

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 10 May 2018

Members: Anomika Bedi, Chris Carrigan, Nicola Fear, Kirsty Irvine (Chair).

In attendance: Kieran Conville (Observer), Dave Cronin, Arjun Dhillon, Louise Dunn, James Humphries-Hart, Dickie Langley, Charlotte Roe (Observer), Aaron White, Vicki Williams.

Apologies: Sarah Baalham, Joanne Bailey, Jon Fistein, Eve Sariyiannidou.

1	<p>Declaration of interests</p> <p>Nicola Fear noted a professional link with Kings College London and is a member of the team which is undertaking the project, and would not be part of the discussion. It was agreed Nicola would not remain in the meeting for the discussion of that application.</p> <p>Review of previous minutes and actions</p> <p>The minutes of the 3 May 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>University of Oxford: Learning from patients (2) – developing a national resource for hip fracture research (Presenter: Dave Cronin) NIC-149784-H9K6B</u></p> <p>Application: This was a new application for Hospital Episodes Statistics (HES) Admitted Patient Care (APC) which will be linked with data from the National Hip Fracture Database (NHFD) for the purpose of developing an improved risk adjustment model for the NHFD using data linkage and prospective collection of additional variables; using the new risk adjustment model to compare high fracture patient outcomes between the UK, USA and Australia to identify opportunities for improving care; and demonstration of the feasibility of using the enriched NHFD to answer specific health policy questions that could inform future priorities and health service planning.</p> <p>NHS Digital noted that under GDPR pseudonymised data will be classed as personal data and the applicant will be required to publish a fair processing notice (FPN) as per current guidelines and that a special condition had been inserted into the data sharing agreement (DSA) regarding publication of an appropriate FPN.</p> <p>Discussion: IGARD queried the data currently held by the applicant and the data requested and NHS Digital explained that the current data held was under a separate DSA and this application was for a separate extract of HES not linked to the data held previously. IGARD suggested that for transparency and audit purposes the abstract be updated to clearly define that there were two separate extracts of HES data, with one already held by the applicant and an additional extract request of pseudonymised HES data.</p> <p>IGARD noted that in supporting document 6 provided “HQIP Data Sharing Agreement” there were numerous references to a “Data Sharing Request Form” and asked that a copy be provided to ensure the terms of arrangements and scope married with the time and scope period.</p> <p>IGARD queried if the applicant was receiving data from the USA and Australia or the data was being shared with those countries as outlined in the project. NHS Digital noted that the</p>

	<p>comparison of aggregated data was being undertaken at the University of Oxford however IGARD suggested that a clear statement be included that only aggregated data with small numbers suppressed will be shared with partners outside of the United Kingdom.</p> <p>IGARD noted the funding arrangements in place and suggested that section 8 of the application be updated to clearly identify UCB (biopharmaceutical company) as the funder organisation and not University of Oxford as currently stated.</p> <p>IGARD suggested that the statement in section 5d of the application “and (3) re-confirm the legal basis on which other researchers might rely to request linked NHFD-HES data” be removed as statement was unclear, noting the good work that had been undertaken to come to this conclusion.</p> <p>IGARD noted that section 5 referred to researchers employed by the University of Oxford and queried who these were. NHS Digital confirmed that one of the researchers was employed by University of Oxford and the other was on an honorary contract from Yale University (USA), however IGARD suggested that section 5 be updated to clearly refer to ‘researchers’ or specifically the ‘University of Oxford researcher’ accessing the data.</p> <p>IGARD noted that the applicant had requested 18 years of HES APC hip fracture episodes data and NHS Digital noted that this was the minimum required for the project and a clear justification had been included in section 3b of the application.</p> <p><i>[deleted because covered above]</i> IGARD noted the detail provided by the applicant with regard to GDPR legal basis for processing and wished to extend their thanks at the level of analysis provided and that NHS Digital may wish to use this as an exemplar of good practice.</p> <p>Outcome: recommendation to approve subject to the following condition:</p> <p>The application was recommended for approval subject to the following condition:</p> <ol style="list-style-type: none"> 1. To provide a copy of the ‘data sharing request form’ as outlined in supporting document 6 ‘HQIP Data Sharing Agreement’. <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update the abstract to clearly define that there are two separate extracts of data with one already held by the applicant and an additional extract request of pseudonymised HES data. 2. To clarify that only aggregated data with small numbers suppressed will be shared to partners outside of the United Kingdom. 3. Section 8 of the application be updated to identify UCB (biopharmaceutical company) as the funder organisation, as reflected in the supporting documentation. 4. To update section 5 to clearly refer to ‘researchers’ or specifically the ‘University of Oxford researcher’. 5. To clarify or remove the statement in Section 5d: “and (3) re-confirm the legal basis on which other researchers might rely to request linked NHFD-HES data.” <p>It was agreed this would be approved OOC by the IGARD Chair</p>
2.2	<p><u>University of Sheffield: the comparative effectiveness and efficiency of Cognitive Behaviour Therapy (CBT), Counselling for Depression (CfD) and other High Intensity Therapies (HIT) in the treatment of depression in the Improvement Access to Psychological Therapies (IAPT) Services (Presenter: Dickie Langley) NIC- 85465-H1W9F</u></p> <p>Application: This was a new application for an extract of pseudonymised IAPT Mental Health dataset to look at the efficiency of CBT, CfD and other HIT’s. The School for Health and</p>

	<p>Related Research (SCHARR) uses data from HQIP (National Audit of Psychological Therapies) and now wishes to expand the work using more up to date data, reflecting the changes in therapies available. SCHARR aim to examine the effectiveness of HIT in the IAPT programme by focussing on the three types of HIT which are most commonly offered in IAPT to determine the effectiveness of IAPT HIT interventions.</p> <p>NHS Digital noted the Data Sharing Agreement start and end dates were incorrect, noted a spelling mistake and V14.1 should be 'self-assessed' within the abstract.</p> <p>Discussion: IGARD noted the good work being undertaken by the study which was well described in the application.</p> <p>IGARD noted the spelling mistake within the abstract and suggested it be updated, along with clearly noting that version 14.1 of the Information Governance Toolkit was 'self-assessed'.</p> <p>IGARD queried if data was being linked and NHS Digital noted that no data linkage would be allowed under this data sharing agreement (DSA). IGARD suggested that confirmation be included within section 5b of the application that the applicant will not link the data further and the only data linkages are those permitted under this application / DSA and that data will not be used for reidentification purposes.</p> <p>Outcome: recommendation to approve</p> <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. Confirmation within section 5b of the application that the applicant will not link the data further and the only data linkages are those permitted under this application / Data Sharing Agreement and that data will not be used for reidentification purposes. 2. The abstract should be updated to clearly note that the Version 14.1 of the IGT is 'self-assessed' and to correct a spelling mistake of the word 'cognitive'. 3. To amend the DSA start and end dates.
2.3	<p><u>Kings College London: the mental health and treatment needs of UK ex-serving personnel (Presenter: Dickie Langley) NIC-142790-C1J9J</u></p> <p>It was noted that due to a conflict of interest Nicola Fear was not present for the discussion of this application and that IGARD would therefore not be quorate for this item.</p> <p>Application: this was a new application requesting the latest available Improvement Access to Psychological Therapies (IAPT) and Adult Psychiatric Morbidity Survey (APMS) datasets. The applicant plans to use IAPT data to compare sociodemographic, welfare and clinical characteristics of veterans and non-veterans who has accessed IAPT services. The APMS data will be utilised to example the prevalence and socioeconomic determinants of mental health in veterans compared to non-veterans.</p> <p>NHS Digital noted that the Data Sharing Framework Contract (DSFC) expiry date should be updated to 2020.</p> <p>Discussion: IGARD noted the worthwhile study being undertaken and that it had been clearly laid out with the application.</p> <p>IGARD noted that the data was being stored on a server and asked if the server accessed the internet and that NHS Digital were content with the security arrangements in place. NHS Digital noted this was a long-standing study with role-based access, approved by NHS Digital's security team.</p>

	<p>IGARD noted that the sentence “the IAPT and APMS datasets will be received in a pseudonymised form so there will be no storage of identifiable data at any point” be updated to include the word ‘directly’ before the word ‘identifiable’.</p> <p>IGARD suggested that the DSFC expiry date be updated from 2010 to 2020, as suggested by NHS Digital.</p> <p>IGARD queried if an ethics review had been undertaken and NHS digital confirmed that it had, however IGARD asked for sight of the applicant’s latest ethics approval letter as referred to in section 7 of the application.</p> <p>IGARD queried if funding was in place for the research period and asked for evidence to be provided in order to be clear that the funder would have no influence on the outputs or results of the study being undertaken by the applicant.</p> <p>IGARD noted the engagement plan and outputs of dissemination to a wide range of parties provided and wished to extend their thanks at the level of information provided and that NHS Digital may wish to use this as an exemplar of good practice.</p> <p>IGARD noted there was an outstanding action with NHS Digital with regard to the National Centre for Social Research APMS data and that the Director Data Dissemination had agreed to forward to IGARD the documentation relied on by NHS Digital to reach this conclusion. IGARD noted that they believed there was an authority to collect the data (based on this assurance provided by NHS Digital), but acknowledged that evidence of the legal basis was not available for IGARD to consider. IGARD recognised the importance of the work involved and although IGARD could not comment on the legal basis (as no evidence had been provided), IGARD were aware that NHS Digital might independently choose to continue to flow data as they had looked into this area and had confidence that an appropriate legal basis existed.</p> <p>Outcome: IGARD were supportive of the application but unable to make a formal recommendation as there was not a quorum of members able to comment on the application. The following comments were made:</p> <ol style="list-style-type: none"> 1. Providing evidence that funding is in place for the research period and providing relevant documentation. 2. Providing a copy of the applicant’s latest ethics approval letter as referred to in the supporting documents section of the application. 3. The DSFC date within the abstract should be updated to ‘2020’. 4. The sentence “the IAPT and APMS datasets will be received in a pseudonymised form so there will be no storage of identifiable data at any point” be updated to include the word ‘directly’ before the word ‘identifiable’.
2.4	<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>The application had been previously considered on the 15 March 2018 when IGARD had 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; confirmation that the Senior Health Practitioners who will access the data are substantive employees of the applicant; clarification within section 5b 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; 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 patient objections will have been applied; to clarify in section 4 that the participants are deceased, and Data Protection does not apply; Section 5 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; a reference to pseudo-anonymised data should be updated to pseudonymised data.</p> <p>NHS Digital noted the special condition in the previous iteration of the application referring to ONS had not been added to this application.</p> <p>Discussion: IGARD welcomed the application and noted the application had been updated to reflect the comments previously raised and thanked the applicant and NHS Digital.</p> <p>IGARD noted that the special condition included in the previous application presented to IGARD with regard to the commissioning letter for ONS was missing and should be reinstated in the relevant section.</p> <p>Outcome: recommendation to approve.</p> <p>The following amendment was requested:</p> <ol style="list-style-type: none"> 1. To reinstate the special condition from the previous iteration of the application referring to the commissioning letter for ONS data.
2.5	<p><u>University of Southampton NHS Foundation Trust: MR1449 Fluid Optimisation in Emergency Laparotomy (FLO-ELA) trial (Presenter: Louise Dunn) NIC-60714-M4T1M</u></p> <p>Application: This was a new application for identifiable Hospital Episodes Statistics (HES) Admitted Patient Care (APC) and Critical Care (CC), and Office for National Statistics (ONS) date of death date linked to a cohort of approximately 8000.</p> <p>The application had been previously considered on the 8 March 2018 when IGARD had been unable to recommend for approval pending: NHS Digital ensuring the appropriate Data Sharing Framework Contracts were in place; to provide a copy of the personal consultee or nominated consultee advice document(s) and the appropriate consent materials to those lacking capacity to consent; NHS Digital work with the applicant to ensure their consent materials meet the General Data Protection Regulation (GDPR) standard of consent, including a clear process for re-consenting the cohort, if necessary, as well as setting up a process for recording and monitoring consent; a clearer explanation about data minimisation and why it would not be sufficient to use a smaller amount of HES APC / CC data for this purpose; reference to S42(4) Statistics & Registration Service Act 2007 be updated to correctly list the appropriate subsection; reference to "more broadly, work will be carried out with patient partners and the PCPIE group at the Royal College of Anaesthetists to plan lay-orientated dissemination of the trial results to</p>

a non-medical audience” be included within section 5; clearly stating the applicant will not share the data in this application apart from aggregated data or publishable data sharing permitted under this application / DSA; clarifying the delineation between the National Emergency Laparotomy Audit (NELA) and FLO-ELA subset; clarification that the Royal College of Anaesthetists cannot access FLO-ELA data and to fully explain their role; the application be amended to confirm that funding is in place and providing relevant evidence; reference to NELA data and HES-ONS data being linked to Health Economics dataset be updated to reflect that this is EPOCH data, as referenced in the data flow diagram, a reference to anonymised data should be updated to pseudonymised data; the applicant update their DPA registration; correcting a website link to the FLO-ELA within the application.

Discussion: IGARD welcomed the application and noted the significant amount of work undertaken by NHS Digital and the applicant, and that application had been updated to reflect the comments previously raised. NHS Digital advised that the applicant would not be relying on the GDPR legal basis of consent and that the application would be updated with the correct GDPR legal basis along with a brief summary for transparency and future audit. Despite consent not being the GDPR legal basis, IGARD noted that the applicant may nonetheless wish to follow current good practice guidance and provide more than one means for participants to opt out, for example an email address as well as a phone number.

IGARD noted that supporting document 9 was provided to outline the funding in place, however it was not clear from the document if it covered the period of the trial and asked that the application be updated to clearly state that funding was in place and to provide a copy of the funding extension letter.

IGARD suggested that NHS Digital may wish to check with the NHS Digital IG Advisor to IGARD the legal basis under the Statistics & Registrations Service Act 2007 and that the correct section was referenced.

IGARD discussed the fact that this was a multiparty contractual arrangement (with associated risks) and noted the outstanding NHS Digital action on this point (see also AOB). NHS Digital explained that while both organisations would be data controllers, from a practical perspective, the data would only be held and accessed at one location i.e. at Queen Mary University London. Both organisations had successfully worked with NHS Digital over the last few years and thus had a number of data sharing agreements in place with no concerns experienced with regard to their management of data. NHS Digital assured IGARD that the contractual arrangements were appropriately structured to this type of arrangement. IGARD noted the comments and suggested that it be explicit within section 5 of the application that individuals could only access, process or store data at the Queen Mary University of London location.

IGARD noted a noted a spelling mistake and suggested that ‘college’ be updated.

Outcome: recommendation to approve subject to the following condition:

1. The application should be amended to confirm that funding is in place and providing relevant evidence including a copy of the funding extension letter.

The following amendments were requested:

1. To explicitly state within section 5 of the application that individuals will only be accessing, processing and storing data at Queen Mary University of London location.
2. The legal basis under the Statistics & Registration Service Act 2007 for the dissemination of data be confirmed within the application
3. The legal basis under GDPR be clearly defined within the abstract along with a brief summary.

	<p>4. The abstract should be updated to correct a spelling mistake of the word 'college'</p> <p>The following advice was given:</p> <ol style="list-style-type: none"> 1. IGARD suggested that, based on current good practice guidance, the applicant may wish to provide more than one means for participants to opt out (for example an email address as well as a phone number). <p>It was agreed this would be approved OOC by the IGARD Chair.</p>
2.6	<p><u>Group of 12 CCGS¹: for Secondary Use Service data for the purpose of commissioning (Presenter: James Humphries Hart) GA05-AMD-SC</u></p> <p>Application: This was an application for the 12 CCG's to receive pseudonymised Secondary Use Service (SUS) for the purpose of commissioning using Optum Health Solutions (UK) Limited as the data processor. The pseudonymised data will 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 CCG area.</p> <p>Discussion: NHS Digital noted that in addition to the information provided IGARD should be aware that 3 newly formed CCG's who did not have existing data sharing agreements were included within the application: NHS Berkshire West CCG, NHS Buckinghamshire CCG and NHS East Berkshire CCG.</p> <p>IGARD queried if the CCG's accessed patient data for the other CCG's within the application and should be referenced as Joint Data Controllers, however NHS Digital confirmed that each CCG was the sole Data Controller accessing and receiving only their own data and that each CCG would receive their own data sharing agreement. IGARD queried why the applicants were listed on one application and NHS Digital noted that due to the similarities of all the applications, the CCG's were listed on the same application form. IGARD noted the historical approach taken by NHS Digital however for transparency suggested that the abstract be clearly updated to reflect that 12 CCG's were grouped together in the one form to ease the administration burden associated with processing many similar applications. NHS Digital confirmed that the application was not a multi-party application with Joint Data Controllers but was in effect multiple applications of individual CCG's presented on one form. It was noted that there were individual NIC numbers, individual data sharing framework contracts and DSA's (with no linkage of data) with each CCG being the sole Data Controller and all CCG's independently using Optum Health Solutions (UK) Limited as the Data Processor.</p> <p>Outcome: recommendation to approve</p> <p>The following amendment was requested:</p> <ol style="list-style-type: none"> 1. To amend the abstract to clearly state that for the purposes of presentation to IGARD and administrative ease, the 12 CCGs had been grouped together. However, the application was not a multi-party application with joint Data Controllers but instead an application of individual CCG's with individual NIC numbers, DSFCs and DSAs with no linkage of data, with the CCG's being sole Data Controllers (each with Optum Health Solutions (UK) Limited as Data Processor).

¹ NHS Berkshire West CCG NIC-127476-B9W0D; NHS Buckinghamshire NIC-127474-F9Z2L; NHS Dorset CCG NIC-127446-P0M0V; NHS East Berkshire CCG NIC-127613-Y3Q2M; NHS North East Hampshire and Farnham CCG NIC-127578-C7N6S; NHS North Hampshire CCG NIC-127466-L4K1Z; NHS Oxfordshire CCG NIC-127470-K6T8J; NHS Portsmouth CCG NIC-127559-B7J9N; NHS South Eastern Hampshire CCG NIC-127490-Z8G0L; NHS Southampton CCG NIC-127492-G3Y1X; NHS West Hampshire CCG NIC-127591-J3P1T

<p>3</p> <p>3.1</p>	<p>AOB</p> <p>NHS Digital regarding multiparty contractual arrangements</p> <p>IGARD discussed with the Director of Data Dissemination the current outstanding action on NHS Digital regarding multiparty contractual arrangements (as detailed in the minutes of 15 March 2018). IGARD noted the pressing nature of the outstanding response from NHS Digital and IGARD wished to expressly note that that the recommendation of the multiparty application in today's meeting was made taking due regard of the facts of the application, reassurances provided by NHS Digital as to the long-standing relationship of the applicant organisations with NHS Digital, and that NHS Digital considered the applicants to be good custodians of data who would ensure relevant security measures in place. NHS Digital noted that the action was with them to provide IGARD with written confirmation as to the manner in which risks were addressed in multiparty applicant arrangements and committed to do so by the 24th May 2018.</p>
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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>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> <p>10/05/18: 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</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>10/05/18: 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>10/05/18: 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

			<p>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.</p> <p>10/05/18: The Director Data Dissemination noted that a briefing note would be provided to IGARD for the 24 May meeting</p>	
12/04/18	<p>IGARD Members to consider the HRA guidance on GDPR published on line</p> <p>IGARD Chair to provide feedback to the Caldicott Guardian</p>	<p>IGARD</p> <p>IGARD Chair</p>	<p>19/04/18: IGARD members had considered the HRA guidance and asked the IGARD Chair to provide feedback to the Caldicott Guardian.</p> <p>26/04/18: IGARD Secretariat awaiting comment following issue of a reminder.</p> <p>03/05/18: the Chair of IGARD to provide a copy of the email sent to the Caldicott Guardian to the Secretariat team</p> <p>10/05/18: IGARD secretariat were awaiting a response following issue of a reminder</p>	Open
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	<p>03/05/18: ongoing</p> <p>10/05/18: A copy of the documentation was provided to IGARD members for consideration. The IG Advisor to IGARD and a member of the IG GDPR team reviewed the documentation and consider that it provides sufficient evidence that NHS Digital where director to undertake the APMS survey activities and satisfy the requirements of the Commencement Order and the Deputy Caldicott Guardian, Programme Lead confirmed they were satisfied that the legal basis for collection and analysis was met and that there was a legal basis to disseminate the data.</p>	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	Stuart Richardson	10/05/18: ongoing	Open

	may be held under a different Data Sharing Agreement / NIC number.			
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	10/05/18: ongoing	Open
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	10/05/18: The Deputy Chair wrote to the Director Data Dissemination in the 08/05/18 and received confirmation from the Director that applications to IGARD hereon would document the legal basis for the Data Controller processing the data (the GDPR legal basis) and would apply where identifiable data is being shared. It was agreed that the action can be closed and removed from the action plan	Close

Appendix B: Out of committee report

Independent Group Advising on Releases of Data (IGARD): Out of committee report 20/04/18

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. 	IGARD Members	Quorum of IGARD Members	N/A

			<ul style="list-style-type: none"> • 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 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. 			
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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