

Data Access Advisory Group

Minutes of meeting held 30 July 2014

Members: Alan Hassey (Acting Chair), Patrick Coyle, Dawn Foster, Sean Kirwan

In attendance: Susan Milner, Diane Pryce, Frances Hancox (Secretariat), Terry Hill (agenda item 300714-a), Stuart Richardson (agenda items 300714-b to 300714-d), Jackie Gallagher (agenda items 300714-d to 300714-f), Garry Coleman (agenda items 300714-e to 300714-i), Paul Niblett (agenda item 300714-e), Graham Swinton (agenda item 300714-e)

Apologies: None

300714-a	<p>Welcome</p> <p>The Acting Chair welcomed the attendees to the meeting.</p> <p>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.</p> <p>It was suggested that Information Asset Owners (IAOs) should be asked to determine unambiguously whether applicants intended to use the data requested for any commercial activity, and in addition it was suggested that DAAG outcome letters should state that data received should not be used for any additional commercial purposes. The Group agreed that this should be discussed with the Chief Executive of the HSCIC.</p> <p>Action: 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.</p> <p>Terry Hill left the meeting at this point.</p>
300714-b	<p>Minutes of the previous meeting</p> <p>Stuart Richardson joined the meeting.</p> <p>The Group reviewed the minutes of the 17 July 2014 DAAG meeting, and a point of accuracy was raised regarding the statement that if a response had not been received from an applicant within 3 months then the application should be closed. It was agreed that the reference to application 191113-d1 would be clarified to show that this time period had already elapsed.</p> <p>In addition, it was agreed that the wording regarding the disclosure of free text fields for HES data applications should be checked for consistency with HSCIC communication materials on this topic.</p> <p>The wording of the discussion around the legal basis for data disclosures was also queried, and it was agreed that this would be discussed and finalised outside the meeting. It was noted that an addendum had been added to the meeting minutes following the meeting, to reflect additional discussions that took place regarding three applications. The Group confirmed that they were content with the wording of this section.</p>

Matters Arising**(a) Overview of outstanding actions**

- *170714-e1: Dawn Foster to review legal counsel's opinion regarding disclosure of pseudonymised data.*

This had been discussed after the 17 July 2014 meeting, and a post-meeting addendum added to the meeting minutes.

- *170714-e2L: Dawn Foster to liaise with HRA CAG to discuss the interim period before new regulations are in place, and what framework could safely be put in place in the meantime.*

A meeting with the Health Research Authority Confidentiality Advisory Group (HRA CAG) had taken place to discuss future ways of working and how HRA CAG could advise the HSCIC.

- *170714-e3: IAOs to prioritise applications that have a clear legal basis until the current position can be clarified with HRA CAG.*

This was noted and the action was closed.

The Group discussed how information was shared with IAOs, and it was suggested that Simon Gray should be invited to send an observer to future DAAG meetings in order to feed back to IAOs.

Action: Frances Hancox to invite Simon Gray to send an observer to future DAAG meetings in order to feed back to IAOs not in attendance.

(b) Overview of outstanding applications260614-e3: PHE – HES/PROMS

The Group discussed a response that had been received from Public Health England (PHE) regarding this application. The applicant had confirmed that only pseudonymised data would be shared with Queensland University and that this would not include any identifiable data fields, but that project specific identifiers would be used to enable data linkage. The Group confirmed that they were satisfied with this response, but it was suggested that the HSCIC should consider the potential implications of onward sharing of pseudonymised (rather than anonymised) data with third party organisations.

Action: 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.

The applicant had also confirmed that they were awaiting a formal response from HRA CAG regarding the renewal of Section 251 approval, but that CAG had confirmed the section 251 approval remained in place while the review process was underway. There was a discussion regarding whether this was the case for all applications where the review process was underway, and it was agreed that CAG should be asked to confirm this. It was also agreed that the applicant should be asked to provide confirmation that their section 251 approval had been renewed as soon as this became available.

Action: Dawn Foster to contact HRA CAG and seek clarification of whether section 251

	<p>approval should be considered to remain in place while a review process is underway, or if this should be confirmed for each individual application.</p> <p>Outcome: Recommendation to approve</p> <p>(c) Recommendations made out of committee</p> <p>The recommendations for three of the applications discussed at the 17 July 2014 meeting had been confirmed following the meeting, and these had been added to the minutes of that meeting as a post-meeting addendum. It was noted that no other recommendations had been made out of committee.</p>
300714-d	<p>Data applications (IAO: Stuart Richardson)</p> <p>Jackie Gallagher joined the meeting at this point via teleconference.</p> <p><u>300714-d1: North of England Commissioning Support Unit (CSU)</u></p> <p>This application was for identifiable data to be used for risk stratification. It was noted that the HRA CAG had given section 251 approval for this; it was noted that this section 251 was due for renewal at the end of August, but that the application had only requested to hold data until the end of August 2014.</p> <p>The Group discussed the inclusion of free text fields and it was proposed that for any free text field that was deemed to be at risk of including identifiable data, these fields should only be shared once they had undergone either data cleaning or anonymisation to remove any identifiable data.</p> <p>Outcome: Recommendation to approve</p> <p><u>300714-d2: Leeds North clinical commissioning group (CCG)</u></p> <p>The applicant had requested weakly pseudonymised data from the Secondary Uses Service (SUS), Choose and Book, the SUS Population Analysis and Reporting System (PARS) and cancer waiting times. It was noted that section 251 approval was in place for this, and the applicant was a stage one Accredited Safe Haven.</p> <p>A query was raised regarding a mention in the application summary provided of enabling clinicians with a legitimate direct-care relationship to contact patients, and whether this had been covered by the section 251 approval. It was agreed that the applicant would be asked to confirm this.</p> <p>As for the previous application, it was proposed that for any free text field that was deemed to be at risk of including identifiable data, these fields should only be shared once they had undergone either data cleaning or anonymisation to remove any identifiable data.</p> <p>Outcome: Recommendation to approve</p> <p><u>300714-d3: Leeds South and East CCG</u></p> <p>This application was also for weakly pseudonymised data from SUS, Choose and Book, the SUS Population Analysis and Reporting System (PARS) and cancer waiting times. It was noted that section 251 approval was in place for this, and the applicant was a stage one Accredited Safe Haven.</p> <p>As for the previous applications, it was proposed that for any free text field that was deemed</p>

	<p>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> <p>Outcome: Recommendation to approve</p> <p><u>300714-d4: Leeds West CCG</u></p> <p>This application was also for weakly pseudonymised data from the SUS, Choose and Book, the SUS Population Analysis and Reporting System (PARS) and cancer waiting times. It was noted that section 251 approval was in place for this, and the applicant was a stage one Accredited Safe Haven.</p> <p>As for the previous applications, 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> <p>Outcome: Recommendation to approve</p> <p><u>300714-d5: North & East London CSU</u></p> <p>The Group were informed that this application was for data from a number of different weakly pseudonymised local datasets in addition to SUS, as this local commissioning data held by Data Services for Commissioners (DSCRO) was required by the CSU to support commissioning. It was noted that these local data flows were collected under a direction from NHS England under the Health and Social Care Act 2012, and that this provided a legal basis for the data to be shared with the applicant.</p> <p>A query was raised regarding a reference in the application summary provided to sharing data with customers and third parties, and what third parties this would include. It was explained that the CSU would be acting as data processor on behalf of the customer CCG, and that data could be shared with other organisations who were also acting as data processors if this was required to support commissioning.</p> <p>Outcome: Recommendation to approve</p> <p><u>300714-d6: Central Southern CSU</u></p> <p>This application was also to receive weakly pseudonymised local data flows in addition to SUS data in order to support commissioning. It was noted that the legal basis for this was a direction from NHS England under the Health and Social Care Act 2012.</p> <p>Outcome: Recommendation to approve</p> <p>Stuart Richardson then left the meeting.</p>
<p>300714-e</p>	<p>Data applications (IAO: Steve Webster)</p> <p>Paul Niblett and Graham Swinton joined the meeting at this point to present application 300714-e2 on behalf of Steve Webster. Garry Coleman also joined the meeting via teleconference.</p> <p><u>300714-e1: Institute of Education (CLS) Consent</u></p> <p>This application was for feedback from DAAG on the proposed consent materials only, and no data was requested at this stage. A number of queries were raised regarding the consent materials provided, and it was agreed that as the IAO was not present to answer queries then</p>

	<p>discussion of this application should be deferred to the following DAAG meeting. It was agreed that if DAAG members had any comments on the consent materials provided in the meantime, these should be emailed to the IAO to raise with the applicant prior to the next meeting.</p> <p>Outcome: Discussion deferred until the following DAAG meeting</p> <p><u>300714-e2: PHE - SRHAD</u></p> <p>This was an application to receive data from the Sexual and Reproductive Health Activity Dataset (SRHAD) in order to analyse this data and provide some data to local authorities. The Group were informed that PHE sponsored the HSCIC to collect this data, and that it was the organisation's view that the HSCIC was the data controller for this data.</p> <p>It was noted that the data requested included local patient identifiers, but would not contain other identifiers such as NHS number. A query was raised regarding the inclusion of lower layer super output area (LSOA) and whether this could potentially lead to data being identified, but it was explained that LSOA was less identifiable than the use of postcodes as each LSOA included a minimum of 1,000 people.</p> <p>Outcome: Recommendation to approve</p> <p>At the end of this agenda item Paul Niblett and Graham Swinton left the meeting.</p>
300714-f	<p>Data applications (IAO: Jackie Gallagher)</p> <p><u>300714-f1: National Centre for Social Research (MR579 – Health Survey for England)</u></p> <p>This application was for the renewal and amendment of an existing data sharing agreement, as the applicant had asked to add one user to the agreement and remove a number of other users. It was noted that the participants had consented to their data being used and that the consent forms used had been regularly updated.</p> <p>Outcome: Recommendation to approve</p> <p><u>300714-f2: Dundee University (MR745)</u></p> <p>This application was also a renewal of an existing agreement. It was explained that the agreement had previously been amended to list a new head researcher, and that it would now be amended to list the same head researcher as previously, although this individual was now based at Dundee University rather than the University of Oxford. The Group noted that the data requested would not contain any identifiers, and that HRA CAG had advised that the proposed data processing did not require section 251 support.</p> <p>Outcome: Recommendation to approve</p> <p>At this point Jackie Gallagher left the meeting.</p>
300714-g	<p>Data applications (IAO: Garry Coleman)</p> <p>The Group asked Garry Coleman for an update on the CRAB Clinical Informatics Limited application (application ref: 170714-e1) which had been discussed at the 17 July 2014 meeting. It was stated that this application would be brought back to the following DAAG meeting for further discussion.</p>

300714-g1: Birkbeck (NIC-211948)

This application was for pseudonymised, non-sensitive Hospital Episode Statistics (HES) data for use in a project examining the role of GPs in hospital choice. It was stated that the legal basis for the provision of this pseudonymised data was the Health and Social Care Act 2012, and it was confirmed that the data requested did not include any identifiable data or sensitive data fields.

A query was raised regarding a reference to HRA CAG in the application summary provided, and it was explained that this was an error and should have said HRA, as HRA had confirmed that the application did not require Research Ethics Committee approval.

Outcome: Recommendation to approve

300714-g2: Competition and Markets Authority (NIC-224636): Analysis of HES data for NHS merger control

The applicant had requested pseudonymised, non-sensitive data in order to analyse the impact of potential mergers of NHS Foundation Trusts. The requested data would be aggregated rather than at record level, and it was stated that the legal basis for providing this data would be the Health and Social Care Act 2012.

The Group confirmed that as the requested data did not include any identifiers or sensitive data fields, they were content to recommend the application for approval.

Outcome: Recommendation to approve

300714-g3: HDIS Imperial College

This application was for access to the HES Data Interrogation System (HDIS) for pseudonymised, non-sensitive data, in addition to accessing Patient Reported Outcome Measures (PROMs) data. It was noted that the applicant had previously had access to HES Business Objects, which HDIS had now replaced.

A query was raised regarding whether the applicant would be able to access data for only their own organisation or for other organisations as well, and it was confirmed that HDIS would provide access to pseudonymised data from all organisations. The Group noted that the application summary provided stated that HDIS data could be exported and shared for onward analysis, and asked if the applicant intended to share HDIS data with any other organisation. It was confirmed that the applicant would not share HDIS data with any third party organisations.

Outcome: Recommendation to approve

300714-g4: HDIS Southampton City Council

This application was from the Public Health team of a local authority, and was also to receive pseudonymised, non-sensitive HDIS data. The Group agreed that they were content to recommend this for approval.

Outcome: Recommendation to approve

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 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.

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.

Outcome: Recommendation to approve subject to confirmation from HRA CAG that the requested data is included in the section 251 approval

300714-q6: University of East Anglia SCOOP (NIC-177785)

This application requested the renewal of an existing data sharing agreement to the end of October 2014, and a refresh of the HES data currently held by the applicant. It was noted that this would include identifiable and sensitive data, and that the trial participants had given their consent.

Concerns were raised regarding the fact that the applicant was not compliant with either the IG Toolkit or ISO 27002, and it was noted that a System Level Security Policy (SLSP) had previously been supplied but that this was dated 2012. It was agreed that the applicant should be asked to provide further details regarding their security arrangements, including when this had last been audited and whether any issues had been raised.

Outcome: Recommendation deferred, pending further information regarding the applicant's security policies

300714-q7: PHE (NIC-176691 ru897): The Burden of Disease and Risk Factors for Severe Disease Due to Acute Respiratory Virus Infection

The applicant had requested an extension to an existing data sharing agreement to receive HES data for use in this study, and also requested the addition of two users to the agreement. In addition the applicant had asked to extend the stated purpose of this agreement, to include the use of this data to estimate the impact of the childhood influenza vaccination programme. It was confirmed that this was supported by section 251 (regulation 3) as part of the mainstream work of PHE.

Outcome: Recommendation to approve

300714-q8: Civil Eyes

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 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.

The Group discussed the potential sensitivities around sharing data with organisations that could potentially use it for commercial purposes, following the discussion under agenda item 300714-a. It was agreed that the outcome letter should include a statement that the data received should not be used for any additional commercial purposes, as per action 300714-a1.

Outcome: Recommendation to approve

300714-q9: Imperial College (NIC-212201): Measuring the burden of harm caused by adverse events in general surgery

	<p>This application was for pseudonymised HES data in addition to ONS mortality data. It was noted that the Health and Social Care Act 2012 provided a legal basis for this data to be shared, and a commissioning letter from ONS had been provided stating that NHS England had commissioned Imperial College to carry out this work.</p> <p>It was noted that the applicant was thought to have completed version 12 of the IG Toolkit, but that this had not yet been published. The HSCIC external IG delivery team had requested additional evidence of this from the applicant.</p> <p>Outcome: Recommendation to approve subject to confirmation that the applicant has completed the IG Toolkit</p> <p><u>300714-g10: Leeds Teaching Hospitals (NIC-230103): Service evaluation of heart failure pathway</u></p> <p>This application was for data linkage of identifiable data, including sensitive fields, for use in service evaluation of the heart failure pathway. The applicant would provide a cohort of identifiable data to the HSCIC, which the HSCIC would then link with HES data and provide the linked data back to the applicant. Confirmation had been received from HRA that this audit did not require Research Ethics Committee approval, but section 251 support was in place. Confirmation from ONS was awaited to confirm that the applicant was an approved researcher, and it was noted that ONS data would not be provided until this had been confirmed.</p> <p>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.</p> <p>Outcome: Recommendation to approve subject to confirmation from HRA CAG that section 251 approval included the identifiers requested</p> <p>Action: 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.</p> <p><u>300714-g11: NHS Scotland (NIC-239120)</u></p> <p>NHS Scotland had requested pseudonymised, non-sensitive HES data to produce indicators for England and Scotland. The Group were content to recommend this application for approval.</p> <p>Outcome: Recommendation to approve</p> <p><u>300714-g12: Imperial College (NIC-217870)</u></p> <p>This application for renewal had previously been considered by DAAG at the 19 November 2013 meeting (191113-g), but had been resubmitted due to changes in process. It was confirmed that the applicant had not requested any sensitive data items.</p> <p>Outcome: Recommendation to approve</p>
300714-h	<p>Discussion: Aligning application processes in Scotland and England</p> <p>The Group discussed the need to align application processes in England and Scotland, and agreed that Simon Gray should be asked to look into this.</p>

	<p>Action: Simon Gray to look into how application processes in Scotland and England could be aligned, and consider discussing this with NHS Scotland.</p> <p>It was noted that a number of similar applications from Scotland might need to be considered by DAAG in the next few months, and it was suggested that if these were sufficiently similar then it might be appropriate for the Group to consider a few examples of these applications, and the rest to be considered out of committee by the Acting Chair.</p>
300714-i	<p>Any other business</p> <p>The Group discussed adding additional independent members to the Group's membership. It was agreed that two additional members should be added, of whom one should have an academic background and one should be a lay member from the GPES Independent Advisory Group (IAG). It was also agreed that an induction process would be provided for the new independent members, which could include scheduling an additional DAAG meeting to discuss a number of applications in detail and answer any questions that might arise.</p> <p>The Acting Chair also raised the possibility of a representative from MedConfidential observing a future DAAG meeting. The Group agreed to this, provided that the HSCIC SIRO confirmed whether or not the meeting papers could be shared with them.</p>

Summary of Open Actions

Reference	Action	Owner
300714-a1	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.	Terry Hill
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.	Frances Hancox
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.	Alan Hassey
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.	Dawn Foster
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.	Dawn Foster
300714-h1	Simon Gray to look into how application processes in Scotland and England could be aligned, and consider discussing this with NHS Scotland.	Simon Gray