Data Access Advisory Group

Minutes of meeting held 20 January 2015

Members: Alan Hassey (Acting Chair), Eve Sariyiannidou, Dawn Foster, John Craven, Patrick Coyle

In attendance: Alex Bell, Karen Myers, Frances Hancox, David Evans, Garry Coleman, Jennifer Donald (application 2.5)

Apologies: Sean Kirwan

1	**Review of previous minutes and actions** The minutes of the 13 January 2015 meeting were reviewed, and it was agreed that the discussion of the Kings College London application (NIC-236594-T3Q6W) would be amended to clarify that only data for the areas surrounding the 8 specified airports had been requested. Other than this the minutes were agreed as an accurate record. Action updates were provided (see table on page 6). **Out of committee recommendations** No recommendations had been made out of committee since the previous meeting. The following applications had previously been recommended for approval with caveats, and it was confirmed that the relevant caveats had now been fulfilled: • CHKS, NIC-292296-Y2M2K • University of Sheffield, NIC-306894-H7B0N • NHS England, NIC-275595-Q5W5Z • King's College London, NIC-269704-S8W6D • United Health UK, NIC-277499-D3D0X
2 **2.1**	**Data applications** <u>Leeds Teaching Hospitals NHS Trust (Presenter: Garry Coleman) NIC-230103-K0K3S</u> **Application summary:** This application had previously been considered at the 30 July 2014, 12 November 2014 and 13 January 2015 meetings. The Group had requested clarification around the section 251 approval, as well as information of fair processing activities and a clearer description of the data flow involved. A query had also been raised regarding the deletion of data, and it was confirmed that the applicant would delete the identifying data that they held once pseudonymised data had been received. It was confirmed that the section 251 approval included the release of Office of National Statistics (ONS) data. The application form had also been amended to clarify that the applicant organisation was an NHS body rather than an academic organisation. **Discussion:** There were concerns that the queries previously raised regarding fair processing activities had not been addressed. In particular, it was noted that the conditional approval letter from the Health Research Authority Confidentiality Advisory Group (HRA CAG) stated that the section 251 approval was conditional on receiving confirmation that reasonable efforts had been made to inform the cohort, and as a final approval letter had not been provided it was not clear if this condition had yet been met. The Group noted that if this condition had not been met then the section 251 approval would not be considered to be in

	place. **Outcome:** Unable to recommend for approval, pending sight of the final section 251 approval letter and details of how fair processing requirements have been met. There was a discussion around the need for applicants to be aware of the requirement under the Care Act 2014 to ensure that any data shared would be used for the provision of care or the promotion of health. The particular relevance of this for research organisations was discussed, as it was noted that publishing research results in academic journals might not be considered to be sufficient to meet this requirement and it would be important for applicants to consider how healthcare benefits could be achieved. It was noted that the HSCIC had begun to work with some research funding organisations to raise awareness of this requirement. There was a suggestion that the application form template could be updated to specifically ask applicants how their application would provide benefit to the health and social care system. **Action:** 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.
2.7	<u>University of Bristol - Identifying the elements of effective management of hospital presenting self-harm (Presenter: Garry Coleman) NIC-256176-K4F3H</u> **Application summary:** This application requested pseudonymised, non-sensitive Hospital Episode Statistics (HES) data, in addition to linked ONS data which was considered to be sensitive. The applicant intended to use this data to investigate the effect of hospital admission due to self-harm and aimed to present the results of this research in relevant academic journals and at conferences, sharing aggregated data and statistical analysis only. **Discussion:** The Group were broadly supportive of the proposed use of data. However, there were some concerns that the proposed dissemination methods would not be sufficient to achieve an appropriate benefit to the health and care system in order to be compliant with the requirements of the Care Act 2014. It was suggested that the applicant should be encouraged to provide a more detailed dissemination and benefits plan to state how the results of the research would be shared with the healthcare system in addition to the planned publication in academic journals. It was also noted that the Research Ethics Committee (REC) approval had been subject to a number of conditions, and the applicant would be asked to confirm that these conditions had been met and the REC approval was therefore now fully in place. **Outcome:** Recommendation to approve subject to confirmation that REC approval is fully in place, and subject to the provision of a dissemination and benefits plan that would be compliant with the Care Act 2014.
2.4	<u>University of Bristol - Socioeconomic position and kidney donation after death in England (Presenter: Garry Coleman) NIC-281848-W3T5B</u> **Application summary:** This was an application for pseudonymised, non-sensitive HES data in addition to ONS data, in order to study whether kidney donation rates following death varied depending on the socioeconomic position of the donor. It was noted that this work was associated with the annual Potential Donor Audit carried out by NHS Blood and Transplant. **Discussion:** There was a discussion regarding whether the applicant should be required to

	ensure fair processing by making information available to patients about this use of data. However, it was noted that the data requested was only for deceased individuals and that this requirement therefore did not apply. A query was raised regarding the identifiability of the data provided, and it was noted that only pseudonymised data would be provided to the applicant. The Group suggested that it would be helpful if the applicant could provide further explanation of how the results of this research would be shared with the healthcare sector and what measurable benefits this could achieve. It was noted that the applicant's REC approval had been subject to a number of conditions, and it was not stated if these conditions had been met. It was agreed the applicant would be asked to confirm whether REC approval was now fully in place. In addition it was noted that the applicant had not yet signed the HSCIC framework contract. **Outcome:** Recommendation to approve subject to HSCIC framework contract being signed. Also subject to applicant meeting the conditions of their REC approval and providing evidence of the specific outputs and expected measurable benefits.
2.5	University of Sheffield (Presenter: Jennifer Donald) NIC-315175-P8X6Z **Application summary:** This application was to link identifiable data provided by two ambulance trusts to HES and ONS data; identifiers would then be removed from the linked dataset and the pseudonymised data returned to the University of Sheffield. This work had been funded by the National Institute for Health Research, and it was noted that section 251 support was in place for the provision of identifiable data from the two ambulance services to the HSCIC. Public information about the use of patient data was available on both ambulance services' websites. It was noted that the application form referred to identifiable data at one point, but it was confirmed that this was an error and that no identifiable data would be made available to the University of Sheffield. **Discussion:** There was a query regarding the terminology used in the section 251 approval letter, as this referred to anonymised data but it was noted that the data provided to the applicant would be pseudonymised. It was suggested that this was due to the fact that the applicant would not be able to identify any of the data, rendering it effectively anonymised. It was agreed that the terminology used to describe data as anonymised or pseudonymised should be discussed with the HRA CAG Secretariat. A further query was raised regarding the other organisations that were referred to in the funding letter provided as co-investigators, and whether any of these organisations would have access to the data provided – and if so what form of data would be shared with them. **Outcome:** Recommendation to approve subject to clarification of the role of other participant organisations; in particular whether these organisations will have access to data, and if so in what form. **Action:** Diane Pryce to speak to HRA CAG Secretariat regarding the use of terminology such as 'anonymised' and 'pseudonymised'. John Craven left the meeting following the discussion of this application.
2.2	Cegedim Relationship Management (Presenter: Garry Coleman) NIC-269175-K4V9G **Application summary:** This application was for an annual refresh of pseudonymised, non-

	sensitive HES data. This data would be used to undertake analysis into health and social care activity, and to provide analysis and consultancy to other organisations including pharmaceutical companies, medical devices and health and social care organisations. It was stated that within the UK, approximately half the customer base for this analysis would be health and social care organisations. **Discussion:** The Group queried the data retention period, as the application form provided had listed this as 'not stated'. It was confirmed that the applicant organisation had not specified a data retention period but would wish to retain data for as long as possible. A query was raised regarding the number of health and social care organisations within the UK that would potentially benefit from the provision of this data, as although the application stated that these organisations were over 50% of the customer base no precise numbers were given. It was agreed that this should be clarified by the applicant. It was noted that the number of customers outside the UK was also not specified, but that only aggregated data would be shared with organisations outside the UK. There were some concerns about the proposed purposes for which data would be used, as it was not felt to be clear how this would be of benefit to the health and social care system and therefore how this was compatible with the requirements of the Care Act 2014. There were also concerns regarding the DPA registration wording provided for the applicant organisation, as this did not refer to the use of healthcare data but did refer to the use of personal data to provide a marketing service. It was noted that the application form stated that there was no commercial aspect to the application, and it was not felt to be clear how this was the case. **Outcome:** Unable to recommend for approval. Applicant asked to demonstrate how the stated purpose is compliant with the Health and Social Care Act 2012 and in particular the Care Act 2014.
2.3	<u>University of Leicester – NAAASP (Presenter: Garry Coleman) NIC-255975-L0F8K</u> **Application summary:** This was a new application for pseudonymised, non-sensitive HES data in order to study the long term effectiveness of abdominal aortic aneurysm screening. The NHS Abdominal Aortic Aneurysm Screening Programme (NAAASP) would identify a screening cohort and provided pseudonymised data for this cohort to the University of Leicester, and it was explained that the same method of pseudonymisation would be used as for the pseudonymised HES data provided to the University of Leicester by the HSCIC. This would mean that the applicant could link the two datasets using the pseudonymised identifiers, but it would not be possible to re-identify the individuals within the dataset. **Discussion:** The Group discussed the potential benefits of this work and the importance of assessing the efficacy of screening. The Group requested further clarity regarding the roles of the different organisations involved in this study, as it was noted that the original section 251 application for this work appeared to have been made by Gloucestershire Hospitals NHS Trust. In particular, the Group queried which organisation would be the data controller for the data provided as this was not stated within the application form. There was some uncertainty regarding the role of consent in this work, and whether individuals who had attended screening had been asked to consent to this use of data. The Group noted that the section 251 approval letter provided referred to consent being obtained once individuals were included in the screening programme. It was agreed that if individuals had been asked to consent, it would be helpful if the applicant could provide details of what information materials had been provided to these individuals and at what point.

	Outcome: Unable to recommend for approval. Clarification requested about the role of different organisations referred to within the application and which organisation will be data controller. Further information also requested about the consent process for individuals who have attended screening, and what information was provided to these individuals at what point in time.
2.6	Health IQ Ltd (Presenter: Garry Coleman) NIC- 307613-J5W8T **Application summary:** This application for HES data had previously been considered at the 8 January 2015 meeting. Concerns had been raised around the proposal that both healthcare and pharmaceutical companies would be able to access data through a health intelligence tool, and how the use of data by these organisations could be managed. The applicant organisation had now confirmed that they would enter into sub-license arrangements with the HSCIC in order to manage the use of data by these organisations. Some concerns had also been raised regarding a reference in the applicant's DPA registration wording to 'our patients', and it was confirmed that the applicant had asked for this wording to be amended to instead refer to customers. **Discussion:** The Group discussed the proposed use of data, and whether this could be considered to be a healthcare purpose. Although it was noted that the health intelligence tool would be used by a number of NHS organisations, there was some uncertainty around the proposal that licenses for NHS organisations to use the tool could be paid for by pharmaceutical companies as part of a 'value added' package. It was felt that this element of the application appeared to be purely commercial. Overall, the Group were content with the proposed use of data by NHS organisations or by pharmaceutical companies subject to appropriate sub-licensing arrangements, but there remained concerns about the proposal for pharmaceutical companies to provide NHS organisations with licenses to access the tool and how this commercial aspect was compatible with the Care Act 2014. **Outcome:** Recommendation to approve the provision of the product directly to the NHS, and recommendation to approve the provision directly to pharmaceutical companies subject to the use of sub-licenses as agreed with the HSCIC. Unable to recommend for approval the provision to the NHS via pharmaceutical companies as part of a 'value added' package; applicant asked to clarify how this commercial purpose is compatible with the Health and Social Care Act 2012 and in particular the Care Act 2014.
3	**Any other business** It was noted that discussion papers had been submitted to the HSCIC Executive Management Team meeting regarding future advisory group functions.

Summary of Open Actions

Date raised	Action	Owner	Updates	Status
09/01/15	DF to look into lower super output areas (LSOA) and if they have previously been discussed at the Small Numbers Panel.	David Evans	13/01/15: This action had been passed to David Evans to provide an update from the Small Numbers Panel. 20/01/15: This would be raised with the Small Numbers Panel the following week.	Open
13/01/15	Alan Hassey to ensure that Martin Severs, Rob Shaw and Chris Roebuck are informed and aware of issues regarding HDIS.	Alan Hassey	20/01/15: The appropriate individuals had been made aware and the action was closed.	Closed
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.	Open
13/01/15	Alex Bell to provide a summary of DAAG's previous consideration of HDIS applications.	Alex Bell	20/01/15: This would be circulated by email.	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		Open
20/01/15	Diane Pryce to speak to HRA CAG Secretariat regarding the use of terminology such as 'anonymised' and 'pseudonymised'.	Diane Pryce		Open