Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held via videoconference 20 May 2021

IGARD MEMBERS IN ATTENDANCE:	
Name:	**Position:**
Paul Affleck	Specialist Ethics Member
Maria Clark	Lay Member / IGARD Alternate Deputy Lay Chair
Kirsty Irvine (Chair)	IGARD Chair / Lay Representative
Dr. Imran Khan	Specialist GP Member
Dr. Maurice Smith	Specialist GP Member
IGARD MEMBERS NOT IN ATTENDANCE:	
Name:	**Position:**
Prof. Nicola Fear	Specialist Academic Member
Dr. Geoffrey Schrecker	Specialist GP Member / IGARD Deputy Specialist GP Chair
NHS DIGITAL STAFF IN ATTENDANCE:	
Name:	**Team:**
Dave Cronin	Data Access Request Service (DARS)
Chiara Garattini	Data Services Directorate (Item 6.1)
Belinda Garrow	Data Access Request Service (DARS) (Observer: item 3.3)
James Gray	Data Access Request Service (DARS)
Rachel Habergham	Data Services Front Door (Item 6.1)
Dickie Langley	Privacy, Transparency and Ethics (PTE)
Karen Myers	IGARD Secretariat
Denise Pine	Data Access Request Service (DARS) (Observer: item 3.1)
Charlotte Skinner	Data Access Request Service (DARS)
Vicki Williams	IGARD Secretariat
Anna Weaver	Data Access Request Service (DARS) (Observer: item 3.1)

1	**Declaration of interests:**

	Dr Maurice Smith declared an interest in item 3.5 in that he is a personal friend of Dr Joel Sanderson (a member of the North West - Greater Manchester South Research Ethics Committee on 8 June 2017) although he has had no contact of any kind with Dr Sanderson regarding the REBOA trial either before or since 8 June 2017. **Review of previous minutes and actions:** The minutes of the 13th May 2021 IGARD meeting were reviewed, and subject to a number of minor amendments were agreed as an accurate record of the meeting. **Out of committee recommendations:** An out of committee report was received (see Appendix A).
2	**Briefing Papers**
2.1	<u>COVID-19 Ethnic Category Data Set – Final Briefing Paper</u> The briefing paper presented on the **6th May 2021**, was to inform IGARD about a small stand-alone data set known as the COVID-19 Ethnic Category Data Set. The data set will be made available for secondary uses in other areas where data relating to ethnic category is useful for the purposes of COVID-19 planning and research. Following comments made by IGARD at the meeting, the presenter made the relevant amendments to the briefing paper, and this was circulated to members out of committee by the IGARD Secretariat. IGARD welcomed the updated briefing paper and made no further comments. IGARD looked forward to receiving this finalised briefing paper as a supporting document, alongside a first of type application.
2.2	<u>Use of consultee lawful basis – Briefing Paper (Presenter: Louise Dunn)</u> Due to the volume and complexity of applications at today's meeting, IGARD and NHS Digital were unable to discuss the briefing paper, and it was agreed that this would be discussed at the IGARD – NHS Digital COVID-19 Response Meeting, on Tuesday 25th May 2021.
3	**Data Applications**
3.1	<u>Imperial College London (ICL): COSMOS: Cohort Study of mobile phone use and health (MR1367) (Presenter: Dave Cronin) NIC-370843-R6V8T-v2.4</u> **Application:** This was an extension and renewal application for identifiable Cancer Registration Data, Demographics data, Emergency Care Data Set (ECDS), Medical Research Information Service (MRIS) data, Hospital Episode Statistics (HES) Accident and Emergency (A&E), HES Admitted Patient Care, HES Critical Care, HES Outpatients and Civil Registration (death) data. The applicants also wish to share pseudonymised data with the Karolinska Institutet in Sweden for the purpose of a pooled analysis. The purpose is for a major international research programme (COSMOS Study) into the possible health effects of long-term use of mobile phones and wireless technologies, and other environmental exposures, in particular addressing limitations of previous studies and gaps in the scientific evidence in order to provide clarity in respect of health effects of long-term use of mobile phones. The cohort consists of approximately 105,000 adult participants in the UK, who were invited to participate in the COSMOS study from mobile phone subscriber lists, data marketing lists and

	electoral register lists, and who consented to participate in the COSMOS study between 2009 and 2012. NHS Digital advised IGARD that following the last review of the application on the 5th March 2020, where IGARD had deferred making a recommendation, that NHS Digital had put a short-term extension in place, permitting retention of the data for a limited period while the applicants addressed the feedback from IGARD. NHS Digital noted that the short-term extension had now expired, and there were ongoing discussions with the applicant, in relation to data controllership. NHS Digital noted that Imperial College London (ICL) had confirmed that, as they were responsible for the UK study, it was their view that they were the sole Data Controller. NHS Digital advised that, in light of other information provided, for example, the role of the international consortium (as outlined in the application and the protocol), and the ICO's definition of a Data Controller, there were ongoing discussions with the applicant in relation the data controllership. **Discussion:** IGARD welcomed the application which came for advice on the data controllership and without prejudice to any additional issues that may arise when the application is fully reviewed. IGARD also noted the importance of the research. IGARD noted that the application had previously been considered on the 5th March 2020, where IGARD had deferred pending a number of points that were raised; however noting that this application was for advice on the data controllership only, IGARD advised that the deferral points would be discussed when the application returned for a full review. An IGARD member advised that they had made some written notes in relation to the application content, and confirmed that they would be content to share this feedback with NHS Digital out of committee with NHS Digital. IGARD noted the verbal update from NHS Digital, in respect of the latest position with the application, and the overview of the ongoing discussion in relation to the data controllership. IGARD advised that a case could be made for ICL being the sole Data Controller, for the UK study using UK data, however the ICL taking *"responsibility"* did not necessarily equate to sole data controllership, and suggested that the protocol should be reviewed to reflect the facts. NHS Digital noted the complexities of organisations outside of England signing a Data Sharing Framework Contract (DSFC) and IGARD noted that based on the supporting documentation, and the facts available, that the pooled study was a joint endeavour with joint data controllership arrangements; IGARD suggested that NHS Digital should explore, whether, other collaborators could sign a DSFC *"light"* without, for example, the requisite security assurances where collaborators were not receiving data, in order to reduce any cost burden. If this approach was not available, IGARD suggested that instead of the DSFC *"light"*, NHS Digital may instead wish to explore sub-licensing arrangements whereby NHS Digital contracted with the UK based organisation and then any other Data Controllers signed up to sub-licencing with the named Data Controller on the Data Sharing Agreement (DSA). If sub-licensing arrangements was a way forward, IGARD asked that section 5 (Purpose / Methods / Outputs) was duly updated to state that this was a **joint** data controllership arrangement, and that NHS Digital was contracting with the UK based researcher institution only via a DSFC, and the other Data Controllers were being brought in to the contractual arrangement via sub-licensing agreements. IGARD noted that this arrangement would not obviate the need for the joint data controllers to comply with the UK General Data Protection Regulation (GDPR) and EU GDPR requirements for Data Controllers.

	IGARD noted that the applicant's DSA with NHS Digital had expired and, in light of this, it was suggested that NHS Digital may wish to consider a short-term extension, with Imperial College London as the sole Data Controller, to receive UK data for processing in the UK only, while work was undertaken to update the application. **Outcome:** IGARD welcomed the application which came for advice on data controllership and without prejudice to any additional issues that may arise when the application is fully reviewed. 1. IGARD noted that the applicant's Data Sharing Agreement with NHS Digital had expired; in light of this, it was suggested that NHS Digital might wish to consider a short-term extension, with Imperial College London as the sole Data Controller, to receive UK data for processing in the UK only, while work was undertaken to update the application. 2. IGARD noted that a case could be made for ICL being the sole Data Controller for the UK study using UK data, but that the protocol should be revised to reflect the facts, and that taking *"responsibility"* does not equate to sole data controllership. 3. Based on the supporting documentation and facts available, IGARD noted that the pooled study was a joint endeavour and a joint data controller arrangement. NHS Digital should explore with the applicant, whether: a) The applicant and other collaborators, could sign a DSFC *"light"* without, for example, the requisite security assurances where collaborators are not receiving data, in order to reduce any cost burden; or b) sub-licensing arrangements could be used; and section 5 to be duly updated to state that this was joint data controllership, but that NHS Digital was contracting with the UK based researcher institution only, and the other Data Controllers were being brought in to the contractual arrangement via sub-licensing. This arrangement would not obviate the need for the joint data controllers to comply with GDPR requirements for controllers.
3.2	<u>University College London (UCL): Centre for Longitudinal Studies (CLS) Next Steps Data Linkage: Next Steps Age 25 Study (Presenter: Dave Cronin) NIC-51342-V1M5W-v4.5</u> **Application:** This was an extension and renewal application for Hospital Episode Statistics (HES) Admitted Patient Care (APC), HES Accident and Emergency (A&E), HES Critical Care, HES Outpatients, and Emergency Care Data Set (ECDS) data. It was also an amendment to **1)** authorise a variation of the sublicence agreement to be issued to UCL employees who successfully apply for data access since UCL's Contracts Department is not content to support the use of sublicensing agreements internally within UCL; ***2)** to grant UCL discretion to use a variation of the standard application and approvals process for UCL employees who are members of the CLS team, to authorise access to data for methodological and research work via the UCL Data Safe Heaven where UCL considers it appropriate to fast-track the application; **3)** to update section 3 (Datasets Held / Requested to describe the data as identifiable and to amend the legal basis for dissemination to Health and Social Care Act 2012 – s261(2)(c). The purpose is for the 'Next Steps Age 25 Study' (previously known as the Longitudinal Study of Young People in England (LSYPE)), which began in 2004 and has collected information about the cohort's education and employment, economic circumstances, family life, physical and emotional health and wellbeing, social participation and attitudes. Following the group into adulthood will improve understanding of how experiences as teenagers affect later life and to evaluate the success of policies aimed at this group of young adults.

	The cohort consist of 4,941 participants who provided consent, during the 2015/16 study survey, for their health data to be linked to the data collected in the study. NHS Digital noted that this application was linked to two other applications (NIC-49297-Q7G1Q and NIC-49826-T0J7C), and that although IGARD had previously requested the three applications returned together, NHS Digital were bringing this application for review first, and that comments / updates from the discussion would feed into the other two applications before they were also brought for review. NHS Digital noted that prior to the meeting, IGARD had raised a query in relation to the UK Data Service (UKDS) and whether they had been consulted on the proposed access process changes. In addition, IGARD had queried whether the proposed changes were compatible with the participation information materials, noting that supporting document 3.0, the participation information sheet, stated "*Researchers who want to use the matched data must be registered with the UK Data Service*", and advised that could imply that all applications would involve the UKDS. In light of this query, NHS Digital advised that further discussions with the applicant were required and confirmed that ***amendment 2 would therefore be withdrawn** from this review. **Discussion:** IGARD noted that this application had been previously seen by the IGARD – NHS Digital COVID-19 Response meeting on the 29th September 2020. IGARD confirmed that they were of the view that the **most recent** consent materials provided the appropriate legal gateway and were broadly compatible with the processing outlined in the application. IGARD noted the verbal update from NHS Digital, in relation to amendment 2, and the subsequent withdrawal of this, in light of the queries raised by IGARD prior to the meeting. IGARD also suggested that, in respect of amendment 2, the applicant may wish to consider formulating a robust use case which outlined the circumstances as to when a fast-track route may be required as a proportionate and appropriate response. IGARD suggested that once a robust use case has been established, the transparency materials to the cohort were updated, to include, but not limited to, the patient information leaflet (PIL) in reference to access measures and assurance, and the update of the out of data protection legislation referred to, for example, *"DPA 1998"*. IGARD noted amendments 1 and 3 and confirmed that they were supportive and had no further comments to make. IGARD queried the benefits outlined in section 5(d) (Benefits), and noted that some of the information provided were outputs, and asked that section 5(d) was updated to remove any outputs and that these were moved to correctly sit in section 5(c) (Specific Outputs Expected); and that section 5(d) should be updated to expand on the ***benefits*** accruing directly to the patients and / or health and social care, in line with NHS Digital's DARS Standard for Expected Measurable Benefits. IGARD queried the information in section 3(c) (Patient Objections), in respect of patient objections, that stated they would apply, and asked that this was updated to accurately reflect that patient objections **will not** apply in light of the legal basis being consent. IGARD noted the reference in section 5 (Purpose / Methods / Outputs) to *"lifestyle choices"*, and noting that not all "*lifestyle choices*" are in fact 'choices', asked that, as section 5 formed NHS Digital's public data release register, this was updated to a different form of words, for example, social or economic determinations of health.

	IGARD suggested that section 5 be updated to remove reference to "*it will*…" and instead use a form of words such as "*it is expected"* or *"it is hoped …".* **Outcome:** recommendation to approve amendments 1 and 3 only, noting amendment 2 was withdrawn by the presenter. 1. To remove any specific outputs from section 5(d) and move to section 5(c). 2. To update section 5(d) to provide further details of the ***benefits*** accruing to patients and/or health and social care. 3. To update section 3(c) to accurately reflect that patient objections **will not** apply. 4. As section 5 forms NHS Digital's public data release register, to update reference in section 5 to *"lifestyle choices"* to another form of wording, since they may not be *"choices"*, for example, social or economic determinations of health. 5. To update section 5 to use a form of wording such as "*it is expected"* or *"it is hoped …"*, rather than "*it will…*". The following advice was given: 1. IGARD noted the verbal update from NHS Digital, in respect of amendment 2 being withdrawn, and suggested that the applicant may wish to consider formulating a robust use case which outlines the circumstances as to when a fast-track route may be required as a proportionate and appropriate response. Once a robust use case has been established, IGARD suggested that the transparency materials to the cohort were updated, to include (but not limited to) the PIL in reference to access measures and assurance, and the update of the out of data protection legislation referred to, for example, *"DPA 1998"*.
3.3	<u>University College London (UCL): MR104a - Regional Heart Study (Female Cohort) (Presenter: Dave Cronin) NIC-148101-R7RSL-v5.8</u> **Application:** This was a renewal and extension application for identifiable Medical Research Information Service (MRIS) data, Cancer Registration data, Civil Registration (Deaths) data and Demographics data; and amendment to 1) update section 5 (Purpose / Methods / Outputs) to reflect the data sharing standards and to permit processing by UCL for the purposes and in the manner described; 2) to update section 5 to reflect that there will be no onward sharing of data. The purpose is for the continued follow-up of the British Women's Heart and Health Study (BWHHS), which is a prospective cohort study of cardiovascular disease in women aged over 60 years, in England, Scotland and Wales. The study was set up in 1999 to complement the British Regional Heart Study (BRHS), to describe and establish risk factors and the differences in their impact in women compared to the men followed up by the British Regional Heart Study (BRHS). The cohort consisted of participants who had provided informed consent for the processing of their data. The application was been previously considered on the 1st March 2018, when IGARD had been unable to recommended for approval pending: the consent materials did not appear to provide a legal basis on which to continue to process data; section 5 of the application to be updated to explicitly state that there is sublicensing, and NHS Digital should work with the applicant to implement an appropriate sub-licencing model; confirmation that both University of Bristol and London School of Hygiene and Tropical Medicine have destroyed previously held data; the title of the application and content of the application do not match in terms of the relevant study and section 5 of the application should clearly explain which study the data is requested for; the list

	of Approved Researchers in section 9 should be updated to reflect the supporting documentation provided and to take into account the fact that the approved research status for one individual has expired. NHS Digital advised that application NIC-174486-Q8J1B (item 3.4) that had also been submitted to IGARD for review, and was for the same study, but the legal basis for processing the data was s251 of the 2006 NHS Act. NHS Digital confirmed that following submission of the papers for review, application NIC-174486-Q8J1B had been withdrawn, due to a number of queries that were outstanding, for example, in terms of the s251 support and the processing it permitted. NHS Digital also advised IGARD that the applicant had reported they still held data for 3,010 individuals who had been invited to participate but did not take part. This data had been held for approximately 20 years. NHS Digital noted that UCL had committed to destroying the data and providing a certificate of data destruction; and that this requirement would be added as a special condition in section 6 (Special Conditions). **Discussion:** IGARD welcomed the application and noted the importance of the study into women's heart health. IGARD noted that the application had been updated to reflect most of the comments previously made. IGARD confirmed that they were of the view that the **most recent** consent materials provided the appropriate legal gateway and was broadly compatible with the processing outlined in the application. IGARD also noted and commended the transparency of the information available on the study website, which also included a clear explanation of the roles and responsibilities of the individuals involved. IGARD noted that supporting document 4.6, the draft 2021 newsletter, had been provided, and advised that they were supportive of the content and suggested that this was sent to cohort members as planned. IGARD noted the verbal update from NHS Digital, in respect of application NIC-174486-Q8J1B and the withdrawal of this application from the agenda. NHS Digital noted the verbal updated from NHS Digital in respect of the patient data that had been held without consent for a number of years. Noting the serious nature of this incident, IGARD suggested that if steps had not already been taken to do so, that the applicant should report this to the UCL Data Protection Officer (DPO), who could then consider whether this should be self-reported to the Information Commissioner's Office (ICO), their ethics committee and any other relevant body. IGARD queried the various cohort figures stated within section 5(a) (Objective for Processing), and noting that it was not clear what each figure related to, asked that for transparency this was updated with further clarity on the cohort numbers and what each figure meant. IGARD also queried if the cohort numbers stated in section 5(a) included only the English cohort members, for example, do the figures also contain the Welsh and Scottish participants; and asked that further clarity was provided in section 5(a). Noting that some of the cohort members were covered under s251 of the NHS Act 2006, IGARD asked that confirmation was provided in section 5(a), that cohort numbers stated **only** included the consented cohort members.

	IGARD noted the references in section 5 to *"type 2 patient objections"* and *"opt out rights"* and asked that if the cohort numbers stated in section 5 **only** included the consented cohort members, that those references were removed, as they were not relevant. IGARD queried the reference to *"LAUNCHES QI team"* in section 5(b) (Processing Activities) and noting that it was not clear what this was, asked that the reference was updated with a further supportive explanation. IGARD noted a number of acronyms and technical terms in section 5 and since this forms NHS Digital's public data release register, asked that this public facing section be updated to ensure that all acronyms upon first use were expanded and clearly defined with a supportive explanation, for example, *"PCSK9 inhibitors"* within section 5(d) (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 expected"* or *"it is hoped …".* IGARD noted the yielded benefits in section 5(d) (iii) (Yielded Benefits) and asked that further details were provided of the specific yielded benefits accrued to date, and asked that it was clear as to the benefits to both the patients and the health and social care system more generally and in line with NHS Digital's DARS Standard for Expected Measurable Benefits. IGARD suggested that NHS Digital may wish to consider auditing this organisation in relation to this application / Data Sharing Agreement in light of the history, namely sharing data with third-party recipients and the retention of patient data without a legal basis. 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 light of the previous handling of patient data and sharing with third parties. **Outcome:** recommendation to approve for the consented cohort only. The following amendments were requested: 1. In respect of the cohort numbers: a) To update section 5(a) with further clarity on the cohort numbers and what each figure means. b) To provide clarification in section 5(a) as to whether the cohort numbers include **only** the English cohort members. c) To confirm if the cohort numbers stated in section 5(a) **only** include the consented cohort members. 2. If the cohort numbers stated only include the consented cohort members, to update section 5 to remove references to *"type 2 patient objections"* and *"opt out rights"*, as this is not relevant. 3. To update the reference to *"LAUNCHES QI team"* in section 5(b) with a further supportive explanation. 4. In respect of the benefits: a) As section 5 forms NHS Digital's public data release register, to amend section 5(d) to ensure acronyms be defined upon first use, and technical terms such as *"PCSK9 inhibitors"* are explained. b) To update section 5(d) to use a form of wording such as "*it is expected"* or *"it is hoped …"*, rather than "*it will…*". c) To provide further details in section 5(d) of the yielded benefits accrued to date and ensure these are clear as to the benefits to both patients and the health care system more generally.

	The following advice was given: 1. IGARD noted the verbal update from NHS Digital, in respect of the discovery of patient data that had been held without consent for a number of years. IGARD suggested that if steps had not already been taken to do so, that the applicant report this to the UCL DPO, who could then consider whether this should be self-reported to the ICO, the study's ethics committee and any other relevant bodies. 2. IGARD suggested that NHS Digital may wish to consider auditing this organisation in relation to this application / Data Sharing Agreement in light of the history, namely, the third-party recipients and the retention of the patient data without a legal basis. 3. IGARD advised that they would wish to review this application when it comes up for renewal, extension or amendment, in light of the previous handling of patient data and sharing with third parties. 4. IGARD suggested that this application would not be suitable for NHS Digital's Precedent route, including the SIRO Precedent, in light of the abovementioned concerns.
3.4	University College London (UCL): MR104C - British Women's Heart and Health Study (s251 cohort) (Presenter: Dave Cronin) NIC-174486-Q8J1B-v3.4 **Outcome:** The application was withdrawn by presenter.
3.5	University of Aberdeen: UK Resuscitative Endovascular Balloon Occlusion of the Aorta (UK-REBOA) study (Presenter: James Gray) NIC-196211-N2W0D-v0.19 **Application:** This was a new application for Hospital Episode Statistics (HES) Admitted Patient Care (APC), HES Critical Care data, HES Outpatients data, Civil Registration (death) data, and Emergency Care Data Set (ECDS). The data is required in two disseminations, one immediately after the Data Sharing Agreement (DSA) is signed, and one when recruitment has completed. The leading cause of preventable death following injury is uncontrolled bleeding (haemorrhage), which usually requires immediate surgery; if bleeding can be controlled quickly, patients often recover, however, some patients die before they can reach an operating theatre. REBOA involves passing a small inflatable balloon into the aorta (the main artery) to stop the bleeding until a patient can be taken to an operating theatre. The UK-REBOA study aims to compare a control arm of the study against REBOA intervention; which comprises standard treatment of patients with life-threatening torso haemorrhage, in the setting of a major trauma centre, which includes a rapid, consultant-led assessment. Life-saving interventions such as intubation of the airway, respiratory support, blood product transfusion, and imaging, are directed by protocols and guidelines, and aimed at minimising the time to control of haemorrhage, by surgical or endovascular means. The control arm of the study is designed to mirror standard care for this cohort of patients. The study aims to compare standard major trauma centre care with REBOA versus standard major trauma care alone, in a fair and balanced way. It is expected that approximately 120 patients are expected to consent to join the study across 10 major trauma centres in England, over four years; recruitment commenced on the 1st April 2017 and is still ongoing as of Spring 2021. NHS Digital advised IGARD that in respect of obtaining consent for those members of the cohort who did **not** have the capacity to provide it, the proposal was to seek advice from a consultee. NHS Digital confirmed that there had been ongoing discussions with the Caldicott

	Guardian in respect of this, who had advised that this did not provide a sufficient legal basis. In addition, NHS Digital confirmed that s251 had been sought from the Health Research Authority Confidentiality Advisory Group (HRA CAG), however, it was HRA CAG's view that it was not appropriate to rely on s251 support as a legal basis in this situation; and advised that the research provisions of the Mental Capacity Act (MCA) should instead be used. NHS Digital advised that they were currently in the process of discussing this with HRA CAG, to try and resolve and agree a way forward. **Discussion:** 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 13th May 2021 and that as part of this review, IGARD had specifically requested that that they would wish to review this application when it comes up for renewal, extension or amendment. IGARD noted the verbal update from NHS Digital in respect of the legal basis, for those members of the cohort who did **not** have the capacity to provide it, and where an opinion might be sought from the consultee; and that s251 had not been provided as a legal gateway for the processing of this data. IGARD also noted that discussions were ongoing with HRA CAG to find a solution to this ongoing issue; and in light of this, would not be able to provide a recommendation on this particular cohort group. IGARD observed that for any cohort members who had died there would be no NHS Digital flowing, and therefore IGARD would not be required to provide a recommendation for this group. IGARD confirmed that they were of the view that the **most recent** consent materials provided the appropriate legal gateway and was broadly compatible with the processing outlined in the application. IGARD queried the commercial aspect of the application, specifically in relation to the REBOA devices that were being used; and asked that, for transparency, section 5 (Purpose / Methods / Outputs) was updated, with confirmation, that the devices had been purchased on normal arm's-length commercial terms. If however, special provision had been made for supply of the REBOA devices for inclusion in the trial, IGARD asked that section 5 was updated with further details of any special arrangements that may be in place with the device manufacturer; and in line with NHS Digital's DARS Standard for Commercial Purpose. IGARD noted the statement in section 5(a) (Objective for Processing) *"Women known or thought to be pregnant at presentation, children (aged, or believed to be aged 15 or younger) and patients with injuries which are deemed unsurvivable on clinical grounds will be excluded."*; and asked that section 5(a) was updated with a rationale for the excluded patient groups. IGARD noted that section 5(a) appeared to indicate that the University of Aberdeen would be pseudonymising the data and queried why this data was not pseudonymised at source. IGARD asked that section 5 was updated, with confirmation that there was no other way to structure the study in a way that removed the flow of identifiers, for example, following the REBOA SNOMED code, rather than using patient identifiers. IGARD noted that although the trial commended in 2017, data was being requested from an earlier data, for example, 2016; and asked that section 1 (Abstract) and section 5 were updated, with confirmation that the data will **only** flow, from the date of consent; and that the applicant did not wish to obtain any patient data prior to the date of consent. IGARD noted the references within section 5(a) and section 5(d) (Benefits) to the *"cost to the NHS"*, and noting section 5 formed NHS Digital's public data release register, asked that the

	references were amended, and replace with an alternative form of wording, for example, *"cost effective method for improving outcomes for patients"*. IGARD suggested that section 5(d) (Benefits) be updated to remove reference to "*it will*…" and instead use a form of words such as "*it is hoped*…" 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 relation to the consultee cohort. **Outcome:** unable to recommend for approval for those cohort members who did **not** recover capacity after the procedure, and were unable to provide informed consent, and where consultee advice was sought. **Outcome:** A recommendation was not required for those cohort members who had died, because no NHS Digital data was flowing. **Outcome:** recommendation to approve for those cohort members who have provided informed consent. The following amendments were requested: 1. As section 5 forms NHS Digital's public data release register, to amend the references in section 5(a) and section 5(d) to the *"cost to the NHS"*, and replace with an alternative form of wording, for example, *"cost effective method for improving outcomes for patients"*. 2. In respect of the REBOA device: a) To provide confirmation in section 5 that the REBOA devices used have been purchased on normal arm's-length commercial terms; or, b) If special provision has been made for supply of the REBOA device for inclusion in the trial, to update section 5 with further details of any special arrangements that may be in place with the device manufacturer. 3. To update section 5(a) with a rationale for the excluded patient groups, for example, pregnant women and children and young people under the age of 15. 4. To provide confirmation in section 5 that there is no other way to structure the study in a way that removes the flow of identifiers, for example, following the REBOA SNOMED code, rather than using patient identifiers. 5. To provide confirmation in section 1 and section 5, that the data will **only** flow from the date of consent, and that the applicant does not wish to obtain any patient data prior to the date of consent. 6. To update section 5(d) to use a form of wording such as "*it is expected"* or *"it is hoped …"*, rather than "*it will…*". The following advice was given: 1. IGARD advised that they would wish to review this application when it comes up for renewal, extension or amendment, in relation to the consultee cohort. 2. IGARD suggested that this application would not be suitable for NHS Digital's Precedent route, including the SIRO Precedent, in relation to the consultee cohort.
3.6	<u>Health IQ Ltd: Request for ONS linked data for a cohort of patients diagnosed with Beta-thallasaemia and myelodysplasia syndrome between 01/01/2015 to 31/12/2019 (Presenter: Charlotte Skinner) NIC-422044-Z5K5Q-v0.10</u> **Application:** This was a new application for pseudonymised Civil Registration (death) data; for the purpose of a retrospective observational study, between the 1st January 2015 and the 31st

	December 2019, aiming to map out the patients journey, from diagnosis of Beta-thalassaemias, including the treatments received, clinical outcomes, and the associated resource usage using data collected in England. Beta-thalassaemias are a group of hereditary blood disorders characterised by anomalies in the synthesis of part of red blood cells that carries oxygen throughout the body resulting in issues ranging from severe anaemia to other medical conditions. While myelodysplastic syndromes (MDS) are often unrecognised, under-diagnosed rare group of bone marrow failure disorders, where the body no longer makes enough healthy, normal blood cells in the bone marrow, where a risk of progression to acute myeloid leukaemia (AML) exists. Although, the prognosis of individuals with beta-thalassaemia (MSD) has substantially improved in the last couple of decades as a result of advances in treatment methods, there is a gap in the knowledge of what a typical patient journey looks like. The data requested, will be linked to a cohort of 2,890 individuals originally provided in a separate Data Sharing Agreement (DSA) (NIC-15293-R6V2H-v9.5). **Discussion:** IGARD noted and commended NHS Digital on quality of the information provided in section 1 (Abstract), which provides historical and additional background information which supported the review of the application by Members. IGARD noted that Bristol-Myers Squibb had contracted Health IQ Limited to undertake this project on their behalf and queried if Bristol-Myers Squibb was considered a joint Data Controller. NHS Digital advised that following discussion with Health IQ Limited, and internal discussions within NHS Digital, it had been agreed that, in light of the evidence presented, Bristol-Myers Squibb were not considered a joint Data controller. IGARD noted and thanked NHS Digital for the verbal update. IGARD noted the statement in section 5(e) (Is the Purpose of this Application in Anyway Commercial?) that *"…Bristol-Myers Squibb has contracted with Health IQ Limited to undertake this project on their behalf…"*, and noting the verbal update from NHS Digital, suggested that this was removed, to avoid any misinterpretation, for example, in respect of data controllership. IGARD noted the commercial element of the application outlined in section 5(e), and noting that section 5(a) (Objective for Processing) was mainly silent on this, asked that for transparency, section 5(a) was updated with a brief explanation of the commercial arrangements between Bristol-Myers Squibb and Health IQ Limited; and in line with NHS Digital's DARS Standard for Commercial Purpose. IGARD noted within section 5(e) that Health IQ Limited would be selling a report to customer groups, for example, pharmaceuticals, clinical groups etc; and queried the latest percentage breakdown of the commercial and clinical split and asked that section 5(e) was updated to reflect this helpful information. IGARD had a lengthy discussion on the benefits noted in section 5(d), and queried how the benefits would be achieved noting that this was not clear; and asked that in line with NHS Digital's DARS Standard for Expected Measurable Benefits, written confirmation was provided in section 5(d) of how the benefits would be achieved, for example, providing further specific details about which channels of communication would be utilised and how. IGARD noted that Bristol-Myers Squibb were developing a drug that appeared to be directly relevant to the research, and asked that as section 5 (Purpose / Methods / Outputs) formed NHS Digital's public data release register, and for transparency, section 5(d) (Benefits) was

	updated, to reflect this, and if available, that a web link was also added that provided further details; and in line with NHS Digital's DARS Standard for Expected Measurable Benefits. In addition, IGARD queried how the research would benefit the health and social care in England and Wales, and asked that section 5(d) was updated with further clarity, and in line with NHS Digital's DARS Standard for Expected Measurable Benefits. IGARD also queried how the research would benefit the NHS, as this was not clear; and asked that section 5(d) was updated with further clarity, and as per the Department of Health and Social Care (DHSC) guidance. IGARD queried if only Bristol-Myers Squibb would be receiving the outputs of the research, or if Health IQ Limited would also generate other outputs and benefits from the research; and asked that section 5(d) was updated with confirmation. IGARD noted the reference in section 5(c) (Specific Outputs Expected) to reports being produced by July 2021 and queried if this was correct; and asked that both section 5(c) and section 5(d) were updated to reflect the latest dates for the projected outputs and benefits. IGARD noted that Health IQ Limited were described as the funder for the study and queried if this was correct; and asked that this was reviewed, and if relevant the application was updated where necessary, to ensure that the stated funding arrangements reflected the factual scenario. IGARD noted the references throughout the application to *"real-world"* data, and asked that these were removed, as they were not relevant. IGARD queried reference to *"…gender…."* data being requested and asked that the datasets requested in the application aligned with the specific NHS Digital data that can flow, for example 'sex' vs 'gender'. IGARD noted the references within section 5 of the application to managing *"patients"* and noting that this formed NHS Digital's public data release register, asked that this was amended to refer to managing the *"condition"*. IGARD noted a number of acronyms in section 5 and asked that this public facing section be updated to ensure that all acronyms upon first use were expanded and clearly defined with a supportive explanation in a language suitable for a lay reader, for example, *"VPN"*. **Outcome:** recommendation to approve subject to the following condition(s) 1. In respect of the benefits and in line with NHS Digital's Expected Measurable Benefits Standard: a) To provide written confirmation in section 5(d) of how the benefits will be achieved, for example, further specific details about which channels of communication will be utilised and how. b) To clarify in section 5(d) how the research will benefit health and social care in England and Wales (as per NHS Digital's requirements). c) To clarify in section 5(d) if the research will benefit the NHS (as per the DHSC guidance). d) To update section 5(d) to confirm if only Bristol-Myers Squibb will be receiving the outputs of the research, or if Health IQ Ltd will also generate other outputs and benefits from the research. e) To update section 5(c) and section 5(d) to reflect the latest dates for the projected outputs and benefits.

	The following amendments were requested: 1. In respect of the commercial element: a) To update the beginning of section 5(a) with a brief explanation of the commercial arrangements between Bristol-Myers Squibb and Health IQ Ltd. b) To remove the potentially misleading statement in section 5(e) that *"…Bristol-Myers Squibb has contracted with Health IQ to undertake this project on their behalf…"*. c) To update section 5(e) with the latest percentage of the commercial and clinical split. 2. As section 5 forms NHS Digital's public data release register, for transparency, to update section 5(d) to reflect that Bristol-Myers Squibb are developing a drug that appears to be directly relevant to the research (and if available, to add a web link with further details). 3. To update the application throughout to remove references to *"real-world"* data. 4. To update the application where necessary to ensure that the stated funding arrangements reflect the factual scenario. 5. To ensure that the datasets requested align with the specific NHS Digital data that can flow, for example refer to *"sex"* not 'gender', if *"sex"* is what is captured in the dataset. 6. As section 5 forms NHS Digital's public data release register, IGARD asked that the reference to "*managing patients"* was amended to refer to managing the *"condition"*. 7. To amend section 5 to ensure that all acronyms upon first use be defined and further explained if the meaning is not self-evident., for example, *"VPN"*. It was agreed the condition would be approved out of committee (OOC) by IGARD members
4	<u>Returning Applications</u> 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 today's meeting, IGARD were unable to review any applications as part of their oversight and assurance role.
5	<u>COVID-19 update</u> To support NHS Digital's response to COVID-19, from Tuesday 21st April 2020, IGARD will hold a separate weekly meeting, to discuss COVID-19 and The Health Service Control of Patient Information (COPI) Regulations 2002 urgent applications that have been submitted to NHS Digital. Although this is separate to the Thursday IGARD meetings, to ensure transparency of process, a meeting summary of the Tuesday meeting will be captured as part of IGARD's minutes each Thursday and published via the NHS Digital website as per usual process. The ratified action notes from **Tuesday 18th May 2021** can be found attached to these minutes as Appendix B.
6 **6.1**	<u>AOB:</u> <u>New Assurance Model (Presenters: Rachel Habergham / Chiara Garattini)</u> NHS Digital attended IGARD to provide a verbal update on the ongoing work, in respect of the New Assurance Model.

6.2	IGARD noted and thanked NHS Digital for the verbal update and looked forward to receiving further information on this issue at a future IGARD meeting. <u>Information Governance</u> A member of NHS Digital's Privacy, Transparency and Ethics, attended the meeting to provide a brief update / overview of ongoing information governance work. IGARD noted and thanked NHS Digital for the verbal update and looked forward to receiving further updates at a future IGARD meeting. There was no further business raised, the IGARD Chair thanked members and NHS Digital colleagues for their time and closed the meeting.

Appendix A

Independent Group Advising on Releases of Data (IGARD): Out of committee report 14/05/21

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

NIC Reference	Applicant	IGARD meeting date	Recommendation conditions as set at IGARD meeting	IGARD minutes stated that conditions should be agreed by:	Conditions agreed as being met in the updated application by:	Notes of out of committee review (inc. any changes)
NIC-109867-M8S6B	University of Leeds	15/04/2021	1. In respect of the HRA CAG support: a) To provide written confirmation that s251 HRA CAG support is continuing, in light of the time-bound condition 3(a) noted in the HRA CAG letter of support. b) To upload the written confirmation to NHS Digital's CRM system. 2. In respect of the sharing of the subset of the UKWSC dataset with the University of Oxford, to provide written confirmation of how the applicant will ensure that the flow of data will be reviewed so as to satisfy condition 3(a) set by HRA CAG.	IGARD members	Quorum of IGARD members	*"IGARD were content, taking the email correspondence and narrative in its entirety, that the spirit of both the CAG conditions had been satisfied"*

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

Appendix B

Independent Group Advising on the Release of Data (IGARD)

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

held via videoconference, Tuesday, 18th May 2021

In attendance (IGARD Members):	Prof Nicola Fear (IGARD Specialist Academic Member)
	Kirsty Irvine (IGARD Chair / Lay Representative)
	Dr. Imran Khan (IGARD Specialist GP Member)
In attendance (NHS Digital):	Vicky Byrne-Watts (DARS)
	Karen Myers (IGARD Secretariat)
	Andy Rees (DARS)
	Vicki Williams (IGARD Secretariat)

2	**Welcome** The IGARD Chair noted that this was a weekly meeting convened to support NHS Digital's response to the COVID-19 situation and was separate from the IGARD business as usual (BAU) meetings. IGARD members present would only be making comments and observations on items that were presented, and were not making formal recommendations to NHS Digital. Should an application require a full review and recommendation, then it should go through the usual Data Access Request Service (DARS) process and be presented at a Thursday IGARD meeting. The action notes from the Tuesday meeting will be received out of committee and then published alongside the minutes of the next Thursday BAU meeting as an appendix. **Declaration of interests:** Nicola Fear noted she was a participant of the Scientific Pandemic Influenza Group on Behaviours (SPI-B) advising the Scientific Advisory Group for Emergencies (SAGE) on COVID-19
2.1	NIC-456088-R0H0V v0.1 University Hospital Southampton NHS FT **Background**: NHS Digital provided a verbal update with regard to a "permission to contact" application from the University Hospital Southampton NHS Foundation Trust. CovBoost is a trial that is looking at giving boosters to the those in the population aged over 70 or health care workers, a minimum of 3 months after their second dose of either the AstraZeneca or Pfizer vaccination. The Trial is looking to recruit, via the permission to contact registry, around 3,000 participants for 4 to 6 arms. The trial is also looking for participants with well controlled co-morbidities. NHS Digital noted that the Foundation Trust is the Data Controller with NHS Digital as the Data Processor (NHS Digital will contact registry participants directly). The following observations were made on the basis of the verbal update only.

	IGARD Observations: IGARD members noted that due to the nature of the meeting and the fact that they had received no draft application or supporting documents, that should a full review of the application and documentation be required, the full suite of documentation should be presented to a IGARD business as usual (BAU) meeting for a recommendation. IGARD members queried the 4 to 6 arms of the trial and NHS Digital confirmed that each arm of the trial would offer a different booster vaccine, several being unlicenced currently. IGARD Members queried if NHS Digital had had sight of the ethics and consent materials and NHS Digital confirmed they had not. IGARD members noted the importance of ensuring a careful review of the ethics and consent materials to ensure they aligned with the processing outlined in the application and protocol, and that the materials did not preclude the applicant from, for example, receiving further additional datasets, linkage to other datasets, and long term follow up due to the nature of the disease and scientific interest in long-term effects. Noting the language used in this and other applications using the permission to contact register (internal process name), consideration should be given to the external name of the registry: "vaccine registry". Since the vaccine registry was a standalone registry that cannot be linked to any other registry, consideration should be given to its external name, since it could imply that the registry contained all those that had had a vaccine, rather than what the database is; a database of those who have consented to be part of a registry of people who are happy to be contacted about vaccine research. NHS Digital noted that the permission to contact / vaccine registry had just over 488,000 cohort members. IGARD suggested that in due course the language within this and other permission to contact applications should be updated to ensure that section 5, which forms part of NHS Digital's data release register, contained an accurate description of the registry and what it was. IGARD members welcomed the verbal update and noted that due to the urgency of the application that it would be progressed under NHS Digital's SIRO Precedent and were supportive of this approach, assuming full ethical support had been received alongside a review of the consent materials.
2.2	<u>NIC-403158-D1L7V v0.7 University of Leicester</u> **Background:** This was a new application from the University of Leicester who are requesting Civil Registration (Deaths) Data, COVID-19 Hospitalization in England Surveillance System (CHESS), COVID-19 Second Generation Surveillance System (SGSS), COVID-19 UK Non-hospital Antigen Testing Results (pillar 2), Emergency Care Data Set (ECDS), GPES Data for Pandemic Planning and Research (COVID-19) (GDPPR) data, Hospital Episode Statistics (HES) Admitted Patient Care (APC) and HES critical care data, for the UK-REACH study: United Kingdom research Study into Ethnicity and COVID-19 outcomes in Healthcare Workers The United Kingdom Research Study into Ethnicity And COVID-19 outcomes in Healthcare workers (UK-REACH) research project is an Urgent Public Health project funded by the Medical Research Council (MRC)-UK Research and Innovation and National Institute for Health Research (NIHR) rapid response panel to tackle COVID-19. The programme will use existing data held by national healthcare organisations to understand if and why ethnic minority healthcare workers are more susceptible to COVID-19 and poorer outcomes. Specifically, the study for this work package will link human resource, health regulator, and NHS outcomes datasets to assess the relationship between ethnicity and COVID-19

	diagnosis, hospitalisation, and death in people working in health care settings, adjusting for known predictors. The following observations were made on the basis of the draft v0.7 application summary and relevant draft supporting documents. **IGARD Observations:** IGARD members noted that due to the nature of the meeting and when papers were disseminated, they had not conducted a full review of the application and supporting documents provided, noting that not all the supporting documents available had been provided for consideration. Should a full review of the application and documentation be required, the full suite of documentation should be presented to a IGARD business as usual (BAU) meeting for a recommendation. NHS Digital noted that the application and relevant supporting document had been submitted to PAG on the 21st April (see appendix A) who recognised the importance of the work, but did not support the application in its current form. IGARD members noted and agreed with the comments made by PAG, including the importance of the work being undertaken across this and other studies in the same arena, such as NHS CHECK. IGARD members suggested that due diligence by NHS Digital was undertaken to ensure there was not an excessive use of work force data across a number of similar applications and studies. IGARD members were unclear from the application whether all the various professional bodies had been consulted, but noted reference to engagement in the study protocol provided as a supporting document. IGARD advised that care should be taken to ensure that efforts were made to consult the widest spectrum of representative members of the NHS workforce as possible, not just those arms of the NHS with the most prominent advocacy bodies. If there was no formal body with an advocacy role, like the Nursing Midwifery Council(NMC) or the General Medical Council(GMC), consideration could be given to informing relevant unions. It was not clear if the registry data being used was the publicly available information that anyone could download for a fee, or whether the applicant required the next layer of more personal information held in the relevant registries. IGARD suggested further questions were asked about the nature of the registry data and if all aspects of it were truly “publicly available” (as advised by the applicant). IGARD members noted that for those work force members that did not have the support of a national / professional bodies, such as those staff employed by a GP practice not the NHS (for example some Health Care Assistants or Practice Nurses) or those staff who were contractors (for example cleaning staff), that it was important that these key members of staff did not fall through the gaps and that the study was capturing **all** those front line workers, including (for example) porters and cleaners who were all instrumental in the fight against COVID-19 and at risk of exposure to the virus. Conversely, IGARD also supported the data minimisation point raised by PAG that care should be taken not to process the data of staff who were in non-clinical non patient facing roles. IGARD members suggested that NHS Digital seek further guidance on the Electronic Staff Register (ESR) data legal basis and stated that they were not able to provide advice on this aspect, since it would be for the Department of Health and Social Care to confirm the legal basis they are using to share that data with NHS Digital.

	While the application was presented as a pseudonymous flow only, there appeared to be some question of whether confidential data would be handled at any point. Regarding the study teams claim that they could use "public interest" as a way to meet the common law duty of confidentiality, IGARD cautioned that legal advice would need to be sought in light of the fact that patient data was not being handled and that the data would be "confidential" in the broader sense. Similarly, on the basis of the information available, the COPI Regs were not a viable gateway as the workforce registries were not "patient information". IGARD members noted that the research had been "commissioned" and suggested careful consideration be given to whether any bodies commissioning the research could be deemed joint data controllers (as per NHS Digital DARS Standard for Data Controllers). On the face of the facts available, it would appear that the commissioners would be joint data controllers. IGARD members offered their support for this potentially very valuable piece of research and invited the presenter to attend either of the Thursday BAU or Tuesday CV19 Response meetings to continue to work through the issues.
2.3	<u>NIC-240279-Y2V2N v3.6 University of Oxford</u> **Background:** this was an update by NHS Digital to note that the application had been approved under the SIRO precedent. NHS Digital noted that due to the application being, inter alia, "*high profile*" the application had not been prioritised as an application to review at an IGARD business as usual (BAU) meeting and had been progressed via NHS Digital's SIRO precedent. The following observations were made on the basis of the verbal update only, noting that although version 3.6 and relevant supporting documentation had been provided, they had not been reviewed since NHS Digital had informed the meeting that this was an update discussion only. **IGARD Observations:** IGARD members thanked the presenter for the update and transparency of process. It was noted that the application had last undergone a full independent review on the 17th January 2019 and was presented to the COVID-19 response meeting on the 21st April 2020. Since April 2020, the application had proceeded via the SIRO precedent on a number of occasions, despite IGARD comments at the COVID-19 response meeting on 21st April 2020 that "*IGARD members advised they would wish to review this application again when it comes up for renewal, amendment or extension. IGARD members suggested this application would not be suitable for NHS Digital's precedent route*." IGARD members reiterated their previous points that that the application, and by inference any "*spin off*" application (including but not limited to: NIC-382794-T3L3M University of Oxford (at the COVID-19 response meetings on the 12th and 19th January 2021), were not suitable for NHS Digital's precedent route, including SIRO precedent, and that they wished to review this application(s) again when it comes up for renewal, amendment or extension due to the high profile nature and significant effect of data flowing under the application. IGARD members noted that due to the nature of the meeting and when papers were disseminated, they had not conducted a full review of the application and supporting documents provided. Should a full review of the application and documentation be required,

	the full suite of documentation should be presented to a IGARD business as usual (BAU) meeting for a recommendation. IGARD members and Secretariat reiterated the existing procedures in place to allow for urgent review of applications at a BAU meeting with 24 hours-notice. IGARD members expressed concern that an application's status as "*high profile*" was seen as a precluding factor in seeking independent review when the obverse should be the case. IGARD also suggested that section 1 (Abstract) be updated with the most recent IGARD action note outputs, including those from the 21st April 2020 and today's meeting. **Significant risk areas:** the application and supporting documents have not had an independent review since January 2019; the SIRO may have been unaware of the request by IGARD to review the application since the abstract did not have the up to date IGARD outputs from 21st April 2020.
3	<u>AOB</u> There was no further business raised, the IGARD Chair thanked members and NHS Digital colleagues for their time and closed the meeting.

Appendix A

GPES Data for Pandemic Planning and Research - Profession Advisory Group

Record of feedback: Wednesday, 21st April 2021

Application & application version number: DARS-NIC-403158-D1L7V-v0.7 **Organisation name: University of Leicester** **Profession Advisory Group Agenda item: 2**
PAG recognises the importance of understanding the risks of Covid infection and outcomes for keyworkers/healthcare workers. However, the application has areas that require further detail before we can our endorsement. The following need to be addressed: - The applicant states that an important work package was commissioned to investigate the legal and ethical implications to link health care data. PAG would like to see the results of that package. - The description of the dataflows and the linkage process requires more clarity. - The applicant needs to provide more explicit detail on the cohort individuals: the number of individuals expected: whether the applicant would expect include also non-clinical staff who could be working in non-patient facing organisations. What effective data minimisation is occurring so that this study focuses specifically on patient-facing organisations where staff have material risk. PAG do not support this application in its current form.

Attendees	Role	Organisation
Peter Short	Chair, Clinical Lead	NHS Digital
Amir Mehrkar	GP, Clinical Researcher	RCGP
Mark Coley	Deputy IT Policy Lead	BMA
Liz Gaffney	Head of Data Access	NHS Digital
Victoria Byrne-Watts	Case Officer	NHS Digital
Pam Soorma	Secretariat	NHS Digital