.<br><br>The request for demographic data was discussed, and it was clarified that this was a one-off request in order to update contact information rather than an ongoing request for regular updates. DAAG discussed whether this use of data would be expected by the participants, as it was noted that the participant information leaflet referred to only sharing data with third parties 'for the purposes of obtaining details regarding death for those participants that may have died', and on balance it was agreed that this use of demographic data to keep details up to date should not be unexpected. It was also noted that if the applicant did not receive demographic data then this would have a negative impact on the study as a whole, and this was felt that this would be disproportionate.<br><br>A reference in the application summary to results influencing the Health and Safety Executive was queried, and it was agreed that the application should include a commitment to share results with this agency to ensure that health benefits would be achieved.<br><br>DAAG agreed that the risk assessment provided had been helpful, but that in future it would be best if all similar documents could list the author and date or version number.<br><br>**Outcome:** Recommendation to approve, subject to the following caveat:<br>• The application summary should be updated to include a commitment that the applicant will provide results to the Health and Safety Executive.<br><br>DAAG suggested that the applicant should make information about the study available online for cohort members. |
| **2.2** | <u>Institute of Occupational Medicine - Rubber and Cable NIC-323309-L2G9T</u><br><br>**Application:** This application for identifiable Personal Demographics Service data, ONS mortality data and cancer registration data for a specific cohort of workers had previously been considered at the 7 July 2015 DAAG meeting, when DAAG had been unable to recommend approval. Additional details had now been provided to make the anticipated health benefits more explicit, to clarify the fair processing activities that had been undertaken via trade unions, to clarify the applicant's section 251 support, and to include all phases of the project. An IG risk assessment had been provided regarding the transfer of de-identified data to the International Agency for Research in Cancer (IARC), which indicated that the risk would be either low or very low.<br><br>**Discussion:** It was noted that only de-identified data would be shared with IARC, and that this de-identified data would remain within the EEA.<br><br>DAAG agreed that the additional information that had been provided was helpful, and welcomed the efforts of the applicant to feed back information about the study via trade unions. Given the age of the cohort and the likelihood that a large proportion would now be deceased, it was suggested that attempting to make direct contact with individuals would have been disproportionate.<br><br>DAAG noted that the applicant's section 251 annual review date was in the next month; it was confirmed that the applicant had submitted a renewal application to HRA CAG, and that CAG had indicated the section 251 support should be considered ongoing while the review process was underway. It was noted that if any concerns were raised as part of the annual review, the HSCIC would be made aware of this and it could be escalated as required. |

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| | **Outcome:** Recommendation to approve. |
| **2.3** | Genomics England – advice on consent (Presenter: Gaynor Dalton) NIC-361343-G9Z4S<br><br>**Application:** DAAG were asked to provide advice on the consent materials used by the 100,000 Genomes Project, ahead of an expected future application for identifiable Hospital Episode Statistics (HES) data for the consented cohort.<br><br>**Discussion:** A reference to consent materials having previously been reviewed by DAAG was queried, and it was clarified that DAAG had only discussed the study protocol at the 24 September 2014 meeting and consent materials had not been provided at that time.<br><br>DAAG noted that the DAIS team had suggested a number of changes that should be made to the consent materials, including to specifically refer to the involvement of the HSCIC and to describe the HSCIC data linkage more clearly. The applicant had indicated that re-contacting individuals with rare diseases who had already consented to participate could pose some privacy concerns.<br><br>DAAG considered the consent materials, and noted that while HES data was not referred to by name the participant information materials did explain that data about hospital stays would be used. DAAG agreed that the materials should be updated to specifically refer to the HSCIC's involvement to ensure that this was clear to participants, but it was suggested that this could be done through relatively minor changes such as adding the HSCIC to the statement regarding data 'held by the NHS, GPs and other bodies like local and national disease registries'. It was noted that the participant information stated that the participant's clinical team would discuss their consent with them every five years, and DAAG commended this commitment to maintain up to date consent.<br><br>DAAG agreed that it would be appropriate for the applicant to make prospective changes to the consent materials used for the ongoing recruitment, rather than attempting to re-contact all the individuals who had already provided consent over the past year. There was a suggestion that the applicant should update materials in a timely manner, given the ongoing recruitment.<br><br>There was some confusion regarding the draft website text that had been provided, as these appeared to be HSCIC webpages but DAAG noted that as the consent materials used to date had not referred to the HSCIC, it was unlikely participants would look for further information on the HSCIC website. It was agreed that further context would be required before DAAG could offer any advice on these draft webpages.<br><br>**Outcome:** DAAG advised that the participant information sheets should be updated prospectively to specifically refer to data received from the HSCIC, for example by amending the statement 'other bodies like local and national disease registries' to also list the HSCIC, and to state that data linkage will be carried out by the HSCIC. DAAG agreed that this should only require minor changes to the consent materials, and suggested that these changes should be made in a timely manner given the ongoing recruitment. |
| **2.4** | University College London (Presenter: Dave Cronin) NIC-346693-F2X1G<br><br>**Application:** This application had previously been discussed at the 15 September 2015 meeting, when DAAG had deferred making a recommendation pending clarification regarding the EU funded project, the legal basis for receipt of cancer registration data, the applicant's fair processing activities and clarification of data flows. Confirmation had now been provided that section 251 support provided the legal basis for use of cancer registration data. The updated application summary clarified the flow of pseudonymised data and clearly state that no data supplied by the HSCIC would be shared with third parties; rather the HSCIC data would be used to validate the self-reported data already held by the applicant, and only the variables derived from this data |

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| | validation would be made available to researchers. DAAG were informed that the applicant organisation's fair processing obligations had been discussed with the applicant, and that they would provide additional information for participants in their next annual newsletter.<br><br>**Discussion:** DAAG noted that the applicant intended to make pseudonymised data available to researchers, while the participant consent materials had only referred to making anonymised data available. While it was acknowledged that this would not include any data received from the HSCIC, DAAG emphasised the importance of fair processing and noted that the applicant intended to clarify this point in a future participant newsletter. It was also acknowledged that the data made available to researchers would be 'doubly pseudonymised' using a different key for each third party accessing data.<br><br>It was noted that there would be some delay before the next participant newsletter was issued, as this was done on an annual basis, and DAAG agreed that it was appropriate and proportionate for the applicant to include clarifications in the next annual newsletter rather than attempting to issue separate communication materials more quickly.<br><br>The use of mortality data was discussed, and it was noted that the participant information materials had previously referred to health status data being provided 'even after incapacity or death'. DAAG agreed that the applicant should include an update about the use of mortality data in the next participant newsletter to ensure that this was clear.<br><br>**Outcome:** Recommendation to approve.<br>DAAG agreed that the applicant had addressed the points raised at the 15 September 2015 meeting, and were now content for HSCIC data to be released for the purpose of validating the self-reported data and maintaining contact details. DAAG noted that the applicant would provide information about the data passed on to third parties, and the use of mortality data, in the next annual newsletter to participants. |
| **2.5** | <u>Knowsley CCG - Risk Stratification (Presenter: Stuart Richardson) NIC-364047-D2S6C</u><br><br>**Application:** This was a new application for Secondary Uses Service (SUS) data identifiable at the level of NHS number (weakly pseudonymised) under the section 251 support for risk stratification. Health Intelligence Ltd would act as data processor on behalf of the CCG and provide a risk stratification tool, which general practices could use to access data about patients registered at their practice. The CCG would only be able to access anonymised outputs. It was noted that both organisations held satisfactory IG Toolkit scores and had appropriate DPA registrations.<br><br>DAAG were informed that this application included a request for the applicant to retain historic SUS data, but that work was underway to clarify the legal basis for this data to be retained.<br><br>**Discussion:** DAAG queried the use of the phrase 'identifiable SUS data' in the application summary and suggested that this should more accurately refer to data identifiable at the level of NHS number.<br><br>A reference in the application summary to linking with primary care data was queried; it was clarified that this referred to processing that takes place within the risk stratification tool, and the application summary would be updated to more clearly explain this and to align the data flow diagram.<br><br>DAAG discussed the applicant's fair processing materials, and there were some concerns that a statement about not sharing patient data with third parties 'without your permission' could be considered misleading as this did not cover circumstances such as the use of section 251 support to provide a legal basis. DAAG suggested that the applicant should update their fair processing notice in line with the ICO Privacy Notices Code of Practice. |

**Outcome:** Recommendation to approve, subject to the following caveats:

- Confirmation of the legal basis for the applicant to retain historic SUS data.

It was agreed the application summary would be updated to clarify the use of primary care data within the risk stratification tool. DAAG advised that the applicant should improve their fair processing materials in line with the ICO Privacy Notices Code of Practice.

**2.6** Newham CCG (Presenter: Stuart Richardson) NIC- 366177-J6V4M

**Application:** This application was for pseudonymised SUS data to flow to the applicant in order to support the commissioning of health services. The applicant held a satisfactory IG Toolkit score and an appropriate DPA registration.

**Discussion:** A query was raised regarding a statement in the application summary regarding data received by Newham CCG being passed on to Newham CCG; it was noted that this was a typographical error and would be corrected.

DAAG noted that the applicant's DPA registration wording as reflected in the application summary was particularly clear and well written.

**Outcome:** Recommendation to approve.

**2.7** Enfield CCG stage one ASH (Presenter: Stuart Richardson) NIC-372021-N7Y6J

**Application:** This application was for SUS data identifiable at the level of NHS number (weakly pseudonymised) to support commissioning of health services, under the section 251 support for stage one accredited safe havens (ASH). Data would flow via North East London commissioning support unit (CSU) who would act as data processor on behalf of the CCG. Both organisations had achieved satisfactory IG Toolkit scores and held appropriate DPA registrations.

**Discussion:** No concerns were raised regarding the requested use of data. However, DAAG noted that the fair processing notice for the CCG did not state how patients could opt out and advised that the CCG should update this notice in line with the ICO Privacy Notices Code of Practice. A typographical error in the notice was also pointed out.

**Outcome:** Recommendation to approve.
DAAG advised that the applicant should update their fair processing materials to include details of how patients can opt out, as well as to correct a typo.

**2.8** University of Nottingham - The epidemiology of obstetric complications (Presenter: Dave Cronin) NIC-383714-V7G7Q

**Application:** DAAG had previously considered an application from the applicant at the 25 August 2015 meeting (NIC-330562-P8S0R) and had recommended approval subject to caveats, which had subsequently been met and agreed out of committee. However, it had now become apparent that the application should also have included a request for HES Critical Care data, in addition to the HES Admitted Patient Care and linked ONS data that were requested. An updated application form was therefore provided that now included the HES Critical Care data.

**Discussion:** DAAG noted that no substantive changes had been made to the application other than the addition of HES Critical Care data, and expressed their hope that quality assurance processes would be improved so that similar mistakes would not be made in future applications.

**Outcome:** Recommendation to approve.

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| **2.9** | University of Cambridge - Understanding the long-term effects of whole blood and platelet donation: a large demonstration study (Presenter: Dave Cronin) NIC-371239-J2S1R<br><br>**Application:** DAAG had previously considered on 16 December 2014 and recommended for approval an application from this applicant for HES data only, with the intention that linked ONS mortality data would be applied for once relevant ONS approvals had been obtained. The applicant had now obtained Approved Researcher accreditation and approval from the ONS Microdata Release Panel; this application was therefore to receive linked ONS data in addition to the HES data already requested as well as to extend the request for HES data for a further year.<br><br>**Discussion:** DAAG noted that the applicant's 251 support was due for annual review in the next month, and it appeared that HRA CAG had not been contacted for confirmation of whether or not the applicant's support should be considered to continue while the annual review was underway. In addition DAAG noted that HRA CAG had previously indicated that the applicant should update the information materials for participants, but no updated materials had been provided with this application. Some concerns were expressed about the fair processing materials provided, and it was agreed that the applicant should update these in line with the advice previously given by HRA CAG. In addition, DAAG noted that the applicant's Approved Researcher accreditation was shortly due to expire and that this would need to be renewed.<br><br>**Outcome:** Unable to recommend for approval.<br>• Confirmation was required of annual review of the applicant's section 251 support.<br>• The applicant should update fair processing materials in line with the comments previously raised by HRA CAG. |
| **3** | **Any other business**<br><br>No other business was raised. |

**Summary of Open Actions**

| Date raised | Action | Owner | Updates | Status |
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| 22/09/15 | To provide DAAG with additional information regarding local data flows through DSCROs, and a proposal for what governance should be in place for changes to these flows. | Kemi Adenubi | 06/10/15: Ongoing. | Open |
| 29/09/15 | University of York to be asked for clarification on their change of policy for providing access to data. | Steve Hudson | 06/10/15: This had been raised with Garry Coleman, and formal contact would be made with the University of York to request clarification. | Open |