Data Access Advisory Group

Minutes of meeting held 29 September 2014

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

Sariyiannidou, John Craven

In attendance: Alex Bell, Garry Coleman, Stuart Richardson, Jim Duffy, Jackie

Gallagher, Frances Hancox

Apologies: None

1 Review of previous minutes and actions

The minutes of the 24 September 2014 meeting were reviewed and agreed as an accurate record.

Action updates were provided and recorded in the applications tracker.

2 Data applications

2.3 Clarity Informatics (IAO: Stuart Richardson) NIC-241549-H4P5V

This application had previously been discussed at the 20 August 2014 and 16 September 2014 DAAG meetings, and DAAG had been unable to recommend it for approval. Concerns had been raised about the fact that the purpose had not been clearly stated in the application form, and the applicant was asked to provide justification for why national data would be required rather than local as well as reassurances that the data received would not be linked with any other data held by the applicant.

The application form had been updated to include additional details of the purpose for which data would be used; specifically data would be used for the Clarity Informatics quality improvement service, using clinical audit to review patient care and working with clinicians to define metrics and indicators. It was confirmed that only pseudonymised data would be provided including the sensitive field Consultant Code in a pseudonymised form.

The applicant had now requested data from only specific geographic areas where they were under contract to provide services, rather than requesting data for the whole country, and it was confirmed that the applicant had committed not to link the data received with any other data they held.

The Group confirmed that they were content with the additional information provided. It was noted that the applicant had previously sought an agreement in principle that they would be able to receive the data for additional trusts at a later date, but this was no longer sought.

Outcome: Recommendation to approve

2.1 and 2.2

<u>National Audit of Cardiac Rehabilitation – HSCIC Clinical Audit Support Unit (IAO: Jackie Gallagher) NIC-288475-P3C3V</u> and <u>University of York (Presenter: Jim Duffy) NIC-291029-X7S8K</u>

Jackie Gallagher and Jim Duffy joined the meeting for these two applications.

It was agreed that the two applications should be considered together; the first application

was for an extract of the National Audit of Cardiac Rehabilitation (NACR) dataset to be used by the HSCIC to trace GP Practice codes that were missing from the data and add Responsible CCG and Strategic Clinical Network codes, while the second application was for a pseudonymised version of this data to be shared with the University of York.

The Group queried how the data would be pseudonymised, and it was explained that all identifiers would be removed from the data and a pseudonymised identifier would be added, meaning that the University of York team would not have access to any identifiers.

The Group also queried a reference in the first application form to 'list cleaning on an annual basis', and asked whether this application would be brought back for regular review. It was confirmed that the ongoing provision of data would be dependent on the renewal of the section 251 approval by the Health Research Authority Confidentiality Advisory Group (HRA CAG), which would be reviewed on an annual basis. It was agreed that the application should be updated to clarify that annual list cleaning would be dependent on the annual review of section 251 approval by HRA CAG.

A query was raised regarding a reference within the papers provided to the possibility of automatically validating NHS numbers at local level using the Personal Demographics Service rather than the HSCIC using identifiers such as patient name, but it was noted that this was not yet technically possible.

The applicant was asked to confirm how they would meet the fair processing requirements under the Data Protection Act 1998 (DPA), including how patients would be informed that data would be used in this way. It was stated that patients would be asked to complete a Patient Reported Outcome Measures (PROMs) questionnaire and that this would include details of the NACR project. The Group agreed that the application should be updated to include details of how fair processing requirements would be met.

It was noted that the British Heart Foundation had funded this audit and would act as data controller, and a query was raised regarding the DPA registration of the British Heart Foundation and whether it included the data processing that had been requested. It was agreed that the DPA registration details for both the HSCIC and the British Heart Foundation should be included in the application form.

Outcomes: Unable to recommend for approval

It was agreed that both applications would be updated and brought back together to a subsequent DAAG meeting.

5 Any other business

It was noted that the Acting DAAG Chair would be unable to attend the 14 October 2014 meeting, and the members were asked to elect one member to act as Chair for that meeting.