

Data Access Advisory Group

Minutes of meeting held 24 September 2014

Members: Alan Hassey (Acting Chair), Sean Kirwan, Eve Sariyannidou, John Craven

In attendance: Alex Bell, Terry Hill, Garry Coleman, Stuart Richardson, Peter Hall, Simon Gray (agenda item 4), Frances Hancox (Secretariat),

Apologies: Dawn Foster (member), Patrick Coyle (member)

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| 1 | <p>Review of previous minutes and actions</p> <p>The minutes of the 16 September 2014 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided and recorded in the applications tracker.</p> <p>There was a discussion of whether the DAAG applications tracker and action list should be published following each meeting, as a replacement for producing formal minutes of each meeting. Members raised the need to provide information in a suitably accessible manner for members of the public, and it was suggested that in addition to recording DAAG recommendations and details of applications the tracker should also record requests for advice on consent materials and details of who had been present when each recommendation was made.</p> <p>It was agreed that the Group would be provided with both formal minutes and the applications tracker for the current meeting, and feedback would be provided on whether publishing the tracker alone would be likely to meet the requirements of the general public.</p> <p>The need to ensure that details included in the applications tracker were consistent with the wider organisational register of data releases was raised.</p> |
| 2 2.1 | <p>Data applications</p> <p><u>Brent CCG (IAO: Stuart Richardson) NIC-267444-F8N4W</u></p> <p>This application was for Secondary Uses Service (SUS), Choose and Book, Population and Analysis Reporting (PARS) and cancer waiting times data in a weakly pseudonymised form based on NHS number. This data was requested under the Health Research Authority Confidential Advisory Group's section 251 approval for the transfer of data to commissioning organisation Accredited Safe Havens, and it was noted that data would be securely transferred from the Data Services for Commissioners Regional Office. It was agreed that for any free text field that was deemed to be at risk of including identifiable data, these fields should only be shared once they had undergone either data cleaning or anonymisation to remove any identifiable data.</p> <p>A query was raised regarding who would be able to access the data provided once it was held within the Accredited Safe Haven. It was agreed that the applicant should be asked to provide details of what roles within the organisation would be able to access the data and that this should also be made clear for any future applications, including renewal applications from other CCGs. It was also agreed that this should be specified in the Data Sharing Agreement between the HSCIC and the applicant.</p> <p>Outcome: Recommendation to approve subject to the applicant providing details of which</p> |

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| <p>3.2</p> | <p>roles within the organisation will have access to the data</p> <p><u>Genomics England – request for advice (IAO: Garry Coleman)</u></p> <p>Genomics England had requested feedback on their project protocol document and advice on their approach to obtaining patient consent. No data was requested at this stage, although it was noted that the applicant intended to submit an application for data at a later date.</p> <p>Martin Dennys, who had been seconded from HSCIC to Genomics England, joined the meeting to provide an overview of the project. The Group were asked to consider whether the document provided sufficiently explained the role of the HSCIC, whether the consent materials were appropriate, and whether there were any particular comments around the potential for data to be used commercially by third party organisations.</p> <p>The Group discussed the need for Genomics England to clearly communicate the potential benefits of this project, particularly given the potential sensitivities around the use of genetic information. Another point raised was the need to ensure that any results fed back to participants would be handled sensitively.</p> <p>Concerns were raised about the intention to ask individuals to consent to the use of their medical records for the whole of their lifetime, due to the need to provide details about the specific purposes for which data would be used and the likelihood that these purposes would change over time, as would the organisations making use of data. It was noted that any future changes in how data would be used would need to be communicated to participants and consent would likely need to be updated. The potential difficulties around monitoring access to and use of data by a wide range of organisations for varying purposes was raised, and the need for a clear governance process around access to data was emphasised. It was also noted that given the focus on rare diseases, the potential for individuals to be re-identified from the data collected could be higher than for more common diseases.</p> <p>Information security arrangements were queried, and it was noted that the applicant would complete the Information Governance Toolkit each year and aim to attain a satisfactory score (level 2). The need to have a mechanism in place to notify participants of any data breaches was raised.</p> <p>The Group noted that a copy of the patient consent form had not been provided and noted that they would require sight of this before making any recommendation about the provision of data.</p> <p>It was agreed that additional feedback would be provided to the applicant by email; following this a revised protocol would be submitted for DAAG members to consider out of committee, ahead of a potential application for data being brought back to a future meeting.</p> <p>Martin Dennys left the meeting.</p> |
| <p>3</p> | <p>Recommendations made out of committee</p> <p><u>Imperial College</u></p> <p>This application had been considered out of committee by the Acting Chair and two independent DAAG members, and had been recommended for approval.</p> <p>Garry Coleman and Stuart Richardson left the meeting at this point.</p> |

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| 4 | <p>DAAG Application Summary</p> <p>Simon Gray joined the meeting and provided an informal update on the DAAG application process and documentation.</p> <p>It was agreed that a further training day for new DAAG members should be scheduled to take place in approximately one month.</p> |
| 5 | <p>Any other business</p> <p>No items of other business were raised.</p> |