

Data Access Advisory Group

Minutes of meeting held 22 May 2013

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

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

Apologies: Sean Kirwan

220513-a	<p>Welcome</p> <p>Mark Davies welcomed everyone to the meeting.</p> <p>The Group discussed a recent article in the Guardian newspaper regarding private firms obtaining access to health records, and it was suggested that the article had contained a number of inaccuracies. It was noted that Clare Sanderson would be working with the Communications team to clarify some points, and in addition it was suggested that a customer case study could be created to demonstrate how data accessed through the HSCIC had been used to benefit patients. It was also agreed that Patrick Coyle would write to the Guardian to provide some clarifications as an independent member of the Group.</p>
220513-b	<p>Minutes of the Previous Meeting</p> <p>The minutes of the 24 April 2013 meeting were agreed as an accurate record.</p>
220513-c	<p>Matters Arising</p> <p>(a) Overview of Outstanding Actions</p> <ul style="list-style-type: none">• <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> The updated data sharing contract had been reviewed and had begun to be used across the Data Linkage Service, and would be used for future applications for HES, MHMDS and MRIS data. It was agreed that a copy of the data sharing contract would be circulated to the Group.• <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> It was noted that Clare Sanderson would ask for this topic to be included on the agenda for the 13-14 June meeting of the HRA Confidentiality Advisory Group. It was agreed that it would still be helpful to reach a consensus on what interim assurances could be accepted from organisations that did not currently complete the IG Toolkit, and particularly what the process should be for Welsh organisations.• <i>260712-f1: Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents.</i> Guidance for the proposed solution had been drafted and circulated to the DAIS and data linkage teams for their comments.• <i>240413-c1: Diane Pryce and Clare Sanderson to discuss differences between the application process in Scotland and England, and consider meeting with NHS Scotland.</i> It was noted that Clare Sanderson and Mark Davies would be attending a separate meeting in Edinburgh during the summer, and it was suggested that a

meeting with NHS Scotland could be scheduled to coincide with this.

- *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 was ongoing. It was agreed that an email would be drafted to formally set out the Group's position.

(b) Overview of Outstanding Applications

MR1316: HCV Research UK

The Group had written to the applicant with a number of questions about this application, particularly whether any identifiable data fields would be released, how data released outside the UK would be coded, and what process would be in place to obtain consent from children as they grew older and gained capacity. The applicant's response had then been circulated to the Group and it was noted that the applicant had undertaken to gain consent from children where appropriate during biannual visits. It was agreed that the questions raised by the Group had been answered to their satisfaction.

Outcome: Approved

310113-g Born in Bradford

This application had initially been discussed under Any Other Business at the 26 February 2013 meeting, and the applicant had requested HES data for mothers and children for use in multiple unspecified projects. The Group had felt that it would be appropriate for the applicant to contact participants to inform them of upcoming studies for which their data might be used. The applicant had written back to the Group stating that there could be difficulties in following up the consent already obtained and that there were doubts about the likely response rate due to language barriers; this letter had been circulated to the Group. The applicant had also noted that they provided updates in letters to participants and on their website.

The Group raised some concerns about the consent form provided, as this did not include the recommended wording and only referred to ONS rather than the HSCIC or other organisations, but it was noted that this consent form had been written and used in 2007.

It was suggested that the applicant should provide the Group with the details of the first project planned to use the HES data requested. The Group could then consider whether the consent provided would be sufficient, or if the applicant would be likely to require Section 251 support to proceed; this could also be discussed with the HRA Confidentiality Advisory Group as appropriate. The Group would then need to agree an appropriate process for considering additional projects from this applicant.

260313-f1 - UHB 'Bosch Health Buddies'

Following discussion at the 26 March 2013 meeting, the Group had written to University Hospitals Birmingham (UHB) regarding the 'Bosch Health Buddies' project stating that the consent forms were not felt to be up to the expected standard, and that there were no explicit statements about data linkage and the involvement of University Hospitals Birmingham.

A response had been received from UHB, which had suggested that the two following clauses adequately covered the points raised by the Group:

1. *"City Health Care Partnership (which includes Bosch) may share information with other relevant organisations as a way to assess care provided to patients and the benefits of Telehealth."*

	<p>2. <i>"I give consent for my personal and medical information (in non-identifiable form), to be used for evaluation purposes."</i></p> <p>The Group reiterated previous concerns that the phrasing used was too generic, and did not provide patients with sufficient information to give their informed consent for their data to be linked with HES data. It was suggested that if the applicant felt it would be impractical to obtain additional written consent from all participants, the participants could instead be contacted by telephone by appropriate medical professionals and asked to give verbal consent, with written records kept of the verbal consent given.</p> <p>(c) Decisions Out of Committee</p> <p>No decisions had been made out of committee.</p>
220513-d	<p>Data Linkage Service (MRIS) Applications</p> <p>It was noted that the applications for this meeting had been provided in an updated format in order to be consistent with other documents across the Data Linkage Service. The Group were asked for their feedback on this format change, and one comment given was that it would be helpful if the Comments section were moved to earlier in the document. It was suggested that additional feedback could be provided once the new format had been used for further meetings.</p> <p><u>MR1322: Cardiac Catheterisation In Pulmonary Hypertension</u></p> <p>This application requested cause of death data to use for clinical audit by doctors within the clinical care pathways of the patients. It was noted that the applicant already had access to the other data required for the audit, such as date of death, and so only cause of death was requested. The Group agreed to approve this request.</p> <p>Outcome: Approved</p> <p><u>MR1308: Sentinel Stroke National Audit Programme (SSNAP)</u></p> <p>This Group were notified that this audit had received Section 251 approval and would proceed.</p>
220513-e	<p>Any Other Business:</p> <p>The Data Linkage Service had proposed to provide a bridging file that would allow customers to link any HES data they held with any MHMDS data that they might also hold. CQC had been the first customer to request this bridging file, as they held both identifiable HES data and sensitive MHMDS data. It was noted that CQC had described the intended purpose for the linked data, and that this differed slightly from the original purpose for which the data was held.</p> <p>The Group were asked for their opinion on the provision of this bridging file to organisations that held HES and MHMDS data. It was suggested that the data sharing agreement between the HSCIC and any customer receiving the bridging file would need to be updated to ensure the data linkage was included. The Group agreed that when a customer requested this bridging file, the Group should be provided with a summary of how the linked data would be used and any changes from the original purpose for which data was provided. It was suggested that this could later be considered by Chair's action, but that initial applications should be brought to a full DAAG meeting.</p>

	It was agreed that the CQC request would be circulated to the Group.
220513-f	Date of Next Meeting: Thursday 27 June 15:00 – 16:00

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
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. (Update: Clare Sanderson to contact the HRA CAG secretariat to request that this be included on the agenda for the next CAG meeting)	Clare Sanderson
260712-f1 (ongoing)	Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents. (Update: Guidance circulated to DAIS team for comments.)	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
240413-c2 (ongoing)	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. (Update: Email to be drafted.)	Mark Davies