

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 30th March 2023

09:30 – 16:20

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser
Maria Clark (MC)	Lay Member Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Vicky Byrne-Watts (VBW)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 5.6) (Observer: item 8.2)
Michael Chapman (MCh)	Data and Analytics representative (not in attendance for items 1, 2, 3, and 6)
Garry Coleman (GC)	Senior Information Risk Owner (SIRO) representative (Presenter: items 8.1 and 9.1) (not in attendance for item 5.2)
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: items 5.2, 5.4 and 5.5)
Louise Dunn (LD)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 5.3) (Presenter: item 8.2)
Dan Goodwin (DG)	Data Access Request Service (DARS) (Presenter: item 5.3 to 5.5)
James Gray (JG)	Digi-Trials (Observer: item 6)
Mathew Jordan (MD)	Data and Analytics (Observer: items 1-7, 8.2, 9.1-9.2)
Tanmai Kalathurvadyer (TK)	Data Access Request Service (DARS) (Observer: item 5.5)

Dickie Langley (DL)	Data Protection Officer (DPO) representative (Delegate for Jon Moore) (not in attendance for items 5.4 – 5.6)
Steve Marks (SM)	Digital and Interoperable Medicines Programme, Transformation Directorate (Observer: item 4.1)
Karen Myers (KM)	Secretariat Team
Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative
Andy Rees (AR)	Digi-Trials (Presenter: item 6)
Jodie Taylor-Brown (JTB)	Data Access Request Service (DARS) (Observer: item 5.4)
Andrew Walsham (AWa)	Digital and Interoperable Medicines Programme, Transformation Directorate (Presenter: item 4.1)
Anna Weaver (AWe)	Data Access Request Service (DARS) (Presenter: item 5.6)
Vicki Williams (VW)	Secretariat Team
Clare Wright (CW)	Data Access Request Service (DARS) (Presenter: item 5.2)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Dr Arjun Dhillon (AD)	Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)
Jon Moore (JM)	Data Protection Officer (interim)

1	<p>Welcome and Introductions</p> <p>The NHS England Senior Information Risk Owner (SIRO) Representative advised attendees that, noting the statutory guidance and the AGD Terms of Reference (ToR) had not yet been agreed, the meeting could not be held under the draft ToR, until they have been approved, and recognised that the draft ToR may change as the statutory guidance evolves. As NHS England would like to seek advice on a number of areas, the NHS England SIRO Representative therefore proposed that:</p> <ul style="list-style-type: none"> • Kirsty Irvine (as an independent adviser) will be asked to Chair the AGD meetings; • The meeting will be minuted, with advice and minutes published;
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	<ul style="list-style-type: none"> Attendees will include both independent advisers from outside NHS England and representatives from within NHS England. Attendees from NHS England include representatives covering the offices of the Data Protection Officer (DPO); the Caldicott Guardian; and the SIRO. Attendees would not be listed as “members” in minutes during the transitional period; NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting; It was agreed to use the Data Access Request Service (DARS) Standards / Precedents in relation to applications for external data sharing. <p>The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis.</p> <p>Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the 23rd March 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.</p>
3	<p>Declaration of interests:</p> <p>Maria Clark noted professional links to the University of York (NIC-409296-H4X9J) but no specific connection with the application or staff involved and it was agreed that there was no conflict of interest.</p> <p>The AGD NHS England representatives in attendance, noted a professional link to NIC-05934-M7V9K, due to NHS England being a ‘client’ of Harvey Walsh Ltd; they all confirmed that they had no additional knowledge / engagement with the application, and it was agreed that the application would be discussed / reviewed as per usual process and that this was not a conflict of interests.</p>
<p>BRIEFING PAPER(S) / LETTER(S) OF NOTE:</p>	
4.1	<p>Title: Secondary Care ePMA Data Collection 2023</p> <p>Presenter: Andrew Walsham</p> <p>Observer: Steve Marks</p> <p>The paper provided to the group, provided details of the proposal to collect patient-level (identifiable) data for medicines prescribed and administered to patients by secondary care providers in England, when this is recorded on electronic Prescribing and Medicines Administration (ePMA) systems. NHS England aim to make the data comparable and make it available for analysis purposes to organisations with a lawful basis.</p> <p>The Department of Health and Social Care (DHSC) has requested NHS England collect this data to support ‘Tackling antimicrobial resistance 2019–2024 - The UK’s five-year national action plan’. Having patient-level hospital prescribing and medicine administration data at scale will help to identify problem areas, understand adherence to antibiotic prescribing policies, and monitor and measure outcomes of prescribing changes. It is hoped that the data will also provide a comprehensive and comparable national patient level data set about medicines use across secondary care providers^[1] to be made available for planning, commissioning and research purposes and when lawfully linked with other data</p>

sets held by NHS Digital, will enable the monitoring of medicines utilisation, pharmacoconomics, and research into the safety and effectiveness of medicines with the aim of supporting improvements in patient outcomes.

^[1]*Secondary care providers are NHS trusts providing acute, mental health and community care services*

Providers will be informed about the collection using established communications, running up to the data collection start date of February 2024. Use case owners and prospective data users can access the data from February 2024.

Outcome of discussion: The group welcomed the briefing paper and made the following observations / comments:

4.1.1 The independent advisers noted that the transparency materials made no reference to the data being processed for the purpose of “research”; and strongly recommended that the materials were updated accordingly to ensure that “research” was accurately reflected, to align with the draft Direction, provided as a supporting document.

4.1.2 The independent advisers noted the content of the draft NHS England privacy notice in respect of this data collection; and suggested that NHS England build on the examples provided for the purpose of the data collection, by providing additional details to make them more meaningful, providing transparency on the potentially excellent work that may be achieved from the processing of this data.

4.1.3 Noting that the privacy notice was going to be published on the NHS England website once finalised, the independent advisers also recommended that it was also published or linked to on the relevant NHS Trust websites, to ensure the information was as transparent as possible to patients and the public.

4.1.4 Noting that it was the intention of NHS England to publish the Data Protection Impact Assessment (DPIA); the independent advisers queried the restriction on sending identifiable data back to the NHS Trust who originally flowed the data to NHS England, as per the advice from NHS England’s Privacy, Transparency, Ethics and Legal (PTEL). The independent advisers cautioned NHS England against this restriction, noting there may be a requirement / need for the NHS Trusts to receive this data, in addition to them having a clear legal basis to receive this flow of data.

4.1.5 Separate to this briefing paper, the independent advisers noted the standard wording in the DPIA in relation to accessing the National Data Opt-out (NDO) that had been suggested by NHS England’s Caldicott Guardian; and advised NHS England that the group would liaise with him separately in respect of some suggested amendments.

ACTION: AGD to liaise with the Caldicott Guardian in respect of the NDO text within the DPIA.

4.1.6 The independent advisers noted the statement in the transparency materials “*If necessary requests to access data includes independent scrutiny from the Advisory Group for Data (AGD)...*”; and suggested that this was updated to state “*where appropriate*”. In addition, it was advised that a link to the [AGD webpage](#) was provided, which will contain the AGD terms of reference moving forward.

4.1.7 The independent advisers queried how the sensitive data fields would be removed; and noting that the transparency materials were silent on this, suggest they were updated with further information, including the decision-making process linked to this.

4.1.8 The independent advisers advised that if it had been agreed within NHS England that this dataset would now be available to researchers, and not just NHS organisations; then that permitted usage for

	<p>research, and the legal basis for this, should be made clear within the draft Direction, in line with other published Directions which expressly allow data to be used for research.</p> <p>4.1.9 Noting the linkage was, currently, seemingly restricted to NHS England datasets, the independent advisers suggested that NHS England give consideration to linkage with other datasets, with the appropriate legal bases in place.</p> <p>4.1.10 In addition, the independent advisers suggested that the draft Direction was updated, to not restrict usage and linkage within the secure data access environment only.</p> <p>4.1.11 The independent advisers queried the references to “<i>gender</i>” within the transparency materials and DPIA, noting that the data fields referred to actually capture sex and not gender; and noted that from a medicines safety perspective, it was advised that sex would be the most appropriate variable to study in this context.</p> <p>4.1.12 The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting (before, or contemporaneously with, any first of type applications received by AGD).</p>
<p>4.2</p>	<p>Title: COVID-19 Therapeutics (Blueteq system) - Letter of Note</p> <p>Presenter: Michael Chapman</p> <p>The Letter of Note was withdrawn by the presenter</p>
<p>EXTERNAL DATA DISSEMINATION REQUESTS:</p>	
<p>5.1</p>	<p>Title: Request for ‘BlueTeq’ Data – University of Oxford</p> <p>Presenter: Vicky Byrne-Watts</p> <p>The request was withdrawn by the presenter</p>
<p>5.2</p>	<p>Reference Number: NIC-05934-M7V9K-v14.2</p> <p>Applicant: Harvey Walsh Ltd</p> <p>Application Title: Harvey Walsh Ltd - data dissemination</p> <p>Presenter: Clare Wright</p> <p>SAT Observer: Dave Cronin</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented at the DAAG / IGARD meetings on the 16th August 2016, 6th September 2016, 20th September 2016, 13th December 2016, 15th June 2016, 22nd June 2016, 8th November 2018, and 31st March 2022.</p> <p>Application: This was a renewal application.</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The group were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:</p> <p>5.2.1 In respect of the outputs register referred to in section 5(a) (Objective for Processing), the independent advisers queried if there had been a recent version shared with NHS</p>

England, and were advised by NHS England that the last version requested / received was from 2018. The independent advisers suggested that NHS England request an updated copy of the outputs register as a matter of urgency, noting that this would enable NHS England to assess the commercial benefit accruing to the commercial organisation and whether this was proportionate to the benefit to health and social care, in line with [NHS Digital DARS Standard for Commercial Purpose](#).

5.2.2 In addition, the independent advisers suggested that a special condition was inserted in section 6 (Special Conditions), in line with [NHS Digital DARS Standard for Special Conditions](#); that the applicant must provide copies of the outputs register to NHS England.

5.2.3 The independent advisers suggested that once the outputs register had been received and reviewed by NHS England, that section 5(a) was updated to make clear that an assessment had been undertaken, in line with the National Data Guardian (NDG) [guidance](#) on enabling better public benefit evaluations when data is to be used in planning, research and innovation; and that the commercial benefits accruing to the commercial organisation is proportionate to the benefit to health and social care, in line with [NHS Digital DARS Standard for Commercial Purpose](#).

In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review:

5.2.4 The independent advisers noted and commended the efforts taken by the applicant on their patient and public involvement and engagement (PPIE).

5.2.5 The independent advisers noted that section 5(a) was not clear that Harvey Walsh Ltd was a commercial company; and suggested that, for transparency, this was updated accordingly to make clear that Harvey Walsh Ltd was a commercial company that generates a profit by providing analysis of health data, or similar; and in line with [NHS Digital DARS Standard for Commercial Purpose](#).

5.2.6 The independent advisers noted the list of the applicant's clients in section 5(a), however, suggested that this was updated to ensure that the list was structured in order of the most significant (in terms of fee revenue or activity) client categories first; noting that the current list gives a misleading impression that NHS organisations, for example Integrated Care Services [*sic*] (ICSs) and Integrated Care Boards (ICBs), were the most significant clients, when in fact commercial organisations were the main source of income/business.

5.2.7 In respect of the expected benefits in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care), the independent advisers suggested that this was edited to ensure this only contained yielded benefits and not outcomes; and that any outcomes should be moved to section 5(c) (Specific Outputs Expected) in line with [NHS Digital DARS Standard for Expected Outcomes](#) and [NHS Digital DARS Standard for Expected Measurable Benefits](#).

5.2.8 In addition, noting that 70% of Harvey Walsh Ltd's clients were commercial companies, then the independent advisers advised that they would expect this to be reflected in section 5(d) in line with [NHS Digital DARS Standard for Expected Measurable Benefits](#); and not just focus on the yielded benefits to NHS organisations.

5.2.9 The independent advisers queried who the projects outlined in section 5(d) (iii) were undertaken for, i.e. who commissioned them; and suggested that further information was

	<p>provided. If this information was considered commercially sensitive, then it was suggested that the 'client type' was referred to instead, for example, a pharmaceutical company.</p> <p>5.2.10 The independent advisers noted the references to cost efficiencies / savings in section 5(d) (iii); and suggested that further information was provided as to who / how the cost efficiencies had been recognised; and if these could be quantified further, in line with NHS Digital DARS Standard for Expected Measurable Benefits.</p> <p>5.2.11 The independent advisers queried the references in section 5(d) (iii) to a local "pathway"; and suggested that this was updated further to provide further information on this yielded benefit, for example, whether the pathway could be rolled out wider.</p> <p>5.2.12 The SIRO representative suggested that in future Section 5(e) (Is the Purpose of this Application in Anyway Commercial) of the application could be replicated in the public facing section 5 for transparency. The independent advisers agreed that this would be helpful, if possible.</p>	
<p>5.3</p>	<p>Reference Number: NIC-23410-W8N9L-v4.10</p> <p>Applicant: The University of Manchester</p> <p>Application Title: The impact of hospital regulation on performance</p> <p>Presenter: Dan Goodwin</p> <p>SAT Observers: Louise Dunn</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented at the DAAG meeting on the 18th October 2016.</p> <p>Application: This was an amendment application.</p> <p>The amendment is to archive the data under this data sharing agreement (DSA), in case any queries arise as a result of the publications.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The group were supportive of the application and wished to draw to the attention of the SIRO the following high-level comments:</p> <p>5.3.1 The independent advisers noted the statement on the University of Manchester website that the research was "A joint research project undertaken by The University of Manchester and The King's Fund..."; and noting that this was not reflected in the application, suggested that NHS England explored further the role of The King's Fund and satisfied itself that they were / were not considered joint Data Controllers in line with NHS Digital DARS Standard for Data Controllers.</p> <p>5.3.2 The independent advisers queried the restrictive text in section 5(a) (Objective for Processing) in respect of the archiving purpose and what the application permits / does not permit the applicant to do; and noting how restrictive the wording was, suggested that NHS England review this and amend if deemed appropriate, for example, in line with other less restrictive archiving applications that had been reviewed by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD).</p>	

	<p>5.3.3 The independent advisers noted the reference in section 5(c) (Specific Outputs Expected) to the “<i>Impact of the Care Quality Commission on provider performance</i>” report; and suggested that section 5(d) (Benefits) (iii) (Yielded Benefits) was updated to include a link to the report, and to reflect the yielded benefits accrued from this report, in line with NHS Digital DARS Standard for Expected Measurable Benefits.</p>	
<p>5.4</p>	<p>Reference Number: NIC-51342-V1M5W-v5.4</p> <p>Applicant: University College London (UCL)</p> <p>Application Title: Centre for Longitudinal Studies Next Steps Data Linkage: Next Steps Age 25 Study</p> <p>Presenter: Dan Goodwin</p> <p>SAT Observer: Dave Cronin</p> <p>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented at the IGARD meetings on the 31st July 2017, 26th September 2019, 31st October 2019 and 20th May 2021.</p> <p>It was also previously discussed at the IGARD – NHS Digital COVID-19 response meeting on the 29th September 2020.</p> <p>Application: This was a renewal and extension application.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>NHS England were seeking advice on the following point:</p> <ol style="list-style-type: none"> 1. Whether UCL’s proposal to facilitate access to the Next Steps study data within UCL’s Data Safe Haven (DSH) rather than via the UKDS is compatible with the consent. <p>Outcome of discussion: The group were supportive of the application. The group made the following observation / points of advice on the application and / or supporting documentation provided as part of the review:</p> <p>In respect of point 1 above:</p> <p>5.4.1 The independent advisers noted that when the application was last reviewed by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) on the 20th May 2021, IGARD had raised a query as to whether the UK Data Service (UKDS) had been consulted on the proposed access process changes at the time. In addition, IGARD had queried whether the proposed changes were compatible with the participation information materials, noting that the participation information sheet, stated “<i>Researchers who want to use the matched data must be registered with the UK Data Service</i>”, and advised that could imply that all applications would involve the UKDS.</p> <p>5.4.2 In light of the previous IGARD queries raised, and in respect of this iteration of the application, the independent advisers suggested that the applicant ensure that any user of the data within UCL was registered with UKDS, which would align with the original consent taken.</p> <p>5.4.3 In addition, it was suggested by the independent advisers that access to the data via UCL was accurately described in the transparency materials.</p>	

	<p>5.4.4 The independent advisers also suggested that the applicant reviewed the transparency materials to determine if they could be further refined to be clear to the cohort members as to the processing taking place.</p> <p>5.4.5 The independent advisers advised that they were broadly supportive of the applicant's suggestion of communicating directly with the cohort members; and that this would comply with ethical obligations, the common law duty of confidentiality and the UK General Data Protection Regulation (UK GDPR).</p> <p>5.4.6 In addition, the independent advisers advised that to ensure alignment with the original consent / transparency materials, the projects should be reviewed by The Centre for Longitudinal Studies (CLS) Data Access Committee.</p> <p>5.4.7 The independent advisers queried the statement in section 5(a) (Objective for Processing) "<i>CLS does not require researchers to be accredited before accessing data...</i>"; and asked that this was reviewed and updated as required, noting that it conflicted with statements in the transparency materials.</p> <p>In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.4.8 The independent advisers queried if the territory of use was the "<i>UK</i>" as stated in the application, or whether this should be amended to "<i>England and Wales</i>"; and suggested that this was reviewed, and the application amended as appropriate.</p> <p>5.4.9 The group discussed the special condition in section 6 (Special Conditions) relating to sublicensing; and agreed that the special condition was relevant to the application, however suggested that this was moved from section 6 to section 10 (Sub-licensing) of the application.</p> <p>5.4.10 In addition, the group noted the reference to the UCL audit rights as part of the sublicensing special condition in section 6 (as above); and supported the proposal put forward by the NHS England SIRO representative to review the UCL audit proposal.</p> <p>5.4.11 Separate to this application, the independent advisers suggested that the sublicensing special condition should be included in all sublicensing applications; and advised that this could be addressed via an update to the NHS Digital DARS standard for sub-licensing and onward sharing.</p> <p>ACTION: NHS England to review / amend the NHS Digital DARS standard for sub-licensing and onward sharing, to reflect the sublicensing special condition.</p> <p>5.4.12 Also separate to this application, the independent advisers suggested that NHS England consider updating all "live" data sharing agreements (DSA), with the additional sublicensing special condition in section 10, noting the breadth of some of the sublicensing DSA's which often include sublicensing to commercial organisations.</p> <p>ACTION: NHS England to review / update "live" DSAs to reflect the sublicensing special condition in section 10.</p>	<p>NHSE</p> <p>NHSE</p>
<p>5.5</p>	<p>Reference Number: NIC-679360-X9X0Y-v0.5</p> <p>Applicant: The University of Manchester</p> <p>Application Title: Invest to detect? The impact of shortfalls in hospital diagnostic imaging capacity on GP identification, management and referrals of suspected cancer cases</p>	

	<p>Presenter: Dan Goodwin</p> <p>SAT Observer: Dave Cronin</p> <p>Observer: Tanmai Kalathurvadyer</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research project examining how gaps in hospital-level capacity, underinvestment, and lack of maintenance of diagnostic imaging equipment (MRI, CT, and PET scans) affects the performance of cancer diagnostic activity for patients referred for cancer investigation by their GP practice.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The independent members were not supportive of the application as currently drafted and wished to draw to the attention of the SIRO the following significant comments, and suggested that the application be brought back to a future meeting:</p> <p>5.5.1 The independent advisers noted that section 7 (Ethics Approval) of the application stated <i>“Ethics approval is not required because... Only non-identifiable data will be received.”</i> and advised that this was incorrect, noting the data was pseudonymised and therefore not fully anonymised, nor obtained under consent.</p> <p>5.5.2 In addition, the independent advisers suggested that the applicant consult their relevant University’s Ethics Committee, and, if required by the University’s research ethics policy, obtain institutional REC approval.</p> <p>5.5.3 The independent advisers noted in the protocol, that as part of the initial consultation, there was some primary care input at a senior level, and suggested that the applicant also engage with GPs, as per the engagement with patient representatives.</p> <p>5.5.4 The independent advisers noted concerns that the questions outlined in the protocol, may not be adequately addressed with the NHS England data requested under this application, for example, some of the questions may not be answered in their current format, i.e. the question relating to <i>“GP-level performance indicators of cancer-related activity”</i>; and questioned whether the data could answer this, noting that GP’s are unable to ‘identify’ cancer, and can only refer a patient for an x-ray, certain scans, or, more commonly where cancer is suspected, to an urgent 2 week wait specialist cancer service.</p> <p>5.5.5 The independent advisers noted this was potentially interesting work, but were concerned about the articulation of the questions asked in this research, whether the data provided could answer the questions posed, and a possible lack of input from practising GPs.</p>	
5.6	<p>Reference Number: NIC-409296-H4X9J-v0.11</p> <p>Applicant: London School of Economics and Political Science (LSE)</p> <p>Application Title: MR1069 – Breakthrough Generations study</p> <p>Presenter: Anna Weaver</p> <p>SAT Observer: Vicky Byrne-Watts</p> <p>Application: This was a new application.</p>	

The purpose of the application is for a project examining the use of the Community Health Services (CHS) by different groups of patients and by geographical area; and will also produce projections of demand for CHS nationally and locally for the next ten years. It is hoped the project will help inform central and local government policy on community healthcare and having access to linked data is vital to further this understanding.

Should the application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

Outcome of discussion: The group were supportive of the application and wished to draw to the attention of the SIRO the following comments:

5.6.1 Noting the large volume of data requested, the independent advisers queried what, if any, data minimisation had been undertaken, noting this was unclear in the application, and asked that section 5(a) (Objective for Processing) was updated with further information, in line with [NHS Digital DARS standard for data minimisation](#).

5.6.2 In addition, the independent advisers queried why the data for individuals under the age of 18 was not required, and asked that a clear justification for this exclusion was added to section 5(a).

5.6.3 If there were future plans to include individuals under the age of 18 in the future, the independent advisers suggested that section 5(a) was updated to clarify this for transparency.

5.6.4 In addition, the independent advisers suggested that if it was not possible to undertake any data minimisation, for example by using a geographical or random sample, that a justification was provided in section 5(a).

5.6.5 The independent advisers noted the information in section 5(a) in respect of the Community Services Data Set (CSDS), for example “*CSDS is a nation-wide data set which includes care contacts recorded from a range of community settings. These activities could take place in settings such as **health centres, Sure Start centres, day care facilities, schools...**” and asked that this was edited / removed, noting that as the cohort was over the age of 18, the community settings referred to were incorrect, i.e. Sure Start centres and schools.*

5.6.6 Noting the references in section 5 (Purpose / Methods / Outputs) to “*ESHCRUII*” and “*ESHCRU*”; the independent advisers suggested that the acronyms were reviewed and amended / aligned if not correct; and each acronym be correctly defined upon first use.

5.6.7 The independent advisers noted in section 5(a) that the University of York would not have access to the data, nor will they have any involvement in the research projects; however, suggested that this was updated to also state that the University of York has no involvement in determining the purpose and means of processing and is **not** carrying out any data controllership activities.

5.6.8 The independent advisers noted that the applicant was planning on consulting with patient advisers, however suggested that the applicant may also wish to consider involving the relevant public and patient groups for the whole lifecycle of the project. The [HRA guidance on Public Involvement is a useful guide](#).

EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL

6	<p>Reference Number: NIC-414067-K8R6J-v1.3</p> <p>Applicant: Our Future Health</p> <p>Application Title: Our Future Health Recruitment Programme</p> <p>Presenter: Andy Rees</p> <p>Observer: James Gray</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the IGARD business as usual (BAU) meeting on the 5th May 2022, 26th May 2022 and 17th November 2022.</p> <p>The application was also discussed under ‘AOB’ at the AGD meeting on the 2nd March 2023.</p> <p>Application: The purpose of the application is for a research programme to support people living healthier lives for longer through better prevention, earlier detection and improved treatment of diseases. The programme will aim to speed up the discovery of new methods of early disease detection, and the evaluation of new diagnostic tools, to help identify and treat diseases early when outcomes are usually better.</p> <p>Outcome of discussion: The group appreciated that the NHS England SIRO representative was seeking advice on 1) whether AGD consider it appropriate to release another 4 million details if further Health Research Authority Confidentiality Advisory Group (HRA CAG) support is obtained; and 2) what position AGD would recommend should the HRA CAG outcome not be confirmed by the end of April.</p> <p>6.1 The independent advisers noted that HRA CAG had provided support for the flow of data for an additional 4 million individuals; with a further review due at the end of April 2023.</p> <p>6.2 The independent advisers advised that NHS England would have a defensible position in terms of legality, if there was HRA CAG support for the flow of an additional 4 million patients; however they reiterated all of the previous issues and risk factors raised at the AGD meeting on the 2nd March 2023 (which in turn referenced points raised at earlier IGARD meetings), including, but not limited to, the commercial involvement, the potentially excessive processing of personal data to send invitations via Digi-Trials, and how this would affect future researchers; which had not been adequately addressed.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
AGD Operations		
7	<p>Standard operating procedures</p> <p>The ongoing forward plan of work for creating Standard Operating Procedures was discussed.</p>	To note
8 8.1	<p>New Operational Actions & those carried forward from previous meetings of AGD:</p> <p>Inside Scope of IR35</p> <p>Garry Coleman provided a further verbal update in respect of IR35 and the impact on independent advisers who were previously on IGARD, noting that they had previously been advised that they would fall inside scope of IR35 from the 1st April 2023.</p>	

8.2	<p>Garry Coleman advised that following extensive discussions within NHS England, it had been agreed that the independent advisers would continue outside the scope of IR35 for a short transitional period, up to the 31st July 2023; whilst NHS England actively worked on putting zero hours based contracts into place for all independent advisers.</p> <p>Garry Coleman thanked all independent advisers for their patience whilst NHS England resolved the IR35 issue and relevant risk.</p> <p>Data sharing standard 7a - Ethical Approval</p> <p>Louise Dunn attended the meeting to provide a verbal update on an ongoing issue with the National Disease Registration Service (NDRS) applications that were novated from Public Health England (PHE) following its cessation in 2021; and the issues with obtaining Health Research Authority ethics approval for these applications, which was previously required by PHE.</p> <p>NHS England advised that there was ongoing work with HRA in respect of this issue, and that an update would be provided as soon as possible.</p> <p>The independent advisers noted and thanked NHS England for the verbal update, and looked forward to a further update at a future AGD meeting in respect of this; and subsequently any update to the NHS Digital DARS Standard for Ethical Approval.</p>	
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Any Other Business

9.1	<p>Department of Health and Social Care (DHSC) / NHS England Data Analytics Memorandum of Understanding (MOU)</p> <p>Garry Coleman advised the independent advisers that there were ongoing discussions in respect of a MOU between DHSC and NHS England; and that further information would be presented at a future AGD meeting.</p> <p>The independent advisers noted and thanked Garry Coleman for the verbal update; and looked forward to further information in due course, at a future AGD meeting.</p>
9.2	<p>Annual Confirmation Report</p> <p>Following the discussion at the AGD meeting on the 16th March 2023, the independent advisers noted that a further updated draft version of the Annual Confirmation Report had been provided.</p> <p>The independent advisers provided some verbal feedback to NHS England on some minor suggested amendments.</p> <p>The independent advisers thanked NHS England for the updated version of this document; however advised that the process / engagement of this document, had been slowed down by NHS England having no recorded user feedback documentation following engagement by NHS Digital with users at workshops over the latter part of 2022, and suggested NHS England ensure it documents user back workshops in line with good practice to ensure it has the relevant evidence to support its work.</p>
9.3	<p>Maria Clark</p>

	Both independent advisers and NHS England noted that this was Maria Clark's final meeting and wished to extend their sincere thanks for her significant contribution over the last five years during her tenure on IGARD and AGD.
	Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.