

# Data Access Advisory Group

## Minutes of meeting held 15 August 2014

Members: Alan Hassey (Acting Chair), Patrick Coyle, Dawn Foster, Eve Sariyannidou (new member) and John Craven (new member)

In attendance: Sam Smith (MedConfidential), Susan Milner, Diane Pryce  
Stuart Richardson (agenda item 150814-d), Garry Coleman (agenda item 150814-e),

**Apologies:** Sean Kirwan (member), Frances Hancox (secretariat)

150814-a	<p><b>Welcome</b></p> <p>The Acting Chair introduced new members, Eve Sariyannidou and John Craven, to the meeting and also an observer, Sam Smith, from MedConfidential.</p> <p>The Acting Chair welcomed the attendees to the meeting.</p>
150814-b	<p><b>Minutes of the previous meeting</b></p> <p>The minutes of the meeting held on 30 July 2014 were discussed.</p> <p>SS queried whether the organisation mentioned in the extract from the minutes below had confirmed to the HSCIC that they had ceased using HES/ONS data provided for a commercial activity which had not been approved.</p> <p><i>Terry Hill attended this section of the meeting in order to inform the Group that one recipient of Hospital Episodes Statistics (HES) and Office for National Statistics (ONS) data appeared to have been using this data for commercial activity in addition to the purposes they had stated when applying for approval to receive this data. It was noted that this data recipient had now been asked to cease using the data received for this purpose.</i></p> <p><b>ACTION: AH to write to SS confirming the outcome of discussions with the customer, that they had confirmed that they had ceased using the data for this purpose and to provide an update for the minutes.</b></p> <p><b>191113-d1 University of Sheffield</b></p> <p>At the previous meeting it had been agreed that as no response had been received from the applicant, they should be advised that this application had now closed.</p> <p><i>Members were advised that the applicant had responded to DAAG immediately after the previous meeting but before the DAAG decision could be advised. It was agreed that this could be discussed under Outstanding Applications.</i></p> <p>Following this discussion, the minutes of the meeting held on 30 July 2014 were agreed.</p>
150814-c	<p><b>Matters Arising</b></p> <p><b>(a) Overview of outstanding actions</b></p> <ul style="list-style-type: none"><li>• <b>300714-a</b> Terry Hill to discuss with Andy Williams the suggestion that DAAG outcome</li></ul>

letters should include a statement that the data received should not be used for any additional commercial purposes.

**Action: AH to check the progress on this with TH.**

- **300714-c1** Frances Hancox to invite Simon Gray to send an observer to future DAAG meetings in order to feed back to IAOs not in attendance.  
AH advised that SH would not be sending an observer to meetings. **Action closed.**

- **300714-h1:** Aligning application processes in Scotland and England - Simon Gray to look into how application processes in Scotland and England could be aligned, and consider discussing this with NHS Scotland.

This item is based on the difference in how applications are dealt with in Scotland. Currently the process differs from England and Wales as there is no equivalent legal basis to Section 251.

**Action: SG to be asked how he wishes to progress this.**

- **300714-c2:** Alan Hassey to discuss with Rob Shaw and Martin Severs the legal basis for sharing pseudonymised data and the potential implications of onward sharing of pseudonymised data with third party organisations.

AH stated that a discussion had been held in the meeting with new members earlier in the day around dissemination of pseudonymised data. Feedback from the Caldicott Guardian had also been provided. AH confirmed that he would provide briefing on this to PC/SK.

**Action: AH to provide briefing on dissemination of pseudonymised data to PC/SK.**

- **300714-c3:** Dawn Foster to contact HRA CAG and seek clarification of whether section 251 approval should be considered to remain in place while a review process is underway, or if this should be confirmed for each individual application.

DF confirmed that it has been agreed with CAG that any applications with Section 251 awaiting clarification of annual review will be flagged to CAG the day after the deadline for submission of applications to DAAG. CAG will then prioritise these and confirm the outcome to DAIS team. It may be that an answer is not provided in time for circulation of papers to members, but it is hoped that a verbal confirmation could be provided at the DAAG meeting. **Action closed.**

- **300714-g1:** DAAG to contact HRA CAG regarding the section 251 approval for Leeds Teaching Hospital (application ref: 300714-g10) and whether this included the identifiers requested, such as postcode.

SM had contacted CAG who confirmed that the Section 251 support does not include postcode.

**Action: Applicant to be advised that if identifiable fields are required, then an amendment will be needed to their current Section 251 support. Action Closed.**

## **(b) Overview of outstanding applications**

### **191113-d1: University of Sheffield**

*This application had been discussed at previous DAAG meetings. The request was for approval consent documentation for The South Yorkshire Cohort Project. The consent initially submitted DAAG did not provide sufficient information to inform the cohort that their personal data would be shared with other organisations and linked. In fact, the consent stated that "the data will not be shared with anyone else". The customer had previously been asked to advise how they proposed to address the issues regarding advising the cohort how their data was being used. The applicant had originally advised that they considered the consent to be appropriate*

The customer has now responded to the letter sent by DAAG in May 2014 and provided amended consent documentation which includes the recommended wording from DAAG. The applicant has advised that the revised questionnaire will be sent to all 22,000+ people who have already given them permission to contact them again.

DAAG members were pleased to note that the applicant had now included the appropriate wording for the newly recruited cohort. However there was no information provided about non-responders. It was stressed that it cannot be assumed that no response implied consent.

Members queried whether any issues around reconsenting of individuals might result in a biased sample which could change the nature of project.

It was noted that the Information Commissioner's Office (ICO) had views on fair processing under the Data Protection Act. The members were made aware that the applicant had been recommended to view the ICO information on fair processing but it was not clear whether they had done so. Under fair processing information must be provided to the cohort explaining what the situation is and they should be provided with the opportunity to opt out if they so wish.

ES agreed to provide some wording relating to fair processing. This is provided below.

*As per actions agreed at the Aug 15<sup>th</sup> meeting of DAAG, I am writing with reference to the outstanding application 191113-d1 University of Sheffield.*

*As discussed in the meeting, it is not a case of having recourse to s.251, which only supports "essential NHS activity". It is rather a matter of 'fair processing' under DPA (also this is the ICO's view, as Patrick has confirmed).*

*The applicant will need to accompany their consent form with the appropriate (depending on age and capacity of the cohort) consent material to inform the participants about what information will be collected and shared (about them), for what specific purposes and with whom. Also, how long they will keep their information for and also offer the option to withdraw consent at any stage, without conditions attached.*

**Outcome: Unable to recommend for approval. Applicant to be asked about the issue of consent and fair processing.**

**300714-g10: Leeds Teaching Hospitals (NIC-230103):**

*This application was for data linkage of identifiable data, including sensitive fields, for use in service evaluation of the heart failure pathway. A query was raised regarding what the section 251 approval for this application had included, as the letter provided mentioned data items such as date of death but not the requested identifiers such as postcode. DAAG members provided a recommendation to approve subject to confirmation from HRA CAG that section 251 approval included the identifiers requested.*

CAG have confirmed that the Section 251 support does not include Postcode and if this field is required the applicant's Section 251 approval would have to be amended.

**Action: Applicant to be advised that if they require Postcode they will have to amend their Section 251 support. Action closed.**

**300714-g5: TARN Manchester University (The Trauma Audit and Research Network)**

*This application was for an amendment to an existing agreement, as the applicant had now requested additional data fields (age, NHS number and NHS trust). The applicant was already*

	<p><i>in receipt of identifiable audit data and intended to use HES data to compare against this and check its completeness, in order to determine if any additional individuals should have been included in the audit.</i></p> <p><i>A query had been raised regarding the section 251 approval for this application, and whether this included the additional data requested. It was agreed that the Group's recommendation should be made pending confirmation from HRA CAG that this was the case.</i></p> <p>CAG have confirmed that the Section 251 support does not include the identifiable field DOB. The customer has been informed and has now advised that they do not wish to receive DOB and have now requested 'age'. JC asked whether 'age' could be clarified.</p> <p><b>Action: The DOB field to be removed from this request and the applicant to clarify 'age'.</b></p> <p><b>(c) Recommendations made out of committee</b></p> <p>The Acting Chair confirmed that no decisions had been made out of committee.</p> <p>SR joined the meeting by teleconference</p>
150814-d	<p><b>Data applications (IAO: Stuart Richardson)</b></p> <p><b>150814-d1 Nottingham City Clinical Commissioning Group (CCG)</b></p> <p>This is a request for weakly pseudonymised data and has support under Section 251. The IAO confirmed this request was for an extract of data and the agreement will expire 31/10/14.</p> <p>The purpose stated is for healthcare planning and commissioning. The IAO confirmed he was satisfied with the request, conditional that free text fields are cleansed/anonymised before data is shared. Note: An issue has come to light that for some Free text fields within the SUS dataset some providers have been inputting data that does not fit with data dictionary definitions. The HSCIC have been working on cleansing the data and talking to providers and asking them to resubmit data.</p> <p>A statement under purpose regarding enabling clinicians with legitimate relationships to identify and contact patients was queried. This was clarified by DF who confirmed that the purpose is included in the Section 251 support and that the organisation has been approved as an ASH (Accredited Safe Haven).</p> <p>A query was raised that the DPA registration had not been confirmed.</p> <p><b>Outcome: Recommendation of approval subject to confirmation of DPA registration.</b></p> <p><b>150814-d2 Dudley CCG</b></p> <p>This request is for SUS Payment by Results data for commissioning purposes. The agreement expires 31<sup>st</sup> October 2014. The applicant has ASH accreditation.</p> <p>It was proposed that for any free text field that was deemed to be at risk of including identifiable data, these fields should only been shared once they had undergone either data cleaning or anonymisation to remove any identifiable data.</p>

Members queried that the purpose stated “the data is used predominantly by the CCG for commissioning purposes”. This implied that the data could be used for other purposes not set out under the purpose. Clarification was requested on this.

A query was raised that the DPA registration had not been confirmed.

**Outcome: Recommendation of approval subject to confirmation of DPA registration and clarification on the purpose wording. Members agreed that this application did not have to come back to a full meeting providing the response was acceptable.**

#### **150814-d3 Imperial College**

This request had been submitted for review out of committee; however the Acting Chair had circulated the papers for full discussion at the meeting. AH apologised for the short notice in providing the paper.

The request was for an extension to an existing agreement in place for SUS data. In addition, a sub-licence is in place for Imperial College to provide data to Dr Foster Intelligence.

The intention had been for the HSCIC to be in a position to stop the SUS feed to Imperial College and provide HES data only and therefore the current agreement had only been provided up to the end of July 2014. In addition, the Section 251 support for provision of identifiable data had been awaiting confirmation of a decision by the Confidentiality Advisory Group (CAG) on the outcome of the annual review. Confirmation has now been received from CAG that the Section 251 support has been extended for a further 6 months only and that a new application is required to be submitted.

The IAO confirmed that there is no issue with free text fields as the data has been cleansed at Imperial College.

A query was raised whether maternity data was included and clarification was given that this dataset was not yet on stream in SUS.

Discussion followed relating to a condition which had been included in the Imperial College CAG annual review letter which requested “confirmation to be provided that the sexual health data provided by the HSCIC is fully anonymised”. The HSCIC are currently discussing with CAG which organisation should provide the definition on this data as Imperial College are working to a specification agreed by PIAG in 2008. The HSCIC work to data standards change notices.

The IAO confirmed that the data provided by the HSCIC has been checked and that the data provided has been anonymised in line with the CAG requirement above.

Members queried whether the contentious fields could be removed from the extract, but it was thought that this may not be possible.

A query was raised whether providers are aware of how their data is used, on what basis data is transferred and is it contrary to what the data was initially provided for.

Whilst it was noted that Imperial College have put much effort into informing what is being done with the data and carry out good work around mortality, the members felt that they did not have sufficient information to recommend this application for approval. It was requested that this application be resubmitted to the next DAAG meeting. This would give the HSCIC an opportunity to provide clarification from CAG on the definition they wish to follow with regard to the condition on provision of sexual health data and the other queries raised.

**Outcome: Unable to recommend for approval.**

150814-e	<p><b>Data applications (IAO: Garry Coleman)</b></p> <p><b>150814-e1 Public Health England</b></p> <p>This application requested an extract of pseudonymised, record level HES data (not the entire HES dataset). Confirmation was given that the request did not include mental health data.</p> <p>Members were content that PHE have regulations in place and that there was a sound legal basis in place for this important work.</p> <p>Members expressed concern, however, that the Information Governance Toolkit did not meet the required level and stated satisfactory with improvement plan. DF explained that following the reorganisation of a number of organisations into PHE, whilst they had not meet the requirements of the IGT, the HSCIC IG Delivery team have put in place an action plan and are in contact with PHE in order that they can be brought up to the standard required.</p> <p><b>Outcome: Recommendation of approval</b></p> <p><u>300714-g8: Civil Eyes</u></p> <p>This application was originally submitted to the meeting held on 30<sup>th</sup> July 2014.</p> <p>The applicant had previously received approval to receive pseudonymised HES data including consultant code, following discussion at the 27 June 2013 DAAG meeting (application ref: 270613-a). This current application was to receive refreshed data and extend the existing agreement by six months. It was noted that the Health and Social Care Act 2012 would be the legal basis for the release of this data.</p> <p>The Group had raised concerns around the potential sensitivities around sharing data with organisations that could potentially use data for commercial purposes. Members requested that the outcome letter should include a statement that the data should not be used for any additional commercial purposes.</p> <p>Following the meeting on 30<sup>th</sup> July, the IAO had provided clarification from the applicant on their application and had requested that the application be discussed at this meeting. This request had been provided at very short notice to members and the Acting Chair apologised for this.</p> <p>The clarification from the customer stated that:</p> <ol style="list-style-type: none"> <li>1. <i>Civil Eyes Research is a commercial organisation.</i></li> <li>2. <i>Civil Eyes Research works only with NHS and Social care providers</i></li> <li>3. <i>We use the HES data supplied to analyse performance. Civil Eyes Research is aware of the small numbers guidance and we suppress numbers below five.</i></li> </ol> <p>Whilst members felt that the applicant appeared to be providing a legitimate service to its clients, concern was raised about commercial use of health data and Information Intermediaries accessing and disseminating data. The purpose appeared to be generic and had a wide connection to healthcare. There was therefore potential for other organisations not connected to health to be provided with data.</p> <p>The IAO stated that the applicant provided reports and summary tables and members asked if the reports were made public or provided only to the Trusts who commission them.</p> <p>Members stressed that applications must be transparent and provide full justification and clarification on how the data is being provided and used.</p>
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	<b>Outcome: Recommendation to approve.</b>
<b>150814-h</b>	<p><b>Any other business</b></p> <p>The Acting Chair requested that the meetings to be held on 9<sup>th</sup> and 16th September be extended by 1 hour.</p> <p><b>Action: September meetings to be extended.</b></p> <p>The Acting Chair asked Diane Pryce if she would like to give a brief outline of the applications with which she is involved for the benefit of the new members. In addition to the requests for HES data, Diane submits applications from the Medical Research Information Service based at Southport. Diane explained that these are mainly research applications mostly based on consent. The applications include requests for cancer registration data, mortality data and patient flagging/tracking.</p> <p>The Acting Chair requested a Chairman's brief to be provided prior to the DAAG meetings and that any applications to be discussed under Outstanding Applications should be shown on the Agenda.</p>
<b>150814-i</b>	Next meeting: 9 <sup>th</sup> September, 2014 9 – 12 – <b>please note change to timing.</b>

## Summary of Open Actions

Reference	Action	Owner
300714-a1	<i>Terry Hill to discuss with Andy Williams the suggestion that DAAG outcome letters should include a statement that the data received should not be used for any additional commercial purposes.</i> <b>Action: AH to check progress on this with TH.</b>	Terry Hill
300714-c1	<i>Frances Hancox to invite Simon Gray to send an observer to future DAAG meetings in order to feed back to IAOs not in attendance.</i> <b>Action Closed.</b>	Frances Hancox
300714-c2	<i>Alan Hassey to discuss with Rob Shaw and Martin Severs the legal basis for sharing pseudonymised data and the potential implications of onward sharing of pseudonymised data with third party organisations.</i> <b>AH advised had been discussed in meeting with new members earlier in the day and would provide a briefing note for PC/SK.</b>	Alan Hassey
300714-c3	<b><i>Dawn Foster to contact HRA CAG and seek clarification of whether section 251 approval should be considered to remain in place while a review process is underway, or if this should be confirmed for each individual application.</i></b> Process agreed with CAG whereby applications where AR underway would be flagged to CAG by DAIS within 1 working day following deadline data for submission of applications to DAIS team. Cag will prioritise such requests and provide advice back to DAIS. It may not be possible to provide an update prior to submission of papers to DAAG members, but a verbal update would be provided at the meeting. <b>Action Closed.</b>	Dawn Foster
300714-g1	<i>DAAG to contact HRA CAG regarding the section 251 approval for Leeds Teaching Hospital (application ref: 300714-g10) and whether this included the identifiers requested, such as postcode.</i> S251 approval discussed with CAG and confirmation received that support not in place for postcode. Applicant to be contacted and advised that if this field is required, then an amendment to the S251 would be required from CAG. <b>Action closed.</b>	Dawn Foster
300714-h1	<i>Simon Gray to look into how application processes in Scotland and England could be aligned, and consider discussing this with NHS Scotland.</i> <b>SG to be asked how he wishes to deal with this.</b>	Simon Gray
150814-h	<i>AH requested that September meetings be extended by 1 hour.</i> <b>This action has been completed. Action closed.</b>	Secretariat