

# Data Access Advisory Group

## Minutes of meeting held 19 December 2012

Members: Clare Sanderson, Patrick Coyle, Sean Kirwan

In attendance: Diane Pryce, Chris Quinn, Mansoor Sahibzada, Frances Hancox  
(Secretariat)

Apologies: Mark Davies

191212-a	<p><b>Welcome</b></p> <p>Clare Sanderson welcomed everyone and chaired the meeting in Mark Davies' absence.</p>
191212-b	<p><b>Minutes of the Previous Meeting</b></p> <p>The minutes of the previous meeting, 22 November 2012, were ratified.</p>
191212-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. (Update: Louise Dunn to provide an update on ongoing work at January 2013 meeting.)</i></p> <p>It was agreed that this action was ongoing, and that Louise Dunn would be asked to provide an update for the following meeting.</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>This meeting had not yet taken place, but it was agreed that this action would remain open as it would still be beneficial to discuss how to manage this with HRA and ECC.</p> <p><i>260712-f1: Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents. (Update: Dave Cronin to provide an update once a solution has been found.)</i></p> <p>It was noted that Dave Cronin continued to look into this, but that no solution had been agreed yet; he had agreed to attend a DAAG meeting and provide an update once this work had progressed further.</p> <p><i>301012-e1: Tom Latham to obtain further information from BMJ Publishing Group regarding the purpose for them receiving the sensitive HES data, and also provide information to DAAG to assist with the applicant's small numbers query.</i></p> <p>An email had been sent out to the applicant regarding this; the applicant had responded to say that an application for sensitive data would be resubmitted in approximately three months' time. This application was now closed. It was agreed that the applicant should be contacted</p>

	<p>again to confirm that this application was now closed, but that any further applications would be welcomed in the future.</p> <p><i>221112-c1: Louise Dunn to send Mark Davies a summary of DAAG activity over the past 12 months.</i></p> <p>This update had been sent, but Mark Davies was not present to provide an update on the outcome of this. It was suggested that an update should be provided at the following meeting.</p> <p><b>(b) Overview of Outstanding Applications</b></p> <p><u>301012-a: University of Edinburgh</u></p> <p>This application had been approved at the 3 October 2012. It was noted that organisations in Scotland do not usually complete the IG Toolkit, and so the applicant had been asked to complete an information security form. The completed form had not yet been received. It was agreed that this should be followed up with the applicant, but that if a response had not been received by the following DAAG meeting then a letter should be sent to the applicant stating that in the absence of a completed information security form it would be assumed their application was closed.</p> <p><u>031012-a University Hospitals Birmingham</u></p> <p>This application had been approved at the 3 October 2012 DAAG meeting subject to the applicant informing patients of the use of HES data and the involvement of the HSCIC in the study. The Group were informed that an approval letter had been sent out to this applicant in October to notify them of this; a response had been received stating that contact had not yet been made with patients regarding the use of HES data, but that the applicant would be in touch once they were able to proceed with this.</p> <p><u>221112-a: Imperial College London</u></p> <p>This application had been approved at the 22 November 2012 DAAG meeting. An information security form had been sent to the applicant for completion, but the completed form returned only referred to an earlier DAAG application. The applicant had been informed that an updated information security form would be required, but this had not yet been received.</p> <p><b>(c) Decisions Out of Committee</b></p> <p><u>OC/HES/025: Million Women Study (University of Oxford)</u></p> <p>It was noted that this application had been sent to the DAAG Chair out of committee but that no decision had yet been made. The Group therefore agreed to discuss the application within this meeting.</p> <p>This was a historic study that had been previously reviewed and approved by the Database Monitoring sub-Group (DMsG) in February 2010. The applicant had requested an update of the data provided, and it was noted that the data linkage for this would now be carried out by the HSCIC rather than Northgate as had previously been the case.</p> <p><b>Outcome:</b> Approved</p>
191212-d	<p><b>NHS Central Register – MRIS Applications</b></p> <p><u>MR1309: BUMPES: A study of position during the late stages of labour in women with an</u></p>

	<p><u>epidural</u></p> <p>This application requested status checking and GP practice code for mothers and status checking for babies 12 months post-discharge prior to sending out questionnaires. It was agreed that the Patient Information Leaflet appropriately described the involvement of the HSCIC and that the consent form was fit for purpose.</p> <p><b>Outcome:</b> Approved</p>
191212-e	<p><b>RCGP Community-Based Surgery Audit</b></p> <p>A draft consent form and patient information leaflet, for a consented audit on minor surgery, had been made available to DAAG members to seek advice on whether the information included the right level of detail to obtain explicit consent. It was noted that the GPs or consultants would be likely to use explicit verbal consent, although the advice given would be to seek explicit written consent where possible.</p> <p>There were some minor concerns raised that the information leaflet contained too much technical jargon, which could be confusing for a lay audience. One suggestion was that it might have been helpful to seek patient review of the information leaflet to obtain feedback on how easy it was to understand. It was also suggested that the consent form should spell out HSCIC in full rather than using the acronym.</p> <p>The Group queried why verbal consent might be sought rather than written consent, and emphasised that obtaining written consent would be best practice.</p> <p>Overall, the Group were satisfied with the consent materials provided.</p>
191212-f	<p><b>Any Other Business:</b></p> <p>The Group were notified of an old study which would be submitted to a future DAAG meeting to request an extension, with the purpose of facilitating contact with study participants via general practices. It was noted that participants would be asked to re-consent to participate in the study, but that the consent materials did not include specific information about data processing. It was agreed that it would be best practice for participants to be provided with information about the data processing involved when they were contacted to re-consent.</p> <p>The Group were also informed that an application from Clatterbridge, requesting updated data years through HES Business Objects, would be submitted to the following meeting.</p> <p>It was noted that the final ECC meeting would be taking place in February 2013, and that Clare Sanderson would be attending this. It was also noted that roles on the HRA Confidentiality Advisory Group (CAG) were in the process of being advertised, and that DAAG would need to consider how to maintain links with this group in the future.</p> <p><b>Action:</b> Clare Sanderson to discuss with Mark Taylor how to maintain links between DAAG and the HRA Confidentiality Advisory Group.</p>
191212-g	<p><b>Date of Next Meeting:</b> Thursday 31 January 2013 11:00 – 12:00</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. (Update: Louise Dunn to provide an update on ongoing work at January 2013 meeting.)	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. (Update: Dave Cronin to provide an update once a solution has been found.)	Diane Pryce and Louise Dunn
221112-c1 (ongoing)	Louise Dunn to send Mark Davies a summary of DAAG activity over the past 12 months. (Update: Mark Davies to provide an update on the outcome of this.)	Louise Dunn
191212-f1	Clare Sanderson to discuss with Mark Taylor how to maintain links between DAAG and the HRA Confidentiality Advisory Group.	Clare Sanderson