

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held via videoconference 26 May 2022

| IGARD MEMBERS IN ATTENDANCE: | |
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| Name: | Position: |
| Paul Affleck | Specialist Ethics Member |
| Kirsty Irvine | IGARD Chair |
| Dr. Geoffrey Schrecker | Specialist GP Member / IGARD Deputy Chair |
| Dr. Maurice Smith | Specialist GP Member |
| Jenny Westaway | Lay Member |
| IGARD MEMBERS NOT IN ATTENDANCE: | |
| Maria Clark | Lay Member |
| Prof. Nicola Fear | Specialist Academic Member |
| Dr. Robert French | Specialist Academic / Statistician Member |
| Dr. Imran Khan | Specialist GP Member |
| NHS DIGITAL STAFF IN ATTENDANCE: | |
| Name: | Team: |
| Helen Buckles | Data Access Request Services (DARS) (Item 2.2) |
| Rhys Bowen | Data Access Request Services (DARS) (Observer: item 3.1) |
| Dave Cronin | Data Access Request Services (DARS) (SAT Observer: item 3.1) |
| Catherine Day | Data Access Request Services (DARS) (Item 2.2, 3.3) |
| Louise Dunn | Data Access Request Service (DARS) (SAT Observer: items 2.1, 3.3 – 3.4) |
| Duncan Easton | Data Access Request Services (DARS) (SAT Observer: item 3.4) |
| Liz Gaffney | Head of Data Access, Data Access Request Service (DARS) (Items 7.1 - 7.3) |
| Lucy Irvine | Information and Analysis (Item 2.1) |
| Mark McDaid | Data Access Request Services (DARS) (Observer: item 7.2) |
| Karen Myers | IGARD Secretariat |
| Amy Ogborne | Privacy, Transparency and Ethics (PTE) (Item 2.1) |

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| Denise Pine | Data Access Request Services (DARS) (Item 3.2) |
| Jamie Sanderson | Privacy, Transparency and Ethics (PTE) (Item 2.1) |
| Charlotte Skinner | Data Access Request Services (DARS) (Item 3.4) |
| Sarah Stevens | Director of the National Disease Registration Service (Item 2.1) |
| Kimberley Watson | Data Access Request Services (DARS) (SAT Observer : items 2.2, 3.2) (Observer : item 2.1) |
| Anna Weaver | Data Access Request Service (DARS) (Item 3.1) |
| James Watts | Data Access Request Services (DARS) (Observer : items 2.2, 3.1 – 3.4) |
| Vicki Williams | IGARD Secretariat (Items 2, 3.5, 4 - 7) |
| *SAT – Senior Approval Team (DARS) | |

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| 1 | <p>Declaration of interests:</p> <p>There were no declarations of interest.</p> <p>Review of previous minutes and actions:</p> <p>The minutes of the 19th May 2022 IGARD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record the meeting.</p> <p>Out of committee recommendations:</p> <p>An out of committee report was received (see Appendix A).</p> |
| 2 | Briefing Notes |
| 2.1 | <p><u>International Benchmarking of Children Cancer Survival by Stage at Diagnosis (BENCHISTA) – Briefing Paper (Presenters: Jamie Sanderson / Sarah Stevens / Lucy Irvine / Amy Ogborne)</u></p> <p>This briefing paper was to inform IGARD about a request that had been received via the National Disease Registration Service (NDRS), from the Istituto Nazionale dei Tumori (INT, a.k.a <i>National Cancer Institute</i> in Italy) to contribute to a common project entitled ‘International Benchmarking of Children Cancer Survival by Stage at Diagnosis’ (BENCHISTA). This request has been made to 45 cancer registries in total, which includes the vast majority of EEA countries, Switzerland, Canada and Australia.</p> <p>The contribution involves a dissemination of pseudonymised personal data regarding tumours into a secure environment. Prior to any dissemination, NDRS will undertake work to prepare a cut of data from the NDRS National Cancer Registration and Analysis Service (NCRAS), which involves a pseudonymisation process and restructuring the data to ensure it meets international standards enabling more straight forward analysis across all contributed data.</p> <p>In addition to the briefing paper, a supporting document was provided that explored NHS Digital’s options to contribute, that was shared with NHS Digital’s Senior Information Risk Officer (SIRO), Executive Director of Privacy Transparency and Ethics, Caldicott Guardian and Director</p> |

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| | <p>of Research and Clinical Trials. The options included 1) proceeding via the Data Access Request Services (DARS); 2) a hybrid approach; or 3) an exception approach.</p> <p>Outcome: IGARD welcomed the briefing paper and made the following high-level comments:</p> <p>In respect of the proposed 'exceptional' route:</p> <ol style="list-style-type: none"> 1. IGARD noted that nature of the data being shared appeared to present a low risk of reidentification or other disclosure. 2. IGARD noted that the draft contract provided was not governed by English law and this may present practical barriers to enforcement of its terms. 3. IGARD noted that utilising an exceptional route may set a precedent for other applicants or create the perception of an unlevel playing field - which could be mitigated by transparently stating that it was a "<i>one-off</i>" due to timing of the application in relation to the transition of the NDRS service and datasets to NHS Digital. 4. IGARD noted that the current transparency was fairly generic and did not cover the processing or specifics of this project. NHS Digital agreed that transparency would be a key undertaking. 5. IGARD suggested that the applicant undertake patient and public involvement and engagement (PPIE) now and throughout the lifetime of the project, and in line with the HRA guidance on Public Involvement. This could explore international data sharing and transparency about that. <p>In respect of sub-licencing:</p> <ol style="list-style-type: none"> 1. IGARD noted the three options put forward in the briefing but suggested that NHS Digital may wish additionally to consider entering into a Data Sharing Agreement (DSA) with UCL, who could then sub-licence the data to the other collaborators. IGARD noted other academic applicants have used this route to share data internationally, and there is a relevant NHS Digital DARS Standard for Sub-licencing and Onward Sharing of Data 2. IGARD noted that using a sub-licence option would ensure visibility to the public via the data uses register and the IGARD published minutes. In practical terms, it would have the advantage of being governed by English law and NHS Digital could terminate individual sub licences, if required. <p>IGARD welcomed the draft briefing paper and welcomed further discussions on this important and valuable project.</p> |
| 2.2 | <p><u>University College London (UCL) application for 'Education and Child Health Insights from Linked Data' (ECHILD) Dataset Sub-Licencing – Briefing (Presenters: Helen Buckles / Catherine Day)</u></p> <p>The purpose of this briefing is to inform IGARD of the sub-licencing proposal.</p> <p>ECHILD links Hospital Episode Statistics (HES) data with the National Pupil Database, is currently being used by academic teams at UCL, London School of Hygiene & Tropical Medicine and Institute for Fiscal Studies, for specific research purposes. ECHILD contains only de-identified data and is accessed via the Office for National Statistics (ONS) Secure Research Service. The partnership between the academic team, NHS Digital and the Department for Education always intended that ECHILD would be made available to the wider research community for a broad range of research purposes relating to benefiting healthcare provision or the promotion of health.</p> |

In order to satisfy the original request, and to make ECHILD available to a wider audience, the study partnership has agreed that the only current way to make the data more widely available is for UCL to make their copy available through sub licencing for a broad range of research purposes (with all the appropriate controls around this) as a non-linkable asset hosted in the ONS Secure Research Service.

To facilitate this application and accommodate the sub-licence request, NHS Digital are proposing that all data will be held under existing UCL data sharing agreements (DSA) NIC-381972-Q5F0V (the data is currently accessed under a consolidated DSA NIC-393510-D6H1D).

NIC-381972-Q5F0V

IGARD noted that the application and relevant supporting documents had previously been presented at the IGARD business as usual (BAU) meetings on the 25th June 2020, 21st October 2021 and the 31st March 2022.

NIC-393510- D6H1D

IGARD noted that the application and relevant supporting documents had previously been presented at the IGARD business as usual (BAU) meeting on the 20th July 2017, 27th June 2019 and the 4th March 2021.

IGARD noted that aspects of this application had been previously seen at the IGARD – NHS Digital COVID-19 Response meeting on the 20th April 2021.

IGARD noted that this application had previously been discussed as part of the ‘returning applications’ section of the IGARD business as usual (BAU) meeting on the 17th February 2022.

Outcome: IGARD welcomed the briefing on sub-licencing and made the following high-level comments:

1. In respect of the sub-licencing:
 - a) IGARD suggested that the [NHS Digital DARS standard for sub-licencing and onward sharing](#) is mapped against the application.
 - b) IGARD noted that NHS Digital should be careful in using previously used sub-licences, as this may not always be best practice due to different facts or evolution of policy.
 - c) IGARD suggested that any Terms of Reference for the oversight panel should include (but not limited to) reference to a requirement for the use of the data to evidence a benefit to health and / or social care.
 - d) IGARD suggested that the oversight panel may wish to put the onus of reporting yielded benefits achieved on sub-licencees.
 - e) IGARD advised the applicant to consider adding lay representatives to the oversight panel to represent the perspectives of data subjects.
2. IGARD endorsed the ethics approval and s251 support obtained.
3. Noting the linkage with educational data, IGARD emphasised the fact that the use of NHS Digital data would need to be for the purpose of health and / or social care in line with NHS Digital’s statutory remit.
4. IGARD noted that they would be happy to receive the draft application with the suite of sub-licencing documents, and the oversight panel’s Terms of Reference as a future ‘advice’ agenda item at an IGARD BAU meeting. IGARD noted that when the application comes for a recommendation, that it would require a double slot at an IGARD BAU meeting.

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| 2.3 | <p><u>Ambulance Data Set Pilot - Briefing Paper (No Presenter)</u></p> <p>IGARD noted that a briefing paper with regard to the Ambulance Data Set (ADS) pilot had been presented at the IGARD – NHS Digital COVID-19 Response meeting on the 7th January 2021 where a number of observations had been made; and at the IGARD BAU meeting on the 4th February 2021, where IGARD had confirmed that they had no further comments to make and the briefing paper had been finalised.</p> <p>Following the previous review of the briefing paper, IGARD noted that NHS Digital had submitted written confirmation that 1) Computer Aided Dispatch (CAD) has gone live, and as such now all eleven Ambulance Trusts will be collecting and sending data to NHS Digital; and, 2) A pilot Electronic Patient Record (EPR) collection will begin prior to EPR going live similar to the CAD Pilot involving three Ambulance Trusts.</p> <p>IGARD noted and thanked NHS Digital for the written update provided.</p> |
| 3 | <p>Data Applications</p> |
| 3.1 | <p><u>Swansea University: TRIM: 'What Triage Model Is Safest & Most Effective For The Management Of 999 Callers With Suspected COVID-19' A Linked Outcome Study (Presenter: Anna Weaver) NIC-387965-T2B5D-v0.17</u></p> <p>Application: This was a new application for pseudonymised Civil Registration (Deaths), Emergency Care Data Set (ECDS), Hospital Episode Statistics Admitted Patient Care (HES APC) and HES Critical Care.</p> <p>Ambulance services cannot and should not attend and convey every patient with COVID-19 symptoms to hospital. There are two stages of triage 1) who to dispatch a response to, for face-to-face assessment and care; and 2) who to convey to hospital. This triage is key to identifying people that need to be treated in hospital; under-triage will result in patient harm, in this case, avoidable serious illness and deaths; and over-triage will result in unnecessary conveyance to the Emergency Department, exposing patients to risk of infection, diverting resources from those in need and overburdening already pressurized services. Different triage models are used by different ambulance services, and are changing over time as call patterns and understanding of the COVID-19 pandemic evolve. It is not clear which of these approaches works best, or which elements lead to a successful triage model.</p> <p>The purpose of the application is for a study that will investigate triage models by looking at outcomes for 999 callers in four ambulance services during the first wave of the pandemic (March to August 2020); which include 1) the East of England Ambulance Service; 2) the East Midlands Ambulance Service; 3) the West Midlands Ambulance Service; and 4) the Yorkshire Ambulance Service.</p> <p>The study team hope that, by identifying which triage models were most successful, future policies and practices can be better informed during the current and future pandemic situations.</p> <p>The study is relying on s251 of the NHS Act 2006, to link and flow the data out of NHS Digital.</p> <p>Discussion: IGARD also noted and commended the applicant on the ongoing patient and public involvement and engagement (PPIE) as outlined in section 5(a) (Objective for Processing).</p> <p>IGARD queried the reference in section 1 (Abstract), to the application being submitted to NHS Digital in 2020 and 2021; and asked that for clarification, this was updated to state that no</p> |

previous application had been made and the dates referred to in 2020 and 2021 were in respect of an initial *enquiry*.

IGARD confirmed that they were of the view that the relevant s251 support was compatible with the processing outlined in the application.

IGARD noted the information near the beginning of section 5(a) that provided clarity on the data requested under the heading “*Data Summary*”; however, asked that this was updated to make reference to the s251 support obtained from the Health Research Authority Confidentiality Advisory Group (HRA CAG) for the identifying data used to create the cohort, noting that this was not made clear until later in the application.

IGARD noted the helpful information within points 2a and 2b under the “*Methods*” heading in the protocol, in relation to the “*forwards*” and “*backwards*” linking of data for 999 calls; and asked that, for transparency, this was replicated in section 5(b) (Processing Activities) which formed part of NHS Digital’s public facing [data uses register](#); and that a description of the data flow was also included, in line with [NHS Digital DARS Standard for processing activities](#).

IGARD queried the statement in section 5(b) “...*a research paramedic from each trust will search the ambulance service database for any 999 calls made by those patients in the preceding 7 days - regardless of whether they made a 999 call or not.*”; and asked that the end of this statement was reviewed and either amended or removed if not deemed relevant.

IGARD noted the reference within section 1 and section 5 (Purpose / Methods / Outputs) to “*correctly*” conveyed, for example “The primary study outcome is the proportion of patients correctly conveyed to hospital...”; and asked that the references to “*correctly*” were removed, as admission to hospital was not necessarily a proxy for whether or not conveyance by ambulance was appropriate.

IGARD noted the information provided within the expected benefits in section 5(d) (Benefits) (ii) , however asked that this was updated further, to be more specific as to what was hoped to be achieved, as this was currently unclear; and in line with the [NHS Digital DARS Standard for Expected Measurable Benefits](#).

IGARD queried the statement in section 5(d) (ii) (Expected Measurable Benefits to Health and / or Social Care) “*future epidemics of coronavirus or other flu-like infections*” and asked that this was reworded as “*future epidemics and pandemics*” which was less restrictive.

IGARD noted the storage location noted in section 2(b) (Storage Location(s)), however asked that this was updated with further details of the campus storage locations.

Outcome: recommendation to approve

1. To update the references in section 1 to the *application* being submitted in 2020 and 2021, to clarify that this was an initial *enquiry*.
2. To update section 2 with the campus storage locations.
3. To update the “*Data Summary*” information in section 5(a) to make reference to the s251 support obtained from HRA CAG for the identifying data used to create the cohort.
4. To remove the reference to “*correctly*” conveyed in section 1 and section 5, as admission to hospital is not a proxy for whether or not conveyance by ambulance was appropriate.
5. To review the statement in section 5(b) “...*regardless of whether they made a 999 call or not...*” and either amend or remove if not deemed relevant.

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| | <p>6. To replicate points 2a and 2b from the protocol relating to “forwards” and “backwards” linking of data into section 5(b), and include a description of the data flow.</p> <p>7. In respect of the benefits in section 5(d)(iii) and in line with the NHS Digital DARS Standard for Expected Measurable Benefits:</p> <p>a) To update section 5(d) (ii) with specific details as to what is hoped to be achieved.</p> <p>b) To remove the statement in section 5(d) “future epidemics of coronavirus or other flu-like infections” and replace with “future epidemics and pandemics”.</p> |
| 3.2 | <p><u>Device Access UK Ltd: Device Access - HES Application 2021 (Presenter: Denise Pine) NIC-05429-H7X6R-v8.3</u></p> <p>Application: This was a renewal application to permit the holding and processing of pseudonymised Emergency Care Data Set (ECDS), Hospital Episode Statistics Admitted Patient Care (HES APC), HES Critical Care and HES Outpatients.</p> <p>Device Access UK Limited (DAUK) conduct bespoke analyses on behalf of commercial companies, the NHS, academics and charities. The analysis carried out by DAUK is on current patient pathways for specific cohorts of patients for each named medical device. The burden to NHS hospitals on increased length of stay, additional complications, further readmissions and other negative effects are studied to determine the benefits of introducing a new technology.</p> <p>DAUK's purpose is to provide Europe-wide support for MedTech companies navigating the complex reimbursement landscapes in healthcare markets</p> <p>This programme of work can be split into five distinct project areas, 1) The National Institute for Health and Care Excellence (NICE) applications on behalf of medical technological device companies; 2) The National Institute for Health and Care Research (NIHR) research applications on behalf of medical technological device companies; 3) NHS adoption support on behalf of medical technological device companies; 4) NHS Consultancy with regards to medical and diagnostic devices for patient diseases; and 5) Department for International Trade (DIT) and Office for Life Sciences (OLS).</p> <p>Discussion: IGARD noted that the application and relevant supporting documents had previously been presented at the IGARD business as usual (BAU) meeting on the 16th March 2017, 15th May 2017, 8th June 2017, 6th July 2017 and the 21st December 2017.</p> <p>IGARD noted that when this application had previously been reviewed on the 21st December 2017, they had expected that the application return for IGARD review upon renewal, and that the applicant should provide evidence of their process for approvals and any benefits achieved from their projects. IGARD noted in section 1 (Abstract) various versions of the application had proceeded via NHS Digital's Precedent route between 2018 and 2021, which IGARD were not supportive of. IGARD queried the application not returning as per the previous advice, noting that they had not been notified of any progression of this application since 2017, and consequently there was no reference of this in any of the published IGARD minutes as per process. NHS Digital noted the queries and concerns raised by IGARD and confirmed that these would be raised internally and for future learning.</p> <p>IGARD noted that prior to the meeting, an IGARD member had submitted a query in respect of whether there was a publicly accessible list of clients and projects to give transparency to data subjects.</p> |

NHS Digital advised that the applicant had confirmed that there was **not** a publicly accessible list of clients and projects, due to strict non-disclosure agreements with commercial companies. IGARD noted the verbal update from NHS Digital, however suggested that the applicant undertake further work in respect of greater transparency to the public on their clients and the work undertaken. Separate to this application, IGARD suggested that NHS Digital reviewed the [NHS Digital DARS Standard for Transparency](#) and [NHS Digital DARS Standard for Commercial Purpose](#) in respect of the commercial use of NHS Digital data to see whether further transparency could be achieved, particularly around a company's clients, and what those clients use the data for.

IGARD asked that for further transparency to the public, section 5(a) (Objective for Processing) was updated with a brief overview of the number of the applicants' clients, the category of clients and the approximate proportion of clients in each of the four sub-categories outlined in section 5(a).

In addition, there was also a query raised as to whether there was any public information available about the DAUK Data Access Review Group (DADARG), for instance whether minutes from DADARG meetings were available to the public.

IGARD had not received any additional information in respect of the query raised on the transparency of DADARG, and were unable to locate any information within the public domain, for example, Terms of Reference (ToR), details of membership etc. However IGARD noted references in section 1 and section 5 (Purpose / Methods / Outputs) to DADARG being "*transparent*". IGARD suggested that in order for transparency to the public to be provided to make this statement correct, information should be published about the DADARG with details including, but not limited to, ToR, membership and minutes. If such transparency is not provided, the reference to DADARG being "*transparent*" should be removed.

IGARD noted the statement in section 5(b) (Processing Activities) that DADARG was formed of five members "*...three of which are external to DAUK and employed by NHS England in a clinical or research role*"; and asked that as section 5(b) formed part of NHS Digital's public facing [data uses register](#), and in the absence of any publicly available information, this was updated with further details of the **specific** NHS England roles of the three members, and in line with [NHS Digital DARS Standard for processing activities](#).

IGARD queried the information within the published privacy notice, that referred to the National Data Opt-out (NDO) operating to remove citizens' data from this processing; and asked that this was updated to remove any incorrect information in respect of the NDO, noting that the NDO would not be upheld in respect of flows of pseudonymised data, as requested under this data sharing agreement, and in line with [NHS Digital DARS Standard for Transparency](#).

IGARD noted a number of references within the application to clients who "*commission*" the activity, and asked that written confirmation was provided in section 5, as to why the clients who "*commission*" the activity were **not** considered a joint Data Controller, in line with [NHS Digital's DARS Standard for Data Controllers](#), and as borne out of the facts.

IGARD noted the statement in section 5(b) "*Data will only be accessed and processed by substantive employees of DAUK...*", and queried if this was correct, noting the reference elsewhere in section 5(b) to "contractors" who may have access to the data; and the numerous references within NHS Digital's Post Audit Review, provided as a supporting document to "contractors". IGARD therefore asked that written confirmation was provided, that there were **no** contractors accessing the data: or, that the application was updated throughout to reflect

the role of the contractor(s), and as borne out of the facts and in line with the relevant [NHS Digital Data Access Request Service \(DARS\) Standards](#) as per process.

IGARD noted the statements in section 5 “...*the commercial gain is a fraction of the NHS savings created from the adoption of new medical devices...*”; and asked that these were reviewed in line with [NHS Digital DARS Standard for Commercial Purpose](#) to ensure the commercial benefit was proportionate to the benefit of health and care system and that this was expressed in an objectively quantifiable way.

IGARD noted a number of statements in section 5 relating to specific savings, for example “...*admissions resulted in significant use of NHS resources, including the use of over 130,000 bed days and estimated £55 million costs.*” and asked that these were reviewed and updated in terms of productivity gain or similar.

IGARD noted the benefits in section 5(d) (Benefits), however asked that they were updated to ensure they aligned with the four key areas of activity outlined in section 5(a). In addition, IGARD asked that each of the specified benefits state whether or not a benefit had been achieved or that quantitative examples were provided, for example, referencing the percentages gain for a benefit; in line with the [NHS Digital DARS Standard for Expected Measurable Benefits](#).

Noting that the public facing section 5 forms [NHS Digital's data uses register](#), IGARD noted the following in respect of the language throughout section 5, and asked that the relevant text highlight below was updated in line with [NHS Digital DARS Standard for Objective for Processing](#) and [NHS Digital DARS Standard for processing activities](#).

IGARD noted the incorrect reference to the “National Institute of Clinical Excellence” in section 5(a), and asked that this was updated to correctly refer to the “National Institute for Health and Care Excellence” as referenced elsewhere in the application.

IGARD asked that section 5(b) was amended throughout, so technical terms were used only where necessary and explained in a manner suitable for a lay audience, for example replacing the reference to “...*MS SQL Server...*” with “*industry standard analysis tool*”.

IGARD queried the reference in section 5(b) specifics of the physical security arrangements and asked that this was removed as it was not necessary, and updated with a reference to “*appropriate physical and technical controls*” or similar.

IGARD noted that some of the information in section 5 was not clear and suggested that it was updated to ensure that it was written in a language suitable for a lay reader including reference to “*burden*” of the illness / care, and that further sensitive consideration was given to the patient audience and how this type of language could be perceived.

IGARD noted the reference in section 5(a) and section 5(d) (iii) (Yielded Benefits) to “*frequent flyers*” when referring to patients with four or more episodes outpatient appointments involving epilepsy, and asked that this was reworded with a less jocular form of words such frequent attenders.

IGARD advised that they would wish to review this application when it comes up for renewal, extension or amendment and that this application would not be suitable for NHS Digital's Precedent route, including the SIRO Precedent, due to the large quantum of data flowing, the transparency and public interest in the use of health data by commercial organisations.

Outcome: recommendation to approve subject to the following conditions:

1. To provide written confirmation in section 5 as to why the clients who “*commission*” the activity are not considered a joint Data Controller, in line with [NHS Digital's DARS Standard for Data Controllers](#), and as borne out of the facts.
2. In respect of the “*contractors*” referenced in section 5(b) and the supporting document(s):
 - a) To provide written confirmation that there are **no** contractors accessing the data: or,
 - b) To update the application throughout to reflect the role of the contractor(s), and as borne out of the facts.

The following amendments were requested:

1. To update the privacy notice to remove any incorrect information in respect of the NDO operating to remove citizens’ data from this processing (as the NDO is not upheld in respect of flows of pseudonymised data).
2. In respect of the commercial aspect:
 - a) To review the statements within section 5 “...*the commercial gain is a fraction of the NHS savings created from the adoption of new medical devices...*” in line with [NHS Digital DARS Standard for Commercial Purpose](#) to ensure the commercial benefit is proportionate to the benefit of health and care system and that this is expressed in an objectively quantifiable way.
 - b) To review the statements in section 5 relating to any specific savings, and update in terms of productivity gain or similar.
 - c) To update section 5(a) with a brief overview of the number of the applicants clients, the category of clients and the approximate proportion of clients in each of the four sub-categories outlined in section 5(a).
3. In respect of the Data Access Review Group:
 - a) To provide publicly accessible, transparent information about the group or amend section 1 and section 5 to remove the reference to the “*transparent*” Data Access Review Group, noting that there is currently no information in the public domain providing such transparency, for example ToR, details of membership etc.
 - b) To update section 5(b) with further details of the specific NHS England roles of the three members of the Data Access Review Group.
4. In respect of the language in section 5:
 - a) To update section 5 to ensure ‘The National Institute for Health and Care Excellence’ is correctly referenced.
 - b) As section 5 forms [NHS Digital's data uses register](#), to amend section 5(b) throughout, so technical terms are used only where necessary and explained in a manner suitable for a lay audience, for example replacing the reference to “...*MS SQL Server...*” with “*industry standard analysis tool*”.
 - d) To remove the reference in section 5(b) to specifics of the physical security and instead refer to “*appropriate physical and technical controls*” or similar.
 - e) To update section 5 to ensure it is written in language suitable for a lay reader and that sensitive consideration is given to the patient audience (for example when referring to the illness being a “*burden*”).
 - f) To replace the reference to “*frequent flyers*” in section 5(a) and 5(d) (iii) with a less jocular form of words.
5. To ensure the benefits in section 5(d) align with the four key areas of activity outlined in section 5(a). Additionally to ensure that each of the specified benefits state whether or not a benefit has been achieved or give quantitative examples, for example, referencing the percentages gain for a benefit. Any updates should be in line with the [NHS Digital DARS Standard for Expected Measurable Benefits](#).

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| | <p>The following advice was given:</p> <ol style="list-style-type: none"> 1. IGARD suggested that the applicant undertake further work in respect of greater transparency to the public on their clients and the work undertaken. 2. IGARD suggested that for greater transparency to the public, the Data Access Review Group referred to within the application, published further details outlining details including (but not limited to) Terms of Reference, membership and minutes. 3. IGARD advised that they would wish to review this application when it comes up for renewal, extension or amendment, due to the large quantum of data flowing, the transparency and public interest in the use of health data by commercial organisations. 4. IGARD suggested that this application would not be suitable for NHS Digital's Precedent route, including the SIRO Precedent, due to the large quantum of data flowing, the transparency and public interest in the use of health data by commercial organisations. <p>Separate to this application: IGARD suggested that NHS Digital review the NHS Digital DARS Standard for Transparency and NHS Digital DARS Standard for Commercial Purpose in respect of the commercial use of NHS Digital data to see whether further transparency could be achieved, particularly around a company's clients, and what those clients use the data for.</p> <p>Separate to this application: IGARD asked NHS Digital to review its internal processes to ensure that only suitable applications proceed down the precedent route (without IGARD review).</p> <p>It was agreed the conditions would be approved out of committee (OOC) by IGARD members.</p> |
| 3.3 | <p><u>University College London (UCL): Evaluating the Family Nurse Partnership in England (Presenter: Catherine Day) NIC-136916-B7D5C-v2.4</u></p> <p>Application: This was an extension application to permit the holding and processing of pseudonymised Civil Registration (Deaths) - Secondary Care Cut, Hospital Episode Statistics Accident and Emergency (HES A&E), HES Admitted Patient Care (APC), HES Outpatients, HES: Civil Registration (Deaths) bridge and Medical Research Information Service (MRIS) – Bespoke.</p> <p>The application was also an amendment to 1) add The Health Foundation as a Data Processor; and 2) request access for two UCL PhD students.</p> <p>The purpose of the application is for a longitudinal research study aiming to evaluate the real-world implementation of the Family Nurse Programme (FNP) in England.</p> <p>FNP is an intensive early home visiting programme for first time young mothers, delivered by trained nurses aiming to improve maternal and child outcomes by providing support throughout pregnancy and until the child's second birthday. The study aims to evaluate the real-world implementation of FNP in England with findings from the study helping policy makers decide whether FNP should be offered to families in their local setting.</p> <p>The study is relying on s251 of the NHS Act 2006, for the flow of contact details out of NHS Digital.</p> <p>NHS Digital advised IGARD that due to a delay in data linkage and supply, there were no yielded benefits associated with this data sharing agreement (DSA) to date.</p> <p>Discussion: IGARD noted that the application and relevant supporting documents had previously been presented at the IGARD business as usual (BAU) meeting on the 25th July 2019, 17th October 2019 and the 28th January 2021.</p> |

IGARD noted and thanked NHS Digital and the applicant for addressing all the previous queries raised at the IGARD BAU meeting on the 28th January 2021, for example, by providing a clear narrative why the large control group was necessary.

IGARD noted and thanked NHS Digital for the verbal update in respect of the yielded benefits.

IGARD noted the amendment to add The Health Foundation as a Data Processor. NHS Digital advised that the purpose of this amendment was for one individual who was previously an employee of UCL and was involved with the study, however, has moved organisations and is now an employee of The Health Foundation. IGARD noted and thanked NHS Digital for the verbal update / background information, however, queried whether adding The Health Foundation as a Data Processor was the best approach, or whether other options could / have been explored, for example, an honorary contract. IGARD therefore asked that NHS Digital provided written confirmation that they were content that adding The Health Foundation as a Data Processor was the most appropriate route; **or**, that written confirmation was provided that a secondment or other honorary contract for the individual from the Health Foundation to UCL was more appropriate.

IGARD asked that in either case a clear statement was made as to why the individual would **not** be carrying out data controllership activities, in line with [NHS Digital's DARS Standard for Data Controllers](#), and as borne out of the facts.

In addition, IGARD asked that for transparency the application was updated as necessary throughout, reflecting the above.

As section 5 (Purpose / Methods / Outputs) forms [NHS Digital's data uses register](#), IGARD asked that section 5(a) (Objective for Processing) was amended throughout, so technical terms were used only where necessary and explained in a manner suitable for a lay audience, for example replacing the reference to "*propensity scores*", in line with [NHS Digital DARS Standard for Objective for Processing](#).

IGARD advised that they would wish to review this application when it comes up for renewal, extension or amendment and that this application would not be suitable for NHS Digital's Precedent route, including the SIRO Precedent, to review the yielded benefits accrued to date or a detailed explanation as to the steps taken toward achieving the benefits outlined in section 5(d) (Benefits).

Outcome: recommendation to approve subject to the following conditions:

1. In respect of the amendment to add The Health Foundation as a Data Processor:
 - a) To provide written confirmation that NHS Digital are content that adding The Health Foundation as a Data Processor is the most appropriate route; or,
 - b) To provide written confirmation that a secondment or other honorary contract for the individual from The Health Foundation to UCL is more appropriate; and,
 - c) In either case to make a clear statement why the individual will not be carrying out data controllership activities, in line with [NHS Digital's DARS Standard for Data Controllers](#), and as borne out of the facts; and,
 - d) To update the application as necessary throughout, reflecting the above.

The following amendments were requested:

1. As section 5 forms [NHS Digital's data uses register](#), to amend section 5(a) throughout, so technical terms are used only where necessary and explained in a manner suitable for a lay audience, for example replacing the reference to "*propensity scores*".

The following advice was given:

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| | <ol style="list-style-type: none"> 1. IGARD advised that they would wish to review this application when it comes up for renewal, extension or amendment, to review the yielded benefits accrued to date or a detailed explanation as to the steps taken toward achieving the benefits outlined in section 5(d). 2. IGARD suggested that this application would not be suitable for NHS Digital's Precedent route, including the SIRO Precedent, to review the yielded benefits accrued to date or a detailed explanation as to the steps taken toward achieving the benefits outlined in section 5(d). <p>It was agreed the condition would be approved out of committee (OOC) by the IGARD Chair.</p> |
| 3.4 | <p><u>Monitor: 12-month Renewal (Presenter: Charlotte Skinner) NIC-15814-C6W9R-v23.2</u></p> <p>Application: This was a renewal application to permit the holding and processing of pseudonymised Civil Registration (Deaths) - Secondary Care Cut, Community Services Data Set (CSDS), Hospital Episode Statistics Admitted Patient Care (HES APC), HES Critical Care, HES Outpatients, Diagnostic Imaging Dataset (DIDs), Emergency Care Data Set (ECDS), HES:Civil Registration (Deaths) bridge, Bridge file: HES to DIDs, Improving Access to Psychological Therapies Data Set (IAPT), Linked-Patient Level Costing Integrated Data Set (Linked-PLCINTDS)_NHSI, Mental Health Services Data Set (MHSDS), National Cancer Waiting Times Monitoring Data Set (NCWTMDS), Patient Level Costing Ambulance Data (NHSI), Patient Reported Outcome Measures (PROMs) (Linkable to HES), Secondary Uses Service Payment By Results Accident & Emergency (SUS PbR A&E), SUS PbR Episodes, SUS PbR Outpatients and SUS PbR Spells.</p> <p>The application was also an amendment to 1) update the Data Processors, Processing and Storage locations; and 2) to request Linked Patient Level Costing Early Implementers Data Set (PLCEIDS) for financial year 20/21 to cover Community Services. This amendment previously progressed via the SIRO approval route.</p> <p>The application seeks to request data for Monitor, the NHS Trust Development Agency and NHS England, as joint Data Controllers and will be used to support the delivery of the applicants' statutory function and support direct improvement and / or oversight of Trusts.</p> <p>Discussion: IGARD noted that the application and relevant supporting documents had previously been presented at the IGARD business as usual (BAU) meeting on the 26th March 2020 and the 2nd July 2020.</p> <p>IGARD noted that aspects of this application had been previously seen at the IGARD – NHS Digital COVID-19 Response meetings on the 26th May 2020.</p> <p>IGARD noted that all previous comments made on this application at either an IGARD business as usual (BAU) or IGARD – NHS Digital COVID-19 Response meeting remained live and that they were only focusing on the two amendments only.</p> <p>IGARD noted serious concerns in respect of transparency to the public, who have been given the impression that there is infrequent sharing of unsuppressed data, and suggested that an internal audit was undertaken by the data applicant to assess compliance with the disclosure rules, for example, by reference to the contractual terms: have the local risk assessments been carried out, were there suitable Information Governance (IG) controls in place, and have the Data Controllers satisfied themselves that the controls were sufficient to manage any risks etc.</p> <p>IGARD noted the statement in section 5(a) (Objective for Processing) that <i>"NHSE's uses of data sourced under this agreement will only be in accordance to its statutory duties and</i></p> |

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| | <p><i>functions, any external sharing of data will comply with the respective disclosure control rules as outlined in the DSA</i>"; and the subsequent information in section 5(b) (Processing Activities) outlining the "<i>disclosure control rules</i>"; and asked that section 5 (Purpose / Methods / Outputs) was updated as may be necessary to ensure that it reflected the appropriate controls that were in place and being followed by the recipients of the data.</p> <p>IGARD also asked that the terms and conditions (T&C) of the User Dashboard were updated and reflect what is contained in section 5 of the DSA.</p> <p>IGARD noted a reputational risk to NHS Digital in respect of the inadequate transparency to the public about use and sharing of the unsuppressed data.</p> <p>IGARD queried the special condition in section 6 (Special Conditions) relating to the register that should be shared with NHS Digital on a quarterly basis, detailing where and when NHS Digital data had been shared with small numbers unsuppressed. Noting that this may not be an appropriate process to accurately capture this information, IGARD asked that the special condition was reviewed and updated, to avoid the applicant being in breach of the data sharing agreement (DSA).</p> <p>Outcome: recommendation to approve for the two amendments only, by a quorum of 4 members, with one member dissenting:</p> <p>The following amendments were requested.</p> <ol style="list-style-type: none"> 1. To update the special condition in section 6 relating to disclosure control to reflect the current status and to avoid the applicant being in breach of the DSA. 2. To update section 5 as may be necessary to ensure that it reflects the appropriate controls that are in place and being followed. <p>The following significant advice was given:</p> <ol style="list-style-type: none"> 1. IGARD noted serious concerns in respect of transparency to the public, who have been given the impression that there is infrequent sharing of unsuppressed data, and suggested that an internal audit was undertaken to assess compliance with the disclosure rules, for example (by reference to the contractual terms): have the local risk assessments been carried out, are there suitable IG controls in place, and have the Data Controllers satisfied themselves that the controls are sufficient to manage any risks etc 2. To ensure that the T&C of the User Dashboard are updated and reflect what is contained in section 5 of the DSA. <p>Significant Risk Factor: Reputational risk to NHS Digital in respect of the inadequate transparency to the public about use and sharing of the unsuppressed data.</p> |
| 3.5 | <p><u>St George's, University of London: MR1485 - Development of a linked, de-identified database resource for research into the health, mortality and educational outcomes of children with a congenital anomaly (No Presenter) NIC-64474-V4B2D-v1.4</u></p> <p>Application: This was a renewal and amendment application to 1) remove the following Data Processors: University of Oxford, University of Leicester, University Hospitals Bristol and Weston NHS Foundation Trust, University Hospital Southampton NHS Foundation Trust and Newcastle University; and 2) to add a new data backup location; 3) to receive data for the remainder of the 2 cohorts.</p> |

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| | <p>The purpose is for the ‘British and Irish Network of Congenital Anomaly Researchers’ (BINOCAR), which is a collaboration of congenital anomaly registries which had been involved in the surveillance of congenital anomalies from as early as 1985 until 2015.</p> <p>This Data Sharing Agreement (DSA) seeks to create a linked de-identified research database through a one-off linkage of previously collected case data from five regional registers in England to subsets of Hospital Episode Statistics (HES) and Civil Registrations (deaths).</p> <p>The historical BINOCAR data will also be independently linked to the National Pupil Database (NPD) under a separate DSA with the Department of Education (DfE), for a different study looking into educational outcomes associated with congenital anomalies and will not involve the use of or linkage to NHS Digital data. However together these linked datasets will enable future, approved outcomes-research into the long-term survival, health and educational achievement of children with congenital anomalies to be conducted without the need or expense of re-linking the historical data.</p> <p>The study is relying on s251 of the NHS Act 2006, for the flow of data out of NHS Digital.</p> <p>Discussion: IGARD noted that the application and relevant supporting documents had previously been presented at the IGARD BAU meeting on the 18th November 2021; where the application had been recommended for approval with conditions and amendments.</p> <p>IGARD noted that as outlined in the Out of Committee (OOC) Standard Operating Procedure, any applications returned to the IGARD Secretariat for review OOC by the IGARD Chair or quorum of IGARD Members which were over three months old, would be automatically placed on the next available BAU meeting agenda for review by IGARD Members as per the current standard processes. Members would only review if the conditions have been met or not, and would not re-review the application, unless significant legislative or policy changes had occurred since last reviewed by a full meeting of IGARD or the application had been significantly updated, in which case the conditions may be updated to reflect such changes which will be noted for transparency in the published minutes and a full review of the application undertaken.</p> <p>The condition from the 18th November 2021 BAU meeting was as follows:</p> <ol style="list-style-type: none"> 1. In respect of the HRA CAG support: <ol style="list-style-type: none"> a) To provide written evidence of the continuing HRA CAG support. b) To upload the written evidence of this to NHS Digital’s CRM system. 2. In respect of the PPIE advice point previously made on the 28th May 2020: to provide a satisfactory indicative plan for the development and implementation of PPIE initiatives. <p>A quorum of IGARD members were content that the multi-limbed condition had been met.</p> |
| 4 | <p><u>Applications progressed via NHS Digital’s Precedent route, including the SIRO Precedent</u></p> <p>Applications that have been progressed via NHS Digital’s Precedent route, including the SIRO Precedent, and NHS Digital have notified IGARD in writing (via the Secretariat).</p> <p><i>No items discussed.</i></p> |
| 5 | <p><u>Oversight & Assurance</u></p> <p>IGARD noted that they do not scrutinise every application for data, however they are charged with providing oversight and assurance of certain data releases which have been reviewed and approved solely by NHS Digital. Due to the volume and complexity of applications at</p> |

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| | <p>today's meeting, IGARD were unable to review any Data Access Request Service (DARS) applications as part of their oversight and assurance role.</p> <p>IGARD Members noted that they had not yet been updated on the issues raised at the 27th May 2021 IGARD business as usual (BAU) meeting with regard to previous comments made on the IG COVID-19 release registers March 2020 to May 2021. IGARD noted that in addition, they had not been updated on the issues raised on the IG COVID-19 release registers June 2021 to January 2022.</p> <p>IGARD noted that the NHS Digital webpage excel spreadsheet had now been updated for the period March 2020 to April 2022: NHS Digital Data Uses Register - NHS Digital</p> |
| 6 | <p><u>COVID-19 update</u></p> <p><i>No items discussed</i></p> |
| 7 | <p><u>AOB:</u></p> |
| 7.1 | <p><u>Head of Data Access Update</u></p> <p>The Head of Data Access attended (part of) the meeting as part of her regular catch-up with IGARD.</p> <p>In addition, and following discussion on NIC-388185-C4D6J - NHS Norfolk and Waveney CCG at the IGARD BAU meeting on the 19th May 2022, IGARD suggested that the Head of Data Access may wish to attend the requested meeting with the PAG Chair in respect of the PAG conditions. IGARD noted that concerns had been raised by IGARD about the blanket ban on performance management.</p> |
| 7.2 | <p><u>Proposal for changes to Standard 2 and 11 (Presenter: Liz Gaffney)</u></p> <p>The Head of Data Access, Data Access Request Service (DARS) attended the meeting to provide IGARD with a brief overview on the proposals to update NHS Digital's Data Access Request Services (DARS) Standard 2 – Processing and Storage Locations, and Standard 11 – Territory of Use.</p> <p>IGARD noted the content of the verbal update and thanked the Head of Data Access for attending the meeting.</p> |
| 7.3 | <p><u>NIC-139035-X4B7K-v10.2 NHS England (Quarry House) (Presenters: Liz Gaffney</u></p> <p>NHS Digital attended IGARD to provide a verbal update on the above application, which had last been reviewed at an IGARD BAU meeting on the 12th May 2022.</p> <p>NHS Digital advised that Continuing Health Care (CHC) Dataset would be added to this DSA and progressed via the SIRO Precedent route as a matter of urgency.</p> <p>In addition, NHS Digital noted that this application would be submitted for a further review in the near future for an additional amendment, and IGARD would be asked for comments on the flow of CHC Dataset at this point, again, noting that this was out of process.</p> <p>IGARD noted and thanked NHS Digital for the verbal update, however reiterated their previous advice that this overarching application and any spin-off applications, would not be suitable for NHS Digital's Precedent route, including the SIRO Precedent. IGARD did not raise any specific concerns on the flow of the CHC Dataset, however supported NHS Digital's advice</p> |

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| | <p>that this application would be brought to a future IGARD BAU meeting for review, as per process.</p> |
| 7.4 | <p><u>NIC 414067-K8R6J-v0.2 Our Future Health: Our Future Health Recruitment Programme (Presenter: Kimberley Watson)</u></p> <p>IGARD noted that NHS Digital had requested advice on the above application being amended to add the COVID-19 Ethnic Category Data Set, partly derived from the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (COVID-19) (GDPPR) dataset.</p> <p>IGARD questioned whether such a use was compatible with the purposes of the GDPPR collection. IGARD also advised that due process should be followed, in that the application should be presented at a GDPPR – Profession Advisory Group (PAG), and then return to a future IGARD BAU meeting for a review of the amendment in line with the PAG advice.</p> |
| 7.5 | <p><u>COVID-19 – Notice under Regulation 3(4) of the Health Service Control of Patient Information Regulations 2002</u></p> <p>IGARD noted that colleagues from NHS Digital had published information on the NHS Digital website on the 18th May 2022, relating to the notice from the Secretary of State for Health and Social Care under the Health Service (Control of Patient Information) Regulations 2002, requiring NHS England and NHS Improvement to process confidential patient information for purposes related to COVID-19.</p> <p>IGARD noted and thanked NHS Digital for bringing this to their attention.</p> <p>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.</p> |

Appendix A

Independent Group Advising on Releases of Data (IGARD): Out of committee report 20/05/22

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) |
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| NIC-148313-G56YY-v1.6 | University of Birmingham | 24/02/2022 | 1. In respect of the HRA CAG support, for the applicant to liaise with HRA CAG and for HRA CAG to confirm that either: <ul style="list-style-type: none"> a) those cohort members who had declined in the past to allow their details to be shared or to take part in the further follow up or processing are covered in the s251 support, OR b) the s251 support does not include those cohort members, and c) To upload the written confirmation in relation to point (a) or point (b) above, to NHS Digital's CRM system, and d) To update the application accordingly. | IGARD members | OOO by quorum of IGARD members | IGARD Comments: We would strongly suggest the applicant continues their extensive PPIE and updates their transparency materials to clearly articulate how cohort members can opt out. |
| NIC-334459-R9H4C | University of York | 21/10/2021 | 1. In respect of the consultee form: <ul style="list-style-type: none"> a) To provide written confirmation from NHS Digital's PTE, on the appropriate legal basis for the 15 participants, who are part of the cohort, where the consultee form was used instead of consent / assent. b) To upload the written confirmation from PTE to NHS Digital's CRM system for future reference. | IGARD members | Approved in the IGARD BAU meeting on the 19/05/2022 by a quorum of IGARD members. | None |

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:

- None

Optum Health Solutions UK Limited Class Actions:

- None

Graphnet Class Actions:

- None