

Data Access Advisory Group

Minutes of meeting held 20 August 2014

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

In attendance: Susan Milner, Frances Hancox (Secretariat), Alex Bell, Stuart Richardson (agenda items 200814-a to 200814-d), Garry Coleman (agenda items 200814-a to 200814-e), Jim Duffy (agenda items 200814-e to 200814-f)

Apologies: Sean Kirwan (member), John Craven (member), Diane Pryce

200814-a	<p>Welcome and introductions</p> <p>The Acting Chair welcomed the attendees to the meeting, and noted that Sean Kirwan, John Craven and Diane Pryce had sent apologies. It was noted that John Craven had supplied written comments on the applications scheduled for discussion at this meeting, and that these would be raised during the relevant discussion.</p>
200814-b	<p>Minutes of the previous meeting</p> <p>The Group reviewed the minutes of the 15 August 2014 meeting, and two minor corrections were raised. It was agreed that these two points would be corrected, and that the Acting Chair would approve the updated wording. Other than these two points, the minutes were agreed as an accurate record of the meeting.</p>
200814-c	<p>Matters Arising</p> <p>(a) Overview of outstanding actions</p> <ul style="list-style-type: none">• <i>300714-a1: Terry Hill to discuss with Andy Williams the suggestion that DAAG outcome letters should include a statement that the data received should not be used for any additional commercial purposes. AH to check progress on this with TH.</i> <p>A form of words had been agreed for use in DAAG outcome letters, and it was agreed that an amended version of this should also be included in the data sharing agreement template.</p> <ul style="list-style-type: none">• <i>300714-c2: Alan Hassey to discuss with Rob Shaw and Martin Severs the legal basis for sharing pseudonymised data and the potential implications of onward sharing of pseudonymised data with third party organisations.</i> <i>AH advised this had been discussed in meeting with new members earlier in the day and would provide a briefing note for PC/SK.</i> <p>It was confirmed that this briefing note had been shared with DAAG members. The legal basis for sharing pseudonymised data had been discussed with Rob Shaw and Martin Severs, and it was suggested that this should be seen as an interim position pending clarification of the role of the Health Research Authority Confidentiality Advisory Group (HRA CAG) later in the year.</p> <p>Discussions were also ongoing regarding the approach DAAG took to reviewing applications, and whether it might be appropriate for the group to consider examples of 'classes' of applications in detail with other applications in that class then being considered out of committee by the Acting Chair and independent members.</p>

	<ul style="list-style-type: none"> • <i>300714-h1: Simon Gray to look into how application processes in Scotland and England could be aligned, and consider discussing this with NHS Scotland. SG to be asked how he wishes to deal with this.</i> <p>It was suggested that discussions would be picked up following the Scottish referendum.</p> <ul style="list-style-type: none"> • <i>150814-h1: AH requested that September meetings be extended by 1 hour.</i> <p>This action had been completed and was closed.</p> <ul style="list-style-type: none"> • <i>150814-b1: Alan Hassey to write to Sam Smith confirming the outcome of discussions with the customer, that they had confirmed that they had ceased using the data for this purpose and to provide an update for the minutes.</i> <p>Alex Bell was asked to seek confirmation of this from Terry Hill, and share this with Sam Smith.</p> <p>(b) Overview of outstanding applications</p> <p><u>150814-d1: Nottingham City Clinical Commissioning Group</u></p> <p>A query had been raised regarding the Data Protection Act (DPA) registration for this applicant; it was confirmed that this had now been checked and was in date.</p> <p><u>150814-d2: Dudley Clinical Commissioning Group</u></p> <p>It was confirmed that the DPA registration for this applicant had also been checked and was in date. The Group had queried the use of the word ‘predominantly’ when listing the purposes for which data would be used, as this could create ambiguity, and it was confirmed that this word had now been removed to make it clear that the data would be used for commissioning purposes only.</p> <p><u>150814-d3: Imperial College</u></p> <p>A query regarding this application had been raised with the HRA CAG secretariat; a response had not yet been received, but it was anticipated that this might be received the following week. The Group were asked whether this response could be considered by Chair’s action ahead of the next DAAG meeting, although it was noted that the Acting Chair would be on annual leave for the following two weeks. It was agreed that Dawn Foster could review the response on behalf of the Acting Chair, with input from Patrick Coyle and any other available DAAG members.</p> <p>For future meetings, it was suggested that the outstanding applications should be listed in the meeting agenda when this was circulated to members ahead of each meeting.</p> <p>(c) Recommendations made out of committee</p> <p>No recommendations had been made out of committee since the previous meeting.</p>
<p>200814-d</p>	<p>Data applications (IAO: Stuart Richardson)</p> <p><u>200814-d1: Camden CCG – Risk Stratification</u></p> <p>This application was for patient level Secondary Uses Service (SUS) data for residents of</p>

Camden CCG, in order for the CCG to use this data for risk stratification. Data would be securely transferred to the CCG, and would be retained by the CCG until the end of August 2014. It was proposed that any free text fields that were deemed to be at risk of including identifiable data should only be shared once they had undergone either data cleaning or anonymisation to remove any identifiable data.

It was noted that section 251 support was in place to cover this use of data by the CCG. A query was raised regarding whether this section 251 support included the flow of general practice data, and it was confirmed that this was the case.

Outcome: Recommendation to approve

200814-d2: Camden CCG – Accredited Safe Haven (ASH)

This application was for weakly pseudonymised SUS, SUS Population Analysis and Reporting System (PARS), Choose and Book, and cancer waiting times data which would be retained until the end of October 2014. This data would be received into the stage 1 accredited safe haven and be used by CCG staff to produce reports for the area, and it was confirmed that the weakly pseudonymised data item would be postcode. It was proposed that any free text fields that were deemed to be at risk of including identifiable data should only be shared once they had undergone either data cleaning or anonymisation to remove any identifiable data.

A query was raised around a statement within the application summary that the data would be used to deliver commissioning responsibilities 'including' a list of examples, as there were concerns that this could create ambiguity around other potential purposes for which the data could be used. It was agreed that for future applications, applicants should be asked to be as specific as possible about the purposes for which data would be used.

Outcome: Recommendation to approve

200814-d3: Clarity Informatics – SUS Payment by Results

The Group were informed that this was a new application for SUS Payment by Results data, which would be pseudonymised and would not contain any sensitive fields. The applicant had requested this data to carry out a feasibility study to examine the benefits of particular treatments. It was noted that this application was from a commercial organisation, but that the tools produced from this data would only be provided to NHS and social care organisations.

The Group briefly discussed the fact that a different form had been used for this application, and it was noted that work was underway to combine the two different application form templates into one standardised template.

The use of the term 'pseudonymised' was queried, and it was clarified that the data would include a randomly generated ID number for each record which would enable linkage but would not allow individuals to be identified.

The Group discussed the fact that SUS data from the whole population had been requested, and whether this was considered to be excessive for the purposes of the feasibility study described. It was suggested that this data would be used for benchmarking, in order to compare data from one NHS organisation against other similar organisations across the country, but there were still concerns around whether providing data for the full population for this purpose would be appropriate. One potential alternative suggested was that the applicant could apply to receive data from additional NHS organisations as new organisations became customers of their services, but it was also suggested that this might not be practical in part due to the commercial tender process for this type of work.

	<p>It was agreed that the applicant should be asked to provide further clarification on the specific purpose for which data would be used and justification for why data for the whole population was required, as well as confirming that the pseudonymised data received would not be combined with the patient identifiable data that the applicant already had access to.</p> <p>Outcome: Unable to recommend for approval</p> <p>Stuart Richardson left the meeting at this point.</p>
<p>200814-e</p>	<p>Data applications (IAO: Garry Coleman)</p> <p><u>200814-e1: CRAB Clinical Informatics Limited - resubmission</u></p> <p>This application was for historic Hospital Episode Statistics (HES) data in addition to ongoing access to monthly HES extracts, and it was noted that this data would be pseudonymised and include the sensitive item Consultant Code. The applicant intended to analyse this data and provide analysis to NHS trusts, and it was noted that role based access controls would be in place to manage who within the trust could access what level of data.</p> <p>Jim Duffy joined the meeting at this point.</p> <p>A query was raised regarding providing the applicant with access to data from all NHS trusts if they could potentially only be providing reports to one trust, and it was stated that this would be required to allow benchmarking against similar organisations across the country. There remained some concerns around the amount of data requested and whether this was justified based on the stated purpose of the application, as for example the Group did not feel that any justification was provided for whether historical data was required or whether a smaller section of more recent data would be sufficient. One option raised was whether it would be possible to give the applicant access to data for a selection of organisations now, and for additional access to data from other organisations to be provided as more organisations became customers of CRAB, although it was noted that this approach could create practical difficulties.</p> <p>The potential use of this service by the Care Quality Commission (CQC) and Monitor was raised, as it was noted that these organisations would most likely require access to national data rather than a subsection of data. It was noted that CQC and Monitor had existing agreements in place to hold HES data, meaning that one option might be for the CRAB IT tool to be used with the data they already held.</p> <p>The Group agreed that in principle they supported the proposed work, but there remained some concerns about whether the stated purpose justified the amount of data requested or whether a smaller amount of data would be sufficient. It was also suggested that the applicant should again be asked to confirm how small numbers would be managed, as it was not thought that this information had been provided.</p> <p>It was agreed that if the applicant provided a response prior to the next DAAG meeting, this could be considered by email out of committee by Dawn Foster on behalf of the Acting Chair with input from other DAAG members.</p> <p>Outcome: Unable to recommend for approval</p> <p><u>200814-e2: i4Health – Proposal for DAAG feedback</u></p> <p>The applicant had requested feedback on the proposed consent model, as well as wider feedback on the proposed project to assess the effectiveness of the 'My Support' programme for Multiple Sclerosis patients. It was noted that no data was requested at this stage.</p>

	<p>The Group agreed that the proposed project could be classed as research, and that if so the applicant would be required to seek research ethics committee approval.</p> <p>There were concerns that the draft consent wording provided was unclear, and did not explain to participants that their data could be shared with other organisations. The importance of ensuring that participants were clearly informed of how their data would be used was emphasised, but it was felt that it would be difficult to provide more detailed feedback without sight of the full consent materials that patients would be provided with. The Group discussed the process for providing feedback on proposed projects, and at what stage it would be most helpful for DAAG to provide input. It was suggested that future submissions to DAAG should include more detail about the proposed consent materials and clearly specify the purpose and anticipated benefits of the proposed use of data.</p> <p>Outcome: Feedback will be provided by the IAO</p> <p><u>070514e1: HALT-IT Trial - Response from applicant</u></p> <p>This application had previously been discussed at the 7 May 2014 and 26 June 2014 DAAG meetings, and the applicant had been asked to confirm that the data shared outside the UK would be fully anonymised to the Information Commissioner's Office (ICO) standard. The applicant had provided a response, but the Group did not feel that this provided sufficient detail. It was suggested that the applicant should have been asked to specify precisely which fields would be released outside the UK.</p> <p>An additional query was raised regarding a statement in the application form provided that the applicant organisation was also involved in an EU-funded project and that it was proposed that aggregated data would be shared with this project. It was suggested that the applicant should be asked to clarify whether the data shared with this project would be used for commercial purposes, and it was proposed that the consent materials should be updated to include specific details of this project and the purposes for which any data shared would be used. It was noted that as linked ONS data was requested, this should not be used for commercial purposes without agreement from ONS.</p> <p>Outcome: Unable to recommend for approval</p> <p>Gary Coleman then left the meeting.</p>
<p>200814-f</p>	<p>Data applications (IAA: Jim Duffy)</p> <p><u>200814-f1: National Audit of Cardiac Rehabilitation – Consent Review</u></p> <p>The Group were informed that this application was for feedback on the proposed consent materials, and no data was requested at this stage. The National Audit of Cardiac Rehabilitation (NACR) was led by the University of York and it was noted that data for this project was currently being collected under a section 251 approval. The Group were informed that as a site in Scotland had become involved in the audit, and section 251 did not apply in Scotland, explicit patient consent would need to be sought for participants in the Scottish pilot.</p> <p>A query was raised regarding a reference on the consent form to linking patient data to other data held by the Office of National Statistics (ONS), as it was not clear from the provided materials what data this could include. It was suggested that the consent form could be updated to include wording such as 'information on your vital status' from ONS to clarify this.</p> <p>The Group suggested that the consent form should provide additional information for participants, such as how long their data would be retained for and what other organisations,</p>

	<p>if any, would have access to the data. A reference within the consent form to linking 'data collected at different times' was queried, as it was not felt to be clear what this would mean, but it was suggested that the questionnaire provided to participants along with the consent form would provide additional context for this statement. The Group suggested that it would have been helpful if a copy of the questionnaire could have been shared with them to provide this context for the consent form.</p> <p>The use of the term 'anonymised' in the consent form was also discussed, and it was suggested that participants could potentially find it helpful if more information could be provided about what this meant in practical terms.</p> <p>Outcome: The Group agreed that other than these points, they were generally content with the materials provided. It was agreed that an updated consent form, based on the feedback provided, would be circulated around the Group for any further comments on the language used.</p> <p>Jim Duffy then left the meeting.</p>
200814-i	<p>Any other business</p> <p>There was a discussion around future meeting dates, and it was proposed that from September the Group should meet for half a day each week. The possibility of holding meetings as a videoconference with the HSCIC's London offices was also discussed.</p>

Summary of Open Actions

Reference	Action	Owner
300714-h1	<p>Simon Gray to look into how application processes in Scotland and England could be aligned, and consider discussing this with NHS Scotland.</p> <p>20/08/14: It was suggested that discussions would be picked up following the Scottish referendum.</p>	Simon Gray
150814-b1	<p>Alan Hassey to write to Sam Smith confirming the outcome of discussions with the customer, that they had confirmed that they had ceased using the data for this purpose and to provide an update for the minutes.</p> <p>20/08/14: Alex Bell was asked to seek confirmation of this from Terry Hill, and share this with Sam Smith.</p>	Alex Bell