Data Access Advisory Group

Minutes of meeting held 9 December 2014

Members: Alan Hassey (Acting Chair), Sean Kirwan, Eve Sariyiannidou, John Craven, Patrick Coyle

In attendance: Alex Bell, Diane Pryce, Frances Hancox, David Evans, Jonathan Jackson, Paula Moss, Garry Coleman (applications 2.1, 2.4, 2.5, 2.6), Jackie Gallagher (applications 2.1 - 2.3), Netta Hollings (application 2.6), Jennifer Donald (application 2.7)

Apologies: Dawn Foster

1	**Review of previous minutes and actions** The minutes of the 2 December 2014 meeting were reviewed; a query was raised regarding the date when the University of Sheffield application (NIC-204484-N8H5N) had first been discussed, and it was agreed that this would be checked and corrected if needed. It was also suggested that the minuted discussion of this application should be amended to make it clearer that the Group had suggested that the applicant should update their consent forms prior to re-submitting an application. Other than these two points the minutes were agreed as an accurate record of the meeting. **Action:** DAAG members to agree updated wording for University of Sheffield application discussion in the 2 December 2014 meeting minutes. Action updates were provided (see table on page 8). **Out of committee recommendations** Two applications (University of East Anglia, NIC- 308892-P2H0Y and Imperial College London, NIC-292308-P3C3Z) had been considered out of committee, but neither had been recommended for approval. It had been requested that the Imperial College London application be brought back to a future DAAG meeting for further discussion, and additional information had been requested regarding the University of East Anglia application.
2 **2.1**	**Data applications** <u>University of Surrey – LOLIPOP study (Presenters: Garry Coleman and Jackie Gallagher) NIC-203503-X7K8K</u> **Application summary:** This application had previously been considered by DAAG at the 9 September 2014 meeting; it was noted that at that point the applicant had not completed the Information Governance Toolkit (IGT), but that this had now been completed with a satisfactory score. It was explained that the applicant would provide patient identifiers for the study cohort, which would then be linked with Office of National Statistics (ONS) mortality data and provided back to the applicant. This data would then be matched within the HSCIC to Hospital Episode Statistics (HES) data, which would be provided to the applicant in a pseudonymised form using Cohort ID rather than HES ID to enable linkage. It was noted that no identifiable HES data would be provided to the applicant. **Discussion:** The Group discussed the need to ensure that the applicant had met the fair

	processing requirements of the Data Protection Act 1998 (DPA), as it was noted that members of the cohort had originally given consent for their data to be used by Imperial College London and not the University of Surrey. It was noted that the University of Surrey had obtained section 251 support from the Health Research Authority Confidentiality Advisory Group (HRA CAG) to cover their use of data, but DAAG agreed that the applicant would still be required to make reasonable efforts to inform the cohort that they would be carrying out this work. It was noted that DAAG had also discussed the issue of fair processing for this application at the 9 September 2014 meeting, and more detailed feedback for the applicant had been shared by email following the meeting. It was agreed that this email would be re-sent, and that David Evans would also provide his feedback on fair processing. The Group noted the use of technical jargon in some sections of the application form provided, and emphasised the need for applications to be comprehensible to a lay audience. A query was raised regarding the section 251 approval for this application, as the application form stated that this was currently due to end in December 2014. It was explained that this was correct, but that HRA CAG had confirmed that if an application was received to extend this approval then the section 251 support would continue to be in place while the renewal process was underway. **Outcome:** Unable to recommend for approval. Clarification requested around fair processing, and whether the applicant had made reasonable efforts to inform the cohort that the University of Surrey will be taking this work forwards rather than Imperial College. **Action:** David Evans to consider the fair processing aspects of the University of Surrey application (NIC-203503-X7K8K) and share comments by email.
2.2	University College London - SABRE (Presenter: Jackie Gallagher) NIC-272372-T7X9J **Application summary:** This application was for an amendment to an existing agreement for flagging and the provision of ONS mortality data and cancer registrations. It was explained that the study had now moved from Imperial College to University College London (UCL), and the applicant had therefore requested cohort addresses and general practice codes in order to contact patients and ask them to re-consent to participation in the study using an updated UCL consent form. The data provided would be used to ensure that participants who were now deceased would not be written to during the next mail-out. **Discussion:** A query was raised regarding the request to retain data for five years, given that the application form stated that the study would end in 2017. The Group were informed that the applicant had indicated data would need to be retained for this period of time to produce key outputs, but that data would be destroyed at the end of this period. The Group provided a number of suggestions on the patient information materials provided, such as that it was not felt to be made entirely clear what information would be shared with what third parties. It was agreed that these comments would be shared with the customer but that these were not caveats to the recommendation for approval. **Outcome:** Recommendation to approve. There was a wider discussion around patient consent materials and the possibility of providing guidance on areas that DAAG would expect to be covered in consent materials. It was noted that the HSCIC had in the past provided recommended consent wording which applicants were advised to use. The Group agreed to discuss this in more detail at an upcoming DAAG training day, and it was also suggested that representatives from HRA CAG

	and ONS should be invited to participate in this discussion. **Action:** Consent materials to be added to agenda for DAAG training day. HRA CAG and ONS representatives to be invited to join discussion. **Action:** Eve Sariyiannidou and David Evans to provide bullet points on consent materials to assist discussions at DAAG training day.
2.3	<u>HSCIC Clinical Audit Support Unit (CASU) - National Oesophago-Gastric Cancer Audit (Presenter: Jackie Gallagher) NIC-292440-R9G8P</u> **Application summary:** This was an application for an internal transfer of data within the HSCIC between the Medical Research Information Service (MRIS) and the Clinical Audit Support Unit (CASU) in order to support the National Oesophago-Gastric Cancer Audit. The CASU team currently received fact of death and date of death information, and in addition to this place of death data was requested in the form of an establishment code. It was noted that requesting establishment code rather than full place of death data was felt to be less disclosive, as this would not include details such as addresses. **Discussion:** The Group queried whether the establishment code requested was an individual code for each care home or hospital, and it was confirmed that the establishment code would only indicate the type of organisation and therefore whether a person had died in a care home, a hospital or at home. There was a discussion around the need for DAAG to consider applications for the internal transfer of data. It was explained that this was due to the fact that the CASU was commissioned to support clinical audits by other organisations such as the Healthcare Quality Improvement Partnership (HQIP), and transferring data to this team therefore usually meant a change in data controller. A query was raised regarding the onward sharing of data, but it was noted that this application was only for the internal transfer of data and an additional application would need to be brought to DAAG for any onward data sharing. A further query was raised regarding whether the additional data item requested was included in the section 251 approval for this audit. It was agreed that confirmation of this should be sought from HRA CAG. References in the application form to 'internal data transfer' were queried, and for clarity it was suggested that it would be clearer to the general public if this were instead described as 'data transfer within the HSCIC'. **Outcome:** Recommendation to approve subject to confirmation that HRA CAG are content the section 251 approval includes the use of the additional code. ***Note:*** *Prior to the end of this DAAG meeting, confirmation was received from HRA CAG that the section 251 approval included the additional data requested. This application was therefore recommended for approval.*
2.4	<u>Queen Mary University of London (Presenter: Garry Coleman) NIC-269858-P4W2T</u> **Application summary:** This application was for pseudonymised HES data, and it was noted that rather than providing the full HES dataset this would be filtered to only include data relating to certain procedures. It was noted that the aggregated outputs of this analysis would be shared with the public sector in Brazil but that no record level data would leave the UK.

	Discussion: Queries were raised regarding the legal basis for the release of data, as although the potential benefits for the Brazilian healthcare system were described it was not felt to be clear what benefits would be achieved for the UK health and care system. It was agreed that the applicant would need to provide a clearer justification on this point, given the restrictions set out by the Care Act 2014. **Outcome:** Unable to recommend for approval. Further information requested to justify how this application will provide benefits to the UK health and care system.
2.5	<u>Imperial College London – IMPROVE trial (Presenter: Garry Coleman) NIC-278518-F3H0X</u> **Application summary:** This was a new application for HES data for the study cohort, which would be linked to other patient data provided by the applicant. It was noted that patient consent had been obtained for this use of data. Data retention to the end of 2016 was requested, subject to moving to use the new data sharing contract before the end of February 2015. The Group were informed that the London School of Hygiene and Tropical Medicine (LHSTM) had been subcontracted to carry out economic analysis on this data for Imperial College London, but it was noted that staff from the LSHTM would only be able to access data from within Imperial College premises and they would not be able to access any identifiable data. In addition it was noted that the University of Cambridge provided database mirroring for Imperial College but it had been confirmed that the data provided by the HSCIC would not be included in the data hosted by the University of Cambridge. **Discussion:** The Group noted the potential public benefit from this work and the fact that patient consent had been given. There was a brief discussion regarding the wording of the requested data retention period, as this was not felt to be clearly worded, and it was noted that updated standard wording for data retention periods had been drafted and shared for comment. It was noted that the patient information materials provided referred to the NHS Information Centre rather than the HSCIC. It was also felt that the materials could have more clearly described what data would be shared with which organisations. The Group confirmed that they were content to recommend approval of this application without any caveats, but it was agreed that feedback on the consent materials should be shared with the applicant. **Outcome:** Recommendation to approve.
2.6	<u>Res Consortium Ltd (Presenters: Garry Coleman and Netta Hollings) NIC-280016-T1G4D</u> **Application summary:** This application was for pseudonymised HES and Mental Health Minimum Dataset (MHMDS) data, in addition to the HES-MHMDS bridging file. This data would be used by Rec Consortium, a commercial company, to carry out a specific piece of work for the NHS investigating the impact of service provisions and outcomes on Parkinson Disease patients' quality of life, mental health and physical health outcomes. It was noted that this work was in partnership with Britannia Pharmaceuticals. The data output produced by Res Consortium would be aggregated data only, and record level data would not be shared outside Res Consortium. **Discussion:** It was felt that the application did not clearly describe the objectives of the proposed data processing or how the data provided would be analysed, and it was agreed that the applicant should be asked to provide additional information regarding this. In addition it was felt that the involvement of a pharmaceutical company could potentially be a cause for

	concern for members of the general public, and it was suggested that the applicant should clarify how Britannia Pharmaceuticals would be involved in this work. The Group queried the request for data for the whole population, and whether instead the data provided should be limited to a certain age range. It was agreed that the applicant should be ask to provide justification for why whole population data was required. A reference in the application to linking data was queried, and it was confirmed that this did not refer to data linkage with data from other sources but instead referred to observing correlations within the data provided. A reference to using the results in other UK nations was also queried, and it was confirmed that the data provided would not be used for any other purposes in addition to those outlined in the application. It was noted that any future use of data for additional purposes would be subject to a further application to DAAG. A reference to Parkinson's UK in the application form was queried, and it was explained that an individual from Parkinson's UK was involved in the project but would not have access to any of the data provided. **Outcome:** Unable to recommend for approval. Further information requested on the specific objectives of data processing, and clarification of the involvement of the pharmaceutical company. Justification requested for why national data is required rather than a sample of the population. Application also to be updated to include a clear statement that the data requested can only be used for the purposes listed, and no additional purposes.
2.7	<u>Institute of Education – Centre for Longitudinal Studies (Presenter: Jennifer Donald) NIC-274440-N1J1Z</u> **Application summary:** This application had previously been brought to DAAG on 4 November 2014 for advice only, and a recommendation was now sought on whether to approve the request for list cleaning. Current address and fact of death were requested for the study cohort to enable the applicant to contact members of the cohort, and it was noted that section 251 approval was in place for this. Copies of the current patient consent materials were provided, and it was stated that the study cohort had been made aware that they would be contacted in future. The applicant had applied for ONS Approved Researcher status but this had not yet been granted, and therefore date of death was not requested at this stage. It was anticipated that if Approved Researcher was granted, a further application would be brought to DAAG for the additional date of death data. **Discussion:** The Group highlighted the importance of ensuring that cohort members who chose to opt out of the study would be given the option for their data to no longer be held by the Institute of Education, rather than only ensuring that they would not be contacted in future. The Group queried the number of different identifiers that had been requested, and whether this amount of data was necessary. It was confirmed that this was a standard requirement to improve data quality and ensure accurate linkage. Some concerns were raised regarding the amount of other data that the applicant received for each participant from sources such as the Department of Work and Pensions and criminal justice records, but it was noted that study participants had consented to this use of data. It was reiterated that ONS data could not be provided to the applicant until Approved Researcher status had been granted, and a further application would need to be brought to DAAG at that stage. **Outcome:** Recommendation to approve.

2.8	NHS England Midlands & East Consortium[1] (NHS Basildon and Brentwood Clinical Commissioning Group) – Stage 1 Accredited Safe Haven (Presenter: Garry Coleman) NIC-302045-N4J5Y **Application summary:** This application had been considered by DAAG at the 12 November 2014 meeting, when DAAG had been unable to recommend approval. Further information had been requested about the 'other agencies' and 'third parties' referred to in the application. It was noted that NHS Basildon and Brentwood Clinical Commissioning Group (CCG) were the lead CCG for this application, and that MedeAnalytics would operate as a data processor for the consortium of CCGs. Due to concerns about the potential impact on the NHS if this application did not proceed the Acting Chair of DAAG had considered this updated application out of committee and recommended a short term approval of one week only, which had been granted. The Group were now asked to consider whether or not to recommend approval for a longer period of time. A response had been received from the applicant clarifying that the 'other agencies' referred to would be other bodies associated with the purpose of the application. An example given was that a CCG within the consortium might need to share data with another CCG outside the consortium if the two CCGs shared a provider trust in their area. **Discussion:** A query was raised regarding the DPA registration expiry dates listed, as the application stated that two of these expired in April 2014. It was confirmed that the DPA registrations in question would not expire until 2015, and the application form would be corrected. There remained concerns that the wording of the application when referring to sharing data with other agencies 'such as' a list of examples was not clear enough, as this could imply that data would also be shared with other types of agencies in addition to the ones listed. It was agreed that this wording should be amended to clarify that only health and care organisations would be able to access data for commissioning purposes. The Group were informed that it was intended that a new application for this purpose would be brought to them for consideration within a few weeks, and that if approved then that application would replace the current application with effect from later in the year. It was noted that the section 251 approval that covered this application was due for renewal in April 2015, and it was agreed that the recommendation to approve this application should be aligned to the same timescales. **Outcome:** Recommendation to approve subject to clarification of the phrase 'such as' to limit the organisations that could receive data to those within the health and care system, and agreement to this clarification by the Group.
2.9	Care Quality Commission (CQC) (Presenter: Garry Coleman) NIC-292297-K3G0K **Application summary:** This application had previously been considered by DAAG at the 14 October 2014 and 18 November 2014 meetings, when the Group had been unable to recommend approval. Additional information had been requested regarding the specific purposes and the benefits that that would be produced, and how patients had been made aware of this use of data. Confirmation had also been requested as to whether identifiable data was required and whether this was in line with the CQC code of practice on confidential personal information.

[1] NHS Bedfordshire CCG, NHS West Essex CCG, NHS Basildon & Brentwood CCG, NHS Castle Point & Rochford CCG, NHS East & North Hertfordshire CCG, NHS Herts Valley CCG, NHS Southend CCG, NHS Thurrock CCG, NHS Luton CCG

	Discussion: It was noted that due to the late submission, members had not had sufficient time to review this application prior to the meeting. It was agreed that the application would be considered out of committee. **Outcome:** To consider out of committee
3	**Any other business** It was noted that 2015 meeting dates had been circulated, and that it was proposed that one meeting a month would now be held mainly in London with a video-conference link to Leeds. It was proposed that DAAG training sessions could be scheduled to take place on the same day as these London meetings. It was also noted that a training day would shortly be taking place for HSCIC staff involved in preparing applications for consideration by DAAG, and the Group were invited to share any suggestions or feedback that could be helpful for this training day.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
09/12/2014	Consent materials to be added to agenda for DAAG training day. HRA CAG and ONS representatives to be invited to join discussion	Alex Bell		Open
09/12/2014	Eve Sariyiannidou and David Evans to provide bullet points on consent materials to assist discussions at DAAG training day.	David Evans		Open
09/12/2014	David Evans to consider the fair processing aspects of the University of Surrey application (NIC-203503-X7K8K) and share comments by email.	David Evans		Open
09/12/2014	DAAG members to agree updated wording for University of Sheffield application discussion in the 2 December 2014 meeting minutes.	Sean Kirwan		Open
02/12/2014	Dickie Langley to circulate the updated DARS application form by email, and DAAG members to provide comments.	Dickie Langley	09/12/14: Updated application form shared by email, and members to provide comments.	Open
12/11/2014	Dawn Foster to discuss with HRA CAG Secretariat whether the addition of the data item Place of Death to the requested dataset could affect identifiability (CASU National Oesophago-Gastric Cancer Audit NIC-292440-R9G8P).	Garry Coleman	18/11/14: This had been raised with HRA CAG Secretariat, who had noted that place of death could in some cases mean a home address. It was agreed that the applicant should be asked to confirm whether they required full addresses for this, and if so to provide justification for why this was needed. 25/11/14: No update available. 02/12/14: Garry Coleman agreed to confirm whether the applicant had addressed this.	Open