

Data Access Advisory Group

Minutes of meeting held 16 September 2014

Members: Alan Hassey (Acting Chair), Patrick Coyle, Sean Kirwan, Eve Sariyiannidou

In attendance: Susan Milner, Alex Bell, Terry Hill, Frances Hancox (Secretariat), Garry Coleman, Paul Niblett (item 3), Sam Widdowfield (item 3), Jackie Gallagher (item 3), Jennifer Donald (item 3), Stuart Richardson (item 3)

Apologies: Dawn Foster (member), John Craven (member), Diane Pryce

1	<p>Review of previous minutes and actions</p> <p>The Group reviewed the minutes of the 9 September 2014 meeting, and a clarification was raised regarding the AstraZeneca application referred to on page 2. It was agreed that this would be updated prior to publication. Other than this, the minutes were agreed as an accurate record.</p> <p>Action updates were provided and recorded in the applications tracker. The possibility of replacing formal minutes with the applications tracker was raised.</p>
2	<p>Recommendations made out of committee</p> <p>No applications had been considered out of committee.</p>
3 3.1	<p>Data applications</p> <p><u>London School of Hygiene and Tropical Medicine - HALT IT (IAO: Garry Coleman) NIC-203382-Y7J2Y</u></p> <p>This application had first been discussed at the 7 May 2014 DAAG meeting (DAAG reference 070514-e1) and had been discussed at a number of subsequent meetings, including most recently the 9 September 2014 meeting when it had been approved subject to confirmation that data would not be shared outside the UK. The applicant had now confirmed that record level data would not be made available outside the UK, but that the aggregated outputs of this data would be made widely available. It was agreed that a statement regarding this, and the fact that data would not be shared with EU projects, should be included in the application summary. It was also noted that the consent form provided stated that data would be shared worldwide, and that this should be updated if recruitment were still ongoing.</p> <p>A query was raised about the potential for this data to be used commercially, as the application summary appeared to contradict itself on this point. It was noted that as the data received would include mortality data from the Office of National Statistics (ONS), this data could not be used for commercial purposes unless ONS had agreed to this. The Group asked for this to be clarified, and noted that if data was to be used for commercial purposes then further detail would be required on what these purposes would entail.</p> <p>It was agreed that a DAAG member would discuss the points raised in more detail with the IAO outside the meeting.</p> <p>Outcome: Recommendation to approve subject to caveats</p>

<p>3.2</p>	<p><u>Public Health England – NCMP (Presenter: Paul Nibblet on behalf of Information Asset Owner (IAO) Steve Webster) NIC-291616-M5L4J</u></p> <p>This application was to share the National Child Measurement Programme (NCMP) dataset with Public Health England (PHE) and had previously been considered at the 9 September 2014 DAAG meeting.</p> <p>Further details had been requested regarding the Information Governance (IG) Toolkit score achieved by PHE, and how the action plan to improve this score was progressing, in addition to clarifying the intended data retention period. It was confirmed that the data sharing agreement for this application would only be valid until the end of January 2015. An update was provided on the IG Toolkit score, and it was noted that some progress had been made and additional work to improve the score was still underway.</p> <p>It was agreed that the application should be updated to remove references to specific DAAG members, and instead reflect the advice of DAAG as a group. The application would also be updated to include the details regarding the PHE IG Toolkit score that had been provided by email.</p> <p>Outcome: Recommendation to approve subject to application form being updated to include the information provided</p> <p>Jackie Gallagher and Jennifer Donald joined the meeting at this point.</p>
<p>3.3</p>	<p><u>University of East Anglia – The ‘Scoop’ Study (IAO: Garry Coleman) NIC-177785-4DK</u></p> <p>This application had been discussed at the 30 July 2014 and 9 September 2014 meetings, and further details had been requested regarding the applicant’s security policy. The applicant had provided some information regarding this but further details had been requested, and it was noted that a recommendation from DAAG was not sought at this stage.</p> <p>The Group expressed some concerns about the difficulty in interpreting IG Toolkit scores and other information about security policies, and it was suggested that it could be helpful for more information security expertise to be made available to DAAG.</p> <p>Action: Alan to update DAAG on discussions around the review of security arrangements and how this should be reflected in DAAG applications.</p> <p>It was agreed that further information would be brought to DAAG for consideration at a future meeting, along with again providing copies of the relevant consent materials.</p> <p>Outcome: Further information requested for review at a future meeting</p>
<p>3.4</p>	<p><u>Barts Health NHS Trust (IAO: Jackie Gallagher) NIC-226652-NIG2N</u></p> <p>This application had previously been discussed at the 4 June 2014 DAAG meeting (DAAG reference MR1356) and DAAG had requested further information from the applicant regarding what data would be shared with a third party organisation (PHAST) for analysis. The applicant had now confirmed that all identifiers would be removed from this data prior to sharing, including date of death which would be replaced with fact of death.</p> <p>A reference within the application form to supplying ‘full patient identifiers’ was queried. It was confirmed that this had meant that identifiers would be provided to the HSCIC in order to carry out the required flagging, but that the output provided would be stripped of identifiers. It was agreed that the application form should be updated to clarify this.</p>

3.5	<p>A query was raised regarding whether consent would be sought for the individuals included in the audit who were still alive. It was noted that the Health Research Authority Confidentiality Advisory Group (HRA CAG) had confirmed that section 251 support was not required to access data relating to the individuals who had died, and it was also suggested that the applicant would be entitled to hold identifying data for the individuals in question due to the legitimate clinical relationship with individuals who had been invited to attend screening. The need for the applicant to meet their fair processing obligations under the Data Protection Act 1998 (DPA) was raised.</p> <p>The applicant's current IG Toolkit score was queried, as only the target score for the current year was provided in the application form. It was also noted that the DPA registration expiry date was not included, and this was requested.</p> <p>Outcome: Unable to recommend for approval</p> <p>Jackie Gallagher and Jennifer Donald subsequently left the meeting, and Stuart Richardson joined the meeting.</p> <p><u>Clarity Informatics (IAO: Stuart Richardson) NIC-241549-H4P5V</u></p> <p>This had previously been discussed at the 20 August 2014 DAAG meeting, and DAAG had been unable to recommend it for approval. Additional information had been requested regarding the purpose for which data would be used and why data from the whole population would be required, and confirmation had been sought that the data received would not be linked with other data held by the applicant.</p> <p>Further information had been provided regarding the purpose of the application and it was confirmed that the data would not be linked with other data held by the applicant. It was also confirmed that the applicant did not initially require data for the whole population, but requested data for specific hospital trusts across the country based on which trusts were currently customers of their service, and data for additional trusts would be requested as more trusts became customers. It was noted that the applicant sought an agreement in principle that they would be able to receive the data for these additional trusts at a later date. Concerns were raised around the potential implications of this type of agreement in principle, and whether it would be considered a pre-approval of applications prior to receiving full details of the particulars involved. It was suggested that this agreement in principle had been requested due to the need for organisations to have access to this data in order to be able to participate in certain NHS tender processes, and the Group acknowledged the need to enable organisations to provide services of this type to the NHS. The need to consider public opinion of commercial uses of data was also raised.</p> <p>Additional concerns were raised about the stated purpose of the application, as it was felt that not enough details were provided on precisely how the data requested would be used. It was noted that some additional information on this had been provided by email, but it was agreed that this additional detail would need to be incorporated into the application form to ensure that this would also be reflected in the data sharing agreement between the HSCIC and the applicant.</p> <p>Outcome: Unable to recommend for approval</p>
4	<p>DAAG Application Summary</p> <p>The Group discussed a new draft application summary form template for DAAG application summaries, and the importance of ensuring that all applications would use the same form was emphasised. It was agreed that members would provide feedback on the form by email and that the new form would begin to be used from the 29 September 2014 meeting onwards.</p>

5	<p data-bbox="264 165 542 201">Any other business</p> <p data-bbox="264 232 1493 302">The Group were informed of work taking place within the HSCIC to ensure that patient preferences regarding the sharing of data from their clinical records would be respected.</p> <p data-bbox="264 333 783 369">No items of other business were raised.</p>
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