Data Access Advisory Group

Minutes of meeting held 30 October 2012

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

In attendance: Tom Latham, Chris Quinn, Diane Pryce, Susan Milner, Frances Hancox (Secretariat), Xanthe Hannah (item 301012-d only)

Apologies: None

301012-a	**Welcome** Mark Davies welcomed everyone to the meeting.
301012-b	**Minutes of the Previous Meeting** The minutes of the previous meeting, 3 October 2012, were ratified.
301012-c	**Matters Arising** **(a) Overview of Outstanding Actions** *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.* It was noted that Louise would now be leading an organisation-wide piece of work on data sharing agreements, and that she would share further details of this work at a future DAAG meeting. *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.* This action was agreed to be ongoing. *260712-f1: Diane Pryce and Louise Dunn to look into finding a technical solution for sharing DAAG documents.* It was noted that this action could be subsumed by other work planned within the Information Centre, but that the individual involved in this work was not yet in post. *031012-f1: Clare to circulate the draft Code of Practice to DAAG members for feedback.* The draft was sent to the Secretariat for circulation to DAAG members. Work on the draft was reported to be ongoing, but members would be welcome to provide comments on the current draft. The deadline for approval of the Code of Practice would be 1st April 2013. **(b) Overview of Outstanding Applications** <u>031012-a: University Hospitals Birmingham</u> This application had been discussed at the 3 October 2012 meeting, and had been approved subject to the applicant informing patients of the use of HES data and the involvement of the

	HSCIC in this study. Confirmation of this had not yet been received, but the customer was reported to have completed the IG Toolkit satisfactorily. OC/HES/024: Department of Health Sciences, University of York This applicant had returned a completed information security assurance form, but there had been problems with some of the links provided in this document and an updated form had been requested from the applicant. It was noted that Dawn Foster would be reviewing this form. MR1304: A phase III study to assess the effect of Ianreotide Autogel 120 mg on tumour progression free survival in patients with non-functioning entero-pancreatic endocrine tumour This study would be taking place abroad, and had been shared with DAAG members for information. It was noted that the applicant had now agreed to use information available from public records, and would not be going forwards with a DAAG application at this time.
301012-d	**HES Extract Service** Xanthe Hannah (Data Services Section Head, HSCIC) gave an overview of the HSCIC's HES Extract Service, which provides bespoke and monthly managed extracts of HES data to customers. The HES Extract Service had recently become an in-house service at the HSCIC, having previously been provided by Northgate Information Solutions. Xanthe requested advice regarding whether it would be appropriate to provide customers with the option of receiving a standard, pre-formatted file in order to streamline the existing extract service. It was explained that the benefits of this would be the ability to provide data much more quickly as well as standardising what customers received, and it was noted that no sensitive data fields would be included in the standard extract. The Group were in agreement that this could proceed, subject to approval at HSCIC management level.
301012-e	**HES and MHMDS Applications** 301012-a: University of Edinburgh This application requested data on falls for people over the age of 65, specifically the type of fall, place of occurrence and the patient output area. The applicant intended to compare this data with the index of multiple deprivation, with the aim of identifying geographical variations and factors that may affect falls. It was noted that the applicant would only publish results in a highly aggregated form and would be asked to suppress small numbers prior to publishing as a condition of the Data Re-Use Agreement covering the sharing of the HES data. Some queries were raised about the methodology of this study, but it was agreed that discussing this would be outside the remit of the Data Access Advisory Group. **Outcome:** Approved 301012-b: BMJ Publishing Group Ltd This applicant had requested HES data with the intention of undertaking individual projects for organisations such as NHS providers, commissioners, private sector providers and charities; the applicant would analyse the data on behalf of these organisations and provide them with a summary of their findings. The applicant indicated that their main focus would be helping clinicians understand activity data, but other potential projects listed included healthcare planning, clinical audit, benchmarking, performance improvement, medical research and policy development. It was noted that this would have some parallels with existing services

	offered by Dr Foster Intelligence, CHKS and BUPA Health Dialog; however, the Group also noted that CHKS did not receive sensitive HES data. There were some concerns that this application did not provide sufficiently specific reasons for why sensitive data would be required, but instead gave a generic 'blanket' reason to cover a wide range of potential projects. It was noted that for similar previous applications from University Hospitals Birmingham and BUPA the applicants had been required to specify exactly how data would be used, as well as what protocols would be in place around access to sensitive data, but that similar governance controls had not been included in this application. The Group agreed that they would in principle support this application proceeding, but that they could not approve it at this time without more specific information on why sensitive data was required and what it would be used for, as well as assurance that appropriate information governance controls would be in place. A further query was raised regarding small numbers, and whether small numbers would need to be suppressed if an organisation were only provided with their own data. **Action:** 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. **Outcome:** Not approved
301012-f	**NHS Central Register – MRIS Applications** <u>MR1277: Trial of probiotic administered early to prevent infection and necrotising enterocolitis (PiPS)</u> This small flagging study had requested cause of death data, as well as PCT exits and re-entries. There was a brief discussion of the fact that PCTs would soon be replaced by CCGs, and whether it would be appropriate to provide applicants with General Practice codes instead; it was agreed that PCT data should be provided for the present, but that this would be replaced by CCG data in the future. It was noted that the consent form provided had used a slightly out-dated form of words, but that as recruitment for the study had begun in 2010 the applicant had taken current advice regarding consent wording at the time this was drafted. It was agreed that as recruitment had almost finished, the applicant would not be required to update the consent wording. **Outcome:** Approved <u>MR1291: Clinical Cohorts in Coronary disease Collaboration (4C)</u> The Group noted that this application had previously been discussed at the DAAG meeting on 29 May 2012, where it had been agreed that the patient information leaflet was inadequate and contradicted the consent form. The applicant had been asked to amend this; it was noted that this had been done and the application now contained the recommended wording. There was a brief discussion around whether the applicant should be required to re-contact individuals who had already consented to participate using the earlier version of the consent materials, but it was agreed that this would not be required. **Outcome:** Approved

301012-g	**Any Other Business:** An update was given on Dame Fiona Caldicott's Information Governance Review and it was noted that representatives from this review, including Dame Fiona, had met with Information Centre staff to discuss key issues.
301012-h	**Date of Next Meeting:** Thursday 29 November 11:00 – 12:00

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
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.	Tom Latham