

# Data Access Advisory Group

## Minutes of meeting held 16 December 2014

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

**In attendance:** Alex Bell, Diane Pryce, Frances Hancox, David Evans, Garry Coleman (applications 2.2, 2.3, 2.5, 2.6), Paula Moss (applications 2.1, 2.4), Stuart Richardson (applications 2.1, 2.4)

**Apologies:** None

1	<p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 9 December 2014 meeting were reviewed and agreed as an accurate record of the meeting.</p> <p>Action updates were provided (see table on page 6).</p> <p><b>Out of committee recommendations</b></p> <p><u>Care Quality Commission (CQC) NIC-292297-K3G0K</u></p> <p>This application had been approved out of committee, and the Group had raised some points around the requirement for identifiable data. It was agreed that for future applications the applicant should be asked to justify the need for identifiable rather than pseudonymised information and confirm that this use of identifiable data was in line with the CQC Code of Practice on confidential personal information.</p> <p><b>Action:</b> Alan Hassey to write to the HSCIC Caldicott Guardian and Senior Information Risk Owner on behalf of DAAG regarding the use of identifiable rather than pseudonymised data by CQC and the need to ensure that this is appropriately justified.</p> <p><u>City University NIC-273840-N0N0N</u></p> <p>This application had been considered out of committee but a further query had been raised regarding the data controller. The IAO confirmed that the Office of National Statistics (ONS) would be the data controller, and it was agreed that the application form would be updated to clarify this.</p> <p><b>Outcome:</b> Recommendation to approve subject to updating the application form to clarify that ONS will be the data controller.</p> <p><u>University of East Anglia – SCOOP NIC-177785-4DK</u></p> <p>This application had been considered at the 2 December 2014 DAAG meeting and recommended for approval subject to confirmation of how participants would be notified of changes to data sharing processes. It had been confirmed out of committee that this caveat had been met and the application had therefore been approved.</p> <p><u>University of Oxford NIC-257796-H0P0C</u></p> <p>At the 2 December 2014 DAAG meeting this application had been recommended for approval subject to caveats. It had been confirmed that the caveats had been met and the Acting Chair</p>
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	<p>had therefore recommended approval of this application out of committee.</p> <p><u>RAND Europe NIC-255450-G2Z6F</u></p> <p>At the 2 December 2014 DAAG meeting this application had been recommended for approval subject to a number of caveats, which included a request for further details on outputs and benefits. The applicant had responded, but it was not thought that the additional detail regarding outputs and benefits had been provided and the caveat had therefore not yet been fulfilled.</p>
<p><b>2</b></p> <p><b>Data applications</b></p> <p><b>2.1</b></p>	<p><u>Medway Clinical Commissioning Group (CCG), Swale CCG and Dartford CCG (Presenter: Stuart Richardson) NIC-301614-G0X0T</u></p> <p><b>Application summary:</b> This was a group of applications from three CCGs for pseudonymised Secondary Uses Service (SUS) Payment by Results (PbR) data to be retained for one year in order to report on and analyse the data provided for commissioning purposes. It was noted that as for all similar applications, free text fields would be cleaned to remove any potentially identifying data. Information Governance (IG) Toolkit scores had been provided, and these were satisfactory for all three CCGs. The Group were informed that a list of activities described in the application form would be amended to confirm that the approval given would be limited to those activities only.</p> <p><b>Discussion:</b> It was suggested that more information on the anticipated benefits of this use of data would have been helpful, but overall the Group were content with these applications. It was noted that the Data Protection Act (DPA) registration wording had not been included, and it was agreed that the application would need to be updated to include this. The Group also noted that the data retention period was stated to be 6 months when in fact data had been requested for 12 months, and it was agreed that this would also be corrected.</p> <p>The Group provided feedback on the language used in the applications, and emphasised the importance of avoiding jargon to ensure that applications could be understood by a lay audience.</p> <p><b>Outcome:</b> Recommendation to approve subject to updating the application form to include DPA registration wording and correcting the data retention period to 12 months.</p> <p><b>2.4</b></p> <p><u>NHS England Midlands &amp; East Consortium<sup>1</sup> (NHS Basildon and Brentwood Clinical Commissioning Group) – Stage 1 Accredited Safe Haven (Presenter: Garry Coleman) NIC-302045-N4J5Y</u></p> <p><b>Application summary:</b> This application had previously been considered at the 12 November and 9 December DAAG meetings and had been recommended for approval subject to the clarification of some wording within the application. This wording had been clarified, but subsequent to this a query had been raised regarding two of the applicant CCGs that were not yet stage 1 accredited safe havens. It was explained that these two organisations would only formally become stage 1 accredited safe havens following the creation of a data sharing agreement with the HSCIC for this data.</p> <p>It was confirmed that data retention until 30 April 2015 was requested, and that this would be</p>

<sup>1</sup> NHS Bedfordshire CCG, NHS West Essex CCG, NHS Basildon & Brentwood CCG, NHS Castle Point & Rochford CCG, NHS East & North Hertfordshire CCG, NHS Herts Valley CCG, NHS Southend CCG, NHS Thurrock CCG, NHS Luton CCG

	<p>co-terminus with the Section 251 approval for this use of data.</p> <p><b>Discussion:</b> The Group queried the use of the term 'weakly pseudonymised' to describe the data requested, and it was clarified that this term had been taken from the Section 251 approval for stage one accredited safe havens, whereby organisations could apply for data pseudonymised by either NHS number or postcode.</p> <p>A query was raised regarding the IG Toolkit score for MedeAnalytics, who would be acting as data processor for the applicants, as this score had not been included in the application form. It was noted that a satisfactory IG Toolkit score for MedeAnalytics International Ltd was recorded online, and it was agreed that the applicant should be asked to confirm that this was the correct score and not from a different organisation or different branch of the same organisation.</p> <p><b>Outcome:</b> Recommendation to approve subject to clarification regarding the listed name and IG Toolkit score for MedeAnalytics.</p> <p><i><b>Note:</b> Prior to the end of this DAAG meeting, confirmation was received that the legal name of the organisation was MedeAnalytics International Ltd, and that a satisfactory IG Toolkit score had been achieved. This application was therefore recommended for approval.</i></p>
2.2	<p><u>Central, North and South Manchester CCG (Presenter: Garry Coleman) NIC-310337-N3Z8X</u></p> <p><b>Application summary:</b> This application was for pseudonymised Hospital Episode Statistics (HES) data to produce an updated business case for service reconfiguration. It was noted that the applicant had received this data the previous year to produce a pre-consultation business case, and an additional data year was now requested.</p> <p><b>Discussion:</b> A query was raised regarding why the sensitive field local patient ID had been requested, as it was not thought that a clear justification for this had been provided. It was suggested that it might be possible to use the HES ID for this purpose instead, and the Group agreed that the applicant should be asked to clarify this. The Group noted that if local patient ID was required, it would be important to consider whether this could lead to data being identifying and the need for fair processing.</p> <p>Although it was noted that the applicant's System Level Security Policy had been reviewed and approved by the relevant HSCIC team, there was a query regarding whether the applicant had completed the IG Toolkit.</p> <p>The Group discussed the outputs and benefits listed, and it was felt that this section could be clearer and provide more detail on what measurable benefits would be realised. It was agreed that if the application was resubmitted then a clearer explanation of anticipated benefits would be helpful.</p> <p><b>Outcome:</b> Unable to recommend for approval. Applicant asked to provide justification for why the local patient ID field would be required.</p>
2.3	<p><u>NHS National Services Scotland (Presenter: Garry Coleman) NIC- 262444-F9K9D</u></p> <p><b>Application summary:</b> This was a new application for pseudonymised, non-sensitive HES data in order to support benchmarking activities in Scotland.</p> <p><b>Discussion:</b> A query was raised regarding the data retention period, and it was confirmed that data would be held for three years. In addition there was a query about whether the</p>

	<p>applicant's information security policy had been reviewed, and it was confirmed that this had been reviewed and approved by the relevant HSCIC team. It was felt that further detail could have been provided regarding the anticipated benefits, but overall the Group were content to recommend approval of this application.</p> <p><b>Outcome:</b> Recommendation to approve.</p> <p>There was a discussion around the potential implications of differences in the English and Scottish legal systems, and it was suggested that the HSCIC should consider the implications of this for the data sharing agreement and contract.</p> <p><b>Action:</b> Diane Pryce to provide a briefing paper on home nations cross-border relationships and known issues.</p>
2.5	<p><u>University of Cambridge - Department of Public Health and Primary Care (Presenter: Garry Coleman) NIC-309034-C7M7W</u></p> <p><b>Application summary:</b> This was a new application for pseudonymised, non-sensitive HES data to support a pilot study around the effects of blood donation. It was explained that NHS Blood and Transplant would provide some identifiers for the study cohort to the HSCIC, which would be linked to HES and then provided to the University of Cambridge in a pseudonymised form. Separately, some pseudonymised data would be provided from NHS Blood and Transplant directly to the University of Cambridge; the same pseudonyms would be used for both flows of data, meaning that the University of Cambridge would be able to combine both datasets. It was noted that the applicant would not receive any identifiable data. It was also noted that Section 251 approval had been granted for this use of data.</p> <p><b>Discussion:</b> There was a discussion around the data that had been requested, and whether this would be sufficient to meet the intended purposes of the study. It was explained that this would be a pilot study which would assess the feasibility of large scale record linkage, and once this pilot had completed the applicant might then wish to request additional datasets. It was noted that HRA CAG had advised the applicant that the second phase of the study ought to rely on patient consent rather than Section 251 support. The Group noted the importance of ensuring that study participants were informed about this use of data as well as the outcomes. It was suggested that the applicant should be asked whether patient information materials had been updated in line with suggestions from HRA CAG.</p> <p>The DPA registration wording for the applicant was queried, as it was noted that this did not appear to cover the use of medical data. It was agreed that the applicant should be made aware of this and asked to ensure that their DPA registration wording was updated if required.</p> <p>It was noted that the data re-use agreement provided referred to 'section 251 of the Health and Social Care Act 2006', when this should have referred to the NHS Act 2006.</p> <p><b>Outcome:</b> Recommendation to approve subject to assurance that the DPA registration wording for the applicant is accurate and reflects the purposes described. Applicant to be encouraged to share information with donors regarding this study, and asked to confirm whether patient information materials have been updated in line with suggestions from HRA CAG.</p>
2.6	<p><u>Northgate Information Solutions UK Limited (Presenter: Garry Coleman) NIC-292301-H3WOF</u></p> <p><b>Application summary:</b> This application was for non-sensitive pseudonymised HES data in order to support work carried out for the National Joint Registry in addition to creating a benchmarking service. It was noted that the data processing address provided was for a</p>

	<p>hosting service and it was confirmed that processing would take place at that address, but that the processing would be carried out by Northgate staff.</p> <p><b>Discussion:</b> The Group queried whether any record level data would be shared outside the applicant organisation, and it was confirmed that any outputs would only include aggregated data. A query was also raised regarding a reference in the application form to small numbers in relation to averages, and it was suggested that this should be clarified.</p> <p>There was a discussion regarding the data retention period, as it was stated in the application that data would only be retained until the end of February 2015. It was noted that this was due to the requirement for all applicants to move to the new data sharing agreement and contract by the end of February 2015, but it was suggested that it would be helpful if application forms could indicate how long the applicant would wish to retain data once this change was completed and if a further approval was granted.</p> <p>The application had been split into 4 separate purposes for which data would be used, and although the Group were content to recommend purposes 2, 3 and 4 for approval there were concerns regarding purpose 1, the creation of a hospital benchmarking service, which was described as a commercial purpose. It was suggested that further information should be requested regarding who the customers for this service would be and how it would benefit the health and social care system in England, as it was noted that although customers in other countries had been listed no customers within England had been identified within the application.</p> <p><b>Outcome:</b> Recommendation to approve purposes 2, 3 and 4 (Best Practice Tariff external reporting, Trust Clinical Annual Report external reporting, and Compliance Monitoring – internal). Unable to recommend purpose 1 (Hospital Benchmarking Services) for approval; further information requested about what data would be provided to which customers and the anticipated benefits to the health and care system in England.</p>
3	<p><b>Any other business</b></p> <p>The Group discussed the need for applicants to provide satisfactory IG Toolkit scores, and it was noted that a self-assessed IG Toolkit score would be acceptable but only if this had been signed off by the IG Toolkit team within the HSCIC. It was noted that this differed slightly from the approach taken by the Data Access Request Service, and it was agreed that this should be discussed with Marie Greenfield, the Information Governance Policy Manager.</p> <p><b>Action:</b> Diane Pryce and Alex Bell to discuss self-assessed IG Toolkit scores with Marie Greenfield.</p> <p><b>Action:</b> Marie Greenfield to be invited to the next DAAG training day to discuss IG Toolkit.</p> <p>The Group discussed three letters that had been received from the HSCIC Caldicott Guardian, and it was agreed that the Acting Chair would respond on behalf of the Group.</p> <p><b>Action:</b> Alan Hassey to respond to letters received from HSCIC Caldicott Guardian.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
16/12/2014	Alan Hassey to write to the HSCIC Caldicott Guardian and Senior Information Risk Owner on behalf of DAAG regarding the use of identifiable rather than pseudonymised data by CQC and the need to ensure that this is appropriately justified.	Alan Hassey		Open
16/12/2014	Diane Pryce to provide a briefing paper on home nations cross-border relationships and known issues.	Diane Pryce		Open
16/12/2014	Diane Pryce and Alex Bell to discuss self-assessed IG Toolkit scores with Marie Greenfield.	Diane Pryce		Open
16/12/2014	Marie Greenfield to be invited to the next DAAG training day to discuss IG Toolkit.	Alex Bell		Open
16/12/2014	Alan Hassey to respond to letters received from HSCIC Caldicott Guardian.	Alan Hassey		Open
09/12/2014	Consent materials to be added to agenda for DAAG training day. HRA CAG and ONS representatives to be invited to join discussion	Alex Bell	16/12/14: This action had been completed and was closed.	Closed
09/12/2014	Eve Sariyiannidou and David Evans to provide bullet points on consent materials to assist discussions at DAAG training day.	David Evans	16/12/14: This action was ongoing.	Open
09/12/2014	David Evans to consider the fair processing aspects of the University of Surrey application (NIC-203503-X7K8K) and share	David Evans	16/12/14: There had been a discussion regarding this application via email, and it was agreed that Garry Coleman would share further details regarding the intended data flow with David Evans.	Open

	comments by email.			
09/12/2014	DAAG members to agree updated wording for University of Sheffield application discussion in the 2 December 2014 meeting minutes.	Sean Kirwan	16/12/14: Garry Coleman and Eve Sariyiannidou to agree revised wording.	Open
02/12/2014	Dickie Langley to circulate the updated DARS application form by email, and DAAG members to provide comments.	Dickie Langley	09/12/14: Updated application form shared by email, and members to provide comments. 16/12/14: The updated application form had been shared by email, and positive feedback had been received from DAAG members. It was suggested that the application form should be reviewed again at a later date to determine if any further improvements could be made.	Closed
12/11/2014	Dawn Foster to discuss with HRA CAG Secretariat whether the addition of the data item Place of Death to the requested dataset could affect identifiability (CASU National Oesophago-Gastric Cancer Audit NIC-292440-R9G8P).	Garry Coleman	18/11/14: This had been raised with HRA CAG Secretariat, who had noted that place of death could in some cases mean a home address. It was agreed that the applicant should be asked to confirm whether they required full addresses for this, and if so to provide justification for why this was needed. 25/11/14: No update available. 02/12/14: Garry Coleman agreed to confirm whether the applicant had addressed this. 16/12/14: It was confirmed that this application had been updated to request establishment code, rather than place of death, and that this would not include addresses. The action was closed.	Closed