

Data Access Advisory Group

Minutes of meeting held 12 November 2014

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

In attendance: Alex Bell, Diane Pryce, Frances Hancox, David Evans, Jackie Gallagher (applications 2.1 and 2.2), Garry Coleman (applications 2.3, 2.8 - 2.11) Stuart Richardson (applications 2.6 - 2.7), Jim Duffy (applications 2.4 - 2.5), Jo Simpson (application 2.12), Terry Hill (application 2.12)

Apologies: None

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 4 November 2014 meeting were reviewed and approved as an accurate record.</p> <p>The Group discussed whether to continue to use the current format of minutes or to publish sections of the applications tracker instead; it was agreed that the current format of written minutes would continue to be used.</p> <p>Updates were given on the following actions:</p> <ul style="list-style-type: none">• 22/10/2014-01: Diane Pryce to circulate questions regarding fair processing and consider including this in the application summary template. This action was ongoing.• 28/10/2014-01: Garry Coleman to speak to Stuart Richardson regarding whether the Local Patient ID field is used in SUS. It was thought that this field was not included in the Secondary Uses Service (SUS), and formal confirmation of this had been sought.• 28/10/2014-02: Garry Coleman to seek confirmation regarding whether any issues had been raised by ONS regarding this use of data (UHB NIC-292303-L4B0Z). It was confirmed that ONS had not formally raised any issues regarding this, and the action was closed.
2 2.1	<p>Data applications</p> <p><u>University of Oxford - Asymptomatic Carotid Surgery Trial (IAO: Jackie Gallagher) NIC-288323</u></p> <p>Application summary: This application was for an amendment to an existing agreement, requesting GP practice codes in addition to the data already received. It was explained that this was a consented study, enrolling asymptomatic patients to compare the safety of two interventions routinely carried out.</p> <p>Discussion: The Group noted that this study had been going on for several years, and it was noted that current Research Ethics Committee approval was in place. A query was raised regarding a reference on the application form to '28th February' and it was confirmed that this should have included the year 2015.</p> <p>There was a discussion around the Data Protection Act 1998 (DPA) registration wording for the applicant, as this did not appear to cover health research. It was suggested that this was due to the new approach taken by the Information Commissioner's Office (ICO) to generic</p>

	<p>DPA registration wording for certain categories, and it was agreed that this issue should be discussed with the ICO.</p> <p>It was noted that the consent materials used by the study had not been included with the application, and the Group requested sight of these.</p> <p>Outcome: Recommendation to approve subject to satisfactory review of consent materials.</p> <p>Action: Dawn Foster to discuss DPA registration concerns with ICO.</p>
2.2	<p><u>HSCIC Clinical Audit Support Unit (CASU) and The Royal College of Surgeons of England - National Oesophago-Gastric Cancer Audit (IAO: Jackie Gallagher) NIC-292440-R9G8P</u></p> <p>Application summary: This application was an amendment to an existing agreement, with Place of Death requested from the Office of National Statistics (ONS) mortality data in addition to the data already received.</p> <p>The aim of the audit was to assess the quality of care received by patients with oesophago-gastric cancer in England and Wales, with linked data returned to the HSCIC CASU team who then anonymise patient identifiers. This anonymised linked dataset was then provided to the Clinical Effectiveness Unit at Royal College of Surgeons for analysis and the production of an annual report.</p> <p>Discussion: It was felt that the application summary provided did not clearly explain what data was shared with whom, and it was noted that the Health Quality Improvement Partnership (HQIP) were referred to as the data controller but that the Information Governance (IG) Toolkit score for the Royal College of Surgeons had been provided.</p> <p>There was a discussion around the description of this data as anonymised, and whether including Place of Death could make it more likely that the individuals could be re-identified. It was agreed that this should be raised with the Health Research Authority Confidentiality Advisory Group (HRA CAG). It was also agreed that clarification should be sought regarding whether the data shared with the Royal College of Surgeons would be anonymised or pseudonymised.</p> <p>Outcome: Unable to recommend for approval. Clarity required around whether the data requested is pseudonymised or anonymised, and clarity around who data will be shared with and for what specific purpose.</p> <p>Action: 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.</p>
2.3	<p><u>CASU University of York - National Audit of Cardiac Rehabilitation (IAO: Garry Coleman) NIC-282388-L2K1Y</u></p> <p>Application summary: This was a new application for pseudonymised, non-sensitive Hospital Episode Statistics (HES) data in order to support the National Audit of Cardiac Rehabilitation. The aim of the audit was to assess the quality of care received by patients with oesophago-gastric cancer in England and Wales.</p> <p>Discussion: It was noted that at one point the application provided referred to 'anonymised' rather than 'pseudonymised' data, and it was agreed that this should be corrected to clearly state that pseudonymised data would be provided. It was noted that all outputs would have small numbers suppressed in line with the HES protocol.</p>

	<p>Outcome: Recommendation to approve subject to updating a reference to 'anonymised' data to clarify that the data is pseudonymised.</p> <p>2.10 <u>University of Oxford - Internet Use and Health Outcomes (IAO: Garry Coleman) NIC-255171-N8Y5L</u></p> <p>Application summary: This application was for tabulated aggregated HES data, grouped by the sensitive field OACODE. It was noted that due to the use of this sensitive field, the aggregated data would need to be shared under a Data Sharing Agreement rather than making it publically available. The data would be used in order to evaluate the number of inpatient and outpatient visits in relation to internet use, and analyse a relative measure of the wellbeing of the population based on the available admission and discharge diagnoses. It was confirmed that the information security policy provided had been reviewed and approved by the relevant HSCIC team.</p> <p>Discussion: The potential for the requested data to include small numbers was discussed, and it was noted that the application asked for small numbers not to be suppressed. The Group felt it would be more appropriate for small numbers to be suppressed in the data provided to the applicant.</p> <p>It was noted that the DPA registration wording on the application form appeared to be incomplete, and this would need to be corrected on the form.</p> <p>The Group discussed the need for applications to have a clear medical purpose, and it was not felt that this application clearly explained what health or healthcare benefits could be derived from this use of data. It was suggested that one option would be for the applicant to provide a copy of their research proposal, as this would contain a higher level of detail than the application submitted. Alternatively, it was noted that the applicant would have the option to receive aggregated data without using the sensitive field OACODE.</p> <p>Outcome: Unable to recommend for approval. Applicant asked to provide a clear statement around health benefits and medical purpose, and provide more detail about the research project.</p>
<p>2.6</p>	<p><u>NHS England Midlands & East Consortium¹ - Risk Stratification (IAO: Stuart Richardson) NIC-302056-T7Y0W</u></p> <p>Application summary: This was a class application from a group of nine clinical commissioning groups (CCGs) for identifiable, non-sensitive SUS data in order to identify at risk patients for additional targeted interventions. The legal basis for this was section 251 support from HRA CAG. It was stated that the organisation MedAnalytics would act as a data processor on behalf of these organisations, and it was confirmed that all nine CCGs had satisfactory IG Toolkit scores. It was noted that the DPA registration for NHS West Essex CCG had expired and the process was underway to renew this, and no data would be shared with that organisation until this renewal had been confirmed.</p> <p>Discussion: The Group noted that no IG Toolkit score had been provided for MedAnalytics, and it was agreed that this would need to be confirmed.</p> <p>A query was raised regarding whether the contracts between the CCGs and MedAnalytics</p>

¹ 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>covered the requirements of the seventh data protection principle, and it was agreed that confirmation of this would be sought.</p> <p>Outcome: Recommendation to approve subject to confirmation out of committee that the requirements of the seventh data protection principle has been satisfactorily covered in contract between data controller and processor, and subject to confirmation of a satisfactory IG Toolkit score for MedeAnalytics.</p>
2.7	<p><u>NHS England Midlands & East Consortium¹ - Accredited Safe Haven (IAO: Stuart Richardson) NIC-302045-N4J5Y</u></p> <p>Application summary: This was a class application for weakly pseudonymised SUS data from a group of nine CCGs, with MedeAnalytics acting as data processor. The legal basis for this was section 251 support from HRA CAG. As for the previous application it was noted that the DPA registration for NHS West Essex CCG was due to be renewed, and no data would be shared with that organisation until this renewal had been confirmed. Data would be used to support commissioning functions including auditing and monitoring patient care delivery, effective pathways and the use of resources and capacity; supporting service redesign and modernisation; understanding health needs on geographical bases; and providing anonymised patient level or aggregate data for commissioning purposes to healthcare providers with a legitimate relationship with the individuals.</p> <p>Discussion: Queries were raised regarding references in the application to 'other agencies' and to 'customers and third parties', and exactly what types of organisations this could include. It was agreed that the applicant would be asked to clarify this.</p> <p>As for the previous application, it was noted that no IG Toolkit score had been provided for MedeAnalytics and it was agreed that this would need to be confirmed. A number of typographical errors in the application form were also noted, and it was agreed that these would be corrected.</p> <p>Outcome: Unable to recommend for approval. Further details requested about reference to 'other agencies' accessing data, as well as clarity about a reference to 'customers and third parties' and what organisations would be included in this category. Confirmation of IG Toolkit score for MedeAnalytics also requested.</p>
2.4	<p><u>Royal College of Surgeons of England - Fracture Liaison Service Database Audit (FLS-DB) Feasibility Study (Presenter: Jim Duffy) NIC-283020-M4X2Z</u></p> <p>Application summary: This was a renewal application to share data from general practice clinical systems and secondary care data from the FLS audit with the Royal College of Surgeons. This data would be pseudonymised, and it was explained that general practice data had been obtained on a practice opt-in basis. The audit aimed to improve care for older patients who have experienced falls and fragility fractures, and to make recommendations to healthcare providers on the provision of services and best practice.</p> <p>Discussion: The Group queried whether the data extracted from general practices had been pseudonymised at source, and it was explained that this was not the case as identifiers were needed to link the data to the FLS audit data. However, it was noted that data would be pseudonymised before it was shared with the Royal College of Surgeons. It was noted that section 251 approval was in place for the flows of data requested.</p> <p>A query was raised regarding the role of various different organisations referred to in the application and it was stated that HQIP had commissioned the Royal College of Physicians to carry out this feasibility study, with the HSCIC and the Royal College of Surgeons being</p>

	<p>subcontractors. It was agreed that the inclusion of a data flow diagram would have made the application easier to follow. A further query was raised regarding the fact that the applicant organisation had been labelled as 'commercial/other' on the application form, while in fact the Royal College of Surgeons was considered to be a research organisation.</p> <p>The application form did not specify whether the applicant's System Level Security Policy had been reviewed by the relevant HSCIC team, and it was agreed that this would need to be confirmed.</p> <p>Outcome: Recommendation for approval subject to confirmation that the applicant's System Level Security Policy has been appropriately reviewed.</p>
2.5	<p><u>CASU University of York - National Audit of Cardiac Rehabilitation - review of consent (Presenter: Jim Duffy) 200814-f1</u></p> <p>Application summary: This was a request to review the consent materials that would be used for a pilot study of participation by cardiac rehabilitation programmes in Scotland. The Group had previously reviewed the consent materials at the 20 August 2014 DAAG meeting and suggested a number of changes to the applicant.</p> <p>Discussion: Overall the Group were content with the updated consent materials. However, it was suggested that as the pilot study would be taking place in Scotland it should be made clear that the HSCIC was an official body in England. In addition, there were some concerns that the phrase 'vital status' might not be clearly understood, and it was suggested that this should be replaced with the phrase 'death statistics held by the Office of National Statistics'.</p> <p>Outcome: Recommendation to approve subject to a clearer reference to HSCIC's role in England, and replacing reference to 'vital status' to statement that researchers will have access to death statistics held by ONS</p>
2.8	<p><u>University Hospitals Birmingham NHS Foundation Trust (IAO: Garry Coleman) NIC-292303-L4B0Z</u></p> <p>Application summary: This renewal application for HES and HES-ONS data had previously been considered by DAAG on 28 October 2014. The updated application contained further details and clarifications, and it was noted that the non-NHS organisations referred to who could access the online Healthcare Evaluation Data tool were PWC Healthcare and KPMG Healthcare.</p> <p>Discussion: The Group confirmed that they were content with the responses provided to their previous queries.</p> <p>It was noted that the applicant had indicated the data would not be used for commercial purposes, but that it was sometimes necessary to recoup the costs associated with providing analytical outputs. The Group agreed that a statement should be added to the application for the avoidance of doubt to clarify that the only purposes for which the data may be used are those outlined within the application.</p> <p>There was a discussion about the fact that the applicant organisation had been described in the application as an 'Other Health and Social Care System Public Body', when it would be more accurate to describe the organisation as a healthcare provider. It was agreed that this should be corrected on the application form.</p> <p>In addition it was agreed that confirmation should be sought regarding which section of the Health and Social Care Act 2012 was applicable as a legal basis.</p>

<p>2.12</p>	<p>Outcome: Recommendation to approve subject to the inclusion of the following sentence in the application form: 'For avoidance of doubt, the only purposes for which the data may be used are those outlined within this application.' Also subject to confirmation of which section of the Health and Social Care Act 2012 is applicable as a legal basis for this request.</p> <p><u>NHS England - Complete pseudonymised MHMDS extract for financial year of 2012/13 and 2013/14 (Presenter: Jo Simpson) NIC-269877-F5B0D</u></p> <p>Application summary: This was a new application for pseudonymised, non-sensitive record-level Mental Health Minimum Dataset (MHMDS) data. NHS England intended to use this data for analysis of commissioning patterns, disease prevalence, treatments and outcomes at practice, CCG and provider level.</p> <p>Discussion: Although it was noted that noted that the data requested was pseudonymised and non-sensitive, there were concerns that the application did not clearly state what the specific outputs of this use of data would be. It was agreed that the applicant should be asked to provide additional detail regarding this for consideration out of committee, and it was also agreed that a higher level of detail would be sought for any future applications.</p> <p>A query was raised regarding whether the data would be used for any commercial purposes, although this had not been specified on the application form. It was agreed that the applicant should be asked to clarify this.</p> <p>Outcome: Recommendation to approve subject to clarification around specific outputs, and clarification regarding if there will be any commercial uses of data.</p> <p>2.9</p> <p><u>IMS Healthcare (IAO: Garry Coleman) NIC-291741-B1B2Y</u></p> <p>Application summary: This application for pseudonymised, non-sensitive HES data had previously been discussed on 28 October 2014, when DAAG had been unable to recommend approval. The data requested would be used to create a linked pseudonymous record primary and secondary care data repository, which would allow researchers an insight into the interaction between disease, treatment and prescribing across primary and secondary care.</p> <p>Discussion: Clarification had been sought regarding whether the applicant had requested identifiable data, and it was confirmed that only pseudonymised data was requested. Additional detail had also been provided regarding the intended outputs of the work. A reference within the application form to 'the Bunker' was queried, and it was clarified that this was the storage facility where data would be held. It was also confirmed that current Research Ethics Approval was in place.</p> <p>The Group were content that the points they had raised on 28 October 2014 had been adequately addressed by the applicant.</p> <p>Outcome: Recommendation to approve.</p> <p>2.11</p> <p><u>Leeds Teaching Hospitals NHS Trust - Service evaluation of heart failure pathway (IAO: Garry Coleman) NIC-230103-K0K3S</u></p> <p>Application summary: This application for identifiable HES and HES-ONS data had previously been considered at the 30 July 2014 DAAG meeting, when it had been recommended for approval subject to confirmation that the section 251 approval covered the identifiers requested. The aim of the application was to audit the efficacy of NICE guidelines</p>
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	<p>to identify left ventricular systolic dysfunction in patients in primary care.</p> <p>Discussion: There was some uncertainty regarding the applicant's response to the queries that had been raised by DAAG, as this still referred to the use of identifiable data while it had been confirmed that the section 251 cover required that data be pseudonymised. It was agreed that the applicant should again be asked to clarify what data was required and the data flows involved.</p> <p>A query was raised regarding whether the study would be classed as research, but it was confirmed that the Research Ethics Committee had confirmed that they did not consider this to be research.</p> <p>It was noted that sectional 251 approval had been granted subject to three conditions, which included the need to make reasonable efforts to inform data subjects of the use of their data. The Group agreed that confirmation would need to be sought that a final section 251 approval letter had been received which confirmed that these conditions had been met, as otherwise the approval was not considered to be in effect. It was suggested that the date of this final approval letter should also be confirmed to ensure the approval was still valid.</p> <p>Outcome: Unable to recommend for approval. Further clarity required about what data is requested and how this will flow, as well as a clearer explanation of the purpose and expected outputs. Confirmation requested regarding whether a final approval letter from HRA CAG was received, and if so what the date of this was.</p>
3	<p>Any other business</p> <p>No other business was raised.</p>