# Data Access Advisory Group (DAAG)

## Minutes of meeting held 19 May 2015

**Members:** Eve Sariyiannidou, Dawn Foster, John Craven, Sean Kirwan, Patrick Coyle

**In attendance:** Frances Hancox, Dickie Langley, Garry Coleman, Diane Pryce, Steve Hudson, Dave Cronin, Stuart Richardson, Paula Moss, Andrew Hall

**Apologies:** Alan Hassey

| | |
|---|---|
| **1** | **Review of previous minutes and actions**<br><br>The minutes of the 12 May 2015 meeting were reviewed and agreed as an accurate record.<br><br>Action updates were provided (see table on page 6).<br><br>**Out of committee recommendations**<br><br>The following application had previously been recommended for approval subject to caveats, and it had been confirmed out of committee that the caveats had now been fulfilled:<br><br>• NHS England – Clinical Commissioning Group (CCG) Allocations (NIC-349867-B1L4C) |
| **2**<br><br>**2.1** | **Data applications**<br><br><u>East Riding of Yorkshire CCG - Risk Stratification (Presenter: Stuart Richardson) NIC-344973-C1R6J</u><br><br>**Application summary:** This application was to renew the flow of non-sensitive SUS data identifiable at the level of NHS number (weakly pseudonymised), covered by the section 251 support for the disclosure of commissioning datasets for risk stratification. Data would flow to Optum Health Solutions (UK), who would act as a data processor on behalf of the CCG. Both organisations had achieved satisfactory IG Toolkit scores and held appropriate Data Protection Act 1998 (DPA) registrations.<br><br>**Discussion:** It was noted that DAAG had considered an earlier application from this CCG as part of a group application on 14 October 2014, but that this application was for the stated CCG only.<br><br>There was some confusion regarding the relationship between Optum Health Solutions and United Health UK, as the application summary referred to one organisation 'incorporating' the other but no additional clarification had been provided. DAAG noted that only United Health UK appeared to be included in the list of approved risk stratification suppliers as part of the relevant section 251 support, and that this would need to be raised with the Health Research Authority Confidentiality Advisory Group (CAG).<br><br>The planned data retention period was queried, as this was listed as 'in line with section 251 for a maximum of 5 years' and this could be interpreted as meaning that the section 251 support was in place for 5 years, rather than being due for renewal in 2016. It was agreed that this wording would be clarified.<br><br>Additional information was requested about what fair processing activities had been undertaken, as it was felt that sufficient detail had not been provided in the application.<br><br>**Outcome:** Unable to recommend for approval. Clarification was requested of the relationship |

| | |
|---|---|
| | between Optum Health Solutions (UK) and United Health UK, and confirmation was requested from CAG as to whether Optum Health Solutions would be classed as being covered by NHS England's section 251 support given their relationship with United Health UK who were on the list of approved organisations.. Further detail was requested about fair processing. The application should be amended to clarify the planned data retention period. |
| **2.2** | University of York - Centre for Health Economics (Presenter: Garry Coleman) NIC-324101-P4Y7Z<br><br>**Application summary:** This application was for pseudonymised, sensitive Hospital Episode Statistics (HES), Mental Health Minimum Dataset (MHMDS) and Patient Reported Outcome Measures (PROMS) data as well as Office for National Statistics (ONS) mortality data. This would combine a number of existing agreements for the applicant to receive these data to support seven separate projects relating to health economics. The application summary specified which data would be required for which projects. Evidence had been provided of Department of Health sponsorship, and it had therefore been confirmed that ONS mortality data could be provided under section 42(4) of the Statistics and Registration Service Act 2007.<br><br>**Discussion:** The practicalities of combining seven projects into one application were discussed and it was suggested that this could improve transparency by more clearly showing the totality of data requested by the applicant. However DAAG noted the large amount of data requested, and emphasised the importance of ensuring that the applicant could not then use this data for any other purposes without making a further application to the HSCIC for the additional purposes. The importance of ensuring that staff working on a particular project could only access the data relevant to that specific project was also emphasised. It was agreed that more information should be provided about the specific purposes of each project, to help ensure that data would not be used for anything outside these purposes.<br><br>It was noted that ONS data was released on a project by project basis, and it was agreed that this would be made clearer in the application summary. The applicant's DPA registration was considered, and it was noted that while this did refer to undertaking research this did not specifically mention the use of healthcare data or the use of data for research into health. It was suggested that the applicant should be asked to update this wording.<br><br>Further information was requested about the data access controls that would be in place between projects, in order to ensure that individuals working on one project could only access the relevant data for that project and not any other data. It was agreed that the application should be considered by DAAG again once this information was available.<br><br>**Outcome:** Recommendation deferred, as further information was required. The application should be updated to include additional detail about the purpose of each project and to include a statement that each project can only use the data that it is specified they require, as well as to clarify that ONS data are released on a project by project basis. Information was requested about the data access controls between projects. The applicant's DPA registration wording should be updated to reflect the use of data for healthcare research. |
| **2.3** | University of Leicester - NAAASP (Presenter: Dickie Langley) NIC-346273-J5L3M<br><br>**Application summary:** This application for pseudonymised, non-sensitive HES data to support the NHS Abdominal Aortic Aneurysm Screening Programme (NAAASP) had previously been considered by DAAG on 20 January 2015 and 10 March 2015. DAAG had previously been unable to recommend approval; confirmation had been requested of section 251 support renewal as well as confirmation that the applicant's DPA registration wording would be updated, and DAAG had requested sight of the relevant consent materials. These consent materials had been reviewed within the HSCIC and draft updates had now been provided. |

| | |
|---|---|
| | **Discussion:** DAAG discussed the consent materials that had been provided, and there were concerns that these could be confusing and potentially be misleading to patients. In particular it was noted that the patient information sheet implied that in order to be screened, participants must consent to their personal data being used 'to provide a safe service' but that this statement was not clearly explained, and this could be interpreted as contradicting a statement elsewhere that individuals could let a member of staff know if they did not wish for their personal details to be kept by NAAASP.<br><br>The consent process itself was discussed, and it was noted that patients were asked to give consent verbally at the screening appointment. Concerns were raised regarding this, and it was suggested a more appropriate alternative would be for a consent form to be included with the letter inviting patients to screening so that this could be read and signed ahead of the appointment. DAAG noted that the application summary listed 'section 251' under legal basis, and it was agreed that it should be clarified that the section 251 support only covered individuals who had not responded to the invitation to attend screening. DAAG requested sight of the letter relating to this section 251 support, as this had not been included with the application papers. There were concerns about the use of the term 'implied patient consent'.<br><br>The proposed data flow was discussed, and DAAG queried whether the pseudonymised data provided to the HSCIC would be used alone to link with other data or if other identifiers would be used. It was thought that the pseudonymised Study Identifier would be used for linkage, with no other identifiable data being used, and DAAG requested confirmation that this would be technically possible.<br><br>DAAG considered the approach that should be taken for participants who had already undergone screening and consented using the existing consent materials. It was agreed that while it was not felt to be appropriate to ask individuals to re-consent, these individuals should be provided with updated information about how data is used, and given the opportunity to opt out of this.<br><br>**Outcome:** Unable to recommend for approval. Materials informing patients about how data will be used needed to be rewritten, and in particular references to using data 'to provide a safe screening service' should be clarified. DAAG suggested that a consent form should be included with the invitation letter sent to applicants, rather than relying on verbal consent obtained at the point of screening. Participants who have already attended screening using older consent materials should be sent updated fair processing materials and given the opportunity to opt out. The application should be updated to clarify that pseudonymised data will be used for linkage, with assurances from the HSCIC that it is possible to link using Study ID alone and no other identifiers. The application should also be updated to clarify that section 251 support covers non-responders, and DAAG requested sight of the section 251 letter relating to this. |
| **2.4** | <u>Harvey Walsh (Presenter: Dickie Langley) NIC-346122-J2J0K</u><br><br>**Application summary:** This application to renew access to pseudonymised, non-sensitive HES data had previously been considered by DAAG on 31 March 2015, when DAAG had been unable to recommend approval. Additional evidence had been requested regarding the purpose and outputs of this work, as well as evidence of compliance with the relevant provisions of the Care Act 2014. An updated application summary had now been provided with additional information on the services provided for NHS organisations and for commercial organisations, with evidence of how this could provide healthcare benefits.<br><br>**Discussion:** The specific outputs and expected measurable benefits were discussed, and DAAG suggested that this should more explicitly state what the healthcare benefits to patients would be.<br><br>DAAG queried the proportion of customers for the applicant's services that were NHS or commercial, and it was noted that this had also been queried when the application was last considered but no additional clarification had been provided. It was agreed that this point would |

| | |
|---|---|
| | need to be clarified. References to customers using the tools provided for 'non-promotional' purposes were discussed, and DAAG noted the importance of ensuring that third-party customer organisations would only be able to use data for non-commercial purposes. It was suggested that the data sharing agreement with this applicant should specify the terms that would be included in licenses with third parties, in order to limit the purposes for which data could be used.<br><br>DAAG noted that the application summary stated the applicant's IG Toolkit score had been reviewed, but not who by. It was confirmed that this had been reviewed by the relevant team within the HSCIC, and it was suggested that this should be stated more clearly on the application summary.<br><br>**Outcome:** Recommendation deferred, as further information was required. Information was requested about what proportion of customers were NHS or commercial organisations. DAAG proposed that a statement should be included in the data sharing agreement regarding terms that would be included in commercial licenses with any third parties accessing the product, which would contain wording to limit use to non-commercial purposes. More specific details were requested about healthcare benefits. |
| **2.5** | University of Edinburgh - Lifelong health and wellbeing of the Scotland in Miniature cohort (Presenter: Dickie Langley) NIC-318704<br><br>**Application summary:** This application was for pseudonymised, non-sensitive HES data for a specific cohort in order to support a long term research study. It was noted that a separate application for patient flagging for this study had been considered by DAAG on 26 March 2013, and that updates to the study consent forms had been requested. The consent materials had been updated at that point and participants had been contacted in 2013 to be asked to re-consent. DAAG were informed that in addition to this participant consent, section 251 support was in place for some elements of the study.<br><br>**Discussion:** The updated consent materials were considered, and while DAAG felt that a reference to 'central UK NHS bodies' might not now be considered appropriate it was acknowledged that these changes had been agreed in 2013 and that no further participant recruitment was planned. The age of the cohort was noted, and DAAG agreed it would not be appropriate to require participants to re-consent again with slightly amended consent materials. DAAG noted that the applicant remained in contact with participants via a newsletter; it was agreed that an update about the use and processing of data should be included in a future newsletter along with a reminder to participants of the opportunity to opt out if they wished to do so. It was agreed that if the applicant were to undertake any further recruitment for the study, the consent materials should first be updated.<br><br>The applicant's updated DPA registration wording was discussed, and there were some concerns that as currently phrased this could be interpreted that healthcare data was used to support fundraising activities. It was suggested that the applicant should amend this wording.<br><br>**Outcome:** Recommendation to approve subject to confirmation that the applicant will include an update in the next newsletter to participants, clarifying how data is used and reminding participants of the opportunity to opt out. DAAG suggested that the applicant's DPA registration wording should be clarified, and suggested that the applicant should consider dissemination and how outputs could be made publicly available. |
| **2.6** | Monitor - Casemix (Presenter: Andrew Hall) NIC-345510-Z5G7X<br><br>**Application summary:** This application was to renew and amend an existing agreement for the provision of pseudonymised, non-sensitive Casemix HES data to the applicant, who would then also share the data with NHS England. This data would be used as part of Monitor's statutory |

| | |
|---|---|
| | functions to facilitate the development, quality assurance and monitoring of the national tariff system policy.<br><br>**Discussion:** DAAG noted that the description of expected measurable benefits was somewhat limited, and suggested that it might be helpful if applications could focus more on the potential benefits to patients. A query was raised regarding the frequency of data dissemination requested, as this was listed as being both 'ad hoc' and '4-5 times per year', and it was confirmed that this was because data would be provided in line with certain requirements but that this could vary throughout the year.<br><br>A reference in the application to the applicant 'outsourcing' analysis work and providing data to subcontractors was queried. It was noted that this could be interpreted to mean that data would be shared with third party organisations, and DAAG agreed that this wording should be clarified. Concerns were raised around sharing data with subcontractors, as it was possible that these would not be subject to the same contractual arrangements as Monitor employees, and it was suggested that both the application summary and the data sharing agreement should include a statement that data should not be shared with subcontractors.<br><br>**Outcome:** Recommendation to approve subject to references to outsourcing analysis to subcontractors being removed from the application, and a statement being included in both the application and the data sharing agreement that data cannot be shared with subcontractors. |
| **3** | **Any other business**<br><br>No other business was raised. |

**Summary of Open Actions**

| Date raised | Action | Owner | Updates | Status |
|---|---|---|---|---|
| 24/02/15 | Dawn Foster to raise with HRA CAG the possibility of stage 1 accredited safe havens receiving both data that is identifiable by NHS number and data that is identifiable by postcode. | Dawn Foster | 03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting.<br>10/03/15: An initial response had been received and this would be shared with DAAG members for information. A further query had been raised and discussions were ongoing.<br>17/03/15: Ongoing.<br>25/03/15: Ongoing.<br>31/03/15: Ongoing.<br>07/04/15: Ongoing.<br>13/04/15: Ongoing.<br>21/04/15: Ongoing.<br>28/04/15: Ongoing.<br>05/05/15: It was agreed that Dawn Foster would raise this separately with CAG.<br>12/05/15: Clarification had been requested from NHS England regarding a particular request for both identifiers.<br>19/05/15: Ongoing. | Open |
| 12/05/15 | DAAG Secretariat to invite the HSCIC Statistics Head of Profession to attend a future DAAG training session regarding sampling techniques. | DAAG Secretariat | 19/05/15: An invitation had been issued, but it had not yet been agreed what date the Head of Profession might be able to attend a DAAG training session. | Open |
| 12/05/15 | Dawn Foster to contact CAG Secretariat regarding their role in considering consent. | Dawn Foster | 19/05/15: Ongoing. | Open |