

# Data Access Advisory Group

## Minutes of meeting held 9 September 2014

**Members:** Alan Hassey (Acting Chair), Patrick Coyle, Sean Kirwan, Eve Sariyannidou

**In attendance:** Susan Milner, Alex Bell, Dickie Langley, Terry Hill, Frances Hancox (Secretariat), Garry Coleman (agenda item 3), Paul Niblett (item 3), Sam Widdowfield (item 3), Jackie Gallagher (item 3), Stuart Richardson (item 3), Dominic Povey (item 3)

**Apologies:** Dawn Foster (member), John Craven (member), Diane Pryce

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| 1        | <p><b>Review of previous minutes and actions</b></p> <p>The Group reviewed the minutes of the 20 August 2014 meeting, and agreed them as an accurate record.</p> <ul style="list-style-type: none"><li>• <i>300714-h1: Simon Gray to look into how application processes in Scotland and England could be aligned, and consider discussing this with NHS Scotland. SG to be asked how he wishes to deal with this.</i></li></ul> <p>It was agreed that Dickie Langley would pick this up following the Scottish referendum.</p> <ul style="list-style-type: none"><li>• <i>150814-b1: Alan Hassey to write to Sam Smith confirming the outcome of discussions with the customer, that they had confirmed that they had ceased using the data for this purpose and to provide an update for the minutes.</i></li></ul> <p>It was noted that for future meetings, actions would be managed through the applications tracker.</p> |
| 2        | <p><b>Recommendations made out of committee</b></p> <p>Two applications had been considered by the Group out of committee:</p> <p><u>CRAB Clinical Informatics (NIC-221785-J4R5F)</u></p> <p>The applicant had responded to the queries previously raised by DAAG, and the application had been recommended for approval.</p> <p><u>University of Surrey – development of safe staffing guidelines (NIC-280526-H7Y6G)</u></p> <p>This application had been recommended for approval, although queries were raised regarding why this application had been considered urgent. It was agreed that the DAAG Terms of Reference should be reviewed and the process for out of committee applications reconsidered, given the increased frequency of DAAG meetings.</p>   |
| 3<br>3.2 | <p><b>Data applications</b></p> <p><u>AstraZeneca (IAO: Garry Coleman)</u></p> <p>The applicant had requested access to a monthly feed of pseudonymised, non-sensitive Hospital Episode Statistics (HES) data. The data would be used to work in partnership with the NHS on specific studies, and to support customer facing teams; the applicant had clarified that the data would not be used for direct marketing purposes, but would be used for</p>  |

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|     | <p>commercial purposes such as identifying drugs to target for particular geographical areas. The applicant had previously stated that data would be stored in the USA, but had now agreed that data would instead be stored in the UK.</p> <p>A query was raised regarding the quantity of data requested and it was explained that the applicant had requested access to a standard monthly extract, with no additional historic data. This data would be pseudonymised, although it was noted that as the data would be at episode level there would remain a risk that individuals could theoretically be re-identified. The Group raised concerns about the stated purpose of the application as this was felt to be too vague, and requested additional details of how the data would be used.</p> <p>It was suggested that the Health Research Authority Confidentiality Advisory Group (HRA CAG) or the Independent Information Governance Oversight Panel (IIGOP) could be asked to provide a view on this type of commercial use of data, and how it fit within current legislation. It was agreed that this would be suggested to the HSCIC Senior Information Risk Officer and the Caldicott Guardian.</p> <p><b>Action:</b> Terry Hill to speak to Rob Shaw and Martin Severs regarding Astra Zeneca application and the use of data for commercial purposes.</p> <p>Garry Coleman notified the Group that he would bring an updated extension application from this applicant to a following meeting for consideration, with a revised purpose.</p> <p><b>Outcome:</b> Unable to recommend for approval</p> |
| 3.1 | <p><u>Public Health England – NCMP (Presenter: Paul Nibblet on behalf of Information Asset Owner (IAO) Steve Webster)</u></p> <p>This application was to share the National Child Measurement Programme (NCMP) dataset with Public Health England (PHE). This dataset contained height and weight measurements of children as well as the school postcode, and would be used by PHE to carry out analysis and populate an interactive data tool to examine trends. The Group were informed that any data disseminated by PHE would be aggregated and would follow standard publication rules. It was noted that data from previous years had already been shared with PHE, and this application was to extend this to include 2013-14 data. It was also noted that PHE had a legal basis to receive this data as part of their statutory functions.</p> <p>A query was raised regarding how the stated aims of the application aligned with the statutory functions referred to. The data retention period was also queried. In addition some concerns were raised around the Information Governance (IG) Toolkit score for PHE, although it was noted that an action plan was in place to improve this score. It was agreed that an update should be requested for the following meeting on how this action plan was progressing, and the application would again be considered at that point.</p> <p><b>Outcome:</b> Unable to recommend for approval; further information requested.</p>   |
| 3.3 | <p><u>BUPA Health Dialog (IAO: Garry Coleman)</u></p> <p>This application was a renewal request for a monthly release of HES and Secondary Uses Service (SUS) Payment by Results (PBR) data, containing the sensitive item of consultant code. The applicant had confirmed that this data would only be used to support the provision of services to patients or for partnership work with the NHS, and would not be accessible by other branches of BUPA (for example, insurance). It was confirmed that the record level data received would not be shared with any other BUPA group or other third parties, although the analysis produced from the data could be shared with other BUPA groups where working in partnership with the NHS.</p>   |

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|     | <p>The Group agreed that they considered this application to be in the public interest, given the intention to use this data for audit purposes. The Group asked for the statement that this data would not be used for insurance purposes to be included in the outcome letter and data sharing agreement for this application.</p> <p><b>Outcome:</b> Recommendation to approve</p>   |
| 3.4 | <p><u>Imperial College London (IAO: Garry Coleman)</u></p> <p>This application was for access to the annual refresh of 2012-13 HES data, in addition to the cumulative monthly data to which the applicant had already been given access (DAAG reference 260614-e7). It was confirmed that this annual refresh data would be used for the same purpose as the previous DAAG application for monthly HES data, and that Section 251 approval was in place.</p> <p>A query was raised regarding why identifying data was required, and it was noted that this was to enable linkage with other data. The Group discussed the need for the applicant to meet the fair processing requirements of the Data Protection Act 1998 (DPA), and it was noted that this had been considered by HRA CAG when the application was considered for section 251 support.</p> <p><b>Outcome:</b> Recommendation to approve</p> |
| 3.5 | <p><u>Kings College, London (IAO: Garry Coleman)</u></p> <p>This was an application for non-sensitive pseudonymised HES data, although it was noted that the dataset provided would be considered sensitive as it would include mortality data from the Office of National Statistics (ONS). This data would be used for research into end of life cancer care.</p> <p>A query was raised regarding whether the applicant had completed the IG Toolkit, and it was noted that the applicant had ISO 27001 accreditation. It was noted that the applicant's DPA registration would shortly expire and require renewal, and the Group asked for this to be noted in the outcome letter.</p> <p><b>Outcome:</b> Recommendation to approve</p>  |
| 3.6 | <p><u>North and East London Commissioning Support Unit (CSU) (IAO: Garry Coleman)</u></p> <p>This application was for pseudonymised, non-sensitive HES and Diagnostic Imaging Dataset (DID) data in order to support contractual and strategic benchmarking. It was noted that other CSUs were likely to also submit applications for this data.</p> <p>It was noted that the applicant's DPA registration would shortly expire and require renewal, and the Group asked for this to be noted in the outcome letter.</p> <p><b>Outcome:</b> Recommendation to approve</p> <p><b>Action:</b> Alex Bell to share an example of the new data sharing agreement and contract with DAAG members.</p>   |
| 3.7 | <p><u>Price Waterhouse Cooper (Presenter: Garry Coleman on behalf of IAO Stuart Richardson)</u></p> <p>This application was for access to monthly HES and SUS data, in order to provide services to clinical commissioning groups (CCGs) and other bodies.</p> <p>Concerns were raised regarding the purpose listed on the application form, as this was felt to</p>  |

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|      | <p>be too vague with not enough detail provided. The data retention period was also queried. It was agreed that the applicant should be asked to provide further information on how the data requested would be used.</p> <p><b>Outcome:</b> Unable to recommend for approval</p>  |
| 3.8  | <p><u>London School of Hygiene and Tropical Medicine - HALT IT (IAO: Garry Coleman)</u></p> <p>This application had previously been considered by DAAG at the 26 June 2014 meeting, and additional details had been requested from the applicant.</p> <p>The applicant had previously stated their intention to upload the data received to a website where it could be accessed by other researchers across the world. The Group acknowledged the importance of making trial data widely available to increase transparency, but confirmed that they did not feel it was appropriate for the data requested to be made available outside the UK.</p> <p>It was confirmed that a reference in the application form to EU-funded projects was incorrect, and that the data provided would not be used for commercial purposes.</p> <p><b>Outcome:</b> Recommendation to approve subject to confirmation that data will not be made available outside the UK</p> |
| 3.9  | <p><u>University of East Anglia – The ‘Scoop’ Study (IAO: Garry Coleman)</u></p> <p>This application had been discussed at the 30 July 2014 meeting, and the applicant had been asked to provide an updated system level security policy. Further details of the applicant’s security arrangements had been provided, and it was agreed that this would be reviewed by a relevant expert with feedback provided to a following DAAG meeting.</p> <p><b>Outcome:</b> To discuss at the following DAAG meeting</p> <p>Garry Coleman left the meeting at this point. Jackie Gallagher, Dominic Povey and Stuart Richardson joined the meeting.</p>  |
| 3.10 | <p><u>London School of Hygiene and Tropical Medicine - A Randomised Trial In Screening To Improve Cytology (ARTISTIC) (IAO: Jackie Gallagher)</u></p> <p>This application was for an amendment to a study which had closed in 2010 and now required updated cohort flagging in order to receive cancer data. It was noted that section 251 approval from HRA CAG was in place.</p> <p>It was noted that the applicant’s DPA registration would shortly expire and require renewal, and the Group asked for this to be noted in the outcome letter.</p> <p><b>Outcome:</b> Recommendation to approve</p>  |
| 3.11 | <p><u>University of Surrey – LOLIPOP study (IAO: Jackie Gallagher)</u></p> <p>This application was for list cleaning and cohort flagging, in addition to an extract of HES data. It was noted that patient consent had initially been given when the study was begun by Imperial College London, but that following the involvement of the University of Surrey section 251 approval had been sought and granted.</p> <p>A query was raised regarding whether the applicant would be meeting the fair processing requirements of the DPA, and it was agreed that this point would be clarified by email.</p>   |

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| 3.12 | <p><b>Outcome:</b> Recommendation for approval subject to clarification of issues around DPA</p> <p><u>Barts Health NHS Trust (IAO: Jackie Gallagher)</u></p>   |
|      | <p>It was agreed that this application would be discussed at the following meeting.</p> <p><b>Outcome:</b> To discuss at the following DAAG meeting</p>   |
| 3.13 | <p><u>Brent CCG (IAO: Stuart Richardson)</u></p> <p>It was agreed that this application would be discussed at the following meeting.</p> <p><b>Outcome:</b> To discuss at the following DAAG meeting</p> <p>Jackie Gallagher left the meeting.</p>  |
| 3.14 | <p><u>Central Southern CSU (IAO: Stuart Richardson)</u></p> <p>This application was for identifying Accident and Emergency, outpatient, admitted patient and critical care SUS data for use in risk stratification. It was noted that the section 251 approval of the disclosure of data to data processors working on behalf of GPs for risk stratification purposes would cover this request. The data retention period was queried, and it was suggested that an end date of January 2015 should be specified due to the applicant's DPA registration expiring in February 2015.</p> <p>It was agreed that for any free text field that was deemed to be at risk of including identifiable data, these fields should only been shared once they had undergone either data cleaning or anonymisation to remove any identifiable data.</p> <p><b>Outcome:</b> Recommendation to approve subject to confirmation of data retention period</p>   |
| 3.15 | <p><u>Liverpool CCG (IAO: Stuart Richardson)</u></p> <p>The applicant had requested weakly pseudonymised data from a number of local datasets for use in contract monitoring, and it was noted that this was covered by the section 251 approval for commissioning organisation Accredited Safe Havens.</p> <p>The Group noted that the applicant's DPA registration expiry date had not been provided, and asked for this to be confirmed. It was agreed that for any free text field that was deemed to be at risk of including identifiable data, these fields should only been shared once they had undergone either data cleaning or anonymisation to remove any identifiable data. It was suggested that as this point around free text had been raised for several applications, it would be beneficial to include this in the updated data sharing agreement template.</p> <p><b>Action:</b> Terry Hill to look into whether a statement on the anonymisation of any potentially identifying free text fields should be included in the new data sharing agreement.</p> <p>A query was raised regarding a reference in the papers provided to datasets 'as otherwise agreed between commissioners and providers', it the Group suggested clarifying that only the datasets listed on page 5 of the data sharing agreement provided would be made available.</p> <p><b>Outcome:</b> Recommendation to approve subject to confirmation that only the datasets listed on page 5 of the Data Sharing Agreement will be provided and confirmation of DPA registration expiry date.</p> |
| 3.16 | <p><u>Sheffield CCG (IAO: Stuart Richardson)</u></p>  |

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|      | <p>This application again requested data under the section 251 approval for commissioning organisation Accredited Safe Havens. Weakly pseudonymised data based on NHS number was requested. It was agreed that for any free text field that was deemed to be at risk of including identifiable data, these fields should only be shared once they had undergone either data cleaning or anonymisation to remove any identifiable data. It was also agreed that the applicant's DPA registration expiry date would be confirmed.</p> <p>Concerns were raised regarding the stated purpose of the application, as using the word 'including' to list possible purposes could potentially cause ambiguity about other possible purposes. There were also concerns about references to sharing data with potential partners, given that the data provided would be weakly pseudonymised. It was agreed that the applicant should be asked to clarify this.</p> <p><b>Outcome:</b> Unable to recommend for approval</p> |
| 3.17 | <p><u>Clarity Informatics (IAO: Stuart Richardson)</u></p>   |
|      | <p>It was agreed that this application would be discussed at the following meeting.</p>  |
|      | <p><b>Outcome:</b> To discuss at the following DAAG meeting</p>  |
| 3.18 | <p><u>Midlands and Lancs CSU (IAO: Stuart Richardson)</u></p>  |
|      | <p>This application requested pseudonymised Accident and Emergency, admitted patient care and outpatient SUS data under the section 251 approval for the disclosure of commissioning data for risk stratification purposes.</p>  |
|      | <p>It was agreed that for any free text field that was deemed to be at risk of including identifiable data, these fields should only be shared once they had undergone either data cleaning or anonymisation to remove any identifiable data. It was also agreed that the applicant's DPA registration expiry date would be confirmed. The Group emphasised the need for this information to be included in application forms that were brought to them for consideration, rather than needing to seek clarification following meetings.</p>   |
|      | <p><b>Outcome:</b> Recommendation to approve subject to confirmation of DPA registration expiry date</p>   |
| 3.19 | <p><u>Great Yarmouth and Waveney CCG (IAO: Stuart Richardson)</u></p>  |
|      | <p>This application from an Accredited Safe Haven was for weakly pseudonymised SUS data (based on NHS number) in addition to Choose and Book, Population and Analysis Reporting (PARs) and cancer waiting times data.</p>  |
|      | <p>It was agreed that for any free text field that was deemed to be at risk of including identifiable data, these fields should only be shared once they had undergone either data cleaning or anonymisation to remove any identifiable data. The DPA registration expiry date was also queried as this was not provided.</p>  |
|      | <p>A query was raised regarding a statement in the application form that some aggregated outputs of this data could be shared with provider trusts, and the Group asked for the applicant to confirm that these aggregated reports would not contain any details that could potentially re-identify individuals, such as small numbers.</p>  |
|      | <p><b>Outcome:</b> Recommendation for approval subject to confirmation that any aggregated reports shared with provider trusts will not contain any data that could potential identify individuals and confirmation of DPA registration expiry date</p>  |

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| 3.20 | <p><u>IBD Registry – review of consent materials (Presenter: Dominic Povey)</u></p> <p>The Group were asked to review the draft consent materials for the British Society of Gastroenterology's Inflammatory Bowel Disease (IBD) Registry. It was noted that section 251 support was currently in place for this registry, but that the applicant intended to move towards using patient consent and had requested feedback on consent materials.</p> <p>The Group were largely content with the materials provided, but it was suggested that the consent materials should also include data retention period, details of the opt-out process if individuals decide they no longer wish to take part, and details of how to make a complaint.</p> <p><b>Outcome:</b> Recommendation for approval subject to inclusion of data retention period, details of the opt-out process if individuals decide they no longer wish to take part, and details of how to make a complaint</p> <p>Stuart Richardson and Dominic Povey left the meeting at this point.</p> |
| 4    | <p><b>Any other business</b></p> <p>The Group were informed that the National Audit Office had requested data from the learning disabilities census, and it was agreed that this application should be brought to a future DAAG meeting.</p> <p>It was noted that a new applications tracker had been produced that would track the progress of applications, as well as recording meeting actions. The Acting Chair noted that the format of meeting minutes would also be updated.</p> <p>The Group raised the need for papers to be circulated sufficiently far in advance of DAAG meetings to allow time to review them, and it was agreed that papers should be sent out no less than two working days in advance of each meeting.</p>   |