

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 3 May 2018

Members: Sarah Baalham, Joanne Bailey, Chris Carrigan (Chair, items 2.1-2.6), Kirsty Irvine (Chair, items 2.6-2.7), Jon Fistein, Eve Sariyannidou.

In attendance: Dave Cronin, Louise Dunn, James Humphries-Hart, Dickie Langley, Stuart Richardson, Rebecca Nutting (Observer), Kimberley Watson, Aaron White, Vicki Williams.

Apologies: Anomika Bedi, Nicola Fear.

1	<p>Declaration of interests</p> <p>Joanne Bailey noted a previous working relationship with the CEO at Isle of Man Department of Education (NIC-173508-F4X6P), but it was agreed this was not a conflict of interest.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 26 April 2018 IGARD meeting were reviewed 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>Health & Safety Executive (HSE): MR5 (a) Patient flagging for asbestos workers (Presenter: Dave Cronin) NIC-337801-K2N5Y</u></p> <p>Application: This was an extension, renewal and amendment application (linked to: NIC-183842-H8L1J) to retain and reuse Personal Demographic data, Cancer Registration data and Office for National Statistics (ONS) data previously provided via the Medical Research Information Service (MRIS) or predecessors which will be linked to a cohort of individuals comprising of 7462 individuals who gave consent from 2006 and 81045 individuals who were not deemed to have given informed consent and for whom s.251 support permits the processing of data.</p> <p>The Asbestos Workers Survey is a health surveillance study which was established by the HSE in 1971 to monitor the long-term health of survey participants in order to evaluate the effectiveness of progressively restrictive regulations to control the risks associated with exposure to asbestos with findings from the survey to form part of the evidence used to inform future decisions.</p> <p>NHS Digital noted incorrect numbering of supporting documents provided to IGARD for review and that a supporting document had not been provided for review by IGARD.</p> <p>NHS Digital also noted that the customer had not yet confirmed the legal basis under GDPR.</p> <p>Discussion: IGARD noted the valuable work undertaken by this study and welcomed the application.</p> <p>IGARD queried why the legal basis under GDPR had not been clearly defined within the application as was the current agreed approach (NHS Digital noted that the applicant was still to confirm the legal basis under GDPR).</p> <p>IGARD noted that there was currently a legal basis to disseminate data however suggested that the legal basis under GDPR be confirmed for data disseminated after 25 May 2018.</p>

	<p>IGARD noted that they were not clear if some supporting documents had just been incorrectly labelled or documents were missing from the pack provided and NHS Digital confirmed that some supporting documents had been mislabelled and one key document had not been provided to IGARD for review.</p> <p>IGARD queried where the mortality cohort data was derived from and suggested that since this was published aggregate data that a clear statement be included in section 5 of the application of same and that no further additional data was being disseminated by NHS Digital.</p> <p>IGARD noted that the abstract stated that no new individual would be added to the cohort however they suggested that this be included in section 5b that the cohort was finite, and no new individuals would be added to the cohort.</p> <p>IGARD also suggested that the HSE update their DPA registration to clearly state that data is processed about patients or health care users</p> <p>Outcome: recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> • The legal basis under GDPR be clearly defined within the application <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • A clear statement within section 5b that no new individuals will be added to the current cohort which is finite. • To clarify within section 5 that the mortality cohort is derived from published data and not any additional data disseminated by NHS Digital. • To update the supporting documents folder with relevant documentation and provide a copy to IGARD. • The applicant should update their DPA registration to more clearly state that data is processed about patients or healthcare users. <p>It was agreed the condition would approved OOC by IGARD Members</p>
2.2	<p><u>Health & Safety Executive (HSE): MR5 (b) patient flagging for asbestos workers (Presenter: Dave Cronin) NIC-183842-H8L1J</u></p> <p>Application: This was a new application (linked to NIC-337801-K2N5Y) to retain and reuse Personal Demographic data, Cancer Registration data and Office for National Statistics (ONS) mortality data previously provided via the Medical Research Information Service (MRIS) or predecessors which will be linked to a cohort of individuals comprising of 7462 individuals who gave consent from 2006 and 81045 individuals who were not deemed to have given informed consent for whom s.251 support permits the processing of data.</p> <p>The Asbestos Workers Survey is a health surveillance study which was established by the HSE in 1971 to monitor the long-term health or survey participants in order to evaluate the effectiveness of progressively restrictive regulations to control the risks associated with exposure to asbestos with findings from the survey to form part of the evidence used to inform future decisions.</p> <p>NHS Digital noted an incorrect reference to the legal basis had been updated within section 9.</p> <p>Discussion: IGARD noted the valuable work undertaken by this study and welcomed the application.</p> <p>IGARD queried why the legal basis under GDPR had not been clearly defined within the application as was the current agreed approach (NHS Digital noted that the applicant was still to confirm the legal basis under GDPR)</p>

	<p>However, NHS Digital had noted that the applicant was still to confirm the legal basis under GDPR. IGARD suggested that the application be updated to clearly state the current and future legal basis post 25 May 2018, since the application and the notes from NHSD appeared contradictory.</p> <p>IGARD queried where the mortality cohort data was derived from and suggested that since this was published aggregate data that a clear statement be included in section 5 of the application of same and that no further additional data was being disseminated by NHS Digital.</p> <p>IGARD noted that the abstract stated that no new individual would be added to the cohort however they suggested that this be included in section 5b that the cohort was finite, and no new individuals would be added to the cohort.</p> <p>IGARD also suggested that the HSE update their DPA registration to clearly state that data is processed about patients or health care users</p> <p>Outcome: unable to recommend for approval</p> <ul style="list-style-type: none"> • The application did not appear to provide a clear legal basis for the release of data. • A clear statement within section 5b that no new individuals will be added to the current cohort which is finite. • To clarify within section 5 that the mortality cohort is derived from published data and not any additional data disseminated by NHS Digital. • The applicant should update their DPA registration to more clearly state that data is processed about patients or healthcare users.
2.3	<p><u>University of Birmingham: supporting health services research activity in the School of Health & Population Sciences (Presenter: Dickie Langley) NIC-02544-M7M7G</u></p> <p>Application: This was an amendment application for additional pseudonymised Hospital Episode Statistics (HES) data and a resupply of HES Admitted Patient Care data along with a flag indicating whether a patient died within the 30 days of the episode for 2 projects funded by NIHR to complete by the end of 2019.</p> <p>The application had been previously considered by IGARD on the 19 April 2018 when IGARD had deferred making a recommendation pending: clarification of the role and relationship of the British Heart Foundation; update section 5 to reflect the project started in 2014; confirmation in section 5b that the applicant will not link the data; proving a clearly justification for the number of years of data requested for project 1; to update the abstract and section 5a to clearly state why the whole data is being re-supplied; to update section 5 to explain the data mortality flag; the abstract be updated to state that project 1 is about maternity and child healthcare; the fair processing section be updated to include new standard wording; to remove the special condition about fair processing; to remove the ICO weblink in the fair processing section; to update the DPA registration.</p> <p>This was a NIHR funded application</p> <p>Discussion: IGARD noted the application had been updated to reflect the comments previously raised, noting the work undertaken by the applicant and NHS Digital.</p> <p>Outcome: recommendation to approve.</p>
2.4	<p><u>Imperial College London: investigation of innovation diffusion within consultant specialities (Presenter: Louise Dunn) NIC-14360-S9G2Y</u></p>

Application: This was an amendment application to amend the scope of the disease area being investigated, which is currently cancer, to include cardiac care date. The study wants to extend their analysis to look at the same factors that might determine the uptake of innovative technology and practice, but outside of cancer services, using the same dataset as previously supplied and requiring no further data.

The data previously supplied was pseudonymised sensitive extract of Hospital Episode Statistics (HES) Admitted Patient Care data linked to data from the Workforce Statistics and locally sourced level 1 consultant data which has been supplied under licence from the General Medical Council (GMC) and then to also link to outcomes from consultant surveys which have been carried out by IPSOS.

NHS Digital noted that the fair processing section needed to be updated to include new standard wording.

Discussion: IGARD suggested that new standard wording for use with pseudonymised data be used: "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the General Data Protection Regulation (GDPR). All Data Controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements."

IGARD queried if further survey work was being undertaken by the applicant and NHS Digital noted they were not currently undertaking more work but may do in future, however IGARD suggested that a clear statement be included in section 5 that no further work was being undertaken.

IGARD noted that workforce identifiable data from the General Medical Council (GMC) / consultants was being received by NHS Digital and they queried if NHS Digital retained the one-off data. NHS Digital noted that they did not retain the data and that if any relink was required by the applicant that the applicant would need to resend the data to NHS Digital. IGARD suggested that it be clarified within section 5a that no new information would be gathered on consultants and that this was part of workforce data previously held by the applicant.

IGARD were unclear when the supporting document 3 was provided to participant, since it was not version controlled and it was suggested that confirmation be sought as to when this document was provided to participants and how it was used including a history of the survey.

Outcome: recommendation to approve

The following amendments were requested:

- To clearly state within section 5 that no further survey work is being undertaken.
- To clarify within section 5a that no new information will be gathered on consultants and that this is part of workforce data previously held by the applicant.
- The Fair Processing section to be amended to include the new standard wording: "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the General Data Protection Regulation (GDPR). All Data Controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements."
- To confirm when supporting document 3 was provided to participants and how it was used, including a history of the survey be provided within section 5.

2.5	<p><u>University College London: evaluating variation in special educational needs provision for children with Down Syndrome and associations with emergency use of hospital care</u> (Presenter: Kimberley Watson) NIC-50975-X6N3J</p> <p>Application: This was a new application for month and year of death to be provided use PDS which will be linked to a cohort of 119,000 derived from the Public Health England (PHE) National Down Syndrome Cytogenetic Register (NDSCR) and the PHE already-held Hospital Episode Statistic (HES) data. The study will look at variation across England in health, social care and education services for children with Down Syndrome and determine the impact on emergency use of hospital care. The study will be conducted in two stages and this application relates to the first stage of the study which is to identify a cohort of children with and without Down Syndrome, using data from HES and the NDSCR already held by PHE and monitor variation in comorbidity, mortality rates and healthcare use in children with Down Syndrome verse the general population over time and by region.</p> <p>NHS Digital noted that no data would flow until the legal basis under General Data Protection Regulation (GDPR) had been confirmed.</p> <p>Discussion: IGARD welcomed the application and noted its significance and complexity.</p> <p>IGARD queried the legal basis under GDPR for the linkage of HES data provided to PHE under the Memorandum of Understanding (MoU) to the registration data held by PHE. NHS Digital confirmed that this linkage was acceptable use under the MoU, however the legal basis for PHE to do the linkage was not clear since the MoU was not a legal gateway. IGARD noted that under GDPR there were different kinds of processing and queried which of the flows of identifiable data from PHE to NHS Digital were covered and that it be clearly stated what legal basis under GDPR was being used for the flow of the identifiable data from PHE to NHS Digital.</p> <p>IGARD queried what was meant by the 'control group' and how numbers were selected of the school aged children and suggested that clarification of the control cohort be provided in section 5 including who is the control group and how the selection is made. IGARD noted that a parent without Down Syndrome would want to understand the selection process, how the data was shared and if linked to other data. IGARD queried the legal basis for PHE to sample childhood data from the general population to generate the control group under GDPR and suggested that a clear statement be included in section 5, for transparency.</p> <p>IGARD noted that the application referred to both Economic Social Research Council (ESRC) and the Administrative Data Research Network (ADRN) / Administrative Data Research Centre for England (ADRC-England) (the new name for the network which seemed to indicate it was in transition) as funders and that supporting evidence 2.1 and 2.2 referred to ESCR as the sole funder and asked for further clarification. It was also noted that ADRN / ADRC-England had an active role in the project since it was the author of the project protocol and the main investigators for it and supporting documents 2.1 and 2.2 stated that the principal investigator for the project is the Director of ADRN / ADRC-England. IGARD noted that the network was led by the University of Southampton which worked in collaboration with a number of organisations including UCL and supporting document 5 also provided evidence of this. IGARD noted that supporting documents 2.1 and 2.2 confirmed that the co-investigators worked for the ADRN / ADRC-England and that the same co-investigators worked for the Institute of Education. IGARD suggested that the role and involvement of ADRN and the other collaborators within the network as well as the Institute of Education be clearly defined including the discrepancy with regard to the information provided by the funders; the role and involvement of the ADRN / ADRC-England; the role and involvement of the University of Southampton that leads the ADRN / ADRC-England as well as that of the other collaborators;</p>
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	<p>the role and involvement of the Institute of Education and to clarify who had access to the data.</p> <p>IGARD noted that the application referenced identifiable data and that the applicant is expected to provide a fair processing notice that meets NHS Digital's fair processing criteria and that the privacy notice be published and accessible.</p> <p>IGARD queried who were the 'Leeds Team' and NHS Digital noted that they were NHS Digital staff. It was suggested that clarification be added to the application that the team was NHS Digital staff based in Leeds. IGARD also suggested that PHE be included in the information governance toolkit special condition along with University College London.</p> <p>IGARD noted on a general point the consistency of the terms 'Down Syndrome' and 'Down's Syndrome' throughout the application and suggested that the correct terminology be used as appropriate.</p> <p>Outcome: recommendation to defer, pending:</p> <ul style="list-style-type: none"> • Clarification of the legal basis under GDPR for the linkage of HES data provided to PHE under the MoU to the registration data held by PHE • Clarification of the legal basis under GDPR for the flow of identifiable data from PHE to NHS Digital. • Clarification of the control cohort and the legal basis for PHE to sample childhood data from the general population to generate the control group under GDPR. • To clearly define the role and involvement of ADRN and the other collaborators within the network as well as the Institute of Education • To clarify within the application that the 'Leeds team' refers to NHS Digital staff based in Leeds. • To ensure consistency of the terms 'Down Syndrome' and 'Down's Syndrome' throughout section 5 of the application. • This application request is for personal data and the applicant is expected to provide a fair processing notice that meets NHS Digital's fair processing criteria including published and accessible. • To add PHE to the information governance toolkit special condition.
2.6	<p><u>Isle of Man Department of Health & Social Care: to receive pseudonymised SUS for the purpose of commissioning (Presenter: James Humphries-Hart) NIC-173508-F4X6P</u></p> <p>Application: This was a new application to receive pseudonymised Secondary Use Services (SUS) data for the purpose of commissioning. Currently patients on the Isle of Man (IoM) requiring treatment from services not available on the IoM travel to England to receive treatment and the IoM Department of Health & Social Care wish to understand the rate of patients being sent to the mainland to better assist what services require commissioning locally. The data will provide intelligence to support of commissioning of health services and 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 IoM area.</p> <p>Discussion: The application set out that the Isle of Man was neither part of the UK nor the EU and NHS Digital noted that since it was a Crown dependency the data could be transferred to the Isle of Man. However, IGARD noted that evidence should be provided which clearly showed the adequacy decision made by the European Commission which allowed such</p>

	<p>transfer of data, with a website link and clear statement explaining the effect of the adequacy decision within section 5 of the application.</p> <p>IGARD were also not clear on reference to 'data controller' and 'data processor' within section 1 'storage' and 'processing' and it was suggested that these erroneous headings be removed from section 1 and that a clear statement be included that these were physical storage locations and no additional data controllers and data processors.</p> <p>IGARD suggested that the ICO web link in section 4 be deleted and it was also suggested erroneous wording "Act 1998." should be removed from the end of section 4 of the application.</p> <p>IGARD noted that Blackpool Victoria Hospital, Hosted Infrastructure and Lima Networks Ltd were listed as storage locations and stated in 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 action with NHS Digital regarding storage locations and how to reflect their role as data processors.</p> <p>Outcome: recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> • To provide evidence of the adequacy decision made by the European Commission with regard to the Isle of Man and provide a website link within the abstract and section 1 'territory of use' and a clear statement within section 5 explaining the effect of the adequacy decision <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • Removing the erroneous references to 'data controller' and 'data processor' within section 1 'processing' and 'storage' and to clarify these are physical storage locations only. • To remove the ICO web link in the Fair Processing section. • To remove erroneous wording "Act 1998" from within the Fair Processing section of the application. <p>It was agreed this would be approved OOC by IGARD members</p>
2.7	<p><u>NHS Rotherham CCG: for commissioning using North of England Commissioning Support Unit and Sheffield Hallam University (Presenter: James Humphries-Hart) NIC-174557-H6J6Y</u></p> <p>Application: This was an amendment application to request SUS+ (all datasets) pseudonymised data for the purpose of commissioning, SUS+ (all datasets) identifiable data at the level of NHS Number for the purpose of risk stratification, SUS+ (all datasets) pseudonymised data for the purpose of invoice validation, Local Provider Flow data, 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 and add an additional Data Processor: Sheffield Hallam University.</p> <p>The application had been previously considered by IGARD on the 26 April 2018 when IGARD had deferred making a recommendation pending: removing reference to invoice validation and all requests for identifiable data for the purpose of invoice validation; the fair processing notice be amended to meet NHS Digital's nine minimum criteria; to remove the special condition about fair processing; to remove the ICO web link in the fair processing section; the data flow diagram to be updated to correctly identify the data flows and wording outlined in section 5; new text be clearly identified within the application; describing social prescribing; and clarify if Attain Health Management Services were listed on the previous application.</p>

	<p>NHS Digital noted that the fair processing notice special condition was still contained within the application and should be removed.</p> <p>Discussion: IGARD noted the application had been updated to reflect the comments previously raised but noted that the Fair Processing notice should be updated to specifically replace all references of ‘anonymised’ information and data with ‘de-identified’ data or information. IGARD also suggested the special condition referencing fair processing notices be removed, since it was not relevant to this application and had been superseded by updated wording within section 4 and to remove the two paragraphs (“all identifiable data is processed...” and “pseudonymised data is considered...”) within the fair processing section.</p> <p>IGARD suggested that on renewal further outputs with regard to social prescribing would be expected in a language that was suitable for a lay reader.</p> <p>Outcome: recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> • The Fair Processing Notice be amended to meet the NHS Digital nine minimum criteria (to be known as NHS Digital’s fair processing criteria) for privacy notices specifically to replace all references to anonymised information and data with de-identified. <p>The following amendments were requested:</p> <ul style="list-style-type: none"> • To remove the special condition about Fair Processing, since this has been superseded by updated wording in the Fair Processing section. • To remove the two paragraphs from the fair processing section (“all identifiable data is processed...” and “pseudonymised data is considered...”), since they were not relevant to this application. <p>The following advice was given:</p> <ul style="list-style-type: none"> • IGARD suggested that on renewal, the applicant would be expected to provide further outputs in respect of social prescribing that would be in language suitable for a lay reader. <p>It was agreed the condition would be approved OOC by the IGARD Chair</p>
<p>3</p> <p>3.1</p>	<p>AOB</p> <p>GDPR Legal basis</p> <p>It was agreed that the Deputy Chair would write to the Director Data Dissemination to ensure the legal basis under GDPR was being correctly referenced within the abstract of appropriate applications to IGARD.</p>

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>05/04/18: to seek clarification from the Chair if stakeholders have been approached and to bring back the draft to the May education session.</p> <p>12/04/18: The Chair noted he was yet to contact external to NHS Digital stakeholders.</p> <p>19/04/18: IGARD chair to update members at May's education session.</p> <p>03/05/18: The Chair of IGARD noted that he would be contacting key stakeholders over the coming weeks.</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</p>	Open

			<p>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>05/04/18: IGARD Secretariat had contacted Garry Colman and were awaiting a response.</p> <p>03/05/18: ongoing</p>	
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	<p>22/02/18: IGARD Secretariat to contact Garry Coleman to suggest presentation at the June education session.</p> <p>05/04/18/18: IGARD Secretariat were awaiting a response.</p> <p>03/05/18: ongoing</p>	Open
15/03/18	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.	Gaynor Dalton	<p>05/04/18: A verbal update was provided that individual Data Sharing Framework Contracts (DSFC) were issued yet Data Sharing Agreements were joint Data Controllership and that DSFC's placed exactly the same terms and conditions upon organisations and NHS Digital believe the position to be acceptable. IGARD noted the verbal update and asked that a briefing note be provided by NHS Digital confirming the arrangements in place by the end of April 2018.</p> <p>26/04/18: IGARD secretariat were awaiting a response following issue of a reminder</p>	Open

			03/05/18: It was noted the issue was wider than DSfC applications and applies to all DARS applications, the action owner was amended to the Head of Data Access, Gaynor Dalton.	
12/04/18	IGARD Members to consider the HRA guidance on GDPR published on line IGARD Chair to provide feedback to the Caldicott Guardian	IGARD IGARD Chair	19/04/18: IGARD members had considered the HRA guidance and asked the IGARD Chair to provide feedback to the Caldicott Guardian. 26/04/18: IGARD Secretariat awaiting comment following issue of a reminder. 03/05/18: the Chair of IGARD to provide a copy of the email sent to the Caldicott Guardian to the Secretariat team	
19/04/18	National Centre for Social Research – Adult Psychiatric Morbidity Survey (APMS): The Director Data Dissemination agreed to forward IGARD the documentation relied on by NHS Digital to reach this conclusion.	Garry Coleman	03/05/18: ongoing	Open
26/04/18	Stuart Richardson to complete, for transparency, on all future CCG applications the data already held information at section 3a, including such data as may be held under a different Data Sharing Agreement / NIC number.	Stuart Richardson	03/05/18: ongoing	
26/04/18	Stuart Richardson to provide for all future CCG applications a data flow diagram detailing all previously approved data flows alongside a new data flow diagram outlining the data flows for the presented application.	Stuart Richardson	03/05/18: ongoing	

03/05/18	The Deputy Chair to write to the Director Data Dissemination to ensure the legal basis under GDPR was being correctly referenced within the abstract of appropriate applications to IGARD.	IGARD Deputy Chair		
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Appendix B: Out of committee report

Independent Group Advising on Releases of Data (IGARD): Out of committee report 27/04/18

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)
GA04-NEL-STP: NIC-160958-K3J4W; NIC-160964-D7X8T; NIC-160972-N7P2J; NIC-160991-T8Y5X; NIC-160996-V3M5Q; NIC-161008-X5W6Y; NIC-161026-R5X1T; NIC-161053-Y7G1K;	NHS Brent CCG; NHS Central London CCG; NHS Ealing CCG; NHS Hammersmith and Fulham CCG; NHS Harrow CCG; NHS Hillingdon CCG; NHS Hounslow CCG; NHS West London CCG;	15/03/18	<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. 	IGARD Chair	IGARD Chair (CC)	N/A

NIC-94250-L8W8T	The Renal Registry	15/03/18	<ul style="list-style-type: none"> • Section 5 should be updated to clearly list the identifiers flowing to NHS Digital, aligning with s.251 support. • Section 5 of the application be updated to explicitly state that the research use of data is not part of the application as it is not covered by s.251 support • The first three bullet points within section 5a should be re-ordered. • A reference to researchers accessing data should be explicit that they are accessing audit data only and not data disseminated by NHS Digital. • A clearer explanation as to how s.42(4) applies in this application as is the legal basis for the receipt of ONS data. • To update the data flow diagram to include only flows relevant to this application. • Confirmation that the individuals accessing the data are substantive employees of The Renal Association working within the renal registry function. • 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 	IGARD Members	Quorum of IGARD Members	N/A
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			listing all the identifiers sent to NHS Digital, updating the opt out information to correct state this refers to any information and that opting out will not affect the care received, and removing references to the use of data for research data and the misleading statement that anonymous data is used for research, before data can flow.			
NIC-10123-M5K5H	University of Oxford	13/04/18	<ul style="list-style-type: none"> Clarifying explicitly within section 5 of the application that cancer data has not been disseminated previously, nor under this application. 	IGARD Chair	IGARD Chair (CC)	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