Data Access Advisory Group (DAAG)

Minutes of meeting held 10 March 2015

Members: Eve Sariyiannidou, John Craven, Patrick Coyle, Dawn Foster

In attendance: Alex Bell, Karen Myers, Frances Hancox, Diane Pryce, Nicola Mallender-Ward, Dickie Langley, Netta Hollings, Jennifer Donald, Dave Roberts, Stuart Richardson, Paula Moss

Apologies: Alan Hassey, Sean Kirwan

1	**Review of previous minutes and actions** It was noted that Alan Hassey (Acting DAAG Chair) was on leave, and Eve Sariyiannidou chaired the meeting. The minutes of the 3 March 2015 meeting were reviewed. A point of accuracy was raised regarding the language used to describe section 251 support; other than this the minutes were agreed as an accurate record. Action updates were provided (see table on page 10). **Out of committee recommendations** The following two applications had previously been considered by DAAG and recommended for approval subject to caveats, and it had been confirmed out of committee that the caveats had now been completed: • Basildon and Brentwood, NIC-310899-B3N7T • The Nuffield Trust, NIC-283419-T9H7X One application (University Hospitals Birmingham, NIC-325819-D6V9H) had been considered at the 24 February 2015 DAAG meeting and recommended for approval subject to caveats which had since been completed, but subsequent to this an error had been found in the dates listed in the application form. This had been amended, and it had been confirmed out of committee that the recommendation to approve was not affected by this change.
2 **2.8**	**Data applications** <u>Clinical Practice Research Datalink (CPRD) (Presenter: Dickie Langley) NIC-326073-Z0M3Q</u> **Application summary:** The applicant already held Hospital Episode Statistics (HES), national cancer registration and Office for National Statistics (ONS) data and this application was to receive Diagnostic Imaging Dataset (DID) data in addition to those datasets. The applicant would then share pseudonymised or anonymised data with researchers for a variety of projects. It was also noted that the applicant intended to apply for Patient Reported Outcome Measures (PROMs) and mental health datasets at a later date, but those two datasets were not part of the current application. It was stated that section 251 support from the Health Research Authority Confidentiality Advisory Group (CAG) was in place. **Discussion:** The Group queried the application process that researchers wishing to use data held by CPRD would undergo. It was stated that all applications to use the data held by CPRD would be considered by the CPRD Independent Scientific Advisory Committee (ISAC) and details of ISAC approvals were made available to CAG. It was also noted that CPRD did not hold any identifiers. The Group requested further information regarding the ISAC process, and in particular whether details of approvals and minutes of meetings were published to ensure transparency.

	There were some concerns that the specific outputs and measurable benefits listed in the application form did not provide sufficient detail, given the amount of data that CPRD already received, and it was suggested that it would have been helpful if examples could have been included of how specific customers had used data to realise benefits. It was agreed that further details should be requested about CPRD's existing customers and how data had been used to the benefit of health and social care. It was noted that the applicant had provided a System Level Security Policy that had been reviewed and approved by the HSCIC security team, but that the applicant would be encouraged to move to completing the Information Governance (IG) Toolkit instead. It was also noted that CPRD would share data with researchers under sublicenses, and the HSCIC could consider specifying clauses that should be added to these sublicenses. A query was raised regarding how patient objections would be managed, both by CPRD and by its customers. In addition the Group queried what information was made available about CPRD's use of data in order to meet fair processing requirements under the Data Protection Act 1998 (DPA). **Outcome:** Unable to recommend for approval. Further details requested about the CPRD approvals process (ISAC) and the transparency of this process, such as whether ISAC minutes are published. Additional information required about the applicant's customers and their usage of data and whether this is compliant with the Care Act 2014. Further details also requested on how the applicant meets fair processing requirements, and how they and their customers handle patient objections.
2.1	2.1 Kings College (Presenter: Netta Hollings) NIC-271579-H1T1S John Craven declared an interest in this application and did not participate in the discussion. **Application summary:** This application was for pseudonymised, non-sensitive Improving Access to Psychological Therapies (IAPT) data, in order to compare access to treatment and outcomes for lesbian, gay and bisexual service users in comparison to heterosexual service users. **Discussion:** The Group queried the security arrangements for the applicant, and it was noted that the relevant security policies had been reviewed and approved by the HSCIC security team. There was a discussion around how the applicant would disseminate the outputs of this work, and whether this would be sufficient to provide benefits to the health and social care system. It was noted that the applicant would feed back the recommendations arising from the work to the national IAPT team, who oversaw IAPT services in England. **Outcome:** Recommendation to approve
2.2	NHS England (Presenter: Netta Hollings) NIC-316000-K7J2H **Application summary:** This application was for the one-off provision of patient identifiable learning disability data from the Assuring Transformation data collection, using patient postcodes in order to map demand on learning disability inpatient services. Section 251 support was in place for this work. **Discussion:** The Group discussed the statement within the application form that this work would identify geographical variations in preventing hospital admissions, and it was suggested that this should be amended to clarify that it only meant inappropriate admissions. In general it was felt that the benefits could be described more clearly to explain that data would be used to support NHS England in their role as a commissioner of learning disability services.

	There was a query regarding whether the section 251 support for this use of data included the use of postcode, and it was confirmed that this was the case. It was noted that the HSCIC had not been listed on the application as a data controller for the learning disabilities data that would be provided, and it was agreed that this would be corrected. **Outcome:** Recommendation to approve subject to updating the outputs and measurable benefits within the application form to clarify that data will be used to help reduce inappropriate hospital admissions and to support NHS England in their role as commissioner. Application form also to be updated to list the HSCIC as a data controller.
2.9	Imperial College London (Presenter: Dickie Langley) NIC-315184-V9T1R **Application summary:** This application was to extend, renew and amend an existing agreement for the provision of pseudonymised, non-sensitive HES data, with HES Accident and Emergency data being requested in addition to the data previously provided. The data would be used to support ongoing research into health policy reform. It was noted that the applicant's DPA registration details had been updated to include the use of data for research purposes. **Discussion:** A query was raised about how this research had been funded, and it was explained that the work was funded through competitively won research grants. It was agreed that the application form should be updated to include further details about this in the relevant section. In particular the Group requested details of whether the funding organisations would receive any outputs from the research or obtain any specific benefits, as well as whether they would have any influence on how the outputs of the research would be communicated. The Group discussed the fact that data had been requested for the whole population, and whether this could be considered proportionate. It was agreed that this amount of data seemed appropriate for the type of work described, but it was suggested that a clearer justification could have been included in the application form. A reference in the form to matching the data provided to other datasets was queried, and clarification was requested about whether this would include any patient level data or whether the matching could increase the risk of individuals being re-identified. **Outcome:** Unable to recommend for approval. Clarification requested regarding a reference to linking to other data, and whether this will increase the risk of re-identification. Further details requested about the organisations that funded this work and whether they will receive any outputs or obtain any benefits from the research, as well as whether they will have any influence on how the outputs of the research will be published.
2.3	University of Essex- UK Household Longitudinal Study Health Linkage (Presenter: Jennifer Donald) NIC-326964-K1J6K **Application summary:** This was a new application to link cohort data to HES and ONS data, based on patient consent. Cohort data would be linked to updated contact information and remove any individuals who were now deceased, and the HES-ONS data provided would be used to investigate precursors to hospitalisation and mortality. The application form described the reports that would be produced based on this research, and stated that findings would be shared with relevant bodies such as the Department of Health. It was noted that a previous application for this use of data had been considered by DAAG at the 27 June 2013 meeting (application reference MR1327), and had been approved subject to the applicant updating the consent materials, and it was confirmed that the changes requested to the

	consent materials had been made. It was also noted that the applicant had contacted the Information Commissioner's Office (ICO) to update their DPA registration details to include health research. **Discussion:** The Group noted that at one point the application referred to the previous DAAG approval as being from 2014, and it was thought that this was a typo and should have read 2013. It was noted that the applicant had ISO 27001 accreditation, but it was not clear from the application form whether the HSCIC had confirmed what was covered by this accreditation. It was agreed that this should be clarified. Concerns were expressed about the various consent forms provided, and the inconsistencies between various historical versions of the forms. As an example it was noted that one form stated that only anonymised data would be used, while identifiable data was requested; another form stated that HSCIC would provide data to the applicant, but not that the applicant would send identifiers to the HSCIC for linkage. It was acknowledged that a number of the consent forms provided were several years old, but there were concerns about using consent obtained through these forms as a legal basis for the linkage of identifiable data requested. In addition it was suggested that the current version of the application forms should more clearly explain how data would be used by what organisation, what data would be held and linked, and what the specific purposes for this use of data were. It was suggested that it would be most appropriate for the applicant to update the consent materials and then contact the study participants to seek their further consent. The Group discussed the expected benefits of the work, and requested further details about how the applicant would ensure the findings of the work were appropriately disseminated to ensure benefit to the health and social care sector. **Outcome:** Unable to recommend for approval. Applicant to be asked to updated consent materials in line with guidance produced by DAAG, and ask participants to re-consent using the updated materials. Further details requested of how the applicant will ensure that the outputs of the work have an impact beyond the academic community.
2.4	<u>Swindon CCG stage 1 accredited safe haven (Presenter: Stuart Richardson) NIC-296588-V6D8G</u> **Application summary:** This application was to extend the provision of Secondary Uses Service (SUS) data to be provided for commissioning purposes under the section 251 support for stage 1 accredited safe havens until 30 April 2015, or in line with extension of the section 251 support. Data identifiable at the level of NHS number was requested (weakly pseudonymised). The applicant had achieved an IG Toolkit score of 64%, but the HSCIC information governance team had confirmed that a satisfactory improvement plan was in place. The applicant's DPA registration was currently in the process of being renewed. A number of clerical errors on the application form were noted, and it was agreed that these would be corrected. **Discussion:** The Group noted that the application contact details listed an individual based at a commissioning support unit (CSU), and queried whether the CSU would be acting as data processor. It was clarified that the CCG would be the only recipient of data and would process the data internally, but that the application form had been completed by an individual employed by a CSU at the request of the CCG. It was agreed that the application form needed to be amended to clarify that the application was on behalf of the CCG, not a CSU. **Outcome:** Recommendation to approve subject to updating the application to clarify that the application is made on behalf of the CCG, and to correct administrative errors.

2.5	NHS Gloucestershire CCG stage 1 accredited safe haven (Presenter: Stuart Richardson) NIC-296669-V6D8G **Application summary:** This application was to extend the provision of SUS data to be provided for commissioning purposes under the section 251 support for stage 1 accredited safe havens until 30 April 2015, or in line with extension of the section 251 support. The data requested was identifiable at the level of NHS number (weakly pseudonymised). The applicant had achieved an IG Toolkit score of 58%, and the HSCIC information governance team had confirmed that a satisfactory improvement plan was in place. The applicant's DPA registration was in the process of being updated. A number of clerical errors on the application form were noted, and it was agreed that these would be corrected. **Discussion:** As with the previous application it was noted that the application form listed the details of an individual based at a CSU, and it was confirmed that the application was made on behalf of Gloucestershire CCG. It was agreed that the application form would be updated to clarify this. **Outcome:** Recommendation to approve subject to updating the application to clarify that the application is made on behalf of the CCG, and to correct administrative errors.
2.6	Yorkshire and Humber CSU stage 1 accredited safe haven (Presenter: Stuart Richardson) NIC-301908-K6H2W **Application summary:** This application was to extend the provision of SUS data for commissioning purposes under the section 251 support for stage 1 accredited safe havens until 30 April 2015, or in line with extension of the section 251 support. The data requested was identifiable at the level of NHS number (weakly pseudonymised). The applicant had achieved a satisfactory IG Toolkit score. A number of clerical errors on the application form were noted, and it was agreed that these would be corrected. **Discussion:** The Group noted that this application was from a CSU, and queried whether data would be provided for all CCG areas or only certain CCGs. It was confirmed that data would only be provided for CCGs with a legitimate relationship with the CSU as authorised by NHS England. It was suggested that it would be helpful if the CCGs with a legitimate relationship with this CSU at the current point in time could be listed in the application form; it was noted that this list was likely to change in future, and there was a suggestion that a link to the updating list could be included. **Outcome:** Recommendation to approve subject to specifying the organisations with a legitimate relationship to the CSU at the current point in time, as well as adding a link to the ongoing list of organisations. Application form to be updated to correct administrative errors.
2.10	BMJ Publishing Group (Presenter: Dickie Langley) NIC-315938-S2D9B **Application summary:** Pseudonymised, sensitive HES data was requested in order to produce the tool Hospital Insights, which would be used for benchmarking by NHS trusts who were customers of the tool. This application had previously been considered by DAAG on 23 December 2014, when they had been unable to recommend approval. The application had now been updated to remove the use of the local patient identifier field, provide further information about the applicant's customers, update the data retention period, minimise the amount of data requested, and clarify that consultant identifiers were only requested for the specific customers listed. The

	applicant's DPA registration details had also been updated with the ICO. **Discussion:** The Group agreed that this application had significantly improved, and a number of their previous concerns had been addressed. It was noted that the work described could provide valuable data to consultants for the re-accreditation process. However, there remained some outstanding concerns. The applicant's updated DPA registration wording was discussed, and there were concerns that this did not refer specifically to the processing of health data for healthcare purposes. It was noted that the applicant had ISO 27001 accreditation but it was not clear what was covered by this accreditation, and it was agreed that further details should be requested regarding security assurance. In addition there were concerns that the organisations who were customers for this tool had not been listed, and it was not clear how many organisations this included. This was felt to be particularly relevant due to the need to ensure that the data requested was proportionate to how it would be used and by how many organisations across the country. **Outcome:** Unable to recommend for approval. Further details were requested about the applicant's security assurance and about the applicant's customer base. There were also concerns that the applicant's DPA registration wording did not reflect the processing of health information for health purposes.
2.11	University of Oxford - NHIR Musculoskeletal Biomedical Research Unit (Presenter: Dickie Langley) NIC-318179-D0V3Q **Application summary:** This application was to extend the current agreement for the provision of pseudonymised, sensitive HES and patient reported outcome measures (PROMs) linked data in order to support research into models of care for hip fractures. Findings of the research were fed back to health professionals and to Public Health England. **Discussion:** The Group queried whether there had been any changes to the amount of data requested, but it was confirmed that the application was only to continue holding data for a longer period of time. There was a further query regarding a reference to data being processed and stored by the Health Economics Research Centre, and it was confirmed that this was part of the University of Oxford. The Group expressed their support for the work described, and it was felt that the expected benefits and outcomes had been clearly described. **Outcome:** Recommendation to approve.
2.12	University of Leicester – NAAASP (Presenter: Dickie Langley) NIC-318414-F4L6J **Application summary:** DAAG had previously considered this application on 20 January 2015 and been unable to recommend approval, and the application had now been updated to clarify the data controller and to provide more information about the consent process. The application was for pseudonymised HES data for a screening cohort, in order to support research into the NHS Abdominal Aortic Aneurysm Screening Programme (NAAASP). **Discussion:** The Group expressed their support for this work, and agreed that the additional detail they had requested to clarify the roles of the organisations involved had now been provided. Nevertheless, there remained some concerns. In particular it was noted that the most recent section 251 support letter had not been provided, and it was not clear if the section 251 support had been renewed or if CAG had raised any outstanding concerns. It was noted that the applicant had made an internal request to update their DPA registration wording to include health information, but it was not known if the ICO had been asked to make this change.

	The Group discussed the consent process, and requested sight of the consent materials as these had not been provided. There were some concerns about the use of data for individuals who did not attend screening and therefore were not asked to give consent, as although the invitation letter stated that some data would still be used it was not clearly explained that this would include data from other sources. The need to ensure fair processing was emphasised. **Outcome:** Unable to recommend for approval. Confirmation required of whether the section 251 support has been renewed, and whether CAG have any outstanding concerns. Confirmation also required that the applicant has requested to update their DPA registration wording to clarify the scope of data used for health research. The Group requested sight of the consent materials, including the participant information leaflet.
2.7	<u>NHS England - National Elective Revascularisation PROMS Pilot (Presenter: Dave Roberts) NIC-324251-J9T5N</u> **Application summary:** This application had previously been considered at the 3 March 2015 DAAG meeting, when the Group had been unable to recommend approval due to the lack of a clear legal basis for the linkage of ONS data. The application had now been updated to remove the provision and linkage of ONS data. **Discussion:** The Group discussed the need for the applicant to update their website to include information for participants about the nature of the data being processed, what organisations were responsible for the pilot and what data they would hold, and what data linkage would take place as well as the process for managing objections. It was noted that the applicant had confirmed they were happy to update the website, and the Group requested sight of the wording that would be used. **Outcome:** Recommendation to approve subject to DAAG members having sight of the updated wording that will be published on the applicant's website and confirming that this reflects the new situation.
2.13	<u>University Hospitals Bristol NHS FT (Presenter: Dickie Langley) NIC-319284-X1J5S</u> **Application summary:** This application was for data linkage to a bespoke extract of pseudonymised, non-sensitive HES and identifiable, sensitive HES-ONS mortality data for a cohort of participants based on their consent. This data would be used to identify co-morbidities within the cohort as part of a feasibility study for work funded by the National Institute for Health Research. **Discussion:** The Group discussed the fact that data would be accessed by an individual under an honorary contract, and queried what disciplinary arrangements were in place for if this individual used data inappropriately. The consent materials were considered, and it was felt that these did not include sufficient information about the data that would be accessed and how individuals could withdraw their consent. The use of the term 'health status' was discussed, as it was felt that participants might not necessarily understand this term. It was noted that this term had previously been suggested by the HSCIC as appropriate for use in consent materials, and it was agreed that the guidance provided on consent materials would need to be reviewed and updated. It was also agreed that the applicant should be asked to confirm whether there had been any patient involvement in the development of the consent materials. In addition, the Group noted that the consent form referred to data held by 'other central UK NHS bodies' and it was felt that this would not be considered to include ONS data. Overall the Group agreed that if participant recruitment was still underway, the applicant should be asked to update the consent materials.

	The expected benefits of this use of data were queried, and while it was acknowledged that the feasibility study would help inform the commissioning of future research it was felt that the potential benefits to health and social care were not clearly described. **Outcome:** Unable to recommend for approval. Applicant to be asked to update consent materials in line with guidance produced by DAAG, and asked to confirm whether there has been patient involvement in developing the materials. 'Purpose' and 'expected benefits' sections of the application form to be updated to clarify the desired benefits. Further details requested about the disciplinary arrangements for the individual with an honorary contract with the Trust.
2.14	Cardiff University (Presenter: Dickie Langley) NIC-322804-H9S9Y **Application summary:** This application was for identifiable, non-sensitive HES data and sensitive linked HES-ONS data to follow up the participants of a previous trial, in order to study the effectiveness and costs of an early-intervention programme involving the family nurse partnership. Section 251 support was in place for the receipt of the data requested. **Discussion:** The Group queried why identifiable data was required for this study rather than using pseudonymised data, and it was felt that a sufficiently clear justification for this had not been provided in the application form. It was also not clear what fair processing activities had been undertaken by the applicant and whether a mechanism was in place to allow individuals to object, as copies of patient information materials had not been provided with the application form. A query was raised regarding the role of the Swansea University in this work, and it was clarified that the data would be linked and held within the safe data haven (SAIL) within Swansea University. There were some concerns that the outputs described did not clearly show how a benefit to health and social care would be achieved, and it was agreed that further details regarding this should be requested. **Outcome:** Unable to recommend for approval. A clear justification is required for why identifiable and ONS data are required rather than using pseudonymised data. The Group requested sight of the patient information leaflet provided to participants, and requested further information on fair processing activities. Applicant to be asked to provide a clearer statement on how the outcomes of the research will be disseminated in compliance with the Care Act 2014.
2.15	Bupa Health Dialog (Presenter: Dickie Langley) NIC-323214-N1Y3W **Application summary:** This application was for pseudonymised HES and SUS data including the sensitive HES data field of consultant code. This data would be used by Bupa to help identify instances of unwarranted utilisation of surgical treatment, in order to benefit their work with patients and their work in partnership with the NHS. The data would be for internal use by Bupa only, and not for onward sharing with any other organisations. **Discussion:** A reference within the application form to 'the Competition Commissioner's initial findings' was queried, as it was not clear what findings this referred to or how this was relevant to the application. The statement that the purpose of the application was commercial was also queried, as this appeared to be solely on the basis that Bupa was a commercial organisation. It was noted that an application by Bupa for this data had previously been considered by DAAG and recommended for approval subject to caveats on 4 November 2014. The Group had requested at that point that when the application returned for renewal the applicant should be asked to provide additional detail of the expected measurable benefits of this work, with specific

	examples of how data had been used. It was agreed that the applicant should be asked to provide this additional detail, particularly given the need to ensure that the use of data was compliant with the requirements of the Care Act 2014. The Group suggested that where the application form stated that data was solely for internal Bupa Group use it should also be specified that the insurance service operated by Bupa would not benefit from or receive any analytical insight gained from the data, although it was noted that this was stated elsewhere in the application form. **Outcome:** Unable to recommend for approval. The Group requested that the applicant provide additional detail around the expected measurable benefits of this use of data with specific examples of how data has been used, as requested when the previous application was considered on 4 November 2014. Application form to be updated to explicitly state that the insurance service operated by Bupa would not benefit from or receive any analytical insight gained from the data.
3	**Any other business** No other business was raised.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
13/01/15	Garry Coleman to provide DAAG with a briefing paper on HDIS.	Garry Coleman	20/01/15: It was agreed that a briefing paper would be circulated, but it was noted that no further HDIS applications would be brought to DAAG at this stage while internal discussions were ongoing. 27/01/15: Ongoing. 03/02/15: A briefing paper had been drafted and would be shared by email following clarification regarding HDIS extracts. 10/02/15: Clarification had not yet been received. 17/02/15: Ongoing. 24/02/15: Ongoing. 03/03/15: Ongoing. 10/03/15: Ongoing. Alex Bell to request an updated from Garry.	Open
20/01/15	Alex Bell to discuss the application form template with DARS team and consider adding a section asking applicants to demonstrate how their intended use of data and dissemination of results would be compliant with the Care Act 2014.	Alex Bell	27/01/15: This discussion had been scheduled, and details would be fed back to DAAG. 03/02/15: It was agreed that this should be discussed with Garry Coleman in the context of the papers on data sharing drafted following the recent DAAG training day. 10/02/15: Discussions had taken place about making changes to how information would be added to application forms. 17/02/15: Ongoing. 24/02/15: Ongoing. 03/03/15: Ongoing. 10/03/15: Ongoing.	Open
24/02/15	DAIS team to dis**c**uss the approach to local patient identifiers (LOPATID) with HRA CAG.	Diane Pryce	03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting. 10/03/15: An initial response had been received and this would be shared with DAAG members for information.	Open
24/02/15	DAIS team to raise with HRA CAG the possibility of stage 1 accredited safe havens	Diane Pryce	03/03/15: Discussions were taking place with HRA CAG, and the response would be fed back to a future DAAG meeting.	Open

	receiving both data that is identifiable by NHS number and data that is identifiable by postcode.		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.	
03/03/15	DAIS team to circulate the current recommended consent wording to DAAG members.	Susan Milner	10/03/15: The action had been completed and was closed.	Closed
03/03/15	DAAG members to discuss the current recommended consent wording.	Alan Hassey	10/03/15: Ongoing.	Open