

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held via videoconference 29 September 2022

IGARD MEMBERS IN ATTENDANCE:	
Name:	Position:
Prof. Nicola Fear	Specialist Academic Member
Dr. Robert French	Specialist Academic / Statistician Member (Items 5 and 7.1)
Kirsty Irvine	IGARD Chair
Dr. Imran Khan	Specialist GP Member / Co-Deputy IGARD Chair
Dr. Maurice Smith	Specialist GP Member
IGARD MEMBERS NOT IN ATTENDANCE:	
Paul Affleck	Specialist Ethics Member / Co-Deputy IGARD Chair
Maria Clark	Lay Member
Dr. Geoffrey Schrecker	Specialist GP Member
Jenny Westaway	Lay Member
NHS DIGITAL STAFF IN ATTENDANCE:	
Name:	Team:
Deepu Austine	Data Access Request Services (DARS) (Observer: items 3.2 to 3.3)
Dave Cronin	Data Access Request Services (DARS) (SAT Observer: items 3.1 to 3.2)
Louise Dunn	Data Access Request Services (DARS) (SAT Observer: items 3.4 to 3.5)
Duncan Easton	Data Access Request Services (DARS) (SAT Observer: item 3.3)
Liz Gaffney	Head of Data Access, Data Access Request Service (DARS) (Item 7.1)
Dan Goodwin	Data Access Request Services (DARS) (Item 3.1)
Karen Myers	IGARD Secretariat
Denise Pine	Data Access Request Services (DARS) (Item 3.5)
Emma Russell	Data Access Request Services (DARS) (Item 5)
Terry Service	Data Access Request Services (DARS) (Item 5)

Anna Weaver	Data Access Request Services (DARS) (Items 3.2 to 3.4)
Vicki Williams	IGARD Secretariat
*SAT – Senior Approval Team (DARS)	

1	<p>Declaration of interests:</p> <p>Nicola Fear noted professional links to the team at University of Leeds (NIC-11809-H1Y3W) <i>(and the sister application NIC-155843-0MQMK not discussed at IGARD today)</i> but noted no specific connections with the application and it was agreed that this was not a conflict of interest.</p> <p>Review of previous minutes and actions:</p> <p>The minutes of the 22nd September 2022 IGARD meeting were reviewed and, subject to a number of minor amendments, were agreed as an accurate record of the meeting</p> <p>Out of committee recommendations:</p> <p>An out of committee report was received (see Appendix A).</p>
2	Briefing Notes
2.1	<p><u>National Disease Registration Service (NDRS) Progression of Applications / Agreements following UKHSA Transfer – Briefing Paper (Presenter: Louise Dunn)</u></p> <p>This briefing paper was to provide a further update to IGARD in relation to the NDRS remit of work, following the responsibility for the management of NDRS transferring from Public Health England (PHE) to NHS Digital on the 1st October 2021. This follows the verbal update from NHS Digital at the IGARD meeting on the 21st July 2022.</p> <p>Since the transition, UK Health Security Agency (UKHSA) have been supporting NHS Digital in assessing and approving applications for The National Cancer Registration and Analysis Service (NCRAS) and National Congenital Anomaly and Rare Disease Registration Service (NCARDS) data, via the existing Office of Data Release function (ODR) within UKHSA but that arrangement has now ceased.</p> <p>Over the summer of 2022, Data Access Request Services (DARS) have assessed the 424 folders passed over from UKHSA; the briefing paper provided further information as to how the folders have been categorised.</p> <p>The briefing paper also outlined a proposal for the process of moving existing agreements on to NHS Digital Data Sharing Agreements, for example, new applications, renewals, extensions etc.</p> <p>IGARD welcomed the briefing paper and looked forward to receiving a further update in due course at a future meeting.</p>
3	Data Applications
3.1	<p><u>Nottingham University Hospitals NHS Trust: Access to HES data via the NHS Digital On-Line Portal (Presenter: Dan Goodwin) NIC-10620-V9D8R-v6.6</u></p>

Application: This was a renewal and extension application to permit the access and processing of pseudonymised Emergency Care Data Set (ECDS), Hospital Episode Statistics Accident and Emergency (HES A&E), HES Admitted Patient Care (APC), HES Critical Care and HES Outpatients via the NHS Digital Portal (data access environment).

It was also an amendment application to **1)** add an additional purpose to section 5(a), to introduce the ability to construct a query for the purposes of checking technical feasibility prior to finalising the request specifications; **2)** to extend the scope to permit the East Midlands Academic Health Science Networks (EMAHSN) analytics team to provide analytical support for the West Midlands AHSN; **3)** to provide further narrative in section 5(a) in relation to the role of the Co- leads as updated with the HES use Governance document and further clarity around the honorary contract for one of the Co-Leads with the Nottingham University Hospitals NHS Trust; **4)** to add the Emergency Care Data Set (ECDS) shaped view of the product; **5)** to provide clarification and evidence that an external Information Governance (IG) person has been employed in response to the previous IGARD recommendation; **6)** to remove the processing and storage locations for Nottingham University Hospitals NHS Trust.

England's fifteen AHSNs were set up by the NHS in 2013, with an initial 5-year licence and a remit to drive healthcare innovation and stimulate economic growth. The EMAHSN is focused on igniting innovation; bringing together the NHS, Universities, Industry and Social Care to transform the health of the 4.5 million East Midlands residents and stimulate wealth creation.

The purpose of the application, is to support the EMAHSN to achieve the following objectives (each of which is underpinned by supporting work in the following domains): **1)** focus on the needs of patients and local populations – support and work in partnership with commissioners and public health bodies to identify and address unmet health and social care needs, whilst promoting health equality and best practice (Domain A); **2)** speed up adoption of innovation into practice to improve clinical outcomes and patient experience – support the identification and more rapid uptake and spread of research evidence and innovation at pace and scale to improve patient care and local population health (Domain B); **3)** build a culture of partnership and collaboration – promote inclusivity, partnership and collaboration to consider and address local, regional and national priorities (Domain C).

There is also a further objective (Domain D), however this version of the application does not relate to this.

Discussion: IGARD noted that the application and relevant supporting documents had previously been presented at the Data Access Advisory Group (DAAG) (*IGARD's predecessor*) meetings on the 6th September 2016, 8th November 2016; and the IGARD meetings on the 24th August 2017, 28th September 2017 and the 15th March 2018.

IGARD noted and commended NHS Digital on the quality of the information within section 1 (Abstract) of the application, for example, how previous points made by IGARD had been addressed, which supported the review of the application by Members.

IGARD queried the references to “*NHS Digital Portal*” throughout the application, and noting that it may be unclear to the public what this was, asked that the application was amended throughout to remove reference to “*NHS Digital Portal*” and replace as appropriate, for example “*NHS Digital's data access environment*” or similar.

IGARD noted that section 2(a) (Processing Location(s)) and section 2(b) (Storage Location(s)) had not been populated, and asked that both sections were updated as appropriate to reflect the processing and storage locations, in line with [NHS Digital DARS Standard for Processing and Storage Locations](#).

Separate to the application: IGARD noted that the NHS Digital Standard for processing and storage locations on the NHS Digital website had a publication date of July 2019. IGARD noted that if an NHS Digital policy decision had been taken to remove processing and storage locations from applications prior to the NHS Digital Standard being updated, or the processing and storage locations were left blank for access to the NHS Digital SDE (or similar) then the NHS Digital policy position should be provided to IGARD and updated on the NHS Digital website.

IGARD queried whether any storage of data may be happening outside the NHS Digital Portal (data access environment) that was **not** aggregated with small numbers suppressed; and asked that section 2(b) was updated to reflect the storage locations of that data.

IGARD noted that there were a number of AHSNs for different geographical locations in England, and noting the application was silent on this point, queried whether the AHSN within this data sharing agreement would only access the data within their own geographical location, i.e. the East Midlands. NHS Digital advised IGARD that they may need to access data outside their geographical area for the purpose of national benchmarking. IGARD noted the verbal update from NHS Digital and asked that for transparency, section 5 (Purpose / Methods / Outputs) which forms [NHS Digital's data uses register](#), was updated with a statement restricting AHSN access to data to citizens within their geographical location, except where national benchmarking was justified.

ACTION: NHS Digital to formulate a statement for **all** AHSN applications, restricting AHSN access to data to citizens in the relevant geographical location, except where national benchmarking was justified.

NHS Digital advised IGARD that the application would be updated to include a special condition in section 6 (Special Conditions), restricting the data years accessed within NHS Digital's Portal (data access environment). IGARD noted the verbal update from NHS Digital and supported the inclusion of a special condition in section 6 restricting the data years accessed, in line with [NHS Digital DARS Standard for Special Conditions](#).

IGARD noted the inconsistent statements in section 5 relating to aggregated data with small numbers suppressed, including (but not limited to) the statement in section 5(b) (Processing Activities) *"There will be no data linkage undertaken with NHS Digital data provided under this agreement that is not already noted in the agreement"*; and asked that this was updated or removed, in line with [NHS Digital DARS Standard for processing activities](#), noting the data could not be linked as it was aggregated with small numbers suppressed. IGARD also asked that section 5 was reviewed and updated throughout as may be necessary to remove or amend inconsistent statements.

IGARD noted the statement in section 5(b) *"When using outpatient data, the data will typically be broken down by diagnosis codes or clinics...and GP practices"*; and asked that the applicant consider whether reference to Primary Care Networks (PCNs) should be included as well as, or instead of, *"GP practices"*.

IGARD queried what outputs were produced from data **not** aggregated data with small numbers suppressed, and asked in line with [NHS Digital DARS Standard for Expected Outcomes](#), further clarification was provided in section 5(c) (Specific Outputs Expected). If the outputs were not anonymous, IGARD asked that section 5(c) was also updated with confirmation of how the data would be stored, and in accordance with what restrictions.

<p>IGARD queried the statement in section 5(c) “<i>Analytical output from projects exploring a specific disease (e.g. Sepsis)...</i>”; and asked that this was removed or updated, noting that Sepsis is a reaction to an infection and not a disease.</p> <p>IGARD noted the references to “<i>Sustainability and Transformation Plans</i>” (STPs) and <i>Accountable Care Organisations</i> (ACOs) in section 5(c), and asked that these were removed, and updated with the correct references.</p> <p>IGARD noted the weblink provided in section 5(d) (Benefits) (iii) (Yielded Benefits) to support a yielded benefit, however advised that the page accessed via the weblink was a general page on the EMAHSN website; and asked that the weblink was updated that provided several examples of yielded benefits accrued to date, in line with the NHS Digital DARS Standard for Expected Measurable Benefits. If there were no yielded benefits accrued to date, then IGARD asked that a statement was provided in section 5(d) (iii) clarifying the reason for this.</p> <p>IGARD noted a number of prospective benefits in section 5(d) (iii) and asked that these were moved to section 5(c) in line with NHS Digital DARS Standard for Expected Outcomes.</p> <p>As section 5 forms NHS Digital’s data uses register, IGARD asked that section 5(b) was amended, to ensure that all acronyms upon first use be defined and further explained if the meaning was not self-evident, for example “GLA”.</p> <p>IGARD noted the references to “<i>NHS Clinical Commissioning Group (CCG)</i>” in section 5(b) and asked that this was updated to correctly reference “<i>Integrated Care Board (ICB)</i>”, noting that ICBs replaced CCGs on the 1st July 2022.</p> <p>IGARD noted the extensive and positive patient and public involvement and engagement (PPIE) that had taken place, and suggested the application was updated to reflect this.</p> <p>Separate to this application: IGARD queried if there was a holistic view taken across all AHSN applications, especially relevant if AHSN’s were undertaking the same benchmarking exercise using different years or data sets which may lead to different conclusions. IGARD suggested DARS investigate further to ensure consistency across AHSNs given that these applications are now starting to come to DARS for renewal.</p> <p>Outcome: recommendation to approve subject to the following conditions:</p> <ol style="list-style-type: none"> 1. In respect of section 2(a) and section 2(b): <ol style="list-style-type: none"> a) To update section 2(a) and 2(b) as required in line with NHS Digital DARS Standard for Processing and Storage Locations; and b) To update section 2(a) and section 2(b) to reflect any storage of data that may be happening outside the NHS Digital data access environment that is not aggregated with small numbers suppressed. 2. To update section 5 with a statement restricting AHSN access to data to citizens within geographical location, except where national bench marking is justified. <p>The following amendments were requested:</p> <ol style="list-style-type: none"> 1. To update section 5 to remove or amend inconsistent statements i.e. aggregated data with small numbers suppressed, for example, the statement in section 5(b) relating to “<i>no data linkage</i>” to other external sources. 2. To amend the application throughout to remove reference to “<i>NHS Digital Portal</i>” and replace as appropriate, for example “<i>NHS Digital’s data access environment</i>” or similar. 3. To insert a special condition in section 6 restricting the data years accessed within NHS Digital’s environment; in line with NHS Digital DARS Standard for Special Conditions (as per NHS Digital’s verbal update).

	<p>4. In respect of section 5(b) and in line with NHS Digital DARS Standard for processing activities:</p> <p>a) To ensure acronyms be defined upon first use, for example “GLA”.</p> <p>b) To remove / update references to “CCG”.</p> <p>5. c) To consider if reference should be made to PCNs as well as, or instead of, “GP practices” with regard to using outpatient data. In respect of section 5(c) and in line with NHS Digital DARS Standard for Expected Outcomes:</p> <p>a) To clarify what outputs are produced from data not aggregated with small numbers suppressed; or,</p> <p>b) If the data is not anonymous, to confirm how the data will be stored and in accordance with what restrictions.</p> <p>c) To remove reference to “Sepsis” being a disease and update as appropriate.</p> <p>d) To remove references to “STPs” and “ACOs” and update with the correct references.</p> <p>6. In respect of the yielded benefits in section 5(d) (iii) and in line with the NHS Digital DARS Standard for Expected Measurable Benefits:</p> <p>a) To add a relevant weblink to provide several examples of yielded benefits accrued to date; or,</p> <p>b) If there are no yielded benefits accrued to date, to provide a brief explanation as to why.</p> <p>c) To remove any prospective benefits from section 5(d) (iii) and move to section 5(c), in line with NHS Digital DARS Standard for Expected Outcomes.</p> <p>The following advice was given:</p> <p>1. Noting the extensive and positive PPIE that has taken place, IGARD suggested the application was updated to reflect this.</p> <p>ACTION: NHS Digital to formulate a statement for all AHSN applications, restricting AHSN access to data to citizens in the relevant geographical location, except where national benchmarking is justified.</p> <p>Separate to the application: IGARD noted that the NHS Digital Standard for processing and storage locations on the NHS Digital website had a publication date of July 2019. IGARD noted that if an NHS Digital policy decision had been taken to remove processing and storage locations from applications prior to the NHS Digital Standard being updated, or the processing and storage locations were left blank for access to the NHS Digital SDE (or similar) then the NHS Digital policy position should be provided to IGARD and updated on the NHS Digital website.</p> <p>Separate to this application: IGARD queried if there was a holistic view taken across all AHSN applications, especially relevant if AHSN's were undertaking the same benchmarking exercise using different years or data sets which may lead to different conclusions. IGARD suggested DARS investigate further to ensure consistency across AHSNs given that they are now starting to come to DARS for renewal.</p> <p>It was agreed the conditions would be approved out of committee (OOC) by IGARD members.</p>
3.2	<p><u>University of Warwick: Prevention of Shoulder Problems Trial (PROSPER): exercise to prevent shoulder problems in patients undergoing breast cancer treatment. (Presenter: Anna Weaver) NIC-75485-J3R9B-v1.9</u></p> <p>Application: This was an extension application to permit the holding and processing of pseudonymised Hospital Episode Statistics Admitted Patient Care (HES APC), HES Critical</p>

Care and HES Outpatients. As the study has now finished the data will be retained for archiving purposes only for 10-years. The Data Controllers would like to retain this data to ensure reconstruction of the trial analysis is possible if required.

It was also an amendment application to add the University Hospitals Coventry and Warwickshire NHS Trust as a Data Controller.

The purpose of the application is for a pragmatic two-arm Randomised Controlled Trial testing a postoperative exercise intervention to prevent shoulder problems in patients following breast cancer surgery.

Following breast cancer surgery, it is common for women to experience a range of postoperative symptoms in the upper arm and shoulder, which can persist for many years after treatment. The intervention in PROSPER builds upon existing evidence that exercise programmes following surgery can improve functional outcomes and reduce risk of complications. The purpose of the PROSPER trial was to examine whether such a programme was clinically and cost-effective in comparison to usual care in the NHS. This was the first multicentre trial testing early, structured postoperative exercise in this patient group.

Recruitment to the trial took place until July 2017 with postal follow-up completed late summer 2018. A total of 951 women were screened at 17 NHS hospitals and 382 women were randomised to either exercise (191) or usual care (191).

Discussion: IGARD noted that the application and relevant supporting documents had previously been presented at the IGARD meeting on the 9th August 2018.

IGARD noted that at the meeting on the 9th August 2018, members had taken the view that the consent materials were **not** compatible with the processing outlined; however noted that NHS Digital had taken a different view that the consent was compatible and had taken the decision to flow the data. IGARD confirmed to NHS Digital that they were still of the same view as the one given in 2018, that consent materials were **not** compatible.

IGARD noted that following the meeting on the 9th August 2018, DARS had discussed the consent materials with NHS Digital's Caldicott Guardian, and the application subsequently went down the SIRO approval route without referral back to IGARD. IGARD asked that for future reference, this sequence of events was referred to in section 1 (Abstract).

IGARD noted a statement in section 1 relating to the previous review on the 9th August 2018, implying that IGARD's 'unable to recommend' for approval, linked to the incoming introduction of the General Data Protection Regulation (GDPR) *"It is worth noting that this IGARD meeting took place shortly after GDPR and it seems there was a question over whether the cohort needed to be reconsented or whether the PN would cover any updates"*. IGARD advised NHS Digital that GDPR did not impact their review of the consent materials as GDPR was a separate consideration from the common law duty of confidentiality (CLDOC) and the application was not advancing GDPR consent. IGARD asked that this incorrect speculation was removed to avoid any misunderstanding in the future.

IGARD noted and commended the applicant on the positive patient and public involvement and engagement (PPIE).

IGARD also noted and commended the applicant on the quality of the yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits) which was a good example of a completed clinical trial with benefits to the health and care system. IGARD asked that in line with the [NHS Digital DARS Standard for Expected Measurable Benefits](#), the yielded benefit relating to

'physiotherapy' was updated with further information, for example has access to physiotherapy improved / increased following this study.

In addition, IGARD also asked that the yielded benefit relating to 'Futurelearn' was updated with metrics if available, for example, user statistics etc.

IGARD noted in section 1 that NHS Digital had received confirmation from the applicant that the University of Oxford was not considered a Data Controller; and that "...a justification had been provided in section 5(a)". IGARD advised that section 5(a) (Objective for Processing) did not contain this information, and asked that this was updated to clarify that the University of Oxford was not a Data Controller.

IGARD suggested that the charges for this application were made clear to the applicant, including (but not limited to) the cost of retaining the data and the frequency of the cost incurred, for example, a one-off payment as opposed to annual payments; and that any correspondence relating to this matter were saved as a supporting document and uploaded to NHS Digital's customer relationships management (CRM) system for future reference.

IGARD commended NHS Digital for bringing the application to IGARD, and that although the application was for non-contentious "archiving", it was essential for IGARD to review because the previous IGARD review had been unable to recommend this application for approval, IGARD's views had not changed in the last four years and the consent underpinning the research remained incompatible with the processing, and this was the first archiving application that had come to IGARD under the revised NHS Digital DARS Standard.

Outcome: recommendation to approve for the archiving aspect of the application **only**.

The following amendments were requested:

1. In respect of the yielded benefits in section 5(d) (iii) and in line with the [NHS Digital DARS Standard for Expected Measurable Benefits](#):
 - a) To update the 'physiotherapy' yielded benefit in section 5(d) (iii) with further information.
 - b) To update the 'Futurelearn' yielded benefit in section 5(d) (iii) with metrics if available.
2. In respect of section 1:
 - a) To remove the incorrect statement in section 1 relating to IGARD / GDPR.
 - b) To update section 1 with a reference to the previous Caldicott Guardian input from 2018.
3. To update section 5(a) to clarify that the University of Oxford are not a Data Controller (as referenced in section 1).

The following advice was given:

1. IGARD reiterated the advice from the 9th August 2018 IGARD meeting, that the consent materials were not compatible with the processing outlined.
2. IGARD suggested that the charges for this application were made clear to the applicant, including (but not limited to) the cost of retaining the data and the frequency of the cost incurred, for example, a one-off payment as opposed to annual payments; and that any correspondence relating to this matter were saved as a supporting document and uploaded to NHS Digital's customer relationships management (CRM) system for future reference.

<p>3.3</p>	<p><u>Imperial College London: Effectiveness and Value for Money of Prescribed Specialised Services Commissioning for Quality and Innovation (CQUIN) - Social Network Research Amendment (Presenter: Anna Weaver) NIC-172334-W0G2L-v4.11</u></p> <p>Application: This was a renewal and extension application to permit the holding and processing of pseudonymised Hospital Episode Statistics Accident and Emergency (HES A&E), HES Admitted Patient Care (APC), HES Critical Care and HES Outpatients.</p> <p>It was also an amendment application to 1) to amend the Territory of Use from England and Wales to the European Economic Area (EEA) to allow for an honorary contracted employee to work remotely via a Screen View to the Big Data Analytical Unit (BDAU); 2) to add in a new study objective and purpose. The previous objective was the 'prescribed specialised services (PSS) commissioning for quality and innovation (CQUIN) project' which has now ended. The new / additional project is the Social Network Research study; 3) to disseminate a bridging file to Imperial College London.</p> <p>The PSS CQUIN project has now been completed and the final report has been submitted to the National Institute for Health and Care Research (NIHR). The data will be retained for use in supplementary analyses needed to ensure the publication of the results in academic journals.</p> <p>The purpose of the application is to process data previously disseminated under this DSA (for PSS CQUIN project) for an additional wider mixed methods research study (CQUIN). It is hoped the additional study will produce a methodology for modelling how knowledge of health policies diffuse amongst health professionals. Knowledge such as that disseminated through CQUIN or through other quality improvement initiatives can spread more widely to groups not targeted by the information campaign or policy. This wider spread of knowledge is known as a spill over effect; and will seek to understand how knowledge spreads through members of a social network.</p> <p>The analysis will investigate how consultants that are and are not exposed to health policies intended to improve the quality of care react to the implementation, and specifically whether the inferred social network between consultants and their characteristics explain variation in the change in quality following the policy.</p> <p>Discussion: IGARD noted that the application and relevant supporting documents had previously been presented at the IGARD meetings on the 17th May 2018 and the 6th February 2020.</p> <p>It was also discussed as part of the 'applications progressed via NHS Digital's SIRO Precedent route' on the 20th August 2020.</p> <p>IGARD noted that section 1 (Abstract) of the application did not make any reference to the IGARD review on the 6th February 2020 where IGARD had recommended for approval subject to conditions amendments and advice; the SIRO approval in August 2020; nor the Caldicott Guardian support in 2020; and that when the application had been discussed at the IGARD meeting on the 20th August 2020 following progression via NHS Digital's SIRO Precedent route, IGARD had clarified in the published minutes that <i>"...when the application returned for independent review, the conditions would still be 'live' and to have been updated to be in line with NHS Digital's DARS standards"</i>. IGARD therefore reiterated to NHS Digital that the conditions, amendments and advice remained outstanding from the 6th February 2020 review and would need addressing as appropriate by NHS Digital and / or the applicant.</p>
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IGARD asked that section 1 was updated to ensure **all** previous IGARD minutes and details of SIRO approval were copied into section 1, as per usual process; and to support NHS Digital staff and IGARD with future reviews.

IGARD also suggested that NHS Digital provide a copy of the **full text** of the IGARD minutes **and** outcomes from the meeting on the 6th February 2020 to the applicant, rather than just the outcomes.

IGARD noted that NHS Digital had suggested to the applicant to consult with GP forums, when the application was clearly about hospital consultants, and suggested that previous advice from the 6th February 2020 in relation to further discussion with industry bodies should be discussed with the applicant. IGARD suggested that the applicant consider, for example, a wider discussion with the [BMA Consultants Committee UK](#); to investigate whether the outputs of the research could be used to reduce differential achievement between consultants / widen access to effective social networks so as to improve consultant performance.

IGARD asked that a special condition was inserted in section 6 (Special Conditions), that, following the signing of the DSA, a detailed annual review was scheduled in twelve months. The relevant supporting documents should be provided by the applicant to NHS Digital no later than one month prior to the annual review. These documents should be uploaded to NHS Digital's customer relationship management (CRM) system for future reference.

IGARD noted that the identifiability status of the HES APC dataset was missing from section 3(b) (Additional Data Access Requested), and asked that this was updated as appropriate.

IGARD noted that the PSS CQUIN had now concluded, however queried what the yielded benefit of this study were, noting that this was not evident in section 5(d) (Benefits) (iii) (Yielded Benefits). IGARD asked that in line with [NHS Digital DARS Standard for Expected Measurable Benefits](#), section 5(d) (iii) was updated to provide explanation as to what the PSS CQUIN yielded benefits were.

Outcome: unable to recommend for approval

1. *To address previous outstanding IGARD conditions, amendments and advice from the IGARD meeting on the 6th February 2020.
2. To update section 1 to ensure **all** previous IGARD minutes / narrative on SIRO approval etc are included.
3. To insert a special condition in section 6, that, following the signing of the DSA, a detailed annual review was scheduled in twelve-months. The relevant supporting documents should be provided by the applicant to NHS Digital no later than one month prior to the annual review. These documents should be uploaded to NHS Digital's customer relationship management (CRM) system for future reference.
4. To update section 3(b) to include the identifiability status of the HES APC dataset.
5. To update section 5(d) (iii) to provide an explanation as to what the PSS CQUIN yielded benefits were, in line with [NHS Digital DARS Standard for Expected Measurable Benefits](#)

The following advice was given:

1. Noting IGARD's previous advice from the 6th February 2020 in relation to further discussion with industry bodies; IGARD suggested that that the applicant consider a wider discussion with the BMA Consultants Committee UK; for example, to investigate whether the outputs of the research could be used to reduce differential achievement between consultants/widen access to effective social networks so as to improve consultant performance.

2. IGARD suggested that NHS Digital provide a copy of the **full text** of the IGARD minutes **and** outcomes from the meeting on the 6th February 2020.

***IGARD published outcomes from the 6th February 2020:**

Outcome Summary: recommendation to approve subject to the following conditions: (IGARD reserve the right to consult with NHS Digital's Caldicott Guardian on the assessment of the responses to the conditions for this application):

1. To update section 5 throughout to address the potential ethical issues raised in the study by clearly outlining the scope of the research being undertaken and addressing any potential misuse of data outputs or potential use of data for any reasons other than those clearly set out in the application.
2. To (a) provide information about any discussions that may have taken place with any industry body such as the BMA about the potentially sensitive nature of this research and (b) set out a plan for engaging with relevant industry bodies, for example the BMA, to ensure that (i) the perspectives of the Consultants subject to the study are considered and (ii) the outputs of the study are disseminated appropriately.
3. To provide the Medical Research Council application/a copy of the protocol or any other supporting document that was provided as supporting evidence in relation to the MRC funding obtained.
4. To update the Ethics approval section of the application to address this new processing; to provide clear confirmation that Ethics approval was not necessary for this study (including any local/university-based Ethics approval). If, in fact, any form of ethical review was required, to provide evidence of such approval.

The following amendments were requested:

1. To explain the purpose and scope of the study in the abstract and section 5(a) by reference to the helpful explanatory form of wording used in section 5(d) of the application.
2. To consider if an alternative Article 9 legal basis would be more appropriate for the research outlined (e.g. service review of scientific research).
3. To review in line with NHS Digital's fair processing notice check of the applicant's Privacy Notice to ensure the new limb of the study and processing is adequately addressed and to update section 1, plus ensure all links to the privacy notice are functioning.
4. To amend section 5(a) to further outline the purpose of the new research and align with information provided in section 5(d).
5. To provide clarification that the consultant code is for **all** years of data, not just the current year.
6. To provide a further explanation within section 5(b) on the reference to "*targeted and non-targeted consultants*".
7. To update section 1 to provide a more explicit description of the study and align with information provided in section 5(d).

The following advice was given:

1. IGARD suggested that the applicant may wish to consider a wider discussion, for example with the GMC and/or BMA to investigate whether the outputs of the research could be used to reduce differential achievement between consultants/widen access to effective social networks so as to improve consultant performance.

3.4 University of Leeds: Yorkshire Specialist Register of Cancer in Children and Young People (Presenter: Anna Weaver) NIC-11809-H1Y3W-v5.13

Application: This was a renewal application to permit the holding and processing of identifiable Emergency Care Data Set (ECDS), Hospital Episode Statistics Accident and Emergency (HES A&E), HES Admitted Patient Care (APC), HES Outpatients, Mental Health and Learning Disabilities Data Set (MHLDDS), Mental Health Minimum Data Set (MHMDS) and Mental Health Services Data Set (MHSDS).

It was also an amendment application to **1)** remove Iron Mountain as a storage location; **2)** to remove University of York as a storage location; and **3)** to reflect the storage of the data being migrated from the 'Standard Energy Efficient Data' (SEED) platform to LASER platform.

The 'Yorkshire Specialist Register of Cancer in Children and Young People' (YSRCCYP), is a regional population-based register containing detailed, record-level demographic and clinical information on children and young adults aged 0-29 years diagnosed with cancer and benign central nervous system tumours since 1974. The purpose of the YSRCCYP is to facilitate population-based epidemiological and health services research.

The YSRCCYP research team's research plans include the following objectives: **1)** to describe the total burden of physical and mental health hospitalisation among the Yorkshire cancer population aged 0 -29 years, to identify clinical and sociodemographic factors which influence the likelihood of hospitalisation and to investigate how hospitalisation rates have changed since 1997; **2)** to understand patient care pathways through the NHS before, during and after cancer diagnosis. This includes assessment of time to diagnosis for children and young adults diagnosed with cancer under the age of 30 years to identify where improvements can be made to minimise delays in diagnosis leading to better prognosis and less stress and anxiety on patients and their families; **3)** to calculate the risks and costs to the NHS of adverse physical and mental health events requiring hospital admission for survivors of cancer in this age group so that clinicians can provide appropriate follow-up care; **4)** to identify the risks of cardio-metabolic disease in long-term childhood and young adult cancer survivors; **5i)** to identify the impact of cancer treatment on kidney toxicity and mental health, specifically anxiety and depression; **5ii)** An extension of this project is to look in more detail at the impact of cancer treatments on kidney toxicity; and **6)** To provide contextual information on existing physical and mental health morbidity when evaluating educational and employment outcomes.

The study is relying on s251 of the NHS Act 2006, for the flow of data out of NHS Digital.

This application has a sister Data Sharing Agreement (DSA) NIC-155843-0MQMK.

NHS Digital advised IGARD that when the application was initially submitted for review, the Mental Health Service Dataset was not available for dissemination and was therefore not included within the data sharing agreement (DSA). NHS Digital noted that following submission of the application, NHS Digital's Data Access Request Services (DARS) Onboarding Team had confirmed that this product was now available for dissemination. NHS Digital queried whether IGARD would be content to provide a recommendation for this amendment to the application, in addition to the renewal and other amendments as outlined in section 1 (Abstract).

Discussion: IGARD noted that the application and relevant supporting documents had previously been presented at the IGARD meetings on the 13th April 2017 and the 23rd July 2020.

IGARD noted that the application and relevant supporting documents for NIC-155843-0MQMK had previously been presented at the IGARD meetings on the 13th April 2017 and the 30th June 2022.

IGARD noted and commended NHS Digital on the quality of the information within section 1 (Abstract) of the application, for example, how previous points made by IGARD had been addressed; which supported the review of the application by Members.

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

IGARD noted the verbal update from NHS Digital, in respect of the addition of the Mental Health Service Dataset, noting that this had only become available following submission of the application to IGARD for review. IGARD confirmed that they would be supportive of the inclusion of the Mental Health Service Dataset, and asked that section 3(b) (Additional Data Access Requested) was updated as appropriate to reflect the addition of this dataset and the application would not need to return to IGARD for a review for this amendment.

IGARD queried point five of the YSRCCYP research team's objectives "*to identify the impact of cancer treatment...*", and the reference to linkage with the national [Systemic Anti-Cancer Therapy \(SACT\) dataset](#); and noted that this dataset was now collected by the SACT Team within the National Disease Registration Service (NDRS) at NHS Digital. IGARD advised NHS Digital that they would be supportive of the flow of this data, subject to the relevant updates being made to the application in line with [NHS Digital's DARS Standards](#), and the application would **not** need to return to IGARD for a review for this amendment.

IGARD queried the inconsistent cohort numbers referenced in section 3 (Datasets Held / Requested), for example, 8,500 versus 9,000; and asked that these figures were reviewed, and section 3 updated as appropriate to reference the correct figures. In addition, IGARD asked that once the correct cohort figures had been clarified in section 3, the application was updated throughout to ensure the correct cohort number was referenced as appropriate.

IGARD noted the references in section 5(a) (Objective for Processing) to the charity "*Candlelighters Trust*", and asked that this public facing section which forms [NHS Digital's data uses register](#), was updated with a brief description of who they are / what they do etc; and / or a weblink.

IGARD noted the yielded benefits outlined in section 5(d) (Benefits) (iii) (Yielded Benefits) were an exemplar of good practice, however asked that this was updated further to also reflect the benefits to patient care; and the direct impact to patients and their families, in line with [NHS Digital DARS Standard for Expected Measurable Benefits](#).

IGARD suggested that section 5(d) be updated to remove reference to "*it will...*", and instead use a form of words such as "*it is hoped...*".

Outcome: recommendation to approve

The following amendments were requested:

1. To update section 3(b) with the inclusion of the Mental Health Service Dataset (as per the verbal update from NHS Digital).
2. In respect of the cohort numbers:
 - a) To review the cohort numbers referenced in Section 3, and amended if necessary; and,
 - b) To update the application throughout to ensure the correct cohort numbers are referenced as appropriate.

	<ol style="list-style-type: none"> 3. To update section 5(a) with a brief description and / or a weblink to the Candlelighters Trust. 4. In respect of the benefits in section 5(d) and in line with the NHS Digital DARS Standard for Expected Measurable Benefits: <ol style="list-style-type: none"> a) To update section 5(d) (iii) to reflect the benefits to patient care; and, b) To update section 5(d) (iii) to reflect the direct impact to patients and their families. c) To update section 5(d) to use a form of wording such as “<i>it is hoped ...</i>”, rather than “<i>it will...</i>”. <p>The following advice was given:</p> <ol style="list-style-type: none"> 1. Noting that NHS Digital now had the Anti-Cancer Therapy (SACT) dataset available for dissemination, IGARD advised that they would be supportive of the flow of this data, subject to the relevant updates being made to the application in line with NHS Digital's DARS Standards, and the application would not need to return to IGARD for a review for this amendment.
3.5	<p><u>University of Oxford: Health economics analysis for FAME: In younger adults with unstable ankle fractures treated with close contact casting, is ankle function not worse than those treated with surgical intervention? (Presenter: Denise Pine) NIC-595090-W5R3K-v0.10</u></p> <p>Application: This was a new application for pseudonymised Civil Registration (Deaths) data, Hospital Episode Statistics Accident and Emergency (HES A&E), HES Admitted Patient Care (APC), HES Critical Care, HES Outpatients and Emergency Care Data Set (ECDS).</p> <p>The purpose of the application is for the ‘Fractured Ankle Management Evaluation’ (FAME) study, which aims to determine whether ankle function, four months after treatment in patients with unstable ankle fractures treated with close contact casting (an alternative to surgery which uses less padding than a traditional cast and sets the bones by being a close anatomical fit), is not worse, than in those treated with surgical intervention, which is the current standard-of-care.</p> <p>The overarching objective of this study is to investigate the difference in ankle function, the risk of late complications and comparative cost-effectiveness between the trial treatment groups over five years.</p> <p>The objectives that are addressed through this data processing are: 1) to assess the longer-term incidence of complications of the two treatments under investigation; 2) to validate patient-reported hospital healthcare use collected during the trial against data collected from NHS Hospital Episode Statistics; and 3) to assess the longer-term cost-effectiveness of close contact casting (CCC) compared with surgery in the patient population of the trial.</p> <p>The aim is to recruit / consent 890 patients over a 24-month period, from more than 26 hospitals within the UK. Recruitment started in December 2019, and as of July 2022, 580 people have been recruited with recruitment ongoing.</p> <p>Discussion: IGARD noted and commended the applicant on the patient and public involvement and engagement (PPIE) as outlined in section 5(c) (Specific Outputs Expected), noting that it was an exemplar of good practice capturing key outputs, despite PPIE not being part of the NHS Digital DARS Standards.</p> <p>IGARD noted that the Principal Investigator was an employee of the Queen Mary University of London (QMUL) and appeared to hold an honorary contract with the University of Oxford; and asked that for transparency, section 1 (Abstract) and section 5 (Purpose / Methods / Outputs) were updated with further details of the honorary contract for the Principal Investigator; and,</p>

that any relevant documentation relating to the honorary contract for the Principal Investigator was uploaded to NHS Digital's customer relationships management (CRM) system for future reference.

IGARD noted the cohort size referenced in the application, and queried if this figure reflected those cohort members who had withdrawn consent as outlined in section 1; and asked that the figure stated was reviewed and the application was updated as appropriate to reflect the correct cohort number.

IGARD noted that the age range of the cohort studied was 18 to 60 years; and that although there was further information within the protocol provided as a supporting document, as to why this age range had been determined, the application was silent on this. IGARD therefore asked that for transparency, the public facing section 5(a) (Objective for Processing) which forms [NHS Digital's data uses register](#), was updated with a justification of the age range 18 to 60 years studied; in line with [NHS Digital DARS Standard for Objective for Processing](#).

IGARD noted the video on the study website relating to consultee advice; and suggested that NHS Digital checked with the applicant to clarify whether or not any cohort members had been included in the study via consultee advice. IGARD also suggested that in line with [NHS Digital DARS Standard for Special Conditions](#), NHS Digital insert a special condition in section 6 (Special Conditions), to clarify that the inclusion of any cohort members via consultee advice would require an amendment to the DSA.

IGARD noted the references in section 5(c) and section 5(d) (Benefits) to "*non-complex fractures*"; and noting that section 5(a) was silent on this, asked that for ease of reference, a brief explanation was added of non-complex fractures, in line with [NHS Digital DARS Standard for Objective for Processing](#).

IGARD queried the paragraph in section 5(b) (Processing Activities) that stated "...*non-parametric bootstrap estimation*...", and asked that this was simplified in a manner suitable for a lay audience; in line with [NHS Digital DARS Standard for processing activities](#).

Outcome: recommendation to approve

The following amendments were requested:

1. In respect of the Principal Investigator:
 - a) To update section 1 with further details of the honorary contract for the Principal Investigator; and,
 - b) To update section 5 with further details of the honorary contract for the Principal Investigator; and,
 - c) To add any relevant documentation relating to the honorary contract for the Principal Investigator to NHS Digital's CRM system for future reference.
2. To update section 5 to review and update the cohort size as necessary.
3. To provide a justification in section 5(a) of the age range 18-60 studied (referred to in the protocol).
4. To provide a brief explanation in section 5(a) of "*non-complex fractures*".
5. To amend section 5(b) to simplify the paragraph "...*non-parametric bootstrap estimation*...".

The following advice was given:

1. In respect of consultee advice:
 - a) Noting the video on the study website relating to consultee advice, IGARD suggested that NHS Digital checked with the applicant to clarify whether or not any cohort members had been included in the study via consultee advice; and,

	<p>b) IGARD suggested that NHS Digital insert a special condition in section 6, to clarify that the inclusion of any cohort members via consultee advice would require an amendment to the DSA.</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.</p> <ul style="list-style-type: none"> <p>NIC-159576-C0V1M-V2.5 - University College London (Precedent: extension & renewal)</p> <p>IGARD noted in section 1 (Abstract) reference to "...this is an APMS application and does not require IGARD approval..." and reminded NHS Digital that IGARD provide "recommendations". IGARD reminded NHS Digital that APMS applications do require review, in line with the agreed APMS precedent, which may indicate IGARD review.</p> <p>IGARD noted the APMS precedent had gone live in February 2022 and that a further training event with DARS staff had taken place in May 2022, and remained unclear why applications were proceeding under the wrong precedent.</p> <p>IGARD noted that section 5(d)(iii) (Yielded Benefits) had not been updated in line with the published NHS Digital DARS Standard for expected measurable benefits, with the exception of reference to one research paper, which was an output, not a yielded benefit.</p> <p>IGARD noted that section 6 (special conditions) did not mention the agreed special condition with regard to the annual confirmation report, noting this was a 3-year DSA extension, and asked that this be inserted in section 6. IGARD advised that NHS Digital should ensure consistency across all DARS DSAs in relation to the annual confirmation report.</p> <p>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 use of sensitive data, lack of yielded benefits and the application had proceeded down the incorrect precedent route.</p> <p>NIC-195377-M9L8Z-V2.6 - The Nuffield Trust (Precedent: extension & renewal)</p> <p>IGARD members noted the benefits in section 5(d)(iii) (Yielded Benefits) were good examples and suggested that this section of the application be used as an exemplar or as part of learning and development of DARS / Digi-Trials / DSfC staff.</p> <p>IGARD noted that section 6 (special conditions) did not mention the agreed special condition with regard to the annual confirmation report, noting this was a 3-year DSA extension, and asked that this be inserted in section 6. IGARD advised that NHS Digital should ensure consistency across all DARS DSAs in relation to the annual confirmation report.</p>

IGARD noted that section 1 (Abstract) did not contain the full approvals history, and reiterated previous comments that section 1 should provide the history of the application to date in order to support oversight & assurance, and the Director / IAO signing off under precedent.

IGARD noted that section 1 stated “*under this agreement, the Nuffield Trust no longer require access to data before 2016/17*” and that the data had been removed from section 3(a) (data access already given), however this had not been done, noting that this data also appeared in section 3(b) (additional data sets requested). IGARD noted that section 5 (purpose / methods / outputs) still referred to the analysis of data from 2016 onwards, which was incorrect if the Nuffield Trust no longer required access to data from 2016/17.

IGARD reiterated previous comments that section 1 should include relevant narrative to support the oversight and assurance, and the Director / IAO signing off under precedent.

- **NIC-268750-B3T4W-v1.4 - University of Bristol (Precedent: extension & renewal)**

IGARD noted that section 1 (Abstract) narrative was unclear if the points to note on page 2 related to this version of the DSA or the previous version of the DSA, since they sat below a previous IGARD outcome. IGARD reiterated previous comments that section 1 should include relevant narrative to support the oversight and assurance, and the Director / IAO signing off under precedent.

IGARD noted that when the application had last had an independent review on the 10th October 2019, IGARD advised: “*IGARD suggested that the applicant may wish to consider (if they haven’t already) the level of PPI currently, and in the future, which may take the form of membership of steering groups or other such initiatives to involve the community*”. IGARD noted that there appeared to have been no update either in section 1 (Abstract) or section 5 (purpose / methods / outputs).

IGARD noted on renewal, extension or amendment they would expect to see narrative in section 1 and section 5 of the development of PPIE activities.

- **NIC-33318-X4Q1B-v5.3 - University of Manchester (Precedent: extension & renewal)**

IGARD noted that section 1 (Abstract) did not contain the full approvals history for example section 1 did not reference that the application had been reviewed as part of oversight and assurance on the 5th December 2019, and reiterated previous comments that section 1 should provide the history of the application to date in order to support oversight & assurance, and the Director / IAO signing off under precedent.

IGARD noted that section 1 narrative was unclear as to why the DSA had been extended and simply stated that they “*wanted more data*” and suggested that a clear justification be included in section 1 and section 5 (purpose / methods / outputs). IGARD reiterated previous comments that section 1 should include relevant narrative to support the oversight and assurance, and the Director / IAO signing off under precedent.

- **NIC-147867-D8128-v4.5 - University of Aberdeen (Precedent: extension & renewal / DSA simple amendment)**

IGARD reiterated previous comments that cancer registration data is personal data.

IGARD were of the opinion that the precedent had not been applied appropriately.

IGARD noted that section 1 (Abstract) narrative was unclear as to why the DSA had been given a 3-year agreement when there were clear issues around security, data destruction and the privacy notice, amongst other things. IGARD reiterated previous comments that

section 1 should include relevant narrative to support the oversight and assurance, but also the Director / IAO signing off under precedent.

IGARD noted that section 1 noted that a previous special condition with regard to data destruction had not been satisfied, and queried if this was a breach of the DSA, noting that section 1 stated that the data would be destroyed by April 2022, but IGARD were unclear if this had been undertaken and NHS Digital were unable to provide clarity in-meeting.

IGARD noted that section 1 noted that the DSPT was still be reviewed “as at 31/01/22” and that no previous versions had been reviewed by NHS Digital, noting that the statement in section 1 was undated and so IGARD were unclear if the DSPT was now in place. NHS Digital were unable to provide clarity in-meeting.

IGARD noted that section 1 noted that the Data Controller had not published a privacy notice. IGARD noted that they had looked for a privacy notice this week, and had been unable to find an accessible one.

IGARD noted in section 1 that an audit had been conducted; however the details of the outcome were not included in the abstract nor as a supporting document.

IGARD noted that there was no ethics in place, and it was not clear if the applicant had ever sought ethical approval.

IGARD noted in section 3(c) (patient objections) issues noted by NHS Digital with regard to consent which stated “*there is no evidence that participants have given informed consent for their data to be processed by NHS Digital for the purpose of this study*”.

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 security, transparency, ethics, consent and recent audit.

- **NIC-233512-B7C4W-v3.5 - NEC Software Solutions UK Ltd (Precedent: extension & renewal / DSA simple amendment)**

IGARD members noted that section 1 (Abstract) was an exemplar of good practice (clear narrative, history of approvals, history of amendments made, how the precedent had been met etc) and could be used by NHS Digital as part of learning and development of DARS / Digi-Trials / DSfC staff.

- **NIC-368020-R5L2K-v10.2 - Telstra Health UK (Precedent: extension & renewal / addition of a processor / storage or processing location change / DSA simple amendment)**

IGARD noted that in NIC-368020-R5L2K and NIC-392201-S6C3W as part of oversight and assurance today, that the company had been described in two completely different ways.

IGARD noted that section 1 (Abstract) did not contain the full approvals history for example section 1 did not reference that the application had been reviewed as part of oversight and assurance on the 11th November 2021, where IGARD had specifically noted that this application was not suitable for the precedent route and should return to IGARD on renewal, amendment or extension. IGARD reiterated previous comments that section 1 should provide the history of the application to date in order to support oversight & assurance, but also the Director / IAO signing off under precedent.

IGARD reiterated points made at the 11th November 2021 meeting, namely: “*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 SIRO Precedent, due to the fact that there was no update with regard to the audit that was underway when last reviewed by IGARD in 2019, the Yielded Benefits were not in line with the NHS Digital DARS Standard for Expected Measurable Benefits and there was no evidence in the application of due diligence having been undertaken on Telstra Health who acquired Dr Foster Limited in 2015. IGARD also noted that this narrative also applied to all current active Dr Foster Limited / Telstra Health UK limited DSAs."

IGARD noted reference in section 1 to Doctor Foster "*changing its name*" to Telstra Health UK limited and suggested that this was factually incorrect, and that the narrative be updated to correctly note that Doctor Foster was acquired by and wholly owned by an offshore Australian company. IGARD noted that it appeared that appropriate due diligence had **not** been undertaken, for example by inserting relevant special conditions that augment the existing territory of use restrictions and that data cannot be shared within the group of companies.

IGARD suggested that NHS Digital may wish to consider auditing this organisation in relation to all DSA's held.

IGARD noted that the application had updated wording from "*working with Dr Foster*" to "*working with Telstra*" and that this use of phrasing was inappropriate since it referred to a date when the relevant party was Dr Foster.

- **NIC-242486-R1G4D-v1.3 – University of Sheffield (class action: risk assessed DSA extension)**

IGARD noted in section 1 (Abstract) reference to "...*this is an APMS application and does not require IGARD approval...*" and reminded NHS Digital that IGARD provide "*recommendations*". IGARD reminded NHS Digital that APMS applications **do** require review, in line with the agreed APMS precedent, which may indicate IGARD review.

IGARD noted the APMS precedent had gone live in February 2022 and that a further training event with DARS staff had taken place in May 2022, and remained unclear why applications were proceeding under the wrong precedent.

IGARD reiterated that they had still **not** seen the risk matrix and scoring, and which had not been included as a supporting document because it had not been labelled as an "*SD*".

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 in line with the APMS scoring matrix.

- **NIC-366216-Z9H9Q-v5.3 - University of Sheffield (class action – risk assessed DSA extension)**

IGARD reiterated that they had still **not** seen the risk matrix and scoring, and which had not been included as a supporting document (SD) because it had not been labelled as an "*SD*".

- **NIC-392201-S6C3W-V3.6 – Telstra UK Ltd (Precedent: addition of processor)**

IGARD noted that in NIC-368020-R5L2K and NIC-392201-S6C3W as part of oversight and assurance today, that the company had been described in two completely different ways.

	<p>IGARD noted that section 1 (Abstract) did not contain the full approvals history for example section 1 did not reference that the application had been reviewed as part of oversight and assurance on the 11th November 2021 where IGARD had specifically noted that this application was not suitable for the precedent route and should return to IGARD on renewal, amendment or extension. IGARD reiterated previous comments that section 1 should provide the history of the application to date in order to support oversight & assurance, but also the Director / IAO signing off under precedent.</p> <p>IGARD reiterated points made at the 11th November 2021 meeting with regard to NIC-368020-R5L2K which now applied to this DSA, namely: <i>“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 SIRO Precedent, due to the fact that there was no update with regard to the audit that was underway when last reviewed by IGARD in 2019, the Yielded Benefits were not in line with the NHS Digital DARS Standard for Expected Measurable Benefits and there was no evidence in the application of due diligence having been undertaken on Telstra Health who acquired Dr Foster Limited in 2015. IGARD also noted that this narrative also applied to all current active Dr Foster Limited / Telstra Health UK limited DSAs.”</i></p> <p>IGARD noted reference in section 1 to Doctor Foster <i>“changing its name”</i> to Telstra Health UK limited and suggested that this was factually incorrect, and that the narrative be updated to correctly note that Doctor Foster was acquired by and wholly owned by an offshore Australian company. IGARD noted that it appeared that appropriate due diligence had not been undertaken, for example by inserting relevant special conditions that augment the existing territory of use restrictions and that data cannot be shared within the group of companies.</p> <p>IGARD suggested that NHS Digital may wish to consider auditing this organisation in relation to all DSA’s held.</p> <p>IGARD noted that the application had updated wording from <i>“working with Dr Foster”</i> to <i>“working with Telstra”</i> and that this use of phrasing was inappropriate since it referred to a date when the relevant party was Dr Foster.</p> <p>The NHS Digital SIRO was currently reviewing the feedback provided on the IG release registers by IGARD for the period March 2020 to May 2022, alongside the process of review, and as discussed on the 11th August 2022, would come back to IGARD in due course with any feedback or response.</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. IGARD noted that May 2022 appeared to be outstanding, following them returning their comments on the May 2022 release register on 1st July 2022.</p>
6	<p><u>COVID-19 update</u></p> <p><i>No items discussed</i></p>

<p>7</p> <p>7.1</p>	<p><u>AOB:</u></p> <p><u>Head of Data Access Update (Liz Gaffney)</u></p> <p>The Head of Data Access attended (part of) the meeting as part of her regular catch-up with IGARD.</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>
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Appendix A

Independent Group Advising on Releases of Data (IGARD): Out of committee report 23/09/22

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)
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