Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 20 September 2018

Members: Anomika Bedi, Jon Fistein, Kirsty Irvine (Chair), Eve Sariyiannidou.

In attendance: Louise Dunn, Rachel Farrand, Dickie Langley, Tim Magor, Karen Myers, James Smith.

Observer: Clare Wright

Apologies: Joanne Bailey, Sarah Baalham, Nicola Fear.

1	**Declaration of interests:** Jon Fistein noted professional links to the University of Cambridge (NIC-147829-5K4QP and NIC-309034-C7M7W) but noted no specific connection with the application or staff involved and it was agreed this was not a conflict of interest. Jon Fistein noted professional links to HQIP (NIC-164830-L7L7C - Kings College London), but noted no specific connection with the application or staff involved and it was agreed this was not a conflict of interest. **Review of previous minutes and actions:** The minutes of the 13 September 2018 IGARD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting. **Out of committee recommendations** An out of committee report was received (see Appendix B).
2	**Data applications**
2.1	<u>National Data Opt-out Launch Briefing Paper (Presenter: Tim Magor)</u> NHS Digital has developed a service to support the implementation of the national data opt-out, as recommended by the National Data Guardian. It allows patients and the public to make an informed choice about whether they wish their confidential patient information to be used for research and planning. NHS Digital is the first organisation to uphold the national data opt-out with implementation across the health and care system by 2020. The purpose of the paper was to provide further information to IGARD. IGARD thanked Tim Magor for attending the meeting and noted the contents of the briefing paper.
2.2	<u>Birmingham Women's and Children's NHS Foundation Trust: Access to NHS Digital Online Portal (Presenter: Dickie Langley) NIC-11544-S1L0R</u> **Application:** This was a renewal application for access to pseudonymised Hospital Episode Statistic (HES) data to support three activities; challenging practice, both at the hospital and across the local economy; contributing to the whole health economy planning process and exploring the strategic future possibilities for the Trust. The NHS Digital Portal gives the ability to design queries that can be appropriately filtered for demographic and clinical care factors. NHS Digital advised that the full name of the Birmingham Women's and Children's NHS Foundation Trust was not reflected in the special conditions and would be updated.

	Discussion: IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was 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 GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". IGARD suggested that the following sentence in section 5(a) "No data included in these reports is at a granularity that would not be available through a freedom of information request route." should be removed since it was not relevant to this application. IGARD noted that some of the acronyms within the application were not always defined upon first use and suggested the application to be amended as necessary to make this clear. **Outcome:** recommendation to approve The following amendments were requested: 1. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". 2. To amend the first Special Condition to reflect the full name of the Birmingham Women's and Children's NHS Foundation Trust. 3. To remove the following sentence in section 5(a) "No data included in these reports is at a granularity that would not be available through a freedom of information request route." 4. IGARD suggested that all acronyms upon first use in the application be defined (and further explained, as may be necessary for a lay reader). The following observation was made: 1. It was IGARD's understanding that this application would be a continuation of the same level of access as previously received on the old system and that the outcome was not an endorsement of the new system. IGARD requested a briefing on the NHS Digital Portal from NHS Digital at an appropriate time in the future.
2.3	University of Cambridge: MR480 - MRC Study of Cognitive Function and Ageing MR490 – Alpha Study (Liverpool) (Presenter: Rachel Farrand) NIC-147829-5K4QP **Application:** This was a new application for identifiable Medical Research Information Service (MRIS) to bring together two study cohorts to form one cohort and to receive further data for the combined cohort. The studies are longitudinal population based epidemiological studies based in six areas of the UK and have recruited over 18,000 people and conducted in excess of 48,000 interviews over a period of more than 25 years. These studies have provided sound evidence generated by high quality population-based research to advance understanding of health and health changes with age. **Discussion:** IGARD noted that it was unclear in the application what the relationship was between the Cognitive Function and Ageing Study (CFAS) and the Ageing in Liverpool Health Aspects (ALPHA) Study and suggested that further clarity be provided in the application. IGARD queried how the two original cohorts (MR480 and MR490) were identified and suggested further clarification be provided in section 5.

	IGARD suggested that it be clearly articulated within section 5 the purpose of the CFAS Study and provide clarity on the studies that sit under this, including clearly stating what is and what is not covered by this application. IGARD noted that it was unclear in section 5 of the application who was the Data Controller and asked for this to be updated to reflect this information. IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was 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 GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". IGARD queried if any yielded benefits had been generated since the study / research commenced and suggested that additional measurable benefits be included within section 5 along with additional yielded benefits with a clear timescale for outputs, for transparency. NHS Digital advised IGARD that the two studies were being brought together for administrative ease, IGAD suggested that this should be clearly stated in the application, along with further information on the historic Data Sharing Agreements (DSA) and to clearly outline how the datasets will be managed going forward. **Outcome:** Unable to recommend for approval 1. To further clarify in section 5 what the relationship is between the two studies referred to within the application. 2. Further information to be included in section 5 about the two cohorts and how they were identified. 3. To provide further information in section 5 of the purpose of the CFAS study and the studies that sit under it, including what is covered by this particular application. 4. To clarify within section 5 who is the Data Controller. 5. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". 6. To provide more examples of measurable and yielded benefits within section 5 of the application with a clear timescale for outputs. 7. To explain that the studies are being brought together for administrative ease, to explain the background of the historic DSAs and to clearly outline in the application how the datasets will be managed going forward.
2.4	<u>Lancashire Care NHS Foundation Trust: A single consolidated new request for commissioning purposes - Lancashire Care NHS Foundation Trust (Hosting the Innovation Agency) (Presenter: Rachel Farrand) NIC-79728-X2C2X</u> **Application:** This was an amendment application for pseudonymised Secondary Use Service (SUS). The applicant would like to amend the existing agreement to add Lancaster University to their agreement as a data processor to support the functions of the Connected Health Cities programme which enables analysis to be undertaken to support and inform improved service understanding and delivery, with a focus on two specific clinical pathways; Alcohol and Emergency Care. **Discussion:** IGARD queried whether NHS Digital had satisfied themselves that the substantive employer of those on honorary contracts agreed to be bound by and take action in line with the

	terms of the relevant honorary contract and asked that confirmation from the substantive employer is obtained by NHS Digital. IGARD also asked that the application clearly state that Lancaster University is a Data Processor not issuing honorary contracts to individuals. IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was 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 GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". IGARD noted that the Data Sharing Agreement (DSA) expiry date was incorrect and asked that this be updated with the correct date. IGARD noted that supporting document 1, the data flow diagram, did not reference all the data processors and suggested that data flow diagram be updated to clearly reference this, and to also make it clear within the diagram that there will be no local provider flow; and to replace any reference to 'anonymised' with 'pseudonymised. IGARD noted that where the data flow is referenced it should be made clear where appropriate this includes AIMES. **Outcome:** recommendation to approve subject to the following condition 1. To obtain confirmation from the substantive employer (by way of a letter of assurance or similar) of those on honorary contracts that they agree to by bound by and take action in line with the terms of the relevant honorary contract. The following amendments were requested: 1. To make clear in the application that Lancaster University is a Data Processor not issuing honorary contracts to individuals. 2. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". 3. To update the DSA with the correct expiry date. 4. Amend supporting document 1, the data flow diagram, to include all data processors, to make clear that there will be no local provider flow, and to replace 'anonymised' with 'pseudonymised'. 5. To amend section 5(b) where the data flow is referenced to include AIMES, where appropriate. It was agreed the conditions be approved OOC by IGARD Members
2.5	University of Cambridge: Understanding the long-term effects of whole blood and platelet donation (Presenter: James Smith) NIC-309034-C7M7W **Application:** The application was been previously considered on the 7th June 2018 when IGARD had deferred making a recommendation pending; providing the relevant sections under Article 6 and 9 of GDPR and a clear justification for the choice of each section; confirmation within section 5(b) that the applicant will not link the data further; providing evidence that s.251 support is still in place for the project; to provide evidence that Office for National Statistics (ONS) legal basis is in place; to reference within the applicant's fair processing notice that anonymised data should be updated to pseudonymised data. IGARD

	also suggested that the study newsletter be updated to provide up to date information with regard to the research being undertaken. **Discussion:** IGARD noted that the pilot study outlined in the application was still ongoing and asked for the application to be updated to clarify how the pilot is progressing. IGARD noted that section 4 incorrectly states that the privacy notice is GDPR compliant and asked that this statement be removed. IGARD advised removing reference to the Statistics and Registration Service Act 2007 (SRSA) and ONS within section 3(b). **Outcome:** recommendation to approve The following amendments were requested: 1. To provide an update to clarify how the pilot outlined in the application is progressing. 2. To remove the statement in section 4 stating that the privacy notice is GDPR compliant. 3. To amend section 3(b) to remove references to SRSA and ONS.
2.6	<u>Civil Eyes Research Ltd: HES data application (Presenter: Rachel Farrand) NIC-35166-B5Y7P</u> **Application:** This was a new application for pseudonymised Hospital Episode Statistics (HES) data to provide aggregated analysis and interpretation of performance and quality issues within healthcare to doctors, clinicians and managers of NHS and Social Care providers. **Discussion:** IGARD suggested that it be clearly articulated within section 5(a) that the purpose of the legitimate interests, and how it relates to the purpose of the research being undertaken, including confirmation within the abstract or as an additional supporting document that NHS Digital have assessed and deemed the Legitimate Interest Assessment (LIA) satisfactory in order to meet its GDPR obligations. IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was 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 GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month”. IGARD noted the following wording in section 5(a): “Civil Eyes Research has not and will not use HES data to undertake sales and / or marketing activities to the healthcare or any other sector.” and suggested this also be duplicated as a special condition in section 6. IGARD asked for a statement to be included in section 5(e) confirming that NHS Digital has analysed the proposed use of data and concluded that there is sufficient benefit generated to health and social care. IGARD noted that the application and the fair processing notice noted the word ‘directly’ when referring to linkage and suggested this be removed throughout the application; and to also clarify if there will be any linkage and to update the application and fair processing notice as necessary to describe the linkage. IGARD noted the applicant should provide a fair processing notice that it is compliant with the notice requirements under the GDPR and suggested that they work with NHS Digital to amend their current privacy notice. **Outcome:** recommendation to approve

	The following amendments were requested: 1. To make reference in the abstract that NHS Digital has considered the LIA produced by the applicant and deemed it satisfactory. 2. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". 3. To duplicate the following sentence from section 5(a) "Civil Eyes Research has not and will not use HES data to undertake sales and / or marketing activities to the healthcare or any other sector." and include it as a special condition in section 6. 4. To remove the word 'directly' within the application and the fair processing notice when referring to linkage and to clarify with the applicant if there will be any linkage and update the application and fair processing notice as may be necessary to describe such linkage. 5. To add a statement within section 5(e) confirming that NHS Digital has analysed the proposed use of data and concluded that there is sufficient benefit generated to health and social care. The following advice was given: 1. The applicant should work with NHS Digital on a fair processing notice which is GDPR compliant including being accessible and transparent.
2.7	<u>London School of Hygiene and Tropical Medicine (LSHTM): Emergency Surgery Or noT (the ESORT study) (Presenter: Rachel Farrand) NIC-185179-V0B0T</u> **Application:** This was a new application for pseudonymised Civil Registration and Hospital Episode Statistics (HES) data. The aim of the study is to estimate the effectiveness and cost-effectiveness of emergency surgery versus non-operative care for patients with common acute conditions presenting as emergency admissions to NHS trust hospitals. **Discussion:** IGARD discussed the large volume of the datasets requested but noted with approval the data minimisation efforts made by the applicant. IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was 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 GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". **Outcome**: recommendation to approve The following amendment was requested: 1. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month".
2.8	<u>University of Birmingham: MR470 – Electricity Supply Industry (ESI) Mortality Study (Presenter: Dickie Langley) NIC-147805-HDHWM</u>

	Application: This was a renewal application for pseudonymised Medical Research Information Service (MRIS) data to monitor the long-term health experience of workers in the electricity supply industry, in order to identify unrecognised health hazards. The study also has a specific aim which is to identify and quantify any health effects from exposure to extremely low frequency electric and magnetic fields. **Discussion:** To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". IGARD asked for the retention date in section 8(a) to be amended to align with the DSA expiry date. **Outcome:** recommendation to approve The following amendments were requested: 1. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". 2. To amend section 8(a) to align with the DSA expiry date.
2.9	<u>Imperial College London: SAHSU annual renewal and amendment – HES (Presenter: Louise Dunn) NIC-204903-P1J7Q</u> **Application:** The application had previously been presented to IGARD on the 30 August 2018 when IGARD had deferred making a recommendation pending: clarity of the involvement of PHE including analysis as to why they are not considered as data controller; to clarify the terminology of "user under contract with Imperial" and what type of individual or organisation involved; to amend section 5 to clearly address the rationale of the frequency of receipt of data. **Discussion:** IGARD noted the statement within the abstract that Public Health England had "full oversight" of the project and the reference in section 5(a) to PHE being part of the approval process and liaison committee and asked for further clarity on this in light of the statement that PHE are not considered a data controller. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". IGARD noted that the explanation of the statement in the abstract about **"**"user under contract with Imperial" and suggested this explanation also be included in section 5. IGARD noted that the supporting documents listed in section 7 were not provided with the application and asked that NHS Digital share these with IGARD. **Outcome:** Recommendation to defer, pending: 1. To provide further clarity on the role of Public Health England, particularly in terms of the reference (in the abstract) to it having "full oversight" of the project and (in section 5(a) to being part of the approval process and liaison committee

	2. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". 3. To duplicate the clarification contained in the abstract about the "user under contract" within section 5. 4. To provide the supporting documents referred to in the application
2.10	Imperial College London: MR735 – Anglo-Scandinavian Cardiac Outcomes Trial (ASCOT) (Presenter: Louise Dunn) NIC-302604-S7H2N **Application:** This was a new application for identifiable and pseudonymised Medical Research Information Service (MRIS) data, Hospital Episode Statistics (HES) extract, Mental Health and Learning Disabilities Data Set (MHLDDS), Mental Health Minimum Data Set (MHMDS) and Mental Health Services Data Set (MHSDS). The ASCOT Trial was a large trial comparing the health of participants randomly allocated to a statin or placebo, and to one of two blood pressure lowering drugs. The ASCOT trail would now like to evaluate the effects of the randomised treatments on dementia and other measures of long term health. **Discussion:** IGARD noted that supporting document 6, the offer of award letter, makes reference to the University of Edinburgh and asked for further clarification on what their role was in relation to this application. **Outcome:** recommendation to approve 1. To clarify the role of the University of Edinburgh as noted in supporting document 6.
2.11	Health IQ Ltd: Benchmarking and reporting (Presenter: Dickie Langley) NIC-15293-R6V2H **Application:** This was a new application for pseudonymised Hospital Episode Statistics (HES) data for research studies which will provide some benefit to healthcare by providing some insights from the data. **Discussion:** IGARD noted that the sub-licence required further work to incorporate the full terms of the data sharing agreement and data sharing contract. IGARD also queried exactly what was being supplied under the sub-licence and asked for further clarity on this. IGARD queried if the NHS Digital Security Advisor was satisfied that the security confirms with the standards set out in the Information Governance Toolkit and asked for confirmation on this. IGARD queried who the customer base were and asked for further information on this, along with details about the percentage of the NHS and life science customers. IGARD noted that it was not clear in the application how the benefits of the work outlined in the application will benefit the wider health and care system and asked for this to be clarified. **Outcome:** Unable to recommend for approval 1. To redraft the sub-licence to incorporate the full terms of the data sharing agreement and data sharing framework contract. 2. To confirm that the NHS Digital Security adviser is satisfied that the security meets the requisite standard set out in the IG Toolkit. 3. To clarify what is being supplied under the sub-licence agreement. 4. To provide further information on the legitimate interest and how it relates to the outputs and benefits.

	5. To provide further information about the customer base, for example the percentage of NHS customers and life science customers 6. To provide further clarity how the work outlined in the application will benefit the wider Health and Social Care system.
2.12	<u>Medicines and Healthcare Products Regulatory Agency (MHRA): Clinical Practice Research Datalink (CPRD) Routine Linkages Application (Presenter: Louise Dunn) NIC-15625-T8K6L</u> **Application:** This was an amendment request for pseudonymised Hospital Episode Statistics (HES) data, Civil Registrations data, Mental Health Minimum Data Sets (MHMDS), Patient Reported Outcome Measures (PROMs), Diagnostic Imaging Dataset (DIDs), Mental Health Services Data Set (MHSDS), Mental Health and Learning Disabilities Data Set (MHLDDS). CPRD services are designed to maximise the way anonymised NHS Clinical data can be used to improve and safeguard public health. **Discussion:** IGARD noted that there were several references to "anonymised data" throughout the application and asked that this be amended to "pseudonymised data". IGARD queried whether the following statement within section 5(b) was misleading "The CPRD Policy for Managing Anonymisation and the Risk of Identification in Observational Research sets out the management processes employed to ensure that CPRD appropriately anonymises patient data for observational research purposes and complies with the Information Commissioner's Office (ICO) Code on Anonymisation and with Office of National Statistics (ONS) requirements on use of death registration data." and suggested this be removed from the application. IGARD queried if any further yielded benefits had been identified and suggested that additional measurable benefits be included within section 5 with a clear timescale for outputs, along with additional yielded benefits. IGARD noted that it was not clear in the application that MHRA was the Executive Agency of the Department of Health and Social Care not CPRD and asked for this to be made explicitly clear in the application. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". **Outcome:** recommendation to approve subject to the following conditions 1. To make reference to pseudonymised data (rather than anonymised data) throughout the application where appropriate. 2. To remove the following paragraph in section 5(b) "The CPRD Policy for Managing Anonymisation and the Risk of Identification in Observational Research sets out the management processes employed to ensure that CPRD appropriately anonymises patient data for observational research purposes and complies with the Information Commissioner's Office (ICO) Code on Anonymisation and with Office of National Statistics (ONS) requirements on use of death registration data." 3. To provide more examples of yielded benefits within section 5 of the application. The following amendments were requested: 1. To clarify in the abstract and throughout the application that the MHRA is the relevant Executive Agency not CPRD.

	2. To update section 4 with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". It was agreed the conditions be approved OOC by IGARD Members
2.13	<u>Medicines and Healthcare Products Regulatory Agency (MHRA): Bowel Cancer Screening Programme – Data Linkage (Presenter: Louise Dunn) NIC-108098-D2L3V</u> **Application:** This was a new application for pseudonymised Medical Research Information Service (MRIS) data to support two separate research projects. The first project is looking at the non-responders to bowel cancer screening (cohort size: 66,275); and the second project is looking at the influence of negative result on the response of screening invitees and healthcare providers to symptoms of colorectal cancer (cohort size: 7,800). **Discussion:** IGARD noted there were references in the application to NHS Digital owned data not being disseminated and suggested these be removed from the application. IGARD queried what the selection criteria was for the cohorts for both the studies as this was not clear in the application and how both studies align with section 251 support and asked for further clarity on this. IGARD noted that section 3 did not accurately reflect the details of the cohorts and asked that this be amended with accurate information. IGARD noted that there were inconsistencies in the supporting documents when describing the nature of the project (in some an audit and others a research project) and asked that this be clarified within the application. IGARD queried what the routes to dissemination of the expected measurable benefits were and for more robust details to be provided within section 5. **Outcome:** Recommendation to defer, pending: 1. To remove any reference to NHS Digital owned data not being disseminated. 2. To provide further clarity in the abstract on the selection criteria for the cohort for both studies and how they align with s.251 support. 3. To clarify the nature of the project given the apparent inconsistencies in the supporting documentation; for example the REC approval describing an audit programme and other documents such as the CAG support referring to a research programme. 4. To provide further details about and more robust routes to dissemination of the expected measurable benefits within section 5. 5. To provide further clarification in the abstract the purpose of the cohorts. 6. To amend section 3 to accurately reflect the cohorts. The following advice was given: 1. IGARD advised that NHS Digital may wish to check with their legal team that the contractual arrangements in relation to this application are satisfactory for NHS Digital, considering that NHS Digital appear to be using the standard DSFC which assumes that NHS Digital is a Data Controller.
2.14	<u>King's College London: Survival and recovery after hip fracture surgery by timing of mobilisation (Presenter: Dickie Langley) NIC-164830-L7L7C</u>

	Application: This was a new application for pseudonymised Hospital Episode Statistics (HES) and Civil Registrations data to provide information on comorbidities and complications for regression adjustment and subgroup analysis to provide the fact of death at 30 days. **Discussion:** IGARD queried the Healthcare Quality Improvement Partnership (HQIP) GDPR legal basis for processing data and made the observation that a public task basis did not appear to be appropriate given HQIP's status as a charity. IGARD also queried if HQIP have authorised the use of data for this particular purpose and asked that this be confirmed within section 5. IGARD noted that it was unclear who the additional Data Controllers were and asked that fair processing notices be provided that are GDPR compliant. IGARD noted that historic phrasing was being used in section 4 Fair Processing and it was 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 GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month". **Outcome:** Recommendation to defer, pending: 1. To confirm the HQIP GDPR legal basis. 2. To provide confirmation that HQIP are authorising the use of data. 3. To clarify who the additional Data Controllers are and to provide fair processing notices which are GDPR compliant. 4. To delete the existing text in section 4 and replace with the standard wording "All data required by the Data Controller under this application is pseudonymised and therefore is considered as personal data under the GDPR. All Data controllers are expected to provide a privacy notice that is compliant with the GDPR notice requirements within a reasonable period after obtaining the personal data, but at least within 1 month".
3	**AOB** IGARD noted that this was Jon Fistein's final meeting and wished to extend their sincere thanks for his significant contribution over the last 18 months during his tenure on IGARD.

Independent Group Advising on Releases of Data (IGARD): Out of committee report 14/09/18

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

NIC Reference	Applicant	IGARD meeting date	Recommendation conditions as set at IGARD meeting	IGARD minutes stated that conditions should be agreed by:	Conditions agreed as being met in the updated application by:	Notes of out of committee review (inc. any changes)
NIC-179115-S0R1W	The Health Foundation	09/08/18	1. To include narrative within the abstract and the purpose section of the application explaining the Legitimate Interests relied on and to make reference in the abstract that NHS Digital has considered the LIA produced by the applicant. 2. To provide further clarity on how the applicant can achieve their stated outputs with the two years data requested.	Quorum IGARD Members	Quorum IGARD members 10/09/18	An amendment to the response to condition 1: The LIA was carried out by The Health Foundation using the ICO template and considered by NHS Digital. The Health Foundation concluded that they can rely on legitimate interests for this processing. A summary of the decision justification is provided below; In addition there appears to be a typo omission in the abstract on page 2. The sentence "There will be no data linkage undertaken with NHS digital data provided under this agreement." should be added on page 2, just above point 3.
NIC-35562-V6G5W	University Hospital Bristol NHS FT	02/08/18	**1.** To agree the wording of a new DSA standard clause with regard to the processing of data by individuals on honorary contracts. 2. To provide the relevant sections under Article 6 and 9 of GDPR and a clear justification for the choice of each section in terms of how the specific criteria and	Quorum IGARD Members	Quorum IGARD Members 11/09/18	To update the abstract to include: PhD or post-doctoral student following last Thursday's IGARD meeting: "*The data controller(s) is/are responsible for the activities of all individuals ("Individuals") who have access to the patient data disseminated by NHS Digital ("Data") and are engaged by any data controller or data processor listed in this agreement, regardless of whether such Individual is described as an employee,*

			additional requirements are met in relation to the University of Oxford.			*contractor, secondee, PhD or post-doctoral student or honorary employee*."
NIC-190996-C4P9G	Royal Marsden NHS FT	23/08/18	1. To explicitly state within the abstract and section 5 that the Royal Marsden NHS Foundation Trust is the Data Controller and remove any reference to (or inference that) the Cancer Alliance(s) being a Data Controller. 2. To clarify if record level data will be shared outside the Royal Marsden NHS Foundation Trust and, if so, why and with whom. If record level data is to be shared outside the Royal Marsden Foundation Trust then appropriate justification for this should be provided. 3. To provide further narrative in the abstract explaining the rationale for the GDPR Article 6(1)(e) and Article 9(2)(j) lawful basis relied on by the Data Controller to process data for the purposes set out in this application.	IGARD Chair	Interim IGARD Chair 13/09/18	To update the abstract to include: - Public authority: The Data Protection Act 2018 s7(1)(a) defines 'public bodies' for the purpose of the GDPR as "a public authority as defined by the Freedom of Information Act 2000". The FOI Act names NHS Foundation Trusts as Public Authorities under Schedule 1 Part 4 Paragraph 40A. - Public task: The NHS Act 2006 section 43(5), which describes the functions of authorised NHS Foundation Trusts, states that 'The authorisation must authorise and may require the NHS foundation trust (a) to carry out research in connection with the provision of health care, (b) to make facilities and staff available for the purposes of education, training or research carried on by others'. Royal Marsden NHS Foundation Trust is acting on NHS England behalf as described in the Cancer Taskforce report, Royal Marsden NHS Foundation Trust is providing services for the purposes of research being carried on by the NHS Commissioning Board (Cancer Taskforce); The NHS Commissioning Board is also a public authority; The FOI Act was amended by the Health and Social Care Act 2012 schedule

						5 paragraph 99(b)to include the NHS Commissioning Board (also known as NHS England) as a named public authority. Royal Marsden NHS Foundation Trust is acting on NHS England behalf as described in the Cancer Taskforce report. Therefore the processing in relation to Public task with regard to NHS England (Cancer Taskforce) processing purposes; the Health and Social Care Act 2012 section 23 13E(1) states that the NHS Commissioning Board 'must exercise its functions with a view to securing continuous improvement in the quality of services provided to individuals for or in connection with— (a)the prevention, diagnosis or treatment of illness, or (b)the protection or improvement of public health". S43 of NHS Act 2005 authorises the Royal Marsden NHS Foundation Trust to provide services to NHS England.

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

- None notified to IGARD