Data Access Advisory Group

Minutes of meeting held 28 October 2014

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

In attendance: Garry Coleman, Diane Pryce, Frances Hancox, Alex Bell, Andrew Hall (application 2.3 only), Neil Clark (application 2.2 only)

Apologies: Sean Kirwan

1	**Review of previous minutes and actions** A number of corrections were raised regarding the minutes of the 22 October 2014 meeting. It was agreed that an amended version of the minutes would be circulated for approval out of committee. Action updates were provided and recorded in the applications tracker.
2	**Data applications**
2.1	<u>BMJ Publishing Group Ltd (IAO: Garry Coleman) NIC-292310-D7B7R</u> This application was for a standard monthly extract of pseudonymised Hospital Episode Statistics (HES) data, to include the sensitive fields Consultant Code and Local Patient ID. It was explained that the data was required to provide clinical benchmarking tools for NHS acute trusts, and in particular these sensitive fields were required to enable individual patients to be reidentified by the trust in the event of any clinical issues, and to enable trusts to monitor the performance of their own consultants. It was noted that an agreement had previously been in place for the applicant to receive this data, and a renewal to the end of February 2015 was sought. A query was raised regarding a statement that the 'majority' of the data would be aggregated, and it was confirmed that disaggregated data would only be accessible with the permission of that trust's Caldicott Guardian. It was agreed that the application form should be updated to more clearly state that disaggregated data would only be made available in these circumstances. The Group noted that at one point in the application form the data retention period was defined as ending on 31 October 2014; it was confirmed that this should be 28 February 2015, and it was agreed that this should be corrected. The legal basis was queried, as the application stated that the Health and Social Care Act 2012 provided a legal basis but did not specify what section of the Act was thought to be applicable. Concerns were raised regarding the fact that BMJ Publishing Ltd had scored 55% on the Information Governance Toolkit, although it was noted that an improvement place was in place. It was suggested that it would be helpful if further information could be provided regarding which areas of the Toolkit the applicant had scored poorly on, in order to determine whether these were particularly relevant to this application. A reference within the application form to data being accessed by users who were 'normally clinical staff' was queried, as it was not felt to be clear what other users would be able to access data. It was agreed that this should be clarified.

The need to ensure fair processing was discussed, and it was suggested that while members of the public might potentially assume that clinicians would make use of their data it might be less clear to them that data would also be processed by commercial organisations. It was agreed that clarification should be sought from the applicant regarding what efforts had been made to inform the general public of this use of data.

Outcome: Unable to recommend for approval

2.2 CHKS: Payment by Results (PbR) National Benchmarker (IAA: Neil Clark) NIC-281120-P8S3P

Neil Clark joined the meeting for this application on behalf of the IAO, Stuart Richardson.

This was a resubmission of an application that had previously been considered by DAAG at the 14 October 2014 meeting. The application was for CHKS, acting on behalf of Monitor, to receive aggregated Secondary Uses Service (SUS) Payment by Results (PbR) data in order to support the PbR Assurance Framework.

The Group had previously noted that the application form had not ticked any box to indicate the requested data level, and it was noted that this was due to a problem with the application form template itself.

Queries had previously been raised regarding the intention to include small numbers in the aggregated data made available and whether this could potentially lead to individuals being re-identified. It was explained that these small numbers would be at Health Resource Group level, and that this would not be likely to re-identify any individuals. Controls were also in place to prevent the onward release of data; the tool would only be accessible by NHS staff or users sponsored by an NHS body, and it was noted that users were required to agree to specific terms and conditions around how the data could be used. It was further explained that the existence of small numbers within the tool could allow NHS organisations to identify potential issues of patient safety where very small volumes of specialist activity were delivered by non-specialist organisations.

Additional detail had been added to the application form regarding the legal basis, and it was noted that section 261 of the Health and Social Care Act 2012 provided a legal basis for the HSCIC to supply this data while section 255 enabled Monitor to receive the data.

It was confirmed that Monitor would be the data controller with CHKS acting as data processor on their behalf, and this had been clarified within the application form. Information Governance Toolkit scores and DPA registration details for both organisations had also been provided.

The Group were content that the majority of the points they had raised had been addressed, but there remained concerns that the explanation regarding why small numbers were required was not sufficiently detailed and would not be understood by most members of the public. It was agreed that the application form should be updated to include a specific, real world example of how small numbers could be used in order to justify why small numbers should not be suppressed.

A query was raised regarding what organisations could access the data, and the statement that non-NHS organisations could be granted access if they were sponsored by an NHS organisation. It was confirmed that health sector organisations such as the Department of Health and regulators such as Monitor would also have access. It was further confirmed that commercial companies could potentially be able to access the data, but only if they were sponsored by an NHS organisation to use the data for a specific purpose within a specific

	timeframe. It was noted that all users would be required to agree to the same terms and conditions regarding how data could be used. **Outcome:** Recommendation to approve subject to the provision of a clearer explanation of why small numbers are required, with a specific example. It was agreed that if an updated application were provided, this could be considered out of committee.
2.3	<u>Monitor - National Casemix Office (IAA: Andrew Hall) NIC-292375-G6Z4Y</u> Andrew Hall joined the meeting for this application on behalf of the IAO, Virginia Jordan. It was explained that this application was to renew an existing data reuse agreement that was in place between the HSCIC and Monitor in order to enable Monitor to continue to hold the data they had receive, in addition to them receiving further pseudonymised HES data with Casemix Grouper results. It was explained that the HES data provided would have been grouped using Casemix Grouper into different Health Resource Groups, which could then be used by Monitor to support the development, setting, quality assurance and monitoring of the PbR Policy, and options for future change of this policy. The Group suggested that the explanation provided in the application form did not clearly explain what data would be used and for what purpose, although it was agreed that the verbal explanation provided was helpful. It was agreed that for future applications a clearer explanation should be included in the papers provided. A query was raised regarding any potential commercial uses of this data, and it was confirmed that while the data provided to Monitor would include information on organisations within the healthcare sector, which could include private providers, the data itself would not be used for any commercial purposes. It was noted that the application stated that the legal basis for this application was the Health and Social Care Act 2012 Part 9 (Chapter 2) and Part 3 (Chapter 4). It was suggested that it would be helpful if the application form could include an explanation for how these specific sections of the Act were applicable, and it was agreed that this should be included for future applications. **Outcome:** Recommendation to approve
2.4	<u>Imperial College London – Dr Foster Unit (IAO: Garry Coleman) NIC-292308-P3C3Z</u> This application requested a renewal of an existing agreement in order for the applicant to receive new sensitive HES data, and in addition an extension to continue to hold data that the applicant had already received. It was noted that this covered an existing flow of data from the HSCIC through to Imperial College London, who then provided an aggregated form of the data to Dr Foster Intelligence, a separate commercial organisation. It was confirmed that the two organisations were separate legal entities, and it was explained that the data provided to Dr Foster Intelligence would include sensitive data items but would not contain identifiable data. The sensitive field Local Patient ID had specifically been requested in order to allow the applicant to reidentify an individual if there were clinical concerns. Section 251 support was in place for both the flow of data from the HSCIC to Imperial College, and from Imperial College to Dr Foster Intelligence. The Group noted that the application had listed the benefits achieved by providing data to Dr Foster Intelligence, but it was less clear what the benefits were of providing data to Imperial

	College London. In particular it was felt that sufficient justification had not been provided for why Imperial College required identifiable data. Concerns were also raised regarding the DPA registration for Imperial College, as it was thought that the wording included in the application form did not reflect the use of identifiable patient data. Significant concerns were raised about the fair processing information provided by Imperial College and Doctor Foster Intelligence, particularly in terms of the accessibility, availability and content of the fair use processing notice provided. It was suggested that the applicant could seek advice on this from the Information Commissioner's Office, and it was also suggested that if the applicant provided updated fair processing information then this could potentially be reviewed by DAAG members out of committee ahead of the Group considering a new application. **Outcome:** Unable to recommend the renewal application for additional data for approval. The application for an extension to continue to hold data until the end of January 2015 was recommended for approval subject to the following caveats: • Further details were requested regarding the role of Imperial College, and specifically what the justification was for why Imperial College required identifiable data. • The DPA registration for Imperial College was also queried, as the wording provided did not appear to cover the data processing described. • In addition members expressed significant concerns about the fair processing information provided by Imperial College and Doctor Foster Intelligence, particularly in terms of the accessibility, availability and content of the notice provided. It was suggested that the applicant should seek advice from the Information Commissioner's Office regarding this.
2.5	<u>IMS Healthcare (IAO: Garry Coleman) NIC-291741-B1B2Y</u> This application was to renew an agreement for this applicant to receive pseudonymised, linked HES data. It was explained that identifiable data from pharmaceutical systems within NHS hospital trusts was collected by the HSCIC, and that this data was linked then pseudonymised before being provided to the applicant with a cohort identifier. It was noted that Section 251 support was in place for these flows of data. The applicant then made this data available for research purposes to researchers, subject to the approval of an Independent Scientific and Advisory Ethical Committee or the Clinical Practice Research Datalink (CPRD) Independent Scientific Advisory Committee. It was noted that at one point the application form stated that IMS Healthcare received identifiable data from pharmaceutical systems, which was incorrect. It was agreed that this should be corrected to clarify that IMS did not receive identifiable data. The Group noted that IMS Healthcare did receive data from a number of other systems, but that these were entirely separate from the data provided by the HSCIC. The Group felt that not enough detail had been provided regarding the specific outputs and expected measurable benefits of this work. It was noted that the 'specific outputs' section of the application form listed the outputs of data that would be provided to the applicant, not the output of the applicant using this data. Concerns were raised around the fact that the application stated data would be made available to researchers but no details were provided regarding where these researchers might be based and, for example, if any would be based outside the UK or EU. **Outcome:** Unable to recommend for approval

2.6	University Hospitals Birmingham (IAO: Garry Coleman) NIC-292303-L4B0Z This application requested a renewal of an existing agreement in order for the applicant to receive new sensitive HES and ONS data, and in addition an extension to continue to hold data that the applicant had already received. This data would be used to provide quality and benchmarking analysis to other organisations through the online Healthcare Evaluation Data (HED) tool or associated aggregate analytical reports. It was noted that while the majority of organisations accessing the HED tool where NHS organisation, other organisations including private sector healthcare consultancy providers could also access the tool. The applicant had stated that the HED tool could only be used for the benefit of NHS organisations, and could not be used for other commercial purposes. Concerns were raised regarding the lack of clarity and detail within the application. It was not felt to be clear what specific organisations would be able to access data, and it was agreed that more specific details should have been provided regarding how organisations would use data and what the outcomes of this would be. It was also noted that the application stated that the applicant was an 'Other Health and Social Care System Public Body' when it would be more accurate to describe the applicant as a healthcare provider. The Group noted that the application stated that ONS data would not be made available to non-NHS organisations, but it was not thought to have been made sufficiently clear within the application form whether sensitive HES fields would be made available to non-NHS organisations. A query was raised regarding whether the DPA registration details provided were for University Hospitals Birmingham, and it was confirmed that this was the case. It was agreed that for future applications the organisation name should be listed next to the DPA registration details for clarity. The legal basis for the provision of data had been recorded as the Health and Social Care Act 2012, and it was agreed that clarification should be sought regarding which sections of the Act were thought to be applicable. **Outcome:** Unable to recommend for approval. Further clarity was requested about the objectives and anticipated benefits of this work, what non-NHS organisations would be able to access data and what data would be available to them. It was felt that there was a general lack of clarity and detail in the application provided, particularly in terms of identifying specific organisations. **Action:** Garry Coleman to seek confirmation regarding whether any issues had been raised by ONS regarding this use of data.
3	**Any other business** There was a discussion of the sensitive HES field Local Patient ID (LOPATID) and whether this should continue to be considered a sensitive item. It was agreed that Garry Coleman would provide a briefing paper on this to the HSCIC Caldicott Guardian. **Action:** Garry Coleman to write a briefing paper on the Local Patient ID field for the HSCIC Caldicott Guardian. **Action:** Garry Coleman to speak to Stuart Richardson regarding whether the Local Patient ID field is used in SUS.

	The Group noted the need to circulate documents far enough in advance of meetings to allow DAAG members sufficient time to read applications. It was agreed that applications should be circulated no less than two working days ahead of meetings. It was noted that an application for the Stampede Trial had been considered out of committee, and it was agreed that details would be provided at the following meeting.