

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 18th May 2023

09:30 – 16:00

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	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 5.3)
Garry Coleman (GC)	Senior Information Risk Owner (SIRO) representative
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (Presenter: item 5.1) (SAT Observer: item 5.2)
Cath Day (CD)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 5.6)
Kate Fleming (KF)	NHS England Data and Analytics Representative (Delegate for Michael Chapman)
Dan Goodwin (DG)	Data Access Request Service (DARS) (Presenter: item 5.2)
Dickie Langley (DL)	Data Protection Officer (DPO) representative (Delegate for Jon Moore)
Abigail Lucas (AL)	Data Access Request Service (DARS) (Observer: item 5.3) (Presenter: items 5.4 to 5.5)
Shaista Majid (SM)	Data Access Request Service (DARS) (Presenter: item 5.3)
Rachael Mann (RM)	Data Liaison Manager, Data, Insights and Statistics (Observer: item 4.1)
Karen Myers (KM)	Secretariat Team

Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative
Richard Steele (RS)	IAO, Data, Insights and Statistics (Presenter: item 4.1)
Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: items 5.4 to 5.5)
Vicki Williams (VW)	Secretariat Team (Presenter: items 8 and 9.1)
Clare Wright (CW)	Data Access Request Service (DARS) (Presenter: item 5.6)
Amanda Young (AY)	Data Access Request Service (DARS) (Observer: item 5.2)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Paul Affleck (PA)	Specialist Ethics Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Michael Chapman (MCh)	Data and Analytics representative
Dr Arjun Dhillon (AD)	Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)

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; • 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); Privacy, Transparency and Ethics (PTE); 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.
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	<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 11th May 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>There were no declarations of interest.</p>
BRIEFING PAPER(S)	
4.1	<p>Title: NHS Scotland Pelvic Floor Registry Pilot Request 2023</p> <p>Presenter: Richard Steele</p> <p>Observer: Rachael Mann</p> <p>The paper submitted to the group provided details of a request received by NHS England from NHS National Services Scotland to join the Pelvic Floor Registry, initially on a pilot basis. NHS National Services Scotland requests NHS England to establish and operate a pilot information system for an initial period of six months from the date of the request.</p> <p>As part of the review of this briefing paper and supporting documents, the group were being asked to review this request, the Requirements Specification, Transparency Notices and National Director's Cover Note; and to specifically seek the group's views on 1) the adequacy of the transparency information provided to patients / the public; 2) whether AGD consider that the common law duty of confidentiality is being met; 3) acknowledge and understand the dissemination specified in this request; and 4) if this type of request needs to be submitted to future AGD meetings or whether a precedent can be recorded that they can go through for approval without.</p> <p>Outcome of discussion: The group welcomed the briefing paper and made the following observations / comments:</p> <p>4.1.1 The independent advisers noted the importance of the work being undertaken, as outlined in the briefing paper, and noted that this was a general discussion prior to further development.</p> <p>4.1.2 Noting the four points of advice NHS England were seeking from this review, the independent advisers suggested that the request to "<i>acknowledge and understand the dissemination specified in this request</i>" was removed and replaced with "<i>to be published for transparency in the AGD minutes</i>" or similar.</p> <p>4.1.3 The independent advisers noted that there needs to be a clear articulation of how the common law duty of confidentiality is satisfied for Scottish citizens' data, for example, is it set aside by way of a Direction?</p>

	<p>4.1.4 The independent advisers advised that “<i>direct care</i>” was not an appropriate basis in these circumstances, noting that not all aspects of the use of the data would be for direct care (e.g research was referenced).</p> <p>4.1.5 The independent advisers also noted the incorrect information within the surgical devices’ privacy notice, stating that confidential data was only shared for the purpose of direct care, however within the documentation provided it was clear that research was anticipated.</p> <p>4.1.6 The independent advisers queried why pseudonymised data cannot be used, with the ability to re-identify for direct care; and were advised by NHS England that this had been explored.</p> <p>4.1.7 The independent advisers confirmed that they were supportive of research being undertaken in the appropriate circumstances, however suggested that the current form of which the providers of Scottish data were consulted and then permission sought, may be unduly burdensome; and suggested that reliance could be placed on the committee set up to approve research requests.</p> <p>4.1.8 NHS England asked if a Precedent could be set for Welsh and Northern Ireland data collections; the independent advisers suggested that this would not be advisable noting the potential divergence in legal gateways.</p> <p>4.1.9 The independent advisers noted there were a number of UK General Data Protection Regulation (UK GDPR) legal bases’ available to use for this data collection; however, suggested that NHS England only use one and ensured that this is used consistently going forward.</p> <p>4.1.10 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: Cardiovascular Disease Prevention Audit (CVDPREVENT Audit) data collection</p> <p>Presenter: None</p> <p>Previous Reviews: The CVDPREVENT Audit briefing paper were previously presented at the IGARD meeting on the 10th December 2020.</p> <p>The updated briefing paper provided details to address the points raised by IGARD on the 10th December 2020; and to address several organisational changes following the review of the original briefing paper.</p> <p>The purpose of the original briefing paper was to provide details of the CVDPREVENT Audit, where routinely recorded General Practice (GP) data will be extracted by NHS Digital via the GP Extraction Service (GPES) with an initial GPES extract containing historical information and then rolling three monthly extracts of routinely recorded GP data. The data will help clinicians to understand how well they are performing in the diagnosis and management of the six high-risk conditions for cardiovascular disease (CVD).</p> <p>Outcome of discussion: The group welcomed the updated briefing paper and made the following observations / comments:</p> <p>4.2.1 The independent advisers noted the references within the updated briefing paper to “<i>NHS Digital</i>” and suggested that these were updated where relevant to correctly refer to “<i>NHS England</i>”.</p> <p>4.2.2 Noting the statement “<i>The data will help clinicians...</i>” within the briefing paper, the independent advisers suggested that this was updated to provide further clarity on which clinicians they were referring to.</p>

	<p>4.2.3 The independent advisers noted the references to “<i>Simon Broome score or a Dutch lipid score</i>”; and asked that further clarity was provided as to what these scores were referring to.</p> <p>4.2.4 The independent advisers noted the references to the various types of diabetes, for example “<i>Type 1 and Type 2</i>”; and suggested that this was amended to refer to “<i>all types of diabetes</i>”.</p> <p>4.2.5 Noting the information provided in the briefing paper in respect of the purpose of processing, the independent advisers suggested that this was reviewed and updated, where appropriate, to use a form of wording such as “<i>it is hoped ...</i>”, rather than “<i>it will...</i>”; and that this should be done in line with the National Data Guardian (NDG) guidance on benefits.</p> <p>4.2.6 The independent advisers noted the statement “<i>The data set also includes sensitive (legally restricted) codes relating to the CAN_COD...</i>”; and suggested that this was updated with a brief explanation as to what “<i>CAN_COD</i>” meant.</p> <p>4.2.7 The independent advisers noted that there were embedded documents within the briefing paper, for example the Data Protection Impact Assessment (DPIA); and asked that any future iterations of this briefing paper (and all briefing papers from NHS England provided for review); did not contain embedded documents, and were provided as separate supporting documents, noting that some independent advisers were unable to access embedded documents.</p>
EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-373563-N8Z9J-v11.8</p> <p>Applicant: IQVIA Ltd</p> <p>Application Title: Analytical Services</p> <p>Presenter: Dave Cronin</p> <p>Previous Reviews: Previous Reviews: The application and relevant supporting documents were previously presented at the IGARD meetings on the 7th February 2019, 6th February 2020, 28th January 2021 and 24th November 2022 where IGARD were unable to recommend for approval.</p> <p>The application and relevant supporting documents were previously presented / discussed at the DAAG meetings on the 13th September 2016, 27th September 2016, 18th October 2016 and the 10th January 2017.</p> <p>Linked applications: This application is linked to NIC-315134-L9Z6B and NIC-210151-K9C7G.</p> <p>Application: This was an amendment application.</p> <p>The amendment is to amend the purpose of the application in section 5(a).</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 not supportive of the application until the following significant comments were addressed, and wished to draw to the attention of the SIRO the following substantive points:</p> <p>5.1.1 The independent advisers highlighted the statement in section 4 (Privacy Notice), that a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible transparency notice was maintained throughout the life of the agreement, in line with UK</p>

GDPR requirements; and advised that there were a number of incorrect statements in the applicants published privacy notice, including, but not limited to, the purpose of the processing and the information relating to opt-outs; and suggested that these were updated as a matter of urgency. These points had been raised at the last IGARD review (as detailed above) and had not been actioned.

5.1.2 The independent advisers noted the expected benefits and yielded benefits in section 5(d) (Benefits), however, noted concerns that there was not an express proposition put forward by the applicant, that the commercial benefit accruing to the commercial organisation is proportionate to the benefit to health and social care; and suggested that these were reviewed and updated in line with [NHS England's DARS Standard for Commercial Purpose](#) and [NHS England's DARS Standard for Expected Measurable Benefits](#); and that these are aligned with the recently published [National Data Guardian guidance on benefits](#).

5.1.3 The independent advisers queried the reference in section 5(d) (iii) (Yielded Benefits) "*The client engaged the NHS...*"; and noting that it was unclear who the "*clients*" were, suggested that further information was provided, for example, by providing examples of the client type; and that the example provided was updated in line with [NHS England's DARS Standard for Expected Measurable Benefits](#).

5.1.4 In respect of 'service 2' the "*Care Pathway Analysis*", it was noted by the SIRO representative that the statement "*This service **can** provide analysis...*" should be updated to state that the service "**will**" provide analysis.

5.1.5 In respect of 'service 5' the "*Services to support the planning and development of epidemiology, health economics and outcomes research studies*", it was noted by the SIRO representative that this should be reduced to specific limited activities, for example, sample size calculations; or removed if this cannot be reduced to specific limited activities.

5.1.6 The independent advisers noted that at the AGD meeting on the 11th May 2023, NHS England had advised that the text used in section 3(c) (Patient Objections) in respect of opt-outs would be reviewed and updated as necessary; and suggested that section 3(c) in this application was aligned with the correct / most recent text used in other applications, and that it was made clear that the National Data Opt-out would **not** be applied.

5.1.7 The independent advisers queried the statement in section 5(a) (Objective for Processing) "*The EBI Module is a **Qlik** Sense dashboard development for 2022/23...*"; and asked that this updated with a further explanation of QLIK, for example, is this IQVIA software or generic software.

5.1.8 The SIRO representative noted the seven outputs expected in section 5(c) (Specific Outputs Expected) and asked that it was made clear for each output, what suppression applies for each one, in relation to each use case; and if there is no suppression, to provide a justification as to why not.

5.1.9 Separate to the application, it was noted that an update had been provided by NHS England, at the AGD meeting on the 23rd March 2023, in respect of potential updates to the [NHS England's DARS Standard for Expected Measurable Benefits](#) and [NHS England's DARS Standard for Commercial Purpose](#), to align with the National Data Guardian (NDG) guidance on enabling better public benefit evaluations when data is to be used in planning, research and innovation. The independent advisers noted their continued support for NHS

	<p>England undertaking this work, and look forward to an update / further engagement in due course.</p> <p>ACTION: NHS England to provide a further updates on the to the NHS England's DARS Standard for Expected Measurable Benefits and NHS England's DARS Standard for Commercial Purpose, to align with the NDG guidance.</p>	DARS
5.2	<p>Reference Number: NIC-338864-B3Z3J-v2.9</p> <p>Applicant: Barts and the London School of Medicine and Dentistry</p> <p>Application Title: Genes and Health</p> <p>Presenter: Dan Goodwin</p> <p>SAT Observers: Dave Cronin</p> <p>Observer: Amanda Young</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 29th October 2020, 6th May 2021 and 15th July 2021.</p> <p>Application: This was an amendment application.</p> <p>The amendments are to 1) add Wellcome Sanger Institute as a Data Processor; 2) to add Cloud Google UK as a Data Processor (under Wellcome Sanger Institute usage); 3) to add the following additional datasets: Patient Record Outcome Measures (PROMS), Demographics and Cancer Registration Data, Improving Access to Psychological Therapies (IAPT), and Community Services Data Set (CSDS); and 4) to add additional year to the data sharing agreement (DSA).</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 substantive comments:</p> <p>5.2.1 The independent advisers noted that the application was reviewed by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) on the 6th May 2021, and advised that several substantive points raised by IGARD, had not been addressed in the papers supporting this iteration of the application, including, but not limited to, the recommended transparency to the cohort on the sub-licensing. The independent advisers suggested that IGARD's amendment points from the last review were addressed.</p> <p>5.2.2 The NHS England Data and Analytics Representative and SIRO representative, noted the concerns raised by independent advisers, relating to the failure of NHS England to address the previous concerns raised by IGARD, in relation to the transparency of use of sub-licenses and other substantive points; and agreed that this would be addressed, and raised specifically with Barts and the London School of Medicine and Dentistry. The SIRO representative confirmed that any short-term extension (to ensure that the applicant is under a data sharing agreement (DSA)) would place a contractual obligation on them to address these outstanding issues.</p> <p>5.2.3 The independent advisers noted that IGARD had asked that the applicant was clear with the cohort on the type of data being shared; and noting that the most recent newsletter</p>	

	<p>seen stated the data was “<i>anonymous</i>”, reiterated the point that the cohort should be made aware that the data being shared was “<i>pseudonymised</i>”.</p> <p>5.2.4 Noting that the applicant was still recruiting, the independent advisers suggested that the applicant updated all transparency materials (not relying on only the website privacy notice) as a matter of urgency.</p> <p>5.2.5 The independent advisers noted in section 2(c) (Territory of Use) that the territory of use was UK / EEA; and noting that some of the users of the data were located outside of this permitted area, suggested that NHS England ensure that these users had access via the Trusted Research Environment (TRE) only.</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>5.2.6 The independent advisers noted that section 5(e) (Is the Purpose of this Application in Anyway Commercial) provided details of the commercial purpose of the application; however, suggested that section 5(a) (Objective for Processing) was updated further to include details of the commercial benefits, in line with NHS England’s DARS Standard for Objective for Processing and NHS England’s DARS Standard for Commercial Purpose.</p> <p>5.2.7 In addition, the independent advisers suggested that the information in section 5(e) in respect of the commercial purpose of the application, would also be suitable for a newsletter to the cohort.</p> <p>5.2.8 The independent advisers queried the reference in section 5(a) to the data being “<i>pseudonymised</i>”; and noting that this was incorrect, suggested that this was updated to accurately reflect that the data was “<i>identifiable</i>”, as per the information in the internal application assessment form.</p> <p>5.2.9 The independent advisers suggested that, noting the scale and nature of the processing, that the applicant undertake a Data Protection Impact Assessment (DPIA).</p> <p>5.2.10 Noting the statement in section 5(c) (Specific Outputs Expected) “...<i>the study team are guided by NIHR INVOLVE...</i>”, the independent advisers suggested that further clarity was provided on what NIHR INVOLVE is, for example, by providing a relevant weblink.</p> <p>5.2.11 Separate to the application, the independent advisers suggested that NHS England review the NHS England DARS Standard for Sub-licencing and Onward Sharing of Data to make clear what is expected of the sub-licensor and what information they should be providing to NHS England.</p> <p>ACTION: NHS England to review the NHS England DARS Standard for Sub-licencing and Onward Sharing of Data to make clear what is expected of the sub-licensor and what information they should be providing to NHS England.</p>	NHSE
5.3	<p>Reference Number: NIC-359940-W1R7B-v9.6</p> <p>Applicant: National Institute for Cardiovascular Outcomes Research (NICOR)</p> <p>Application Title: NICOR National Cardiac Audit Programme (Previously known as CCAD - Central Cardiac Audit Database - MR1233)</p> <p>Presenter: Shaista Majid</p>	

	<p>SAT Observer: Vicky Byrne-Watts</p> <p>Observer: Abigail Lucas</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented at the IGARD meetings on the 10th August 2017, 4th July 2019 and 20th June 2019 where the application when the application had been deferred.</p> <p>Linked applications: This application is linked to NIC-143888-H0W2N and NIC-343380-H5Q9K.</p> <p>Application: This was an amendment application.</p> <p>The amendments are to 1) to remove the Healthcare Quality Improvement Partnership (HQIP) as a Data Controller; 2) to remove Barts Health NHS Trust as a Data Processor, and add NHS Arden and Greater East Midlands (GEM) Commissioning Support Unit (CSU) as a Data Processor; 3) to include the UK Transcatheter Aortic Valve Implantation (TAVI) registry alongside the existing six National Cardiac Audit Programme (NCAP) audits; 4) to add further lay explanations and points of clarity throughout the existing data sharing agreement (DSA); and ensure objectives, outputs and benefits are reflected under the correct sections of the DSA; and 5) to add a justification as to why the National Data Opt-out (NDO) will not be applied to future data releases to within section 5(a).</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 comments:</p> <p>5.3.1 NHS England advised the group that prior to the meeting, further discussions had taken place internally in respect of the role of Data Health and Care Wales (DHCW); and that although further discussions would need to take place with the applicant, it was the view of NHS England, that DHCW should be added to the data sharing agreement (DSA) as a Data Controller. The independent advisers noted the verbal update from NHS England, and advised that as some of the Health Research Authority Confidentiality Advisory Group (HRA CAG) documentation provided, did state that DHCW were the Data Controller for the Welsh data, they were therefore supportive of the relevant update to the application to add DHCW as a joint Data Controller.</p> <p>5.3.2 In addition, the independent advisers highlighted that although they were supportive of DHCW being added to the application as a joint Data Controller; the legal bases and statutes for Welsh law may differ from English law, and that NHS England should ensure the appropriate advice on this was sought from NHS England's Privacy, Transparency and Ethics (PTE) team.</p> <p>5.3.3 The independent advisers noted and commended the information on the applicants website, noting that this was a good source of information and provided good examples of the public benefits of the study.</p> <p>5.3.4 Noting the reference in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care) to "ICT", the independent advisers suggested that the acronym be correctly defined upon first use.</p>	
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	<p>5.3.5 The independent advisers queried the statement in section 5(d) (ii) <i>“This reduces gaming by various hospitals leading to benefits for the health services”</i>; and suggested that this was reworded in non-pejorative language.</p>	
5.4	<p>Reference Number: NIC-01207-V9G9P-v9.3</p> <p>Applicant: Compufile Systems Limited</p> <p>Application Title: ESPRIT tool</p> <p>Presenter: Abigail Lucas</p> <p>SAT Observer: Kimberley Watson</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 14th December 2017, 21st December 2017, 28th November 2019, 3rd September 2020, 17th February 2022 and 12th May 2022.</p> <p>The application and relevant supporting documents were previously presented / discussed at the DAAG meetings on the 16th February 2016, 23rd February 2016 and 20th December 2016.</p> <p>Application: This was a renewal application.</p> <p>The purpose of the application is for the purpose of Compufile Systems Limited providing data analytics and consultancy services to clients in the health sector.</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 comments:</p> <p>5.4.1 NHS England advised the group that following submission of the application to the group for review, they had identified three further updates that would need making to section 5(a) (Objective for Processing), which included 1) further text to clarify that Compufile Systems Ltd could hold the data for a period of five years, 2) further clarification of the commercial purpose, as outlined in section 5(c) (Is the Purpose of this Application in Anyway Commercial); and 3) confirmation that the privacy notice had been updated to reflect the role of NHS England (previously undertaken by NHS Digital). The group noted the verbal updates from NHS England.</p> <p>5.4.2 The independent advisers commended NHS England and the applicant on the work undertaken on the application.</p> <p>5.4.3 The independent advisers also noted and commended the applicant on the excellent transparency / transparency materials; and advised NHS England, that this could be used as an example of good practice.</p> <p>5.4.4 Noting the statement in section 5(c) (Specific Outputs Expected' <i>“CCG's - as known at the time; now ICS's” (*Integrated Care Systems)</i>; the independent advisers suggested that this was reviewed to note that this was not a name change; and that this was updated as may be necessary.</p>	

	<p>5.4.5 In addition, noting the references in section 5 (Purpose / Methods / Outputs) to “ICS”, the independent advisers suggested that these were reviewed and updated to “<i>Integrated Care Boards (ICBs)</i>” where appropriate.</p> <p>5.4.6 The independent advisers queried the statement in section 5(a) in respect of data minimisation “<i>Limited to episodes that are not required for CSL’s clients based on the “main specialty” of the consultant overseeing the episode</i>”; and suggested that this was reviewed and updated as appropriate, for example, to reflect that it was limited to episodes that are required / not required, and to reflect the factual scenario.</p> <p>5.4.7 Noting the statement in section 5(a) “...<i>CSL go through a multi-layered procedure to ensure the organisation and each user who will access the data, is aware of the limited way the data may be used and the consequences of its misuse...</i>”; the independent advisers advised that there should be limited options available for “<i>misuse</i>”, and therefore suggested that this should be amended to make reference to the contract governing the use and there would be consequences for any misuse of the data, or similar.</p> <p>5.4.8 The independent advisers noted that when the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) had reviewed the application on the 17th February 2022, they had asked that the yielded benefits were updated in line with NHS Digital (now NHS England) DARS Standard for Expected Measurable Benefits and that applicant provide 2 or 3 specific yielded benefits accrued to date in section 5(d) (Benefits) (iii) (Yielded Benefits) and to ensure these are clear about the benefits to both patients and the health care system more generally. The independent advisers noted that this had been done, however, suggested that, if possible, quantitative analysis was also added to section 5(d) (iii) to support the yielded benefits outlined.</p> <p>5.4.9 Separate to the application, the independent advisers suggested that in relation to commercial applications, NHS England should ensure that all yielded benefits are aligned with the recently published National Data Guardian guidance on benefits.</p> <p>ACTION: NHS England to ensure that all yielded benefits are aligned with the recently published National Data Guardian guidance on benefits.</p>	DARS
5.5	<p>Reference Number: NIC-534549-M1N3P-v0.9</p> <p>Applicant: University of Bristol</p> <p>Application Title: ELUCIDate: “ELUCidate long-term consequences of Childhood Infections using administrative and research Data”</p> <p>Presenter: Abigail Lucas</p> <p>SAT Observer: Kimberley Watson</p> <p>Application: This was a new application coming for advice.</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. The use of the General Practice Extraction Service (GPES) data for Pandemic Planning and Research (GDPPR) dataset. 	

<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 response to point 1</p> <p>5.5.1 The group advised that they were supportive of the application based on the evidence provided; however awaited feedback from NHS England's Caldicott Guardian Team representative regarding General Practice Extraction Service (GPES) data for Pandemic Planning and Research (GDPPR) – Profession Advisory Group (PAG) comments on the request / use of the GDPPR dataset requested, as advised in-meeting.</p> <p>5.5.2 Separate to this application, the independent advisers reiterated advice previously given to NHS England, that there should be a clear, consistent, and transparent approach to the review of applications / applicants requesting the GDPPR dataset; and that this was clearly communicated to the public, profession etc; for example, in respect of the process for applications that have previously received PAG support.</p> <p>ACTION: NHS England to ensure there is a clear, consistent, and transparent approach to the review of applications / applicants requesting the GDPPR dataset; and that this was clearly communicated to the public, profession etc; for example, in respect of the process for applications that have previously received PAG support.</p> <p>Subsequent to the meeting: NHS England's Caldicott Guardian Team representative provided an update to the group as to when NHS England should / should not seek the views of PAG; and advised that, any further queries should be directed to the PAG Chair for discussion / clarity.</p> <p>5.5.3 The independent advisers queried the statement in section 5(a) (Objective for Processing) <i>“Medicines dispensed in Primary Care NHS Business Services Authority (NHSBSA) – necessary to capture relevant prescriptions and identifying other areas of concern in the cohort”</i>; and suggested that this was removed, noting the information elsewhere in section 5(a) that describes the purpose of requesting the NHSBSA data.</p> <p>5.5.4 The independent advisers noted the statement in section 5(a) that referred to <i>“...the relevant 15 chapters of the British National Formulary (BNF)...”</i>; and suggested that this was amended to provide further clarity on what this means, suitable for a lay reader.</p> <p>5.5.5 The independent advisers queried the statement in section 5(a) <i>“It still needs to be understood whether post-COVID syndrome is a new condition in itself, or a group of conditions like post viral fatigue, which are already known about”</i>; the independent advisers suggested that the end of this sentence was removed as it was not necessary.</p> <p>5.5.6 Noting that the territory of use in section 2(c) (Territory of Use) was stated as <i>“UK”</i>; the independent advisers queried the statement in section 5(b) (Processing Activities) <i>“The data will not leave England/Wales at any time”</i>; and suggested that either section 2(c) was updated to reflect that the territory of use was <i>“England and Wales”</i>; or, if the territory of use is the <i>“UK”</i>, then remove the incorrect statement in section 5(b).</p> <p>5.5.7 The independent advisers noted that updates on the study would be sent to the parents of the children and young people in the cohort; however, noting that some of the young people in the study would become adults during the period of the study, suggested that communication was sent to the relevant people in line with their age.</p>	<p>NHSE / PAG Chair</p>
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5.6	<p>Reference Number: NIC-135277-R8M3G-v7.7</p> <p>Applicant: Regional Drug & Therapeutic Centre (RDTC)</p> <p>Application Title: Regional Drug and Therapeutics Centre (RDTC Newcastle) access to HES and GPES Data for Pandemic Planning and Research (COVID-19)</p> <p>Presenter: Clare Wright</p> <p>SAT Observer: Cath Day</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 16th November 2017, 18th June 2020, 17th November 2020 and 3rd December 2020.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meeting on the 1st September 2020.</p> <p>The application was previously presented at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 7th October 2020, 28th October 2020 and 6th July 2022.</p> <p>Application: This was a renewal and amendment application.</p> <p>The amendments are to 1) add Medicines Dispensed in Primary Care data set (NHSBSA); and 2) to update all references from “<i>Clinical Commissioning Groups</i>” (CCGs) to “<i>Integrated Care Boards</i>” (ICBs) and/or Sub ICB Location (SICBL).</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 substantive comments:</p> <p>5.6.1 The independent advisers noted that General Practice Extraction Service (GPES) data for Pandemic Planning and Research (GDPPR) dataset; and the Medicines Dispensed in Primary Care data set (NHSBSA) datasets were flowing / had been requested; and noted concern that the information provided within section 5 (Purpose / Methods / Outputs) does not always align with the restrictions in place as outlined in the COVID-19 Public Health Directions 2020 and the NHS BSA Medicines Data Directions 2019.</p> <p>NHSBSA Dataset:</p> <p>5.6.2 The independent advisers queried the statement in section 5(a) (Objective for Processing) “...requires access to NHSBSA data from NHS England as there are additional fields within this dataset when acquired through NHS England such as ethnicity...”; and suggested that this was updated further in line with the parameters of the NHSBSA Direction, noting that this data cannot be processed solely for the purpose of augmenting the ethnicity data if not otherwise within the scope of the NHSBSA Direction.</p> <p>5.6.3 The independent advisers queried the statement in section 5(a) “<i>The Regional Drug and Therapeutics Centre at Newcastle (RDTC) hosted by the Newcastle Upon Tyne Hospitals Foundation Trust (the trust) extracts and analyses prescribing data to identify trends and variation, and to support medicines optimisation</i>”; and suggested that this was updated further in line with the parameters of the NHSBSA Direction.</p>	
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<p>5.6.4 The independent advisers queried the expected benefit in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care) that states “...<i>can work to identify ways to optimise prescribing, enabling the most cost effective use of medicines across the health economy</i>”; and suggested that this was updated further in line with the parameters of the NHSBSA Direction.</p> <p>5.6.5 Separate to this application, the independent advisers advised NHS England, that they would welcome a discussion with the NHS BSA Information Asset Owner (IAO) in respect of the content of the Direction and the onboarding instructions, and any potentially restrictive wording; and be provided with a copy of the onboarding instructions as part of this discussion. The AGD Secretariat advised the group that this action was in process and that the NHS BSA Information Asset Owner (IAO) was due to attend an AGD meeting in June 2023.</p> <p>ACTION: NHS BSA IAO to attend AGD meeting to discuss the content of the Direction and the onboarding instructions, and any potentially restrictive wording.</p> <p>GDPPR Dataset:</p> <p>5.6.6 Noting the previous PAG support obtained on the 7th October 2020 for the General Practice Extraction Service (GPES) data for Pandemic Planning and Research (GDPPR) dataset; NHS England advised the group that they did not think a further PAG review was required for the processing of this dataset under this iteration of the application, noting there was no change to the processing.</p> <p>5.6.7 Separate to this application, the independent advisers advised NHS England that there should be a clear, consistent, and transparent approach to the review of applications / applicants requesting the GDPPR dataset; and that this was clearly communicated to the public, profession etc; for example, in respect of the process for applications that have previously received PAG support.</p> <p>ACTION: NHS England to ensure there is a clear, consistent, and transparent approach to the review of applications / applicants requesting the GDPPR dataset; and that this is clearly communicated to the public, profession etc; for example, in respect of the process for applications that have previously received PAG support.</p> <p>Subsequent to the meeting: NHS England’s Caldicott Guardian Team representative provided an update to the group as to when NHS England should / should not seek the views of PAG; and advised that, any further queries should be directed to the PAG Chair for discussion / clarity.</p> <p>5.6.8 Noting the statement in section 5(d) (ii) “<i>The vast majority of this research is about improving population health...</i>”, the independent advisers suggested that this was reviewed, noting the restrictions of the use of the GDPPR data to COVID-19 purposes as set out in the relevant Direction.</p> <p>5.6.9 The independent advisers queried the special condition in section 6 (Special Condition) in respect of the GDPPR dataset; and asked that this was reviewed and updated as may be necessary, to ensure the correct wording is used, and that this dataset can only be used for the purpose of COVID-19 research.</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>NHSE</p> <p>NHSE / PAG Chair</p>
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5.6.10 NHS England advised the group that following submission of the application to the group for review, they had identified two further updates that would need making to the application, which included **1)** to remove the reference in section 5(a) to “NHS Digital” and replace with “NHS England”; **2)** to complete the last paragraph in section 5(a), noting this had ended mid-sentence; and **3)** to amend the NHS England citation wording in section 6, to state that where practicable, outputs cite the source of the data as “*This work uses data provided by patients and collected by the NHS as part of their care and support*”. The group noted the verbal updates from NHS England.

5.6.11 The independent advisers noted that at the AGD meeting on the 11th May 2023, NHS England had advised that the text used in section 3(c) (Patient Objections) in respect of opt-outs would be reviewed and updated as necessary; and suggested that section 3(c) in this application was aligned with the correct / most recent text used in other applications, and that it was made clear that the National Data Opt-out would **not** be applied.

5.6.12 The independent advisers noted several suggested updates to section 5(d) in line with [NHS England’s DARS Standard for Expected Measurable Benefits](#); which are as follows:

5.6.13 The independent advisers queried the statement “*The short-term cost impact of changes in prescribing over the last few months and additionally the impact of changes in prescribing throughout the pandemic and for the foreseeable future, as the Mid to long term effects of post COVID-19 recovery health needs are seen*”; and suggested that this was either updated in language suitable for a lay reader or removed.

5.6.14 Noting the statement “...to support the SICBL in meeting their statutory functions during the pandemic”; the independent advisers suggested that this was updated further to address the reference to “statutory functions”; and to review the language used when referring to “during the pandemic”, noting that we were no longer in the COVID-19 pandemic.

5.6.15 The independent advisers queried the statement “*It will also support identification of potential mis-management of prescribing in COVID-19 infection and subsequent management, which is needed to ensure optimum patient care*”; and asked that this was reviewed for accuracy and updated as may be necessary.

5.6.16 The independent advisers noted the statement “*The GPES data **will help to fight against the pandemic** by predicting increased usage of different medicines groups due to COVID-19 in the long term and by attributing usage to COVID-19 impact in the short-term. This will help to manage the impact of the virus and thus ease pressures in the NHS system*”; and queried if this was correct, and that this was reviewed and updated as may be necessary.

5.6.17 Noting the statement “*High dose ICS are associated with an increased risk of systemic side effects, including adrenal suppression and growth retardation in children...*”; the independent advisers advised that although this was correct, it was not relevant to the preamble regarding Chronic Obstructive Pulmonary Disease (COPD), and suggested that this was removed.

5.6.18 The independent advisers noted the yielded benefit “*RDTC have not had access to GDPPR data under the previous iteration of this Agreement as the NHS England platform was not available. No additional benefits have therefore been yielded through the use of*

	<p><i>GDPPR data</i>"; and queried if this was an actual yielded benefit; and suggested that this was reviewed and updated or removed if not relevant.</p> <p>5.6.19 Noting the reference to “<i>GIMMMG</i>”, the independent advisers suggested that the acronym be correctly defined upon first use.</p>	
AGD Operations		
6	<p>Statutory Guidance</p> <p>The independent advisers queried whether there was any update on the Statutory Guidance; and were advised by NHS England there was currently no update / information to share with the group.</p> <p>It was agreed that this would be a standing item on the AGD meeting agenda going forward.</p>	
7	<p>AGD Terms of Reference</p> <p>The independent advisers queried whether there was any update on the AGD Terms of Reference; and were advised by NHS England there was currently no update / information to share with the group.</p> <p>It was agreed that this would be a standing item on the AGD meeting agenda going forward.</p>	
8	<p>Standard operating procedures</p> <p>The ongoing forward plan of work for creating Standard Operating Procedures was discussed.</p>	To note
9	<p>New Operational Actions & those carried forward from previous meetings of AGD:</p>	To note
9.1	<p>IR35 / Zero Hours contracts for independent advisers</p> <p>Vicki Williams noted that NHS England were actively working on putting zero hours contracts in place for all independent advisers.</p>	
Any Other Business		
10	No items for discussion.	
	<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>	