

Data Access Advisory Group

Minutes of meeting held 4 November 2014

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

In attendance: Garry Coleman (until application 3.6), Diane Pryce, Frances Hancox, Stuart Richardson (applications 3.4 – 3.5), Jennifer Donald (application 3.6 only)

Apologies: None

1	<p>Review of previous minutes and actions</p> <p>The minutes of the 28 October 2014 meeting were reviewed and approved as an accurate record. The updated minutes of the 22 October 2014 meeting were also reviewed and approved.</p> <p>Action updates were provided and recorded in the applications tracker.</p>
2	<p>Out of committee applications</p> <p>Two applications had been considered out of committee:</p> <p><u>University Hospitals Birmingham (NIC-292303-L4B0Z)</u></p> <p>Following the discussion of this application at the DAAG meeting on 28 October 2014, when DAAG had been unable to recommend approval for the requested renewal, clarification had been sought whether DAAG would consider recommending the approval of an extension to allow the applicant to continue to hold data they currently held until the end of February 2015. The DAAG Chair made this recommendation out of committee.</p> <p>Outcome: Recommendation to approve an extension to cover the data already held up to 28 February 2015.</p> <p><u>STAMPEDE Trial: Systematic Therapy in Advancing or Metastatic Prostate Cancer – Evaluation of Drug Efficacy</u></p> <p>The consent materials for this application had been considered out of committee by the Acting DAAG Chair and one independent member.</p> <p>Outcome: Recommendation to approve</p>
3	<p>Data applications</p>
3.1	<p><u>BUPA Health Dialog (IAO: Garry Coleman) NIC-300172-K4X1P</u></p> <p>This application was for renewal of the agreement to provide pseudonymised Hospital Episode Statistics (HES) and Secondary Uses Service (SUS) data, the application for which had previously been considered and recommended for approval by DAAG on 9 September 2014. It was confirmed that additional monthly releases of data were requested but that there were otherwise no changes from the previous request.</p>

<p>3.2</p>	<p>It was confirmed that the data requested would only be used Bupa Health Dialog in order to optimise the provision of health care, and that other parts of the Bupa Group would not have access to the record level data provided. In particular it was noted that the insurance service operated by Bupa would not benefit from or receive any analytical insight gained from the data. A query was raised regarding this, as there was also a statement within the application form that the insurance service would have 'no direct use' of the data, and there were concerns that this could imply that the insurance service could indirectly benefit. It was agreed that this sentence should be removed for clarity, as it could be considered to contradict the statement elsewhere that the insurance service would not benefit from the data.</p> <p>It was suggested that more detail could have been provided around the expected measurable benefits of this use of data, and it was agreed that the applicant should be asked to provide additional detail when the application was next due for renewal, with specific examples of how data had been used.</p> <p>It was also noted that the application form incorrectly listed some dates, and it was agreed that these would be corrected.</p> <p>Outcome: Recommendation to approve subject to removal of statement that the BUPA 'insurance business component has no direct use of the HES data', as this was felt to weaken statements made elsewhere in the document. Application form also to be updated to correct errors regarding dates.</p> <p><u>Hspot Ltd (IAO: Garry Coleman) NIC-197680-G2L7Q</u></p> <p>The applicant had requested tabulated, aggregated HES data with small numbers suppressed but with the sensitive field Consultant Code included, in order to publish data on the number of specific procedures carried out by consultants. It was noted that this application had previously been considered by DAAG on 31 July 2013, but due to changes in processes this had been brought back to DAAG for further review prior to data release.</p> <p>There was a discussion around whether it was appropriate for DAAG to review applications for anonymised aggregated data with small numbers suppressed. It was confirmed that although the data was not patient identifiable, it would contain the sensitive field Consultant Code which would allow consultants to be identified and it was therefore felt to be appropriate for DAAG to review the application.</p> <p>The Group discussed the applicant's intention to publish this aggregated data on a website (FindMeHealth.com) to help inform patients about clinician experience for specific surgical procedures, and it was confirmed that data would only be published when the consultant in question had consented to the publication of data about them.</p> <p>A query was raised regarding the relationship between Hspot and the website FindMeHealth, and whether these were separate legal entities or the same company. It was confirmed that these were part of the same legal entity.</p> <p>Some points of accuracy were raised regarding what appeared to be cut and paste errors in the application, and it was agreed that these should be corrected. It was noted that the DPA registration details listed in the application had expired, but that the applicant's DPA registration had been renewed until October 2015.</p> <p>There was a brief discussion around the possibility that the data provided would be linked with data from other sources, but it was noted that the data provided was not patient identifiable and so this query was not felt to be applicable to this application.</p>
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	<p>Some concerns were expressed around the fact that the applicant would be provided with data for all consultants regardless of whether they had provided consent for their data to be published, although it was noted that no data would be published without the consent of consultants. The Group suggested that in future, the applicant should consider requesting data only for those consultants who had given their consent, with the possibility of requesting additional data as more consultants opted in.</p> <p>Outcome: Recommendation to approve</p>
<p>3.3</p>	<p><u>University of York - The Economics of Social and Health Care Research Unit (IAO: Garry Coleman) NIC-239673-L1H1V</u></p> <p>This application was for HES, HES-ONS and Patient Reported Outcome Measures (PROMS) data in order to support a range of academic projects funded by the Department of Health.</p> <p>Clarification was sought about the statement in the application form that training courses using HES data would be made available to both NHS and commercial customers, as it was not thought to be clear whether this training was provided on a commercial basis. It was also not thought to be clear whether this aspect of work was included by the Department of Health funding referred to, or if this should be considered to be a separate purpose and submitted as a separate application for data.</p> <p>A query was raised regarding why identifiable and sensitive data were required rather than pseudonymised data, and it was confirmed that only the ONS data would be identifiable and sensitive. It was noted that the legal basis for the provision of ONS data was section 42 of the Statistics and Registration Service Act 2007.</p> <p>Queries were raised about how the data would be used by each project and what the outputs and benefits would be, and it was felt that it would be helpful if further details with specific examples of uses of how data had been used could be provided for future applications.</p> <p>Clarification was requested about a reference within the application to providing reports for 'funders', and whether this meant only the Department of Health or if reports would also be provided to any other funding organisations. It was noted that the application elsewhere referred to work funded by the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) and further details were requested around this and the role of the CLAHRC as funders.</p> <p>A query was raised regarding information security, as it was noted that the applicant had not completed either the Information Governance Toolkit or ISO 27002. It was explained that the applicant had provided a system level security policy, which had been approved by the HSCIC information governance team.</p> <p>Outcome: Recommendation to approve subject to clarification around the provision of reports to 'funders', and what organisations this would include; also subject to confirmation whether training courses are run on a commercial basis.</p> <p>Stuart Richardson joined the meeting to present the following two applications.</p>
<p>3.4</p>	<p><u>NHS Liverpool Clinical Commissioning Group (IAO: Stuart Richardson) NIC-292083-R2Y3M</u></p> <p>This application for pseudonymised SUS data had been considered by DAAG at the 9 September 2014 meeting and recommended for approval subject to confirmation that only the datasets listed on page 5 of the Data Sharing Agreement would be provided, confirmation of the applicant's DPA registration expiry date, and subject to the anonymisation of any free text</p>

	<p>fields that could contain identifiers. It was confirmed that the application had been updated to remove references to any other datasets and the applicant's DPA registration expiry date was provided. It was also confirmed that free text fields would be subject to data cleaning prior to release to the applicant.</p> <p>It was noted that the application had originally been to receive data until the end of October 2014, which had now passed. As the relevant section 251 approval from the Health Research Authority Confidentiality Advisory Group (HRA CAG) had now been extended to April 2015, it was agreed that the data sharing agreement for this application should also be extended to April 2015.</p> <p>The Group confirmed that the conditions set by their previous recommendation had been met to their satisfaction.</p> <p>Outcome: Recommendation to approve</p>
<p>3.5</p>	<p><u>Great Yarmouth and Waveney Clinical Commissioning Group (IAO: Stuart Richardson) NIC-285509-J7G7G</u></p> <p>This application for pseudonymised SUS data had been considered by DAAG at the 9 September 2014 meeting and recommended for approval subject to confirmation that any aggregated reports shared with provider trusts would not contain any data that could potential identify individuals (such as small numbers), confirmation of DPA registration expiry date, and anonymisation of any free text fields that could contain identifiers. The DPA registration expiry date was provided, and it was confirmed that free text fields would be subject to data cleaning prior to release to the applicant. The applicant had confirmed that any reports shared with providers would not contain patient identifiable data, and that reports would only be shared if small numbers had been appropriately obscured.</p> <p>It was noted that as with the previous application, this application had originally been to receive data until the end of October 2014. As the relevant section 251 approval from HRA CAG had now been extended to April 2015, it was agreed that the data sharing agreement for this application should also be extended to April 2015.</p> <p>The Group confirmed that the conditions set by their previous recommendation had been met to their satisfaction.</p> <p>Outcome: Recommendation to approve</p> <p>John Craven, Stuart Richardson and Garry Coleman left the meeting at this point, and Jennifer Donald joined the meeting.</p>
<p>3.6</p>	<p><u>Institute of Education - Centre for Longitudinal Studies (IAO: Jennifer Donald) NIC-274440-N1J1Z</u></p> <p>This was an application for list cleaning and Office of National Statistics (ONS) mortality data to support the Next Steps longitudinal study, which had originally been launched by the Department of Education in 2004. It was noted that ONS approval had not yet been granted, and DAAG were therefore not asked to make a recommendation on the application at this stage. It was explained that list cleaning had been requested to provide current address details for study participants, so that they could be asked to re-consent, and mortality data had been requested to ensure that the study would not attempt to contact individuals who were now deceased.</p> <p>A query was raised regarding whether the data was requested for a medical purpose, and it</p>

	<p>was confirmed that this was the case as the study would consider the physical and mental health of study participants.</p> <p>It was agreed that the study was felt to be in the public interest and it was noted that section 251 support was in place from HRA CAG. However the Group noted that before making a recommendation they would wish to see the consent materials used by the study, as well as the original fair processing notice from when the study began.</p> <p>Outcome: For consideration at a future meeting. DAAG requested sight of patient information materials and the original fair processing notice from when the study began, as well as confirmation of ONS approval.</p>
4	<p>Any other business</p> <p>No other business was raised.</p>