

# Data Access Advisory Group (DAAG)

## Minutes of meeting held 2 June 2015

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

**In attendance:** Joanne Bailey, Frances Hancox, Victoria Williams, Diane Pryce, Steve Hudson, Dave Cronin, Susan Mayne, Helen Lewis, Kate Morris

**Apologies:** None

1	<p><b>Review of previous minutes and actions</b></p> <p>The Acting Chair formally welcomed Joanne Bailey to the meeting. It was confirmed that she would be joining DAAG as a member, and that she was in attendance to observe the current meeting for training purposes.</p> <p>The minutes of the 27 May 2015 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 8).</p> <p><b>Out of committee recommendations</b></p> <p>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:</p> <ul style="list-style-type: none"><li>• NIC-342590-T2B7L University College London</li><li>• NIC-300343-D5G8J University of Leeds</li><li>• NIC-309500-F4X1B University of Birmingham</li></ul>
2	<p><b>Data applications</b></p> <p><b>2.1</b> <u>HSCIC Clinical Audit Support Unit (CASU) National Pregnancy in Diabetes (NPID) Audit (Presenter: Garry Coleman) NIC-348988-V6G1J</u></p> <p><b>Application summary:</b> This application, which had previously been considered by DAAG at the 7 April 2015 meeting, was for linked Hospital Episode Statistics (HES) data for the study participants who had given their consent to participate in the NPID audit commissioned by the Healthcare Quality Improvement Partnership (HQIP). DAAG had previously expressed concerns regarding the audit consent materials, and updates to these had subsequently been drafted. DAAG had also recommended that fair processing activities should be undertaken for those participants who had already provided consent, and the applicant had provided a response to this stating that it would not be practical or appropriate to directly contact these individuals.</p> <p><b>Discussion:</b> The updated consent material wording was considered, and it was agreed that this now seemed appropriate. However, references to GPs in the patient information leaflet were queried as it was noted that no general practice data had been requested, and DAAG advised that the consent materials would need to be revised again in future if general practice data were requested.</p> <p>DAAG noted that the fair processing section of the application form appeared to have been removed, and expressed concerns about the submission of an incomplete application. The applicant's response was discussed, and it was noted that ensuring fair processing was a requirement under the Data Protection Act 1998 (DPA). DAAG agreed that the applicant should be</p>

asked to consider what reasonable efforts could practically made to inform participants who had already provided consent, such as publishing updated materials online and making information available at relevant points of care.

A query was raised regarding the DPA registration wording for the HQIP, as the application form stated that this would shortly expire. It was confirmed that this registration had been renewed for a further year.

**Outcome:** Recommendation to approve subject to confirmation being provided of how the applicant will meet fair processing requirements under the DPA's first principle and subject to the application form being updated to include details of fair processing. DAAG advised that fair processing materials should be made available on the applicant's website and at the points of care where women who are diabetic or pregnant may attend.

**2.2** Royal Brompton and Harefield Hospital NHS Foundation Trust (Presenter: Garry Coleman) NIC-352381-P0L2S

**Application summary:** This application, which requested HES and Office for National Statistics (ONS) linked mortality data in order to support research into morbidity in patients with congenital disorders and pulmonary hypertension, had previously been considered by DAAG on 31 March 2015. DAAG had been unable to recommend approval due to an outstanding query regarding the legal basis for the provision of ONS data, and an updated commissioning letter had now been provided with confirmation that the request was covered by Section 42(4) of the Statistics and Registration Services Act 2007.

**Discussion:** DAAG discussed the importance of ensuring that study outputs would be fed back to appropriate organisations and clinicians within the NHS, in order to ensure benefits to health as per the requirements of the Care Act 2014. It was agreed that a renewal application from this applicant would be expected to provide an explicit link to the health and care benefits that had been realised as a result of using this data.

The commissioning letter provided was discussed, and a query was raised regarding the fact that this was from the same organisation carrying out the work but it was confirmed that this was considered appropriate. DAAG noted that funding was in place until April 2016 and that an alternative legal basis might be required if the work continued past that date. It was suggested that the proposed agreement end date should be changed to April 2016 to align with this.

**Outcome:** Recommendation to approve. DAAG agreed that when a renewal application was submitted, this would need to include clear evidence of an explicit link to health and care benefits in compliance with the Care Act 2014.

**Action:** DAAG Secretariat to schedule a training session to discuss mechanisms to feed research outputs back to the NHS.

**Action:** Acting DAAG Chair to discuss benefits and feeding research outputs back to the NHS with Chris Roebuck and with the Health Research Authority Confidentiality Advisory Group (CAG).

**2.3** Harvey Walsh Limited (Presenter: Garry Coleman) NIC-346122-J2J0K

**Application summary:** This application to renew access to pseudonymised, non-sensitive HES data had previously been considered by DAAG on 19 May 2015. Further information had been requested regarding the proportion of the applicant's customers that were NHS or commercial organisations, and the applicant had now confirmed that approximately 20% of work was directly for NHS organisations with the remainder being for pharmaceutical companies working with the NHS or for medical devices companies. Additional information regarding benefits had been

provided and a draft statement for inclusion in the data sharing agreement, which limited the use of data to the purpose of provision of healthcare or health promotion, had been provided.

**Discussion:** DAAG noted that the additional information previously requested had been provided. The proposed wording for inclusion in the data sharing agreement was discussed, and it was agreed that this should be amended to specifically state that no use could be made of the data for sales and marketing purposes.

**Outcome:** Recommendation to approve, subject to the inclusion of a statement in the application and data sharing agreement that 'Furthermore, no use may be made of the data (directly or indirectly) for sales or marketing purposes.'

#### 2.4 ICON Health Economic (Presenter: Dave Cronin) NIC-332923-M5B8F

**Application summary:** This was a new application for pseudonymised, non-sensitive HES data in order to develop epidemiological estimates of prevalence, patient demographics, and hospital resource utilization of patients with status epilepticus. This work was funded by Sage Therapeutics

**Discussion:** DAAG noted that the application summary stated the applicant had requested 'only the fields necessary to complete the analysis' and queried precisely what data fields this included. A reference to the applicant partnering with a 'leading clinical expert' was also queried, as it was not clear whether this partnership meant that the clinician would have access to the data provided and it was also not clear whether this was a UK-based clinician.

It was noted that Sage Therapeutics were a company based in the USA, and while the application summary stated that this organisation 'will not have any access to the raw HES data' DAAG requested clarification of the role of this organisation in the application and whether they would have access to any other data. The commercial aspects of the application were discussed, and DAAG requested confirmation that data would not be used for sales or marketing purposes.

The need to ensure benefits to health and care in the UK was discussed in light of the requirements of the Care Act 2014. DAAG noted the potential public interest in increasing the amount of information about this condition publicly available, given the current lack of information available. It was suggested that the applicant should provide further details of how outputs would be fed back to the NHS and to relevant organisations such as the Epilepsy Society or Epilepsy UK.

**Outcome:** Unable to recommend for approval. Additional information was required about Sage Therapeutics, their role and what data this organisation would have access to. Further details were required about how the outputs will be fed back to the NHS and to key organisations in the field such as Epilepsy UK or the Epilepsy Society. Clarification was requested of a reference to 'only the fields necessary' to be clear what fields are requested, and of the reference to partnering with 'a leading clinical expert', and whether this is a UK-based clinician. Clarification was also needed about commercial aspects, and whether this is linked to potential sales and marketing work.

#### 2.5 Primary Care Mortality Data (PCMD) Test Case (Presenter: Susan Mayne)

**Application summary:** DAAG had previously been asked to consider the process for applications from Local Authority public health teams to access the Primary Care Mortality Database (PCMD), which was maintained by the HSCIC under delegated authority from ONS, at the 12 May 2015 DAAG meeting. The recommendation had been made to approve the continued use of data for a period of two months, in order to provide the opportunity to develop an appropriate scrutiny and assurance process within DAAG. An updated test case had now been provided to inform discussions of processes. An example table of differences had been provided to demonstrate the differing information that would be provided for each organisation, but it was noted that further work was required to determine how fair processing information would be provided.

**Discussion:** A reference to providing data to analysts in Local Authorities and to those in NHS organisations was queried, and it was confirmed that to date only one NHS organisation had been given access to the data described. In addition a reference to sharing data by secure email was queried; it was confirmed that the data provided would be stored securely by the recipient organisation and that this was covered by the ONS data access agreement.

The legal basis for this use of data was discussed, and DAAG were informed that Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002 provided a legal basis for the provision of health data. A reference to linking GP practice code with births data was queried and it was confirmed that this was an error as only NHS number would be linked to those data, while both NHS number and GP practice code would be linked with PCMD deaths data.

The need for identifiable data was queried, and it was agreed that organisations would need to provide a clear justification for why identifiable data were required and why pseudonymised data could not be used instead. DAAG emphasised that each organisation would need to provide details of what purposes data would be used for and the expected outputs and benefits, and specify how these uses justified the need for identifiable data.

DAAG agreed that they would welcome example applications from one or two organisations, and that in particular these would need to provide evidence of the benefits that had been realised due to data previously received as well as a clear justification for why identifiable data were required. Evidence would also be needed that applicant organisations had met the fair processing requirements of the DPA. It was agreed in principle that DAAG would be prepared to extend the timeframe of the current recommendation to approve for two months if this would allow higher quality applications to be prepared, but that this would need to be confirmed out of committee.

**Outcome:** Advice was given on the expected content of future applications to DAAG. Example applications should be provided from specific organisations, with particular emphasis on the need to provide evidence of benefit for data received in past and clear justification for why identifiable data is needed rather than using pseudonymised person-level data. Evidence would also be required that organisations had met their fair processing obligations under the Data Protection Act 1998.

## 2.6 HSCIC and HMRC - Workforce Data (Presenter: Helen Lewis) NIC-319693-G3C6Q

**Application summary:** This application requested the release of GP and dentist workforce data to HMRC, in order for HMRC to link this and provide aggregated data on pay and expenses back to the HSCIC. This was required for the HSCIC to produce official statistics.

**Discussion:** DAAG discussed the described data flow, and it was confirmed that this work was taking place at the request of the HSCIC and the HSCIC should therefore be considered the applicant rather than HMRC.

The legal basis for the data release was discussed, and the need to ensure that GPs and dentists were aware of this use of data was noted. DAAG noted that these clinicians were informed of the use of workforce data via their contracts, and most GPs were thought to be broadly aware that data were used in this way.

It was confirmed that only workforce data would be disclosed, and that no patient data would be involved. DAAG were asked to consider whether this data release should be included on the HSCIC register of data releases, and it was agreed that it would be appropriate for this to be included. It was also suggested that other similar releases should also be included on the register.

**Outcome:** Recommendation to approve subject to amending the application form to state that the HSCIC is the applicant.

**Action:** Acting Chair to notify the SIRO and Caldicott Guardian that this data release should be added to the data release register, and that DAAG's view was that other such releases should also be reflected on the register.

**2.7** HSCIC CASU Chronic Obstructive Pulmonary Disease (COPD) Audit (Presenter: Garry Coleman) NIC-349273-T3L4K

**Application summary:** This application had previously been considered by DAAG at the 17 March and 5 May 2015 meetings. DAAG had requested clarification of the intended data flows, particularly those involving Wales, and recommended that fair processing materials should be updated. These materials had now been updated.

Two options for the data flow to Wales were outlined: either identifiable data for the entire cohort would be provided to the NHS Wales Informatics Service (NWIS) in order for this to be linked, or alternatively identifiable data for only the cohort members who attended hospital in Wales would be provided for linkage. Confirmation from CAG Secretariat had been received that the second option was covered by the relevant section 251 support, but confirmation was still awaited regarding whether the first option was also covered.

**Discussion:** Concerns were raised that the first option described, whereby the entire dataset was transferred to Wales for linkage, could be considered disproportionate and a clearer justification for this was requested. It was suggested that the second option might be considered more appropriate in terms of data minimisation, although it was acknowledged that there would be some drawbacks to this approach as it would provide less complete data.

DAAG were informed that confirmation had previously been received from CAG Secretariat that the section 251 support covered the data processing outlined in the second option, and the group asked for evidence of this confirmation to be provided by email. The importance of ensuring that this clearly explained what precisely was covered by the section 251 support was emphasised.

DAAG noted that fair processing materials had been improved and queried the timescales for making these updated materials available to the public.

**Outcome:** Unable to recommend for approval. Evidence was requested that the applicant's section 251 support covered the data sharing with Wales described in the application. Clarification was requested of when fair processing materials will be made available to the public.

**2.8** University of Sheffield - Virtual Physiological Human (VPH) (Presenter: Garry Coleman) NIC-345279

**Application summary:** This application for HES and Diagnostic Imaging Dataset (DIDs) data was presented for advice only. It was stated that this project had previously received EU funding but that the University of Sheffield now sought to fund the work directly. Advice was requested regarding whether the described purpose, to develop models and algorithms for a tool to test new devices, drugs and treatment virtually, would be considered to comply with the requirements of the Care Act 2014.

**Discussion:** Queries were raised regarding the EU funding for this work, and in particular whether the applicant would participate in any other VPH Share projects in future that would make use of the data provided. If this was the case it was agreed that details would be required of these projects and the other organisations involved in the project consortium, as well as whether the projects involved any elements of commercialisation.

DAAG discussed the expected benefits for healthcare and patients, and it was agreed that there

was potential for these to be significant. However it was emphasised that confirmation would be needed of whether the project included any elements of commercialisation.

Clarification was requested regarding the organisations involved in this work, and whether the Insigneo Institute was a separate legal entity to the University of Sheffield. A reference to an honorary contract was also queried.

**Outcome:** Advice was given on the expected content of a future application. Clarification was required regarding EU funding, particularly whether the applicant participates in any other EU-funded VPH projects and if so details should be provided of these projects, any commercialisation aspects and what other organisations are members of the project consortium.

**2.9** Rod Gibson Associates (Presenter: Garry Coleman) NIC-340660-Z7B8Y

**Application summary:** This application for an extract of pseudonymised, non-sensitive HES data had previously been considered on 31 March 2015, when DAAG had been unable to recommend approval. A number of queries had been raised including the need for a clearer explanation of the organisations involved, clearer evidence of expected benefits and the need for a statement that data would not be used for any additional purposes. Additional information had now been provided in response to these queries, and it was explained that the applicant would receive record level HES data that would be aggregated for provision to the Birth Choices UK website and to the Which Birth Choice website.

**Discussion:** DAAG noted that three purposes had been outlined for which data would be used. The first two purposes detailed the provision of data for the Birth Choices UK and the Which Birth Choice website, and DAAG expressed their support for these two purposes, but there were concerns that the third purpose was not sufficiently well defined. DAAG requested that a separate application should be submitted for the third purpose, with a clearer explanation of what work would be involved and how this would provide health or care benefits.

The security information provided was discussed, and it was noted that while at one point the application summary stated that only one individual would have access to the record level HES data a statement in the security information appeared to contradict this. Clarification was requested of this point. In addition a reference to a USB drive being 'securely stored' was queried as no additional explanation of this was available, and it was suggested that the applicant's DPA registration wording should be amended.

**Outcome:** Recommendation to approve purposes 1 and 2 outlined in the application summary only, subject to confirmation that only one individual will have access to the record level HES data and clarification of the phrase 'stored securely' in relation to an encrypted USB drive. The applicant's DPA registration wording should be amended as the phrase 'anonymised summaries' was considered misleading.

**2.10** Northgate Information Solutions UK – National Joint Registry (Presenter: Garry Coleman) NIC-309284-N4T2H

**Application summary:** This was a new application for identifiable, sensitive HES, HES-ONS and HES-Patient Reported Outcome Measures (PROMs) linked data in order to support the work of the National Joint Registry. It was explained that HQIP would act as data controllers for this work but would not themselves receive any data, while Northgate Information Solutions and the University of Bristol would act as data controllers. Only Northgate Information Solutions would have access to the identifiable data provided.

**Discussion:** The potential benefits of this work were discussed, and it was noted that in addition to the benefits outlined in the application summary the participants who consented to join the

	<p>register could also be contacted in future in the event of a device fault. The consent materials were considered and DAAG noted that these contained some outdated references, such as a reference to the National Strategic Tracing Service, which the applicant should consider updating.</p> <p>DAAG noted that the DPA registration wording for the University of Bristol did not currently include the handling of healthcare data for health research, and it was agreed that this should be amended.</p> <p>A reference in the application summary to entering into arrangements to share data with 'other third parties' was queried. DAAG agreed that appropriate sub-licensing controls would need to be in place for any such onward sharing of data. A reference to international regulators making use of intelligence from the National Joint Registry was also queried, and it was confirmed that this would involve the use of aggregated analyses rather than identifiable or pseudonymised data.</p> <p><b>Outcome:</b> Recommendation to approve subject to the University of Bristol DPA registration wording being updated to reflect the handling of healthcare data, and subject to sub-licensing arrangements being agreed by the HSCIC as part of the DSA.</p>
3	<p><b>Any other business</b></p> <p>An update was given on the DAAG dashboard and on the forthcoming consultation on the Independent Group Advising on Releases of Data (IGARD).</p> <p>The dates for future DAAG training sessions were queried, and it was agreed that a list of dates would be circulated.</p> <p><b>Action:</b> DAAG Secretariat to circulate dates for DAAG training sessions.</p>

## 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	<p>03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting.</p> <p>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.</p> <p>17/03/15: Ongoing.</p> <p>25/03/15: Ongoing.</p> <p>31/03/15: Ongoing.</p> <p>07/04/15: Ongoing.</p> <p>13/04/15: Ongoing.</p> <p>21/04/15: Ongoing.</p> <p>28/04/15: Ongoing.</p> <p>05/05/15: It was agreed that Dawn Foster would raise this separately with CAG.</p> <p>12/05/15: Clarification had been requested from NHS England regarding a particular request for both identifiers.</p> <p>19/05/15: Ongoing.</p> <p>27/05/15: Ongoing.</p> <p>02/06/15: Ongoing.</p>	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	<p>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.</p> <p>27/05/15: Ongoing.</p> <p>02/06/15: Ongoing.</p>	Open
19/05/15	Dawn Foster to contact CAG to discuss the approach to accepting IG Toolkit scores for data processors in instances when the data controller did not handle data.	Dawn Foster	<p>02/06/15: This had been raised with the CAG Secretariat, who had confirmed that this was in line with their approach.</p>	Closed



02/06/15	DAAG Secretariat to schedule a training session to discuss mechanisms to feed research outputs back to the NHS.	DAAG Secretariat		Open
02/06/15	Acting DAAG Chair to discuss benefits and feeding research outputs back to the NHS with Chris Roebuck and with the Health Research Authority Confidentiality Advisory Group (CAG).	Acting DAAG Chair		Open
02/06/15	Acting Chair to notify the SIRO and Caldicott Guardian that this data release (HSCIC and HMRC workforce data) should be added to the data release register, and that DAAG's view was that other such releases should also be reflected on the register.	Acting DAAG Chair		Open
02/06/15	DAAG Secretariat to circulate dates for DAAG training sessions.	DAAG Secretariat		Open