

Data Access Advisory Group

Minutes of meeting held 17 July 2014

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

In attendance: Susan Milner, Diane Pryce, Frances Hancox (Secretariat), Stuart Richardson (agenda items 170714-a to 170714-g), Jackie Gallagher (agenda items 170714-g to 170714-d), Garry Coleman (agenda items 170714-e to 170714-i), Dominic Povey (agenda items 170714-e to 170714-f), Steve Smith (agenda items 170714-e to 170714-h)

Apologies: None

170714-a	<p>Welcome</p> <p>The Acting Chair welcomed the attendees to the meeting. It was noted that due to external commitments, agenda item 170714-g would be considered earlier on in the meeting's agenda than previously scheduled.</p>
170714-b	<p>Minutes of the previous meeting</p> <p>The minutes of the 26 June 2014 meeting were agreed as an accurate record.</p>
170714-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>The Group discussed this later in the meeting, and the action was closed.</p> <p>There were concerns around the high number of upcoming applications for DAAG to consider, and how the Group could manage these. The importance of increasing the independent membership of the Group was emphasised, and suggestions to help facilitate this included either holding some meetings in London or establishing a video conference between offices in London and Leeds for attendees unable to travel to Leeds. In order to address the current backlog of applications, it was suggested that any applications with Section 251 approval from the Health Research Authority Confidentiality Advisory Group (HRA CAG) could potentially be considered by the Caldicott Guardian without necessarily needing DAAG input, although it was also suggested that the Caldicott Guardian might require some support from the DAAG Acting Chair and others for this.</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 noted that this had been discussed, and the action was closed.</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 now been sent to the applicant asking them to confirm that data would be</p>

	<p>anonymised to the Information Commissioner's Office (ICO) standard.</p> <p><u>191113-d1: University of Sheffield</u></p> <p>A reminder had been sent to the applicant but no response had been received. It was agreed that the application should be closed, as no response had been received after more than 3 months.</p> <p><u>040614-e: UK Biobank</u></p> <p>An outcome letter had been sent to the applicant, and a data sharing agreement had been drafted.</p> <p>(c) Recommendations made out of committee</p> <p><u>DAAG/OC/01: Public Health England</u></p> <p>This had been a request to consolidate four existing data sharing agreements with the Thames Cancer Registry and the National Cancer Intelligence Network into one agreement, as following reorganisations these organisations were now part of Public Health England. This request had been considered by DAAG out of committee and recommended for approval.</p> <p><u>DAAG/OC/02: Royal College of Surgeons – HES/ONS data</u></p> <p>This application had been considered out of committee and all DAAG members had provided comments before recommending for approval. The application had been to continue the provision of linked HES and ONS data, and Section 251 support was in place.</p>
<p>170714-g</p>	<p>Data applications (IAO: Stuart Richardson)</p> <p><u>170714-g1: NHS Wales - SUS data</u></p> <p>Patrick Coyle declared a conflict of interests for this application due to his involvement with the NHS Wales Informatics Service, and agreed not to participate in this discussion.</p> <p>This application was for an extension of a data reuse agreement for the NHS Wales Informatics Service to receive SUS data, in order to use this for commissioning and planning purposes as NHS commissioners within England currently did. It was noted that Section 251 approval was in place until the end of October 2014, and so the data reuse agreement extension was also requested until the end of October. It was anticipated that in future NHS Wales would move to access this data through the use of smartcards and role based access controls rather than through a transfer of SUS data.</p> <p>Outcome: Recommendation to approve</p> <p>Jackie Gallagher joined the meeting via teleconference at this point.</p> <p><u>170714-g2: East Riding of Yorkshire CCG</u></p> <p>This application was for data to be used for risk stratification. It was noted that Section 251 approval was in place until the end of October 2014, and that this application was only to hold data until the end of August 2014.</p> <p>There was a discussion around the inclusion of free text fields within HES, and the potential that these fields could inadvertently include identifiable data. It was proposed that for any free</p>

	<p>text field that was deemed to be at risk of including identifiable data, these fields should only been shared once they had undergone either data cleaning or anonymisation to remove any identifiable data.</p> <p>Some concerns were raised around the stated purpose of this application and why patient identifiable data was required rather than pseudonymised data that could then be reidentified at the originating general practice, but on the basis that Section 251 approval was in place the Group agreed to recommend this application for approval.</p> <p>Outcome: Recommendation to approve</p> <p><u>170714-g3: North Lincolnshire CCG</u></p> <p>This application was also for data for use in risk stratification until the end of August 2014, and it was again noted that free text HES fields could inadvertently include identifiable data and should therefore be anonymised or undergo data cleaning. It was confirmed that Section 251 approval was in place.</p> <p>Outcome: Recommendation to approve</p> <p><u>170714-g4: Halton CCG</u></p> <p>This application was for pseudonymised data over 4 years that the applicant intended to use for performance management and benchmarking. As with the previous two applications, it was noted that free text HES fields could inadvertently include identifiable data and should therefore be anonymised or undergo data cleaning. It was confirmed that the data requested did not include any sensitive fields, and that only local data was requested rather than all national data.</p> <p>A query was raised regarding the legal basis for data disclosure, and it was agreed that further clarity would be required before the Group could recommend for this application to proceed.</p> <p>Outcome: To be confirmed</p> <p>Stuart Richardson left the meeting at this point.</p>
170714-d	<p>Data applications (IAO: Jackie Gallagher)</p> <p><u>MR1316: Nottingham University - HCV Research UK</u></p> <p>It was noted that this application had previously been considered by DAAG on 26 February 2013 and 22 May 2013, and had been recommended for approval. However due to delays and changes in processes, the application had been resubmitted for consideration. It was noted that the applicant's completed IG Toolkit score was not yet available, and it was agreed that the Group's recommendation should be subject to confirmation of IG Toolkit score.</p> <p>A query was raised regarding a statement within the application that data would be anonymised, and whether it had been confirmed that this meant truly anonymised and not pseudonymised. It was confirmed that clarification had been sought following the discussions at previous DAAG meetings and a satisfactory response had been provided. The Group agreed that the consent materials provided appeared to be adequate.</p> <p>Outcome: Recommendation to approve subject to confirmation of IG Toolkit score</p> <p><u>MR1109: University of Oxford, CTSU – Renewal of Agreement – UK Biobank</u></p>

	<p>This application was for renewal of an existing agreement between the HSCIC and UK Biobank, and it was confirmed that this had previously been considered by DAAG in 2013.</p> <p>A query was raised regarding a reference in the application form to using data from 5,000,000 people aged 40 to 69; it was confirmed that this was a typographical error, and the correct figure was 500,000 individuals.</p> <p>Outcome: Recommendation to approve</p> <p><u>MR1347: University of Birmingham – MR1347</u></p> <p>It was noted that this application had previously been considered and approved by DAAG at the 30 January 2014 meeting, but that due to changes in process the application had been resubmitted for consideration. The Group confirmed that the consent materials provided were appropriate.</p> <p>Outcome: Recommendation to approve</p> <p>Jackie Gallagher left the meeting at this point.</p>
170714-e	<p>Data applications (IAO: Garry Coleman)</p> <p>Garry Coleman and Dominic Povey joined the meeting at this point.</p> <p><u>170714-e1: CRAB Clinical Informatics Limited (C-CI)</u></p> <p>Sean Kirwan declared a potential conflict of interest for this application due to a previous working relationship with the applicant, and did not participate in the discussion.</p> <p>This application was for pseudonymised HES data including consultant code, and it was noted that the application had previously been considered by DAAG at the 17 December 2013 meeting. This data would then be used to provide reports to NHS organisations, providing each trust with only the data from that particular organisation. The Group discussed the fact that the applicant had requested access to HES data from all NHS organisations rather than only specifically requesting data for the organisations they would be providing reports to. It was noted that this mirrored current arrangements in place for a number of information intermediaries who could access HES data in order to provide services to NHS organisations. A query was raised regarding whether the applicant would also be providing data to non-NHS organisations, but it was confirmed that the applicant would only provide reports to NHS trusts.</p> <p>The Group again discussed the legal basis for disclosure, and it was agreed that further clarity would be required. The potential need to raise this with HRA CAG was discussed.</p> <p>Outcome: To be confirmed</p> <p>Steve Smith joined the meeting at this point.</p> <p><u>170714-e2: University of Sheffield – ScHARR</u></p> <p>The applicant had requested pseudonymised HES data in addition to linked ONS mortality data. This data would be used as part of a project commissioned by the National Institute for Health Research (NIHR) to study vascular services, and a commissioning letter from NIHR evidencing the approval to receive ONS data had been provided. The Group stated that they felt it would clearly be in the public interest for this work to proceed.</p>

The Group again discussed the legal basis for the disclosure, and it was agreed that further clarity would be required.

Outcome: To be confirmed

170714-e3: London School of Economics

This application was for pseudonymised HES data in order to calculate estimate patient population weights and compare these to data that had been gathered by the Adult Inpatient Survey. The Group again discussed the legal basis for the disclosure, and it was agreed that further clarity would be required.

Outcome: To be confirmed

Action: Dawn Foster to review legal counsel's opinion regarding disclosure of pseudonymised data.

Action: Dawn Foster to liaise with HRA CAG to discuss the interim period before new regulations are in place, and what framework could safely be put in place in the meantime.

Action: IAOs to prioritise applications that have a clear legal basis until the current position can be clarified with HRA CAG.

170714-e4: Royal College of Surgeons – Maternity Information System (MIS)

This application was for the provision of HES IDs to allow the applicant to link audit data with HES data they already held. It was explained that the HSCIC would receive patient identifiers and match these against pseudonymised HES IDs, then provide the HES IDs to the applicant so that the applicant would not themselves need to have sight of the original patient identifiers. The Group noted that Section 251 approval was in place to obtain the identifiers.

Outcome: Recommendation to approve

170714-e5: Royal College of Surgeons – National Prostate Cancer Audit (NPCA)

This application was also for the provision of HES IDs to allow the applicant to link audit data with HES data they already held, in order to support the national prostate cancer audit. It was noted that Section 251 approval was in place for the provision of identifiers to the HSCIC. The Group confirmed that they were content to recommend this application for approval.

Outcome: Recommendation to approve

170714-e6: Royal College of Physicians – Sentinel Stroke National Audit Programme (SSNAP)

This application was to extend an existing data reuse agreement between the HSCIC and Royal College of Physicians, which was due to expire at the end of July 2014, and to additionally include refreshed data. It was stated that the applicant received ONS mortality data, but that no other sensitive or identifiable data was included. It was confirmed that Section 251 support was in place and due for renewal in December 2014. The Group confirmed that they were content to recommend this application for approval.

Outcome: Recommendation to approve

170714-f	<p>Data applications (IAO: Dominic Povey)</p> <p><u>170714-f1: National Chronic Obstructive Pulmonary Disease (COPD) Audit</u></p> <p>This application was for linked, pseudonymised HES data to be shared with the Royal College of Physicians for use in their work on the National COPD Audit, supported by the British Thoracic Society. A data flow diagram was provided. The Group were satisfied this was covered by the Section 251 approval that was in place for the Royal College of Physicians.</p> <p>Outcome: Recommendation to approve</p> <p>At this point Dominic Povey left the meeting.</p>
170714-h	<p>Data applications (IAO: Steve Smith)</p> <p><u>170714-h1: University of Oxford – NHS Number for Babies (NN4B) MBRRACE UK</u></p> <p>This application was from the national perinatal unit at the University of Oxford, who had been commissioned by NHS England to carry out the MBRRACE-UK initiative to identify rates of neonatal mortality and any potential poor performance. The applicant requested NN4B data for all newborn babies, which would include ethnicity and gestational age. It was noted that NN4B was not usually retained for more than 6 months, meaning that the currently held data might need to be retained for longer than usual to ensure this could be provided to the applicant.</p> <p>It was confirmed that Section 251 approval was in place, and that CAG had approved the provision of this data from the HSCIC rather than ONS. The Group stated that they felt this work was very much in the public interest, and were content to recommend approval.</p> <p>Outcome: Recommendation to approve</p> <p>It was noted that an additional query had been received from the applicant about using the NN4B data for a different project, and it was confirmed that this would need to be brought to DAAG as a separate application.</p> <p>Steve Smith left the meeting at this point.</p>
170714-j	<p>Additional data applications (IAO: Garry Coleman)</p> <p><u>170714-j1: Clinical Practice Research Datalink (CPRD)</u></p> <p>This application was for the HSCIC to link cancer data and identifiable general practice data in order to provide a pseudonymised copy of this data to CPRD with the identifiers removed, in addition to providing ONS data. It was confirmed that this had Section 251 approval in place until February 2015, and that HRA CAG had confirmed that CPRD did not need to complete the IG Toolkit as they would not be processing identifiable data.</p> <p>A query was raised regarding free text fields, as these could potentially contain identifiers, and it was confirmed that CPRD no longer received free text fields.</p> <p>Outcome: Recommendation to approve</p> <p><u>170714-j2: CPRD – Air Pollution Study</u></p> <p>This application was to receive air pollution scores into the HSCIC and link these to HES data</p>

	<p>based on postcodes, before providing the pseudonymised data to CPRD. It was confirmed that CPRD would only receive the additional linked air pollution data and would not receive any identifiers. It was confirmed that Section 251 support was in place.</p> <p>A query was raised regarding a reference in the application summary to anonymised data, and whether this truly meant anonymised data or if it instead referred to pseudonymised data. It was agreed that the applicant would be asked to confirm this.</p> <p>Outcome: Recommendation to approve pending clarification regarding whether data will be anonymised or pseudonymised.</p>
170714-i	<p>Any other business</p> <p>Future meeting dates were discussed, and it was noted that there had been some difficulties finding August and September dates due to annual leave. It was suggested that the scheduled meetings could be extended to allow more time to consider applications.</p> <p>There was a brief discussion of the new process of sharing DAAG meeting papers via SharePoint, and members stated that they were happy with this process.</p>
	<p>Post-meeting addendum</p> <p>The chair clarified the HSCIC's position with regard to pseudonymised data flows in an email exchange with the DAAG members after the meeting. On this basis, the members agreed that the following applications should be recommended proceed:</p> <ul style="list-style-type: none"> – 170714-g4: Halton CCG – 170714-e3: London School of Economics – 170714-e2: University of Sheffield – SchARR <p>The CRAB application (as below) would be held back for further review by the IAO.</p> <ul style="list-style-type: none"> – 170714-e1: CRAB Clinical Informatics Limited (C-CI)

Summary of Open Actions

Reference	Action	Owner
170714-e1	Dawn Foster to review legal counsel's opinion regarding disclosure of pseudonymised data.	Dawn Foster
170714-e2	Dawn Foster to liaise with HRA CAG to discuss the interim period before new regulations are in place, and what framework could safely be put in place in the meantime.	Dawn Foster
170714-e3	IAOs to prioritise applications that have a clear legal basis until the current position can be clarified with HRA CAG.	Information Asset Owners