

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 13 July 2017

Members: Sarah Baalham, Jon Fistein, Kirsty Irvine, Eve Sariyiannidou

In attendance: Louise Dunn, Frances Hancox, Louise Hill, Dickie Langley, Kirsty Oldroyd, Stuart Richardson, Dave Roberts, Steve Smith, Joanne Treddenick, Kimberley Watson, Vicki Williams

Apologies: Joanne Bailey, Anomika Bedi, Chris Carrigan, Nicola Fear, James Wilson

1	<p>It was agreed that Sarah Baalham would act as chair for this meeting.</p> <p>Declaration of interests</p> <p>Jon Fistein declared a conflict of interests in the University of Leeds application NIC-315999-W2W4C due to working relationships with the particular applicant. It was agreed that he would not participate in the discussion of that application.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 6 July 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>Out of committee recommendations</p> <p>An out of committee report was provided (see Appendix B).</p>
2	<p>Data applications</p>
2.1	<p><u>NHS England data sharing - GP appointments and waiting times (Presenter: Dave Roberts)</u></p> <p>Application: This paper on aggregated management information for General Practice Workload Data was presented to IGARD for information only. IGARD were informed that aggregated data would be made publically available via the NHS Digital website as part of a statistical publication at a later date, but that prior to this there was a need to share aggregated data with NHS England in order to work collaboratively to improve data quality.</p> <p>Discussion: IGARD expressed their support in principle for this use of data but it was agreed that it would be helpful for the paper to more clearly describe what type of data NHS Digital envisaged would be published as a later date. It was acknowledged that at present this could not be completely confirmed due to ongoing work to review and improve data quality.</p> <p>IGARD queried whether small number suppression would be applied and it was confirmed that this would be reviewed by NHS Digital's Disclosure Control Panel.</p> <p>Outcome: IGARD suggested that it would be helpful for the paper to contain more information about what type of data NHS Digital intended to publish. In addition IGARD agreed they would welcome an update on this work in future.</p>

2.2

CHKS Ltd (Presenter: Louise Dunn) NIC-10891-M2Y6Z

Application: This application requested an amendment to the applicant's current data sharing agreement, which had most recently been renewed via IAO and Director approval in April 2017. No additional data was requested at this time with the requested amendment being to use data for an additional purpose relating to performance improvement. IGARD were informed that although section 3B of the application listed data requested, the dissemination of this data had already been approved but had not yet been disseminated.

Discussion: IGARD suggested that where the application described how information would be put into the public domain, it would be helpful for this to be explained more clearly and to state that the applicant would issue press releases. In addition IGARD suggested that CHKS should update their information so that references to the HSCIC instead referred to NHS Digital.

A reference to 'substantive employees' was queried and IGARD suggested this wording should be amended to be clear this referred to substantive employees of CHKS Ltd only. It was noted that the applicant's DPA registration wording currently did not refer to using data about patients and that NHS Digital had raised this with the applicant. There was a discussion about the amendments made to section five of the application and IGARD suggested that while section 5A had been somewhat confusingly written, section 5B had described the use of data more clearly.

IGARD noted that there was currently an open action for NHS Digital regarding the use of data storage or backup locations and how the data processing role of these organisations should be reflected in applications. IGARD highlighted that it would be important to resolve this action to determine any implications for this type of application, and in particular suggested that NHS Digital should consider the involvement of Six Degrees in this application in light of the open action.

Outcome: Recommendation to approve.

Section five of the application should be amended to include more detail about how information will be made publicly available and to explain that CHKS will publish press releases about the outcomes. A reference to substantive employees should be amended to be clear this refers to employees of CHKS. In addition IGARD suggested that CHKS should update any references to HSCIC to instead refer to NHS Digital.

IGARD noted that there was currently an open action with NHS Digital regarding data storage and backup locations and how their data processing role was reflected in applications and suggested that NHS Digital should consider the involvement of Six Degrees in this application in light of that action.

IGARD advised the applicant should review their websites 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 notices 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.

2.3

Cardiff University - The LUCI Study: The long-term follow-up of urinary tract infection (UTI) in childhood (Presenter: Kimberley Watson) NIC-74625-S1Q8X

Application: This was a new application for the dissemination of pseudonymised Hospital Episode Statistics (HES) data for a specific cohort, with the applicant to provide cohort identifiers to NHS Digital to enable linkage before providing the pseudonymised data to Swansea University's Secure Anonymised Information Linkage (SAIL) Databank acting as data processor.

2.4	<p>Discussion: There was a discussion about the cohort that would be included in this data dissemination and it was confirmed that this consisted of the former DUTY and EURICA cohorts, with the 'routinely sampled' participants who had not been part of those cohorts only being part of the SAIL data processing. It was noted that fair processing efforts had been made to contact the existing cohorts. A query was raised about descriptions in the application of SAIL as handling 'anonymised' data as IGARD suggested it would be more appropriate for the data usage described in this application to be considered pseudonymised.</p> <p>IGARD discussed the identifiers that would be provided to NHS Digital and noted that this included sex, which was not specifically listed as part of the applicant's section 251 support. Confirmation was requested of whether sex was considered an identifier, and if so whether it was covered by the section 251 support.</p> <p>There was a brief discussion about the role of the funder in reviewing reports prior to publication. It was agreed that this wording in the application should be amended that this would not involve any suppression of outputs, and to more clearly explain the reason for this review.</p> <p>IGARD noted that a supporting document provided with the application referred to co-investigators based at the University of Bristol and the University of Oxford. It was agreed the application should be amended to include a clear statement that these organisations would not be involved in this application as data processors.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Confirmation of whether sex is considered an identifier, and if so whether sending this data item to NHS Digital is covered by section 251 support. • Confirmation that the University of Bristol and the University of Oxford are not involved in this application as data processors. <p>A reference to SAIL as an anonymised database should be amended to remove the reference to 'anonymised'. A reference to the funder reviewing the report prior to publication should be amended to explain the reason for this and to be clear that outputs would not be suppressed. IGARD advised that both organisations should update their DPA registration to reflect the use of healthcare data about patients or health service users.</p> <p>It was agreed the above conditions would be reviewed out of committee by IGARD.</p> <p><u>Imperial College London – Single Sigmoidoscopy Screening in Prevention of Bowel Cancer (Presenter: Louise Dunn) NIC-148071-QHNM8</u></p> <p>Application: This application requested an extension for the applicant to continue to hold Personal Demographics Service (PDS) data, cancer registrations and ONS mortality data. No further data was requested other than the data that had been previously provided to the applicant.</p> <p>Discussion: IGARD discussed the legal basis for this data processing and given the dates of the supporting documents provided, requested confirmation that the section 251 support continued to be in place. It was suggested that this could be confirmed by providing the most recent letter, if available. In addition it was agreed that the Microdata Release Panel approval details should be added to the application alongside the Approved Researcher details.</p> <p>It was agreed that as no new data would be disseminated under this agreement, instances where the application described how data would be processed once received should be updated to be applicable to how data was currently being processed.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Confirmation from NHS Digital of the legal basis under section 251, with provision of the most recent letter from CAG.
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2.5	<ul style="list-style-type: none"> • Details of the Microdata Release Panel approval should be provided. References to how the applicant will process data once received should be updated to be clear that no new data will be provided under this application. It was agreed the above conditions would be reviewed out of committee by IGARD. <p><u>London School of Hygiene and Tropical Medicine - Cytogenetic Assessment of British Nuclear Test Veterans and their Families (Presenter: Kimberley Watson) NIC-104802-G2J0P</u></p> <p>Application: This was a new application requesting linkage of a specific patient cohort to PDS data under section 251 support, as part of a study into health outcomes for nuclear test veterans and their families. It was noted that the study was in collaboration with the Brunel London University but that organisation would not access record level data or act as data controller in any way as part of this application. IGARD were informed that this application focused on confirming which cohort members were deceased or had certain cancer diagnoses, and providing demographic details including general practice information to the applicant. The applicant would then contact the cohort to seek their consent to participate in the study, and it was noted that NHS Digital were currently working with the applicant to review the consent materials that would be used.</p> <p>Discussion: IGARD noted that the section 251 support indicated that children would not be included, and queried what steps had been taken to ensure that children would be excluded from the data processing described in this application. In addition it was noted that the section 251 application indicated that HES data was not requested and IGARD suggested that the abstract should be updated to remove a statement that the section 251 approval included the use of HES data. It was confirmed that HES data was not requested under this application. Overall it was agreed that the abstract was not sufficiently clear about what data processing would take place under this application, versus what would likely be requested in future and it was agreed this should be amended for greater clarity.</p> <p>A query was raised about whether the section 251 support covered the case cohort of veterans in addition to the control cohort, as in some places the outcome letter only seemed to refer to the control cohort. It was agreed that this would need to be confirmed.</p> <p>There was a discussion about the importance of fair processing and IGARD queried at what point in time information would be made available on the study website. It was agreed that this should be published a minimum of one month before data would be disseminate, to ensure that individuals would have the opportunity to opt out if they wished to do so. IGARD acknowledged that individuals would later have the option to choose not to consent to participate in the study, but IGARD felt that individuals should also have the ability to opt out of all data sharing before their details were shared as part of this application particularly given the possible sensitivities around nuclear testing and the fact that family members would be contacted.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • Confirmation that the section 251 support is considered to cover the case cohort as well as the control cohort. • Confirmation that data will not be disseminated until one month after fair processing information has been published, to allow the opportunity for individuals to opt out first. <p>The application should be amended to provide more information about what controls are in place to ensure that children under a certain age will not be included in the cohort, given that the section 251 support excludes children. A reference in the abstract to the study having section 251 support for the use of HES data should be removed as from the documents provided this did not appear to be covered. The abstract should also be amended to more clearly explain what use of data is requested in this application versus any future uses that the applicant intends to request at a later date.</p> <p>It was agreed the above conditions would be reviewed out of committee by IGARD.</p>
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University of Leeds - Liaison Psychiatry Service configurations and referral patterns and their effects on outcomes (Presenter: Louise Dunn) NIC-315999-W2W4C

It was noted that due to a conflict of interest, Jon Fistein would not participate in the consideration of this application and that IGARD would therefore not be quorate for this item.

Application: This application was to extend an existing data sharing agreement for the use of pseudonymised HES data for academic research. IGARD were informed that there had been delays following the applicant's original approval that meant data had not been disseminated as quickly as originally planned, and therefore the analysis set out in the original application was now incorporated into a sub-project of the funded research project.

Discussion: IGARD queried the history of this application and when data had been disseminated, as this was unclear from the description given within the application. Clarification was requested of when data had first been disseminated and whether this was the result of an earlier DAAG recommendation.

It was noted that the funding letter provided referred to a contract, but that the funding contract had not been provided. IGARD agreed it would be helpful to have further details of the funding conditions.

IGARD noted that the application referred to a wider project of which this work was a sub-project, but it was considered unclear how the processing activities described related to the wider project. It was agreed it would be helpful to clarify this within the processing activities section of the application.

The role of Iron Mountain was queried and IGARD suggested that NHS Digital should consider this in light of the currently open action relating to data storage locations and how this data processing is reflected in applications.

It was noted that the legal basis for dissemination under the Health and Social Care Act referred to section 261(1), and IGARD suggested this should be updated to also refer to section 261(2)(b)(ii).

Outcome: *IGARD were unable to reach a recommendation as there was not a quorum of members able to comment on the application. The following comments were made:*
The application should be amended to be clear at what point in time data was disseminated to the applicant, and whether this had been under an older DAAG recommendation.
Confirmation of the funding conditions and dates should be provided, possibly by providing a copy of the funding contract referred to.
Section five should more clearly explain the wider project and how the processing activities described relate to the wider project.
The legal basis under the Health and Social Care Act 2012 should be amended to also refer to section 261(2)(b)(ii).
IGARD noted that there was currently an open action with NHS Digital regarding data storage and backup locations and how their data processing role was reflected in applications and suggested that NHS Digital should consider the involvement of Iron Mountain in this application in light of that action.

2.7

Morecambe CCG (Presenter: Stuart Richardson) NIC-90135-P7Z0F

Application: This was a new application from Morecambe CCG, a newly formed CCG that included the former North Lancashire CCG as well as some general practices that had formerly been part of Cumbria CCG. The application requested pseudonymised Secondary

	<p>Uses Service (SUS), local flows, mental health (MHMDS, MHLDDS, MHSDS), Improving Access to Psychological Therapies (IAPT), maternity (MSDS), Children and Young People's Health (CYPHs), and Diagnostic Imaging Dataset (DIDs) data for the purpose of commissioning as well as pseudonymised SUS data for invoice validation and SUS data identifiable at the level of NHS number for risk stratification. Midlands and Lancashire CSU and North of England CSU would act as data processors. IGARD were informed that the CCG had been reviewed as passing NHS Digital's nine point privacy notice check.</p> <p>Discussion: IGARD suggested that the CCG should update their privacy notice to reflect the new CCG name, and also to include the role of North of England CSU as a data processor. In addition it was noted that the special condition wording around privacy notices in the application should be updated in line with current advice wording. An error was noted in the application summary section as this referred to using identifiable data for invoice validation, which was incorrect.</p> <p>A query was raised about the data destruction process following the change in CCG boundaries. It was agreed that the data sharing agreement should include a special condition that any parts of the former CCGs that had not merged into Morecambe CCG, but had previously held NHS Digital data for areas that were now within Morecambe CCG, should be required to provide relevant data destruction certificates.</p> <p>Outcome: Recommendation to approve.</p> <p>A reference to invoice validation using identifiable data should be amended to refer to pseudonymised data. A special condition should be added that any parts of the former CCGs that have not merged into Morecambe Bay CCG should provide appropriate data destruction certificates.</p> <p>IGARD noted that the CCG should update their privacy notice to reflect the change of CCG name, and to mention North of England CSU as a data processor. The privacy notice special condition should be updated in line with the current IGARD standard advice wording.</p> <p>2.8 <u>Group 2 CCGs¹ (Presenter: Stuart Richardson) GA03-AMD-SC</u></p> <p>Application: This application requested an amendment to an existing agreement to add the use of identifiable SUS data for invoice validation, to change the data processor for commissioning purposes from South East CSU to South Central and West CSU, and to change the data processor for risk stratification South East CSU to Docobo Ltd. IGARD were informed that both CCGs had been reviewed as passing NHS Digital's nine point privacy notice check.</p> <p>Discussion: IGARD noted that the DPA registration expiry date listed on the application for Docobo Ltd had now passed, and asked for the application to be amended to reflect the new expiry date.</p> <p>The CCGs' privacy notices were discussed and IGARD raised some concerns about the use of the term 'anonymised' to describe some of the data that would be used, as it was felt this could be misleading and did not fully reflect the data processing that would take place.</p> <p>It was agreed that a special condition should be included in the application about the requirement for the CCGs' former data processors to appropriately destroy data.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • The CCGs should update their privacy notices in line with NHS Digital's nine criteria and in particular ensure the use of anonymised data is described appropriately and to
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¹ NHS Crawley CCG NIC-91838-H0B9N; NHS Horsham & Mid Sussex CCG NIC-91871-D2W1N

	<p>remove any misleading statements.</p> <p>The application should be amended to include the new DPA registration expiry date for Docobo Ltd.</p> <p>A special condition should be added that the former data process South East CSU (now part of North East London CSU) should provide a data destruction certificate for the data that they will no longer process on behalf of the CCGs, allowing for a one month overlap with the new data processor. The privacy notice special condition should be updated in line with the current IGARD standard advice wording.</p> <p>It was agreed the above conditions would be reviewed out of committee by IGARD.</p>
2.9	<p><u>Group 2 CCGs² (Presenter: Stuart Richardson) GA05-AMD-CM</u></p> <p>Application: This application requested an amendment in order for the two CCGs to use PI Limited (PI Care and Health) to link pseudonymised SUS data with social care data (provided by the Local Authority) for the purpose of commissioning. PI Limited would make use of the Open Pseudonymiser tool to carry out this linkage in a way that would not enable the data to be re-identified by the CCG, and it was confirmed the linked data would not be provided back to the Local Authority. IGARD were informed that the privacy notices for these CCGs had not yet passed the NHS Digital nine point review.</p> <p>Discussion: IGARD welcomed the provision of the privacy notice checklists for these CCGs. It was suggested that reviewers should carefully consider how they reviewed CCGs' use of wording such as 'we may', as in some cases this could be confusing or misleading but in other cases this wording might be appropriate. IGARD noted that the privacy notices should be updated to refer to PI Health and Care Ltd and to the particular data processing described in this application.</p> <p>A query was raised about how the application described the new purpose for which the linked data would be used and it was felt that this was not sufficiently clear, particular regarding population health profiling.</p> <p>There was a brief discussion about what contractual agreements would be in place for the Local Authority sharing data for linkage, and how the general public would be informed that their data would be shared by the Local Authority for this purpose. It was suggested that it might be helpful for IGARD to discuss this at a future educational session in light of wider discussions around privacy notices or providing case studies of how data is used.</p> <p>IGARD queried the legal basis for social care data to flow from the Local Authority for linkage; it was confirmed that the Local Authority would pseudonymise data using the Open Pseudonymiser tool before the data was transferred to PI Health and Care Ltd and that PI Health and Care Ltd would not be able to re-identify the data. It was agreed that the application should be amended to specify that the DSCRO would not participate in the pseudonymisation of social care data, unlike other similar applications where the DSCRO would have a role in this.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • The CCGs must update their privacy notices in order to meet the NHS Digital nine point criteria. In particular IGARD advised that the notices should be updated to reflect the involvement of PI Health and Care Ltd, and to describe the particular use of data set out in this application. <p>Section five should be amended to provide more specific details about the new purpose for which health data will be used in relation to health population profiling. In addition section five should be amended to include a statement that the DSCRO is not involved in the pseudonymisation of social care data.</p>

² NHS Shropshire CCG NIC-41543-R8Q9Q; NHS Telford & Wrekin CCG NIC-41537-D0P0M

	<p>IGARD advised that the PI Health and Care Ltd DPA registration should be updated to include patients or health service users. The privacy notice special condition should be updated in line with the current IGARD standard advice wording.</p> <p>It was agreed the above conditions would be reviewed out of committee by IGARD.</p>
2.10	<p><u>Group 4 CCGs³ (Presenter: Stuart Richardson) GA01-CS-AMD</u></p> <p>Application: This was an amendment application to link pseudonymised SUS, local provider flows, mental health data, IAPT, CYPHS, MSDS and DIDS data to social care and general practice data (provided by Local Authorities and general practices directly to the data processor). IGARD were informed that two of the CCG privacy notices had not yet passed the NHS Digital nine point check.</p> <p>Discussion: IGARD discussed the described pseudonymisation process, as it was noted that the DSCRO would provide a pseudonymisation key to the Local Authority and also to the CSU in order for them to consistently pseudonymise data but that this flow of a pseudonymisation key did not seem to be reflected on the data flow diagram. It was agreed that further clarification was needed about the black box process and the use of pseudonymisation keys, with a clear explanation of why the applicant felt that the DSCRO was not participating in the pseudonymisation process.</p> <p>There was a discussion about the risk stratification data flows, and it was noted that while the data flow diagram indicated that pseudonymised risk stratification data would flow from 'database 1' to 'database 2' within the CSU this was not described as part of the processing activities within the actual application. It was agreed the application should be amended to reflect the processing set out in the diagram.</p> <p>IGARD discussed the CCG privacy notices and noted that although the application itself stated that two had passed the nine point review, the actual checklists provided showed that all four CCGs had failed the review.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • The CCGs must update their privacy notices in order to meet the NHS Digital nine point criteria. • Clarification of the process described in section five around the use of black box and pseudonym keys to clarify the process and why the applicant considers that the DSCRO does not participate in the pseudonymisation process of social care data. <p>The data flow diagram should be updated to reflect the flow of a pseudonymisation key from the DSCRO to the Local Authority. The risk stratification data flows within the CSU should be reflected within the application. The privacy notice special condition should be updated in line with the current IGARD standard advice wording.</p> <p>It was agreed the above conditions would be reviewed out of committee by IGARD.</p>
2.11	<p><u>Group 5 CCGs⁴ (Presenter: Stuart Richardson) GA03-AMD-CM</u></p> <p>Application: This was an amendment application to link pseudonymised SUS, Local Provider flows, Mental Health Data, IAPT, CYPHS, MSDS and DIDS data to social care data provided by Local Authorities, with use of the Open Pseudonymiser tool to enable linkage. IGARD were informed that the CCG privacy notices had been reviewed as passing the NHS Digital nine</p>

³ NHS Bath and North East Somerset CCG NIC-116524-S2N2H; NHS North East Hampshire and Farnham CCG NIC-116548-M7Z5F; NHS Oxford CCG NIC-116582-F2F2J; NHS Wiltshire CCG NIC-116560-R7F9J

⁴ NHS Birmingham Cross City CCG NIC-41087-X6Y1L; NHS Birmingham South and Central CCG NIC-41097-Y5P2Y; NHS Sandwell and West Birmingham CCG NIC-41125-L4F2X; NHS Walsall CCG NIC-41140-T4H0T; NHS Wolverhampton CCG NIC-41158-X3V7D

	<p>point check.</p> <p>Discussion: There was a discussion of the CCG privacy notices and IGARD noted that the description of how anonymised and ‘pseudo-anonymised’ data would be used seemed unclear, and did not seem to reflect the use of social care data described in this application or the involvement of PI Health and Care Ltd as a data processor. IGARD noted that some of the privacy notice reviews seemed to have taken place some months previously, and it was suggested that they should be re-reviewed to take into account this new use of data.</p> <p>IGARD asked for the application to be amended to reflect that the DSCRO would not participate in the pseudonymisation of social care data.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> The CCGs must update their privacy notices in order to meet the NHS Digital nine point criteria. In particular IGARD advised that the notices should be updated to reflect the involvement of PI Health and Care Ltd, to describe the particular use of data set out in this application, and to more clearly describe the use of anonymised or pseudonymised data. <p>Section five should be amended to provide more specific details about the new purpose for which health data will be used in relation to health population profiling. In addition section five should be amended to include a statement that the DSCRO is not involved in the pseudonymisation of social care data.</p> <p>IGARD advised that the PI Health and Care Ltd DPA registration should be updated to include patients or health service users. The privacy notice special condition should be updated in line with the current IGARD standard advice wording.</p> <p>It was agreed the above condition would be reviewed out of committee by IGARD.</p>
2.12	<p><u>North Cumbria CCG (Presenter: Stuart Richardson) NIC-36767-G4H9Z</u></p> <p>Application: This application was from North Cumbria CCG, which had formerly had a data sharing agreement in place for Cumbria CCG before the change in CCG name and boundaries. This application was to reflect the change in name and to request additional historic pseudonymised data due to the change. IGARD were informed that the privacy notice had been reviewed as passing the NHS Digital nine point check.</p> <p>Discussion: IGARD agreed that due to the change in CCG boundaries, a special condition should be added to the application to ensure appropriate data destruction.</p> <p>Some concerns were raised about the CCG privacy notice as it was felt that the terminology used was unclear, and a description about the type of data that would be stored within a safe haven could be potentially misleading. It was also suggested that references to the former North Lancashire CCG should be removed to avoid confusion.</p> <p>IGARD queried a reference to the Nexent Data Centre and asked for the application to be amended to reflect that this data centre was part of the North of England CSU.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> The CCG must update their privacy notice in order to meet the NHS Digital nine point criteria. In particular IGARD advised that the notice should be updated to remove a statement that health data would not be shared without a patient’s explicit consent, and to clarify a statement that data within a safe haven cannot be identified. <p>A special condition should be added that North Cumbria CCG and its data processors should provide appropriate data destruction certificates for data relating to any parts of the former Cumbria CCG that have not merged into North Cumbria CCG.</p> <p>Section one of the application should be amended to be clear that the Nexent Data Centre address listed is part of North of England CSU. The privacy notice special condition should be</p>

	<p>updated in line with the current IGARD standard advice wording. It was agreed the above condition would be reviewed out of committee by IGARD.</p>
2.13	<p><u>NHS Thurrock CCG (Presenter: Stuart Richardson) NIC-81831-Y2N8H</u></p> <p>Application: This application for pseudonymised SUS, local provider flows, mental health data, IAPT, CYPHS, MSDS and DIDS data requested the use of the MedeAnalytics pseudonymisation at source tool. IGARD were informed that the CCG's privacy notice had passed the NHS Digital nine point check.</p> <p>Discussion: A query was raised about the role of Interxion and it was confirmed that a special condition was in place, as had been agreed with NHS Digital information security staff, to confirm that Interxion staff must not access the data shared under this agreement.</p> <p>There was a discussion of the CCG privacy notice and IGARD queried a reference to collaboration and data sharing between CCGs, as this was not part of the current application; it was clarified that this was covered under a separate data sharing agreement. A reference to sharing data with NA Wilson Boston Consulting Group was queried as it was unclear whether this referred to any NHS Digital data and if so what data sharing agreement this was covered by. In addition IGARD noted that some of the privacy notice links currently did not seem to work.</p> <p>IGARD queried whether the CCG and its data processors already held any NHS Digital data for the purpose of commissioning, as this was not currently reflected in the application. It was agreed that section three should be updated to record the data already held. IGARD also queried a reference in the application to linking 'data provided by NHS Digital with historical data already held within the MedeAnalytics system' as it was unclear what historic data this referred to.</p> <p>It was suggested that some of the detail provided in the summary section of the application should also be incorporated into section five to ensure this was reflected in the data sharing agreement and in the information published on the NHS Digital data release register. IGARD queried the description in the application of this data as anonymised, as it was considered more appropriate to describe the data as pseudonymised.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • The CCG must update their privacy notice in order to meet the NHS Digital nine point criteria. In particular IGARD advised that the notice should be updated to refer to MedeAnalytics and to correct any broken links, and IGARD queried a reference to NA Wilson Boston Consulting Group receiving anonymised patient data. • Clarification of a reference to linkage with 'historic data already held by MedeAnalytics'. <p>Section three should be updated to list the data already held for the purpose of commissioning. In addition section five should be amended to incorporate some of the detail from the summary section. The application should be amended to refer to the data as pseudonymised rather than anonymised. The privacy notice special condition should be updated in line with the current IGARD standard advice wording.</p> <p>It was agreed the above condition would be reviewed out of committee by IGARD.</p>
2.14	<p><u>HMRC (Presenter: Steve Smith) NIC-124179-S2G0T</u></p> <p>Application: This application was for HMRC to provide (based on parental consent) the NHS number and date of birth of newborn children to NHS Digital, and for NHS Digital to use PDS data to confirm either a match or no match. If a match was confirmed then HMRC would use this confirmation to assist in processing Child Benefit payments more quickly.</p>

	<p>Discussion: IGARD acknowledged the potential benefits of this use of data and in processing benefits payments more quickly for new parents and it was felt that it was likely that this could result in health and adult social care benefits in line with the requirements of the Care Act 2014. However it was felt that the application should be amended to more explicitly describe the potential health or social care benefits, potentially by explaining the possible harm that could arise from delays to benefit payments.</p> <p>IGARD discussed the proposed consent process and queried what limitations were in place to ensure that the person completing the online form and therefore providing a child's NHS number, and consent for the child's details to be shared with NHS Digital, was an appropriate individual to consent on behalf of the child. It was agreed that either the consent form should be updated to explicitly require confirmation of this, or alternatively if appropriate controls were already in place earlier in the consent process then HMRC should confirm this. In addition it was agreed that the consent form itself should be updated to include some brief details about the data processing that would be carried out by NHS Digital using the data provided by individuals.</p> <p>A query was raised about how HMRC would act in instances where NHS Digital was unable to confirm a match, and whether in future parents would be expected to consent to this use of data as standard practice. IGARD were informed that no implications should be drawn from the lack of a match, as this could be due to a number of reasons such as poor data quality; any requirement from HMRC to use the data for any other purposes would need to be subject to an updated application to NHS Digital.</p> <p>An error was noted in how the legal basis for dissemination under the Health and Social Care Act 2012 was described in section three of the application, as it was explained that references to consent by 'the relevant person' in this section of the Act did not refer to an individual.</p> <p>Outcome: Recommendation to approve, subject to:</p> <ul style="list-style-type: none"> • The consent form should be updated to include a requirement for individuals to confirm that they are able to give consent on behalf of the child for the child's data to be processed. Alternatively HMRC should confirm that an individual could not complete the form unless they are an appropriate person to give consent on behalf of the child. • The consent form should also more clearly explain the data processing that will be carried out by NHS Digital. <p>The application should be amended to more clearly describe the benefits of this use of data, including the potential harm that could be caused by delays to payments of child benefit. The legal basis under consent referred to in section three should be amended to instead refer to informed patient consent.</p> <p>It was agreed the above conditions would be reviewed out of committee by IGARD.</p>
3	<p>Any other business</p> <p><u>National Audit Office NIC-382334-Y2B1C</u></p> <p>IGARD received a verbal update that following IGARD's discussion of this application at the 6 July 2017 meeting NHS Digital had approved the dissemination of data as requested, on the basis that NHS Digital felt the points raised by IGARD had been addressed including confirmation of legal basis. IGARD were presented with this update for information only and were not asked to reach a recommendation; IGARD noted they had previously deferred making a recommendation as they had not been satisfied that the legal basis was clearly demonstrated and that this update did not alter the previous deferral.</p> <p>IGARD noted the update and requested sight of an email confirming the reason for this approval, as this document had been inadvertently omitted from the meeting papers.</p>

	Action: Dickie Langley to provide an email relating to the approval of NIC-382334 National Audit Office.
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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>	Open

			and to raise the topic again at a later date. 13/07/17: Ongoing.	
23/03/17	To provide a response to previously raised IGARD queries about indemnity.	IGARD Secretariat	06/04/17: An update had been provided and the action remained open. 13/04/17: This was ongoing within NHS Digital. 01/06/17: The Caldicott Guardian had request a meeting with the IGARD Chair and others to discuss this. 08/06/17: A call had been scheduled to discuss this. 15/06/17: Ongoing pending the scheduled call. 22/06/17: This call had taken place and a note would be circulated to confirm the outcome. 29/06/17: Ongoing. 13/07/17: This action had been completed and was closed.	Closed
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	13/07/17: 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. 13/07/17: Ongoing.	Open
04/05/17	Robyn Wilson and Joanne Treddenick to agree updated wording for the PCMD application template on type two objections, ensuring that this is consistent with published NHS Digital information about exceptions to type two objections.	Robyn Wilson	11/05/17: The IG Advisor gave a verbal update with confirmation that in October 2016 NHS Digital had confirmed a decision that type two objections would not be considered to apply to this flow of data due to the specific legal gateways around ONS data sharing. Further work was planned to agree the specific application wording to describe this. 18/05/17: IGARD were informed by the Secretariat that Robyn and Joanne had agreed new draft wording, and that this would be circulated to IGARD for discussion out of committee. 25/05/17: The new draft wording had been circulated out of	Open

			<p>committee and members were reminded to provide any comments by email if they wished to do so.</p> <p>08/06/17: There had been a further discussion of the wording by email.</p> <p>15/06/17: IGARD had received an updated email response to the queries raised. IGARD were asked to provide any comments on this by the following week's meeting.</p> <p>22/06/17: This was currently with an IGARD member to respond.</p> <p>29/06/17: Ongoing pending a response from IGARD members.</p> <p>13/07/17: It was agreed IGARD members would be reminded of the need to respond and close this action.</p>	
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	<p>15/06/17: IGARD had been advised by email that a paper about this would be submitted to an upcoming IGARD meeting.</p> <p>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.</p> <p>13/07/17: Ongoing.</p>	Open
01/06/17	Garry Coleman to provide information about the process for applicants moving from the use of identifiable to pseudonymised data and what standard steps are taken when they opt to retain identifiable data as well as receiving new pseudonymised data.	Garry Coleman	13/07/17: Ongoing.	Open
15/06/17	NHS Digital to provide information about the standard approach to data destruction where an applicant has been provided with data for linkage, and whether the original data should be retained as well as the linked data.	Jen Donald	13/07/17: Ongoing.	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	Stuart Richardson	<p>29/06/17: Ongoing. It was suggested it would be helpful to discuss this at an upcoming educational session.</p> <p>13/07/17: Ongoing.</p>	Open

	the ongoing training, and provide a copy of the outcome of this check to IGARD for information.			
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	13/07/17: Ongoing.	Open
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	13/07/17: 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.	Open
13/07/17	Dickie Langley to provide an email relating to the approval of NIC-382334 National Audit Office.	Dickie Langley		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		Open

Appendix B: Out of committee report (as of 07/07/17)

These applications were previously recommended for approval with conditions by IGARD, and the conditions have subsequently been agreed as met out of committee.

The following application conditions have been signed off by the IGARD Chair:

- NIC-86861 Doncaster CCG (*Considered at 20 April 2017 IGARD meeting*)

IAO and Director approvals

The following applications were not considered by DAAG or IGARD but have been progressed for IAO and Director extension/renewal only:

- NIC-351722-W7D4N CRAB Clinical Informatics
- NIC-09519-D5G0R Methods Analytics Ltd