

# Data Access Advisory Group (DAAG)

## Minutes of meeting held 27 January 2015

**Members:** Alan Hassey (Acting Chair), Eve Sariyiannidou, Dawn Foster, John Craven (applications 2.1 to 2.8), Patrick Coyle

**In attendance:** Alex Bell, Karen Myers, Frances Hancox, David Evans, Dave Roberts (application 2.1), Kathryn Knight (application 2.1), Dickie Langley (applications 2.2 to 2.12)

**Apologies:** Sean Kirwan

<b>1</b>	<p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 20 January 2015 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 7).</p> <p><b>Out of committee recommendations</b></p> <p>The following applications had previously been recommended for approval with caveats, and it was confirmed that the relevant caveats had now been fulfilled:</p> <ul style="list-style-type: none"><li>• Leeds Teaching Hospitals NHS Trust, NIC-230103-K0K3S</li><li>• Res Consortium, NIC-280016-T1G4D</li><li>• University of Bristol, NIC-2 81848-W3T5B</li></ul>
<b>2</b>  <b>2.1</b>	<p><b>Data applications</b></p> <p><u>Public Health England – Diabetic Retinopathy (Presenter: Dave Roberts) NIC-154590-YG6QH</u></p> <p><b>Application summary:</b> This application was for primary care data that would be extracted via the General Practice Extraction Service (GPES). The applicant requested identifiable data for patients with a diagnosis of diabetes, enabling these patients to be invited for diabetic eye screening appointments. Data would be provided to the Public Health England (PHE) NHS Diabetic Eye Screening Programme and then on to local screening programmes, and it was noted that the organisation Quicksilver managed the screening database and would act as data processor. It was also noted that Redcentric provided hosting services.</p> <p>The Group were informed that the application had previously been considered in August 2013 by the GPES Independent Advisory Group (IAG), who had made a recommendation for the requirement to proceed to extraction.</p> <p><b>Discussion:</b> Some differences were noted between this application and the papers that had been considered by the GPES IAG in August 2013. In particular it was noted that the data requested would now only be used to support direct care, and not for any secondary purposes outlined to the GPES IAG.</p> <p>There was a query regarding the role of DAAG in considering requests for data to support direct care. It was noted that the Patient Information Advisory Group, predecessor of the Health Research Authority Confidentiality Advisory Group (HRA CAG) had advised that the proposed use of data was considered to be direct care and therefore approval under section</p>

	<p>251 of the NHS Act 2006 was not required. It was also noted that further clarification had been sought regarding security assurances for Quicksilver and Redcentric, and the Group requested sight of this information once available.</p> <p><b>Outcome:</b> Recommendation to approve. Application form to be updated to explicitly link sections 2 and 7 and to clarify information security arrangements for Quicksilver and RedCentric.</p>
2.2	<p><u>University of Manchester (Presenter: Dickie Langley) NIC-317873-H3L1R</u></p> <p><b>Application summary:</b> This application for a standard extract of pseudonymised, non-sensitive Hospital Episode Statistics (HES) data had previously been considered at the 2 December 2014 DAAG meeting, when the Group had been unable to recommend approval. Further information had been requested about a number of aspects including the details of the projects, the duration of project 3 specifically and confirmation of whether any of the projects would be linked together. It had been confirmed that the data would only be used for the five projects described, and only the University of Manchester would have access to the data. The relevant HSCIC team had confirmed that both data centres where data would be held had adequate security policies in place. It had also been clarified that project 3 was ongoing and expected to end in January 2017.</p> <p><b>Discussion:</b> The Group agreed that the responses provided appropriately answered the questions raised at the 2 December 2014 meeting. There was a discussion regarding the need to ensure appropriate dissemination to relevant parts of the health service, to encourage the realisation of potential healthcare benefits. It was noted that the applicant had not yet signed a HSCIC framework contract, and no data would be shared until this had been signed.</p> <p><b>Outcome:</b> Recommendation to approve. SIRO letter to reflect that DAAG suggest the applicant should consider further how to best disseminate the results of these projects to ensure clear evidence of potential healthcare benefits.</p>
2.4	<p><u>Queen Mary University of London (Presenter: Dickie Langley) NIC-316335-R5V1J</u></p> <p><b>Application summary:</b> This application was for pseudonymised, non-sensitive HES data and had previously been considered by DAAG on 9 December 2014. The Group had requested further details of how this use of data could benefit the UK health and care system, and the applicant had now provided this information. It was noted that some data would be used in Brazil, but that this would only be aggregated data or indicators and not record level data.</p> <p><b>Discussion:</b> Overall the Group felt that the application had improved and that the question raised at the 9 December 2014 meeting had been appropriately answered. However there were some concerns regarding the additional sentences that had been added to page 4 of the application form, as it was felt that this was not clearly phrased. It was agreed that these sentences should be replaced with a statement that the project could potentially be used to identify opportunities for the re-allocation of resources to ensure more equitable treatment across the country.</p> <p><b>Outcome:</b> Recommendation to approve. Application to be updated to replace the amended sentences on page 4 with a statement that the project could potentially be used to identify opportunities for the re-allocation of resources to ensure more equitable treatment across the country.</p> <p><b>Action:</b> John Craven to draft guidelines for applicants requesting data as part of PhD studies.</p>

2.5	<p><u>University of Oxford – Internet Use and Health Outcomes (Presenter: Dickie Langley) NIC-317612-V1Q3X</u></p> <p><b>Application summary:</b> This application for tabulated HES data had previously been considered by DAAG at the 12 November 2014 and 13 January 2015 meetings and the applicant had been asked to provide a clear medical purpose, justify the number of data years requested, and clarify the retention period. Further details had been provided regarding the purpose, and it was confirmed that while study data would be retained by the University for a minimum of 3 years the HES data itself would be destroyed at the end of the term of agreement. The number of data years requested had also been reduced from 11 to 4.</p> <p><b>Discussion:</b> The Group discussed the additional information that had been provided regarding purpose. It was agreed that as with other similar applications, the applicant should be encouraged to consider how the research results would be disseminated in order to encourage the realisation of potential healthcare benefits. A query was raised regarding the secure disposal of HES data, as the application form had stated that data would be ‘discarded’ without providing additional details.</p> <p><b>Outcome:</b> Recommendation to approve subject the applicant specifying how data will be destroyed appropriately.</p>
2.6	<p><u>RAND Europe (Presenter: Dickie Langley) NIC-255450-G2Z6F</u></p> <p><b>Application summary:</b> This application for HES data had been considered at the 2 December 2014 meeting, when the Group had requested clarification of the data required and retention period, more information regarding the specific outputs and benefits, and clarification of the relationship between the organisations involved. It was noted that the data retention period had now been updated to specify that data would be retained for 3 years subject to the applicant moving to the new contract framework by the end of February 2015.</p> <p><b>Discussion:</b> There remained some uncertainty regarding the flow of data between the organisations described, and what processing would be carried out by which organisation. It was suggested that the use of a data flow diagram could clarify this.</p> <p><b>Outcome:</b> Recommendation to approve subject to a clearer explanation of the role of each participating organisation and the provision of a data flow diagram.</p>
2.8	<p><u>Specialist Orthopaedic Alliance (Presenter: Dickie Langley) NIC-275445-L6X9T</u></p> <p><b>Application summary:</b> This was a new application for a bespoke HES extract in order to produce an orthopaedic and spinal performance dashboard. It was noted that the dashboard would not contain any patient level data. The applicant had previously held HES data to populate this dashboard, but this agreement had expired and the data had been deleted. Data processing would be carried out on behalf of the Alliance by the Royal National Orthopaedic Hospital NHS Trust and by NA Wilson Associates.</p> <p><b>Discussion:</b> There was a query regarding the Information Governance Toolkit score provided, and it was confirmed that this score was for the Royal National Orthopaedic Hospital NHS Trust.</p> <p>A further query was raised regarding the services offered by the applicant to other organisations, and whether there was a commercial aspect to this application. It was clarified that the Specialist Orthopaedic Alliance was an NHS based alliance providing services to other NHS bodies, and that the data would not be used for commercial purposes.</p>

	<p><b>Outcome:</b> Recommendation to approve.</p> <p>John Craven left the meeting at this point.</p> <p><b>2.9</b>      <u>Salford Royal NHS FT - AQuA (Presenter: Dickie Langley) NHS FT NIC-292305-D5Z1B</u></p> <p><b>Application summary:</b> This application was from the Advancing Quality Alliance AQuA, which was described as a shared service that was part of Salford Royal NHS Foundation Trust but provided services to other NHS and social care organisations as well as private sector organisations working under NHS contracts. The applicant had previously received standard HES extracts and this application was to continue to receive that data along with ONS linked mortality data. It was intended that this would replace all existing data sharing agreements with this applicant, with the applicant with the exception of a separate agreement for Summary Hospital-level Mortality Indicator data.</p> <p><b>Discussion:</b> The Group queried what ONS data had been requested and whether this only included fact of death, or if any identifiable data was included. Specific queries were raised regarding the potential for data to be used for commercial purposes, as members of the alliance were required to pay a membership fee in order to access services that made use of both HES and ONS data.</p> <p>There was a discussion of the status of AQuA, and whether it was a separate legal entity to Salford Royal NHS Foundation Trust. The description of it as a 'shared service' was not thought to be compatible with the understood usage of the term within the NHS. In addition it was noted that the application form stated that 'nearly all' members of the alliance were from the North-West region, and the Group queried why data was therefore requested for the whole country as this was not clearly justified.</p> <p><b>Outcome:</b> Unable to recommend for approval. Clarification requested regarding the status of AQUA and whether this is a separate organisation to Salford Royal NHS FT, or what is meant by the description of it as a 'shared service'. Further details requested about the commercial elements of this application, as well as specifically what ONS data is requested and what the basis is for requesting this ONS data. Applicant to provide justification for the amount of data requested and why data is required for the whole country. Specific examples requested of current customers, the use of data and the outputs created.</p> <p><b>2.10</b>      <u>Nuffield Trust (Presenter: Dickie Langley)</u></p> <p><b>Application summary:</b> This application was for advice on consent materials only, and not for dissemination of data at this stage. The applicant intended to obtain patient consent to use HES data to evaluate the impact of services on older people's use of hospital services.</p> <p><b>Discussion:</b> The Group did not feel that the consent forms provided were adequate as they did not provide the necessary information for individuals to be able to make an informed choice regarding the use of their data. There were 7 different consent forms for the different organisations involved, and it was agreed that these forms should be more consistent. Moreover the applicant should be encouraged to consider the Information Commissioner's Office (ICO) code of practice for privacy notices, and ensure that the consent materials would follow this code of practice.</p> <p><b>Outcome:</b> Unable to recommend for approval as the consent materials provided were inadequate. DAAG recommended the applicant should consider the Information Commissioner's Office (ICO) privacy notices code of practice and demonstrate how they have followed this code.</p>
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2.7	<p><u>7.7 University of Manchester (Presenter: Dickie Langley)</u></p> <p><b>Application summary:</b> This application was for pseudonymised, sensitive HES data including the sensitive fields date of birth, sex of patient, NHS number, local patient identifier and consultant code. It was noted that the applicant's section 251 approval had expired and the applicant had applied to HRA CAG for a renewal of this.</p> <p><b>Discussion:</b> The Group noted that HRA CAG had not yet confirmed whether section 251 support could still be considered to be in place for this applicant while the annual renewal process was underway. It was agreed that it was inappropriate for DAAG to review this application until a response had been received from HRA CAG.</p> <p><b>Outcome:</b> Application to be considered at a future meeting following response from HRA CAG.</p>
2.12	<p><u>Nine Health CIC (Presenter: Dickie Langley) NIC-230924-V2R0V</u></p> <p><b>Application summary:</b> This application was to amend an existing agreement for the applicant to hold an addition 3 years of pseudonymised, non-sensitive HES data in addition to the Diagnostic Imaging Dataset (DID). This would be used to create computer models to measure risks and improve the care provided to cardiac patients. A number of organisations were involved in this work with the University of Sheffield acting in a project coordination role and Nine Health receiving and processing data from the HSCIC. It was noted that European funding was in place for this work.</p> <p><b>Discussion:</b> The Group noted that details of the relevant EU funding had not be supplied in the application form. It was felt that the roles of the different organisations involved in the consortium were not clearly described, and it was not clear which organisations would receive data and for what purpose. There were some concerns regarding the purpose described and how this aligned with the Care Act 2014 requirement for the HSCIC to share data only for the purpose of healthcare or the promotion of health.</p> <p>Questions were raised regarding how this work fit within the wider project that had received European funding, and in particular what the relationship was with the funders and how the statement that this work would not include any commercial aspects was compatible with the wider project. In addition the Group asked for the application form to more clearly explain how this application aligned with previous agreements, including assurances that the purposes had not changed.</p> <p><b>Outcome:</b> Unable to recommend for approval. DAAG found the application confusing and requested clarification regarding the objectives of the project and in particular the role of Nine Health and all partner organisations in the consortium, and their use of data. Clarification requested regarding the relationship to funders and further details of the commercial aspects of the project. Application to be updated to link back to existing agreement with assurance that the purposes for which data will be used have not changed in any way. Applicant to also provide evidence of how the stated purpose complies with the Care Act 2014 requirement for data shared to be used for the promotion of health.</p>
2.3	<p><u>Kings College London (Presenter: Dickie Langley) NIC-236594-T3Q6W</u></p> <p><b>Application summary:</b> This application had previously been considered at the 18 November 2014, 23 December 2014 and 13 January 2015 meetings and recommended for approval subject to clarification regarding why an IG Toolkit score was not provided, and further details regarding benefits and the intended specific outputs. It was clarified that while some areas of</p>

2.11	<p>Kings College London had completed the IG Toolkit, this particular team had not and therefore a System Level Security Policy had been provided and reviewed. Further information regarding benefits had also been provided.</p> <p><b>Discussion:</b> The Group were content that the previous caveats had been appropriately addressed.</p> <p><b>Outcome:</b> Recommendation to approve.</p> <p><u>McKinsey and Company (Presenter: Dickie Langley) NIC-292306-S7Y2V</u></p> <p><b>Application summary:</b> This application was to renew an existing agreement for the applicant to receive HES and Secondary Uses Service Payment by Results (SUS PbR) data, for use in benchmarking and analysis.</p> <p><b>Discussion:</b> The Group considered the amount of data requested, and whether this was justified by the stated purposes. It was agreed that the applicant should be asked to provide a clearer justification for the amount of data. It was also felt that it would be helpful if the applicant could provide a list of current customers for these benchmarking and analysis services, and specific examples of benefits to the health service and patient care that had been realised through this use of data.</p> <p>There was a brief discussion regarding the application form template, and whether this should be updated to ask applicants to clearly specify how the intended use of data would be consistent with the purposes for which the HSCIC could disclose data as set out in the Care Act 2014.</p> <p><b>Outcome:</b> Recommendation to approve subject to receiving evidence to justify the disclosure and retention of such large datasets and a list of the applicant's customers, plus examples of benefits to the NHS and to patient care.</p>
3	<p><b>Any other business</b></p> <p>No other business was raised.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
09/01/15	DF to look into lower super output areas (LSOA) and if they have previously been discussed at the Small Numbers Panel.	David Evans	13/01/15: This action had been passed to David Evans to provide an update from the Small Numbers Panel. 20/01/15: This would be raised with the Small Numbers Panel the following week. 27/01/15: A response from the Small Numbers Panel had been received, and David Evans would circulate this to DAAG members.	Open
13/01/15	Garry Coleman to provide DAAG with a briefing paper on HDIS.	Garry Coleman	20/01/15: It was agreed that a briefing paper would be circulated, but it was noted that no further HDIS applications would be brought to DAAG at this stage while internal discussions were ongoing. 27/01/15: Ongoing.	Open
13/01/15	Alex Bell to provide a summary of DAAG's previous consideration of HDIS applications.	Alex Bell	20/01/15: This would be circulated by email. 27/01/15: Ongoing.	Open
20/01/15	Alex Bell to discuss the application form template with DARS team and consider adding a section asking applicants to demonstrate how their intended use of data and dissemination of results would be compliant with the Care Act 2014.	Alex Bell	27/01/15: This discussion had been scheduled, and details would be fed back to DAAG.	Open
20/01/15	Diane Pryce to speak to HRA CAG Secretariat regarding the use of terminology such as 'anonymised' and 'pseudonymised'.	Diane Pryce	27/01/15: A phone call had been scheduled to discuss this.	Open
27/01/15	John Craven to draft guidelines for applicants requesting data as part of PhD studies.	John Craven		Open