

# Data Access Advisory Group

## Minutes of meeting held 27 June 2013

Members: Mark Davies (Chair), Clare Sanderson, Sean Kirwan

In attendance: Susan Milner, Nicola Mallender-Ward, Diane Pryce, Charlotte Skinner, Trevor Anders, Frances Hancox (Secretariat)

Apologies: Patrick Coyle

270613-a	<p><b>Welcome</b></p> <p>Clare Sanderson welcomed the attendees and opened the meeting. It was noted that Mark Davies had stepped out of the meeting and would return shortly.</p>
270613-b	<p><b>Minutes of the Previous Meeting</b></p> <p>The minutes of the 22 May 2013 meeting were agreed as an accurate record.</p>
270613-c	<p><b>Matters Arising</b></p> <p><b>(a) Overview of Outstanding Actions</b></p> <ul style="list-style-type: none"><li>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. An updated data sharing contract had been drafted, and further work would be taking place to ensure that it would meet business requirements as well as ICO requirements.</li></ul> <p>At this point Mark Davies re-joined the meeting.</p> <ul style="list-style-type: none"><li>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 would be producing a report for the HRA Confidentiality Advisory Group that would compare potential methods of assurance, and following discussion of the report an approach would be agreed. The action was closed.</li><li>260712-f1: Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents. Guidance for the technical solution had been shared, and the action was closed.</li><li>240413-c1: Diane Pryce and Clare Sanderson to discuss differences between the application process in Scotland and England, and consider meeting with NHS Scotland. A meeting had been scheduled to take place in July, which Mark Davies and Clare Sanderson would attend. Diane Pryce agreed to provide a summary for use at the meeting.</li><li>240413-c2: Mark Davies to contact Professor Sir Bruce Keogh regarding the need to inform consultants that their data will be used to monitor excess mortality in acute trusts. This action had been completed and was closed.</li></ul>

	<p><b>(b) Overview of Outstanding Applications</b></p> <p>Following discussions at the 22 May 2013 meeting, letters had been sent to the Born in Bradford study (310113-g) and to University Hospitals Birmingham (260313-f1) but no responses had yet been received.</p> <p>Patrick Coyle had raised some queries regarding the MHMDS and HES bridging file discussed under Any Other Business on 22 May 2013, and responses to these queries had been circulated to the Group.</p> <p><b>(c) Decisions Out of Committee</b></p> <p>A CQC application for sensitive MHMDS data had been considered out of committee (OC/HES/031) and approved by Chair's action. This application requested 2012-13 data; CQC had previously submitted a request for 2010-11 and 2011-12 data, which had been discussed at the 29 May 2012 DAAG meeting and approved (reference 290512-b).</p>
270613-d	<p><b>MHMDS and HES Bridging File</b></p> <p>CQC had requested a bridging file to link the identifiable HES data with the sensitive MHMDS data that they held, and it was noted that they had statutory powers to hold this data. There were some concerns that providing this bridging file would potentially make the MHMDS data identifiable, and it was suggested that the HRA Confidentiality Advisory Group should be informed of this.</p> <p><b>Action:</b> Mark Davies to write to HRA Confidentiality Advisory Group regarding the provision of a HES and MHMDS bridging file to CQC</p> <p>It was noted that CQC had previously published a code of practice that stated the organisation would aim to use anonymised or pseudonymised data rather than identifiable data wherever possible, and a query was raised regarding whether the HSCIC could instead link the HES and MHMDS data and then provide pseudonymised data for use by CQC. However, it was thought that pseudonymised data would not be sufficient for the planned collaborative data analysis.</p> <p>The Group suggested that in order to minimise the potential privacy impact, CQC should be asked to provide assurances that appropriate access controls would be in place for the linked HES and MHMDS data; these assurances should be consistent with the CQC code of practice on confidential personal information.</p> <p>It was noted that any other organisation who applied for a HES and MHMDS bridging file would potential require Section 251 approval.</p> <p><b>Outcome:</b> Approved subject to assurances from CQC that appropriate access controls will be in place.</p>
270613-e	<p><b>HES Applications</b></p> <p><u>270613-a: Civil Eyes Research</u></p> <p>The applicant had previously requested HES data including the consultant code field; this had been approved by the DMsG in October 2010 and an updated extract was approved by the DAAG Chair out of committee in July 2012. An additional data year was now requested, and it was confirmed that the data requested would be used for the same purpose as given in their</p>

	<p>previous applications.</p> <p><b>Outcome:</b> Approved</p> <p><u>270613-b: CHKS Ltd.</u></p> <p>The applicant had requested HES data including consultant codes to enhance their existing consultant revalidation product (CLIP). It was intended that the analysed data would be fed back to consultants, but that it would not be possible to identify other individual consultants from the data provided to them.</p> <p>It was noted that the applicant currently received a pseudonymised monthly managed extract of HES data, and that this application would add the consultant code field to the data already received. A query was raised regarding whether including the consultant code field would make any data patient identifiable, but it was noted that this would not be the case.</p> <p>It was also noted applications for consultant code data, and that it would be important to be consistent between these. The HSCIC had asked the applicant to provide an access control protocol covering access that there were a number of similarities between this application and previously received to sensitive fields; this had not been provided, although some details of access control measures had been given. It was agreed that the applicant should be asked again to provide this.</p> <p><b>Outcome:</b> Not approved</p>
<p><b>270613-f</b></p>	<p><b>Data Linkage Service (MRIS) Applications</b></p> <p><u>MR1327: Understanding Society – The UK Household Longitudinal Study (UKHLS) Health Linkage</u></p> <p>This request was for ONS mortality, NHS registration and HES data, and included the identifiable data fields of patient date of birth and baby date of birth. It was noted that the consent materials did not use the recommended wording, but were thought to adequately describe the data requested as well as the data processing. It was proposed that if recruitment for this study were still ongoing, the consent materials should be updated to include an up to date organisational structure, but that if recruitment had ended this would not be required.</p> <p><b>Outcome:</b> Approved subject to the applicant updating consent materials if recruitment is still ongoing and confirmation if children will be asked to consent when they reach capacity.</p> <p><u>MR1109: UK Biobank</u></p> <p>UK Biobank had previously been given approval to receive mortality data for their cohort, and this application now requested exit, re-entry, PCT data and general practice code as well as participant postal addresses. The applicant had been informed that patient postal addresses were not routinely released, but the applicant had stated that the consent obtained from participants should allow for this. It was suggested that the applicant should make the Research Ethics Committee aware that they intended to obtain postal addresses in this way, as it was not felt that this was clear from the protocol provided.</p> <p>Some concerns were raised regarding the legal justification for providing participant postal addresses, and whether the consent provided adequately covered this use of data. It was agreed that this should be discussed with the HRA Confidentiality Advisory Group.</p> <p><b>Action:</b> Clare Sanderson to discuss UK Biobank application (MR1109) with the HRA Confidentiality Advisory Group.</p>

	<p>It was proposed that UK Biobank should update their website to include a statement that participants' consent could be used to access updated contact details.</p> <p><b>Outcome:</b> Approved subject to the outcome of discussions with the HRA Confidentiality Advisory Group, and subject to UK Biobank publishing details of the planned use of contact details on their website.</p>
<b>270613-g</b>	<p><b>Any Other Business:</b></p> <p>It was noted that due to the changes that had taken place after 1 April 2013, work was taking place with a number of class action studies that had previously received data under the former HSCIC's Section 251 approval. The studies would receive deidentified data as an interim measure, but the studies would be encouraged to apply for Section 251 approval individually so that this would be in place before the end of March 2014.</p> <p>There was a brief discussion of a request that had been received from a customer to use National Joint Registry data to link with HES and CQC data, and it was noted that the request included the consultant code field. The customer intended to obtain online consent from clinicians for this. It was noted that there would be some changes to the availability of consultant code data due to a number of planned publications of consultant clinical outcomes by NHS England, and that the impact of this on DAAG's discussions would need to be considered.</p>
<b>220513-h</b>	<p><b>Date of Next Meeting:</b> Wednesday 31 July 2013</p>

## Summary of Open 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: Updated data sharing contract being used from May 2013. Updated data sharing contract to be sent to DAAG.)	Diane Pryce and Louise Dunn
240413-c1 (ongoing)	Diane Pryce and Clare Sanderson to discuss differences between the application process in Scotland and England, and consider meeting with NHS Scotland. (Update: Meeting proposed to coincide with separate meeting in Edinburgh.)	Clare Sanderson
270613-d1	Mark Davies to write to HRA Confidentiality Advisory Group regarding the provision of a HES and MHMDS bridging file to CQC	Mark Davies
270613-f1	Clare Sanderson to discuss UK Biobank application (MR1109) with the HRA Confidentiality Advisory Group.	Clare Sanderson