

Data Access Advisory Group

Minutes of meeting held 18 November 2014

Members: Alan Hassey, Dawn Foster, Eve Sariyannidou, John Craven, Sean Kirwan, Patrick Coyle

In attendance: Alex Bell, Diane Pryce, Frances Hancox, Karen Myers, Dickie Langley, Dave Roberts, Dave Cronin, Andrew Hall (application 2.10)

Apologies: None

1 Review of previous minutes and actions

The minutes of the 12 November 2014 meeting were reviewed and approved as an accurate record.

Action updates were provided (see table on page 8).

Recommendations out of committee

Accredited Safe Haven applications

These applications had previously been considered by DAAG in August and September 2014 and had subsequently been approved by the HSCIC Senior Information Risk Owner (SIRO), but the agreement had since expired. The Section 251 approval for these applications had now been extended and there were no substantive changes to the applications, so the DAAG Chair had approved an extension out of committee until the end of April 2015.

Public Health England (cancer registry) NIC-214596-Q1T6Q

This application had been discussed at the 9 October 2014 DAAG meeting, and the applicant had been asked to clarify a statement that data derived from HES could not be deleted as this would not be practicable. It was noted that a detailed explanation of this had been received, and the DAAG Chair noted that he was content with the explanation provided but would circulate the response to members.

Action: DAAG Chair to circulate the response received about PHE retaining data derived from HES.

Midlands and Lancashire Commissioning Support Unit (CSU) NIC-277269-G9Q3P

This application had been considered at the 22 October 2014 DAAG meeting and recommended for approval subject to satisfactory IG Toolkit score for pre-merge organisation, and confirmation of why Diagnostic Imaging Dataset data was required. This clarification had been provided and the DAAG Chair had confirmed out of committee that DAAG's requirements had now been met.

Monitor CHKS: Payment by Results (PbR) National Benchmarker NIC-281120-P8S3P

This application had been considered on 28 October 2014 and a clearer explanation had been requested of why small numbers were required. The applicant had now responded with additional information on this point, and the DAAG Chair had confirmed that he was content with this explanation. It was agreed that the DAAG Chair would circulate this to members for information.

	<p>Action: DAAG Chair to circulate the response received for the Monitor CHKS application (NIC-281120-P8S3P).</p> <p>The Group discussed the process for the DAAG Chair to consider updates of this kind out of committee, and it was agreed that while the Group was happy for this to take place it would be helpful if a written report could be provided on recommendations made out of committee. This could then be accurately reflected in the Group's minutes.</p> <p>Action: Alex Bell to provide a report on applications considered out of committee.</p>
2	<p>Data applications</p>
2.1	<p><u>City University London – Office of National Statistics (ONS) (Presenter: Dickie Langley) NIC-273840-N0N0N</u></p> <p>Application summary: This renewal application was for identifiable, non-sensitive Hospital Episode Statistics (HES) data to be linked to ONS birth registration data. It was explained that linked data would be provided to ONS and stored in a database within the ONS secure environment (Virtual Microprocessor Laboratory), and initially used by City University London to investigate the outcome of pregnancy in relation to time of day, day of week and season. The application also requested the approval in principles that this maternity database could then be made available to other researchers, subject to approvals by a Research Ethics Committee, Health Research Authority Confidentiality Advisory Group (HRA CAG), ONS and HSCIC as applicable.</p>
2.2	<p>Discussion: The Group expressed their support in principle for this work; however it was not felt that the application had clearly explained which organisation had obtained Section 251 approval from HRA CAG, and which processes this approval covered. It was also not felt to be clear which organisations would have access to identifiers. A query was raised regarding a reference to the use of the database by City University London 'and its collaborators' as it was not clear what organisations these collaborators included, and it was noted that Data Protection Act (DPA) registration details had not been provided for either City University London or these collaborators. The Group also queried which organisation would be the data controller for the data provided, and which organisation's DPA registration details had been provided in the application form as the organisation name was not given.</p> <p>It was felt that a reference to City University London accessing 'unlinked' data was confusing, and it was suggested that a data flow diagram could help clarify what data would be shared with which organisation. A query was raised regarding fair processing obligations under the DPA and what efforts had been made to inform patients of this use of data, as well as what the duration of the project would be. An additional query was raised regarding a statement in the HRA CAG approval letter provided that the approval 'would not include Patient Episode Database Wales (PEDW) data until satisfactory responses were received' as it was not clear whether the approval did or did not now include PEDW data.</p>
2.3	<p>There was a discussion of the potential for this application to be split into two applications, with one application covering the sharing of data with ONS and a further application covering the use of data by City University London and potentially other researchers. Overall it was agreed that this should remain as one application to attempt to clarify the eventual uses of the data provided.</p> <p>Outcome: Unable to recommend for approval. Clarification needed regarding which organisation Section 251 approval was granted to, which processes this approval covers, and what organisation will be able to access identifiers. Further detail requested regarding City University London's 'collaborators' - specifically what organisations this includes, what access</p>

2.4	<p>to data they will have and their DPA registration details, as well as DPA registration details for City University London and clarification about the DPA registration details provided in the application. Details also requested of how the applicant has informed patients of this use of data, the duration of the project, and whether the CAG approval now covers PEDW data. Reference to City University London accessing unlinked data was also queried.</p> <p><u>Methods Insights (Presenter: Dave Roberts) NIC-292309-L2M4X</u></p> <p>Application summary: This application was both for a renewal of the agreement to continue to receive pseudonymised, non-sensitive HES and Secondary Uses Service (SUS) Payment by Results (PbR) data, and an amendment to begin receiving the sensitive field Consultant Code. This data would be used to support the organisation's work with NHS organisations by populating a quality variation tool and bespoke tools for individual NHS customers, as well as creating dashboards specifically for the Royal College of Surgeons and explorer tools that were publically available. It was explained that the Consultant Code field was requested specifically in order to develop tools for consultants to be able to access data on their own performance via a password protected portal, and to enable NHS trusts to compare the variations in care across the consultants within their organisation.</p> <p>Discussion: It was noted that the application referred to 'Methods Analytics' as well as 'Methods Insights', and a query was raised regarding whether these were two different organisations. It was confirmed that both names referred to the same organisation. The data retention period was queried, and it was noted that data would not be retained after 28 February 2015 unless a further approval was given for the applicant to retain data for longer.</p> <p>Some concerns were raised around the stated objectives for processing, as it was felt that the way this had been written appeared quite open-ended. The Group queried whether the data requested could be used for any additional purposes, but it was confirmed that the data would only be used for the purposes listed in the application summary.</p> <p>It was not felt that the benefits of this work had been clearly described, but there was a discussion around the potential value of this data for NHS trusts and individual consultants in order to benchmark performance and it was noted that this data would not normally be available to hospitals from within their own data systems. The question of whether consultant consent was required was also raised, and it was noted that data on performance would not require consent particularly as Consultant Code would be used rather than the individual consultant's name or other details.</p>
	<p>The Group queried whether it would be possible for the work described to be carried out without using the sensitive field Consultant Code, and it was confirmed that this would not be possible.</p> <p>Outcome: Recommendation to approve</p>
2.5	<p><u>Device Access Ltd (Presenter: Dave Roberts) NIC-263878-H2J7T</u></p> <p>Application summary: This was a new application for pseudonymised, non-sensitive HES data in order to analyse patient care pathways and identify where devices could best be used by providers. The applicant would use this analysis to work with UK Trade and Investment (UKTI), the Office of Life Sciences (OLS), the National Institute for Health Research (NIHR), and the National Institute for Health and Care Excellence (NICE) as well as medical technology clients. It was noted that the applicant had stated the data received would not be used for direct marketing purposes.</p> <p>Discussion: Overall the Group were content with this application. However two points of</p>

<p>2.6</p> <p>2.7</p> <p>2.8</p>	<p>accuracy were raised; firstly, a reference in the DPA registration wording to 'our patients' was queried, as it was not thought that the applicant was a provider of health services, although it was noted that this could be due to the generic wording used by the Information Commissioner's Office (ICO) for certain classes of organisations. Secondly a statement that 'medical technology clients will carry out bespoke analysis of the data' was queried. It was suggested that this statement was misleading due to a grammatical error, and it was agreed that this would be clarified.</p> <p>Outcome: Recommendation to approve subject to confirmation of DPA registration wording and clarification of reference to 'our patients', and subject to IAO clarifying grammar in the statement that 'medical technology clients will carry out bespoke analysis of the data'.</p> <p><u>FTI Consulting (Presenter: Dave Roberts) NIC-231179-J3J6Q</u></p> <p>Application summary: This applicant was one of the ten organisations selected by Monitor and the National Trust Development Authority to carry out the assessment of financially challenged NHS trusts in England, and the application was therefore for pseudonymised, non-sensitive HES data to support this work.</p> <p>Discussion: A reference to a separate application to store data in the USA was queried, and it was confirmed that this application was solely to store data within the UK. The Group also queried the statement in the application form that the applicant 'may' perform assessments of financially challenged trusts, and it was confirmed that the applicant would be asked to perform these assessments but that it was not yet known which trusts this would be for.</p> <p>Outcome: Recommendation to approve</p> <p><u>City University London – geographical variation (Presenter: Dickie Langley) NIC-256929-M9C4B</u></p> <p>Application summary: This application was for pseudonymised, non-sensitive data in order to create indicators for the quality of care, and to examine the differences between geographical areas over time. It was noted that only aggregated data with small numbers suppressed would be published. Data would be stored in a database which would be made accessible to other researchers although it was noted that any applicants wishing to use this database in future would need to apply to the HSCIC for access.</p> <p>It was noted that the applicant's Information Security Policy was in the process of being reviewed by the relevant HSCIC team.</p> <p>Discussion: It was felt that this application did not clearly explain the anticipated benefits to the health and social care system or the outputs. It was also felt that the section title 'How the data will be used' should have explained the methods of analysis that would be used, rather than explaining how data would be stored.</p> <p>A query was raised regarding the statement in the application form that the data provided 'will be merged with other secondary data' as it was not clear what data this would include, how it would be linked and whether this could lead to any of the data becoming potentially identifiable. A reference to measuring variations in hospital mortality was also queried, as it was not clear whether this would require the use of ONS mortality data.</p> <p>The need to consider the principle of data minimisation was raised, as the applicant had requested a large amount of data for the whole population. It was agreed that the applicant should be asked to provide a clearer justification for why this amount of data was required.</p>
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2.9	<p>Outcome: Unable to recommend for approval. Further detail requested on the anticipated benefits, outputs and method of analysis, and justification for why such an extensive dataset is needed for the whole population. Clarification requested about the statement that 'the data provided by HSCIC will be merged with other secondary data' - particularly what datasets this will include, and whether this could lead to the data becoming potentially identifiable. Clarification also requested regarding a reference to measuring variations in mortality, and whether ONS data is required for this. Review of security policy also required.</p>
	<p><u>King's College London (Presenter: Dickie Langley) NIC-236594-T3Q6W</u></p>
2.10	<p>John Craven declared an interest in this application and did not participate in the discussion.</p> <p>Application summary: This application requested pseudonymised, non-sensitive HES data in order to analyse health outcomes related to proximity to airports. It was confirmed that the data would not be used for commercial purposes.</p> <p>It was noted that the applicant had research ethics approval until 23 October 2016, and data retention until that date was requested subject to moving to the new Data Sharing Agreement documentation by 28 February 2015.</p> <p>Discussion: The Group expressed their support for this research, but a number of queries were raised that required clarification from the applicant. It was not felt to be clear from the application form whether data was requested for the whole country, or only for certain geographical areas based on the location of airports. In addition a query was raised regarding a reference to using HES data 'together with environment and airport related data', as the Group were unclear whether this would involve data linkage. Further details regarding the anticipated benefits to the health and social care system were also requested, as well as the target date for these benefits, as it was not felt that these were adequately described. It was suggested that the applicant's research protocol could potentially provide these details and help to clarify the methodology.</p>
	<p>Outcome: Unable to recommend for approval. Clarification requested regarding the extent of the data requested, i.e. whether this would be for the whole population or only certain geographic areas. Clarification also requested around the use of environment and airport related data, and whether the HES data will be linked to these datasets. Further details requested regarding the anticipated health and social care benefits as well as target dates for these benefits.</p> <p><u>i5 Health (Presenter: Dave Roberts) NIC- 249530-Q5J8H</u></p> <p>Application summary: This application was from a commercial organisation with the purpose of evaluating non-medical prescribing on behalf of the Health Education Board and supporting clinical commissioning groups in their decision making for commissioning purposes. The application requested non-sensitive, pseudonymised HES and SUS PbR data.</p> <p>Discussion: A query was raised regarding the DPA registration details provided, as the year was given as 2013-15 and it was noted that registration was usually only for one year. The wording of the stated data retention period was also queried.</p> <p>The Group asked for clarification of the statement that the applicant would 'review existing data sources' and whether this was intended to mean that other data sources would be linked with the HES data provided. Clarification was also requested of a reference to 'NHS Halton CCG, C4G CCG, Brent CCG, Ashford CCG, etc.'</p> <p>Outcome: Recommendation to approve subject to clarification of DPA registration dates and</p>

the data retention period wording. Also subject to clarification of reference to reviewing 'existing data sources' and what this entails, and elaboration of the term 'etc.' on page 4 of the application summary.

Care Quality Commission (CQC) (Presenter: Dickie Langley) NIC-292297-K3G0K

Application summary: The Group had previously discussed this application at the 14 October 2014 meeting and been unable to recommend approval, and the applicant had now provided a response to the concerns raised. The application was for HES, HES-ONS and Mental Health Minimum Dataset (MHMDS) data as well as the MHMDS bridging file to allow data linkage. It was explained that this data was needed for CQC to meet its statutory responsibilities.

Discussion: The Group were content with the clarification provided around the data retention periods and the legal basis for the application, but there remained significant concerns. It was not felt that the applicant had sufficiently describe the health and care benefits and the outputs of this work in the application form, although it was noted that some additional detail had been provided in the response letter. Furthermore it was noted that the applicant had not provided details of how members of the public would be informed about this use of data.

It was also noted that the applicant had recorded their organisation type as 'Local authority' on the application form, and it was felt that the category 'Commercial / Other' would be more appropriate. It was agreed that the application form template should be updated so that 'Commercial' and 'Other' were separate categories.

It was agreed that the applicant should asked to provide a clearer justification for why patient identifiable data was required, and to confirm whether this was in line with the CQC code of practice on confidential information.

Outcome: Unable to recommend for approval. Clarification requested regarding the specific purposes and the benefits and outputs that will be produced. Further details requested regarding fair processing and how patients have been made aware of this use of data. Applicant also asked to confirm whether identifiable data is required and if this is in line with the CQC code of practice on confidential personal information.

Imperial College London – Dr Foster Unit (Presenter: Dave Roberts) NIC-292308-P3C3Z

Application summary: This application for identifiable, sensitive HES data had previously been discussed at the 28 October 2014 meeting, when DAAG had been unable to recommend approval. Further information had been requested regarding why Imperial College required identifiable data, and the DPA registration wording had also been queried. The Group had also expressed concerns about the fair processing materials provided. The applicant had now provided justification for why identifiable data was needed and included an update to the DPA registration wording given. Updated fair processing materials had also been provided.

Discussion: The Group were content that the first two of the three points raised at the previous meeting had been addressed.

There was a detailed discussion of the updated fair processing notice provided, and there remained a number of concerns. Specifically it was felt that the information was not easy to follow from a lay perspective, and the process to withdraw consent in particular was discussed. There were also concerns that the fair processing notice was not easy to find on the Imperial College website. It was suggested that the applicant should refer to the ICO privacy notices Code of Practice.

	<p>It was noted that the applicant's Section 251 approval was due to be considered for renewal by HRA CAG by 7 February 2015, and it was noted that HRA CAG would be considering fair processing as part of the renewal process. It was agreed that the Group's recommendation to approve should be subject to the renewal of Section 251 approval by 7 February 2015.</p> <p>Outcome: Recommendation to approve extension to 28 February 2015, subject to renewal of Section 251 approval by HRA CAG. DAAG expressed significant concerns about the fair processing materials supplied, and agreed to provide detailed feedback by email. Applicant also advised to review the ICO privacy notices Code of Practice.</p> <p><u>NHS England - Casemix (Presenter: Andrew Hall) NIC-302643-R3R2H</u></p> <p>Application summary: This application was to renew an existing agreement for NHS England to receive pseudonymised Casemix HES data, which was described as HES data that had been processed by the Casemix grouper product to create resource groups. This data would be used to support the development and quality assurance of new and existing currencies within the healthcare system.</p> <p>Discussion: Clarification was requested regarding the statement that the analysis undertaken by the NHS England pricing team would be shared outside the team for purposes 'including, but not limited to' as it was felt that this statement was very open-ended. The Group also requested clarification of references to 'Organisations involved with currency development' and 'governance groups', and it was suggested that the application should be updated to either include a full list of these organisations and groups or a link to where the full list could be found.</p> <p>There was a discussion around whether the data could potentially be used for commercial purposes and it was explained that while data on Health Resource Groups was publicly available and could therefore be accessed by commercial organisations, the data requested would not be used directly for any commercial purposes.</p> <p>Outcome: Unable to recommend for approval. Clarification requested regarding reference to data being 'shared outside of the NHS England Pricing Team, including, but not limited to' and what data would be shared with who. Clarification also requested regarding 'Organisations involved with currency development' and what organisations this included, and similar which organisations were included in the term 'governance groups'.</p>
3	<p>Any other business</p> <p>It was noted that a response had been received for the two group applications that had been considered at the 12 November 2014 DAAG meeting (NHS England Midlands & East Consortium - Risk Stratification and NHS England Midlands & East Consortium – Accredited Safe Haven). It was agreed that this response would be circulated to members by email.</p>

Summary of Open Actions

Date raised	Action	Owner	Updates
18/11/2014	DAAG Chair to circulate the response received for the Monitor CHKS application (NIC-281120-P8S3P).	Alan Hassey	
18/11/2014	Alex Bell to provide a report on applications considered out of committee.	Alex Bell	
18/11/2014	DAAG Chair to circulate the response received about PHE retaining data derived from HES.	Alan Hassey	
12/11/2014	Dawn Foster to discuss DPA registration concerns with the ICO.	Dawn Foster	18/11/14: This had been raised with the ICO and a response was awaited.
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).	Dawn Foster	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.
28/10/2014	Garry Coleman to speak to Stuart Richardson regarding whether the Local Patient ID field is used in SUS.	Garry Coleman	04/11/14: Ongoing. 12/11/14: Formal confirmation requested that LOPATID is not included in SUS. 18/11/14: No update available.
22/10/2014	Diane Pryce to circulate questions regarding fair processing and consider including this in the application summary template.	Diane Pryce	28/10/14: Ongoing. DP has raised this with colleagues who are drafting application summary template. 04/11/14: Ongoing. 12/11/14: Ongoing. 18/11/14: A meeting had been scheduled to discuss this, and an update would be provided at the next DAAG meeting.