NHS
Health Research Authority

Minutes of the meeting of the Confidentiality Advisory Group

25 February 2016 at 10am at Barlow House, Manchester M1

Present:

Name	Capacity
Dr Mark Taylor (CAG Chair)	Chair, items 2a, 2b, 3a.
Dr Patrick Coyle (vice-Chair)	Chair, items 3b, 3c.
Dr Tony Calland	
Professor Jennifer Kurinczuk	
Dr Rachel Knowles	
Dr Lorna Fraser	
Ms Hannah Chambers	
Mr C. Marc Taylor	

Also in attendance:

Name	Position (or reason for attending)
Ms Joan Kirkbride	HRA Director of Operations, items 1, 3.
Ms Natasha Dunkley	Head of Confidentiality Advice Service, item 3.
Mr Christopher Ward	Senior Confidentiality Advisor.
Dr Natalie Banner	Policy Officer at the Wellcome Institute, item 4.
Ms Amanda Hunn	HRA Engagement and Policy Manager, item 4.

1. INTRODUCTION, APOLOGIES AND DECLARATIONS OF INTEREST

Apologies were received from Mr David Smallacombe.

There were no declarations of interest.

2. ITEMS FOR CONSIDERATION

a. Discussion of position paper for SABRE, ECC 8-02(FT5) 2010

Purpose of application

This project is a follow-up of a unique cohort of 4,858 people of South Asian, African Caribbean and European origin who were aged 40 to 69 and living in northwest and west London when first studied. The South Asian and African Caribbean participants are all first generation migrants to the UK. The study set out to examine the association between insulin resistance and cardiovascular risk in people of European, South Asian and African Caribbean origins who were living in West London.

The 3,400 surviving participants are now aged between 65 and 98. They underwent very detailed clinic profiling at baseline, at 20 years and a third wave of follow-up is currently in progress at 25 years.

Support was sought in order to permit access to cancer registration and mortality data in order to link to mortality data. A recommendation for class 1, 2, 4 and 6 support was requested to cover access to these datasets.

Query received

The applicant had conducted a large pilot study which includes consent for data linkage, in order to assess loss to follow-up and non-response.

As the researchers were writing to participants to inform them of the follow-up and to invite their participation (particularly in terms of attending clinic and completing questionnaires), it seemed appropriate to should inform them of and ask for consent for the data linkage components of the study. Consent had not previously been sought for data linkage.

For this pilot they wrote to 773 people who had attended our clinic at visit 2. Of these people, who should be considered highly motivated participants, they received positive responses from 65%, negative responses from 9%, and no response from 17%. The address was incorrect for 1% and a further 10% requested time to consider/to be contacted again in the future. This last group is likely to fall into the 'non-response' category, bringing the total estimated non-response rate in this group to approximately 25%. This non-response rate is unexpectedly high and is likely to be related to ill health, particularly cognitive impairment.

With a 17-25% non-response rate already demonstrated in this pilot study of a highly motivated group, the researchers considered that they had reasonable grounds for assuming a much higher non-response rate in the rest of the cohort (2070 survivors), this posing an undoubted risk to the scientific integrity of the follow-up study.

The researcher sought guidance, with specific reference to the ICO guidance, from CAG as to the best mechanism for capturing as much information as possible from this valuable cohort.

Confidentiality Advisory Group Advice

For those participants who have already been approached for consent as part of the pilot, support under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process patient identifiable information without consent would not be possible. This is in line with principles established in the 'Managing non-response guidance' published here: http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/

However, for the remaining cohort, there would potentially be grounds to seek future support for any participant who did not return the questionnaire or who did not actively opt-out of data linkage on returning the questionnaire. Members recommended that, if this mechanism is adopted, the opt-out should be included in the body of the questionnaire. Sufficient patient notification with regards to the data-linkage should also be included with the questionnaire.

Members advised that consent for future data linkage should be sought from those who attend the clinic as this provided reasonable opportunity for consent to be obtained. As consent constitutes a practicable alternative it was identified that it would be unlikely that support could be provided for this sub-cohort.

It was noted that support would not be required for those participants who provide consent for data linkage in clinic. However the group did recommend that the applicant seek guidance from the HSCIC with regards to the consent wording to ensure that this will satisfy the HSCIC internal advisory group's current requirements.

It was advised that an amendment or new application to a Research Ethics Committee (REC) to cover the changes to the study design and updated participant information would also be required; precise requirements should be discussed directly with the REC.

b. Amendment to SABRE, ECC 8-02(FT5) 2010

Purpose of application

This project is a follow-up of a unique cohort of 4,858 people of South Asian, African Caribbean and European origin who were aged 40 to 69 and living in northwest and west London when first studied. The South Asian and African Caribbean participants are all first generation migrants to the UK. The study set out to examine the association between insulin resistance and cardiovascular risk in people of European, South Asian and African Caribbean origins who were living in West London.

The 3,400 surviving participants are now aged between 65 and 98. They underwent very detailed clinic profiling at baseline, at 20 years and a third wave of follow-up is currently in progress at 25 years.

Support was sought in order to permit access to cancer registration and mortality data in order to link to mortality data. A recommendation for class 1, 2, 4 and 6 support was requested to cover access to these datasets.

Confidential patient information requested

Access was requested to name, NHS number, date of birth, date of death, gender, postcode (at unit level), and ethnicity.

Amendment request

Support was requested for a further HES extract to April 2016 in order to bring the hospital admission data up to date for this study's long-standing cohort. The researchers last received this information in 2011.

Participants who have asked to be removed from the study or who have indicated that they do not wish for data linkage to their records will be excluded (by pseudonymised study ID) from the requested dataset.

Confidentiality Advisory Group Advice

The amendment requested was considered at the CAG meeting on 25 February 2016 in conjunction with separate advice request (item 2a on the agenda). This advice request described a pilot which had recently been conducted. This pilot included consent for data linkage, in order to assess loss to follow-up and non-response

The Group agreed that the amendment was in the public interest and were generally supportive in principle, subject to the following points:

1. Members recommended that the applicant consider further public engagement, especially before submitting any further applications for support.
2. The committee confirmed that section 251 support for the data-linkage set out in the amendment would not apply to those participants who have already been approached for consent as part of the pilot
3. Concern was raised as to the extent to which the information sheet (11/5/15) sufficiently explained past and future data-linkages, and process whereby an objection may be expressed. It was specifically recommended that the phrase 'cannot be linked' on page 11 be changed to read 'held separately and is not linked'.
4. It was noted that the explanation of HSCIC acronym was incorrect in the consent form (post), version 1.1, 21/02/14.

Confidentiality Advisory Group conclusion

In line with the considerations above, the Confidentiality Advisory Group agreed that the minimum criteria under the Regulations appeared to have been met for this amendment, and therefore advised recommending support to the Health Research Authority subject to a response to the conditions below.

Specific conditions of support

5. The data-linkage set out in the amendment does not apply to those participants who have already been approached for consent as part of the pilot
6. Receipt of revised information sheets setting out past and future data-linkages, and the process whereby an objection may be expressed.
7. Confirmation of a favourable opinion from a Research Ethics Committee for the amended documentation.

Response to points 1 and 2 above will be reviewed by the Chair and the reviewers who considered the amendment at the meeting.

3. NEW APPLICATIONS – Research

a. A Comparative Study of Hospital Discharge for Homeless People; 16/CAG/0021

Purpose of application

This application from King's College London/UCL (data controller and processor to be confirmed as per specific conditions of approval section) set out the purpose of establishing the ways in which Specialist Integrated Homeless Health and Care (SIHHC) services are being developed and used to facilitate hospital discharge in England. The study also aims to examine the impact this is having on quality of care for homeless people admitted to hospital and whether this care can help prevent readmission to hospital shortly afterwards.

The first work package (WP1 –for which support is not requested) seeks to gain an informed understanding of the ways in which SIHHC services are being developed and implemented to facilitate hospital discharge in England and the impact this is having on quality of care and organisational outcomes such as the prevention of readmission to hospital. For this work package, local service providers will be asked to identify and nominate potential participants.

The second work package (WP2, for which support is requested for datasets 1, 3, 4, and 5) is a data linkage and health economic analysis work package that will work with twenty sites across England where homeless patients have been admitted to hospital. A cohort of homeless people who have used specialist discharge scheme will be compared to a cohort of homeless people who have not used such provision. The study will also compare patient's hospitalisation history before and after engagement with specialist services. Analysis will also be undertaken to understand whether the outcomes are a factor of homelessness specifically or are tied to deprivation.

A recommendation for class 1, 2, 4, 5, and 6 support was requested to cover the activity specified in the application for work package 2, datasets 1, 3, 4, and 5.

Confidential patient information requested

Access was requested to:

- Dataset 1: Data from homeless healthcare users, as outlined in SIHHC data variables in the 'Data Flow Diagram' document, including forename, surname, aliases, date of birth, sex, address, contact number(s), hospital of admission, date of hospital admission, nationality, ethnicity, and NHS number; from study fieldwork sites: November 2013 to a maximum of November 2016
  At each site the research team will create a unique study identifier for each record for the service provider. The data requested for the study will then be securely uploaded and processed at University College London (UCL). The data will be stored and cleaned. Identifiable information required by the Health and Social Care Information Centre (HSCIC) for the linkage to Hospital Episode Statistics/Office for National Statistics (HES/ONS) will at this point be transferred to HSCIC.
  When HSCIC have confirmed that the list is clean, and linkage to HES has been completed, the researchers will de-identify all data.

- Dataset 3: Data from homeless healthcare users, as outlined in SIHHC data variables in the 'Data Flow Diagram' document, including forename, surname, aliases, sex, address, and contact number(s); from Find and Treat Service: November 2008 to November 2016.

The data requested for the study will then be securely uploaded and processed on the data safe haven at UCL. The data will be stored and cleaned. Identifiable information required by HSCIC for the linkage to HES/ONS will at this point be transferred to HSCIC. When HSCIC have confirmed that the list is clean, and linkage to HES has been completed, the researchers will de-identify all data.

- Dataset 4: Personal Demographics Service (PDS) data from homeless healthcare users, including date of hospital admission, date of hospital discharge, date of hospital appointment, and date of death: November 2008 to November 2016.
  The HSCIC will use data within PDS to provide missing NHS numbers for the two previous datasets. The research team will not at any point have access to these NHS numbers, which will be used to improve the linkage of data to HES.

- Dataset 5: HES ONS mortality data from homeless healthcare users and a geographically comparable and representative sample of lowest quintile of deprivation population in HES (based upon the index of multiple deprivation) equal in size to the Find and Treat dataset during the hospital admission study period: November 2008 to November 2016.
  This data will have already been de-identified by the HSCIC.

Confidentiality Advisory Group advice

Public interest

Members agreed that projects of this type were clearly in the public interest.

Practicable alternatives

Members considered whether a practicable alternative to the disclosure of patient identifiable data without consent existed, taking into account the cost and technology available in line with Section 251 (4) of the NHS Act 2006.

- Feasibility of consent

The group was content that it would be unfeasible to seek consent from such a large group, especially one which posed such specific difficulties in terms of seeking consent. Seeking consent would introduce a bias into the study which would significantly lessen its value.

However, for work package 2, dataset 2, where consent was being sought the members requested further clarification from the researcher. The researcher had confirmed that anyone who dissented from inclusion in this part of the study would be excluded from data-collection in the remaining work packages, but had requested that non-responders be included.

The members noted that this programme of work included two stages, contact with the care worker and with the researcher. In relation to this, the following was requested of the research team:

1. That they confirm that those who dissent from inclusion when contacted by the care worker would be excluded from data-collection in the remaining work packages, as well as those who dissent from inclusion when contacted by the researchers.
2. That, as excluding non-responders most unambiguously reflects the guidance from the ICO, they justify why it is necessary to include this cohort in the data-collection for the remaining

work packages. In particular, this justification should make clear how the purposes for which consent would be sought (and in relation to which there would be non-response) may be distinguished from the purposes for which support is sought. It should also clarify which stage of non-response (care worker and/or research team) they are seeking support for.

- Use of anonymised/pseudonymised data

It was agreed that data was de-identified in this study design as soon as was reasonably practicable.

Justification of identifiers

The members were content that the number of identifiers requested, though large, was the least required in order to answer the research question posed.

Additional points

The group commended the research team on the mechanisms for patient notification and objection included in the research proposal, and for the extent to which they had engaged in patient and public involvement.

Confidentiality Advisory Group advice conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met and that there was a public interest in projects of this nature being conducted, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Confirmations required

1. The research team should confirm that those who dissent from inclusion when contacted by the care worker (as part of work package two, dataset 2) would be excluded from data-collection in the remaining work packages, as well as those who dissent from inclusion when contacted by the researchers.
2. The research team should justify why it is necessary to include the non-response cohort (from work package two, dataset 2) in the data-collection for the remaining work packages. This justification should also clarify which stage of non-response (care worker and/or research team) they are seeking section 251 support for.

Once provided, the response to the confirmations will be reviewed by the chair and original reviewers.

Specific conditions of support

1. Confirmation as to who will be acting as Data Controller and as Data Processor(s) must be provided.
2. CAG receipt of a favourable opinion from a Research Ethics Committee.
3. Confirmation from the IGT Team at the Health and Social Care Information Centre of suitable security arrangements via Information Governance Toolkit (IGT) submission.

Once provided, the response to the conditions will be reviewed by the Confidentiality Advisory Team.

b. Feasibility of an impact analysis of a tool to predict abuse; 16/CAG/0022

Purpose of application

This application from Cardiff University set out the purpose of assessing the Feasibility of using an impact analysis tool to predict abuse. Abusive Head Trauma is the leading cause of death and disability in young children who have suffered abuse; however it can be difficult to tell if a head injury is the result of abuse. The researchers have created a tool to facilitate clinicians in this judgement. They will collect:

1. The probability assessment provided by the tool;
2. The probability assessment of the clinician pre and post use of the tool [with consent of the clinician];
3. The child protection decisions of the clinician pre and post use of the tool [with consent of the clinician, s251 is not sought for this]; and
4. Whether the child was deemed abused or not.

Support for activities 2 and 3, above, was not requested.

The researchers will identify cases by attending child protection and radiology peer review meetings. The notes will then be consulted to discover the six clinical indicators the tool uses as the basis for its prediction (seizure, apnoea, long-bone fracture, rib fracture. Head/neck bruising, and retinal haemorrhages). These cases will be given a study identifier and the link between study identifier and NHS number will be retained separately by the CI to allow data-linkage for follow-up.

Clinicians will then be approached to take part in the study. If they agree they will be asked to make an assessment pre and post use of the tool, and what their child protection decisions are pre and post use of the tool.

The research student will follow up each case to determine abuse/non-abuse. This will be determined by the decision of the multidisciplinary assessment conducted by the clinicians, social workers, police, and other relevant agencies at a strategy meeting, case conference, or child death case review meeting. These outcomes will be determined from the children's case notes or child protection peer review meeting. Abuse will also be confirmed if witnessed or admitted to. Where abuse is not suspected (and therefore no multidisciplinary assessment meeting is held), the clinician will be followed up after six months to determine if they have any child protection concerns – unless there is an independently witnessed accidental injury or confirmed underlying organic disease. Follow up data will be obtained from health visitor records.

In addition, they will collect quantitative process data (e.g. the number of eligible patients) and qualitative process data (e.g. researcher observations, structured field notes arising from informal conversations and stakeholder organisations.)

A recommendation for class 1 and 6 support was requested to cover the activity specified in the application.

Confidential patient information requested

Access was requested to access case note data (NHS number, name, and date of birth) relating to head trauma in fifty 0—3 year olds presenting with head injury; from Bristol Royal Hospital for Children and University Hospital Wales.

Confidentiality Advisory Group advice

Public interest

Members agreed that studies of this type had potential medical benefit and were in the public interest.

Practicable alternatives

Members considered whether a practicable alternative to the disclosure of patient identifiable data without consent existed, taking into account the cost and technology available in line with Section 251 (4) of the NHS Act 2006.

- Feasibility of consent

The group was content that it was impracticable to seek consent for access to the data used in this study as the parents of abused children were likely to withhold consent which would have the consequence of invalidating the study.

- Use of anonymised/pseudonymised data

Members agreed that the interests of consistency of information and to minimise the number of places data is held meant that it was impracticable to ask members of the care teams to collect and de-identify data

Justification of identifiers

The members concluded that the identifiers requested were necessary and appropriate to achieve the purposes.

Exit strategy

The group noted that the researcher had confirmed via e-mail that all identifiable data will be destroyed not less than three months after the last follow up and this was confirmed to be satisfactory.

Patient notification and objection

Members were content that no notification was, in this specific instance, preferable to a partial notification, as notification could seriously bias the outcomes and potentially place abused children at risk should their parents decide to not to seek care, or seek care elsewhere, as a result of the notification.

As such, it was agreed in this specific instance that the usual condition to provide patient notification materials would go against the public interest due to the reasons cited above.

Additional points

The group was unclear how and by whom data would be extracted from the Health Visitor Records. Clarification on this point should be provided.

The members were of the opinion that greater public involvement could have taken place through organisations working in the field of safeguarding children prior to application and recommended that this take place before the larger follow-up study is conducted. An update on this participation should be provided at time of annual review.

The group requested clarification as to what data would be recorded on the i-pad and what security was in place for this information.

Confidentiality Advisory Group advice conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met and that there was a public interest in projects of this nature being conducted, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Clarifications required

3. Clarification is required as to what data will be recorded on the i-pad and what security will be in place for this information. What organisation is responsible for the security and management of data on the i-pad?
4. Clarification should be provided as to how and by whom data would be extracted from the Health Visitor Records.

Specific conditions of support

1. An update on patient and public involvement is to be included in the first annual review submitted to CAG.
2. CAG receipt of a favourable opinion from a Research Ethics Committee. **This had already been received, letter dated 21 January 2016**
3. Confirmation from the IGT Team at the Health and Social Care Information Centre of suitable security arrangements via Information Governance Toolkit (IGT) submission. **Confirmation had already been received by e-mail dated 24 November 2015, version 12, 97%**

Once provided, the response will be reviewed by the chair and original reviewers.

c. The UK Renal Registry: a research database; 16/CAG/0020

Purpose of application

This application from The UK Renal Registry set out the purpose of:

1. Conducting research on an existing non-research database (reference: PIAG 1-07c/2004).
2. Adding additional data-linkages for the purpose of research.

The proposed research would cover:

- Epidemiology, including the reporting of disease rates, treatment rates and outcomes and associations between these and practice patterns.
- Linkage to existing databases.
- Providing end-points to quality improvement initiatives, including before-and-after studies and stepped wedge cluster randomised trials in which an intervention is being rolled out, but the order in which that happens at a unit level is randomised.
- Providing end-points to other previously recruited cohort studies and trials, providing these already have the necessary permissions and consent.

A recommendation for class 1, 2, 4, 5, and 6 support was requested to cover the activity specified in the application.

Confidential patient information requested

The following information is already collected under reference PIAG 1-07(c)/2004: name, address, postcode, date of birth, NHS number, hospital number, date of death, and data from NHS Blood and Transplant relating to kidney transplantation (such as transplant waiting list status and kidney donor characteristics).

In England, reporting to the database is written into the national service specification for providers of dialysis services and is mandatory. Reporting by sites in Wales, Scotland and Northern Ireland is voluntary. Since 2007, the UK Renal Registry has had 100% coverage of the UK.

Support exists to receive data from renal IT systems and Laboratory Information Management Systems. An amendment has been submitted to PIAG 107c/2004 to cover linkage with HES, Public Health England, and ONS.

The following additional linkages for research were requested, using the identifiers listed above: the Clinical Practice Research Datalink, the Intensive Care National Audit and Research Centre, the National Chronic Kidney Disease Audit, the National Diabetes Audit, the Sentinel Stroke National Audit Programme, the National Joint Registry, the National Hip Fracture Registry, the National Institute for Cardiovascular Outcomes Research.

Confidentiality Advisory Group advice

Members agreed that projects of this type could be in the public interest but the application raised a number of issues as set out below.

The Group considered the application in two parts:

1. **The conduct of research on an existing non-research database (reference: PIAG 1-07c/2004).**

The Group was supportive, in principle, of the addition of a research purpose to cover the use of currently held data. Members agreed that the use of the identifiers already approved for a non-research purpose was justified in the research context. However concerns were expressed over the general governance arrangements.

The committee were unclear how research applications will be assessed. The applicants were advised to examine the criteria used by other research databases and ensure that their mechanism follows similar standards or explains deviations, and includes a risk assessment.

The applicant should also clarify how the information released to researchers will be de-identified.

The use of anonymised/pseudonymised data

Members considered whether a practicable alternative to the disclosure of patient identifiable data without consent existed, taking into account the cost and technology available in line with Section 251 (4) of the NHS Act 2006.

The researcher confirmed (in the advice form) that it would be possible to reduce date of birth to age or month-year of birth and could reduce postcode to a higher level.

The application had also stated that all analysis files currently leaving the main UK Renal Registry database are pseudonymised, with identifiable information removed and replaced by a registry number. However it appeared that some items of identifiable information (date of birth, postcode, gender, and ethnicity) do remain in the analysis file. Members noted that support does not allow for the onward release of identifiable data unless the onward applicant has been granted support or there is another legal basis. A separate letter on this matter will be issued and it will be advised that a response on this matter should be provided as a priority.

Where an applicant for data wishes to use identifiable information from the Renal Registry for the purpose of research, a new CAG and REC application would be required in each instance.

Feasibility of consent

The Group was content that the large numbers of patients included in the existing database made consent for research impracticable.

Patient Notification

It is a principle of support that suitable information is reasonably provided to the cohort where feasible to enable them to understand the uses of their data, and to provide a mechanism to enable patient objection to be respected. The Group did not consider that sufficient patient notification was included in the information sheet provided. In particular it should be clearly explained what data will be accessed by whom, and what data-linkages will occur if they do not opt out of having their data used for research.

The applicant was advised to refer to the ICO *Privacy Notices Code of Practice*: https://ico.org.uk/media/for-organisations/documents/1610/privacy_notices_cop.pdf

Patient Objection

In line with the above, the mechanism for patient objection should be explained more clearly (e.g. through the use of examples) in the patient notification material.

It was advised that patient objection should be split for clarity. As there is the possibility that future support will be sought to allow additional linkages to other databases, patients should be able to:

- Opt-out of the use of data collected and/or linked under the existing approval (PIAG 1-07c/2004) being used in research.
- Opt-out of future data-linkage.

2. **Additional data-linkage for research over and above that already conducted with support.**

Members were concerned as to whether the additional data-linkages requested, over and above those already supported, were justified given that the same outcomes could potentially be achieved using existing resources (e.g. CPRD) in a de-identified manner. In particular, members could not identify sufficient evidence to provide assurance that the safeguards in place are equivalent to those in place for the databases they plan to link to.

Confidentiality Advisory Group advice conclusion

In line with the considerations above, the CAG agreed that further information would be required from the applicant in order for a recommendation under the Regulations to be provided.

Further information required

The committee advised that they would not be able to support the application for future data-linkage until support to add research as an additional purpose with regards to the existing dataset was in place.

Once this support is in place a second new application could be made, in line with the discussion above, to allow further linkages. Any future application of this type should justify why it is necessary to do this and why similar results could not be achieved using existing datasets, thereby limiting the extent to which identifiable information would be linked across multiple resources.

The following information should be provided to allow the CAG to continue their consideration of the application:

1. The information sheets should be revised with a clear avenue for patient objection provided.
2. Patient objection should allow patients to object to the use of existing data and linkages being used in research and, separately, to the use of future linkages for research.
3. The researchers should clarify how they intend to de-identify the information released to researchers.
4. The applicants should examine the criteria used by other research databases and ensure that their mechanism is commensurate (and includes a risk assessment).
5. Confirmation that support to add additional data linkages, over and above those already supported under PIAG 1-07c/2004, would be made in a new full submission to the Group.
6. Provision of a favourable opinion from a Research Ethics Committee.
7. Confirmation from the IGT Team at the Health and Social Care Information Centre of suitable security arrangements via Information Governance Toolkit (IGT) submission.

4. **Presentations**

   a. **Natalie Banner: Wellcome research on public attitudes to commercial use of health data.**

Following Chair invitation, Ms Banner provided a presentation to members on the outputs from the work undertaken to assess public attitudes to the commercial use of health data. This presentation

was not minuted but the slides would be circulated to all members. It was noted that these should be treated as confidential until the report to which they refer is released on 8 March 2016.

b. Amanda Hunn: PPI engagement presentation.

The presentation delivered by Ms Hunn set out to explain the work the Health Research Authority (HRA) is undertaking with regards to Patient and Public Engagement, and to stimulate discussion as to how the HRA and CAG could work together in this field. Ms Hunn confirmed that four workshops had been conducted in England and Wales looking at:

- Access to notes and the role of the research nurse.
- Consent to approach.
- Proportionate consent.

Guidance is presently being developed on the identification and recruitment of participants into health research. In addition, work is ongoing within the HRA on the provision of information to participants; current thinking is that a layered approach to this is most appropriate.

The group considered ways in which they could engage better with patients and the public. They agreed that it would be good to include a section on the website setting out the aspects CAG considers when providing a recommendation. It was acknowledged that much of this information was already online but that it is hard to know what to communicate given the lack of context available to the public. Given the public sensitivities, shown in both presentations, to the provision of data to commercial organisations, CAG should carefully consider how best to be transparent in this area – with particular reference to explaining the benefits that can arise from this.

Members were updated that there will be two workshops run in conjunction with the University of Sheffield. Members' views on this would be welcomed.

5. CHAIR'S REPORT

The report dated January 2016 (amended) was provided to the group for information.

In discussion arising from the Chair's Report it was agreed that in future minutes would be circulated to all members now that members attended different meetings at different times.

6. MINUTES OF THE MEETING HELD ON 28 JANUARY 2016

Some corrections were noted. Subject to these changes, the minutes were agreed to be a true record of the meeting of the 28 January 2016.

7. ANY OTHER BUSINESS

No other business was noted.

Signed – Chair	Date
Signed – Confidentiality Advice Team	Date