Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held via videoconference 1 October 2020

IGARD MEMBERS IN ATTENDANCE:	
Name:	**Position:**
Paul Affleck	Specialist Ethics Member
Maria Clark	Lay Member / IGARD Alternate Deputy Lay Chair
Kirsty Irvine (Chair)	IGARD Lay Chair
Dr. Imran Khan	Specialist GP Member
Dr. Geoffrey Schrecker	Specialist GP Member / IGARD Deputy Specialist GP Chair
Dr. Maurice Smith	Specialist GP Member
IGARD MEMBERS NOT IN ATTENDANCE:	
Name:	**Position:**
Prof. Nicola Fear	Specialist Academic Member
NHS DIGITAL STAFF IN ATTENDANCE:	
Name:	**Team:**
Garry Coleman	Data Access Request Service (DARS) (Item 5.1)
Arjun Dhillon	Caldicott Guardian (Item 5.2)
Louise Dunn	Data Access Request Service (DARS)
Duncan Easton	Data Access Request Service (DARS)
Dan Goodwin	Data Access Request Service (DARS)
Richard Hatton	Clinical Informatics and Deputy Caldicott Guardian (Observer: 2.1 – 2.3)
Karen Myers	IGARD Secretariat
Kimberley Watson	Data Access Request Service (DARS)
IBM STAFF IN ATTENDANCE:	
Emily Cross	IBM (Item 5.3)
Jerome Greutmann	IBM (Item 5.3)
Stephen Pettitt	IBM (Item 5.3)

1	**Declaration of interests:** There were no declarations of interest. **Review of previous minutes and actions:** The minutes of the 24th September 2020 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 A).
2	**Data Applications**
2.1	Public Health England**:** Understanding COVID-19, its trends and risks to public health, and controlling and preventing the spread of COVID-19 (Presenter: Louise Dunn) NIC-390154-Z4M0F **Application:** This was a new application for identifiable GPES Data for Pandemic Planning and Research (GDPPR) data, for the purpose of understanding COVID-19 and risks to public health, trends in COVID-19 and such risks, and controlling and preventing the spread of COVID-19 and such risks, for monitoring and planning purposes. COVID-19 presents a significant threat to the population in terms of increased morbidity and mortality, particularly among vulnerable groups such as those with pre-existing disease. PHE will undertake analysis to assess the relationship between COVID-19 and potential risk factors including pre-existing medical conditions such as diabetes, heart disease, etc. behaviours such as smoking, obesity, etc. The results will contribute to future policy decisions regarding those most at risk of contracting COVID-19. **Discussion:** IGARD welcomed the application and noted the importance of the study. IGARD noted that this application had been previously seen by the IGARD – NHS Digital COVID-19 Response meeting on the 7th July, 28th July, 25th August and the 1st September 2020. IGARD noted that this application had also been reviewed by the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) (see Appendix B) on the 9th September 2020. IGARD supported and endorsed all the comments made by PAG, and noted that NHS Digital had provided responses to the points raised by PAG within the application. In relation to the request from PAG that *"PHE to demonstrate that they have GP representation in their governance / decision making process"*, IGARD noted that although NHS Digital had discussed this with PHE, the point did not appear to have been suitably addressed, and asked that NHS Digital discuss this matter with PHE further, and that the response from PHE was shared with PAG, and provide confirmation that PAG were satisfied with the response. IGARD also discussed the point made by PAG, that they *"…would not support the application unless the application was to clarify that the service use element was confirmed to be in line with existing policy agreements and did not duplicate existing work."*, and PHE's response that they had *"…removed the reference to "Service Use" altogether. PHE would welcome information on where this work is already being carried out given the concerns of any replication."*; and advised that PAG provided clarification to PHE as to where the service evaluation work referred to was being carried out, since it was not clear.

	IGARD queried the reference in section 1 (Abstract) that stated *"PHE has confirmed research proposals will seek section 251 approval from CAG upon cessation of the COPI Legislation*."; and asked that this was updated to remove reference to s251 being a future legal gateway for the GDPPR data, as this was incorrect. IGARD noted that the Article 9 legal bases stated within section 1 did not align with the legal bases stated in the Data Protection Impact Assessment (DPIA) provided, and asked that these were reviewed and aligned as appropriate. IGARD queried the statement in section 5 to *"The results will contribute to future policy decisions regarding those most at risk of contracting COVID-19 and having a* ***worse outcome such as death****."*; and asked the end of this statement was revised accordingly. IGARD suggested that section 5 was also updated to ensure this reflected the latest guidance from NHS England in respect of the language used and making this accessible, for example when describing citizens, and domestic abuse. IGARD noted the references throughout section 5 to the work outlined as being *"research"*, and asked that this was revised to ensure the language accurately reflected that the NHS Digital data flowing under this application was for **surveillance**, and it was clear that any references to *"research"* were for future research projects. IGARD also asked that other references to *"research"* within section 5(c) (Specific Outputs Expected) were revised, including, but not limited to the reference to "*phenomenology"*. IGARD noted a number of acronyms in section 5 (Purpose / Methods / Outputs) and asked that this public facing section be updated to ensure that all acronyms upon first use were expanded and clearly defined with a supportive explanation in a language suitable for a lay reader for technical jargon such as *"line list"*. IGARD asked that a special condition was inserted in section 6 (Special Conditions) that this application was for surveillance purposes only, and should the applicant wish to use the data for research, then this would need an amendment application to NHS Digital. IGARD noted in section 5(b) (Processing Activities) the information relating to the access management controls and governance arrangements, however noted that there was no reference to the oversight for the GDPPR research plan, and asked that this was updated to reflect that currently there was **no** oversight in place for this. IGARD noted that identifiable data would flow to PHE to enable linkage to take place before being pseudonymised, and asked that section 5 was updated with clarification of how and when the identifiers would be destroyed when the datasets were being pseudonymised; and in addition, that clarification that the identifiers would be destroyed on a rolling basis. IGARD had a lengthy discussion on the data minimisation, and queried what, if any, data minimisation efforts were being applied to the data requested, and were advised by NHS Digital that no data minimisation had been undertaken in respect of this application, as the applicant required all the data available. IGARD noted the update provided and asked that section 5 was updated to clearly reflect that **no** data minimisation would be undertaken. In addition, IGARD queried why, for example, the applicant would require the administrative GDPPR data that had been requested, and asked that a justification was provided for the request of this data. NHS Digital advised IGARD that senior colleagues within NHS Digital had been consulted in respect of the data minimisation consideration for this application, for example NHS Digital's Information Asset Owner (IAO), and it had been acknowledged that whilst no data

	minimisation would be undertaken by the applicant for the data, further data minimisation may take place before it is onwardly shared within PHE. IGARD noted the update from NHS Digital and asked that section 5 was updated further to outline the consideration taken when considering data minimisation, including the involvement of NHS Digital's IAO. IGARD noted that it was not clear within section 5(b) that the NHS Digital data would not be shared with any third parties, and asked that this was updated to clarify this. IGARD noted that section 5(c) referred to PHE's People Panel, however queried what the specific patient and public involvement (PPI) was, since it was not clear within the application if any PPI had been undertaken; and asked that this was updated to include a brief summary of what the PPI involvement was in relation to the specific data flowing under this agreement. IGARD also noted some target dates outlined in section 5(c), and asked that these were updated where relevant, as some of the dates noted were imminent, and others were not very specific on what the dates were for. IGARD suggested the applicant give consideration to the use of other technology such as that utilised by the OpenSafely Project. IGARD suggested that NHS Digital may wish to consider auditing this organisation in relation to this application / Data Sharing Agreement. **Outcome:** recommendation to approve subject to the following condition(s) 1. In respect of the outstanding PAG points raised: To ask PHE to review the specific PAG requirement for PHE to demonstrate that they have GP representation in their governance / decision making processes, and to share the PHE response with PAG and for PAG to confirm their satisfaction with that response. The following amendments were requested: 1. In respect of the outstanding PAG points raised: PAG to provide clarification to PHE as to where the service evaluation work referred to is being carried out. 2. To update section 1 to remove reference to s251 being a future legal gateway for the GDPPR data. 3. To align the Article 9 legal bases in section 1 and the DPIA. 4. To amend section 5: a) To ensure that all acronyms and technical jargon are defined or further explained upon first use, such as 'line list'. b) To ensure the language reflects that the data flowing under this application is for surveillance, and that references to *"research"* are for possible future projects. c) To revise the statement *"worse outcome such as death".* d) To clarify in section 5 that there is currently no oversight of the proposed GDPPR research plan. 5. In respect of the data minimisation: a) To update section 5 to make clear that **no** data minimisation will be undertaken. b) To provide justification for requesting the administrative GDPPR data. c) To outline the consideration taken when considering data minimisation, including the involvement of NHS Digital's IAO. 6. To update section 5(b) to clarify that PHE will not share any NHS Digital data with any third parties. 7. In respect of section 5(c):

	a) To include a brief summary of what the PPI involvement is in relation to the specific data flowing under this agreement. b) To review the target dates and update where relevant. 8. In respect of the identifiers: a) To clarify in section 5 how and when the identifiers are destroyed when the datasets are being pseudonymised. b) To clarify that the identifiers will be destroyed on a rolling basis. 9. To revise the various references to *"research"* in section 5(d) including (but not limited to) *"phenomenology"*. 10. To insert a special condition in section 6 that this application is for surveillance purposes only, and should the applicant wish to use the data for research, then this would need to be requested via an amendment application to NHS Digital. The following advice was given: 1. IGARD suggested the applicant give consideration to the use of other technology such as that utilised by the OpenSafely Project. 2. To update the section 5 to ensure this reflects the latest guidance from NHS England in respect of the language used and making this accessible, for example when describing citizens, and domestic abuse. 3. IGARD suggested that NHS Digital may wish to consider auditing this organisation in relation to this application / Data Sharing Agreement. It was agreed the conditions would be approved out of committee (OOC) by IGARD Members.
2.2	<u>Dr Foster Limited: Dr Foster direct feed (Presenter: Louise Dunn) NIC-392201-S6C3W</u> **Application:** This was a new application for pseudonymised Hospital Episode Statistics (HES), Emergency Care Data Set (ECDS) and Civil Registrations data, for the purpose of helping healthcare organisations achieve sustainable improvements in their performance, to gain insight and to inform decision making. Dr Foster uses the data provided to provide a management information function in the form of analysis and clinical benchmarking for healthcare organisations and to increase the power of predictive models for rare diseases, procedures and events. Dr Foster currently receives the requested data under this application via the Dr Foster Unit (DFU) at Imperial College London under agreement NIC-68697-R6F1T. DFU first received this data under agreement NIC-12828-M0K2D, Dr Foster will end this process and replace it with the direct receipt of data from NHS Digital. NHS Digital advised IGARD that the applicant is wishing to receive the same data as currently agreed under NIC-12828-M0K2D, and in addition, has also requested that they receive data from **both** NHS Digital directly and Imperial College London for an initial period, to ensure continuity and until the new system is aligned. **Discussion:** IGARD noted the update from NHS Digital in respect of the applicant receiving the data from both NHS Digital and Imperial College London; and asked that in light of this, section 5(a) (Objective for Processing) was updated to provide a brief explanation of the change of processing arrangements. IGARD queried what would happen to the data that was re-identified under the existing Data Sharing Agreement (DSA) in terms of the Duty of Confidence; and asked that a clear justification was provided in section 5 (Purpose / Methods / Outputs) for what purpose (if any)

	the customer Trusts may wish to re-identify patients; and to confirm that the use of any such data is compatible with treating the data as not being owed a Duty of Confidence. IGARD queried the data minimisation that had been applied to the data requested, and asked that in line with NHS Digital's DARS Standard for Data Minimisation, an analysis was provided of whether further data minimisation could be undertaken. IGARD noted the request for the HES Accident and Emergency (A&E) data and queried if this was correct, noting that this data was no longer being produced by NHS Digital; and asked that section 3(b) (Additional Data Access Requested) was updated to clarify HES A&E was the correct dataset required, or if data from the Emergency Care Data Set (ECDS) was required. If ECDS was required, to provide clarity if it would replace or run alongside HES A&E for a short time period. IGARD noted that 11-years' worth of data had been requested and asked that section 3(b) was updated to provide a clear justification of the years of data requested. In addition, IGARD asked that section 5 was updated to clarify that the datasets requested were on a rolling basis and include further details of how the datasets would also be deleted on a rolling basis. IGARD queried if some of the NHS Digital data that currently flowed to Imperial College London was linked before the applicant received it, and were advised by NHS Digital that under the DSA, they were not permitted to link the data; IGARD noted and asked that section 5 was updated to reflect that this. IGARD queried why the applicant was not using pseudonymised consultant codes and GP codes, and asked that section 5 was updated with a justification of this; or that a justification was provided as why identifying consultant codes and GP codes were being used. IGARD queried if the 'date of death' was an identifier and were advised by NHS Digital that they had considered this and had determined that it was not an identifier; IGARD noted the update from NHS Digital and advised that they were content with NHS Digital's consideration and conclusion. IGARD noted the information in section 5 relating to the 'Getting It Right First Time' (GIRFT) national programme, and asked that it was clarified that GIRFT only applied to hospital care and not primary care. IGARD queried the three processing locations listed in section 2(a) (Processing Locations), and asked that these were reviewed, in light of previous reviews, where IGARD had been advised that one of the sites was being phased out, and that section 2(a) was updated if relevant to remove any defunct locations. IGARD noted the statement in section 5(a) that *"Dr Foster will inform NHS Digital of analysis it provides to non-NHS organisations and will list this in any renewal or amendment to the agreement"*, and asked that this was replicated as a special condition in section 6 (Special Condition). IGARD noted that section 5(d) (Benefits) (iii) (Yielded Benefits) had not been completed and asked that this was updated to include the yielded benefits accrued to date. IGARD queried the benefits that were outlined in section 5(d) and advised that some of the information listed were in fact outputs, and asked that this was reviewed to ensure that only the benefits were noted; and that any outputs that were in section 5(d) were added to section 5(c) (Specific Outputs Expected) if deemed relevant. IGARD noted and endorsed NHS Digital's review that the applicant did **not** meet NHS Digital's Standard for privacy notices; and asked that a special condition was inserted in section 6 that

	within 1 month of signing the DSA, the applicant will have published a General Data Protection Regulation (GDPR) compliant privacy notice, which addressed the National Data Opt-out in light of any new processing arrangements. IGARD queried if Dr Foster had previously provided a report of analysis that it provides to non-NHS organisations, and if there was any such report, that this was upload to NHS Digital's Customer Relationship Management (CRM) system, and tabled upon renewal or amendment. **Outcome:** recommendation to approve subject to the following condition: 1. To provide a clear justification in section 5 for what purpose (if any) the customer Trusts may wish to re-identify patients; and to confirm that the use of any such data is compatible with treating the data as not being owed a Duty of Confidence. The following amendments were requested: 1. In respect of section 3(b): a) To update to reflect the data minimisation consideration and analyses, and in line with NHS Digital's DARS Standard for Data Minimisation. b) To clarify in section 3(b) the interplay between the ECDS and the HES A&E data. c) To provide a clear justification of the years of data requested. 2. To update section 5 to clarify that the datasets requested are on a rolling basis and include details of how the datasets will also be deleted on a rolling basis. 3. To update section 5(d): a) To include the yielded benefits. b) To ensure **only** the benefits are noted (and not outputs). c) To remove any outputs listed and if deemed relevant, to add to section 5(c). 4. To update section 5(a) to provide a brief explanation of the change of processing arrangements. 5. To insert a special condition in section 6 that within 1 month of signing the DSA, the applicant will have published a GDPR compliant privacy notice, which addresses the National Data Opt-out in light of any new processing arrangements. 6. To update section 5 to reflect that there will be no linkage of any NHS Digital data. 7. To update amend section 5 to either provide a clear justification of not using pseudonymised consultant codes and GP, or provide a justification of using the identifying consultant and GP codes. 8. To clarify in section 5 that the GIRFT only relates to hospital care. 9. To review the storage locations listed in section 2(a) and remove any defunct locations. 10. To replicate the statement that *"Dr Foster will inform NHS Digital of analysis it provides to non-NHS organisations and will list this in any renewal or amendment to the agreement"* as a special condition in section 6. The following amendments were requested: 1. IGARD queried if Dr Foster had previously provided a report of analysis it provides to non-NHS organisations, and if there is any such report, to upload to CRM, and tabled upon renewal or amendment. It was agreed the condition would be approved OOC by IGARD Members.
2.3	<u>The University of Manchester: Trauma Audit and Research Network HES and Civil Registrations Mortality application (Presenter: Kimberley Watson) NIC-338773-H5J5S</u> **Application:** This was a new application for identifiable and pseudonymised Hospital Episode Statistics (HES) and identifiable Civil Registrations data, for the purpose of supporting the

	Trauma Audit and Research Network (TARN), which is a is a non-commercial organisation affiliated with the University of Manchester, to support service improvement by providing analytical feedback to Trusts. The data requested will help to measure completeness of submission to the TARN database for individual Trusts and Hospitals, and to supplement data already collected (concerning the acute phase of care for patients that have suffered a traumatic injury). NHS Digital advised that the applicant previously had a Data Sharing Agreement (DSA) in place, and had destroyed the data instead of submitting an amendments / extension request to NHS Digital; and that this application was exactly the same as the previous DSA seen by IGARD's predecessor the Data Access Advisory Group (DAAG), with the exception of the inclusion of mortality data. NHS Digital also advised that the previous DSA had been the subject of an audit by NHS Digital in June 2020, however a post-audit review had not taken place due to the current COVID-19 pandemic, and advised that no further NHS Digital data would flow until any issues that had arose from the audit had been reviewed. **Discussion:** IGARD noted the update from NHS Digital in respect of the previous DSA held by the applicant, and that an audit that had taken place in June 2020 by NHS Digital. IGARD agreed with NHS Digital that no data should flow until the post-audit review had taken place, and asked that a special condition was inserted in section 6 (Special Conditions) that no data would flow until the outstanding NHS Digital audit findings had been addressed to a satisfactory level which had been reviewed and approved by the NHS Digital Security Consultant. IGARD queried the information in section 5 (Purpose / Methods / Outputs) that stated identifiable data at patient level, would be shared with the Hospital who originally treated the patient, and asked that section 1 (Abstract) and section 5 were updated with a clear explanation of the uses of the identifying extract of data. IGARD also queried the outlier policy that would be assisted by the three years of NHS Digital data requested, and asked that section 1 and section 5 were updated to include further details of the policy. IGARD queried why NHS Digital did not filter the flow of data by audit criteria, in light of the information provided in section 5(b) (Processing Activities) that stated HES data was required for at least one ICD-10 code relating to traumatic injury, and that any of these patients were potentially eligible for the TARN audit, and asked that a clear explanation was provided in section 5(b) as to why NHS Digital did not filter the flow of data by audit criteria. IGARD queried how the non-relevant fields were deleted and what data management processes were in place, and asked that section 5 was updated to clarify. IGARD noted that it was not clear within the public facing section 5 of the application why both identifiable and pseudonymised HES data was required, and asked that, for transparency, section 5 was updated with clarification as to why data in both forms was required. IGARD noted the references to *"type 2 patient Objections"* in section 5(b) and asked that this was removed and updated with the correct reference to the *"National Data Opt-out"*. IGARD noted that section 5(d) (Benefits) (iii) (Yielded Benefits) had not been completed and asked that this was updated to include the yielded benefits from the applicant's previous DSA. IGARD noted the historical information in the HRA CAG supporting documents, and suggested that on renewal of s251 support, the applicant notified HRA CAG that the terminology when

	referring to *"PCTs"*, should now refer to Clinical Commissioning Groups (CCGs) or any successor or other organisation carrying out a similar function. **Outcome:** recommendation to approve subject to the following condition: 1. To insert a special condition in section 6 that no data will flow until the outstanding NHS Digital audit findings have been addressed to a satisfactory level which have been reviewed and approved by the NHS Digital Security Consultant. The following amendments were requested: 1. To update section 1 and section 5 with a clear explanation of the uses of the identifying extract of data. 2. To update section 1 and section 5 with a clear justification of **why** 3 years of data has been requested. 3. To provide a clear explanation in section 5(b) as to why NHS Digital does not filter the flow of data by audit criteria. 4. To update section 5 to clarify how the non-relevant fields are deleted, and how this data management is handled. 5. To update the reference to *"type 2 patient objections"* in section 5(b). 6. To update section 5 to make it explicitly clear why the HES data is required in both identifiable and pseudonymised form. 7. To update section 5(d) to provide yielded benefits from the previous DSA. The following advice was given: 1. IGARD suggested that on renewal of s251 support, the applicant notifies HRA CAG that the terminology when referring to *"PCTs",* should now refer to CCGs or any successor or other organisation carrying out similar function. It was agreed the condition would be approved out of committee (OOC) by the IGARD Chair.
2.4	[1]Group Application: DSfC - Joint Controller Agreement: NHS Birmingham and Solihull CCG, Birmingham City Council, Solihull Metropolitan Borough Council - Comm (Presenter: Dan Goodwin) NIC-360432-Z1Q8K **Application:** This was a new application for pseudonymised Secondary Uses Service (SUS+), Local Provider Flows, Mental Health Minimum Data Set (MHMDS), Mental Health Learning Disability Data Set (MHLDDS), Mental Health Services Data Set (MHSDS), Maternity Services Data Set (MSDS), Improving Access to Psychological Therapy (IAPT), Child and Young People Health Service (CYPHS), Community Services Data Set (CSDS), Diagnostic Imaging Data Set (DIDS), National Cancer Waiting Times Monitoring Data Set (CWT), Civil Registries Data (CRD), National Diabetes Audit (NDA), Patient Reported Outcome Measures (PROMs) and e-Referral Service (eRS) The purpose of the application is to provide intelligence to support the commissioning of health services. NHS Digital advised IGARD that the Data Security and Protection Toolkit (DSPT) security dates had been updated following submission of the application.

[1] NHS Birmingham and Solihull CCG, Birmingham City Council and Solihull Metropolitan Borough Council

	Discussion: IGARD noted and supported the update from NHS Digital in respect to the DSPT security dates being updated. IGARD queried the conflicting information in respect of the legal basis between the advice from NHS Digital's Information Governance and the application, and asked that a copy of the IG advice which confirmed the appropriate legal basis for dissemination of the data was provided; and that this was uploaded to NHS Digital's Customer Relationship Management (CRM) system. In addition, IGARD asked that section 3 (Datasets Held / Requested) of the application was updated to accurately state the correct legal basis for each dataset. IGARD queried the patient stratification arrangements, in particular if the application allowed the identification of individuals or cohorts of patients with common identifying features, and asked that this was clarified in section 5(b) (Processing Activities). IGARD asked that if the application did allow the identification of individuals, that a further explanation was provided which explained the mechanism for the re-identification and the legal gateway for doing so; and that if no individuals were re-identified, that section 5 (Purpose / Methods / Outputs), including section 5(d) (Benefits) where this is specifically referenced, was updated to make this explicitly clear. IGARD queried the role of the Local Authorities, Birmingham City Council and Solihull Metropolitan Borough Council, as this was not clear within the application, and asked that section 5(a) (Objective for Processing) was updated with clarification. In addition, IGARD asked that if this application permitted the re-identification of individuals, that clarification was provided confirming that the Local Authorities would not be involved in this activity nor have access to this data. IGARD noted within the application and supporting documents provided that the data risk model ranking for the Cloud Storage was assessed as class 4, high-risk; and asked that in light of this, a brief statement was provided in section 1 (Abstract), confirming that NHS Digital's Security Advisor was satisfied with the data risk model ranking. IGARD queried the eleven storage locations outlined in section 2(b) (Storage Location(s)) of the application, and the reference to data being stored within a *"single platform"* in section 5(b), and asked that this mis-match was addressed to state the correct number of storage locations throughout the application. IGARD noted the references in section 5(b) to data being linked, and asked that this was updated to be clear as to what datasets were being linked, and if this included other datasets already held or external datasets. IGARD noted the paragraph in section 5(a) relating to data minimisation, and asked that this was either removed, or if this information was not included elsewhere, to add this to the data minimisation information in section 5(b). IGARD queried what the benefits of the collaborative working of the larger group of Data Controllers would be, and suggested that section 5(d) (Benefits) was updated to clarify this. In addition, IGARD also asked that the outputs in section 5(d) were amended to reflect that the parties involved were commissioning **only** and to ensure that the stated aims were appropriate given the role and nature of the Data Controllers. IGARD noted and endorsed NHS Digital's review that Birmingham City Council and Solihull Metropolitan Council did **not** meet NHS Digital's Standard for privacy notices; and asked that a special condition was inserted in section 6 (Special Conditions) that within 1-month of signing

	the DSA the applicant will have published a General Data Protection Regulation (GDPR) compliant privacy notice. IGARD suggested that, upon renewal or amendment, the applicants took the opportunity to restate the outputs by aligning the activity/output to the applicants' statutory requirements, rights and obligations. **Outcome:** Recommendation to defer, pending: 1. In respect of the legal basis: a) To provide a copy of NHS Digital's IG advice which confirms the appropriate legal basis for dissemination of the data. b) To ensure that the IG advice is uploaded to NHS Digital's CRM system. c) To update the legal basis table in section 3 accordingly. 2. In relation to patient stratification: a) To update section 5(b) to clarify if the application allows the identification of individuals *or* cohorts of patients with common identifying features. b) If the application does allow the identification of individuals, to explain the mechanism for the re-identification and the legal gateway for doing so. c) If no individuals are re-identified, to update section 5 (including section 5(d) where this is specifically referenced) to make this explicitly clear. 3. In respect of the Local Authority: a) To update section 5(a) to provide clarification of the role of the Local Authority. b) If this application permits re-identification of individuals, to clarify that the Local Authority will not be involved in this activity nor have access to this data. 4. To provide a brief statement in section 1 that the NHS Digital Security Advisor is satisfied with the data risk model ranking for the cloud storage (as outlined in the supporting documents). 5. To address the mismatch between the 11 storage locations in section 2(b) and the reference in section 5 to one platform. 6. To insert a special condition in section 6 that within 1 month of signing the DSA the applicant will have published a GDPR compliant privacy notice. 7. To update section 5(b) be clear what datasets are being linked, and if this includes other datasets already held or external datasets. 8. To amend section 5(a) to remove the paragraph on data minimisation, and if there is any relevant information not included elsewhere, to add this to the data minimisation paragraph in section 5(b). 9. In respect of section 5(d): a) To clarify what benefits will flow from the collaborative working of the larger group of Data Controllers. b) To amend the outputs to reflect that the parties involved are commissioning only and to ensure that the stated aims are appropriate given the role and nature of the data controllers. The following advice was given: 1. IGARD suggested that, upon renewal or amendment, the applicants took the opportunity to restate the outputs by aligning the activity/output to the applicants' statutory requirements, rights and obligations.

2.5	<u>NHS Doncaster CCG: Cancer Alliance access to National Cancer Waiting Times Monitoring Data Set (NCWTMDS) from the Cancer Wait Times (CWT) System (Presenter) NIC-204562 - J5W0T</u> **Application:** This was an amendment application for NHS England to share aggregate National Cancer Waiting Times Monitoring DataSet (CWT) with small numbers, with NHS Doncaster CCG, for the purpose of essential to Cancer Alliances to enable analyses to be carried out and to understand local performance, both of individual providers and of the system in general. The analysis has to be undertaken at the most appropriate level for action to be taken and performance to be benchmarked; thus allowing patients to experience improvements to the system. For Cancer, this is specific tumour site level which is only possible with unsuppressed data. Introducing small number suppression would result in these reports having no practical use and leave Cancer Alliances without a way in which they can understand variation in performance between providers and improve the system. NHS Digital advised IGARD that the reference within the application to *"Doncaster CCG Cancer Alliance"* was incorrect and had been amended following submission of the application. **Discussion:** IGARD noted and supported the update outlined by NHS Digital to remove the references within the application to *"Doncaster CCG Cancer Alliance".* IGARD queried the amount of data the applicant was requesting in terms of aggregated data with small numbers unsuppressed and any potential risk around this, in light of the applicant being able to request this data from other sources, and asked if a Data Protection Impact Assessment (DPIA) had been completed, which NHS Digital had advised had not. IGARD asked that a special condition was inserted in section 6 (Special Conditions), that before receipt of NHS Digital Data, the applicant should produce a DPIA, which addressed the specific risks raised by the dissemination of aggregated data with small numbers unsuppressed. **Outcome:** recommendation to approve. The following amendment was requested: 1. To insert a special condition in section 6 that before receipt of NHS Digital Data, the applicant should produce a DPIA, which addresses the specific risks raised by the dissemination of aggregated data with small numbers unsuppressed.
3	<u>Returning Applications</u> Due to the volume and complexity of applications at today's meeting, IGARD were unable to review any applications as part of their oversight and assurance role.
4	<u>COVID-19 update</u> To support NHS Digital's response to COVID-19, from Tuesday 21st April 2020, IGARD will hold a separate weekly meeting, to discuss COVID-19 and The Health Service Control of Patient Information (COPI) Regulations 2002 urgent applications that have been submitted to NHS Digital. Although this is separate to the Thursday IGARD meetings, to ensure transparency of process, a meeting summary of the Tuesday meeting will be captured as part of IGARD's minutes each Thursday and published via the NHS Digital website as per usual process.

	The ratified action notes from Tuesday 29th September 2020 can be found attached to these minutes as Appendix C.
5	AOB:
5.1	Associate Director, Data Access The Associate Director, Data Access attended (part of) the meeting as part of his regular catch-up with IGARD.
5.2	Caldicott Guardian NHS Digital's Caldicott Guardian attended (part of) the meeting as part of his regular catch-up with IGARD.
5.3	IBM update In addition to the update provided to IGARD members in the weekly (Tuesday) IGARD – NHS Digital COVID-19 Response Meetings, IBM attended the meeting to discuss a number of materials that IGARD members had been asked to review. The IGARD Chair thanked IBM colleague for attending and looked forward to a further update on progress at the next IGARD – NHS Digital COVID-19 Response Meeting, as per usual process. There was no further business raised, the IGARD Chair thanked members and NHS Digital colleagues for their time and closed the application section of the meeting.

Appendix A

Independent Group Advising on Releases of Data (IGARD): Out of committee report 25/09/20

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-401171-F9Z8T	National Institute for Health Research (St George's University Hospitals NHS FT)	17/09/2020	1. To provide written evidence that the applicant has successfully secured ethics approval.	IGARD Chair	OOC by IGARD Chair	N/A
NIC-297783-V4P6H - Ignite Data Ltd	NIC-297783-V4P6H - Ignite Data Ltd	03/09/2020	1. To update section 5(e) to reflect that GSK who is funding the study, is also the manufacturer of the device being studied and therefore potentially stands to have commercial benefit. 2. To insert a special condition in section 6 that within 1 month of signing the DSA, the applicant will have published a GDPR compliant privacy notice, and before any data flows.	IGARD members	OOB by quorum of IGARD members	N/A

In addition, a number of applications were processed by NHS Digital following the Precedents approval route. IGARD carries out oversight of such approvals and further details of this process can be found in the Oversight and Assurance Report.

In addition, a number of applications were approved under class action (addition of Liaison Financial Service and Cloud storage):

- NIC-41531-X2G56
- NIC-41556-H6V2V

Appendix B

GPES Data for Pandemic Planning and Research - Profession Advisory Group

Record of feedback: Wednesday, 9th September 2020

Application: DARS-NIC-390154-Z4M0F Public Health England **Organisation name: Public Health England** **Profession Advisory Group Agenda item: 3**
PAG noted the number of data extracts being requested across applications, and were supportive of NHS Digital (and the wider system) increasing the use of Trusted Research Environments rather than providing individual extracts. For this and future applications, PAG asked that NHS Digital included greater explanation around why a TRE was not used. *PAG wanted to ensure maximum benefit from data sharing, and would ask that PHE liaise with other national bodies to ensure that the research was complementary and not duplicative.* *PAG supported the application if the following points were addressed:* *PAG noted the typo "our" instead of "out" was corrected on page 3; typo on page 12 regarding community datasets.* *PAG recommended that NHS Digital clarify that no pseudonymised data could be downloaded to a laptop that was not encrypted at rest (and specifically that any local device was not included within the definition of the environment).* *PAG recommended that NHS Digital clarified that there was no research being carried out on PID.* *PAG recommended that NHS Digital confirm with PHE that the data would not be used for performance management, and would require PHE to demonstrate that they have GP representation in their governance / decision making processes.* *PAG would not support the application unless the application was to clarify that the service use element was confirmed to be in line with existing policy agreements and did not duplicate existing work. To be clear, this has been subject to high level discussions between the DHSC and the Profession, and this section appeared to replicate the agreed position. PAG suggested that the service use section was omitted.* *PAG suggested that the data could be pseudonymised prior to the data flowing.* *PAG stated that any outputs created from the GP dataset should be shared with the BMA / RCGP at the same time as others.* *PAG noted the DSA end date needed correcting.*

Attendees	Role	Organisation
Arjun Dhillon	Chair, Caldicott Guardian	NHS Digital
Garry Coleman	Associate Director of Data Access	NHS Digital
Anu Rao	GPC IT Policy Lead	BMA
Amir Mehrkar	GP, Clinical Researcher	RCGP
Helen Buckels	Secretariat	NHS Digital

DRAFT

Appendix C

Independent Group Advising on the Release of Data (IGARD)

Action Notes from the IGARD – NHS Digital COVID-19 Response Meeting

held via videoconference, Tuesday, 29th September 2020

In attendance (IGARD Members):	Prof. Nicola Fear (Specialist Academic Member)
	Kirsty Irvine (IGARD Lay Chair)
	Dr. Geoff Schrecker (Specialist GP Member)
In attendance (NHS Digital):	Duncan Easton (Item 3.2)
	Karen Myers (IGARD Secretariat)
	Kimberley Watson (Item 3.1)
In attendance (external):	Emily Cross (IBM – item 2 only)

2	**Welcome** The IGARD Chair noted that this was a weekly meeting convened to support NHS Digital's response to the COVID-19 situation and was separate from the IGARD business as usual (BAU) meetings. IGARD members present would only be making comments and observations on any items that were presented, and were not making formal recommendations to NHS Digital. Should an application require a full review and recommendation, then it should go through the usual Data Access Request Service (DARS) process and be presented at a Thursday IGARD meeting. The action notes from the Tuesday meeting would be received at the next Thursday meeting of IGARD and published as part of those minutes as an appendix. **Declaration of interests:** Nicola Fear noted she was a participant of the Scientific Pandemic Influenza Group on Behaviours (SPI-B) advising on COVID-19. Nicola Fear noted a personal and professional link to the Head of the Centre for Longitudinal Studies (CLS) unit at University College London (NIC-49297-Q7G1Q UCL, NIC-51342-V1M5W UCL, NIC-49826-T0J7C UCL) but noted no specific connection with the application or staff involved. It was agreed that this was not a conflict of interest at the COVID-19 response meeting, including because no recommendations are made.
2	<u>IBM update</u> IGARD members were given a brief update to the IBM work underway in NHS Digital including improvements to the customer experience and current projects. It was agreed that this would be a weekly update to the COVID-19 response meeting. IGARD members thanked IBM and NHS Digital for the update and noted receipt of materials for review.

3.1	[2]University College London Group Application **Background:** This was an amendment application from the University College London Institute of Education: Centre for Longitudinal Studies (CLS), to add GPES Data for Pandemic Planning and Research (GDPPR) (COVID-19) for the purpose of sub-licensing to researchers. The three original Data Sharing Agreements (DSA) presented to the IGARD business as usual (BAU) meeting on 6th August 2020, for consideration of the sub-licensing model, which IGARD recommended for approval with conditions. NHS Digital advised IGARD that all the conditions for the three applications had now been approved via IGARD's out of committee (OOC) process. In addition, NHS Digital advised that work was ongoing with the applicant to resolve a number of outstanding queries, including (but not limited to) identifying the purpose for the GDPPR data and that the Terms of Reference reflected the additional purpose (once confirmed) that covers the use of the GDPPR data. NHS Digital advised IGARD that NHSX had reviewed these applications in terms of the sub-licensing arrangements for GDPPR data, and in line with NHS Digital's Public Health Direction. **IGARD Observations:** IGARD members welcomed and supported the update from NHS Digital with regard to the outstanding issues still to be confirmed with the applicant. IGARD discussed the consent materials / models used for the studies outlined within the DSA's, in respect of the proposed addition of the GDPPR data, and agreed that the information provided in respect of these well-established studies was clear and should provide no surprises for the cohort, for example the reference in some of the consent materials to data being shared following a *"visit to the family doctor".* IGARD did query the reference to *"administrative information"* collected within the one suite of materials and advised that this could be confusing to participants. On balance, however, there was sufficient information in that cohort's consent form (and other public facing study materials) referring to health data that the study cohort would be unlikely to be surprised that their GP data was being shared and linked. IGARD agreed with NHS Digital's view that further information was required on the purposes for requiring these data as these purposes need to align with pandemic planning, and IGARD noted that similar applications had set out a clear justification for requesting the GDPPR data and how this linked to a COVID-19 purpose. IGARD advised that if a clear justification could not be provided, with specific examples of what they were hoping to achieve with the data, which would align with the requirements in the GDPPR directions, that the applicant may wish to consider waiting for the availability of the GP data set for research. IGARD noted that NHSX had reviewed the request from the applicant for the addition of the GDPPR data, which included sublicensing, and suggested that NHS Digital's Public Health Direction was shared with the applicant and that narrative was requested with specific details of which sub-paragraphs the proposed COVID-19 work relates to.

[2] NIC-49826-T0J7C, NIC-49297-Q7G1Q, NIC-51342-V1M5W

	IGARD queried the data minimisation that had been considered and applied, if possible, to the data requested, and noted that similar applications that had requested the GDPPR data had been minimised by code set, and asked that in line with NHS Digital Data Sharing Standard 3, an analysis was provided of whether data minimisation could be undertaken.
3.2	<u>NIC-396095-H1P1D - Cheshire & Merseyside STP</u> **Background:** This was a verbal presentation to support a set of COVID-19 related population health analytics, designed to inform both population level planning for COVID-19 recovery and to support the targeting of direct care to vulnerable populations across the Cheshire and Merseyside Sustainable Transformation Partnership (STP). One of the outcomes they are hoping to achieve, is automated dashboards to support COVID-19 recovery, which would be broken down into three main sub areas, 1) Capacity and Demand - monitoring the changing demand across acute, community, mental health and local authority services in as near real time as possible, including the ability to understand if there is a possible surge or 'second wave' emerging. It will enable understanding of whether there is enough capacity to meet that demand; 2) Epidemiology - enabling monitoring of mortality and incidence over time at differing levels of geography. It will also provide insight in terms of demographic and health characteristics of individuals most affected by COVID-19 and will enable identification of geographical 'hot spots' of emerging infection; and 3) Population Stratification - enabling GP practices and / or PCN's responsible for a registered population to identify individuals with certain characteristics that will be vulnerable to adverse outcomes as a result of COVID-19 and target services / interventions appropriately. NHS Digital advised IGARD that this application was still in the early stages, and that work was ongoing with the applicant to resolve a number of outstanding queries, including (but not limited to) data controllership and legal basis. NHS Digital advised that they had received confirmation that there would be no sub-licensing under this agreement, and that if this was to happen in the future, then this would come back to NHS Digital for the relevant approvals. **IGARD Observations:** IGARD members noted the update from NHS Digital, including the fact that this application was still in the very early stages, and welcomed the opportunity to have early sight of the suggested work outlined in the verbal update. IGARD noted that any sub-licensing arrangements would not form part of this agreement and advised NHS Digital that, in accordance with the NHS Digital Standard on Sub Licensing, this would not go down the precedent route when the application was ready for a full review. IGARD queried if the applicant already had a DSA in place for any other purposes, and were advised by NHS Digital that the applicant did have another DSA in place for the purpose of commissioning (NIC-140059-P1J9L); in addition, NHS Digital advised that a further discussion was due to take place with the applicant to discuss a number of issues, including clarification that there was no duplication of purpose with the two separate DSA's. IGARD noted and asked that for ease of reference, the separate DSA was referred to in both section 1 (Abstract) and section 5 (Purpose / Methods / Outputs) of the application. IGARD noted that whilst this was a verbal presentation, NHS Digital had provided a copy of the applicant's Data Protection Impact Assessment (DPIA) in advance of the meeting, and advised that the DPIA did not clearly define the severity grades, and asked that this was

	updated accordingly. In addition, IGARD suggested that, noting the potential large volumes of data that may be requested, that covered a large number of people and involved a number of data processors, that the DPIA should be published for transparency purposes. IGARD queried the reference within the DPIA to *"other research organisation(s)"* and asked for clarification if this was generic wording or if there was a research organisation involved. IGARD also noted and commended that the proposed work outlined mapped to the Shielded Patient List (SPL) release letter dated the 27th April 2020, and clearly set out who the recipients could be, what level of data they could process and the terms of the release of the data. IGARD asked that as the application progressed, this should continue to be aligned with the SPL letter, and that the application is clear on what processing is related to the SPL and what they will be doing more generally with the other datasets. IGARD queried how the applicant would use Risk Stratification and if they would be using this to identify individuals, noting that the data would be processed as pseudonymised, which would then become identifiable following the onward sharing; and how National Data Opt-outs would be respected are then identified for the purpose providing appropriate care (and noting the SPL release letter specifically addresses National Data Opt-outs for pseudonymised data). In addition, IGARD queried the automated processing elements of the processing, for example those individuals who were not added to the Shielded Patient List. IGARD advised NHS Digital that as per previous advice, a special condition should be inserted in section 6 that placed an obligation on the Data Controller to ensure that they had appropriate contractual arrangements in place with the Data Processor(s) which satisfied Regulation 7 of COPI. IGARD noted the volume of proposed Data Controllers for this application, and suggested that alongside a factual analysis of responsibilities (which would naturally reduce this number), the applicant might wish to consider the appropriate use of honorary contracts if there were a few key individuals involved in an advisory capacity.
4.	<u>AOB</u> There was no further business raised, the IGARD Chair thanked members and NHS Digital colleagues for their time and closed the meeting.