Data Access Advisory Group (DAAG)

Minutes of meeting held 10 November 2015

Members: Joanne Bailey, John Craven, Dawn Foster, Alan Hassey (Interim Chair), Eve Sariyiannidou

In attendance: Garry Coleman, Dave Cronin, Gaynor Dalton, Adam Grindrod, Frances Hancox, Netta Hollings, Steve Hudson, Mark Irons, Dickie Langley, Vicki Williams

Apologies: Sean Kirwan, James Wilson

1	**Declaration of interests** No conflicts of interests relevant to this meeting were declared. **Review of previous minutes and actions** The minutes of the 3 November 2015 meeting were reviewed and agreed as an accurate record. Action updates were provided (see table on page 10). **Out of committee recommendations** The following applications had previously been recommended for approval subject to caveats, and it had been confirmed out of committee that the caveats had now been met: • NIC-326033-G1P7Q University of Manchester • NIC-381984-B7X3S University Hospitals Birmingham • NIC-376374-F8D0M Central Manchester University Hospitals NHS Foundation Trust • NIC-380902-S7H1C PricewaterhouseCoopers LLP
2 **2.1**	**Data applications** <u>North of England Commissioning Support Unit (CSU) (Presenter: Dickie Langley) NIC-376059-T5F8S</u> **Application:** This application was for pseudonymised, sensitive Hospital Episode Statistics (HES) data for use in a dashboard analysis and reporting tool for NHS commissioners named RAIDR. DAAG had previously discussed the application at the 16 June 2015 meeting, when they had been unable to recommend approval. Additional information had now been provided about the applicant's customer organisations, examples of benefits, and the data already used in the RAIDR tool which would be presented alongside the data requested. It was noted that the application summary referred to weakly pseudonymised data being included in the RAIDR tool, when in fact this was not used. It was agreed the application summary would be amended to remove this reference. **Discussion:** DAAG discussed the amount of data requested, and whether this could be considered excessive. The need for national data was queried, as it was noted that the majority of customers listed were based in the same geographical area as the CSU. DAAG noted that the applicant had stated this data was required to support national projects, but it was unclear whether this meant national level work or whether this referred to local work as part of wider national projects.

DAAG queried a reference to Local Authorities being customers of the RAIDR tool, as the customer list provided did not list any Local Authorities. Confirmation was requested of whether the customer list was accurate and complete. DAAG also requested confirmation of whether any internal customers within the CSU would also make use of the data, and in particular whether any internal customers would therefore have access to record level data. Furthermore, DAAG noted that another CSU was listed as a customer and it was unclear whether this meant that that CSU would also make the tool available to their own customers in turn.

DAAG also queried why the applicant had requested sensitive data items, as it was thought that these had not been included in their previous application and no clear justification had been provided.

Outcome: Unable to recommend for approval. DAAG requested clarification of the following points:

- Clarification of the customer list provided and whether this is complete and accurate, particularly in reference to Local Authorities and whether there are any internal customers within North of England CSU.
- Clarification of the implications of a CSU being listed as a customer organisation.
- Clarification of why sensitive data items were required, given that these had not previously been requested.
- Confirmation whether this data is required to support local work on national projects or national work on national projects.
- Application summary to be updated to remove references to weakly pseudonymised data.

2.2 Ramsay Health Care (Presenter: Dickie Langley) NIC-355868-H2R2D

Application: The applicant organisation was a provider of independent hospital services in England, and pseudonymised HES data was requested for comparative analysis with other healthcare providers. DAAG were informed that the applicant was a commercial organisation, but that the purpose of this application was not considered to be commercial.

Discussion: The need for national data was queried, and on balance DAAG felt that the applicant had provided sufficient justification for the use of national data.

DAAG stated that the expected benefits could have been more clearly written, in particular by focussing on the benefits of measuring performance and quality of healthcare in comparison to other healthcare providers and sharing this comparison with NHS commissioners. It was suggested that the application summary should include a statement that data would not be used for any other sales or marketing purpose. In addition, DAAG noted that any future renewal applications would be expected to provide examples of the healthcare benefits that had been achieved by using this data.

The planned data retention period was discussed, and DAAG felt that the reason given indicated that data would in fact only be required for a specific period of time rather than needing data on an ongoing basis. DAAG queried a reference to mapping provider data to 'the equivalent tabulation', as it was unclear what tabulation this referred to and whether this could increase the risk of individuals being reidentified from the data.

Outcome: Recommendation to approve, subject to caveats:

- Updating the planned data retention period to a rolling three years rather than 'ongoing'.
- Clarifying a reference to mapping to tabulated data, and what risk this would have of reidentification.
- The expected benefits section should be updated to clarify the benefits will relate to comparing their performance to organisations providing similar services and communicating this comparison to NHS commissioners, and that data will not be used to

market services outside of sharing this comparison with NHS commissioners.

DAAG commented that a renewal application would be expected to provide details of the benefits that have been achieved with the data provided.

2.3 North and East London CSU – HES Cube (Presenter: Dickie Langley) NIC-371243-H1P5T

Application: This application was to renew, extend and amend several existing agreements into a single data sharing agreement for the applicant to receive pseudonymised HES and Diagnostic Imaging Dataset (DIDs) data. This data would be used within the CSU to carry out analysis for CCG and other NHS clients, as well as to use aggregated data with small numbers not suppressed to populate a data tool named HES Cube. Clients of the CSU would be able to apply to access the tool solely for the purpose of supporting CCGs to meet their statutory requirements.

Discussion: DAAG discussed the local data sharing template that the applicant used for data being reused by third parties. There were some concerns regarding the terminology used in this, such as references to sharing weakly pseudonymised data when it was thought that this was only available in very specific circumstances.

The relationship and controls in place between NHS England and CSUs were discussed, as it was noted that CSUs themselves were not separate legal entities. DAAG noted that an email from a senior member of staff at NHS England had been provided which indicated support for this application, but it was agreed that more formal confirmation should be requested as for example this email did not state the individual's job title.

DAAG noted the importance of providing evidence of healthcare benefits that had been achieved using the data provided to applicants, and emphasised that in future the applicant would be expected to provide specific examples of benefits achieved.

Outcome: Recommendation to approve, subject to:
- Provision of more formal confirmation from NHS England that this use of data is supported.

DAAG advised that in future they would expect to see examples of benefits achieved with the data already received. In addition DAAG suggested that the HSCIC should consider auditing this organisation in relation to the reuse of data.

Action: Dawn Foster and Alan Hassey to contact NHS England Director for Data and Information Management Systems regarding the need for more formal evidence that NHS England support certain applications from CSUs, and invite her to attend a future DAAG training session.

2.4 Non-Acute data sets to flow to commissioners

DAAG were asked to provide advice on a potential new approvals process for four datasets for use by commissioners that had not previously been considered by DAAG: Mental Health and Learning Disabilities Data Set (MHLDDS), Improving Access to Psychological Therapies Data Set (IAPT), Maternity Services Data Set (MSDS) and the Children and Young People's Data Set (CYPHS). DAAG were informed that the majority of applicants for these datasets would be CCGs, but that Local Authorities would also be expected to apply for CYPHS given their role in commissioning services for children ages 0-5.

DAAG queried which department within a Local Authority would require access to CYPHS, as it was noted that DAAG had previously emphasised the importance of ensuring that data provided to a Local Authority would only be used for the specified health purpose and not to support other activity within the Local Authority. It was explained that this could vary depending on the structure of each Local Authority. Some concerns were expressed regarding whether commissioning of

	children's services could in some Local Authorities be outsourced to external organisations, as well as regarding the risk that data might be reidentified by Local Authority staff familiar with particular at risk children. A potential approach suggested was that the Director of Children's Services within each Local Authority could be responsible for ensuring that only appropriate individuals would have access to the data provided. The possible practical difficulties of reviewing a large number of applications were acknowledged, and it was suggested that applications should be grouped together where possible, for example by grouping CCG applicants based on a shared data processor. DAAG suggested that this should be discussed with other teams within the HSCIC working on grouping similar applications together. It was agreed that an example application would be brought to a future DAAG meeting for further discussion and review.
2.5	<u>University of Aberdeen - A pragmatic multicentre randomised controlled trial comparing stapled haemorrhoidopexy to conventional excisional surgery for haemorrhoidal disease (Presenter: Dave Cronin) NIC-384722-W7Y8W</u> **Application:** This application was for identifiable HES data based on patient consent, as part of a trial to compare two different treatments and determine which offered the best clinical outcomes and patient quality of life following treatment. DAAG were informed that the HSCIC had previously raised concerns that the trial consent materials did not provide an adequate legal basis to share patient identifiers with the HSCIC for this purpose, as the patient information leaflet stated that only members of the research team would have access to information, although it was noted that the consent materials referred to collecting information from NHS central registers. Based on this feedback from the HSCIC, the applicant had begun to issue a newsletter to participants which included information about the involvement of the HSCIC as well as reminding participants of the opportunity to opt out of the trial. It was noted that newsletters had not yet been sent to all participants, but had been sent to any participant who had been due to receive a patient questionnaire. The newsletter had also been published online. The applicant had indicated that it would not be feasible to ask every participant to re-consent for data to be shared due to a number of practical concerns. **Discussion:** DAAG noted the potential benefits of this use of data and expressed their support for the trial. The newsletter was discussed, and DAAG expressed some concerns that this did not make it sufficiently clear how participants could opt out of the study. It was agreed that this should be amended to clarify what participants needed to do to withdraw their consent. DAAG noted that the applicant had indicated a 78% response rate to patient questionnaires sent out to participants, and there were some concerns that this might indicate the addresses being used to send updated materials to participants were no longer up to date. It was suggested that the HSCIC should undertake list cleaning for the applicant in order to update address details, to ensure maximum penetration of the updated newsletter being issued to participants. The applicant should then send out the updated newsletter to these updated addresses, and ensure that any individuals who opted out were removed from the cohort. There was some uncertainty expressed regarding the involvement of other organisations referred to in the supporting documents for this application, but it was confirmed that for the purpose of this application only the University of Aberdeen would have access to data. DAAG noted that the DPA registration details for the University of Aberdeen included a statement that the sensitive personal data they processed was 'about survey respondents', and DAAG suggested that this sentence was misleading and should be removed. It was also suggested that the DPA registration should be updated to specifically refer to processing data about patients or healthcare users. In addition,

	DAAG suggested that the outputs section of the application summary should be updated to include how information would be made available to patients. **Outcome:** Recommendation to approve for the purpose of list cleaning only. An updated application should be brought back to DAAG subject to the removal of any individuals who have opted out from the cohort, with an updated newsletter to be provided to the remaining cohort to make clear that data will be shared with HSCIC and inform individuals how to opt out.
2.6	University of Nottingham - Helicobacter Eradication Aspirin Trial (Presenter: Dave Cronin) NIC-389320-R4M6Z **Application:** This application for a bespoke linkage of HES and Office for National Statistics (ONS) mortality data for the trial cohort had previously been discussed at the 8 September 2015 meeting, when DAAG had been unable to recommend approval. DAAG had asked for the patient consent materials to be updated for ongoing recruitment, and had requested clarification of a reference to patient initials as well as an updated data flow diagram. An updated consent form had now been provided along with the clarification previously requested. DAAG were informed that the applicant would issue a follow-up letter to participants who had given consent using the old version of the consent materials, and this letter included an explanation about the involvement of the HSCIC. **Discussion:** DAAG discussed the updated follow-up letter provided, and suggested that this should be updated to include details of how participants could withdraw their consent. DAAG also discussed the updated consent materials and agreed that the applicant should begin to use these with participants in a timely fashion, as any participants who consented using the older materials would need to receive a follow-up letter. A query was raised regarding whether ONS had confirmed that they were content with the consent materials, given the request for ONS data, and it was noted that this would need to be confirmed prior to data being shared. A reference in the application summary to using GP records was queried, and DAAG requested confirmation that HES data would not be linked with GP record data. In addition, DAAG discussed the DPA registration entries for the applicant and its data processors and noted that these ought to be updated, as for example the University of Nottingham entry did not state that they process data about patients or health service users. **Outcome:** Recommendation to approve, subject to: • Amending the follow up letter to include clear details of how participants can opt out. • Updated consent materials should begin to be used within 8 weeks. • The application summary should be updated to clarify that HES data will not be linked to GP data. DAAG advised the applicant organisations to consider updating their DPA registration wording. **Action:** Dave Cronin to report back to DAAG by 5 January 2016 to confirm progress for NIC-389320-R4M6Z University of Nottingham.
2.7	Imperial College London – SIGGAR/SOCCER (Presenter: Steve Hudson) NIC-291981-Y7J2F **Application:** This application related to two studies, the Special Interest Group in Gastrointestinal and Abdominal Radiology (SIGGAR) and the Symptoms of Colorectal Cancer Evaluation Research (SOCCER). The application requested to extend and amend an existing data sharing agreement for identifiable Patient Demographic Service (PDS) data, ONS mortality data and cancer registration, in order that the applicant could retain the data already held for the SIGGAR trial and use this for the new purpose of the SOCCER trial, as well as receiving new

pseudonymised data for the SOCCER trial. DAAG were informed that the applicant had NIHR funding in place until the end of November 2015, meaning the ONS data could be provided before this date under Section 42(4) of the Statistics and Registration Service Act 2007, and that the applicant had applied for Approved Researcher accreditation from ONS to support the use of data after that date.

Discussion: DAAG noted the complexity of this application, particularly given the combination of the SIGGAR and SOCCER trials into a single application summary. Some concerns were raised about the lack of transparency regarding the extensions that the HSCIC had previously granted to the applicant, following DAAG's suggestion at the 13 April 2015 meeting that the HSCIC should consider issuing a data destruction notice. However it was acknowledged that the applicant had made steps towards addressing the concerns previously raised by DAAG, such as achieving a satisfactory IG Toolkit score and renewing their section 251 support.

DAAG raised concerns regarding the continued lack of clarity about legal basis for various elements of the requested use of data. In particular it was felt to be unclear whether the applicant's section 251 support included retaining and sharing data for both the participants who had consented to participate and those who had not consented, and DAAG agreed that this key point would need to be clarified with HRA CAG. The legal basis for receipt and retention of cancer registration data was also queried, as this did not appear to be specifically referred to in the section 251 support letters.

The importance of fair processing was discussed, and DAAG were informed that the applicant had recently created a website that gave details of the two trials for members of the public.

The planned data retention period was queried, as DAAG noted that a section 251 letter in the application pack stated that data would be retained for ten years from 2011 whereas the application summary referred to retaining for ten years from 2015 onwards. DAAG requested clarification of a reference to 'additional data', as it was unclear what data this referred to and what the specific legal basis for linkage with this data would be. In addition, a reference to the applicant sharing information with the HSCIC about individuals who had withdrawn their consent was queried and DAAG also requested clarification of the legal basis for sharing this information.

Concerns were raised regarding the lack of clarity and potentially conflicting statements in some section 251 support letters and the differences between these letters and the HRA CAG register. It was agreed that this would be discussed with HRA CAG.

It was suggested that a DAAG member could provide support for the HSCIC outside the meeting to clarify the application and ensure the concerns raised by DAAG had been addressed before an updated application was brought back to a future meeting. In addition there was some confusion regarding terminology used to refer to different elements of the cohorts used for each study and what the legal basis for each element was, and DAAG suggested that a flow diagram might be helpful in future.

Outcome: Unable to recommend for approval. DAAG requested clarification of the legal bases (one or more in each case) for retaining and sharing data for each group of patients (the group of registered patients who had not consented to participate in the study and the group of patients who had consented). Specifically:

- Clarification is required of the legal bases for retention of SIGGAR data
- Clarification is required of what is covered by the section 251 support, including with regards to cancer registration data.
- Clarification from HRA CAG is requested of the legal bases for the SOCCER cohort and whether this covers the retention of identifiable data; if so, the HRA CAG register should be updated to confirm this.
- The data retention period should be confirmed in line with the stated period in the section 251 letter.
- Clarification is also needed of the legal bases for sharing information with the HSCIC about

participants who have withdrawn consent.
- A reference to 'additional data' should be clarified with the legal bases for linkage with this data.

Action: Dawn Foster to contact HRA CAG regarding lack of clarity in section 251 support letters.

2.8 Newcastle University - The Future Children's Neurorehabilitation Project (Presenter: Steve Hudson) NIC-380680-T6F4D

Application: This application had previously been discussed at the 4 August 2015 meeting (NIC-337938-M5Q4W) when DAAG had been unable to recommend approval. DAAG had requested clarification of the employment arrangements between Newcastle Upon Tyne Hospitals NHS Foundation Trust and Newcastle University and confirmation of whether the two organisations were acting as joint data controllers for this application. The application had now been updated with Newcastle University as the applicant organisation, and it was confirmed that only University staff would be able to access the data from inside Newcastle University premises.

Discussion: DAAG agreed that the queries previously raised had now been addressed. As had been raised during the previous discussion of this application, DAAG reiterated that data could only be used for the first phase of this work and any additional uses of data would need to be subject to a new application.

The expected benefits of this work were discussed, and DAAG agreed that this section of the application summary should be updated to more clearly state what benefits were expected and how these would be achieved, for example by disseminating any learning to appropriate clinicians or professional groups. In addition, DAAG noted that the applicant organisation's DPA registration did not refer to using data about healthcare users or patients and suggested that the applicant should update this to accurately reflect the work carried out.

Outcome: Recommendation to approve, subject to:

- Application summary being updated to confirm that data can only be used for the first phase of this work.
- Application summary being updated to provide additional information about benefits.
- The applicant updating their DPA registration wording to cover the use of data about healthcare users or patients.

2.9 Imperial College London – Small Area Health Statistics Unit (SAHSU) (Presenter: Gaynor Dalton) NIC-204903-P1J7Q

Application: This application was for the receipt of identifiable HES data for the purpose of academic research. DAAG were informed that the applicant had previously also received linked HES-ONS mortality data for this purpose, but that ONS data was not included in the current application and a separate application would be submitted at a later date for the retention of ONS data. The HES data requested would be used by the applicant to maintain a health research database, to carry out a programme of research projects and studies, and to provide ad hoc support to Public Health England (PHE) and the Department of Health about unusual clusters of disease.

An error in the application summary was acknowledged, as data was referred to as 'not pseudonymised' rather than 'pseudonymised', and DAAG were informed that this would be corrected.

Discussion: DAAG queried the legal basis for the applicant to receive ordnance survey grid reference and census output area data, and it was confirmed that the applicant's section 251

	support covered the receipt of location data including postcode. A reference within the application study to US Centres for Disease Control was queried, and it was clarified that this referred to use of the SAHSU tool in the USA but that the data itself provided to the applicant would not be made available outside England. In addition a query was raised regarding whether the applicant's section 251 support included access to data about date of birth for mothers and babies, and it was confirmed that this data was covered by this support. Fair processing was discussed, and DAAG noted that one of the conditions of the applicant's section 251 support had been to create a patients and public section on their website which would include information about the data being processed and how individuals could object. The applicant had stated that this would be completed prior to the section 251 annual review date, but DAAG noted that the webpages had not yet been created and emphasised the need to ensure that this was completed. It was agreed that the applicant should be asked to provide details about the planned website content, with a specific timeline for when this content would be published. DAAG noted that the most recent section 251 letter provided stated that the application was conditionally approved, and that a final approval letter confirming the annual review date had not been provided. DAAG requested confirmation of the annual review date, particularly given that the applicant had committed to publish information for patients and the public online before the next annual review. **Outcome:** Recommendation to approve, subject to: • Provision of the final section 251 support letter, with confirmation of the annual review date for applicant's section 251 support. • The applicant providing evidence of the planned content for the patient information webpage within 4 weeks, with a clear timeline for implementation. **Action:** Gaynor Dalton to inform DAAG once Imperial College London (SAHSU) have published information for patients and the public as per their implementation timeline.
2.10	<u>University of York - Life Limiting conditions in children and young people in England: Prevalence and Survival (Presenter: Dickie Langley) NIC-379681-D6L7G</u> Steve Hudson provided an update on the action he had previously been given to clarify potential changes to the University of York data management policy. It was confirmed that there had been no changes to how the data previously applied for would be stored. DAAG were informed that the majority of applications from the University to date had been made from within the Centre for Health Economics and it was possible that other departments would apply for data and store this in different locations within the University in future. DAAG supported the aim to avoid duplication of datasets by encouraging organisations to make use of the data already held for different projects if this was appropriate and subject to the necessary approvals. **Application:** This application was for HES data linked with identifiable ONS mortality data, including the field Date of Death. This data would be used to create updated analysis of the prevalence and survival rates of children and young people with life-limiting conditions. DAAG were informed that funding had been provided by Martin House Children's Hospice and that this organisation would receive a final report, but would not have any influence over the outcome of the work. **Discussion:** DAAG acknowledged the potential importance of this study. However, it was felt to be unclear whether the applicant should have applied for ethical approval from a Research Ethics Committee prior to applying for data, as a document provided as evidence that this was not required stated that only pseudonymised data would be used whereas the applicant had in fact applied to use identifiable data. It was agreed that the application should be withdrawn until this point could be clarified.

	In addition, DAAG noted that the applicant's DPA registration wording did not refer to processing data about patients or healthcare users. **Outcome:** Application withdrawn, pending confirmation of whether the applicant requires ethical approval.
3	**Any other business** A question was raised regarding the structure of the application summary template, and it was suggested that the form should be amended to provide a separate section for the history of each application rather than including these details in the summary. The importance of including a clear summary of the key points of each application was noted. DAAG discussed next steps for the draft paper on data minimisation. It was agreed this would be shared initially with Steve Webster, who had previously attended a DAAG training session to discuss sampling techniques, and then shared with Terry Hill, Garry Coleman and Steve Hudson for their comments. DAAG were informed that Alan Hassey would be on leave for the following two weeks, and members would need to agree an acting chair for the two DAAG meetings in that time.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
29/09/15	University of York to be asked for clarification on their change of policy for providing access to data.	Steve Hudson	06/10/15: This had been raised with Garry Coleman, and formal contact would be made with the University of York to request clarification. 27/10/15: Ongoing. It was expected a response would be available for the 3 November DAAG meeting. 10/11/15: An update was given under agenda item 2.10, and the action was closed.	Closed
20/10/15	Paula Moss to provide an updated paper on DSCRO local data flows.	Paula Moss	27/10/15: Ongoing. 10/11/15: A draft paper had been provided to the DAAG Chair by email but had not yet been circulated to the group.	Open
03/11/15	Information Governance team to liaise with MedeAnalytics regarding their DPA registration to ensure that it reflects recent applications.	Dawn Foster	10/11/15: Ongoing.	Open
03/11/15	Dickie Langley to confirm that the previous data processor acting on behalf of Monitor (CHKS) will delete data following transfer to the new data processor (PricewaterhouseCoopers).	Dickie Langley	10/11/15: Confirmation had been received.	Closed
10/11/15	Dawn Foster and Alan Hassey to contact NHS England Director for Data and Information Management Systems regarding the need for more formal evidence that NHS England support certain applications from CSUs, and invite her to attend a future DAAG training session.	Alan Hassey		Open
10/11/15	Dave Cronin to report back to DAAG by 5 January 2016 to confirm progress for NIC-389320-R4M6Z University of Nottingham.	Dave Cronin		Open

10/11/15	Dawn Foster to contact HRA CAG regarding lack of clarity in section 251 support letters.	Dawn Foster		Open
10/11/15	Gaynor Dalton to inform DAAG once Imperial College London (SAHSU) have published information for patients and the public as per their implementation timeline.	Gaynor Dalton		Open