

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 15 March 2018

Members: Sarah Baalham, Joanne Bailey, Anomika Bedi, Jon Fistein, Kirsty Irvine (Chair), Eve Sariyannidou.

In attendance: Helen Buckles, Arjun Dhillon, Duncan Easton, Belinda Garrow (observer), James Humphries-Hart, Dickie Langley, Stuart Richardson, Joanne Treddenick (item 2.6), Vicki Williams.

Apologies: Chris Carrigan, Nicola Fear.

1	<p>Declaration of interests</p> <p>Jon Fistein noted his professional links to NIC-77953 University of Leeds and would not be part of the discussion. It was agreed that Jon would not remain in the meeting for the discussion of that application.</p> <p>Review of previous minutes and actions</p> <p>The outcomes of the 8 March IGARD meeting were reviewed and were agreed as an accurate record of that aspect of the meeting.</p> <p>The minutes of the 8 March IGARD meeting were reviewed out of committee by IGARD following conclusion of the meeting, and subject to a number of minor changes were agreed as an accurate record of the meeting.</p> <p>Out of committee recommendations</p> <p>An out of committee report was received (see Appendix B).</p>
2	<p>Data applications</p>
2.1	<p><u>Group of 11 CCG's¹: A new application for 11 CCGs to act as Joint Data Controller and receive pseudonymised data based on the Sustainable Transformation Partnership (STP) Footprint to allow collaborative working (Presenter: Stuart Richardson / James Humphries Hart) GA01-NW-STP</u></p> <p>Application: This was a new application to receive pseudonymised data: Secondary Use Service+ (SUS+), Local provider flows (for commissioning), Mental Health Minimum Data Set, Mental Health Learning Disability Data Set, Mental Health Services Data Set, Maternity Services, Improving Access to Psychological Therapies, Children & Young People's Health Service, Community Services Data Set and Diagnostic Imaging Data Set to provide intelligence to support the commissioning of health services. The data (containing both clinical and financial information) is analysed so that health care provision can be planned to support the needs of the population within the Sustainable Transformation Partnership (STP) area. Each CCG will receive data for the entire STP region covered by all the CCG's in order to support each other proactively in delivering their commissioning agendas.</p> <p>NHS Digital noted that NHS West Cheshire CCG had updated the expiry date of their DPA, but it was not noted in the application presented.</p> <p>Discussion: IGARD noted that the data protection registrations for NHS Halton CCG and</p>

¹ NIC-140059-P1J9L - NHS Eastern Cheshire CCG; NIC-140060-F9N0T - NHS Halton CCG; NIC-140062-H3Z0Z - NHS Knowsley CCG; NIC-140065-F8D0Z - NHS Liverpool CCG; NIC-140068-N0H9G - NHS South Cheshire CCG; NIC-140073-W4P9Y - NHS South Sefton CCG; NIC-140074-C5C2Y - NHS Southport & Formby CCG; NIC-140078-H0X3Z - NHS St Helens CCG; NIC-140081-T0L8R - NHS Vale Royal CCG; NIC-140083-S4L3M - NHS Warrington CCG; NIC-140086-B5J9R - NHS West Cheshire CCG

NHS Knowsley CCG were due to expire in April 2018 and that NHS West Cheshire DPA registration expiry date would be updated within the application. IGARD also suggested that the CCG's update their DPA registration to clearly state that data is processed about patients or health care users.

IGARD suggested that the CCG's should review their fair processing against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice standards and update their privacy notice as soon as possible, and the CCG's consider the EU's GDPR on pseudonymised data. The EU General Data Protection Regulation (GDPR) 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 queried if the CCG's held data and if they would destroy the current data held. NHS Digital confirmed that only replicated data would be destroyed and IGARD suggested that it be clear within the special condition if any data is required to be destroyed and what that data would be, for transparency.

IGARD queried section 3 and the variability of years of data requested between the different datasets. NHS Digital confirmed that this was common and down to when various data sets were available and that some datasets were only available for those specific periods of time that had been requested.

IGARD queried section referencing 'each CCG to sign' and suggested that it be updated to read 'all CCG's to sign' for clarity and transparency. It was also suggested that section 5 be updated to reflect the fact that the CCG's were requesting 'locality data' rather than 'not national data'

IGARD suggested, to be clearer to a lay reader when published as part of the data release register, that additional background information about STP's be included at the start of section 5a, including their role.

IGARD suggested that section 5 be updated to reflect who would undertake the audit.

IGARD discussed the contractual arrangements in place (see AOB). **ACTION:** Stuart Richardson to provide a briefing note clarifying the contractual arrangements in place, the structure, enforcement strategy and how the agreements worked together so that the data disseminated by NHS Digital would be protected. Stuart Richardson agreed to provide an update to IGARD on the progress of this note by 5 April 2018.

Outcome: recommendation to approve. The recommendation to approve was reached by a vote of those present, with one member dissenting.

The following amendments were requested:

- To clarify if any data is to be destroyed and be clear what data is to be destroyed.
- To add to the start of section 5a additional background information from section 5b about STP's and their role.
- To amend relevant sentences in section 5 from 'each CCG to sign' to 'all CCGs to sign' for clarity.
- To amend section 5 to be clear that the CCG's require 'locality data'.
- To clarify in a section 5 where it references data is audited who would undertake the audit.

The following advice was given:

	<ul style="list-style-type: none"> • IGARD suggested West Cheshire CCG update their DPA expiry date within the application. • IGARD suggested all the CCG's update their DPA registration to more clearly state that data is processed about patients or healthcare users. • IGARD advised the CCG's should review their fair processing against the ICO's Privacy Notices Code of Practice to ensure it reflects 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.
2.2	<p><u>Group of 10 CCG's²: A new application for 10 CCGs to act as Joint Data Controller and receive pseudonymised data based on the Sustainable Transformation Partnership (STP) Footprint to allow collaborative working (Presenter: Stuart Richardson / James Humphries-Hart) GA02-NW-STP</u></p> <p>Application: This was a new application to receive pseudonymised data (Secondary Use Service+, Local provider flows (for commissioning), Mental Health Minimum Data Set, Mental Health Learning Disability Data Sets, Mental Health Services Data Set, Maternity Services, Improving Access to Psychological Therapies, Children & Young People's Health Service, Community Services Data Set and Diagnostic Imaging Data Set) to provide intelligence to support the commissioning of health services. The data (containing both clinical and financial information) is analysed so that health care provision can be planned to support the needs of the population within the Sustainable Transformation Partnership (STP) area. Each CCG will receive data for the entire STP region covered by all the CCG's in order to support each other proactively in delivering their commissioning agendas.</p> <p>Discussion: IGARD suggested that the CCG's should review their fair processing against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice standards and update their privacy notice as soon as possible, and the CCG's consider the EU's GDPR on pseudonymised data. The EU General Data Protection Regulation (GDPR) 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.</p> <p>IGARD queried if the CCG's held data and if they would destroy the current data held. NHS Digital confirmed that only replicated data would be destroyed and IGARD suggested that it be clear within the special condition if any data is required to be destroyed and what that data would be for transparency.</p> <p>IGARD queried section 3 and the variability of years of data requested between the different datasets. NHS Digital confirmed that this was common and down to when various data sets were available and that some datasets were only available for those specific periods of time that had been requested.</p> <p>IGARD queried section referencing 'each CCG to sign' and suggested that it be updated to</p>

² NIC-139091-F3T3H - NHS Bolton CCG; NIC-139113-X4X0L - NHS Bury CCG; NIC-139122-N4Y3Y - NHS Heywood, Middleton and Rochdale CCG; NIC-139139-M7X1M - NHS Manchester CCG; NIC-139169-Z2F1W - NHS Oldham CCG; NIC-139187-M9L0Y - NHS Salford CCG; NIC-139224-R7N7K - NHS Stockport CCG; NIC-139243-H6B1F - NHS Tameside & Glossop CCG; NIC-139233-S5R1F - NHS Trafford CCG; NIC-139257-D7C4N - NHS Wigan Borough CCG

	<p>read 'all CCG's to sign' for clarity and transparency. It was also suggested that section 5 be updated to reflect the fact that the CCG's were requesting 'local? data' rather than 'not national data'</p> <p>IGARD suggested, to be clearer to a lay reader when published as part of the data release register, that additional background information about STP's be included at the start of section 5a, including their role.</p> <p>IGARD suggested that section 5 be updated to reflect who would undertake the audit.</p> <p>IGARD noted that the Data Centre and the Tameside and Glossop Integrated Care NHS Foundation Trust Data Centre were listed as a storage locations and stated their view that it would be more appropriate to also list these organisations as additional data processors. It was acknowledged that there was currently an open action with NHS Digital regarding storage locations and how to reflect their role as data processors.</p> <p>IGARD discussed the contractual arrangements in place (see AOB). ACTION: Stuart Richardson to provide a briefing note clarifying the contractual arrangements in place, the structure enforcement strategy and how the agreements worked together so that the data disseminated by NHS Digital would be protected. Stuart Richardson agreed to provide an update to IGARD on the progress of this note by 5 April 2018.</p> <p>Outcome: recommendation to approve. The recommendation to approve was reached by a vote of those present, with one member dissenting.</p> <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • To clarify if any data is to be destroyed and be clear what data is to be destroyed. • To add to the start of section 5a additional background information from section 5b about STP's and their role. • To amend relevant sentences in section 5 from 'each CCG to sign' to 'all CCGs to sign' for clarity. • To amend section 5 to be clear that the CCG's require 'locality data'. • To clarify in a section 5 where it references data is audited who would undertake the audit. <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD advised the CCG's should review their fair processing against the ICO's Privacy Notices Code of Practice to ensure it reflects 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.
2.3	<p><u>Group of 8 CCG's³: An amendment for 8 CCGs to receive pseudonymised data based on the Sustainable Transformation Partnership (STP) Footprint to allow collaborative working. (Presenter: Stuart Richardson / James Humphries-Hart) GA04-NW-STP</u></p>

³ NHS Brent CCG - NIC-160958-K3J4W; NHS Central London CCG - NIC-160964-D7X8T; NHS Ealing CCG - NIC-160972-N7P2J; NHS Hammersmith and Fulham CCG - NIC-160991-T8Y5X; NHS Harrow CCG - NIC-160996-V3M5Q; NHS Hillingdon CCG - NIC-161008-X5W6Y; NHS Hounslow CCG - NIC-161026-R5X1T; NHS West London CCG - NIC-161053-Y7G1K

Application: This was a new application to receive pseudonymised data (Secondary Use Service+, Local provider flows (for commissioning), Mental Health Minimum Data Set, Mental Health Learning Disability Data Sets, Mental Health Services Data Set, Maternity Services, Improving Access to Psychological Therapies, Children & Young People's Health Service, Community Services Data Set and Diagnostic Imaging Data Set) to provide intelligence to support the commissioning of health services. The data (containing both clinical and financial information) is analysed so that health care provision can be planned to support the needs of the population within the Sustainable Transformation Partnership (STP) area. Each CCG will receive data for the entire STP region covered by all the CCG's in order to support each other proactively in delivering their commissioning agendas.

NHS Digital noted that it should clearly state in the application that the CCG's were joint Data Controllers; that the application should be referenced as new rather than amendment; and that section 5a should be updated to clearly state this was a 'STP area' rather than a 'CCG area'.

Discussion: IGARD noted NHS Digital's suggested amendments.

IGARD noted that NHS Central London CCG, NHS Ealing CCG and NHS West London CCG' DPA's had expired and that data should not flow until the DPA's had been renewed and confirmed back to NHS Digital.

IGARD suggested that the CCG's should review their fair processing against the ICO's Privacy Notices Code of Practice to ensure it reflects best practice standards and update their privacy notice as soon as possible, and the CCG's consider the EU's GDPR on pseudonymised data. The EU General Data Protection Regulation (GDPR) 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 queried if the CCG's held data and if they would destroy the current data held. NHS Digital confirmed that only replicated data would be destroyed and IGARD suggested that it be clear within the special condition if any data is required to be destroyed and what that data would be, for transparency.

IGARD queried section 3 and the variability of years of data requested between the different datasets. NHS Digital confirmed that this was common and down to when various data sets were available and that some datasets were only available for those specific periods of time that had been requested

IGARD queried section referencing 'each CCG to sign' and suggested that it be updated to read 'all CCG's to sign' for clarity and transparency. It was also suggested that section 5 be updated to reflect the fact that the CCG's were requesting 'locality data' rather than 'not national data'

IGARD suggested, to be clearer to a lay reader when published as part of the data release register, that additional background information about STP's be included at the start of section 5a, including their role.

IGARD suggested that section 5 be updated to reflect who would undertake the audit. IGARD also noted that the applicant should spell out acronyms upon first use in section 5.

IGARD noted that Interxion UK was listed as a storage location and stated their view that it would be more appropriate to also list this organisation as an additional data processor. It was acknowledged that there was currently an open action with NHS Digital regarding storage locations and how to reflect their role as data processors.

IGARD discussed the contractual arrangements in place (see AOB). **ACTION:** Stuart Richardson to provide a briefing note clarifying the contractual arrangements in place, the

	<p>structure enforcement strategy and how the agreements worked together so that the data disseminated by NHS Digital would be protected. Stuart Richardson agreed to provide an update to IGARD on the progress of this note by 5 April 2018</p> <p>Outcome: recommendation to approve subject to the following condition. The recommendation to approve subject to a condition was reached by a vote of those present, with one member dissenting.</p> <ul style="list-style-type: none"> NHS Central London CCG, NHS Ealing CCG and NHS West London CCG to update their DPA expiry date and before data can flow. <p>The following amendments were requested:</p> <ul style="list-style-type: none"> To clarify if any data is to be destroyed and be clear what data is to be destroyed. To add to the start of section 5a additional background information from section 5b about STP's and their role. To amend relevant sentences in section 5 from 'each CCG to sign' to 'all CCGs to sign' for clarity. To amend section 5 to be clear that the CCG's require 'locality data'. To clarify in a section 5 where it references data is audited who would undertake the audit. The application should be referenced as 'new' rather than 'amendment'. Section 5a should be updated to clearly state this was a 'STP area' rather than a 'CCG area'. Section 1 should clearly state that the CCG's are joint Data Controllers. <p>The following advice was given:</p> <ul style="list-style-type: none"> IGARD advised the CCG's should review their fair processing against the ICO's Privacy Notices Code of Practice to ensure it reflects 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.
2.4	<p><u>Nottingham University Hospital NHS Trust: access to HES Data Interrogation Systems (HDIS) (Presenter: Helen Buckles / Dickie Langley) NIC-10620-V9D8R</u></p> <p>Application: This was an application from Nottingham University Hospitals NHS Trust which is the host organisation for East Midlands Academic Health Science Network (AHSN) for pseudonymised Hospital Episodes Statistics (HES) data accessed via the HES Data Interrogation Service (HDIS), including the ability to download aggregated data containing small numbers.</p> <p>The application had been previously considered on the 24 August 2017 when IGARD had deferred making a recommendation pending further information of the governance processes in place and principles used to determine how data would be used and for what purposes; clarification regarding the involvement of partner organisations clarifying which are partners and which are customers; section 5 more clearly describe the criteria for data use as set out in the supporting documentation; providing more information about the benefits achieved using this data over the last few years; section 5 be updated to clearly reflect the special conditions described in section 6.</p>

NHS Digital noted that a template application had been included with the applicant's application in order to gain feedback from IGARD.

NHS Digital also noted that the applicant's DPA was due to expire on the 2 April 2018 and the customer had been made aware and was in the process of renewing.

NHS Digital suggested the previous issue around governance and the criteria on how Nottingham NHS Trust decides which projects to accept had been made clearer with the application.

NHS Digital also noted that the data will only be accessed by the staff from the Trust and the projects will only be for this particular AHSN, with no third parties involved.

Discussion: IGARD noted that the application had been updated to reflect some of the comments previously raised and noted NHS Digital's comments, but queried the governance arrangements in place for the applicant, noting that the applicant had provided a governance structure but suggested that the applicant consider an IG person to be on the Board, who was outside of the AHSN's informatics Team and outside of the project, for transparency.

IGARD noted that a statement in the section 8a (data retention table) that 'all data will be destroyed' was incorrect and should be updated to clearly state that the applicant could retain anonymised data.

IGARD noted that the section with regard to Domains in Section 5 was confusing and that the sentence "The AHSN requires Hospital Episodes Statistics (HES) data for use in Domain A, B and C. Data will only be used in support of these three areas, and specifically not for Domain D" in section 5a to be moved to before the sentence "The AHSN exists to achieve the following four objectives (each of which is underpinned by supporting work in the following domains):"

IGARD queried if the applicant held a copy of HDIS on their server and NHS Digital confirmed that they did not but would access the data via the secure log on provided, if approved. IGARD noted that they found some inconsistency in the terms used and that the applicant clarify and update the terminology used within section 5. IGARD also noted that the application contained excessive generality content which was not applicable to the application and that this should be removed from section 5a.

IGARD noted that the application was commercial because the Trust made a charge, but that the reference to the healthcare industry in section 5a was not relevant to this application and that this should be made clear in section 5e.

IGARD suggested that a number a HDIS special conditions from section 6 be added to section 5b and NHS Digital suggested adding them under a heading 'Conditions for using HDIS are the following:' for transparency.

Template Application: IGARD noted the work NHS Digital had undertaken to produce the template application but that moving forward NHS Digital needed to ensure that updates relevant to the applicant to the template were easy to differentiate from agreed standard template wording. IGARD wished to provide the following comments and advice on the template application provided:

For transparency and clarity, IGARD suggested that some of the explanatory content from the abstract be included in section 5a of the template and that paragraphs 5 and 6 on page 1 of the template which refer to 'commercial uses' be merged and updated. IGARD suggested that the terminology should be updated to be consistent and clarified which would support the production of future applications. IGARD noted that reference to 'sensitive data' terminology should be updated moving forward. IGARD suggested that the sentence "Governance arrangements to be amended to reflect each AHSN's governance arrangements" should be amended to make only references to each AHSN's relevant domains and be moved to the part

of section 5 that describe the AHSN objectives. IGARD strongly advised that applicants consider an Information Governance (IG) person who is outside of the AHSN informatics team to be on the Board and that NHS Digital have a minimum IG standard in place and apply that standard to all similar arrangements. NHS Digital noted that different governance structures may be in place across the AHSN's and that there would not be a standard model of governance imposed but that appropriate controls would be put in place via the Data Sharing Agreement.

Outcome: recommendation to approve

The following amendments were requested:

- The data retention table in section 8a be updated to correct a reference that 'all data will be destroyed' to be clear that the applicant can retain anonymised data.
- To clarify the terminology throughout section 5 in order to be consistent and for transparency.
- The sentence "The AHSN requires Hospital Episodes Statistics (HES) data for use in Domain A, B and C. Data will only be used in support of these three areas, and specifically not for Domain D" in section 5a to be moved to before the sentence "The AHSN exists to achieve the following four objectives (each of which is underpinned by supporting work in the following domains):"
- To remove the excessive generality content from section 5a, which is not relevant to this applicant.
- To move the relevant HDIS special conditions from section 6 to section 5b under the heading "conditions for using HDIS are the following"
- Clarifying in section 5e that health care industries do not apply for this application, as outlined in section 5a.

The following advice was given:

- IGARD strongly advised that the applicant consider an IG person, outside of the AHSN informatics team, to be on the board.

IGARD offered the following comments and advice for the template application only:

- The abstract be included in section 5a of the template for transparency and clarity.
- The terminology to be updated to be consistent and clarified in order to feed into the applications.
- To update reference to 'sensitive data' terminology moving forward.
- Paragraphs 5 and 6 on page 1 of the template which refer to 'commercial uses' be merged and updated.
- The sentence "Governance arrangements to be amended to reflect each AHSN's governance arrangements" should be amended to make only references to each AHSN's relevant domains and be moved to the part of section 5 that describe the AHSN objectives.
- IGARD strongly advised that the applicant consider an independent IG person who is outside of the AHSN informatics team to be on the board
- IGARD advised NHS Digital to have a minimum information governance standard in place and apply that standard to all similar arrangements.

University of Leeds: Liaison Psychiatry – measurement and evaluation of service types, referral patterns and outcomes (workstream 2 – phase 1) (Presenter: Louise Dunn) NIC-77953-C4M3T

It was noted that due to a conflict of interest Jon Fistein was not present for the discussion of this application.

Application: This was a new application for pseudonymised Hospital Episode Statistics (HES) data linked to pseudonymised Primary Care Data (using SALT methodology – in cryptography a salt is random data that is used as an additional input to a one-way function that ‘hashes’ a data item) for a defined cohort of patients. The output will be used in the Liaison Psychiatry: Measurement & Evaluation of Service Types, Referral Patterns and Outcomes (LP-MAESTRO). The aim of LP-MAESTRO is to evaluate the cost effectiveness and efficiency of particular configurations of liaison psychiatry services for specified target populations

Discussion: IGARD noted that the application and data flow diagram did not reflect the data processing activities or protocol document provided and suggested the data flows be clarified and updated to be clear that descriptions match throughout the application and supporting documentation. IGARD also suggested providing a copy of the HRA CAG application to be clear what evidence was provided to them.

IGARD noted that the NHS Digital Security Advisor had not confirmed if they were content with the location or data held and that evidence be provided and updated within the application that the Security Advisor was content.

IGARD noted that the application referenced work streams and packages, but it wasn't clear how they were relevant to the application or projects, and how they fitted together. IGARD suggested that further clarification be given including updating the data flow diagram to reflect the new wording for transparency.

IGARD queried reference to the University of York in section 2b and NHS Digital confirmed that this was a storage location and that University of York did not access the data, however IGARD suggested that further clarity be given that they could not access data.

IGARD noted the funding arrangements but asked that evidence of National Institute for Health Research (NIHR) funding be provided the funding was still current and in place. IGARD also noted that evidence of Research Ethics Committee (REC) approval be provided and evidence that it covered the extension date of the project, noting that a supporting document 7 had been provided but that it did not contain up to date information reflecting the project end date.

IGARD noted that as part of the HRA CAG support copies of current approval letters should have been provided, however it was noted that a number of approvals letters from the Hospitals Trusts were missing or dated 2016 or earlier and updated / current approvals letters should be provided clearly detailing the duration of the project and the end date of the project.

IGARD also noted that section 5 of the application would not be easily understood by a lay audience and suggested the applicant may wish to use Plain English.

IGARD queried how the applicant was engaging with patients and charities and suggested that the applicant consider partnership with relevant mental health charities to maximise the benefit of disseminating outputs to the general public. IGARD also suggested that the applicant may wish to consider speaking with GP's in order to disseminate outputs.

IGARD noted that Iron Mountain was listed as a storage location and stated their view that it would be more appropriate to also list this organisation as an additional data processor. It was acknowledged that there was currently an open action with NHS Digital regarding storage

	<p>locations and how to reflect their role as data processors.</p> <p>IGARD suggested that a reference to supporting document 8 in the abstract be corrected to supporting document 5.</p> <p>Outcome: unable to recommend for approval</p> <ul style="list-style-type: none"> • To amend the application and the data flow diagram to accurately reflect the data processing activities and to align with the protocol. • To provide a copy of the HRA CAG application. • To provide current and updated approvals letters from the Hospital Trusts⁴ as part of the HRA CAG support, detailing the duration and end date of the project. • To provide evidence that REC approval is in place which covers the extension date of the project. • To provide evidence of NIHR funding. • To provide evidence and update the application to confirm that the NHS Digital security advisor has confirmed they are content with the location and data held. • To clarify the work streams and packages referenced in section 5a and to be relevant to the application including how they fit together and update the data flow diagram provided to reflect the new wording. • To clarify in section 2b reference to University of York that they will not access the data and provide further explanation to the abstract. • To update the abstract to amend reference to SD8 to SD5. <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD suggested that the applicant may wish to consider partnering with relevant mental health charities to maximise the benefit of disseminating outputs to the general public and find wider routes of dissemination including via GP practices.
2.6	<p><u>University of Bristol: Learning Disabilities Mortality Review Programme - ONS mortality data link (Presenter: Louise Dunn) NIC-121996-T2R7B</u></p> <p>Application: This was a new application for Office for National Statistics (ONS) Mortality Data. The Learning Disabilities Mortality Review (LeDeR) programme is delivered by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The LeDeR programme commenced in 2015 is support local areas to review the deaths of people with learning disabilities by developing and rolling out a review process for the deaths of people, helping to promote and implement a new review process by supporting local areas to take forward lessons learnt and other improvements to service provision.</p> <p>NHS Digital noted that the Data Sharing Agreement start and end date in section 1 should be updated. It was also noted that the patient objectives section currently said 'no' but that this would be updated to 'yes' to reflect that patient objections would be applied, and that confirmation would be added that when the first flow of data was disseminated it will contain</p>

⁴ James Paget University Hospital (James Paget University Hospitals NHS Foundation Trust); Diana, Princess of Wales Hospital (North Lincolnshire and Goole NHS Foundation Trust); Scunthorpe General Hospital (North Lincolnshire and Goole NHS Foundation Trust); Rotherham Hospital (Rotherham NHS Foundation Trust); Pilgrim Hospital (United Lincolnshire Hospitals NHS Trust); Lincoln County Hospital (United Lincolnshire Hospitals NHS Trust); County Hospital (University Hospitals of North Midlands NHS Trust) - previously Stafford Hospital (Mid Staffordshire NHS Foundation Trust)

patient objections.

Discussion: IGARD noted that valuable project outlined and welcomed the application.

IGARD noted the difficult position they found themselves in with regard to the fact that it was not clear that the applicant had a legal basis for the ONS data, whilst NHS Digital was still in a transition period of ONS delegating to NHS Digital, and suggested that confirmation be sought from ONS that they are content that the University of Bristol can process the data under the old commissioning letter provided to IGARD and until a new commissioning letter is issued that meets relevant new requirements. NHS Digital noted that the correct legal basis was listed within the application and that that standard ONS terms and condition should be included within the application which outlines how ONS data will be processed.

IGARD noted that section 4 had been updated to reflect fair processing activities but noted that reference to the Data Protection Act was inaccurate and did not apply, since the participants were deceased.

IGARD suggested that the DPA registration for University of Bristol should be updated to more clearly state that data is processed about patients or health care users and that they should update their DPA expiry date.

IGARD noted that supporting document 4 had been provided which was a signed contract between HQIP and the University of Bristol but noted that since this was due to expire at the end of May 2018 that an updated signed contract be provided.

IGARD noted that section 5 of the application described the purpose of the application was to link ONS to HES but that this was not part of the s251 support documentation provided and queried if data would be linked to any other data and that it be explicit within section 5b of the application that the applicant will not link data in this application except those permitted under this application / agreement.

IGARD also noted that it was not clear who the LeDeR programme will collate or share the deaths of people with and suggested that a clear statement be included in section who the LeDeR programme are sharing data with.

It was noted that IGARD found inconsistencies in the terms used and that the applicant clarify and update the terminology used within section 5b when referencing sharing with the programme, the team, the steering group. It was also suggested that the application be updated to include sharing with any 3rd parties, if applicable.

IGARD noted that the LeDeR programme had Senior Health Practitioners but queried if these were substantive employees of the applicant or a 3rd party and asked for confirmation that the Practitioners were in fact substantive employees of the University of Bristol.

It was suggested that reference to pseudo-anonymised data within the application should be updated to the correct terminology: pseudonymised data.

IGARD noted that supporting document 2 (HRA CAG support letter) noted support for personal details and death up to May 2018 and that section 3 of the application be updated to correctly reference the data set date period required.

Outcome: IGARD deferred making a recommendation pending:

- Confirmation from the ONS that they are content that the applicant can process the data under the old commissioning letter until a new commissioning letter is issued that meets the new requirements.
- To provide an updated signed contract between HQIP and University of Bristol to replace supporting document 4 which expires at the end of May 2018.

	<ul style="list-style-type: none"> • Confirmation that the Senior Health Practitioners who will access the data are substantive employees of the applicant. • Clarification within section 5b of the application that the applicant will not link the data in this application and the only data linkages are not within the scope of this application. • A statement that LeDeR programme will also collate and share the pseudonymised information about deaths of people with learning difficulties be clarified to specify who they are sharing the data with. • To clarify the terminology with section 5b when referring to sharing with the programme, the team and the steering group and be specific within the application what is shared and with which group, including any 3rd parties. • To update section 3 of the application to correctly reference the dataset date period. • To change the patient objection section from 'No' to 'Yes' and confirm that when the first flow of data is disseminated it will contain patient objections. • To clarify in section 4 that the participants are deceased, and Data Protection does not apply. • Section five should reflect the special condition that ONS data must be processed in accordance with their terms and conditions. • University of Bristol should update their DPA expiry date and their DPA registration to more clearly state that data is processed about patients or healthcare users. • A reference to pseudo-anonymised data should be updated to pseudonymised data • To update the DSA start date and end date in section 1 of the application.
<p>3</p> <p>3.1</p>	<p>AOB</p> <p><u>Optimal contractual structure to be used in multiple-party applications for dataset(s)</u></p> <p>In the context of a discussion about NHS Digital's approach to contracting arrangements, and at the specific request of one member, IGARD raised an action during applications 2.1, 2.2 and 2.3 for NHS Digital to provide an advice note (liaising with NHS Digital's legal advisers) confirming the optimal contractual structure to be used in multiple-party applications for dataset(s).</p> <p>IGARD noted that an example of such type of application is where a number of CCG's ask for an agreed dataset (to be used by them for collaborative working) and that in such a situation, typically all CCG's would use the same subcontractor(s) / data processor(s) to carry out the processing activities. IGARD also noted that CCG's may act independently or jointly when instructing the subcontractor(s) / data processor(s) to carry out specific processing.</p> <p>IGARD asked for clarification on a number of points including:</p> <ul style="list-style-type: none"> • How the contractual arrangements should be structured e.g. whether NHS Digital would enter into individual contracts with each applicant, a multi-party contract with all applicants or any other arrangements. • Whether NHS Digital would expect all applicants for the dataset(s) to accept joint and several liability. <p>IGARD noted that the assumption is the applicant requesting the data are/is the Data Controller(s) in respect of the dataset(s) applied for.</p> <p>ACTION: Stuart Richardson to provide a briefing note clarifying the contractual arrangements</p>

	in place, the structure and how NHS Digital are protected and agreed to provide an update to IGARD on the progress of this note by 5 April 2018.
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Appendix A: Summary of Open Actions

Date raised	Action	Owner	Updates	Status
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	<p>14/09/17: Ongoing. It was agreed this would be discussed during the educational session.</p> <p>07/12/17: Ongoing. It was agreed to bring the first draft to January's education session.</p> <p>08/02/18: it was agreed the updated draft be brought to the March education session</p> <p>01/03/18: the March education session was cancelled, and it was agreed to take the draft annual report to the April education session.</p> <p>15/03/18: Ongoing</p>	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	<p>10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.</p> <p>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.</p> <p>31/08/17: IGARD were notified that the requested written confirmation should be provided within one day.</p> <p>14/09/17: An email response had been circulated on 31 August, and IGARD noted that they were awaiting receipt of the post-audit report.</p> <p>15/03/18: Ongoing</p>	Open

31/08/17	Garry Coleman to report back on how cancer registration data was previously described as pseudonymised PDS data within older versions of applications, and present to a future education session on changes to how Medical Research Information Service (MRIS) reports are now shown within applications.	Garry Coleman	22/02/18: IGARD Secretariat to contact Garry Coleman to suggest presentation at the June education session. 08/03/18: ongoing	Open
19/10/17	Stuart Richardson to provide a briefing on the Temporary National Repository infrastructure.	Stuart Richardson	16/11/17: Stuart Richardson noted discussions were ongoing. 22/02/18: IGARD Secretariat to contact Stuart Richardson to provide an update 01/03/18: Stuart Richardson noted he and Dickie Langley had met recently with NHS England and would provide a briefing note when an updated application was presented to IGARD. 15/03/18: This action can be closed and removed from the action plan.	CLOSE
02/11/17	NHS Digital to consider the responses provided by an applicant (Imperial College London NIC-27085) in relation to the language and terminology used in patient information materials.	Louise Dunn	15/03/18: Ongoing.	Open
07/12/17	Stuart Richardson to provide a briefing note outlining NHS Digital's work with STP's to clarify the legal / access arrangements in place between CCG's to ensure responsibilities are clearly defined	Stuart Richardson	22/02/18: IGARD Secretariat to contact Stuart Richardson to provide an update 01/03/18: Stuart Richardson noted that STP's group CCG's together in the main (noting some STPs only have one CCG) to form larger population patches to aim for efficiencies in healthcare provision over the wider patch. They are not legal entities but have started asking for data sharing on the non-identifiable data across the CCGs involved. This has been requested (and approved by IGARD) for a London set of CCGs already under a joint data controllership model.	Open

			<p>Other CCGs grouped as CCGs and as the legal entities are likely to request the same sort of model. Moving forwards, STPs will be moving to being IHSs (Integrated Health Systems) and will involve lead providers, possibly under a data processor model, and involvement of the local councils etc. So, we will be needing to then seek amendments to bring in data sharing across those additional organisations for the non-identifiable data. Identifiable data will need to be just shared with single CCGs as legal entities under CCG, sole data-controllership, DSAs.</p> <p>15/03/18: IGARD queried the statement in the above text: 'other CCG's groups as CCG's and as the legal entities are likely to request the same sort of model' and asked for clarification on this point.</p>	
15/03/18	<p>Stuart Richardson to provide a briefing note clarifying the contractual arrangements in place, the structure, enforcement strategy and how the agreements worked together so that the data disseminated by NHS Digital would be protected and provide a verbal update to IGARD on the progress of this note by 5 April 2018.</p>	Stuart Richardson		Open

Appendix B: Out of committee report

Independent Group Advising on Releases of Data (IGARD): Out of committee report 09/03/18

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-69751-COM8P	Nottinghamshire Healthcare NHS Foundation Trust	15/02/18	<ul style="list-style-type: none">The fair processing notice for the applicant be updated to meet NHS Digital's nine minimum criteria (to be known as NHS Digital's fair processing criteria) for privacy notices including ensuring the privacy notice is accessible, the language is appropriate to the audience and not misleading, before data can flow.Clearly describe in section 5 of the application how the linkage of the NHSD data to the MoJ data serves a healthcare purpose in a way that is compatible with the Care Act 2014.Clarify in section 5 of the application that no further linkages are permitted, except from those described in the application.	IGARD Members	Quorum of IGARD Members	N/A
NIC-30493-YOCOK	University College London	08/02/18	<ul style="list-style-type: none">The applicant should work with DARS IG to ensure the correct legal basis for dissemination is listed before data can flow.Confirmation that University College London and National Centre for Social Research are shown as joint Data Controllers.Removing current data minimisation	IGAD Chair	IGARD Chair	N/A

			<p>identifiable wording within section 3 of the application.</p> <ul style="list-style-type: none"> • A special condition be added to the application that the patient information leaflet (SD7) will be sent to the participant cohort and they will be given one month from the date sent to reply before data can flow. 			
NIC-32854-Y8P8B	Institute of Fiscal Studies	08/02/18	<ul style="list-style-type: none"> • The applicant should work with DARS IG to ensure the correct legal basis for dissemination is listed before data can flow. • Confirmation that the Institute of Fiscal Studies and National Centre for Social Research are shown as joint Data Controllers. • Removing current data minimisation identifiable wording within section 3 of the application. • A special condition be added to the application that the patient information leaflet (SD7) will be sent to the participant cohort and they will be given one month from the date sent to reply before data can flow. 	IGARD Chair	Deputy IGARD Chair (delegated)	N/A

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

- None notified to IGARD