

# Data Access Advisory Group (DAAG)

## Minutes of meeting held 13 December 2016

**Members:** Joanne Bailey (items 1 - 2.4 only), John Craven, Dawn Foster, Eve Sariyiannidou, Peter Short, James Wilson

**In attendance:** Noela Almeida, Anomika Bedi, Chris Carrigan, Garry Coleman, Dave Cronin, Louise Dunn, Nicola Fear, Frances Hancox, Dickie Langley, Paul Nibblet, Vicki Williams, Robyn Wilson

**Apologies:** None

<p>1</p>	<p><b>Welcome and introductions</b></p> <p>It was agreed that as Joanne Bailey would leave the meeting after item 2.4, James Wilson would act as chair for the remainder of the meeting.</p> <p><b>Declaration of interests</b></p> <p>John Craven declared a conflict of interest in the King's College London application (NIC-25051-V0K1X) due to being a student with that organisation. In addition it was noted that Joanne Bailey, Eve Sariyiannidou and James Wilson had previously worked on an advisory group with an individual involved with the University of Surrey application (NIC-203503-X7K8K). Nicola Fear, who was present as an observer, declared a working relationship with the King's College London applicant (NIC-25051-V0K1X) and had undertaken a doctorate at the University of Oxford (NIC-148322-TMFVQ) some years previously. It was also noted that Anomika Bedi, who was present as an observer, had previously been a student at King's College London (NIC-25051-V0K1X).</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 6 December 2016 meeting were reviewed and agreed as an accurate record.</p> <p>Action updates were provided (see table on page 11).</p> <p><b>Out of committee recommendations</b></p> <p>The following applications had previously been recommended for approval subject to caveats, and it had been confirmed out of committee that the caveats had now been met:</p> <ul style="list-style-type: none"><li>• NIC-383345 Royal College of Surgeons</li><li>• NIC-43496 NHS West Kent CCG</li><li>• NIC-382718 London School of Hygiene and Tropical Medicine</li><li>• Group application for 7 CCGs (GA01-CON-SC) - <i>NIC-65339 NHS West Hampshire CCG only</i></li><li>• NIC-147931 University of Oxford (AgeX)</li><li>• NIC-161339 University College London</li></ul>
<p>2</p>	<p><b>Data applications</b></p>

**2.1**Group application for 5 Local Authorities<sup>1</sup> - PCMD (Presenter: Robyn Wilson)

**Application:** This was an application for access to Office for National Statistics (ONS) births and deaths data via the Primary Care Mortality Database (PCMD). The application was based on an earlier application for 81 Local Authorities, which had been considered at the 8 November 2016 DAAG meeting and recommended for approval subject to caveats; it was noted that application had subsequently been updated to include only 79 Local Authorities. It was confirmed that the five Local Authority applicants for this application had achieved satisfactory reviewed IG Toolkit scores and had provided a privacy notice link.

**Discussion:** DAAG noted that the application summary included the minutes from the application that had been considered on 8 November, and suggested that it would have been helpful if this had included a response for how each caveat had been addressed within this application.

There was a discussion of the process to review privacy notices and it was confirmed that this was based on a revised template created by the IG ISA team within NHS Digital. Some concerns were raised that the current privacy notices would not meet the minimum criteria agreed for CCGs requesting data, but it was acknowledged that those criteria had been agreed for a specific purpose and were currently under review. It was agreed that as with the previous application, the data sharing agreement would need to include appropriate special condition wording to cover the need for the applicant to amend their privacy notice within twelve weeks, to reflect the work that would take place between the applicant organisations and NHS Digital. DAAG were informed that if applicants did not take reasonable steps to address problems with their privacy notices within this period then it was anticipated that their access to data could be halted, and it was confirmed that DAAG would be updated on progress once twelve weeks had passed.

The DPA registrations for the applicant Local Authorities were noted and DAAG noted that in some cases these did not seem to appropriately describe the use of healthcare data for public health purposes.

**Outcome:** Recommendation to approve, subject to:

- Including appropriate special conditions wording around the process for applicant organisations to update their privacy notices within twelve weeks.

DAAG advised that Stockport Council, Salford City Council and Bath & North East Somerset Council should update their DPA registration wording to more clearly refer to processing data for public health purposes.

It was agreed these caveats would be reviewed out of committee by the Director for Data Dissemination.

**2.2**University of Surrey – London Life Sciences Prospective Population (LOLIPOP) study (Presenter: Jen Donald) NIC-203503-X7K8K

**Application:** This application for pseudonymised Hospital Episode Statistics (HES) linked to ONS mortality data for the LOLIPOP cohort had previously been considered at a number of DAAG meetings, most recently the 7 June 2016 meeting. Queries had been raised about the legal basis for identifiable data to be shared, as it was not felt that this was covered by the participant consent and it was unclear whether the applicant's section 251 support applied to the consented cohort or to only the control group. The applicant had subsequently contacted HRA CAG, who had clarified that while the section 251 did not apply to the datasets to

<sup>1</sup> NIC-35519-S2R9Y Stockport Council; NIC-37891-V3K0S London Borough of Sutton; NIC-39089-Q7S0Q Bath and North East Somerset Council; NIC-51920-R5F1K Salford City Council; NIC-52264-C5F5F Blackburn with Darwen Borough Council

which consent had been provided by the cohort, it did provide support to allow access to the broader datasets for which consent had not been provided by the cohort. HRA CAG asked for clarification of whether the participant consent covered those proposed data flows that were not covered by the section 251 support..

**Discussion:** DAAG discussed the legal basis for this data flow in consent, and reiterated their previous comments that the consent did not appear to allow for the applicant to receive identifiable data. However DAAG noted that the updated application had provided additional information about the controls that would be in place to ensure that the data provided to the applicant would be anonymised in context, rather than identifiable, and could not be re-identified. It was acknowledged that while the consent materials had not been ideal, they contained wording that would have been considered appropriate at the time and the consent did appear to cover the provision of anonymised data for research purposes. DAAG noted that when they had previously considered this application, the additional information to support the data being considered anonymised in context had not been available. It was also noted that a special condition had been added to the application prohibiting the applicant from attempting to re-identify the data.

DAAG queried whether any new identifiable data would flow into NHS Digital for this application, and if so what the legal basis for this was. It was clarified that the consent cohort had already been flagged and therefore no new identifiers would be required. DAAG asked for the application to be updated to more clearly state this. In addition it was noted that in some places the application referred to data about 'the cohort' without being clear if this referred to the consented cohort or the control group; it was agreed the application wording, and in particular the table of data requested, should be updated to be clear that only data about the consented cohort was requested as part of the current application.

The potential benefits of this study were noted and DAAG noted the fair processing efforts that had been made to keep participants informed about data processing. In addition DAAG noted that the study had a volunteer group with participant representatives, and it was suggested that it might have been helpful to have more information about these participants' support for the ongoing work and planned data processing.

**Outcome:** Recommendation to approve, subject to:

- Updating the table of data requested to be clear that only data for the consented cohort is requested, not for the control cohort.
- Updating the application wording to clarify that the existing flagged cohort will be used, rather than new identifiable data flowing into NHS Digital.

It was agreed these caveats would be reviewed out of committee by the Director for Data Dissemination.

## 2.3

Harvey Walsh Ltd (Presenter: Jen Donald) NIC-05934-M7V9K

**Application:** This application for pseudonymised HES data had previously been considered at the 20 September 2016 DAAG meeting and recommended for approval, for a limited purpose that did not include the use of HES data within the AXON tool. Following the completion of an investigation by NHS Digital into the use of this tool, the applicant had now requested to resume the use of HES data within this tool with clients being able to access aggregated data with appropriate small number suppression. DAAG were informed that the final investigation report was not yet available, but that the NHS Digital SIRO would consider this report as well as DAAG's recommendation before confirming whether or not data could be released.

**Discussion:** DAAG noted that the application referred to 82 distinct projects for which HES data had been used, and confirmation was requested of what proportion of these projects had been solely for NHS family organisations compared to what proportion had involved commercial organisations.

The planned data retention period was queried, as it appeared from the number of data years requested that the applicant would hold more than five years of data. It was confirmed that only a rolling five years of data would be retained at any time, and DAAG asked for the application to be updated to state this more clearly.

There was a brief discussion of the importance of openness and transparency, as it was noted that DAAG had previously advised the applicant to make more information about this use of data available to the general public. It was confirmed that the applicant had published a privacy notice and that further work to improve this was underway with NHS Digital staff.

DAAG discussed the NHS Digital investigation into the AXON tool and noted that although the investigation had completed, the final report was not yet available. It was agreed that if the final report raised any additional concerns of which DAAG had not been made aware for this application, DAAG should be informed and NHS Digital might wish to consider submitting an updated application to DAAG.

**Outcome:** Recommendation to approve, subject to:

- Clarifying a reference to 82 projects carried out using data to be clear what proportion of these projects were for NHS organisations and what proportion for pharmaceutical or other commercial organisations.
- Updating the table of data requested to be clear that only a rolling five years of data will be held at any time.

DAAG noted that if the finalised investigation report raised any additional issues not addressed in this application, then an updated application ought to be brought back to DAAG. It was agreed these caveats would be reviewed out of committee by the DAAG Chair.

2.4

King's College London - Identifying Genetic and Environmental Interactions in Psychosis (Presenter: Jen Donald) NIC-25051-V0K1X

**Application:** This application requested list cleaning for a small cohort of individuals who had previously consented to participate in a study, but who had been lost to further contact. The applicant intended to contact individuals and ask them to re-join the study. It was confirmed that section 251 support was in place for the processing of identifiers.

**Discussion:** DAAG queried the requested cohort and it was thought that data was only requested for a subset of a larger cohort with whom the study had lost contact. There was a discussion of the planned data retention and DAAG suggested that the application should be updated to be clear that data would be destroyed for any individuals who did not respond or who chose not to give updated consent.

Queries were raised about the purpose for which data would be used and whether this was a continuation of the original EU-funded project, which appeared to have finished some time previously, or whether this was a separate new study using the same cohort as the original study. DAAG suggested that it might be helpful to have sight of the original study consent materials, although it was acknowledged that participant consent was not cited as the relevant legal basis for the proposed data processing.

DAAG noted that the applicant's IG Toolkit score was listed as being for version 14 rather than 13; confirmation was requested that this was correct. The importance of fair processing was emphasised and DAAG suggested that when the applicant did make contact with participants, this should include information about the data processing that had taken place.

**Outcome:** Recommendation deferred, pending:

- Clarification regarding the status of the EU funded project and whether this data will be used to support the original project or a new project.

- Updating the planned data retention period and including a special condition that data on non-responders or individuals who do not wish to re-consent will be destroyed within an appropriate time period.
- Confirmation that the re-consenting process will include making information available to the cohort about this use of data for list cleaning.

2.5

Cardiff University - Health Care Utilisation, Care Pathways and Educational Status in Adolescents with Mental Health Disorders and Children with Cerebral Palsy (Presenter: Dickie Langley) NIC-42321-K7G1C

**Application:** This application for HES, Improving Access to Psychological Therapies (IAPT), mental health data (MHMDS, MHLDDS) and ONS mortality data had previously been discussed at the 6 December 2016 meeting, when DAAG had deferred making a recommendation. The updated application now clarified a number of points including the cohort age range, and further data minimisation efforts had been proposed. It was noted that the signed HQIP contract previously requested had not been available in time to include with the meeting papers.

**Discussion:** There was a discussion of the HQIP contract and why a signed copy of this was required. DAAG considered that this document was important to confirming the role of HQIP as a data controller, rather than Cardiff University or a different organisation acting as data controller, and the final signed copy was requested in order to confirm that the contract had been fully agreed.

DAAG discussed the proposed data minimisation efforts and while there was some disappointment that further minimisation had not been considered practical, such as using a sample of national data for the control group rather than using full national data as the control, it was acknowledged that reasonable efforts had been made to reduce the amount of data used. It was suggested that minimisation should continue to be considered in future, as DAAG noted there was currently an open action for NHS Digital to consider the feasibility of making further use of sampling techniques.

**Outcome:** Recommendation to approve, subject to:

- Providing a signed copy of the HQIP contract (SD6)

DAAG noted that for future applications where HQIP acts as data controller, an update would be expected regarding security assurances for HQIP.

It was noted that when a renewal or amendment application was submitted, this should include a clearer justification for the need to retain data for 15 years.

It was agreed these caveats would be reviewed out of committee by the acting DAAG chair.

2.6

University of Liverpool - UK Lung Cancer Screening Trial Lung Cancer Registry and Mortality data for consented individuals (Presenter: Dickie Langley) NIC-19237-R3T6S

**Application:** This application requested cancer registration and mortality data for a cohort who had previously consented to participate in a cancer screening trial. DAAG were informed that the pilot trial had ended and the decision had been made not to continue to a full trial. The applicant wished to use the requested data to produce outputs for the UK National Screening Committee, which could be considered alongside outputs from other relevant studies.

**Discussion:** Some concerns were raised that the application did not clearly articulate what healthcare benefits could be achieved through this use of data, given the limitations of the pilot study. It was agreed that a clearer justification was needed of how benefits would be realised.

There was a discussion of the fair processing statement (SD2) and it was suggested that some of the language used in this document could be potentially confusing for the general

public. DAAG queried whether this document was still in use, and if so it was agreed it should be updated to make better use of Plain English.

DAAG queried references to possible future data sharing or linkage and it was confirmed that this was not part of the current application. It was agreed a special condition would be added to the application to be clear that data would not be shared or linked at this point in time, without submitting a further application to NHS Digital to allow this.

**Outcome:** Recommendation to approve, subject to:

- A clearer justification for how this use of data will provide benefits to the health and social care system in line with the requirements of the Care Act 2014.
- Including a special condition that data will not be linked or shared in any way not described in the current application.
- Confirmation of whether the fair processing statement is currently still in use, and if so this should be updated to make better use of plain English.

It was agreed these caveats would be reviewed out of committee by DAAG members.

## 2.7

### Queen Mary University of London - Enhanced Peri-Operative Care for High-risk patients (EPOCH) Trial (Presenter: Garry Coleman) NIC-55950-Y5Y2Y

**Application:** This application requested pseudonymised HES data linked to ONS mortality data, including the identifier date of death, with the applicant intending to link this data to HQIP audit data provided by the Royal College of Surgeons. DAAG were informed that the applicant would separately apply to HQIP for the audit data, and that shared study identifiers would be used to enable linkage of the datasets without having to provide any other identifiers to the applicant.

**Discussion:** DAAG queried the legal basis for the different flows of data described; it was noted that section 251 support was in place for the flow of identifiers into NHS Digital and that ONS data could be shared under section 42(4) of the Statistics and Registration Service Act 2007. DAAG felt that the 'Permissions and data flow' diagram provided with the application was unhelpful and potentially confusing, and that it would have been more useful to have a data flow diagram that included the legal basis for each separate flow. The description of the data as anonymised in context was challenged and DAAG suggested that in this instance it was more appropriate to describe the data as pseudonymised.

A reference to NHS Digital 'copying in HQIP' when sharing data was queried; it was clarified that this was intended to refer to informing HQIP that data sharing had taken place, rather than providing HQIP with any data. It was agreed the application wording should be amended to clarify this. DAAG also queried the data sharing framework contract expiry date for the applicant organisation, as the date listed within the application had passed.

DAAG noted that the described benefits appeared to rely on the data being linked to audit data following HQIP approval, and it was unclear whether any processing could be carried out or any benefits could be derived solely from the NHS Digital data. It was agreed that a special condition should be added to the application that if the applicant did not obtain permission from HQIP to make use of the audit data, the applicant should destroy any data received from NHS Digital for this purpose.

Fair processing was discussed and DAAG noted that the information provided seemed to relate to the collection and processing of audit data, rather than the specific data processing set out in this application. DAAG requested further information about what fair processing efforts had been undertaken for this particular use of data.

**Outcome:** Recommendation to approve, subject to:

- Clarifying a reference to HQIP being 'copied in' to clarify that this does not refer to

providing HQIP with any data.

- Providing assurance that appropriate fair processing efforts are being made in relation to the use of data by Queen Mary University of London, rather than fair processing solely for the audit.
- Including appropriate special condition wording that if the applicant does not obtain permission from HQIP for the proposed use of data, then any data provided by NHS Digital for this purpose should be securely destroyed.

It was agreed these caveats would be reviewed out of committee by DAAG members.

2.8

IMS Health Information Solutions Medical Research Ltd (Presenter: Dave Cronin) NIC-24629-X6B6N

**Application:** This application for pseudonymised HES data had previously been discussed at the 15 November 2016 meeting, when DAAG had deferred making a recommendation. The updated application now provided further information including the purposes for which data had been shared under sub-license, clarification about the IMS Health legal entities involved and further restrictions around the purposes for which data could be used at this point in time. It was acknowledged that work was underway to improve governance processes and sub-licensing arrangements, in order to better reflect the terms and conditions set by NHS Digital on data sharing.

**Discussion:** DAAG noted the work that had been undertaken to improve this application and expressed their thanks to NHS Digital staff for their efforts. DAAG also noted the applicant's intentions to improve their existing governance processes, which was welcomed, but it was unclear what the timescales for these improvements would be. There was a suggestion that once the strengthened governance processes were established, these could be used to review the existing sub-licensing arrangements. It was agreed that at the present time the applicant should not issue any new sub-licenses and should not approve any additional purposes for which data could be used, and it was agreed that special condition wording should be added to the application to restrict this.

A query was raised about the linked HES-THIN data, and whether the applicant had retained any HES data that had not been linked to THIN. It was agreed that if this was the case, the unlinked HES data should be securely destroyed. DAAG noted the information provided about various purposes for which the data could be used under sub-license and suggested that in the interests of openness and transparency, the applicant should consider making this information publicly available. The use of honorary contracts was discussed and it was agreed that the assurances provided seemed appropriate.

DAAG queried the application wording used to describe the data requested, as in some places this was referred to as anonymised in context or as being in line with the ICO anonymisation code of practice. It was suggested that given the ongoing uncertainties around the context in which data was used, particularly given the use of sub-licenses that at present did not reflect the controls set by NHS Digital around the purposes for which data could be used, it was not appropriate to describe the data as anonymised or anonymised in context and that this wording should be amended.

There remained some concerns about the number of data years that the applicant had requested to retain, as DAAG felt that there was not a clear enough justification to retain roughly twenty years of data or for their clients operating under sub-license to retain this amount of data. However it was acknowledged that because of the particular data linkage and processing undertaken by the applicant, destroying the linked data held could jeopardise the possibility of future data linkage. DAAG agreed that it would be appropriate for the applicant to continue to hold this amount of data for a further six months while work was undertaken to consider further data minimisation efforts, and that a clearer justification for the amount of data would need to be included as part of any renewal or amendment application.

DAAG noted that the sub-license agreement for Lyon University had been extended and queried the expiry date for this.

**Outcome:** Recommendation to approve for a period of six months only, subject to:

- Updating the proposed agreement end date to limit this to six months.
- Providing further information about the expected timescales for the applicant to improve existing governance processes.
- Including appropriate special condition wording that the applicant cannot approve the use of this data for any additional purposes at this point in time.
- Clarification regarding whether the applicant still holds any HES data that was not linked to THIN data, and if this is still held then confirmation that this data will now be destroyed.
- Amending any statements within the application that the data is considered to be anonymised in context in compliance with the ICO's anonymisation code of practice.
- Confirmation of the expiry date for the renewed sub license agreement with Lyon University.

DAAG noted that when a renewal application was submitted, this would need to include either further data minimisation efforts or a clear justification for why this number of data years are required.

DAAG noted the information provided about the purposes for which data was used under sub licenses and encouraged the applicant to consider making this data publicly available in the interests of openness and transparency.

It was agreed these caveats would be reviewed out of committee by DAAG members.

2.9

Royal Liverpool and Broadgreen University Hospitals NHS Trust - Outcomes for paediatric pyeloplasty, fundoplication, oesophageal atresia repair and testicular torsion in England (Presenter: Dave Cronin) NIC-45533-H3M8X

**Application:** This was a new application for pseudonymised HES data to support a study commissioned by Alder Hey Children's Hospital.

**Discussion:** DAAG noted the potential benefits of this study. However it was felt that the outputs and benefits section of the application did not clearly articulate how outputs would be communicated to relevant clinicians to deliver an impact across the health service.

The role of the principal investigator based at Alder Hey was noted and DAAG queried whether Alder Hey should in fact be considered the data controller for this work. It was confirmed that the principal investigator would only receive aggregated outputs with small numbers suppressed, and that the applicant organisation would determine the way in which data would be processed to produce the outputs.

**Outcome:** Recommendation to approve, subject to:

- Providing further information about how outputs will be communicated to ensure appropriate impact and benefits to health or social care.

DAAG noted that the applicant's DPA registration should be amended to refer to processing data about patients more widely rather than solely 'our patients'.

It was agreed these caveats would be reviewed out of committee by the acting DAAG chair.

2.10

University of Oxford – EPIC (Presenter: Dave Cronin) NIC-148322-TMFVQ

**Application:** This application requested linked HES data as well as demographic, mortality and cancer registration data for a specific study cohort flagged through the Medical Research Information Service (MRIS) patient tracking service. The application had previously been considered for advice at the 26 July 2016 meeting, when DAAG had advised that there did not appear to be a legal basis under participant consent for this data to be shared. The applicant



had since obtained Approved Researcher accreditation and ONS Microdata Release Panel approval, and the study's section 251 support had been extended. The applicant had requested confirmation from HRA CAG of whether an amendment was also required, but had not yet received a response.

Two errors within the application abstract were noted and it was confirmed these would be corrected within the application system.

**Discussion:** DAAG noted that HRA CAG had not yet confirmed whether an amendment to the applicant's section 251 support was required in relation to the MRIS patient tracking service, but it was thought that the support clearly covered the requested HES data linkage. In light of this DAAG agreed that the application should include a special condition to specify that while HES linkage could take place, no further patient tracking reports should be issued until clarification had been received regarding the section 251 support.

The involvements of DPhil or MSc students in data processing was noted but it was not thought that this should raise any concerns.

DAAG noted that they had previously raised some concerns regarding the relative lack of fair processing information for participants and queried whether any progress had been made regarding this. DAAG were informed that the applicant had made some additional fair processing information available online and DAAG emphasised the importance of raising awareness of this use of data.

**Outcome:** Recommendation to approve, subject to:

- Updating the abstract to correct errors.
- Including a special condition that no further patient tracking reports can be issued until confirmation is received from HRA CAG that the applicant's section 251 support includes this use of data.

DAAG advised that the applicant should consider undertaking further fair processing activities to raise awareness of the ongoing work.

It was agreed these caveats would be reviewed out of committee by the Director for Data Dissemination.

## 2.11

### University of Cambridge – Fenland study (Presenter: Louise Dunn) NIC-43771-N0W3Q

**Application:** This application requested list cleaning using identifiable MRIS data for the study cohort, with fact of death being provided along with up to date contact details to allow the study to re-contact participants and ask them to provide updated consent. It was confirmed that section 251 support was in place to cover the flow of identifiers.

**Discussion:** DAAG noted that the application referred to providing current address, general practice code and fact of death but that the table of data requested also listed other identifiers including name, NHS number and date of birth. Confirmation was requested that these identifiers were all requested and that the applicant's section 251 support included these fields.

**Outcome:** Recommendation to approve, subject to:

- Clarifying which identifiers are requested, with confirmation that these are covered by the applicant's section 251 support.

DAAG suggested that the applicant should consider updating their DPA registration wording to include reference to health research.

It was agreed these caveats would be reviewed out of committee by the acting DAAG chair.

<p>2.12</p>	<p><u>Westminster City Council (Presenter: Louise Dunn) NIC-63798-B9T0B</u></p> <p><b>Application:</b> This application requested pseudonymised HES data and was based on the standard template for Local Authority Public Health requests for this data. It was noted that the applicant organisation's privacy notice required updating and the agreed special condition wording regarding this had been included in the application.</p> <p><b>Discussion:</b> DAAG noted that queries had previously been raised regarding whether Local Authorities could make use of local data or a sample of data rather than the full national dataset. No other concerns were raised.</p> <p><b>Outcome:</b> Recommendation to approve. DAAG suggested that the applicant should consider updating their DPA registration wording to include processing data about patients or healthcare users.</p>
<p>3</p>	<p><b>Any other business</b></p> <p><u>Advice on NCMP data applications (Presenter: Paul Nibblet)</u></p> <p>DAAG were asked to provide advice on possible applications for the release of National Child Measurement Programme (NCMP) data. DAAG were informed that to date NHS Digital had taken the position that pseudonymised NCMP data could not be released to other organisations due to the theoretical risk of re-identification, but that this position was not aligned with the approach to pseudonymised data sharing for other datasets. DAAG queried whether a risk assessment had been undertaken, and noted that any applications for this data would need to include clear information about the controls in place to ensure that data would be anonymised in context.</p> <p>The potential sensitivities around this dataset were noted, and DAAG suggested that the general public might raise more concerns about NCMP data being used by commercial organisations than they might about NHS organisations. There was a discussion of the consent process, where a letter was sent to parents offering them the chance to opt their child out of the measurement programme, and DAAG offered some comments on this letter but noted that this opt-out process would likely not be considered to provide a legal basis in consent for data to be shared. Any application for the data should therefore clearly state the relevant legal basis.</p> <p>This advice was given without prejudice to the consideration of future applications.</p>

## Summary of Open Actions

Date raised	Action	Owner	Updates	Status
15/11/16	To update DAAG on the feasibility of providing random samples of data to applicants, and to ask the Production Team to provide DAAG with further information about the options for data minimisation	Garry Coleman / Peter Short	06/12/16: This action was ongoing and it was anticipated an update would be available in mid-January. There had also been a discussion during the training session about data minimisation, with a suggestion for Peter Short to contact the Production Team for further information, and it was agreed that would be incorporated into this action. 13/12/16: Ongoing.	Open
29/11/16	To contact Steve Smith regarding the work taking place with Leeds City Council on fair processing/privacy notice updates as a result of an application for PCMD access.	Noela Almeida	13/12/16: This action had been completed and was closed.	Closed
06/12/16	To hold a training session item covering the GDPR, anonymisation in context and re-identification.	Eve Sariyiannidou	13/12/16: It was agreed that this would be covered at a future training session and the action was closed.	Closed
06/12/16	To provide feedback to the NHS Digital Caldicott Guardian on the minimum criteria for privacy notices and to suggest any necessary additional criteria.	DAAG Chair	13/12/16: Ongoing.	Open
06/12/16	To query the privacy notice review process within NHS Digital.	Peter Short	13/12/16: This had been discussed with the Caldicott Guardian but further clarification was needed.	Open