Independent Group Advising on the Release of Data (IGARD) Minutes of meeting held 14th December 2017

Members: Anomika Bedi, Joanne Bailey, Chris Carrigan (Chair), Jon Fistein, Eve Sariyiannidou.

In attendance: Arjun Dhillon, Jen Donald, Rachel Farrand, James Humphries, Dickie

Langley, Stuart Richardson, Jan Spence, Vicki Williams.

Apologies: Sarah Baalham, Kirsty Irvine, Nicola Fear.

1	1	Declaration of interests					
		Jon Fistein noted his professional links in relation to GA06-SCW-AMD but noted no specific connection with that project or the staff involved.					
		Review of previous minutes and actions					
		The minutes of the 7 December 2017 IGARD meeting were reviewed and subject to a number of minor changes were agreed as an accurate record of the meeting.					
		Action updates were provided (see Appendix A).					

Out of committee recommendations

An out of committee report was received (see Appendix B).

2 Data applications

2.1 Nuffield Department of Surgical Sciences - MR1004 Arterial Revascularisation Trial (ART) (Presenter: Jen Donald) NIC-147755-C5H4X

Application: This was a renewal application for one final 'MRIS' report to be provided to the University of Oxford in for the Arterial Revascularization Trial (ART) cohort (~1837) for identifiable data.

The purpose of ART is to compare 10-year survival status between two types of heart bypass surgery and December 2017 marks the study's 10-year anniversary. The ART study wishes to retain the data for 5 years following closure in order to answer any queries that may arise from publication of outputs.

Discussion: IGARD welcomed the study and noted that they would have expected to see more information with regard to improving the care of patients and how this would be achieved in the benefits section of the application.

IGARD noted this was an older study and had reviewed the consent materials provided. Although considerable effort had been made to update fair processing materials, IGARD sought confirmation that the information provide to study participants was easily accessible and asked that the website be updated to include current newsletter wording.

Outcome: Recommendation to approve subject to the following condition:

 Confirmation that the fair processing information is easily accessible on the study website and is amended to include the information contained in the current newsletter.

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

2.2 Compufile Systems Limited - ESPRIT tool (Presenter: Rachel Farrand) NIC-01207-V9G9P

Application: This application was to renew and extend an existing agreement for the receipt of HES Critical Care (CC), Outpatients (OP) and Admitted Patient Care (APC) data for use in the ESPRIT analytical tool, to add an additional data processor, to receive 2016/17 monthly data releases for each dataset and continue to process data already held.

Discussion: IGARD acknowledged the updated information provided detailing changes to the

application and the additional documentation provided.

IGARD discussed the due diligence process undertaken by NHS Digital and were assured this was consistent across all applicants including a number of checks for example, that there is a valid contract in place.

IGARD queried access to the data via the ESPRIT analytical tool and requested that the applicant provides details that the data held would not be used to support services associated with financial or incentive programmes.

IGARD noted that the current approvals board for the applicant had three board members however it was not clear if the applicant had clear decision making principals around information governance or any Terms of Reference for the approvals board and requested further details of the information governance procedures in place. IGARD suggested that the applicant may wish to seek appropriate lay and / or patient representation on the approvals board.

Outcome: Recommendation deferred, pending:

- Confirmation that the data would not be used to support services associated with financial or incentive programmes.
- The applicant provides evidence that formal information governance procedures are in place.

The following advice was given:

• the applicant seeks appropriate lay and/or patient representation on its boards, following best practice.

Action: Dickie Langley to bring back to a future IGARD meeting a briefing note on NHS Digital's due diligence policy and process.

2.3 <u>University College London - The Relationship Between Education and Health Outcomes For Children And Young People Across England: The Value Of Using Linked Administrative Data (Presenter: Dickie Langley) NIC-27404-D5Z3F</u>

Application: This application had been considered at the 21/09/2017 meeting when IGARD had not recommended to approve. The application had now been updated to address the previous points raised including providing a briefing note to IGARD, confirming ONS Legal Basis, providing evidence that this use of data had been agreed by the appropriate Department for Education internal processors, clarifying a statement that the study has a significant methodological element and correcting a link to the Statutory Instrument.

This study by UCL (part of the Methodology Research programme run by the Administrative Data Research Centre (ADRCE), which is funded by ESRC) intends to link health and education data. The study has a significant methodological element (rather than the linkage process being only incidental), though there remains some expected benefit in the form of informing health/education policy.

Discussion: IGARD noted that NHS Digital had identified a legal gateway which establishes NHS Digital as the Data Controller in England for the Civil Registrations Data it holds and that NHS Digital were working with ONS for the transition of this function, and that the content was for data to be disseminated under S261 of the Health & Social Care Act. IGARD acknowledged the efforts by NHS Digital to progress this.

IGARD noted the lack of clarity with regard to the ONS legal basis and requested explicit confirmation around the flows of identifiers from the Department of Education to NHS Digital and evidence of the legal basis for NHS Digital to disseminate data to be outlined in the application and briefing paper. IGARD also noted that the Department for Education should update their fair processing notice

IGARD suggested that a briefing paper be drafted to add context regarding ONS.

Outcome: Recommendation deferred, pending:

The application and briefing note provided is to be updated to incorporate comments made by the NHS Digital IG Advisor to IGARD to explicitly address the legal basis, especially with regard to the flow of identifiers from the Department of Education to NHSD, to provide clear evidence of the legal basis for the dissemination of ONS data and to update the fair processing for Department for Education.

2.4 Group Application for 7 CCGs¹ - To receive pseudonymised data (Presenter: James Humphries/Stuart Richardson) GA02-NEL-STP

Application: This was an amendment application for 7 CCGs to receive pseudonymised data based on the STP Footprint to allow collaborative working.

Discussion: IGARD queried what data was being held and it was confirmed the main difference between data currently held and data being requested was the geographical area across the STP footprint.

IGARD queried who would be accountable should any issues arise and accepted NHS Digital's proposed that all the CCG's within the group application be shown as Joint Data Controllers. IGARD requested reference to the patient level data not leaving each CCG should be clarified within section 5. It was noted the data sharing agreement as a model, which was a new way of working, should be clearly defined with regard to how this type of collaboration will work in practice and that each CCG will have access to each other's data.

IGARD queried the plans for the destruction of current data and suggested that this should be clarified within the application that data currently held by each CCG will not be destroyed but that new data added to each CCG is for the STP geographical area.

IGARD noted that Anti-terrorism initiatives appeared to be part of commissioning and requested further detail be added to the application for clarity in section 17c that the CCG's are looking at the impact of terror on services.

IGARD noted that Interxion 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.

Outcome Recommendation to approve subject to the following condition:

• Confirmation that all CCGs are shown as joint data controllers and reference to patient level data not leaving CCG is clarified accordingly

The following amendments were requested:

- Section 5 of the application be amended to clearly describe that this type of data sharing as a model is a new way of working and how this type of collaboration will work in practice and that each CCG will be accessing each other's data
- To be clear in section 5 (17c) of the application that the CCG's are looking at the impact of a terror on services.
- Clarification that data currently held by each CCG will not be destroyed and that the new data is to be added to each CCG is for the STP geographical area.

ACTION: To provide a briefing note which clarifies NHS Digital will work with STP to clarify the legal and access arrangements in place between CCG's to ensure responsibilities are clearly set out.

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

2.5 Group Application for 5 CCGs₂ - To receive pseudonymised data (Presenter: James Humphries/Stuart Richardson) GA03-NEL-STP

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¹ Barking and Dagenham CCG - NIC-56039-T9H7X; Havering CCG - NIC-55703-H0T1C; City and Hackney CCG - NIC-99319-F0R8C; Newham CCG - NIC-95884-F9J1V; Tower Hamlets CCG - NIC-95867-F5F0L; Redbridge CCG - NIC-41646-V9N9J; Waltham Forest CCG - NIC-55709-D8W3P.

Application: This was an amendment application for 5 CCGs to receive pseudonymised data based on the STP Footprint to allow collaborative working.

Discussion: IGARD queried what data was being held and it was confirmed the main difference between data currently held and data being requested was the geographical area across the STP footprint.

IGARD queried who would be accountable should any issues arise and accepted NHS Digital's proposal that all the CCG's within the group application be shown as Joint Data Controllers. IGARD requested reference to the patient level data not leaving each CCG be clarified within section 5. It was noted the data sharing agreement as a model, which was a new way of working, should be clearly defined with regard to how this type of collaboration will work in practice and that each CCG will have access to each other's data.

IGARD queried the plans for the destruction of current data and suggested that this should be clarified within the application that data currently held by each CCG will not be destroyed but that new data added to each CCG is for the STP geographical area.

IGARD noted that Anti-terrorism initiatives appeared to be part of commissioning and requested further detail be added to the application for clarity in section 17c that the CCG's are looking at the impact of terror on services.

IGARD noted that Interxion 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.

Outcome Recommendation to approve subject to the following condition:

 Confirmation that all CCGs are shown as joint data controllers and reference to patient level data not leaving CCG is clarified accordingly

The following amendments were requested:

- Section 5 of the application be amended to clearly describe that this type of data sharing as a model is a new way of working and how this type of collaboration will work in practice and that each CCG will be accessing each other's data
- To be clear in section 5 (17c) of the application that the CCG's are looking at the impact of a terror on services.
- Clarification that data currently held by each CCG will not be destroyed and that the new data is to be added to each CCG is for the STP geographical area.

ACTION: Stuart Richardson to provide a briefing note which clarifies NHS Digital will work with STP to clarify the legal and access arrangements in place between CCG's to ensure responsibilities are clearly set out.

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

2.6 Group Application for 6 CCGs₃ - To receive pseudonymised data (Presenter: James Humphries/Stuart Richardson) GA05-NEL-STP

Application: This was an amendment application for 6 CCGs to receive pseudonymised data based on the STP Footprint to allow collaborative working.

Discussion: IGARD queried what data was being held and it was confirmed the main difference between data currently held and data being requested was the geographical area across the STP footprint.

² Barnet CCG - NIC-55719-Q0T3Z; Camden CCG - NIC-41632-C6X9D; Enfield CCG - NIC-41640-G0C5N; Islington CCG - NIC-95815-C3W0W; Haringey CCG - NIC-95817-Q6V9N

³ Croydon CCG - NIC-43431-N0G4J; Kingston CCG - NIC-43450-C7M7C; Merton CCG - NIC-43498-C6X1S; Richmond CCG - NIC-43547-B4R5Q; Sutton CCG - NIC-43527-T7P7R; Wandsworth CCG - NIC-43405-T5C4G

IGARD queried who would be accountable should any issues arise and asked for confirmation that all the CCG's within the group application be shown as Joint Data Controllers with reference to the patient level data not leaving each CCG be clarified within section 5. It was noted the data sharing agreement as a model, which was a new way of working, should be clearly defined with regard to how this type of collaboration will work in practice and that each CCG will have access to each other's data.

IGARD queried the plans for the destruction of current data and suggested that this should be clarified within the application that data currently held by each CCG will not be destroyed but that new data added to each CCG is for the STP geographical area.

IGARD noted that Anti-terrorism initiatives appeared to be part of commissioning and requested further detail be added to the application for clarity in section 17c that the CCG's are looking at the impact of terror.

IGARD noted that Interxion 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.

Outcome Recommendation to approve subject to the following condition:

 Confirmation that all CCGs are shown as joint data controllers and reference to patient level data not leaving CCG is clarified accordingly

The following amendments were requested:

- Section 5 of the application be amended to clearly describe that this type of data sharing as a model is a new way of working and how this type of collaboration will work in practice and that each CCG will be accessing each other's data
- To be clear in section 5 (17c) of the application that the CCG's are looking at the impact of a terror
- Clarification that data currently held by each CCG will not be destroyed and that the new data is to be added to each CCG is for the STP geographical area.

ACTION: Stuart Richardson to provide a briefing note which clarifies NHS Digital will work with STP to clarify the legal and access arrangements in place between CCG's to ensure responsibilities are clearly set out.

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

2.7 <u>Group Application for 9 CCGs4 – (Presenter: James Humphries/Stuart Richardson) GA05-NoE-AMD</u>

Application: This was an amendment application for 9 CCGs to include additional datasets linkable via a common pseudo approach.

This application had been to IGARD on both 3rd August 2017 and 24th August and was deferred. The applicant has updated as per comments from IGARD.

Discussion: IGARD queried the use of the data which was confirmed as being for commissioning purposes, however it was noted that it was not clear who was processing the data and asked for clarification in section 5 of the application. IGARD also asked for clarity in section 5 that NHS Digital was not involved in the processing of social care data.

IGARD discussed the use of the algorithm for risk stratification purposes and requested clarity for Data Processor 1.

IGARD noted that the invoice validation diagram provided with the application needed to be updated to accurately reflect the application including the master patient list which was not

⁴ NIC-134643-Q8C2V; NIC-134694-Y1K6S; NIC-134638-Z3C2N; NIC-134663-P4Z4Z NIC-134666-G5H1F; NIC-134656-N8S3W; NIC-134613-G2M6G; NIC-134653-R5S3P; NIC-134630-K0M4D;

listed in the application but was on diagram.

IGARD noted a minor typo in section 5 of the application which should be corrected around outputs expected and clearly reference the correct point.

IGARD noted that the details of the Nexent Data Centre were not clear and requested clarification of the correct legal entity.

Outcome: Recommendation to approve

The following amendments were requested:

- Reference to the use of the algorithm for risk stratification should be clearly specified for Data Processor 1 in the application.
- The data flow diagram should be corrected to accurately reflect the application summary.
- A typo in section 5, point 10 should be amended to clearly reference the right point.
- Clarification of the correct legal entity for Nexent Data Centre.
- Clarification in section 5 of the application who was processing personal data.
- Section 5 of the application be amended to clearly state that NHS Digital is not involved in any processing of social care data.

2.8 Group Application for 4 CCGs5 - To receive pseudonymised data (presenter: James Humphries/Stuart Richardson) GA06-NEL-STP

Application: This was an amendment application for 4 CCGs to receive pseudonymised data based on the STP Footprint to allow collaborative working.

Discussion: IGARD gueried what data was being held and it was confirmed the main difference between data currently held and data being requested was the geographical area across the STP footprint.

IGARD queried who would be accountable should any issues arise and accepted NHS Digital's proposal that all the CCG's within the group application be shown as Joint Data Controllers. IGARD requested reference to the patient level data not leaving each CCG be clarified within section 5. It was noted the data sharing agreement as a model, which was a new way of working, should be clearly defined with regard to how this type of collaboration will work in practice and that each CCG will have access to each other's data.

IGARD queried the plans for the destruction of current data and suggested that this should be clarified within the application that data currently held by each CCG will not be destroyed but that new data added to each CCG is for the STP geographical area.

IGARD noted that Anti-terrorism initiatives appeared to be part of commissioning and requested further detail be added to the application for clarity in section 17c that the CCG's are looking at the impact of terror.

IGARD noted that Interxion 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.

Outcome Recommendation to approve subject to the following condition:

Confirmation that all CCGs are shown as joint data controllers and reference to patient level data not leaving CCG is clarified accordingly

The following amendments were requested:

Section 5 of the application be amended to clearly describe that this type of data

⁵ East Surrey CCG - NIC-43439-N1L6G; Guilford and Waverley CCG - NIC-43466-P5J3F; North West Surrey CCG - NIC-43559-M1Z8L; Surrey Downs - CCG NIC-43421-F1R6G.

sharing as a model is a new way of working and how this type of collaboration will work in practice and that each CCG will be accessing each other's data

- To be clear in section 5 (17c) of the application that the CCG's are looking at the impact of a terror on services.
- Clarification that data currently held by each CCG will not be destroyed and that the new data is to be added to each CCG is for the STP geographical area.

ACTION: To provide a briefing note which clarifies NHS Digital will work with STP to clarify the legal and access arrangements in place between CCG's to ensure responsibilities are clearly set out.

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

2.9 Group Application for 8 CCGs⁶ - To receive pseudonymised datasets (Presenter: James Humphries/Stuart Richardson) GA06-SCW-AMD

Application: This was an amendment application to receive pseudonymised datasets and link with GP data and Social Care data for the purpose of commissioning.

Discussion: IGARD discussed the described pseudonymisation process and suggested that NHS Digital satisfy itself with the black box process and pseudonymisation process.

IGARD queried who would be accountable should any issues arise and accepted NHS Digital's proposal that all the CCG's within the group application be shown as Joint Data Controllers. IGARD requested reference to the patient level data not leaving each CCG be clarified within section 5. It was noted the data sharing agreement as a model, which was a new way of working, should be clearly defined with regard to how this type of collaboration will work in practice and that each CCG will have access to each other's data. IGARD suggested that NHS Digital may wish to assure itself that appropriate safeguards were in place for data storage in line with the Data Sharing Agreement (DSA) and Data Sharing Framework Contract (DSFC)

IGARD requested confirmation that NHS Digital would not be processing personal data and this should be clearly referenced in section 5 of the application. IGARD also asked for clarity in section 5 that NHS Digital was not involved in the processing of social care data

Outcome: Recommendation to approve subject to the following condition:

 Confirmation that all CCGs are joint data controllers and reference to patient level data not leaving CCG is clarified accordingly.

The following amendments were requested:

- Section 5 of the application be amended to clearly describe that this type of data sharing as a model is a new way of working and how this type of collaboration will work in practice and that each CCG will be accessing each other's data.
- Confirmation that the NHS Digital is not involved in any processing of personal data and confirmed in Section 5 of application.
- Section 5 of the application be amended to clearly state that NHS Digital is not involved in any processing of social care data.

The following advice was given:

- NHS Digital satisfies itself with the Black Box arrangements.
- NHS Digital should assure itself that appropriate safeguards are in place for data

⁶ NHS Fareham and Gosport CCG - NIC-54736-M5M1L; NHS Isle of Wight CCG - NIC-54756-R4Y4V; NHS North East Hampshire and Farnham CCG - NIC-43549-Z5T2V; NHS North Hampshire CCG - NIC-54781-M2F2K; NHS Portsmouth CCG - NIC-54764-N1C1J; NHS South Eastern Hampshire CCG - NIC-54738-M4C8H; NHS Southampton City CCG - NIC-54796-Z0Q1P; NHS West Hampshire CCG - NIC-54743-X9B7K

storage in line with standard DSA and DSFC provisions.

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

2.10 <u>Group Application for 3 CCGs7 – To receive pseudonymised datasets (Presenter: James Humphries/Stuart Richardson) GA09a-SCW-AMD</u>

Application: This was an amendment application to receive pseudonymised datasets and link with GP data and Social Care data for the purpose of commissioning.

Discussion: IGARD discussed the described pseudonymisation process and suggested that NHS Digital satisfy itself with the black box process and pseudonymisation process.

IGARD queried who would be accountable should any issues arise and accepted NHS Digital's proposal that all the CCG's within the group application be shown as Joint Data Controllers. IGARD requested reference to the patient level data not leaving each CCG be clarified within section 5. It was noted the data sharing agreement as a model, which was a new way of working, should be clearly defined with regard to how this type of collaboration will work in practice and that each CCG will have access to each other's data.

IGARD requested confirmation that NHS Digital would not be processing personal data and this should be clearly referenced in section 5 of the application. IGARD also asked for clarity in section 5 that NHS Digital was not involved in the processing of social care data. IGARD suggested that NHS Digital may wish to assure itself that appropriate safeguards were in place for data storage in line with the Data Sharing Agreement (DSA) and Data Sharing Framework Contract (DSFC)

IGARD noted a reference to Section 251 in section 4 of the application should be removed.

IGARD queried whether this was a commercial application due to OBH's involvement and it was confirmed that this was not the case. IGARD requested this to be made clear within the application and that OBH are a data processor only. IGARD also queried the need for OBH to receive the whole HES dataset and suggested the data minimisation table within the application be updated to justify this activity.

Outcome: Recommendation to approve subject to the following condition:

 Confirmation that all CCGs are joint data controllers and reference to patient level data not leaving CCG is clarified accordingly.

The following amendments were requested:

- Section 5 of the application be amended to clearly describe that this type of data sharing as a model is a new way of working and how this type of collaboration will work in practice and that each CCG will be accessing each other's data.
- Confirmation that the NHS Digital is not involved in any processing of personal data and confirmed in Section 5 of application.
- Section 5 of the application be amended to clearly state that NHS Digital is not involved in any processing of social care data.
- Reference to S251 should be removed from Section 4 of the application.
- Clarification that this is not a commercial application and OBH are a data processor only.
- The data minimisation table should be updated to justify the reason for OBH receiving the whole HES dataset.

The following advice was given:

NHS Digital satisfies itself with the Black Box arrangements.

⁷ Bristol CCG - NIC-43358-L8W2Q; North Somerset CCG - NIC-43354-B7P4H; South Gloucestershire CCG - NIC-43355-Q4R2Y.

• NHS Digital should assure itself that appropriate safeguards are in place for data storage in line with standard DSA and DSFC provisions.

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

2.11 North Cumbria CCG – To receive additional Datasets (Presenter James Humphries/Stuart Richardson) NIC-134552-B5T6B

Application: This was an application for North Cumbria CCG to include additional datasets linkable via a common pseudo approach.

Discussion: IGARD queried the use of the data which was confirmed as being for commissioning purposes, however it was noted that it was not clear who was processing the data and asked for clarification in section 5 of the application. IGARD also asked for clarity in section 5 that NHS Digital was not involved in the processing of social care data.

IGARD discussed the use of the algorithm for risk stratification purposes and requested clarity for Data Processor 1.

IGARD noted that the invoice validation diagram provided with the application needed to be updated to accurately reflect the application including the master patient list which was not listed in the application but was on diagram.

IGARD noted a minor typo in section 5 of the application which should be corrected around outputs expected and clearly reference the correct point.

IGARD noted that the details of the Nexent Data Centre were not clear and requested clarification of the correct legal entity.

IGARD noted that the applications referenced SCW CSU and requested this be amended to North of England CSU.

Outcome: Recommendation to approve.

The following amendments were requested:

- Reference to the use of the algorithm for risk stratification should be clearly reference for Data Processor 1 in the application.
- The data flow diagram should be corrected to accurately reflect the application summary.
- A typo in section 5, point 10 should be amended to clearly reference the right point.
- Clarification of the correct legal entity for Nexent Data Centre.
- Clarification in section 5 of the application who was processing personal data.
- Section 5 of the application be amended to clearly state that NHS Digital is not involved in any processing of social care data.
- Reference to the SCW CSU should be amended to North of England CSU.

2.12 NHS Hambleton and Richmondshire CCG (presenter: James Humphries/Stuart Richardson) NIC-90670-W8H6P

Application: This was an application to link datasets via a common pseudo approach.

Discussion: IGARD queried the use of the data which was confirmed as being for commissioning purposes, however it was noted that it was not clear who was processing the data and asked for clarification in section 5 of the application. IGARD also asked for clarity in section 5 that NHS Digital was not involved in the processing of social care data.

IGARD discussed the use of the algorithm for risk stratification purposes and requested clarity for Data Processor 1.

IGARD noted that the invoice validation diagram provided with the application needed to be updated to accurately reflect the application including the master patient list which was not

listed in the application but was on diagram.

IGARD noted a minor typo in section 5 of the application which should be corrected around outputs expected and clearly reference the correct point.

IGARD noted that the details of the Nexent Data Centre were not clear and requested clarification of the correct legal entity.

IGARD suggested that the CCG's update their fair processing in line with NHS Digital's nine minimum criteria for privacy notices and suggested that the privacy notice on the applicant's website needed to be reviewed against best practice standards to ensure it was accessible to members of the public.

Outcome: Recommendation to approve.

The following amendments were requested:

- Reference to the use of the algorithm for risk stratification should be clearly reference for Data Processor 1 in the application.
- The data flow diagram should be corrected to accurately reflect the application summary.
- A typo in section 5, point 10 should be amended to clearly reference the right point.
- Clarification of the correct legal entity for Nexent Data Centre.
- Clarification in section 5 of the application who was processing personal data.
- Section 5 of the application be amended to clearly state that NHS Digital is not involved in any processing of social care data.

The following advice was given:

• IGARD advised the applicant should review their website against the ICO's Privacy Notices Code of Practice to ensure they reflect best practice standards, and in the interests of transparency, update their privacy notice as soon as possible to ensure it was accessible to members of the public and met NHS Digital nine minimum criteria.

3 Any other business

3.1 NIC-27085-C5L5G Imperial College London

IGARD noted that following the 2 November 2017 meeting, when IGARD had been unable to recommend the application for approval:

Outcome: Not able to recommend.

- Based on the materials provided as evidence there did not appear to be a legal basis in consent for identifiers to flow to NHS Digital, as the information provided to parents states that access to personal identifiable data will be limited to the Imperial College London research team and this did not seem compatible with the data sharing described in this application.
- Confirmation that the latest versions of consent materials have been provided to IGARD as the REC approval appeared to refer to later versions.
- Confirmation of whether the applicant's REC approval includes the flow of identifiers to NHS Digital including NHS number and date of birth, and if not, then the applicant should seek to update this approval.
- Confirmation that the penetration testing has been completed and signed off by NHS Digital
- References to 'patient consent' or 'participant consent' within the application should be corrected to refer to parental consent.

The following advice was given:

 IGARD advised that if recruitment is ongoing then the applicant should update the consent materials to meet current standards as well as the requirements of the upcoming implementation of GDPR.

NHS Digital had taken the decision to disseminate the data. The IGARD Chair and IGARD Deputy Chair had been informed of this out of committee.

3.2 NIC-14340-R7G1F Meditrends Limited

IGARD noted that following the 2 November 2017 meeting, when IGARD had deferred making a recommendation:

Outcome: Recommendation deferred, pending:

- More clearly explain the purposes for which data can be used under purpose two as
 previously raised by IGARD, with clarification of what governance process is used and
 what explicit criteria the applicant will use to determine whether a project can proceed
 under purpose two.
- Clarifying how the applicant will seek to evidence that any work taking place under purpose two is NHS-led.
- Providing more information about the due diligence undertaken by NHS Digital with regard to Meditrends Ltd and the trading name Beacon Consulting, with confirmation of whether Beacon Consulting has been dissolved and updating the application to clarify this.
- Amending a statement that the applicant will only work with six customers at a time to further clarify this.
- References to purpose two using historical data should be clarified.
- References to applying scrutiny to the purposes for which data can be used should be clarified to be clear who will apply this scrutiny.
- Reference to the requirement for potential customers to undertake governance training should be clarified.
- Section five should be updated to include a special condition that refers to data destruction.

The following advice was given:

3.3

IGARD advised that given that the applicant's previous DSA had expired, NHS Digital
might wish to consider putting a short term extension in place for a limited time period
to enable the applicant to continue processing data for purpose one only, with no
processing permitted for purpose two, while further work was undertaken to address
the queries raised.

NHS Digital had taken the decision to disseminate the data. The IGARD Chair and IGARD Deputy Chair had been informed of this out of committee.

NIC-376603-K2J9R NHS Digital National Bowel Cancer Audit

IGARD noted that following the 19 October 2017 meeting, when IGARD had deferred making a recommendation on this application:

Outcome: Recommendation deferred, pending:

- Providing evidence that appropriate approvals are in place for the use of data under section 42(4) of the SRSA 2007.
- Confirmation of whether the applicant has acted on advice from HRA CAG to update the statement of use provided to CPES respondents.

The following amendments were requested:

• Amending the abstract to state that the request for ONS data is an amendment rather than a renewal.

NHS Digital had taken the decision to disseminated the data. The IGARD Chair and IGARD Deputy Chair had been informed of this out of committee.

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	14/09/17: Ongoing. It was agreed this would be discussed during the educational session.07/12/17: Ongoing. It was agreed to bring the first draft to January's education session.14/12/17: Ongoing.	
27/04/17	IGARD Chair to contact the NHS Digital Caldicott Guardian regarding GPs' data controller responsibilities for fair processing around risk stratification.	pair to contact the NHS Digital Caldicott regarding GPs' data controller Caldicott 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.		Closed
18/05/17	Garry Coleman to provide information about different arrangements for data storage and backup locations,	Garry	15/06/17: IGARD had been advised by email that a paper about this	Open

for consideration of whether the organisations	Coleman	would be submitted to an upcoming IGARD meeting.	
involved would be considered to be processing data.		22/06/17: It was anticipated that this would be discussed at the 6 July 2017 IGARD meeting. IGARD asked for some information to be circulated by email prior to the meeting in order to inform members who would not be present at that particular meeting.	
		27/07/17: An email had been circulated requesting further information from IGARD members.	
		03/08/17: Two IGARD members had responded by email and the action remained ongoing.	
		10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks.	
		24/08/17: The paper was in the process of being updated based on recently published ICO guidance.	
		14/09/17: Ongoing. IGARD noted that given the amount of time that had passed, they would consider starting to note this on relevant applications where a data storage location was not listed as a data processor.	
		21/09/17: Ongoing. IGARD asked for Dickie Langley to provide an update on Garry Coleman's open actions at the next meeting to help ensure timely progression.	
		02/11/17: IGARD discussed this action with Garry Coleman and requested a written update in response to the points previously raised by IGARD. Some difficulties were acknowledged as this specific scenario did not seem to be addressed in existing ICO guidance; IGARD suggested that NHS Digital should seek legal advice and if necessary then contact the ICO directly.	
		16/11/17: Ongoing. IGARD queried the progress made regarding this action and there was a suggestion that this should be discussed at an education session; however it was suggested that it would be	

			necessary to receive an updated response from NHS Digital before this. 14/12/17: Ongoing	
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.		10/08/17: It was anticipated that a paper on this would be brought to IGARD within the following two weeks. 24/08/17: IGARD received a verbal update on the work that had taken place following both audits and verbal assurances that NHS Digital were content with the level of risk involved in this organisation continuing to act as a data processor. IGARD welcomed this update and requested written confirmation. 31/08/17: IGARD were notified that the requested written confirmation should be provided within one day. 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.	Open
20/07/17	Garry Coleman to categorise different standard lengths of indicative data retention periods for general research and clinical trials, with appropriate justification.	Garry Coleman	14/12/17: Ongoing	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 MRIS reports are now shown within applications.		14/12/17: Ongoing.	Open
21/09/17	Dickie Langley to provide a briefing paper (with	Dickie	07/12/17: Dickie Langley noted that a briefing paper would be	

	relevant supporting documents) regarding the legal basis for receipt of data from Department for Education, and for this to be reviewed by the IG Advisor prior to circulation to IGARD.	Langley	presented to IGARD in December / January. 14/12/17: The briefing paper was presented to IGARD on 14 th December 2017.	
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. 14/12/17: Ongoing	Open
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	14/12/17: Ongoing.	Open
14/12/17	Dickie Langley to bring back to a future IGARD meeting a briefing note on NHS Digital's due diligence policy and process	Dickie Langley		Open

Appendix B: Out of committee report

Independent Group Advising on Releases of Data (IGARD): Out of committee report 08/12/17

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

NIC reference	Applicant	IGARD meeting date	Recommendation conditions as set at IGARD meeting	IGARD minutes stated that conditions should be agreed by:	Conditions agreed as being met in the updated application by:	Notes of out of committee review (inc. any changes)
None	None		•			

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

None notified to IGARD