

Data Access Advisory Group

Minutes of meeting held 26 June 2014

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

In attendance: Susan Milner, Diane Pryce, Frances Hancox (Secretariat), Alyson Whitmarsh (agenda item 260614-d), Garry Coleman (agenda item 260614-e)

Apologies: None

260614-a	<p>Welcome</p> <p>The Acting Chair welcomed the attendees to the meeting.</p>
260614-b	<p>Minutes of the previous meeting</p> <p>The minutes of the 6 June 2014 meeting were discussed, and two points of accuracy were raised. It was agreed that these would be corrected, and other that this the minutes were agreed as an accurate record.</p>
260614-c	<p>Matters Arising</p> <p>(a) Overview of outstanding actions</p> <ul style="list-style-type: none">• 130514-c1: <i>Members to provide feedback on how more applications might be managed.</i> <p>Feedback had been provided to the Acting Chair, and this would be discussed under agenda item 260614-f.</p> <ul style="list-style-type: none">• 130514-c2: <i>RL to raise with Simon Gray the requirement to have another meeting/workshop to discuss how the DAAG workload could potentially be managed and invite key participants to attend.</i> <p>It was suggested that this should be discussed under agenda item 260614-f.</p> <ul style="list-style-type: none">• 040614-d1: <i>Diane Pryce to confirm whether there were any additional outstanding queries regarding the UK Biobank application (040614-e).</i> <p>It was confirmed that there were no outstanding queries.</p> <p>(b) Overview of outstanding applications</p> <p><u>070514-e1: The HALT-IT Trial, London School of Hygiene and Tropical Medicine</u></p> <p>A letter had been sent to the applicant requesting further information, and the response had been circulated to the Group. The Group were content with the updated consent wording required. There was also a discussion of the fact that the applicant intended to share some data outside the UK, and that the applicant had stated it would not be possible to identify patients from the data that was shared. The Group agreed that the applicant should be asked to confirm that the data shared would be fully anonymised to the Information Commissioner's Office (ICO) standard, and if this was not the case then further details should be requested around what safeguards would be in place.</p>

	<p><u>191113-d1: University of Sheffield</u></p> <p>An outcome letter had been sent to the applicant some time ago, but no response had yet been received.</p> <p><u>070514-e2: Choosing Healthcare Options in Chronic Care Emergencies (CHOICE) quantitative study, Manchester Mental Health & Social Care Trust</u></p> <p>The applicant had been contacted as they had not responded to the DAAG letter. The customer advised that they had withdrawn their request.</p> <p>Outcome: Request closed.</p> <p>(c) Recommendations made out of committee</p> <p><u>260614-c1: PHE (Surveillance)</u></p> <p>This application from Public Health England (PHE) for Hospital Episode Statistics (HES) data had been considered out of committee due to the urgency involved and the potential for clinical safety issues to arise. The Group had been informed of this by email, and it was noted that making recommendations out of committee would continue to be avoided unless there were exceptional circumstances.</p>
<p>260614-d</p>	<p>Clinical audit applications</p> <p>Alyson Whitmarsh joined the meeting for this agenda item.</p> <p>It was stated that all the audits for consideration at this meeting were commissioned on behalf of the Health Quality Improvement Partnership (HQIP).</p> <p><u>260614-d1: Head and Neck Cancer Audit</u></p> <p>The first application discussed was to link head and neck cancer audit data with HES data for analysis of patient outcomes by the HSCIC clinical audit team.</p> <p>It was confirmed that Section 251 approval was in place for this audit until the end of 2014, although it was suggested that the applicants should consider whether there could be any other legal basis for this work for future years. The Group agreed the importance of this work, and that it was in the public interest to proceed.</p> <p>Outcome: Recommendation to approve</p> <p><u>260614-d3: National Diabetes Audit</u></p> <p>This application was to link data from the previous year's National Diabetes Audit to HES data. A query was raised regarding the collection of general practice data as part of the audit, as it was noted that some of this data had been collected through Apollo and some concerns had been raised regarding whether general practices had been fully informed of these data extractions. It was noted that in future years it was hoped this data could be extracted through GPES instead, but that this had not yet been possible. In addition it was noted that work was underway to explore whether the Health and Social Care Act 2012 could provide an alternative legislative basis for these audits, but until this work had been completed Section 251 approval was in place.</p> <p>Outcome: Recommendation to approve</p>

	<p><u>260614-d2: National Bowel Cancer Audit</u></p> <p>This application was to link HES data to the audit data already held and then share this linked data with the Royal College of Surgeons for further analysis. It was noted that Section 251 approval was in place for this data. The Group were informed that a data sharing agreement was currently in place to share the linked data with the Royal College of Surgeons, and that this had been covered in the existing Section 251 approval.</p> <p>Outcome: Recommendation to approve</p> <p><u>260614-d4: OG Cancer Audit</u></p> <p>The Group were informed that this application was also to link HES data with audit data and then share this linked data with the Royal College of Surgeons, although it was noted that there was not currently a data sharing agreement in place with the Royal College of Surgeons for this particular audit. It was noted that Section 251 approval was in place, and the Group were content to recommend the application for approval.</p> <p>Outcome: Recommendation to approve</p> <p>There was a discussion around the plan for upcoming clinical audit applications to be brought to DAAG, and it was noted that there would be a number of upcoming applications. It was noted that these would be tracked through the new application tracker once this was available.</p>
<p>260614-e</p>	<p>Hospital Episode Statistics applications</p> <p>Garry Coleman joined the meeting for this agenda item.</p> <p><u>260614-e1: PHE – National Drug Treatment Monitoring System</u></p> <p>The applicant had requested feedback on their proposed consent model, with the intention of later requesting HES data for the participants who provided their consent. A number of help sheets were provided along with an example consent form, and it was stated that the help sheets would be used by the professionals asking patients for their consent. The Group were told that based on this consent the HSCIC would be provided with the date of birth, sex and partial postcode for participants, with the full postcode being included if patients had consented to this.</p> <p>The Group did not feel that the example consent form provided was appropriate, as it was felt to be too vague and could potentially mislead patients regarding how their data would be used. It was noted that the consent form referred to patients' right to object, but did not provide details of how to do so. It was suggested that the applicant should be asked to amend their consent form to include the recommended consent wording, and the HSCIC should offer to support the applicant in re-writing the consent form if required.</p> <p>Outcome: Unable to recommend to approve</p> <p><u>260614-e2: PHE – Diagnostic Imaging Dataset (DID)</u></p> <p>This application was for a six month extension of a previous data sharing agreement between the HSCIC and the Eastern Cancer Registry, now part of PHE, to receive DID data for linkage with cancer registration data. It was noted that the application had Section 251 approval.</p> <p>There was a discussion around PHE's Information Governance (IG) Toolkit score and it was noted that PHE had submitted an action plan to improve their score, which had now been approved. In addition it was noted that some areas within PHE had higher IG Toolkit scores</p>

than the overall organisation score, and the team that would be holding the data requested had achieved a satisfactory score.

Outcome: Recommendation to approve

260614-e3: PHE – HES/PROMS

This application was for HES, Office of National Statistics (ONS) mortality and Patient Reported Outcome Measures (PROMs) linked data for use in a specific research project around reducing the risk of healthcare acquired infection following a hip replacement. The applicant had previously had a data sharing agreement in place to receive this data, and as this agreement had now expired a six month extension was requested. It was confirmed that ONS approval was in place.

It was agreed that the applicant should be asked to confirm that any data shared outside the EU would be anonymised to the ICO standard, and subject to this and to confirmation of Section 251 approval the Group were content to recommend the application for approval.

Outcome: Recommendation to approve subject to confirmation of Section 251 renewal and confirmation that data shared outside the EU will be anonymised to ICO standard

260614-e4: PHE – LAPH Leicestershire

Both this application and the following application (260214-e5) were for PHE to provide pseudonymised, non-sensitive HES data to Local Authorities' public health teams.

Some concerns were raised around the proposal for this data to be received by a Data Services for Commissioners Regional Office (DSCRO) on behalf of the Local Authority, as it was felt that this might not be appropriate and the application paper provided did not provide a rationale for this. It was stated that the DSCRO had achieved a higher IG Toolkit score than the Local Authority and that the DSCRO also had more appropriate capabilities and expertise in handling this data. However, there were concerns about the fact that DSCROs were hosted by the HSCIC and whether this type of work would fall within their future functions, and it was noted that this had been raised with the HSCIC Caldicott Guardian and the Senior Information Risk Owner (SIRO). It was agreed that a response from the HSCIC Caldicott Guardian and SIRO would be required before the Group could recommend this application for approval.

Outcome: Unable to recommend for approval

260614-e5: PHE – LAPH Lincolnshire

As with the previous application, this application was for PHE to provide HES data to a Local Authority – in this case, Lincolnshire.

A query was raised regarding the list of data requested, and whether this included any sensitive fields. It was confirmed that a number of additional fields were included in addition to the standard HES extract, but that none of these were considered sensitive.

The Group noted that this would potentially be the first time that such a large amount of patient level health data would be shared with Local Authorities, and the importance of a robust data sharing agreement was emphasised. It was agreed that for this application and any similar Local Authority applications, the new HSCIC data sharing agreement should be used as this was felt to be more robust.

Outcome: Recommendation to approve subject to confirmation that the updated data sharing agreement will be used

One other application from PHE was raised, and it was noted that this had not been included

	<p>on the DAAG agenda circulated. As the meeting papers did not seem to be available, it was suggested that this should be re-circulated and discussed either out of committee or at the next meeting.</p> <p><u>260614-e6: University of Birmingham - PD MED - An assessment of the relative cost-effectiveness of different classes of drugs for Parkinson's disease</u></p> <p>For this application it was proposed that the HSCIC to link cohort data from an active study (MR785) to HES data and provide the pseudonymised data back to the applicant. It was noted that the study had gained patient consent from participants, but that it was felt that this was not sufficient for the data requested and Section 251 approval had also been obtained. This Section 251 approval was due for renewal, and the HRA Confidentiality Advisory Group (CAG) had confirmed that the application for renewal was currently being processed.</p> <p>Outcome: Recommendation to approve subject to Section 251 renewal</p> <p><u>260614-e7: Imperial College London - Dr Foster Unit</u></p> <p>The applicant had requested an extension of their existing data sharing agreement so that they could continue to receive sensitive and identifiable HES data under their Section 251 approval. A sub license had previously been in place for Imperial College to share pseudonymised data with Dr Foster Intelligence, but this had expired and was under review. It was stated that the data received by the applicant would be used to produce HSMRs and mortality indicators.</p> <p>It was noted that the Section 251 approval for this data was due to expire at the end of July 2014, and that the applicant would be seeking renewal for this from HRA CAG. The Group agreed that they were content to recommend this application for approval, but that the applicant should be asked to confirm later in the year that their Section 251 approval had been renewed.</p> <p>Outcome: Recommendation to approve subject to confirmation of Section 251 renewal</p> <p><u>260614-e8: Methods Insight</u></p> <p>This application was from an information intermediary seeking to receive HES and ONS linked data, and it was noted that the applicant already received non-linked HES data. A data sharing agreement had been in place for the applicant to receive this data until the end of March 2014, and a six month extension was now requested to that agreement. It was confirmed that the organisation had achieved a satisfactory IG Toolkit score, and that ONS approval had been obtained.</p> <p>Outcome: Recommendation to approve</p>
260614-f	<p>Discussion: DAAG update, format and management of DAAG applications</p> <p>There was a discussion around the process for sharing DAAG meeting papers, and it was noted that a SharePoint site would be set up to host these papers. The need to avoid circulating late papers was agreed, and it was suggested that applicants should be given a cut-off date after which point no other papers could be submitted to a particular meeting.</p> <p>Plans for the future of DAAG were also discussed, including the importance of lay membership. The Group were invited to offer their comments and any suggestions on future arrangements.</p>

Summary of Open Actions

Reference	Action	Owner
130514-c1	Members to provide feedback on how more applications might be managed.	DAAG members
130514-c2	RL to raise with Simon Gray the requirement to have another meeting/workshop to discuss how the DAAG workload could potentially be managed and invite key participants to attend.	Richard Langley