

Data Access Advisory Group

Minutes of meeting held 26 July 2012

Members: Clare Sanderson, Patrick Coyle, Sean Kirwan

In attendance: Louise Dunn, Diane Pryce, Frances Hancox (Secretariat)

Apologies: Mark Davies

260712-a	<p>Welcome</p> <p>Clare Sanderson welcomed everyone and chaired the meeting in the absence of Mark Davies.</p>
260712-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the previous meeting, 26 June 2012, were ratified.</p>
260712-c	<p>Matters Arising</p> <p>(a) Overview of Outstanding Actions</p> <p>260612-c1: A letter had been drafted and sent to ECC regarding MR1113, and a response had been received extending S251 support for the application in question.</p> <p>260612-c2: This action was regarding MR1287, where it had been thought that the customer were applying for S251 but instead the existing HSCIC s251 approval had been extended without consulting the Information Centre. DAIS had contacted ECC, who confirmed that nothing needed to be formally submitted by the HSCIC to validate that change. MRIS would be providing REC and ECC with a draft of the HSCIC covering letter that would go out to mothers in the mail out, and it was noted that a draft of this was currently with Mark Davies and Clare Sanderson for comment and approval.</p> <p>260612-f1: It was noted that there would now be a clash with the ECC meeting in September, and that a new date would be set for the September DAAG meeting.</p> <p>(b) Overview of Outstanding Applications</p> <p>There were no outstanding applications at this meeting.</p> <p>(c) Decisions Out of Committee</p> <p><u>OC/HES/020 - Civil Eyes Research Ltd</u></p> <p>This application was an update of a previous extract. The applicant had requested data for an additional year for the same purpose as previously, with no additional sensitive fields requested. The requested data (including the sensitive Consultant Code field) would support research projects with healthcare organisations on medical productivity and benchmarking analysis. Analyses of HES data would be conducted by Civil Eyes and delivered to clinical and medical directors and managers. The Consultant Code field was required in order to produce activity profiles that the doctors and managers could recognise.</p>

The application had been approved by the DAAG Chair and an outcome letter had been sent to the customer.

MR1293 - Targets and self-management for the control of blood pressure in stroke and at risk groups (TASMIN-SR)

This application requested flagging for cause of death and the consent wording was as per the current recommendation. The application had been approved by the DAAG Chair.

(d) SLSP/IG Toolkit DH Announcement

The Group had previously written to Phil Walker regarding the use of the IG Toolkit to assure customers' information governance controls, and a response had been received and circulated to the Group. A number of concerns were raised, particularly regarding whether the IG Toolkit alone would be sufficient assurance for some applications, and what the implications would be for customers who would not normally complete the IG Toolkit, such as academic organisations. Furthermore it was noted that the IG Toolkit was only used in the NHS in England and so this would also cause difficulties for any customers in Scotland, Wales or Northern Ireland.

There was a brief discussion of how IG Toolkit scores would be assessed, and it was noted that organisations were usually expected to achieve level 2 in all areas of the Toolkit, but that a judgement might need to be made if a customer had failed to achieve level 2 in an area that was not relevant to their DAAG application. Clare Sanderson reported that she had held discussions with the IG Toolkit team and that they had offered to provide a 'deep dive' review of IG Toolkit submissions from DAAG customers to provide assurance of the quality of evidence submitted. This would help alleviate any concerns regarding the robustness of IG Toolkit submissions.

For organisations who did not complete the IG Toolkit, one suggestion was that the data sharing agreement could be updated to include clear expectations for information governance controls, and that the data sharing agreement should be signed by an appropriately senior individual from that organisation such as the Caldicott Guardian or SIRO. It was also suggested that organisations should be required to provide a signed security statement at the beginning of the application process in addition to the Data Sharing/Re-use Agreement signed towards the end of the process, in order to emphasise the importance of appropriate IG controls.

It was agreed that it would be important to ensure that the agreed DAAG process was aligned with the future approach for S251 approval.

Action: Diane Pryce and Louise Dunn to review the existing Data Sharing/ Re-Use Agreement and suggest how this could be updated to form a two-stage process.

Action: 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.

It was noted that this issue was already creating delays in providing customers with data, as a number of applications approved at the previous DAAG meeting were from academic organisations who had not completed the IG Toolkit. It was suggested that to prevent further delays the Information Centre should consider making short-term arrangements to review the SLSPs submitted for applications that have already been approved by DAAG.

Action: Louise Dunn to speak to Andrew Haw regarding interim arrangements to review SLSPs that have already been submitted.

260712-d	<p>HES and MHMDS Applications</p> <p><u>260712-a - Dr Foster Ltd MHMDS</u></p> <p>Dr Foster Ltd had submitted this application as an update to an application for v3 MHMDS data which was approved by DMSG in 2009 and 2010. The updated application requested sensitive data from v4 of MHMDS.</p> <p>Members of the Group felt that the application did not sufficiently justify the need for sensitive fields to be included in the extract, as no specific purpose was given for requiring these particular fields and it was not clear why non-sensitive information would not be sufficient. It was agreed that the customer should be asked to supply clear examples of how each sensitive field would be used. It was also agreed that once this information had been received the updated application could be considered out of committee.</p> <p>A further query was raised regarding what the customer meant by stating that they could 'juxtapose' MHMDS data with other datasets, and how this differed from data linkage.</p> <p>Action: 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.</p> <p>Action: Louise Dunn to confirm whether Dr Foster Ltd complete the IG Toolkit.</p> <p>Outcome: Not approved</p>
260712-e	<p>NHS Central Register – MRIS Applications</p> <p><u>MR1295 - SCALOP: Selective Chemoradiation in Advanced Localised Pancreatic cancer</u></p> <p>This application was for current status and cause of death. It had been pointed out to the customer that the consent form and patient information leaflet used were slightly contradictory, and the customer will look to update this; it was noted that there would be no change to consent materials for those already recruited. There were no other concerns raised.</p> <p>Outcome: Approved</p> <p><u>MR1296 - The Bullous Pemphigoid Steroids and Tetracyclines Study</u></p> <p>This was a small flagging study for cause of death. The customer had confirmed that they would only follow up individuals who had been recruited using the updated consent materials.</p> <p>Outcome: Approved</p>
260712-f	<p>Any Other Business:</p> <p>A brief update was given on the discussions taking place regarding the future of ECC, and it was noted that while it was likely the majority of ECC's functions would move to HRA this had not yet been finalised.</p> <p>It was also noted that using the new customer relationship management system (CRM) had</p>

	<p>caused problems in sharing information for DAAG meetings.</p> <p>Action: Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents.</p>
260712-g	<p>Date of Next Meeting: 30 August 2012 11:00 – 12:00</p>

Summary of Actions

Reference	Action	Owner
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.	Diane Pryce and Louise Dunn
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.	Clare Sanderson
260712-c3	Louise Dunn to speak to Andrew Haw regarding interim arrangements to review SLSPs that have already been submitted.	Louise Dunn
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.	Louise Dunn
260712-d2	Louise Dunn to confirm whether Dr Foster Ltd complete the IG Toolkit.	Louise Dunn
260712-f1	Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents.	Diane Pryce and Louise Dunn