

## Data Access Advisory Group

### Minutes of meeting held 30 August 2012

Members: Mark Davies (Chair), Clare Sanderson, Patrick Coyle, Vanessa Kaliapermall

In attendance: Tom Latham, Dawn Foster, Chris Quinn, Diane Pryce, Frances Hancox (Secretariat)

Apologies: Sean Kirwan

300812-a	<p><b>Welcome</b></p> <p>Mark Davies welcomed everyone to the meeting, and noted that Vanessa Kaliapermall was attending on behalf of Sean Kirwan.</p>
300812-b	<p><b>Minutes of the Previous Meeting</b></p> <p>The minutes of the previous meeting, 26 July 2012, were ratified.</p>
300812-c	<p><b>Matters Arising</b></p> <p><b>(a) Overview of Outstanding Actions</b></p> <p><i>260712-c1: Diane Pryce and Louise Dunn to review the existing data sharing agreement and suggest how this could be updated to form a two-stage process.</i></p> <p>This action was reported to be ongoing, and it was proposed that it would be completed by the end of November subject to resources.</p> <p><i>260712-c2: Clare Sanderson and Louise Dunn or Diane Pryce to meet with ECC and HRA representatives to discuss the use of IG Toolkits and the process for customers who do not complete the IG Toolkit; Patrick Coyle and Sean Kirwan to be invited once a meeting date is set.</i></p> <p>It was noted that this action had not yet been completed, but that a procedure had been drafted by Magi Nwolie and that Dawn Foster and Natasha Dunkley (ECC) had provided comments. A final draft of the procedure was expected by the end of August.</p> <p>There was a discussion around transition arrangements for customers without an acceptable IG Toolkit score, and it was noted that an assurance form for customers to sign had been drafted.</p> <p><b>Action:</b> Dawn Foster to circulate the draft assurance form to DAAG members.</p> <p><i>260712-c3: Louise Dunn to speak to Andrew Haw regarding interim arrangements to review SLSPs that have already been submitted.</i></p> <p>This action had been put on hold while the document discussed above was drafted.</p> <p><i>260712-d1: DAAG outcome letter to be sent to Dr Foster Ltd requesting examples of why and how sensitive MHMDS fields will be used, and to clarify what is meant by 'juxtaposing' data with other datasets.</i></p> <p>This letter had been sent, and response was received from Dr Foster Ltd stating that they</p>

	<p>would not be taking the application forward at this time.</p> <p><i>260712-d2: Louise Dunn to confirm whether Dr Foster Ltd complete the IG Toolkit.</i></p> <p>This action had been completed and Dr Foster Ltd had completed the IG Toolkit, but as above they will not be taking this application forward.</p> <p><i>260712-f1: Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents.</i></p> <p>The Group were informed that this action was not currently a priority and that it would be followed up when resources permitted. Diane Pryce agreed to keep the Group updated.</p> <p><b>(b) Overview of Outstanding Applications</b></p> <p>The Group were informed that Dr Foster Ltd had withdrawn their application for sensitive MHMDS data which had been discussed but not approved at the July DAAG meeting.</p> <p><b>(c) Decisions Out of Committee</b></p> <p><b>MR21:</b> This application from The 1970 British Cohort Study requested contact details to re-contact individuals who had previously consented to take part in the study. Individuals would be given the opportunity to withdraw.</p> <p><b>MR1297:</b> This was a small flagging study requesting cause of death. It was noted that there were no issues with the consent materials and that this had been approved by the Deputy Chair.</p> <p><b>OC/HES/022:</b> The University of York had requested an additional year of data for a study which examined whether better GP practice performance scores on the Quality and Outcomes Framework (QOF) were associated with lower emergency admissions for people with serious mental illness, with the key aim being to help inform national policy on QOF. Their initial application had been approved at November 2011 DAAG meeting. This new application was approved by the Chair out of committee.</p> <p>It was noted that a HES application from the Institute for Fiscal Studies (300812-a) had initially been considered out of committee, but that it had been agreed the application should instead be brought to a full DAAG meeting.</p>
300812-d	<p><b>HES and MHMDS Applications</b></p> <p><u>300812-a Institute for Fiscal Studies</u></p> <p>The applicant had requested GP data at individual GP level, which they would then link with an existing episode level extract of HES data at general practice level. The dataset produced would be used in two pieces of statistical analysis on sources of variation in where patients were referred for secondary care.</p> <p>The decision had been made to submit the application for consideration by DAAG due to the inclusion of GMC numbers, which would be roughly analogous to the 'Consultant Code' field which was deemed sensitive and subject to DAAG approval. The application was subsequently brought to a full DAAG meeting because the DAAG Chair felt there would be a potential conflict of interest in approving the application himself out-of-committee, due to his role as a GP and Cabinet Advisor on Open Data. The Group discussed whether it would be appropriate to disclose this data on clinicians, and it was agreed that this would be acceptable</p>

	<p>and in the public interest.</p> <p>There was a discussion around why the applicant had requested data items such as age and gender of GP, and whether this was a reasonable request. It was agreed that there could be a number of legitimate reasons why this was required, but that the applicant had not provided sufficient justification for why this information was required for their analysis and that they should be asked for this justification.</p> <p><b>Outcome:</b> Approved subject to applicant providing justification for specific data items (GP age and GP gender)</p> <p><u>300812-b Department of Health</u></p> <p>A HES Business Objects user at the Department of Health had requested access to the sensitive referrer code within HES Business Objects for use in work carried out by the NHS Commissioning Board Transition Team to define the source of referral for dental treatment. It was noted that sensitive data would be required as the alternative pseudonymised data item could not be used to identify whether the referrer were a GP or dentist. It was also noted that it would be possible to provide the data through an extract rather than through Business Objects, but that this would provide less up-to-date data and would not allow the type of exploratory analysis the applicant hoped to carry out.</p> <p>There was a discussion around the referrer code and whether this would be the same thing as a GDC number. There were also some concerns around the exploratory analysis planned and the ‘fishing trip’ nature of this analysis. However it was agreed that the application should be approved, provided that members were satisfied with the explanation of the referrer code field.</p> <p><b>Action:</b> Tom Latham to circulate an explanation of the referrer code.</p> <p><b>Outcome:</b> Approved subject to clarification of referrer code field</p>
300812-e	<p><b>NHS Central Register – MRIS Applications</b></p> <p><u>MR1245 - New EPOC: an open-label randomised trial</u></p> <p>This was a small flagging study for deaths for a cohort of 320 patients in England and Wales and 20 in Scotland. It was noted that the consent materials had been amended and now reflected the recommended wording. It was also noted that an SLSP had been provided, but that this would come under the transition arrangements discussed earlier.</p> <p><b>Outcome:</b> Approved</p> <p><u>MR1298 - UK Lung Screening Trial (UKLS)</u></p> <p>This study had received Section 251 support to facilitate the consent process, and the application to MRIS was for flagging for cause of death, cancer, PCT, exit and re-entry data. The Group agreed that the consent materials were adequate for this purpose, and noted that the applicant had agreed to update the consent materials if the study moved to a full trial.</p> <p><b>Outcome:</b> Approved subject to review of data flow and security documents</p>

	<p><u>MR1299 - Emerging ethnic differences in type 2 diabetes risk: role of maternal and birth factors</u></p> <p>This application requested birth weight, singleton/twin status and hospital of birth (if available) for study participants; it was noted that this data was available from the ONS birth database, and that ONS were content to release this data on the legal basis of parental consent.</p> <p>It was suggested that the consent material should be more explicit about the role of national databases in the study. The Group agreed that this feedback should be passed on to the applicant, but that approval would not be dependent on this.</p> <p><b>Outcome:</b> Approved</p>
300812-f	<p><b>Any Other Business:</b></p> <p>One item raised was that the clinical audit team would like to see input from DAAG on consented audits. It was agreed that it would be appropriate for DAAG to provide this input.</p> <p>It was also noted that an application had been received for a study that would take place Europe, meaning that data collected would be sent outside of the UK. There was some uncertainty regarding this and whether a legal opinion would be required. It was agreed that the application should be circulated for members of the Group to consider.</p> <p><b>Action:</b> Diane Pryce to circulate further details of the study taking place outside the UK.</p> <p>In addition there was a brief discussion on the progress of the IG review being conducted by Dame Fiona Caldicott. It was noted that the HSCIC had been very engaged with the review, and that a broad themed session had been scheduled with Dame Fiona Caldicott and other committee members to take place at the HSCIC in Leeds.</p>
300812-g	<p><b>Date of Next Meeting:</b> Wednesday 3 October 10:00 – 11:00</p>

## Summary of Actions

Reference	Action	Owner
260712-c1 (ongoing)	Diane Pryce and Louise Dunn to review the existing data sharing agreement and suggest how this could be updated to form a two-stage process.	Diane Pryce and Louise Dunn
260712-c2 (ongoing)	Clare Sanderson and Louise Dunn or Diane Pryce to meet with ECC and HRA representatives to discuss the use of IG Toolkits and the process for customers who do not complete the IG Toolkit; Patrick Coyle and Sean Kirwan to be invited once a meeting date is set.	Clare Sanderson
260712-f1 (ongoing)	Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents.	Diane Pryce and Louise Dunn
300812-c1	Dawn Foster to circulate the draft assurance form to DAAG members.	Dawn Foster
300812-d1	Tom Latham to circulate an explanation of the referrer code.	Tom Latham
300812-f1	Diane Pryce to circulate further details of the study taking place outside the UK.	Diane Pryce