

# Independent Group Advising on the Release of Data (IGARD)

## Minutes of meeting held 24 August 2017

**Members:** Sarah Baalham, Chris Carrigan (Chair), Nicola Fear, Kirsty Irvine, Eve Sariyannidou, James Wilson

**In attendance:** Garry Coleman, Gaynor Dalton, Tom Denwood (observer), Louise Dunn, Rachel Farrand (observer), Frances Hancox, Louise Hill, James Humphries-Hart, Dickie Langley, Victoria May, Emily Parker (observer), Kimberley Watson, Vicki Williams

**Apologies:** Joanne Bailey, Anomika Bedi, Jon Fistein

1	<p><b>Declaration of interests</b></p> <p>No relevant interests were declared.</p> <p><b>Review of previous minutes and actions</b></p> <p>The minutes of the 10 August 2017 IGARD meeting were reviewed and agreed as an accurate record of the meeting.</p> <p>Action updates were provided (see Appendix A).</p> <p><b>Out of committee recommendations</b></p> <p>An out of committee report was provided (see Appendix B).</p> <p>IGARD noted that in one instance an application's conditions had been agreed out of committee by only two members rather than the usual quorum of three members, and there was a brief discussion about the importance of responding promptly to out of committee emails. IGARD noted that it would be helpful for NHS Digital to more clearly indicate where changes had been made to an application.</p>
2  2.1	<p><b>Data applications</b></p> <p><u>London Borough of Enfield – HDIS access (Presenter: Victoria May) NIC-35531-X3Y7Q</u></p> <p><b>Application:</b> This was an amendment application to change from the receipt of a Hospital Episode Statistics (HES) extract to instead access the HES Data Interrogation Service (HDIS0, due to a data sharing agreement breach that had occurred in relation to the previous agreement. It was noted that as a result of this the applicant organisation would not be able to download any aggregated data from HDIS that did not have small number suppression applied. IGARD were informed that this was likely to be a temporary measure while work was underway relating to the data breach, and that following an upcoming audit the applicant was expected to submit an updated application to request renewed access to data extracts. It was noted the applicant had been advised to update their DPA registration wording, as well as their privacy notice.</p> <p><b>Discussion:</b> IGARD discussed the additional controls that would be in place around downloading data from HDIS for this particular applicant and noted that while these were described in the abstract section of the application, section five of the application (which would form part of the data sharing agreement) did not clearly describe the relevant controls. In addition it was noted that section five should be updated to clearly reflect the special conditions listed in section six. There was a discussion about the process to suppress small</p>

numbers in tabulations generated by HDIS and it was noted that this check would be carried out by NHS Digital rather than being a purely automated process.

IGARD noted that the applicant had previously been advised to update their privacy notice but that this advice did not seem to have been acted upon; it was noted that if the applicant wished in future to apply to restore their access to other data flows such as PCMD, this would include a thorough review of their privacy notice against NHS Digital's nine minimum criteria. It was also noted that this would be picked up as part of any data sharing audit.

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

- Updating section five of the application to reflect the controls around downloading data as described in the abstract.
- Section five of the application should be updated to more clearly reflect the special conditions described in section six.

The following advice was given:

- IGARD advised the applicant should review their website against the ICO's Privacy Notices Code of Practice to ensure they reflect best practice standards, and in the interests of transparency, update their privacy notice as soon as possible. The EU General Data Protection Regulation recognises that pseudonymised data should be considered as information on an identifiable natural person and also places a greater focus on the need to demonstrate transparency of data processing in the information provided to data subjects. IGARD noted that this would be reviewed as part of an upcoming data sharing audit.

It was agreed the above conditions would be reviewed out of committee by the IGARD Chair.

## 2.2

Bradford Teaching Hospitals NHS Foundation Trust – HDIS access (Presenter: Dickie Langley) NIC-49238-R7G6V

**Application:** This was a new application requesting access to HDIS, including the download of aggregated data that could contain small numbers, to support a programme of work relating to child health and elderly frailty as part of the broader Connected Health Cities programme. The applicant would use HDIS to determine what HES data would be necessary for their work, and to then request a HES extract of that data under a separate application.

**Discussion:** IGARD queried what level of data minimisation was possible within HDIS and it was noted that with some specific exceptions it was not usually feasible to restrict an organisation's access by geography or data years. IGARD noted that section five of the application should be updated to more clearly reflect the special conditions listed in section six, including a statement that the applicant would not be able to download record level data under this agreement.

A query was raised about why it would be necessary to request a HES extract in addition to HDIS access; it was explained that HDIS would only permit users to download aggregated data, whereas the applicant intended to request a record level extract once they had determined what data would be necessary. A further query was raised about a reference within the application to the University of Leeds, University of Sheffield, and University of York and it was confirmed that these organisations were not involved in this particular programme of work; however IGARD noted that it would be helpful for future applications to have sight of the collaboration agreement between the four partner organisations, to be clear on any requirements around data sharing under that agreement.

A minor typographical error was noted and it was agreed this would be corrected. The use of the word 'identify' in section five of the application was queried, as IGARD considered that this could be misleading, and it was agreed this wording should be clarified to be clear that this did not refer to identifying individual patients within the data. A reference to identifying children 'at risk of being diagnosed with autism' was similarly queried and it was agreed this wording

	<p>should be amended.</p> <p><b>Outcome:</b> Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> <li>Section five of the application should be updated to more clearly reflect the special conditions described in section six, including to more clearly state that the applicant will only be able to download aggregated data from HDIS, rather than record level data.</li> </ul> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>A reference to the 'Bradford Teaching Hospitals NHS Financial Trust' should be corrected to 'Foundation Trust'.</li> <li>The use of the term 'identify' within section five should be clarified.</li> <li>A statement about 'identifying children at risk of autism' should also be clarified.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>IGARD advised that when a future application was submitted to request a HES extract, it would be helpful to have sight of the additional supporting documents relating to the collaboration agreement between Bradford Teaching Hospitals NHS Foundation Trust and the three Universities.</li> </ul> <p>It was agreed the above condition would be reviewed out of committee by the IGARD Chair.</p>
2.3	<p><u>University of Warwick - Prevention of Falls Injury Trial (Presenter: Kimberley Watson) NIC-302792-X4T6B</u></p> <p><b>Application:</b> This application was to renew and amend an existing agreement, with the requested amendment being to receive Office for National Statistics (ONS) mortality data, and for a refresh of HES data with the previously held HES data to be destroyed. IGARD were informed that the legal basis for this was patient consent, and that although the consent materials did not explicitly refer to the use of ONS data the study website had been updated to provide fair processing information about this.</p> <p><b>Discussion:</b> IGARD noted that the application stated that the applicant's data sharing framework contract had been conditionally approved, and although verbal assurances were given that there were no outstanding conditions IGARD noted that this should be more clearly explained within the application.</p> <p>Concerns were raised regarding the consent materials and IGARD did not consider that the materials would provide an appropriate legal basis for the use of ONS mortality data. In particular it was noted that although the materials referred to 'health status', the patient information sheet specifically listed a number of datasets that would be used and this did not include mortality data, meaning that patients would likely assume that only the listed data would be used. The consent materials also stated that data would not be shared with third party organisations, which appeared to rule out the involvement of University of Leeds staff as set out within this application. In addition IGARD noted that the fair processing information stated that data would be used by the study team up to three years after the date of consent, meaning that participants would likely not expect their data to still be in use past that time. IGARD acknowledged that due to the age of the cohort it would probably be impractical to seek updated consent from the cohort and suggested that the applicant should consider alternative legal bases, such as section 251 support.</p> <p>The fair processing materials were discussed more broadly and IGARD agreed that these would need to be updated in line with NHS Digital's nine minimum criteria for privacy notices. A query was raised about the honorary contract arrangements for a member of staff from the University of Leeds and whether that should be noted as an amendment to this application, and a query was raised about involvement by the University of Oxford.</p> <p><b>Outcome:</b> Not recommended for approval.</p> <ul style="list-style-type: none"> <li>IGARD did not consider that there was a legal basis in consent for this use of data, as the materials appeared to exclude the use of ONS mortality data, stated that data</li> </ul>

	<p>would not be shared with third parties (such as the University of Leeds), and stated that data would only be used for three years after the date of consent.</p> <ul style="list-style-type: none"> <li>• The applicant should provide a copy of the honorary contract of the member of staff employed by the University of Leeds.</li> <li>• Further clarification was requested regarding the amendment to add the University of Leeds to the contract, and clarify whether the University of Oxford is also involved.</li> <li>• The applicant should update their fair processing information in order to meet the NHS Digital nine point check, and specifically explain how participants can withdraw their consent.</li> </ul>
2.4	<p><u>Group application for 4 CCGs<sup>1</sup> (Presenter: James Humphries-Hart) GA04a-AMD-NoE</u></p> <p><b>Application:</b> This was an amendment application to add a flow of identifiable Secondary Uses Service (SUS) data for the purpose of risk stratification, in addition to the existing flows of SUS and local provider data for the purposes of commissioning and invoice validation. North of England CSU would act as the data processor for risk stratification and IGARD were informed that the four CCGs had been reviewed as meeting the nine minimum privacy notice criteria.</p> <p><b>Discussion:</b> IGARD noted that the DPA registration details listed in the application seemed to have expired and that the renewal details would need to be added to the application.</p> <p>There was a discussion of the CCG privacy notices and IGARD considered that although NHS Digital's privacy notice review indicated that these met the minimum criteria, IGARD's own review indicated that all but Hardwick CCG failed one or more of the minimum criteria. In particular it was noted that the privacy notices needed to make better use of accessible language, clearly describe what organisations data would be shared with, set out the role of Optum as a data processor, correct any broken links, and ensure not to conflate opting out with patient consent in a way that could be confusing or misleading. IGARD asked for the three privacy notices to be re-reviewed by a senior NHS Digital employee with appropriate IG knowledge to confirm whether NHS Digital was content that these met the minimum necessary criteria. A query was raised about the description of some criteria as 'red/amber' within the checklist provided and IGARD considered that this combination of categories was confusing.</p> <p>A query was raised about a reference to Pulsant Data Centre as a data processor; it was clarified that this data centre was part of North of England CSU and IGARD asked for this to be clarified within the application.</p> <p>IGARD advised that the standard template wording used in section five of the application would likely be confusing for a general public audience, and that in future NHS Digital should consider revising this wording to be more accessible.</p> <p><b>Outcome:</b> Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> <li>• The CCGs (other than Hardwick CCG) should update their privacy notices in line with NHS Digital's nine criteria, in particular ensuring to use accessible language, be clear who data will be shared with, describe the involvement of Optum as a data processor, ensure that all website links are functioning and ensure not to conflate opting out with patient consent in a way that could be misleading. This should be confirmed by a senior member of NHS Digital staff with appropriate IG expertise.</li> </ul> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• The table of differences should be updated to include the details of CCG privacy notice review and the renewed DPA registration details.</li> <li>• The data storage locations should be updated to be clear that Pulsant Data Centre is</li> </ul>

<sup>1</sup> NIC-134337-C2C8Q NHS Erewash CCG; NIC-134460-X5B7B NHS Hardwick CCG; NIC-134486-C9C7S NHS North Derbyshire CCG; NIC-134495-Q1M6S NHS Southern Derbyshire CCG

	<p>part of North of England CSU.</p> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that in future NHS Digital should update the standard application template wording used in section five to be more accessible to the general public.</li> <li>• IGARD advised that Optum should update their DPA registration wording to reflect the use of data about patients or health service users.</li> </ul> <p>It was agreed the above condition would be reviewed out of committee by the IGARD Chair.</p>
2.5	<p><u>Brighton &amp; Hove CCG (Presenter: James Humphries-Hart) NIC-91808-P5Z1F</u></p> <p><b>Application:</b> This application requested an amendment to an existing data sharing agreement to add the flow of identifiable SUS data for invoice validation, amend the data processor for risk stratification from South East CSU to North East London CSU, and amend the data processor for commissioning purposes to South Central and West CSU. Sollis Partnership Ltd would also act as a data processor as they would provide technical support to North East London CSU regarding the use of their risk stratification tool. IGARD were informed that the CCG's privacy notice had failed the nine criteria check.</p> <p><b>Discussion:</b> IGARD discussed the involvement of South Central and West CSU as a data processor, given recent discussions around this CSU and its recent data sharing audits. It was noted that there was currently an open action for NHS Digital around this and that verbal assurances had been provided, but a written response was awaited. IGARD were informed that the action plan from the second audit should shortly become available to share, and IGARD requested sight of this to confirm that all relevant actions had been completed particularly regarding governance and the management of data.</p> <p>There was a brief discussion of the involvement of the Sollis Partnership and IGARD noted that more detail than usual had been provided about this organisation's role, which it was explained was because this was the first time that this type of technical support role had been included within an application.</p> <p><b>Outcome:</b> Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> <li>• The CCG should update their privacy notice in line with NHS Digital's nine criteria.</li> <li>• Providing evidence that the South Central and West CSU's action plan relating to the second data sharing audit has been completed, particularly in relation to any points around governance and the management of data.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that in future NHS Digital should update the standard application template wording used in section five to be more accessible to the general public.</li> <li>• IGARD advised that Sollis Partnership should update their DPA registration wording to reflect the use of data about patients or health service users.</li> </ul> <p>It was agreed the above condition would be reviewed out of committee by the IGARD Chair.</p>
2.6	<p><u>Luton CCG (Presenter: James Humphries-Hart) NIC-113365-W5V2Z</u></p> <p><b>Application:</b> This was an amendment application for the addition of Optum as a data processor for commissioning purposes, in addition to extending the existing data flows for risk stratification, invoice validation and commissioning. IGARD were informed of an error in the application as three points listed in the summary section about Optum's role were incorrect and would be removed. It was noted that the CCG's privacy notice had failed the NHS Digital review.</p> <p><b>Discussion:</b> IGARD queried the involvement of North of England CSU in the data flow to Optum, as the application indicated that they would act as a landing stage only but did not further explain this or state how soon data would be deleted by the CSU once it had been</p>

passed on to Optum. It was noted that North of England CSU were already acting as a data processor for commissioning purposes under a separate application and it was unclear how the services provided by Optum would be different, and what additional benefits would arise from the use of an additional data processor. Some concerns were therefore raised that this additional flow of data could be considered excessive processing. It was agreed that more information was required about the expected benefits of this additional data processing with a clear justification for why this was required in addition to the existing data flows.

A reference to Optum sharing 'linked' data with the CCG was queried but it was explained that this referred to linking fields within the SUS data, rather than linking with other datasets.

IGARD noted the involvement of Interxion as a data storage location and asked for the application to be updated with the standard special condition wording for this organisation.

**Outcome:** Recommendation deferred, pending:

- Providing a clearer explanation of the role of Optum with a justification for why it will be beneficial for this organisation will act as an additional processor as well as the existing data flows.
- The CCG should update their privacy notice in line with NHS Digital's nine criteria.
- The standard special condition regarding Interxion should be added to the application.

The following amendments were requested:

- An error in the summary section should be corrected to remove the three final points describing Optum's role.

The following advice was given:

- IGARD advised that in future NHS Digital should update the standard application template wording used in section five to be more accessible to the general public.
- IGARD advised that Optum should update their DPA registration wording to reflect the use of data about patients or health service users.

## 2.7

Bedfordshire CCG (Presenter: James Humphries-Hart) NIC-120080-Q2K6T

**Application:** This was a new application for the CCG to use PI Limited (PI Care and Health) as a data processor to link pseudonymised SUS with social care data, using the University of Nottingham Open Pseudonymiser tool, for the purpose of commissioning. It was confirmed that this would be in addition to the existing data sharing agreement for invoice validation and commissioning purposes. The CCG privacy notice had been reviewed by NHS Digital as meeting the minimum criteria.

**Discussion:** IGARD requested a clearer explanation of the additional benefits that would arise from this use of linked data and from the use of PI Ltd as a data processor, as it was considered that this was not clearly described within the mostly standard application text provided.

IGARD considered that the CCG's privacy notice did not meet the nine minimum criteria.

There was a discussion of the pseudonymisation process. It was explained that the Open Pseudonymiser tool would be used by both the DSCRO to pseudonymise the SUS data, and by the Local Authority to pseudonymise the social care data, which would enable the data processor PI Ltd to link the two datasets without having access to any identifiable data and without the DSCRO needing to carry out the linkage..

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

- The CCG should update their privacy notice in line with NHS Digital's nine criteria. This should be confirmed by a senior member of NHS Digital staff with appropriate IG expertise.
- The standard special condition regarding Interxion should be added to the application.

2.8	<p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>Updating the application to provide a clearer explanation of the benefits arising from the use of PI Ltd as a data processor.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>IGARD advised that PI Ltd should update their DPA registration wording to reflect the use of data about patients or health service users.</li> </ul> <p>It was agreed the above condition would be reviewed out of committee by the IGARD Chair.</p> <p><u>Group application for 9 CCGs<sup>2</sup> (Presenter: James Humphries-Hart) GA05-NoE-AMD</u></p> <p><b>Application:</b> This amendment application asked for additional pseudonymised datasets (GP data, social care data and consented data) to be linked to SUS data via a common pseudonym. IGARD were informed that North of England CSU would receive these datasets into a ring-fenced area and use a one-time pseudonymisation key provided by the DSCRO, or that in some cases the social care data would be pseudonymised by the Local Authority before being sent to the CSU. The CCG privacy notices had all been reviewed by NHS Digital as meeting the minimum criteria</p> <p><b>Discussion:</b> IGARD noted that the summary section of this application indicated that the data flows were similar to an application from Hartlepool &amp; Stockton on Tees CCG (NIC-115934-P8P0X) considered at the 3 August 2017 IGARD meeting; it was considered that a number of the points raised in relation to that application had not been sufficiently addressed in this application, and IGARD asked for the relevant amendments to be applied.</p> <p>Some queries were raised regarding the pseudonymisation process. A reference to a 'black box' as part of the pseudonymisation process was queried and IGARD asked for this to be explained within the application. Moreover IGARD queried the legal basis for identifiable social care data to flow into the CSU, as this was not specified within the application, and requested an explanation of the legal basis for this data to be collected by the Local Authority to ensure that this would not prevent the data from being linked with healthcare data as requested.</p> <p>Concerns were raised about the CCG privacy notices as these did not explain the mechanism for individuals to opt out sufficiently clearly and seemed to use language that could potentially be considered coercive. In addition IGARD noted that the privacy notices should be updated to explain the intended linkage to social care and other data as requested in this application. There was a discussion about the standard process when NHS Digital had reviewed a privacy notice as meeting the minimum criteria but IGARD disagreed with the review, and it was noted that there would be a discussion at the October educational session about whether it would be appropriate to continue bringing applications to IGARD where the applicant's privacy notice had failed the review.</p> <p><b>Outcome:</b> Recommendation deferred, pending:</p> <ul style="list-style-type: none"> <li>Confirmation of the legal basis for identifiable social care data to flow into the CSU, as well as clarifying the legal basis for the Local Authority to collect this data.</li> <li>Clarification of the term 'black box'.</li> <li>The CCGs should update their privacy notices in line with NHS Digital's nine criteria, in particular to more clearly explain how individuals can opt out and to describe the linkage to social care data. This should be confirmed by a senior member of NHS Digital staff with appropriate IG expertise.</li> <li>The application should be amended in line with the points raised at the 3 August 2017</li> </ul>
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<sup>2</sup> NIC-134638-Z3C2N NHS Newcastle Gateshead CCG; NIC-134656-N8S3W NHS North Tyneside CCG; NIC-134613-G2M6G NHS Northumberland CCG; NIC-134630-K0M4D NHS South Tyneside CCG; NIC-134663-P4Z4Z NHS Sunderland CCG; NIC-134666-G5H1F NHS North Durham CCG; NIC-134694-Y1K6S NHS Durham Dales, Easington and Sedgfield CCG; NIC-134643-Q8C2V NHS Darlington CCG; NIC-134653-R5S3P NHS South Tees CCG

	<p>meeting in relation to a similar CCG application. The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that in future NHS Digital should update the standard application template wording used in section five to be more accessible to the general public.</li> </ul> <p><b>2.9</b>      <u>North Cumbria CCG (Presenter: James Humphries-Hart) NIC-134552-B5T6B</u></p> <p><b>Application:</b> This amendment application asked for additional pseudonymised datasets (GP data, social care data and consented data) to be linked to SUS data via a common pseudonym. IGARD were informed that this was very similar to the group application for nine CCGs (GA05-NoE-AMD) discussed earlier in the meeting, with the exception that this application did not include data processing for invoice validation.</p> <p><b>Discussion:</b> IGARD reiterated the concerns raised in relation to the group application for nine CCGs (GA05-NoE-AMD). An error in this application was noted as page nine of the application listed that data would be used for invoice validation; it was confirmed that this was incorrect and would be removed.</p> <p>IGARD noted that the CCG's privacy notice met the minimum criteria but suggested that the CCG should consider updating this to amend a potentially misleading description of de-identified data as 'anonymised'.</p> <p><b>Outcome:</b> Recommendation deferred, pending:</p> <ul style="list-style-type: none"> <li>• Confirmation of the legal basis for identifiable social care data to flow into the CSU, as well as clarifying the legal basis for the Local Authority to collect this data.</li> <li>• Clarification of the term 'black box'.</li> <li>• The application should be amended in line with the points raised at the 3 August 2017 meeting in relation to a similar CCG application.</li> <li>• A reference to requesting data for IV should be removed from page nine.</li> </ul> <p>The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD advised that in future NHS Digital should update the standard application template wording used in section five to be more accessible to the general public.</li> <li>• IGARD advised that the CCG should consider updating their privacy notice to correct a description of de-identified data as anonymised.</li> </ul> <p><b>2.10</b>      <u>Group application for 8 CCGs<sup>3</sup> (Presenter: James Humphries-Hart) GA04-AMD-SC</u></p> <p><b>Application:</b> This application requested additional flows of pseudonymised SUS and local provider data to support the Sussex and Surrey Sustainable Transformation Plan (STP), with South Central and West CSU and Carnall Farrar acting as data processors. The application had previously been considered at the 3 August 2017 IGARD meeting when IGARD deferred making a recommendation pending further information about the security arrangements for Carnall Farrar; an updated response had been provided by NHS Digital's data security centre.</p> <p><b>Discussion:</b> As with an earlier application IGARD noted the involvement of South Central and West CSU and requested the same level of assurance regarding their second audit action plan.</p> <p>There was a discussion about the security assurances for Carnall Farrar, and whether it was</p>
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<sup>3</sup> NIC-91808-P5Z1F NHS Brighton & Hove CCG; NIC-91799-G0T9X NHS Coastal West Sussex CCG; NIC-91838-H0B9N NHS Crawley CCG; NIC-91865-Y2L1H NHS East Surrey CCG; NIC-91866-V4R5J NHS Eastbourne, Hailsham and Seaford CCG; NIC-91825-W4M1H NHS Hastings & Rother CCG; NIC-91827-P6J6X NHS High Weald Lewes Havens CCG; NIC-91871-D2W1N NHS Horsham & Mid-Essex CCG.



	<p>appropriate to disseminate data before Penetration Testing had taken place. IGARD requested a clearer response on this point with confirmation that NHS Digital was content with the level of risk involved.</p> <p>IGARD considered that the majority of CCG privacy notices within this group did not meet the minimum criteria, and a discrepancy was noted regarding Brighton &amp; Hove CCG as an earlier application had stated that their privacy notice failed the review whereas this application stated that it had passed.</p> <p>A reference to Rotherham was noted within a supporting document and IGARD suggested that this should be corrected to instead refer to Rother. It was noted that the application omitted some DPA registration details and that these would need to be added.</p> <p><b>Outcome:</b> Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> <li>• A clearer response should be provided regarding the security assurances for Carnall Farrar with confirmation that NHS Digital is content with the level of risk ahead of Penetration Testing taking place.</li> <li>• The CCGs (with the exception of Brighton &amp; Hove, West Sussex, High Weald Lewes Haven CCG, and East Surrey CCG) should update their privacy notices in line with NHS Digital's nine criteria. This should be confirmed by a senior member of NHS Digital staff with appropriate IG expertise.</li> <li>• Providing evidence that the South Central and West CSU's action plan relating to the second data sharing audit has been completed, particularly in relation to any points around governance and the management of data.</li> </ul> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• The application should be updated to include the DPA registration details for all organisations.</li> <li>• Updating the application to list the correct privacy notice review details for Brighton &amp; Hove CCG.</li> <li>• A reference to Rotherham should be corrected to Rother.</li> </ul> <p>It was agreed that the above conditions would be reviewed out of committee by the IGARD Chair.</p>
2.11	<p><u>South Central &amp; West CSU – HDIS access (Presenter: Kimberley Watson) NIC-99675-X5S7X</u></p> <p><b>Application:</b> This request for HDIS access had previously been discussed at the 11 August 2017 meeting when IGARD deferred making a recommendation pending additional information about the follow-up from the two data sharing audits and the related ICO investigation. Both audit reports had now been published and confirmation had been received that the ICO investigation had closed. Section five of the application had been updated to more clearly explain the controls in place that would mean the organisation would not be permitted to download data from HDIS directly, but would have to request aggregated small number suppressed outputs from NHS Digital and provide a copy of the relevant query to produce the outputs.</p> <p><b>Discussion:</b> IGARD welcomed the update provided and agreed that section five of the application should be updated to include a clearer statement about the data sharing breach, the two audits that had taken place and a link to the published audit reports to ensure suitable transparency for the general public. Section five should also be updated to include information about the steps taken following the two audits.</p> <p>IGARD queried the process for the CSU to request aggregated HDIS outputs from NHS Digital. It was explained that the organisation would need to provide NHS Digital with the query used to generate the required output, in order to provide additional assurance that only appropriate aggregate outputs with small numbers suppressed would be provided to them by NHS Digital. IGARD asked for section five of the application to be updated to more clearly</p>

2.12	<p>reflect the controls in place around downloading data as currently set out within the abstract section of the application.</p> <p>IGARD agreed that the relative risk involved in this data dissemination would be low, as while the applicant would be able to view record level data through HDIS the only outputs they would have access to would be aggregated with small numbers suppressed to the point that the data could be considered publishable. However, there remained some concerns that the data sharing audit process was not yet fully complete and when comparing the first audit action plan to the second audit report, it appeared that some relevant issues had continued to be raised. IGARD were informed that the two audits had taken place against different data sharing agreements, which could explain some differences between the two reports. IGARD requested sight of the final post-audit report, noting that if this raised any new issues or indicated that earlier concerns had not been adequately addressed then this should be brought back to a future IGARD meeting for further discussion.</p> <p>IGARD noted the assurances given that the ICO had confirmed no regulatory action was required and that the investigation was closed, but requested clearer confirmation within the application's abstract that no further actions had been required.</p> <p>It was agreed that the application should be amended so that section five would more clearly reflect the special conditions listed in section six. In addition a reference to the applicant needing to 'write a query' was noted and IGARD asked for this wording to be more clearly explained.</p> <p><b>Outcome:</b> Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> <li>• Updating section five of the application to reflect the controls around downloading data as described in the abstract.</li> <li>• Providing a copy of the final post-audit report, noting that if this raises any new substantive issues then the application should be brought back to IGARD for further discussion.</li> <li>• A statement should be added to section five that a data breach took place and that this was followed by two audits, with a link to the two audits reports and information about the steps that have been taken since.</li> </ul> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• A description in section five of the applicant needing to 'write a query' should be explained more clearly.</li> <li>• Section five of the application should be amended to more clearly reflect the special conditions described in section six.</li> <li>• The abstract should be updated to confirm that no further actions were required following the ICO investigation.</li> </ul> <p>It was agreed that the above conditions would be considered out of committee by the IGARD Chair.</p> <p><u>University of Birmingham - TargetCOPD (Presenter: Kimberley Watson) NIC-81519-G1T5F</u></p> <p><b>Application:</b> This was a new application requesting identifiable HES and ONS mortality data for a specific study cohort, with section 251 support and Section 42(4) of the Statistics and Registration Service Act 2007 providing the relevant legal basis.</p> <p><b>Discussion:</b> IGARD noted the potential benefits of this NIHR funded study, and expressed that this seemed to be a good example of a well-written application. It was confirmed that the section 251 support would cover both the previously consented cohort and the wider cohort.</p> <p>A query was raised about the description of the legal basis within the application, as it was noted that in some places this was referred to as 'consent on an opt-out basis' whereas in fact the relevant legal basis would be section 251 support. It was agreed this wording should be</p>
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2.13	<p>amended for clarity.</p> <p>IGARD queried the indicative data retention period, as this seemed potentially excessive and the application did not provide a clear justification for retaining data for this length of time. It was agreed the data retention period should be updated in line with relevant legislation relating to clinical trial data.</p> <p><b>Outcome:</b> Recommendation to approve.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> <li>• The application should be updated to provide a clearer explanation of the indicative data retention period, with this period to be updated in line with relevant legislation regarding data retention in clinical trials.</li> <li>• References to 'consent on an opt-out basis' should be amended to be clear that section 251 will provide a legal basis for this use of data rather than relying on the previous trial consent.</li> </ul> <p><u>Nottingham University Hospitals NHS Trust – HDIS access (Presenter: Dickie Langley) NIC-10620-V9D8R</u></p> <p><b>Application:</b> This application was to renew the applicant's access to HDIS, including the ability to download aggregated data containing small numbers. Data would be used by the East Midlands Academic Health Science Network (AHSN) and additional information had now been provided about the AHSN governance arrangements that would apply to this data and control the purposes for which it could be used.</p> <p><b>Discussion:</b> IGARD noted that this application had previously been considered by DAAG on 8 November 2016 and deferred with a request that an updated application should be submitted within six weeks. It was confirmed that it had not been possible to submit an updated application that would address the issues raised by DAAG within the requested timescale.</p> <p>There remained some concerns that the points previously raised by DAAG had not been fully addressed, as in particular it was unclear how the AHSN would apply the criteria set out in order to ensure that data would only be used for appropriate purposes that would be for the benefit of health or social care and IGARD noted that while the criteria were set out in supporting documents, these should be more clearly detailed in section five of the application itself. IGARD suggested that it might be helpful for NHS Digital to consider how this had been detailed for similar previous AHSN applications and to work towards greater consistency.</p> <p>There also continued to be a lack of clarity about the involvement of AHSN partner organisations, and the differentiation between those partner organisations and 'customer' organisations requesting the use of data.</p> <p>Queries were raised regarding the project scoping tool provided as a supporting document, as for example this referred to sharing patient level data or identifiable data. It was clarified that this document was not limited to the data that would be disseminated by NHS Digital under this agreement, and that this therefore would likely refer to uses of data from other sources. A further query was raised about a reference in an earlier document to the Network Steering Group that contained industry representatives, but it was explained that this group was not relevant to the governance of how NHS Digital data would be used.</p> <p>Given that data had previously been shared for this purpose, IGARD requested more information about the purposes for which data had been used and the benefits that had already been achieved to date. It was suggested that the AHSN Impact Assessment might describe the benefits that had been achieved. As with similar HDIS applications IGARD asked for section five to be updated to reflect the special conditions currently listed in section six.</p>
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2.14	<p><b>Outcome:</b> Recommendation deferred, pending:</p> <ul style="list-style-type: none"> <li>• Further information is required about the governance processes in place and principles used to determine how data will be used and for what purposes.</li> <li>• Clarification regarding the involvement of partner organisations, as raised in November 2016, with clarification of which organisations are partners and which are customers.</li> <li>• Section five should be updated to more clearly describe the criteria for data use as set out in supporting document.</li> <li>• Providing more information about the benefits achieved using this data over the last few years, such as might have been described in the AHSN Impact Assessment.</li> <li>• Section five of the application should be updated to more clearly reflect the special conditions described in section six.</li> </ul> <p><u>Oldham Metropolitan Borough Council – Early Help / Troubled Families for advice on consent (Presenter: Dickie Langley) NIC-386015-X1X5Z</u></p> <p><b>Application:</b> This application was presented to IGARD for advice only. IGARD were asked to consider the consent materials used to recruit participants and whether any version of these would provide a legal basis to share healthcare data; in addition IGARD were asked to consider whether it would be appropriate to share pseudonymised data about the cohort using the Health and Social Care Act 2012 as a legal basis.</p> <p><b>Discussion:</b> IGARD agreed with the conclusion reached by NHS Digital that the consent materials did not seem to provide a legal basis to share data.</p> <p>There was a discussion of the wider principle of whether it would be appropriate to identify a cohort based on consent, and then share pseudonymised data under the Health and Social Care Act 2012. IGARD agreed that in principle this might be possible under some circumstances, but that this would not be appropriate for this application due to the poor quality of the consent materials and it was considered that participants would not expect NHS Digital to share healthcare data about them based on the fact that they had consented to participate in the programme. It was agreed that in this instance, the consent did not seem of sufficient quality to provide a legal basis for participant identifiers to flow into NHS Digital. In addition, IGARD noted that under the described process the applicant would be able to re-identify the pseudonymised data provided to them and that this should be considered personal data.</p> <p><b>Outcome:</b> The following advice was given:</p> <ul style="list-style-type: none"> <li>• IGARD agreed with the assessment by NHS Digital that the consent materials would not provide a legal basis for this data to flow. It was suggested that the applicant should consider the ICO guidance on consent materials, particularly in light of the upcoming implementation of the EU General Data Protection Regulation.</li> <li>• IGARD advised that the data dissemination requested within this application should be considered personal data and that it would not be appropriate to disseminate this under the described legal basis.</li> </ul> <p>IGARD offered this advice without prejudice to the consideration of future applications.</p>
3	<p><b>Any other business</b></p> <p>No other business was raised.</p>

## Appendix A: 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	<p>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.</p> <p>20/12/16: It was anticipated an update would be available in mid-January.</p> <p>10/01/17: Ongoing. It was agreed that this action would be taken forward by Alan Hassey rather than Peter Short.</p> <p>17/01/17: A number of internal discussions had taken place and it was anticipated an update would be brought to DAAG within the next few weeks.</p> <p>31/01/17: Ongoing. It was agreed the IGARD Chair would request an update on progress of this action.</p> <p>09/03/17: Ongoing. A number of internal discussions continued to take place and it was agreed the action would be taken forward by Garry Colman.</p> <p>23/03/17: Ongoing. There was a suggestion it might be helpful to discuss the type of sampling used by the Department for Work and Pensions.</p> <p>11/05/17: This action was not discussed due to time restrictions.</p> <p>18/05/17: IGARD received a verbal update on work underway to develop 'dummy data' for the purpose of developing tools and algorithms.</p> <p>15/06/17: It was agreed the IGARD Chair would contact Garry Coleman about this action and ask whether an update could be provided in the near future, or if not then agree to close the action</p>	Closed

			and to raise the topic again at a later date. 10/08/17: The action remained ongoing. It was agreed the Acting Chair would contact the IGARD Chair to confirm whether he would be content for this action to be closed. 24/08/17: It was agreed the action should be closed. The IGARD Chair noted this had also been raised with RAG.	
20/04/17	IGARD Chair to contact key stakeholder organisations regarding the benefits of uses of data to feed into the IGARD annual report.	IGARD Chair	24/08/17: Ongoing.	Open
27/04/17	IGARD Chair to contact the NHS Digital Caldicott Guardian regarding GPs' data controller responsibilities for fair processing around risk stratification.	Arjun Dhillon	18/05/17: Ongoing. It was agreed this would be discussed with the Deputy Caldicott Guardian. 22/06/17: Ongoing; it was suggested the Deputy Caldicott Guardian should discuss this in more detail with Joanne Bailey. 29/06/17: It was noted this action would be taken forward by the Deputy Caldicott Guardian, and the action owner was updated. 20/07/17: It was agreed the Deputy Caldicott Guardian would provide an update on the current status of this. 10/08/17: An update from NHS England had been requested. 24/08/17: Ongoing.	Open
18/05/17	Garry Coleman to provide information about different arrangements for data storage and backup locations, for consideration of whether the organisations involved would be considered to be processing data.	Garry Coleman	15/06/17: IGARD had been advised by email that a paper about this would be submitted to an upcoming IGARD meeting. 22/06/17: It was anticipated that this would be discussed at the 6 July 2017 IGARD meeting. IGARD asked for some information to be circulated by email prior to the meeting in order to inform members who would not be present at that particular meeting. 27/07/17: An email had been circulated requesting further information from IGARD members. 03/08/17: Two IGARD members had responded by email and the action remained ongoing. 10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks. 24/08/17: The paper was in the process of being updated based on recently published ICO guidance.	Open

15/06/17	Data Services for Commissioners to work with NHS Digital IG staff to check the privacy notices for these 4 CCGs (South Kent Coast CCG; Ashford CCG; Thanet CCG; Canterbury & Coastal CCG) as part of the ongoing training, and provide a copy of the outcome of this check to IGARD for information.	Stuart Richardson	29/06/17: Ongoing. It was suggested it would be helpful to discuss this at an upcoming educational session. 24/08/17: Ongoing.	Open
22/06/17	NHS Digital to ensure that in future applications using the Health and Social Care Act 2012 as a legal basis provide more detail about the applicable subsections, such as section 261(2)(b)(ii).	Garry Coleman	10/08/17: This was now being checked as part of the Pre-IGARD process, and further work would be undertaken to clearly document which subsections would be likely to apply to certain data flows. 24/08/17: It was agreed this action should be closed and that any updates regarding the table of legal bases should be brought to a future educational session.	Closed
29/06/17	Stuart Richardson to contact DARS regarding standard data destruction timescales and processes where data processing is moving from one data processor to another.	Stuart Richardson	03/08/17: It was thought that this had now been completed. IGARD requested an email summary of the action taken so that the action could be closed. 24/08/17: Ongoing.	Open
06/07/17	Stuart Richardson to circulate a suggested change to the updated 'substantive employees' wording for discussion out of committee.	Stuart Richardson	13/07/17: This proposed change had been circulated by email and IGARD members were asked to respond. 24/08/17: It was anticipated an update on this would be brought to the following IGARD meeting.	Open
06/07/17	Stuart Richardson to ensure that privacy notice checklists are provided for all DSfC applications for a trial period of three months from 13 July IGARD meeting.	Stuart Richardson	24/08/17: Ongoing.	Open
20/07/17	Garry Coleman to provide an update within two weeks on how NHS Digital manage the risk involved in CCGs using South Central and West CSU as a data processor in light of data sharing breaches and recent audits.	Garry Coleman	10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks. 24/08/17: IGARD received a verbal update on the work that had taken place following both audits and verbal assurances that NHS Digital were content with the level of risk involved in this organisation continuing to act as a data processor. IGARD welcomed this update and requested written confirmation.	Open
20/07/17	Garry Coleman to categorise different standard	Garry	24/08/17: Ongoing.	Open

	lengths of indicative data retention periods for general research and clinical trials, with appropriate justification.	Coleman		
27/07/17	Arjun Dhillon to provide information for IGARD about the robustness of different funding processes and how this might affect the level of scrutiny applied to or information included in applications provided to IGARD.	Arjun Dhillon	10/08/17: Ongoing. It was thought that this action might be addressed within the context of a forthcoming paper on a risk-based approach to application, which it was anticipated would be brought to IGARD for discussion soon. 24/08/17: Ongoing, pending wider work on a risk-based approach.	Open



## Appendix B: Out of committee report (as of 11/08/17)

These applications were previously recommended for approval with conditions by IGARD, and since the previous Out of Committee Report the conditions have been agreed as met out of committee.

NIC reference	Applicant	IGARD meeting date	Recommendation conditions as set at IGARD meeting	IGARD minutes stated that conditions should be agreed by:	Conditions agreed as being met in the updated application by:	Notes of out of committee review (inc. any changes)
NIC-148100-6RFK9	University College London (MR1)	03/08/2017	<ul style="list-style-type: none"> <li>Confirmation of whether the study privacy notice is considered to meet NHS Digital's nine criteria.</li> </ul>	IGARD Chair	Acting IGARD Chair (Kirsty Irvine)	The IGARD Chair requested additional text insertion: <i>NHS Digital has reviewed the draft Privacy Notice (and now included in section 4 - Fair Processing) against the criteria and confirm we are content that this meets the 9-point check.</i>
NIC-10459-G9T3P	London Borough of Richmond Council	20/07/2017	<ul style="list-style-type: none"> <li>Confirmation that the individuals who will access the data are substantive employees of both Councils.</li> <li>Adding a special condition that data should not be disseminated until the relevant data destruction certificates have been provided.</li> </ul>	IGARD Quorum (3)	IGARD Quorum (3)	IGARD suggested text be amended to 'Richmond' within Section 5b text: "substantive employees of either <b>Richard</b> or Wandsworth Council"
NIC-302473-	University of	27/07/2017	<ul style="list-style-type: none"> <li>Providing evidence of renewed REC</li> </ul>	IGARD Chair	Acting IGARD	N/A

K6R0Z	Cambridge		approval as the documentation provided appeared to have expired in January 2017		Chair (Kirsty Irvine)	
NIC-359603-D2Q6M	CQC	01/06/2017	<ul style="list-style-type: none"> <li>Confirmation that NHS Digital are content that the privacy notice for CQC meets the nine minimum criteria. In order to meet these nine point criteria IGARD noted that CQC should update their privacy notice to explain the role of ATOS in processing this data, to remove a statement that certain identifiers are 'deemed identifiable' by NHS Digital, and to clarify a statement that they will not identify individuals. IGARD requested sight of the updated privacy notice.</li> </ul>	IGARD Quorum (3)	IGARD Members (2), Deputy Caldicott Guardian, Director Data Dissemination	IGARD requested additional text insertion: <i>NHS Digital has reviewed the draft Privacy Notice (and now included in section 4 - Fair Processing) against the criteria and confirm we are content that this meets the 9-point check.</i>
NIC-112258-C9G8J; NIC-94822-W1K3T; NIC-94879-K5S4D; NIC-82384-W1T6C	Group 4 CCGs: NHS Erewash CCG; NHS Hardwick CCG; NHS North Derbyshire CCG; NHS Southern Derbyshire CCG	29/06/2017	<ul style="list-style-type: none"> <li>The CCGs should update their privacy notices to accurately describe the type of data used, how individuals can opt out, what organisations data is shared with and correct any misleading statements.</li> </ul>	IGARD Chair	Acting IGARD Chair (Kirsty Irvine)	N/A

In addition the following applications were not considered by IGARD but have been progressed for IAO and Director extension/renewal:

- None