Minutes of the meeting of the Sub Committee of the Confidentiality Advisory Group

March 2025

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1. NEW APPLICATIONS (RESPONSE TO PROVISIONAL OR CONDITIONAL OUTCOME)

1.1	**25/CAG/0006**	**The UK Colorectal Cancer Intelligence Hub**
	Contact:	Dr Chris Marsden
	Data controller:	University of Oxford
	Application type:	Non-research

Present:

Name	Capacity
Dr Tony Calland, MBE	CAG Chair
Mr Anthony Kane	CAG Lay Member
Ms Rose Payne	CAG Lay Member
Mr Dan Roulstone	CAG Lay Member

Also in attendance:

Name	Position (or reason for attending)
Dr Paul Mills	HRA Confidentiality Advice Service Manager

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from the University of Oxford set out the purpose of using a registry containing data for all individuals who are at risk of, or are diagnosed with, colorectal cancer in the UK for non-research purposes.

Colorectal cancer is a major public health problem and each year in the UK around 41,000 people are diagnosed with the disease and 16,000 die from it. High-quality data could support improved service evaluation and resource planning by health services and improve colorectal cancer outcomes. Good intelligence underpins patient choice, helping individuals reduce the risk of disease and access the best care. It identifies and quantifies inequalities, improves the cost-effectiveness and quality of services, and supports cancer research.

This resource already has Regulation 5 support for research purposes (23/CAG/0151) and is now seeking support to use the information for non-research purposes, such as audits and evaluations. The data flows remain the same, with information flowing from national datasets and audits from England and Wales, as well as Scotland and Northern Ireland.

Confidential information requested

Cohort	All patients in England and Wales with a diagnosis of, or suspect diagnosis of, colorectal and/or anal cancer since 01 January 1997. Expected to be about 41,000 new cases per year
Data sources	1. National Cancer Registration and Analysis Service a. Cancer Registry Data b. National Radiotherapy Dataset (RTDS) c. Systematic Cancer Therapy Dataset (SACT) d. Patient Reported Outcomes (PROMS) e. Patient Reported Experience Survey 2. NHS England a. Hospital Episode Statistics (HES) b. Diagnostic Imaging Dataset (DID) c. Cancer Waiting times (CWT) d. NHS Bowel Cancer Screening Programme 3. Health Quality Improvement Partnership (controller) a. National Bowel Cancer Audit (processors - NHS England and Royal College of Surgeons of England) b. National Emergency Laparotomy Audit (processors - Royal College of Anaesthetists and Royal College of Surgeons of England) 4. Welsh Cancer Intelligence and Surveillance Unit a. Cancer Registry Data b. National Radiotherapy Dataset (RTDS) c. Systematic Cancer Therapy Dataset (SACT)

	d. Patient Reported Outcomes (PROMS) e. Patient Reported Experience Survey 5. Public Health Wales a. Patient Episode Database Wales (PEDW) b. Bowel Screening Wales
Identifiers required for linkage purposes	1. NHS number 2. Date of birth 3. Postcode of residence at diagnosis 4. Full name
Identifiers required for analysis purposes	No identifiers required for analysis, but may be used in the background to derive variables (e.g. such as age at diagnosis or treatment or index of multiple deprivation score)

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	The following points relate to the notification strategy: Please provide a coherent plan detailing the notification strategy. This should include example wording explaining: • the use of confidential patient information without consent and; • that there is a legal basis under Section 251 of the NHS Act following CAG advice • Ensure a contact email address and telephone number are included on the notification materials to allow patients to enact the local opt-out if desired. The project	The applicants explained that discussions are still underway with NHS England on the precise nature of the flows which may be updated, and it is therefore difficult to provide a full plan at this stage. The applicants indicated information will be available on the University of Oxford website, awareness rising with charities and information leaflets available for patients that will be produced with patients. CAG considered the response and agreed to provide support to enable conversations with NHS England to continue. Members however agreed that the support is condition on the applicants providing a full plan on communication routes **(Condition 1)** and draft materials **(Condition 2)** for

	specific opt-out details should be presented on the notification materials with more prominence than the National Data Opt-Out, which should just acknowledge the fact that it will be applied.	CAG review and approval prior to any flow of confidential patient information.
2.	Provide more information about the project funding arrangements.	The applicants confirmed that the resource will continue supported by funding from the Oxford Cancer Research UK Centre, the Oxford Biomedical Research Centre Translational Data Science theme and Health Data Research UK. Members accepted this response.
3.	Confirm data flow frequency (i.e. how often the data will flow between organisations).	The applicants confirmed that this will be an annual data flow. The CAG accepted this response.

Confidentiality Advisory Group advice: Conditionally supported

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Secretary of State for Health and Social Care, subject to compliance with the specific and standard conditions of support as set out below.

Number	Condition
1.	Provide CAG for approval a full communications plan to be used, prior to any flow of Confidential Patient Information beginning.
2.	Provide CAG for approval a full suite of materials that will be used to information patients of this activity, prior to any flow of Confidential Patient Information beginning.
3.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. Confirmed: The NHS England 23/24 DSPT review for NHS England, Royal College of Surgeons of England, Royal College of Anaesthetists and University

	of Oxford - Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences Big Health Data Group were confirmed as 'Standards Met' on the NHS England DSPT Tracker. A satisfactory Welsh IG Toolkit for Public Health Wales was confirmed as met on the Digital Health and Care Wales tracker.

1.2	**25/CAG/0002**	**Investigating equity and outcomes of genetic testing in Wales, v1.0**
	Chief Investigator:	Dr Andrew Fry
	Sponsor:	Cardiff University
	Application type:	Research

Present:

Name	Capacity
Dr Murat Soncul	CAG Alternate Vice-Chair
Dr Malcolm Booth	Expert Member
Professor Sara Randall	Lay Member

Also in attendance:

Name	Position (or reason for attending)
Rachel Katzenellenbogen	HRA Approvals Specialist

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from Cardiff University is for the purpose of medical research to study geography, gender, socioeconomic factors and language influence the uptake of genetic testing.

Genetic testing is changing medical diagnosis and treatment. However, it is important to ensure that there is fair access to and equal uptake of such testing. This study plans to investigate what factors are barriers to genetic testing so it can be approved.

The applicants will collect data from All Wales Medical Genomics Service (AWMGS). Two files will be created, with a study code to link them. File 1 will contain identifiable data and be sent to Digital Health and Care Wales (DHCW) while File 2, containing link anonymised data, will be sent to Secure Anonymised Information Linkage (SAIL)

Databank. DHCW will use the information in File 1 to add the relevant Anonymous Linking Field (ALF). File 3, consisting of the study code and the ALF, will then be sent to SAIL to allow them to match records to their existing data. Support is requested for the applicants to access confidential patient information at AWMGS to prepare files to send to DHWC and SAIL.

Confidential information requested

Cohort	The cohort is everyone who has been referred to the All Wales Medical Genomics Service (AWMGS) for genetic testing over the last 30 years. This is a retrospective cohort of between 50,000 and 100,000 people. Until the data is analysed it is not possible to be more precise on numbers, nor is it possible to know how many of the records are of now deceased people.
Data sources	• All Wales Medical Genomics Service, Cardiff and Vale University Health Board • Digital Health and Care Wales
Identifiers required for linkage purposes	• Name • NHS number • Date of birth • Postcode
Identifiers required for analysis purposes	• Postcode – sub-sector level • Lower Super Output Area

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Following the meeting, security assurances for 2023/2024 for the following organisations were confirmed. Cardiff and Vale Health Board (Hosts the All Wales Medical Genomics Service)	This was already confirmed following the meeting, and no further action was required from the applicant.
2.	The CAG request that further public involvement should be	a. Applicants presented the study at a Women's Institute branch meeting at

	conducted to ensure feedback received is representative of the research participatory group: a. Ensure that responses from people with a lay background are recruited b. Recruit those who have lived experience of undergoing genetic testing c. It is recommended that people who have undergone genetic testing but tested negative should be approached to partake in any public involvement activities d. It advised that any support groups that actively engaged with research participatory group should be approached	the end of February, consulting primarily on the readability of the amended Participant Information Sheet, but also discussing the concept of anonymised health data linkage, which was unfamiliar to the group. The members, some of whom had prior knowledge of genetic testing through family experience, agreed that the information provided was accessible and expressed interest in the project itself, suggesting a follow-up engagement once the study is in progress. We are planning to organise a simillar presentation at a Merched y Wawr meeting to inform about the study and to consult on the readability of the Welsh language version of the Participant Information Sheet. a,b,c Applicants have provided information about the proposed study to a number of charities and support organisations for the conditions included in the project. Applicants have received responses from : Nerve Tumours UK, The Fragile X Society, Haemochromatosis UK, and Breast Cancer Now. Applicants are going to provide these organisations with further information about the project with the aim for the finalised Participant Information Sheet being shared with the members, whether via the respective websites or social media pages. Applicants have been invited to present the study at the Welsh members of the Haemochromatosis UK at the end of March. d. Applicants will be presenting the project at the Genomic Partnership Wales Sounding Board on April 2nd where we will also consult on the participant information material and the clarity of the opt-out arrangements.

		The CAG found the information provided made no mention of discussion of the use of Confidential Patient Information without consent and requested this be undertaken before the first annual review.
3.	The CAG note that the Patient Information Sheet is written using complex terminology which may be difficult for a lay person to understand. It is requested that the patient information sheet is rewritten using plain English and presented to a public involvement group for feedback on its accessibility.	The applicants have redrafted the Participant Information Sheet to be more accessible, and tested its readability at a WI meeting and are planning further consultation at the GPW Sounding Board, and at a Merched Y Wawr meeting, for the Welsh language version. The CAG was content with this.
4.	Confirm whether all patient notification materials will be translated into Welsh.	Yes. The CAG was content with this.
5.	The CAG request that the following information should be provided in the patient notification materials: 1. State that the study along with the supporting documentation has been reviewed by CAG under section 251 of the NHS Act 2006. 2. State that identifiable information will be accessed prior to the data linkage process.	Applicants have included this information in the Participant Information Sheet and will include it in the information provided on AWMGS website. The CAG noted the wording about CAG support was not accurate and requested it be correct.
6.	The CAG state that the specific opt-out process should be centralised with the contact details of the organisation genetic testing centres rather than providing a list of data controllers: a) Include an institutional telephone, email and postal address	Applicants are going to place the information about the project on the AWMGS website, including the information about opt-out arrangements. Applicants have provided a single, project-specific email address, which is included on the Participant Information Sheet and will also be sent, together with other contact details, to the organisations representing individuals affected by

		the conditions included in the study. The CAG was content with this.
7.	The CAG suggested that potential participants should be provided with a 2-month period via AWMGS to opt-out of the study if they wish to do so. It is advised that notices should displayed on specific websites to increase accessibility to information on how to withdraw from the study	This information will be placed on the AWMGS website and will be sent to organisations supporting individuals affected by the conditions included in the study. The CAG was content with this.

Confidentiality Advisory Group advice: *Conditionally supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Number	Condition
1.	The information about public involvement makes no mention of discussion of the use of Confidential Patient Information without consent. The CAG asks that you cover this in your ongoing engagement with patient representatives and provide feedback about this at the first annual review.
2.	Please add the following to the Participant Information Sheet: '*The application was reviewed by the Confidentiality Advisory Group (CAG). CAG is an independent group of lay people and professionals which provides expert advice on the use of confidential patient information without consent. CAG recommended that our application should be supported and the Decision Maker within the Health Research Authority approved this.'*
3.	Favourable opinion from a Research Ethics Committee. **Confirmed 14 June 2024.**
4.	Confirmation provided from the DSPT/WIGTK Team at NHS England/ NHS Wales to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. The DHCW Welsh IG Toolkit review for Cardiff and Vale Health Board was confirmed as satisfactory on 22 January 2025.

1.3	**24/CAG/0149**	**UK Registry for Thymic Epithelial Tumours**
	Chief Investigator:	Dr Eleni Karapanagiotou
	Sponsor:	Guy's and St Thomas' NHS Foundation Trust
	Application type:	Research Database

Present:

Name	Capacity
Dr Murat Soncul	CAG Alternate Vice Chair
Dr Martin Andrew	CAG Expert member
Mr Dan Roulstone	CAG Lay Member
Mary Thomas	CAG Lay Member

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from Guy's and St Thomas' NHS Foundation Trust (GSTT) is for the purpose of medical research which aims to create a research database of retrospective and prospective patients diagnosed with thymic cancers.

Thymic epithelial tumours (TETs) are rare, leading to a significant lack of standardised treatment options and clinical knowledge. The UK Registry for TETs will be the first national-level effort to systematically collect and analyse clinical and demographic data for patients with TETs. This project is essential to support clinicians in making informed decisions, advancing patient care, and reducing the long-term burden on patients and their families. The primary purpose of this project is to compile a dataset that can be used for research into the clinical characteristics, treatment outcomes, and survival rates of patients with thymic epithelial tumours. This registry aims to provide real-world data that can help answer research questions on disease incidence, progression, treatment efficacy, and recurrence patterns. There is a corresponding non research application for non research purposes (24/CAG/0153).

GSTT will serve as the lead centre for this registry, with identifiable data being uploaded from participating centres to a central REDCap database managed and

maintained by GSTT. Prospective patients will provide consent, and any patient included with consent is outside of the scope of 's251' support. 's251' support is requested for the inclusion of confidential patient information regarding retrospective cases, from 1st January 2014, and for linkage of their data to outcome data, via NHS England, Digital Health and Care Wales (DHCW) and participating sites.

Only anonymised or pseudonymised data (which is effectively anonymous) will be released to external researchers from NHS and academic centres nationally. All data access requests will require approval from the Data Access Committee (DAC), which will review applications based on scientific merit, ethical considerations, and alignment with the registry's objectives. The DAC is already established and comprises lay representation.

Confidential information requested

Cohort	All individuals diagnosed and/or treated for thymic epithelial tumours (TET)s at Thoracic Oncology Centres across the UK, who are 18 and above. Only patients with histologically confirmed thymoma, thymic carcinoma or thymic neuroendocrine tumours will be included in the Registry Retrospective data will be captured for patients diagnosed from 1st January 2014 to date of study initiation. Approximate total for UK retrospective cohort is 3795, however Scottish and Northern Irish patients are out of scope. Approximately 10% of the retrospective cohort will be deceased. Prospective data will be included with consent and is out of scope for 's251' support.
Data Sources	Thoracic Oncology Centres across the UK; medical records. Scope of CAG application are English and Welsh centres only. NHS England – HES, SUS and Civil Registrations of Death. Digital Health and Care Wales (DHCW) – Patient Episode Database for Wales (PEDW).
Identifiers stored within the registry	NHS number Date of birth Date of death Gender

	Ethnicity
Identifiers required for linkage purposes	NHS number Date of birth
Identifiers required for analysis purposes	Date of death –modified for analysis/release to external researchers Gender Ethnicity Age (effectively anonymous)
Additional information	Health outcome updates will be requested annually.

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Support cannot be issued until a Favourable opinion from a Research Ethics Committee is in place.	This was provided in December.
2.	Provide feedback received from the planned video, including feedback about the use of confidential patient information without consent, and a description of how many people provided feedback, and how they represent the cohort.	To engage the thymic cancer community and gather feedback on the use of confidential patient information without consent, applicants have created a dedicated webpage through ThymicUK: https://www.thymicuk.org/uk-registry-for-thymic-epithelial-tumours/ This webpage hosts an informational video (hosted on YouTube for accessibility) and a feedback survey. It also provides clear details on how individuals can opt out if they wish. Patients and carers are being directed to this resource during clinic visits, ensuring widespread awareness. **Video Engagement and Survey**

		Participation **Video Views**: Over 80 views to date. **Survey Responses**: 33 individuals directly or indirectly affected by thymic epithelial tumours (TETs) provided feedback. **Representation of Respondents**: 20 (61%) were patients diagnosed with a TET. 13 (39%) were carers or family members. **Feedback on the Use of Confidential Patient Information Without Consent** 67% (22/33) strongly agree that identifiable data (e.g., NHS numbers, dates of birth) is necessary for the registry's success. 30% (10/33) agree, indicating broad support. 3% (1/33) were neutral, and no respondents disagreed. **Comfort Level with Data Use** 91% (30/33) feel very comfortable with their (or their loved one's) data being used for research. 9% (3/33) feel somewhat comfortable – no one expressed discomfort. **Perceived Benefit vs. Privacy Concerns** 88% (29/33) believe the benefits outweigh privacy concerns. 12% (4/33) feel privacy and benefits are equally balanced. No one expressed opposition to data use. **Key Themes from Free-Text Comments** Overwhelming support for the registry, particularly given the rarity of TETs. A desire for ongoing updates on how data is being used, which we will ensure through continued patient engagement. The video was well received, helping to humanise the registry team and build trust. This feedback demonstrates strong patient and carer endorsement for the registry's data use approach. The clear majority understand the necessity of using identifiable data, feel comfortable with it, and believe the registry's

		benefits justify its use. CAG were content with this response.
3.	Revise all notification materials, ensuring that they: a. Explain how the retrospective cohort will be included under 's251' support, with support of the HRA and SofS following CAG advice. b. Reference all opt-out options, including stating that the National Data Opt-Out will be respected. c. The summary material (newsletter and social media post) could link to the website for further information. d. Provide all draft texts for review, including newsletters, website texts, etc. e. Ensure a notification is also included on the Guy's and St Thomas' NHS Foundation Trust website	Applicants have ensured that all notification materials align with CAG's guidance, providing clear information on data use, opt-out options, and patient rights. **Dedicated Webpage on ThymicUK Website** A dedicated webpage has been created on the ThymicUK website to provide transparency about the UK Registry for Thymic Epithelial Tumours: https://www.thymicuk.org/uk-registry-for-thymic-epithelial-tumours/ This webpage hosts an informational video, which explains: The purpose of the registry and how it will improve care. How patient data is collected, stored, and used. Security measures in place to protect patient confidentiality. Patient rights and opt-out options. The page also includes a survey feedback link for viewers to share their thoughts and clear opt-out instructions, directing individuals to email thoracicresearchgroup@gstt.nhs.uk if they do not wish their data to be included. **Revised Newsletter and Social Media Post** Applicants provided updated versions of the newsletter and social media post for review. **Response to Guy's and St Thomas' NHS Foundation Trust (GSTT) Website Notification** Applicants have made multiple attempts to get Guy's and St Thomas' NHS Foundation Trust (GSTT) to publish a notification on their website, but so far, have been unsuccessful. Applicants have had extensive discussions with a key contact in GSTT Research &

		Development (R&D), who is currently working on developing a dedicated research website. Once this is live, applicants have been assured that a notification about the thymic registry can be included on that site. However, there is no confirmed timeline for when this will be available. Given GSTT's role as a data controller, applicants will continue advocating for greater transparency in research involving patient data. In the meantime, it is hoped that the ThymicUK webpage will be sufficient, as we are actively directing patients and carers to this resource when they attend clinic visits and through our other notification channels. CAG were content with this response, and included a condition for annual review to update CAG on progress regarding GSTT website.
4.	Please confirm if the notification added to the Guy's and St Thomas' NHS Foundation Trust website will take the form of a registry webpage, or merely a singular notification about the registry.	See response above. CAG were content with this response, and included a condition for annual review to update CAG on progress regarding GSTT website.
5.	Please confirm if you plan to attempt to consent any retrospective patients who are already included in the registry with 's251' support, if they are seen in clinic.	Applicants do not plan to approach any retrospective patients to seek consent. CAG were content with this update.

Confidentiality Advisory Group advice: *Conditionally supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Number	Condition
1.	Support is provided for 5 years, at which time point a duration amendment is required.
2.	Please follow up with GSTT regarding the Trust R&D website to include details of this register, and update CAG at annual review.
3.	Favourable opinion from a Research Ethics Committee. **Confirmed 11 December 2024**
4.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England **23/24** DSPT reviews for **Guy's and St Thomas' NHS Foundation Trust & NHS England** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 14 November 2024) The **23/24** Welsh IG toolkit for **Digital Health and Care Wales (DHCW)** was confirmed as 'Action plan received - Minimum Expectations not met with an action plan in place' on the WIGTK Tracker (checked 14 November 2024) Due to the number of participating organisations involved (NHS Trusts and Welsh health boards), It is the responsibility of Guy's and St Thomas' NHS Foundation Trust as controllers, to ensure that participating organisations meet the minimum required standard in complying with DSPTs/Welsh IG toolkits, and take remedial action if they become aware of any that fall below this, or where any concerns are raised about an organisation.

1.4	**24/CAG/0153**	**UK Registry for Thymic Epithelial Tumours (TETs)**
	Contact:	Eleni Josephides
	Data controller:	Eleni Karapanagiotou
	Application type:	Non-research – registry

Present:

Name	Capacity
Dr Murat Soncul	CAG Alternate Vice Chair
Dr Martin Andrew	CAG Expert member

Mr Dan Roulstone	CAG Lay Member
Mary Thomas	CAG Lay Member

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from Guy's and St Thomas' NHS Foundation Trust (GSTT) is for the non-research purpose of the management of health and care services which aims to create a registry of retrospective and prospective patients diagnosed with thymic cancers.

Thymic epithelial tumours (TETs) are rare, leading to a significant lack of standardised treatment options and clinical knowledge. The UK Registry for TETs will be the first national-level effort to systematically collect and analyse clinical and demographic data for patients with TETs. This project is essential to support clinicians in making informed decisions, advancing patient care, and reducing the long-term burden on patients and their families. The primary purpose of this project is to compile a dataset that can be used for non-research into the clinical characteristics, treatment outcomes, and survival rates of patients with thymic epithelial tumours. The registry aims to establish the foundation for developing future national management guidelines and contribute to a deeper understanding of TETs in the UK and potentially worldwide. There is a corresponding research application for research purposes (24/CAG/0149).

GSTT will serve as the lead centre for this registry, with identifiable data being uploaded from participating centres to a central REDCap database managed and maintained by GSTT. Prospective patients will provide consent, and any patient included with consent is outside of the scope of 's251' support. 's251' support is requested for the inclusion of confidential patient information regarding retrospective cases, from 1st January 2014, and for linkage of their data to outcome data, via NHS England, Digital Health and Care Wales (DHCW) and participating sites.

Confidential information requested

Cohort	All individuals diagnosed and/or treated for thymic epithelial tumours (TET)s at Thoracic Oncology Centres across the UK, who are 18 and above. Only patients with histologically confirmed thymoma, thymic carcinoma or thymic neuroendocrine tumours will be included in the

	Registry. Retrospective data will be captured for patients diagnosed from 1st January 2014 to date of study initiation. Approximate total for UK retrospective cohort is 3795, however Scottish and Northern Irish patients are out of scope. Approximately 10% of the retrospective cohort will be deceased. Prospective data will be included with consent and is out of scope for 's251' support.
Data Sources	Thoracic Oncology Centres across the UK; medical records. Scope of CAG application are English and Welsh centres only. NHS England – HES, SUS and Civil Registrations of Death. Digital Health and Care Wales (DHCW) – Patient Episode Database for Wales (PEDW).
Identifiers stored within the registry	NHS number Date of birth Date of death Gender Ethnicity
Identifiers required for linkage purposes	NHS number Date of birth
Identifiers required for analysis purposes	Date of death –modified for analysis/release to external researchers Gender Ethnicity Age (effectively anonymous for analysis)
Additional information	Health outcome updates will be requested annually.

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for

further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Provide feedback received from the planned video, including feedback about the use of confidential patient information without consent, and a description of how many people provided feedback, and how they represent the cohort.	To engage the thymic cancer community and gather feedback on the use of confidential patient information without consent, applicants have created a dedicated webpage through ThymicUK: https://www.thymicuk.org/uk-registry-for-thymic-epithelial-tumours/ This webpage hosts an informational video (hosted on YouTube for accessibility) and a feedback survey. It also provides clear details on how individuals can opt out if they wish. Patients and carers are being directed to this resource during clinic visits, ensuring widespread awareness. **Video Engagement and Survey Participation** **Video Views**: Over 80 views to date. **Survey Responses**: 33 individuals directly or indirectly affected by thymic epithelial tumours (TETs) provided feedback. **Representation of Respondents**: 20 (61%) were patients diagnosed with a TET. 13 (39%) were carers or family members. **Feedback on the Use of Confidential Patient Information Without Consent** 67% (22/33) strongly agree that identifiable data (e.g., NHS numbers, dates of birth) is necessary for the registry's success. 30% (10/33) agree, indicating broad support. 3% (1/33) were neutral, and no respondents disagreed. **Comfort Level with Data Use**

		91% (30/33) feel very comfortable with their (or their loved one's) data being used for research. 9% (3/33) feel somewhat comfortable – no one expressed discomfort. **Perceived Benefit vs. Privacy Concerns** 88% (29/33) believe the benefits outweigh privacy concerns. 12% (4/33) feel privacy and benefits are equally balanced. No one expressed opposition to data use. **Key Themes from Free-Text Comments** Overwhelming support for the registry, particularly given the rarity of TETs. A desire for ongoing updates on how data is being used, which we will ensure through continued patient engagement. The video was well received, helping to humanise the registry team and build trust. This feedback demonstrates strong patient and carer endorsement for the registry's data use approach. The clear majority understand the necessity of using identifiable data, feel comfortable with it, and believe the registry's benefits justify its use. CAG were content with this response.
2.	Revise all notification materials, in line with the following advice: a. Explain how the retrospective cohort will be included under 's251' support, with support of the HRA and SofS following CAG advice. b. Reference all opt-out options, including stating that the National Data Opt-Out will be respected. c. The summary material (newsletter and social media post) could link to	Applicants have ensured that all notification materials align with CAG's guidance, providing clear information on data use, opt-out options, and patient rights. **Dedicated Webpage on ThymicUK Website** A dedicated webpage has been created on the ThymicUK website to provide transparency about the UK Registry for Thymic Epithelial Tumours: https://www.thymicuk.org/uk-registry-for-

	the website for further information. d. Provide all draft texts for review, including newsletters, website texts, etc. e. Ensure a notification is also included on the Guy's and St Thomas' NHS Foundation Trust website	thymic-epithelial-tumours/ This webpage hosts an informational video, which explains: The purpose of the registry and how it will improve care. How patient data is collected, stored, and used. Security measures in place to protect patient confidentiality. Patient rights and opt-out options. The page also includes a survey feedback link for viewers to share their thoughts and clear opt-out instructions, directing individuals to email thoracicresearchgroup@gstt.nhs.uk if they do not wish their data to be included. **Revised Newsletter and Social Media Post** Applicants provided updated versions of the newsletter and social media post for review. **Response to Guy's and St Thomas' NHS Foundation Trust (GSTT) Website Notification** Applicants have made multiple attempts to get Guy's and St Thomas' NHS Foundation Trust (GSTT) to publish a notification on their website, but so far, have been unsuccessful. Applicants have had extensive discussions with a key contact in GSTT Research & Development (R&D), who is currently working on developing a dedicated research website. Once this is live, applicants have been assured that a notification about the thymic registry can be included on that site. However, there is no confirmed timeline for when this will be available. Given GSTT's role as a data controller, applicants will continue advocating for greater transparency in research involving patient data. In the meantime, it is hoped that the ThymicUK webpage will be sufficient, as

		we are actively directing patients and carers to this resource when they attend clinic visits and through our other notification channels. CAG were content with this response, and included a condition for annual review to update CAG on progress regarding GSTT website.
3.	Please confirm if the notification added to the Guy's and St Thomas' NHS Foundation Trust website will take the form of a registry webpage, or merely a singular notification about the registry.	See response above. CAG were content with this response, and included a condition for annual review to update CAG on progress regarding GSTT website.
4.	Please confirm if you plan to attempt to consent any retrospective patients who are already included in the registry with 's251' support, if they are seen in clinic.	Applicants do not plan to approach any retrospective patients to seek consent. CAG were content with this update.

Confidentiality Advisory Group advice: *Conditionally supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Secretary of State for Health and Social Care, subject to compliance with the specific and standard conditions of support as set out below.

Number	Condition
1.	Support is provided for 5 years, at which time point a duration amendment is required.
2.	Please follow up with GSTT regarding the Trust R&D website to include details of this register, and update CAG at annual review.
3.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:**

	The NHS England **23/24** DSPT reviews for **Guy's and St Thomas' NHS Foundation Trust & NHS England** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 14 November 2024) The **23/24** Welsh IG toolkit for **Digital Health and Care Wales (DHCW)** was confirmed as 'Action plan received - Minimum Expectations not met with an action plan in place' on the WIGTK Tracker (checked 14 November 2024) Due to the number of participating organisations involved (NHS Trusts and Welsh health boards), It is the responsibility of Guy's and St Thomas' NHS Foundation Trust as controllers, to ensure that participating organisations meet the minimum required standard in complying with DSPTs/Welsh IG toolkits, and take remedial action if they become aware of any that fall below this, or where any concerns are raised about an organisation.

1.5	**25/CAG/0023**	**IMPALA: Increasing informed participation in lung cancer screening**
	Chief Investigator:	Associate Professor Anna Bibby
	Sponsor:	North Bristol NHS Trust
	Application type:	Research

Present:

Name	Capacity
Ms Clare Sanderson	CAG Alternate Vice Chair
Mr David Evans	CAG Member (Expert)
Mr Anthony Kane	CAG Member (Lay)
Ms Mary Thomas	CAG Member (Lay)

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from North Bristol NHS Trust is for the purpose of medical research to evaluate the impact of pathway navigation intervention (in the form of telephone-based motivational interviewing) on CT scan attendance within the NHS Targeted Lung Health Check programme.

Lung cancer is more common in disadvantaged and under-served populations. The same groups of people are less likely to access healthcare and less likely to participate in lung cancer screening. IMPALA aims to increase informed participation in lung cancer screening, and in doing so, address current health inequality in lung cancer diagnosis and survival. It has been designed as a pragmatic, low-burden, decentralised trial. All trial activities will be delivered remotely, participants will not be required to attend any additional trial visits; the navigator contact for people in the intervention arm will be undertaken over the phone, all data will be collected through linkage with routine datasets.

People become eligible for the trial if they have not attended a scheduled CT scan appointment. The study aims to enrol people who find it difficult to access or are less likely to engage with healthcare, with the goal of facilitating access and increasing participation in screening. Patient details are passed to the research team with their consent for use in future research. Patients are randomised to either intervention or control arm. Information sheets will be sent to all participants, explaining the intervention and offering a chance to opt out. Intervention patients are verbally consented during the phone call. Identifiers for all patients are disclosed to NHS England, for linkage with NCRAS and HES data after 3 years, with ‘s251’ support for the control group only. No identifiers are required for analysis.

Confidential information requested

Cohort	People eligible to participate in NHS England's Targeted Lung Health Check (TLHC) screening programme and missed an appointment for a scan. In total, applicants are aiming to recruit 2,400 people from across England over 1 year. However, this will only be regarding the control arm (who are not able to verbally consent to NHS E linkage on the phone) – so, 1,200 total.
Data Sources	Targeted Lung Health Check (TLHC) screening programme records disclosed from Inhealth and other providers, and retained at North Bristol NHS Trust. NHS England - National Cancer Registration and Analysis Service (NCRAS) - Hospital Episode Statistics (HES)
Identifiers required for linkage	1. NHS number 2. Date of birth 3. Name

purposes	4. Study ID
Identifiers required for analysis purposes	1. Gender 2. Ethnicity This is effectively anonymous for analysis.
Additional information	Follow up in the form of a one off linkage will be 3 years.

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Support cannot be issued until a Favourable opinion from a Research Ethics Committee is in place.	This was provided to CAG on 24 March 2025.

The Sub-Committee of the CAG also reviewed the following provisional specific conditions of support:

Number	Condition	Response from the applicant
1.	Please update the Participant Information Sheet (PIS) to make it that, if participants do not opt-out, their data will be linked, within one month of support being provided	The applicant updated this, and CAG were content with this response

Confidentiality Advisory Group advice: *Fully supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Favourable opinion from a Research Ethics Committee. **Confirmed 24 March 2025**

2.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England **23/24** DSPT reviews for **North Bristol NHS Trust and NHS England** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 28 February 2025)

1.6	**25/CAG/0011**	**Oxy-PICU neurodevelopmental (ND) follow-up study**
	Chief Investigator:	Dr Doug Gould
	Sponsor:	Intensive Care National Audit & Research Centre (ICNARC)
	Application type:	Research

Present:

Name	Capacity
Professor William Bernal	CAG Alternate Vice Chair
Dr Joanne Bailey	CAG Expert Member
Mrs Sarah Palmer-Edwards	CAG Expert Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from ICNARC set out the purpose of medical research to assess whether the randomised treatments received in the Oxy-PICU trial has a longer term impact on neurodevelopmental function defined as the overall adaptive behaviour score assessed using the Vineland Adaptive Behaviour Scales, third edition (VABS-3).

Around 20,000 children in the UK are admitted to paediatric ICU's each year. 75% of these children will receive support from a ventilator, alongside additional oxygen. The recently completed Oxy-PICU randomised clinical trial investigated whether

children in PICU receiving help from a ventilator with additional oxygen should have their oxygen levels kept at a lower or higher level. This trial showed that aiming for lower oxygen levels resulted in a small but significant reduction in the number of days children spent on machines or who died at 30 days. However, while in the short-term targeting lower oxygen levels appears better, the effects on children's longer-term development are unknown. This new study has been created to assess whether the randomised treatments received in the Oxy-PICU trial has a longer-term impact on neurodevelopmental function.

The Parents/caregivers of children enrolled into Oxy-PICU, and who provided consent to be contacted about future related research, will be identified and approached to participate in the Oxy-PICU neurodevelopmental follow-up study. Prior to approaching parent/caregivers about participation, the up-to-date survival status of children will be ascertained through NHS Spine by clinical members of the research team at Great Ormond Street Children's Hospital (GOSH). The parents/carers of surviving patients will then be contacted and participation in this study.

A recommendation for class 3 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential information requested

Cohort	Total UK sample size: 556 Total international sample size (including UK): Further details: A total of 1112 (569 conservative group and 543 liberal group) parents of children enrolled into the Oxy-PICU trial and known to have survived to 12 months post randomisation provided consent to be contacted about future related research. Assuming 50% of these agree to participate in the longer-term neurodevelopmental outcomes study, we anticipate 556 parents/caregivers will take part in interviews.
Data Sources	The Oxy-PICU RCT study database
Identifiers required for linkage purposes	Name NHS Number Date of birth
Identifiers required for analysis purposes	Name Date of birth Gender

	Ethnicity

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Support cannot be issued until a Favourable opinion from a Research Ethics Committee is in place.	The REC Favourable Opinion was confirmed on 03 March 2025.
2.	Modify the data flow diagram to include full details of the flow process between GOSH and ICNARC.	A revised data flow, and explanation of the flows involved was provided. These were reviewed and accepted by the CAG.
3.	Confirm when the NDO process will be applied to the study.	The applicants advised that the NDO will be applied during the identification of potentially eligible participants and will be applied prior to confidential patient information being uploaded into the study database. The CAG noted this and raised no further queries.
4.	Make the following changes to the study privacy notice. a. include an explicit route to the study specific opt-out process i.e. include contact details to opt out or further information. b. Explicitly state that once data has been disclosed it is no longer possible to opt out.	A revised Privacy Notice was provided. This was reviewed and accepted by the CAG.

5.	Make the following changes to the PIS document a. Revise the PIS document stating that the Health Research Authority has approved the study following advice from the Confidentiality Advisory Group (CAG) under section 251 of the NHS Act 2006 b. State that section 251 of the NHS Act 2006 will be followed to update patient contact details.	Revised documents were provided. These were reviewed and accepted by the CAG.

Confidentiality Advisory Group advice: *Fully supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Favourable opinion from a Research Ethics Committee. **Confirmed 03 March 2025.**
2.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England **2023/24** DSPT review for I**CNARC** was confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 03 March 2025).

1.7	**24/CAG/0145**	**Machine learning analysis of chest x-rays in cystic fibrosis**
	Chief Investigator:	Dr Julian Legg
	Sponsor:	University Hospitals Southampton NHS Foundation Trust
	Application type:	Research

Present:

Name	Capacity
Ms Clare Sanderson	CAG Alternate Vice Chair
Dr Martin Andrew	CAG Expert Member
Dr Ben Gibbison	CAG Expert Member
Mrs Catherine Bernadette Trigwell	CAG Lay Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from University Hospitals Southampton NHS Foundation Trust set out the purpose of medical research into whether existing x-ray images, associated medical and demographic information and corresponding Chrispin-Norman scores can be used to develop a machine learning system that is able to produce scores from images.

Cystic fibrosis patients are routinely monitored using radiography. Ideally, the images produced are then assessed by a specialist clinician. The aim of this study is to automate this process using machine learning. The creation of a system that can score cystic fibrosis images would reduce the workload of clinicians and would also help medical facilities that don't have access to specialists, both in the UK and in developing countries. Machine learning models have been train to score x-rays according to the Brasfield scoring system used in North America, but has not yet been done for the Chrispin-Norman system used in the UK.

The applicants will use existing x-ray images and patient data, including the Chrispin-Norman score. The Chrispin-Norman score comprises 5 numbers, each a score for a different feature associated with cystic fibrosis. The pseudonymised data will be transferred to the University of Southampton, where it will be stored on University computers and used to train a number of machine learning models, with the aim of predicting each of the components of the Chrispin-Norman score from the images.

A recommendation for class 1, 4 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential information requested

Cohort	Patients aged 0-18 years with a diagnosis of Cystic Fibrosis, who received an annual review at University Hospitals Southampton NHS Foundation Trust between 1/1/2010 and 1/12/2024. 1500 patients will be included.
Data Sources	X-rays and patient data from electronic patient records at University Hospitals Southampton NHS Foundation Trust.
Identifiers required for linkage purposes	Name NHS Number Hospital ID Number Date of birth
Identifiers required for analysis purposes	Gender

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Submit a copy of evidence that public involvement was conducted and provide all feedback that was obtained.	The applicants provided details of the public involvement carried out. The CAG reviewed this information and raised no further queries.
2.	Submit a copy of all patient notification materials that will be used in the study A. Ensure that all patient	The patient notification materials were provided. These were reviewed and accepted by the CAG.

	notification materials from provide details of the National Data Opt Out service B. Provide details of how patients can opt out of the study C. It is advised that the notification materials are presented to a public involvement group for feedback	

Confidentiality Advisory Group advice: *Fully supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority subject to compliance with the standard conditions of support.

Number	Condition
1.	The poster and information sheet need to be revised as below: The reference to CAG needs to be changed to *"The Health Research Authority following advice from the Confidentiality Advisory Group (CAG) (reference number 24/CAG/0145)."* Also, the Legal Compliance section should include details of the GDPR compliance.
2.	The patient notification materials need to be reviewed by a public involvement group.
3.	Please provide a response to the above two points within three months of the issuing of this outcome letter.
4.	Favourable opinion from a Research Ethics Committee. **Confirmed: 16 December 2024.**
5.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:**

	The NHS England **2023/24** DSPT review for University Hospitals Southampton NHS Foundation Trust was confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 05 March 2025).

1.8	**25/CAG/0005**	**Motor Neuron Disease (MND) Alert: a mixed-method feasibility and acceptability pilot study**
	Chief Investigator:	Dr Liam Knox
	Sponsor:	Sheffield Institute for Translational Neuroscience (SITraN), University of Sheffield
	Application type:	Research

Present:

Name	Capacity
Professor William Bernal	CAG Alternate Vice Chair
Dr Martin Andrew	CAG Expert Member
Mr Dan Roulstone	CAG Expert Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from the University of Sheffield set out the purpose of medical research into whether implementation of the MND Alert can help GPs identify early signs of MND and whether the MND Alert Toolkit is helpful and acceptable to GPs in their everyday practice.

Motor Neuron Disease (MND) is an incurable disease, causing progressive muscle weakness, leading to progressive disability and eventual respiratory failure. There

are approximately 5000 people with MND in the UK. The average life expectancy is two to three years, but can vary from a few months to over ten years. The interval between the first symptoms of MND and diagnosis can vary from nine to twenty-seven months. A recent study across five European countries found that the median diagnostic delay was eleven months. Data from the UK has indicated that fast-track referrals to neurologists can halve the time from referral to diagnosis, and that delays are longer when patients are referred to non-neurology specialties. GPs are often the first clinicians to see patients with undiagnosed MND, but given the rarity of the disease, may only encounter one patient with MND in their career.

The MND Association and the Royal College of General Practitioners developed with Red Flag Tool for MND in 2014, with the aim of improving timely referrals from primary care to neurology. The applicants have developed the MND Alert system, based on the validated Red Flag Tool. The system is an automated alert, designed to integrate directly into existing GP electronic patient record software. The system can trigger alerts in real-time during a GP consultation when information is added to the record that suggests undiagnosed MND or on opening a patient record during a consultation where the existing symptoms indicate possible MND, and will prompt GPs to use the Red Flag Tool to determine whether a referral is needed.

The applicants seek to undertake research into assessing how effectively the alert captures relevant signs and symptoms, and how GPs respond to the alerts. Stage one is a mixed-methods study to test the Toolkit in up to thirty GP practices, to see if the automated alert system can help identify potential cases of MND in patient records over a six-month period. The second stage will involve interviews with up to twenty GPs to evaluate how acceptable the MND Alert toolkit is to GPs.

A recommendation for class 5 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential information requested

Cohort	247,000 The MND Alert tool will be active for 6 months in each practice. If a patient attends a GP consultation and has one or more symptoms from the first image, and none in the second, an alert will trigger for the GP. If the patient does not attend a GP consultation during the study period, an alert will not trigger for the GP, regardless of their symptoms.

Data Sources	Patient records held at participating GP practices.
Identifiers required for linkage purposes	No linkage will be undertaken
Identifiers required for analysis purposes	• Gender • Age

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	As up to 30 GP practices will be involved in the study project, it is the applicant's responsibility to ensure that there are in place. Please contact NHS England at exeter.helpdesk@nhs.net and provide the CAG reference number, the organisational names and references that require review, and ask NHS England to review the DSPT submissions due to a CAG application.	The applicants confirmed that they will ensure all DSPTs are up to date before continuing with study set up. The CAG noted this and raised no further queries.
2.	Confirm the number of case notes that are expected to be reviewed for stage one of the project.	The applicants advised that there will be a maximum of approximately 960 case notes that will be relevant for review. However, which notes are reviewed will depend on the performance of the MND Alert tool in each practice and the availability of researchers to conduct the review. The applicants anticipate that up to 450 notes will be reviewed during the study. The CAG noted this and raised no

		further queries.
3.	The CAG request for the following information regarding the notification materials for the study. a. Submit a copy of the text information that will be included in the study website and posters for GP practices b. Confirm that physical patient notification materials can be circulated within GP practices c. State that the National Data Opt Out process in all notification materials d. Explain the project specific opt out process for the study e. Include a statement explaining that the study has been reviewed and given approval by CAG and REC in advance of data extraction. f. Provide a copy of the privacy notice that will be hosted in the GP practices website.	The applicants provided the text information that will be included on the study website and posters for GP practices. They also advised that the physical notification materials will be circulated within GP practices. The National Data Opt-Out and project specific opt-out are described in the materials and a statement explaining REC and CAG approvals included in these documents. GP practice websites have their own privacy notices that describe the use of data for research and provide contact details in case service users do not wish their data used. The CAG noted this information. Members asked for a revision to the poster, described in the conditions below, but accepted the materials.

Confidentiality Advisory Group advice: *Conditionally supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Number	Condition
1.	The following wording on the poster, "*To see how well MND Alert is doing and to make it better, trained researchers from the University of Sheffield will review a small set of people where the tool has highlighted symptoms that may be related to MND. Again, no personally identifiable information will be used"* needs to be revised to advise patients that patients case notes will be accessed and confidential patient information

	seen by the researchers, but that no information will be recorded or captured. The revised poster is to be provided for review within one month of the issuing of this letter.
2.	Favourable opinion from a Research Ethics Committee. **Confirmed 19 December 2024.**
3.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** Due to the number of participating sites where confidential patient information will be accessed, individual DSPT submissions are not required for the purpose of the application. Support is recommended on the basis that the applicant ensures the required security standards are in place at each site prior to any processing of confidential patient information with support under the Regulations.

1.9	**24/CAG/0091**	**Incidence Study of Clinically Significant Structural Hypotony in UK**
	Chief Investigator:	Ms Rana Khalil
	Sponsor:	NHS Greater Glasgow and Clyde
	Application type:	Research

Present:

Name	Capacity
Ms Clare Sanderson	CAG Alternate Vice Chair
Mr Umar Sabat	CAG Expert Member
Dr Stephen Mullin	CAG Expert Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application NHS Greater Glasgow and Clyde set out the purpose of medical research to determine the prevalence of eye pressure low enough to cause visual disturbance.

Ocular hypotony is the medical condition in which intraocular pressure (IOP) of the eye is very low. Many definitions of ocular hypotony are given in the literature, but these simpler definitions fail to fully capture the extent of this complex condition, as defining hypotony as low pressure resulting in visual loss does not take into account the potential extent and severity of vision loss, or allow for other forms of visual compromise such as loss of contrast sensitivity or colour vision. Defining hypotony in numerical terms also presents problems, such as not taking into consideration the physiological differences in IOP between individuals. Also, existing definitions do not designate a timeframe in which hypotony will cause permanent changes. The applicants seek to identify patients with low IOP, worsened visual burden and predetermined ocular structural changes.

The BOSU methodology is established and has received support in principle from the CAG. Reporting clinicians will anonymously indicate that they have seen a new eligible patient through the BOSU reporting system via University of Dundee. The University of Dundee system will generate the initial questionnaire for the reporting clinician to fill in via the University of Dundee data safe haven online platform. The completion of this questionnaire will contain confidential patient information, and therefore requires ‘s251’ support. Each case will be given a unique study number by the BOSU study centre. NHS Number, Hospital number, month and year of birth, gender, ethnicity and partial postcode will be recorded alongside clinical data on the questionnaires. A follow up questionnaire will be undertaken at 6 months. All identifiers will be deleted once the follow-up is completed, and duplicates identified.

A recommendation for class 1, 5 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential information requested

Cohort	Patients aged 18 years and over with persistent hypotony and one of the structural changes listed in the application. An estimated sample size was not provided, as the aim of the application is to establish the number of patients.
Data Sources	1. Clinical records at the Trusts of BPSU reporting clinicians
Identifiers required for	1. Hospital ID number 2. Date of birth

linkage purposes	3. Postcode – district level
Identifiers required for analysis purposes	1. Date of birth 2. Gender 3. Ethnicity

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Provide feedback to CAG from the proposed discussion with the Royal College of Ophthalmologists Lay Advisory Group	The applicant provided feedback. This was reviewed and accepted by the CAG.
2.	Support cannot be issued until a Favourable opinion from a Research Ethics Committee is in place.	Confirmed 29 January 2025
3.	PBPP approval is required as evidence of security assurances to CAG regarding University of Dundee. Please provide once this is in place.	This was confirmed 07 March 2025.

Confidentiality Advisory Group advice: *Fully supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Favourable opinion from a Research Ethics Committee. **Confirmed 29 January 2025.**

2.	Public Benefit and Privacy Panel approval is in place for the application on 07 March 2025, as evidence of security assurances regarding the University of Dundee.

1.10	**24/CAG/0132**	**SPIDeRR** **Stratification of Patients using advanced Integrative modelling of Data Routinely acquired for diagnosing Rheumatic complaints**
	Chief Investigator:	Dr Arthur Pratt
	Sponsor:	Newcastle University
	Application type:	Research

Present:

Name	Capacity
Ms Clare Sanderson	CAG Alternate Vice Chair
Dr Stephen Mullin	CAG Expert Member
Dr Martin Andrew	CAG Expert Member
Dr Pauline Lyseight-Jones	CAG Lay Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from Newcastle University set out the purpose of medical research into whether digital tools can be used to provide better and more efficient healthcare for patients with musculoskeletal problems.

Musculoskeletal disorders are the most significant contributor to pain and disability. Around 50% of the adult population experiences some sort of musculoskeletal symptoms and 40% has long-lasting problems. Although musculoskeletal problems are common, the patient journey from symptoms to diagnosis and treatment can be long. Effective treatment can also be difficult to identify, with first-line treatment

failing in 60% of patients. Early identification of disease can prevent chronic pain in osteoarthritis (OA) and fibromyalgia.

The applicants seek to investigate whether data already collected in primary and secondary care can be used in machine learning to develop digital tools that could be applied on a patient-by-patient basis to help professionals streamline diagnostic and therapeutic decision-making, thereby improving both the experience and the health outcome of patients.

Confidential information requested

Cohort	4500 patients with musculoskeletal complaints in contact with primary and/or secondary care.
Data Sources	Secondary care data from Newcastle Hospitals NHS Foundation Trust routine electronic health record Newcastle region primary care (GP) data
Identifiers required for linkage purposes	1. NHS Number 2. GP Registration 3. Date of birth 4. Postcode – unit level
Identifiers required for analysis purposes	1. Postcode – district level 2. Gender 3. Ethnicity

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Support cannot be issued until a Favourable opinion from a Research Ethics Committee is in place.	Confirmed 19 December 2024.
2.	The CAG request for the following information relating to	The applicants confirmed that any digital tool emergent from the SPIDeRR project

	the collaboration of activities with the EU Partner: a. Confirm whether the data tool will be made available to NHS services in the UK once created b. Ensure that the data agreement between the EU partner explicitly states that data transferred to the secure data environment will only be used for purposes supported under section 251 of the NHS Act.	will, subject to regulatory approvals, be made available to NHS services in the UK once created. The applicants also confirmed that nodata will be transferred from primary care providers to the proposed secure data environment (MyDRE) for any purpose other than those supported by Section 251 of the NHS Act. The CAG noted this information and raised no further queries.
3.	Provide confirmation on whether an iterative process will be conducted continually throughout the study to evaluate whether the correct cohort group is being targeted.	The applicants advised that a key will be retained by NuTH and NECS to facilitate this process (including linkage to secondary care data), but will not be shared beyond these parties. The CAG noted this information and raised no further queries.
4.	Confirm and state the kind of data that would be collated and extracted from GP records.	Data to be extracted by NECS will typically be handled under four categories; namely, Demographic, Encounter, Observation, Medication. To achieve its objectives, extensive, granular data will be required. The applicants provided an exemplar data dictionary of fields to be targeted. The CAG noted this information and raised no further queries.
5.	Conduct a public involvement consultation, particularly with patients who access primary care services as some potential participants identified for the research study may not access secondary care services.	The applicants provided details of the further public involvement undertaken. The CAG noted this information and raised no further queries.
6.	The CAG request for the following information regarding the patient information and opt-out process: a) Create an English specific website explicitly states the use of confidential participation information and unconsented data use will be used in the	The applicants liaised with the SPIDeRR Project Lead and it has been agreed that a web page will be added to the current SPIDeRR website specifically for UK participants. A link to this site will also be made available on the NIHR Newcastle Biomedical Research website. The text of the website information was

	study. b) ensure that information provided in the study website can be made available in Plain English c) explain how participants would be made aware of the website and directed to it. d) state and develop the further methods of publishing the study to the potential cohort group and submit for review i.e. confirm whether notification materials can be shared in rheumatology clinics e) In the study website explain the local opt out process.	provided. The CAG noted this information and raised no further queries.
7.	Provide confirmation on the proposed sample size and the minimum recruitment number.	The proposed sample size is 10,000. The CAG noted this and raised no further queries.

Confidentiality Advisory Group advice: *Fully supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Favourable opinion from a Research Ethics Committee. **Confirmed 19 December 2024.**
2.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England **2023/24** DSPT reviews for **Newcastle University, Newcastle upon Tyne Hospitals NHS Foundation Trust and NHS North of England CSU** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 19 March 2025).

1.11	**25/CAG/0021**	**Using Artificial Intelligence to predict future risk of stroke, from routine hospital investigations**
	Chief Investigator:	Dr Stephen Mullin
	Sponsor:	University of Plymouth
	Application type:	Research

Present:

Name	Capacity
Ms Clare Sanderson	CAG Alternate Vice Chair
Dr Pauline Lyseight-Jones	CAG Lay Member
Dr Sandra Duggan	CAG Lay Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from the University of Plymouth set out the purpose of medical research into whether AI can be used to analyse routine data collected for other purposes to predict stroke risk.

Stroke is a leading cause of disability and death in the UK. The costs of treatment is also a significant economic burden. A number of established risk factors, in particular high cholesterol, high blood pressure, diabetes, the presence of an irregular heartbeat and smoking, are the major causes of stroke. Evidence shows that modification of these risk factors, either through lifestyle interventions or medications, can drastically reduce the risk of stroke. Ensuring the risk factors are addressed is a challenge, as not all those with the risk factors will have a stroke and some people without the risk factors will have a stroke, making it difficult to predict who interventions and treatments should be targeted towards. Also, antiplatelet and blood thinning medications increase the risk of a bleed in the brain or other part of the body, so understanding of in which individuals the benefit outweighs the risk is needed.

The applicants seek to investigate whether AI can be used to analyse routine hospital data and predict the risk of stroke. A computer model, designed to predict

future risk of stroke, will be created. Novel risk factors for stroke will also be identified.

A recommendation for class 1, 2, 4 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential information requested

Cohort	Stroke cases (patients with a clinical diagnosis of stroke/TIA) – 9155 Control group (patients with no clinical diagnosis of stroke/TIA) – 109,875 Total sample size - 119,030
Data sources	University Hospitals Plymouth NHS Trust (UHPNT) NHS Devon Integrated Care Board (ICB)
Identifiers required for linkage purposes	NHS Number Date of birth Postcode – sector level
Identifiers required for analysis purposes	Date of birth Postcode – sector level Gender Ethnicity

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Security assurances for 2023/24 are outstanding for the following organisations: • Devon Integrated Care Board Please contact NHS England at exeter.helpdesk@nhs.net and	Confirmed 13 March 2025.

	provide the CAG reference number, the organisational names and references that require review, and ask NHS England to review the DSPT submissions due to a CAG application.	
2.	Provide further information about the data sources for which support is required, including: a. Whether the data is coded or free text. b. And, if free text, how the potential for identifiable data within the free text will be handled.	The applicants advised that only coded data, including past medical history and medication history, along with the date(s) of the clinical event or prescription, would be collected. Also, outcomes of physical observations, such as BMI, blood pressure and weight, along with the date(s) of these observations. No free text will be collected. The CAG noted this information and raised no further queries.
3.	Revise the notification poster to include alternative routes for the cohort to opt out (i.e., in addition to the QR code).	A revised poster was provided. This was reviewed and accepted by the CAG.
4.	Review the wording on the poster to make it clearer and more understandable to the average patient. As an example (and not exhaustive), the wording that states ‘opt your data out’ is not reader friendly and could be replaced with ‘if you don’t want your data to be used’.	A revised poster was provided. This was reviewed and accepted by the CAG.

Confidentiality Advisory Group advice: *Fully supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Favourable opinion from a Research Ethics Committee. **Confirmed 19 June 2023.**
2.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England 2023/24 DSPT reviews for **University Hospitals Plymouth NHS Trust and Devon Integrated Care Board** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 13 March 2025).

1.12	**25/CAG/0013**	**CANDITATE**
	Chief Investigator:	Dr Louise Carter
	Sponsor:	University of Manchester
	Application type:	Research

Present:

Name	Capacity
Professor William Bernal	CAG Alternate Vice Chair
Mr Dan Roulstone	CAG Expert Member
Dr Joanne Bailey	CAG Expert Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from the University of Manchester set out the purpose of medical research to develop algorithms designed to assess data obtained from initial clinic visits to determine whether patients are suitable for early phase clinical trials.

Clinical trials of new cancer treatments have strict eligibility criteria that patients must meet in order to participate. It is also important that patients stay in the trial for at least 28 days after starting treatment so that any side effects are assessed and so replacement participants don't need to be sought, which would cause delays in how quickly new drugs are developed. Currently, assessments for suitability are undertaken by the clinical team, relying on their expertise and experience to determine whether patients are likely to be suitable. However, patients who consent for clinical trials are regularly found to be unsuitable for trials or discontinue participation at an early stage.

The applicants seek to use an artificial intelligence tool to assess clinical data and predict how likely patients are to be eligible for trial and to continue for at least the minimum period required.

A recommendation for class 1, 2, 5 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential information requested

Cohort	Patients aged 18 years and over who attended clinic between 01 January 2017 and 31 December 2023. 4500 patient records will be examined. The maximum total number of unique patients attending the clinic during the study period, as determined by a service evaluation, was 3,318. The final number is expected to be less than this due to the national data opt-out.
Data Sources	Electronic patient records at the Christie NHS Foundation Trust
Identifiers required for linkage purposes	Hospital ID number Postcode – district level
Identifiers required for analysis purposes	Date of birth

	Date of death Postcode – sector level Gender Ethnicity

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Support cannot be issued until a Favourable opinion from a Research Ethics Committee is in place.	Confirmed 25 February 2025.
2.	The CAG request for the additional information on the use of the algorithm tool 1. Provide details of the anonymisation pre-processing and its effectiveness in removing identifiable free text data. 2. This could include a trial to de-identify synthetic (artificially generated) data in the same format	An initial test of the de-identification tool has been performed on 220 free text data files. The results of which were reviewed by a clinical fellow who noted that all data still retained clinically relevant information after censoring. The results of which demonstrated that 89.5% of identifying words that should have been censored were censored. The precision of tool was 90.4%, meaning that almost 10% of the words that were censored were not identifying. A test portion of data will be performed initially on the free text used in the study. A member of the direct care team will be asked to review the censoring of the free text data being used in this study. CAG requested that further information on steps that will be taken to manage any risk of case re-identification using the algorithm was provided as a condition of support.
3.	Revise the data flow diagram	A revised data flow diagram was

	to state the specific processing elements that require Section 251 support.	provided. The CAG requested further details on Data Flows 6 and 7. Further clarification was provided. CAG agreed that support under s251 should extend to Data Flow 6.
4.	Confirm the period in which the notification period to opt out of the study will be held prior to the database locking process.	The study team commits to display the poster for a minimum of 3 months from the start of study to allow for sufficient time for patients to be made aware of the collection and use of data for this study. The database cannot be locked for the first 3 months. Should more time be needed to confirm database lock, the notification poster will remain on display until the last day of the data collection phase. At database lock, a final reconciliation of the project-specific opt out and national opt-out systems will be performed.
5.	The CAG request for the following changes to be made to all of the patient notification materials: 1. Include a contact telephone details for patients to utilise if they wish to opt out of the study 2. Develop a study project website for the research study with links from the poster and include the information text provided in the patient poster, along with the opt out process to increase accessibility on information for the study 3. Include a sentence explaining that identifiable data will be accessed via medical	A revised poster was provided. The CAG asked that more information about the de-identification process and mitigation steps were included. Further depth of information was also added to the website about these topics. The CAG requested further revisions, detailed below, as a condition of support.

	notes and will be anonymised 4. Add a sentence stating the study has been reviewed and supported by CAG and REC.	

Confidentiality Advisory Group advice: *Conditionally supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Number	Condition
1.	The CAG agreed that support should also extend to the approved researchers accessing data within the Christie network to generate the algorithm that may retain residual identifiers (data flow 6 in the revised data flow diagram).
2.	The CAG requests further information is provided within 3 months on steps that will be taken to manage any risk of case re-identification using the algorithm.
3.	At annual review, an update is to be provided on the following: a. An assessment of the performance of the de-identification techniques used. b. Rates of patient opt-out from participation and any patient feedback received.
4.	The poster should be revised as below, and the updated version provided with a month: a. Further explanation of the process to be utilised explanation should be included, The CAG suggested the wording: *There is a risk that a small amount of identifiable data may still remain – however any such data will only be kept on NHS computers with access to it securely controlled, and it will be deleted once the project is complete.* b. The text that says *The artificial intelligence does not keep or copy this data* should be removed.
5.	Favourable opinion from a Research Ethics Committee. **Confirmed 25 February 2025.**

6.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England 2023/24 DSPT review for The Christie NHS Foundation Trust was confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 19 March 2025).

1.13	**25/CAG/0014**	**Outcomes of septal reduction surgery in paediatric hypertrophic cardiomyopathy in the United Kingdom**
	Chief Investigator:	Professor Juan Pablo Kaski
	Sponsor:	University College London
	Application type:	Research

Present:

Name	Capacity
Ms Clare Sanderson	CAG Alternate Vice Chair
Dr Pauline Lyseight-Jones	CAG Lay Member
Dr Malcolm Booth	CAG Expert Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from University College London set out the purpose of medical research into the effectiveness of surgery to relieve obstruction in children with hypertrophic cardiomyopathy.

Hypertrophic cardiomyopathy (HCM) is a rare disease in children and is defined as unexplained thickening of the heart muscle. In up to two thirds of patients, the blood flowing out of the heart is obstructed, a condition called obstructive HCM (oHCM), which is responsible for a significant burden of symptoms and has been associated

with an increased risk of sudden death. Treatment includes medicines and surgery to relieve the obstruction. As HCM is a rare disease, current understanding of the outcomes of children requiring surgery is limited.

This study will use data collected in the National Congenital Heart Disease (NCHDA) dataset to describe the early outcomes of left ventricular myectomy in children with HCM in the United Kingdom. Data from the NCHDA data set will be linked with Hospital Episode Statistics (HES) data to provide information on longer term outcomes following surgery. The data from this study will be used to inform national service development and provision for this patient group with the aim of improving patient outcomes and care.

A recommendation for class 1, 4, 5 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential information requested

Cohort	All patients aged 18 years and under with Hypertrophic Cardiomyopathy who have undergone surgical LV septal myectomy in England and Wales. 75 patients will be included.
Data sources	• National Congenital Heart Diseases Audit (NCHDA) - NICOR (managed by NHS Arden and Greater East Midlands CSU) • HES and ONS Data – NHS England • Patient Episode Database for Wales (PEDW) - Digital Health and Care Wales • Patient Benefit and Privacy Panel (PBPP) Public Health Scotland - National Records of Scotland (NRS) data on mortality (Scotland) and Scottish Morbidity records (SMR) data on hospital admissions (Scotland).
Identifiers required for linkage purposes	Name NHS Number Hospital ID Number Date of birth Date of death Postcode – sector level
Identifiers required for analysis purposes	Gender Ethnicity

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Support cannot be issued until a Favourable opinion from a Research Ethics Committee is in place.	Confirmed 21 January 2025.
2.	Complete further Public Involvement relating to the specific research study. The CAG noted that the application referred to the establishment of a young person's advisory group (YPAG) and suggested that, if the timescales work, this group be used to complete the requested Public Involvement. Once completed provide a report on the Public Involvement to CAG, in line with published guidance.	The applicants provided CAG with a PPIE involvement report. This was reviewed and accepted by the CAG.
3.	Provide details about how the YPAG will be engaged in the project moving forward.	The applicants noted that the Young Person Advisory Group (YPAG) is not yet established, but is planned to be set up in future. This was noted and accepted by the CAG.
4.	a. Develop patient notification materials to notify the cohort about how their data will be used, including details of how patients can opt out, including the NCHDA.	A privacy notice was developed and submitted to the CAG. This will be submitted to NCHDA to be published on their public website of approved data sharing applications. It will also be published on our

	b. Explore methods for advertising the requested notification materials and specify which methods will be used.	Centre for Paediatric Inherited and Rare Cardiovascular Diseases website. This was reviewed and accepted by the CAG.

Confidentiality Advisory Group advice: *Fully supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Favourable opinion from a Research Ethics Committee. **Confirmed 21 January 2025.**
2.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed**: The NHS England 2023/24 DSPT reviews for **NHS England, NHS Arden and Greater East Midlands CSU** were confirmed as 'Standards Met' on the NHS England DSPT Tracker And Digital Health and Care Wales was confirmed to have submitted a WIGTK by NHS Wales (checked 31 March 2025).

1.14	**24/CAG/0160**	**LGMD Patient Registry UK**
	Chief Investigator:	Professor Jordi Diaz Manera
	Sponsor:	The University of Newcastle upon Tyne
	Application type:	Research Database

Present:

Name	Capacity
Dr Tony Calland, MBE	CAG Chair
Mr Thomas Boby	CAG Expert Member
Mr David Evans	CAG Expert Member
Mr Anthony Kane	CAG Lay Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome and line with the CAG considerations in correspondence.

Summary of application

This application from Newcastle University set out the purpose of creating a research database, to be used in research into Limb Girdle Muscular Dystrophy.

Limb Girdle Muscular Dystrophies (LGMD) are rare genetic diseases characterised by muscle fibre loss and replacement by fibrotic and fatty tissue, leading to permanent muscle weakness and disability. Despite several therapies developed in the last 20 years, none have changed the natural history of patients and there is no curative treatment for LGMD. Identifying therapies to slow down muscle degradation, stabilise, or improve muscle function is a significant challenge in research.

The LGMD Registry will collect and analyse clinical, demographic, genetic, and functional data from patients diagnosed with LGMD. The data will be used to develop understanding of the natural history of the disease, to aid planning of clinical trials and to identify patients who may benefit from emerging treatments.

The Registry will include data for living patients and those who are no longer attending the centre or who have died.

Confidential information requested

Cohort	Patients who attend the John Walton Muscular Dystrophy Research Centre at Newcastle Upon Tyne Hospitals NHS Foundation Trust. Support is sought for the inclusion of patient records from deceased patients and those no longer attending the centre.
Data Sources	Patient records held at Newcastle Upon Tyne Hospitals NHS Foundation Trust.
Identifiers required for linkage purposes	1. Name 2. NHS Number 3. Hospital ID Number 4. Date of birth 5. Date of death 6. Postcode – unit level
Identifiers required for analysis purposes	1. Date of birth 2. Date of death 3. Gender

	4. Occupation 5. Ethnicity
Identifiers held in data records	1. Full name 2. Address 3. NHS number 4. Hospital ID no. 5. GP registration 6. Date of birth 7. Year of birth 8. Date of death 9. Postcode – Unit level 10. Country 11. Gender 12. Occupation 13. Ethnicity

Confidentiality Group Advice

A Sub-Committee of the CAG considered the applicant's response to the request for further information detailed in the provisionally supported outcome in correspondence

Number	Action required	Response from the applicant
1.	Support cannot be issued until a Favourable opinion from a Research Ethics Committee is in place.	Confirmed 17 January 2025
2.	Security assurances for 2023/24 are outstanding for the following organisations: • TREAT-NMD Services Ltd Please contact NHS England at exeter.helpdesk@nhs.net and provide the CAG reference number, the organisational names and references that require review, and ask NHS England to review the DSPT submissions due to a CAG application.	Confirmed 31 March 2025.
3.	Please provide a coherent plan detailing the notification	The applicants provided a revised Participant Notification Form.

	strategy. This should include example wording that explains: a. the use of confidential patient information without consent, b. that there is a legal basis for this through CAG support, c. where funding for the project has come from for transparency, d. details of both the local and National Data Opt-Out options with a contact email address and telephone number to allow patients to enact them if desired.	This was reviewed by the CAG, who accepted the form but asked that the explanation of the CAG role on page 3 of the Participant Notification Form was revised, as detailed below.
4.	Confirm how data will be processed through the TREAT-NMD global platform and what, if any, data will be leaving the UK.	The applicants advised that data inputted into the TREAT-NMD Global Registries Platform is securely processed and stored to support research, trial planning, and patient care improvement. Data shared with TREAT-NMD is deidentified. TREAT-NMD does **NOT** request any patient identifiable data from any Member Registries and does not have direct access to patients. The applicants confirmed that no data will leave the UK. This was reviewed and accepted by the CAG.
	Recommendation only	
1.	Consider putting a notice about the project on relevant charity websites or newsletters, as this is an effective notification strategy.	The applicants advised that they will ensure that a notice about the project is placed on relevant patient groups and charity websites. This was noted and accepted by the CAG.

Confidentiality Advisory Group advice: *Conditionally supported*

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Number	Condition
1.	The CAG asked that the explanation of the CAG role on page 3 of the Participant Notification Form is revised, as the current description is not accurate. The following wording is suggested: The application was reviewed by the Confidentiality Advisory Group (CAG). CAG is an independent group of lay people and professionals which provides expert advice on the use of confidential patient information without consent. CAG recommended that our application should be supported and the Decision Maker within the Health Research Authority approved this.
2.	Favourable opinion from a Research Ethics Committee. Confirmed 17 January 2025.
3.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England 2023/24 DSPT review for Newcastle Upon Tyne Hospitals NHS Foundation Trust was confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 31 March 2025).

2. NEW AMENDMENTS

2.1	**24/CAG/0025**	**West Midlands Secure Data Environment**
	Chief Investigator:	Dr Elizabeth Sapey
	Sponsor:	University Hospitals Birmingham NHS Foundation Trust
	Application type:	Research Database

Present:

Name	Capacity

Dr Tony Calland, MBE	CAG Chair

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

A CAG Officer reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

The West Midlands Secure Data Environment (SDE) currently has Section 251 support for all NHS primary and secondary care organisations within the West Midlands SDE footprint to share confidential patient information with University Hospitals Birmingham NHS Foundation Trust for linkage and retention within the SDE environment.

This amendment seeks to include further data sources, from NHS England, for inclusion into the West Midlands SDE. These data sources are listed below:

- Civil Registrations of Death
- Hospital Episode Statistics (HES A and E)
- Hospital Episode Statistics (HES APC)
- Hospital Episode Statistics (HES Critical Care)
- Hospital Episode Statistics Outpatients (HES OP)
- Maternity Services Data Set (MSDS) v1.5 and v2.0
- Mental Health Minimum Data Set (MHMDS)/ Mental Health Services Data Set (MHSDS)
- Adult Social Care Client Level Data Set (ASCCLDS)
- Community Services Data Set (CSDS)
- Diagnostic Imaging Data Set (DID)
- Emergency Care Data Set (ECDS)
- Medicines dispensed in Primary Care (NHSBSA data)
- Demographics
- NDRS Quality of Life of Cancer Survivors in England
- NDRS Cancer Consolidated Data Set
- NDRS National Radiotherapy Dataset (RTDS)
- NDRS Systemic Anti-Cancer Therapy Dataset (SACT)
- NDRS Somatic Molecular Data Set

The applicant has confirmed that NHS England will be providing this data to the West Midlands SDE alongside the NHS number. This data will be provided for any patient who receives care at any organisation within the West Midlands SDE footprint, regardless of their place of residence. This is due to some West Midlands organisations providing national specialist treatment centres where patients may travel from outside the area.

Confidentiality Advisory Group advice*:* Fully supported

The CAG Officer agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold **Confirmed:** The NHS England 23/24 DSPT reviews for University Hospitals Birmingham NHS Foundation Trust & NHS England were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 18 February 2025)
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed** in scope of original REC FO

2.2	**22/CAG/0125**	**Management of Patients with Chronic Liver Disease Admitted to Hospital as an Emergency** **Short title: Link MAP-CLD**
	Chief Investigator:	Professor William Bernal
	Sponsor:	King's College Hospital NHS Foundation Trust
	Application type:	Research

Also in attendance:

Name	Position (or reason for attending)
Dr Paul Mills	HRA Confidentiality Advice Service Manager

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

The overall aim of this study is to identify which characteristics of treatments and services for acutely ill people with CLD impact on care processes and outcomes, in order to improve the national organisation and delivery of care for all people acutely ill with chronic liver disease. The application has 's251' support to link together data from NHS England (previously NHS Digital), Intensive Care National Audit & Research Centre (ICNARC), and NHS Blood and Transplant (NHSBT) about 100,000 patients with Chronic Liver Disease (CLD). NHS England will identify the

eligible cohort using Hospital Episode Statistics and ONS Mortality Datasets.

This amendment is seeking to extend the time period currently supported by the existing approved application, which covered the period from 1 April 2009 to 31 March 2022, to include Hospital Admission Statistics (HES) data relating to patients with hospital admissions up to 31 March 2025. This will include the data from HES-APC, HES-OP, HES-ECDS and HES critical care datasets.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold **Confirmed:** The NHS England 23/24 DSPT reviews for **Intensive Care National Audit & Research Centre, NHS Blood and Transplant, NHS England & London School of Hygiene and Tropical Medicine** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 07 March 2025)
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed non substantial 07 March 2025**

2.3	**24/CAG/0146**	**National Paediatric Diabetes Audit (NPDA)**
	Contact:	Amani Krayem – NPDA Project Manager
	Data controller:	Joint data controllers: The Healthcare Quality Improvement Partnership (HQIP) & NHS England for English data and The Healthcare Quality Improvement Partnership (HQIP) & Digital Health and Care Wales (DHCW) for Welsh data
	Application type:	Non-research

Also in attendance:

Name	Position (or reason for attending)
Dr Paul Mills	HRA Confidentiality Advice Service Manager

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

The National Paediatric Diabetes Audit (NPDA) has operated under Regulation 5 support for a number of years, and is party of the Healthcare Quality Improvement Partnership (HQIP) portfolio of audits, run by Royal College of Paediatrics and Child Health. HQIP have awarded Royal College of Paediatrics and Child Health a new tender to continue delivery of the audit, and this amendment is an extension of support to reflect this new tender.

This amendment sought support to extend the duration of support to 30 April 2027.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Secretary of State for Health and Social Care, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. Confirmed: Due to the number of organisations involved it is the responsibility of The Healthcare Quality Improvement Partnership, NHS England, & Digital Health and Care Wales, as joint controllers, to ensure that participating organisations meet the minimum required standard in complying with DSPTs in England, and WIGTKs in Wales, and take remedial action if they become aware of any that fall below this, or where any concerns are raised about an organisation.

2.4	**24/CAG/0116**	**Unrecognised COmorbidity DETECTion in hospitalised patients (CODETECT)**
	Chief Investigator:	Professor Peter Watkinson
	Sponsor:	University of Oxford
	Application type:	Research

Also in attendance:

Name	Position (or reason for attending)

Dr Paul Mills	HRA Confidentiality Advice Service Manager

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This application from University of Oxford is for the purpose of medical research to design, validate, and test a real-time, digital platform to prospectively validate prediction models to identify hospitalised patients with potentially undiagnosed chronic health or at high-risk of developing them in the future. Iin order to undertake this pseudonymised information is requested from trusts. Where pseudonymisation cannot be undertaken at source, Section 251 support allows the transfer of confidential patient information from that participating Trust, to the Thames valley and Surrey SDE at Oxford University Hospitals NHS Trust, where a pseudonym will be applied.

As part of the original support, the patient notification materials informed patients that they could opt out centrally through the research team or through each NHS organisation's R&D team. However, not all NHS trust R&D team are able to offer this project specific opt out service.

This amendment therefore sought support for the opt out methodology to be updated to the central study team as the main opt out option, and via the Trust where this is possible. The National Data Opt Out (NDOO) will still apply. The amendment therefore also changes the poster to allow the statement for patients to contact the R&D team at the trust to be optional, and only used by those that can offer that service. The NDOO will continue to apply, and patients at all trusts can still opt out of the study by contacting the central research team.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England 23/24 DSPT review for **Oxford University Hospital NHS Trust** was confirmed as 'Standards Met' on the NHS England DSPT Tracker.
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed 18 January 2025**

2.5	**22/CAG/0086**	**The Norfolk Arthritis Register (NOAR)**
	Chief Investigator:	Professor Alexander Macgregor
	Sponsor:	University of East Anglia
	Application type:	Research

Also in attendance:

Name	Position (or reason for attending)
Dr Paul Mills	HRA Confidentiality Advice Service Manager

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This amendment sought to clarify the geographical cohort inclusion criteria from Norfolk to Norfolk and Waveney. This is due to changes in primary care organisations structured and boundaries which mean that some patients may be recruited from the Waveney area, which includes parts of Suffolk.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England **2023/24** DSPT reviews for **University of Manchester, University of East Anglia, Norfolk and Norwich University Hospital NHS Foundation Trust and Norfolk and Waveney CCG** were confirmed as 'Standards Met' on the NHS England DSPT Tracker.
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed non substantial 29 January 2025**

2.6	**22/CAG/0130**	**ELUCIDate: ELUcidate long-term consequences of Childhood Infections using administrative and research Data**
	Chief Investigator:	Dr Rachel Denholm
	Sponsor:	University of Bristol
	Application type:	Research

Also in attendance:

Name	Position (or reason for attending)
Dr Paul Mills	HRA Confidentiality Advice Service Manager

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This study aims to investigate the health consequences of SARS-CoV-2 infection in children and young people (CYP) using two school surveys: the Schools Infection Survey (SIS) in England, and the Bristol-based COVID-19 Mapping and Mitigation in Schools (CoMMinS) study.

This amendment sought support for an additional flow of patient information from NHS England to ONS to support the outputs of the study. This flow would include the General Practice Extraction Service (GPES) Data for Pandemic Planning and Research (GDPPR) dataset from NHS England. Once the flow has occurred, the applicant expects that the information will be anonymised and the study can potentially withdraw from support.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. **Confirmed:** The NHS England **23/24** DSPT reviews for **NHS England, and the Office of National Statistics** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 11 March 2025)

2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed non substantial 10 February 2025**

2.7	**18/CAG/0003**	**FAST- Febuxostat versus Allopurinol Streamlined Trial A prospective, randomised, open-label, blinded endpoint (PROBE) clinical trial evaluating long term cardiovascular safety of febuxostat in comparison with allopurinol in patients with chronic symptomatic hyperuricaemia**
	Chief Investigator:	Professor Isla Mackenzie
	Sponsor:	University of Dundee
	Application type:	Research

Also in attendance:

Name	Position (or reason for attending)
Dr Paul Mills	HRA Confidentiality Advice Service Manager

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This application has support to retain identifiers without consent in its dataset.

This amendment sought to change the Chief Investigator from Professor T.M. MacDonald to Professor Isla Mackenzie.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Security assurance requirements **Confirmed:** Health Information Centre - University of Dundee – Data safe haven – security is assured via NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (PBPP) Approval **– reference 2122-0072 Saywood**

2.	Confirmation of a favourable opinion from a Research Ethics Committee. **N/A – this study is already closed with REC, and remains open with CAG via special agreement.**

2.8	**22/CAG/0154**	**Evaluating the clinical and cost-effectiveness of a conservative approach to oxygen therapy for invasively ventilated adults in intensive care: UK-ROX**
	Chief Investigator:	Professor Daniel Martin OBE
	Sponsor:	The Intensive Care National Audit & Research Centre (ICNARC)
	Application type:	Research

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This application from The Intensive Care National Audit & Research Centre (ICNARC) set out the purpose of medical research which aims to evaluate the clinical effectiveness of conservative versus usual oxygen therapy on 90-day all-cause mortality.

Following recruitment completion on 27 November 2024, the final patient 90-day follow-up timepoint is expected to be 25 February 2025.
This amendment sought support to extend the duration of 's251' support from the current date of 28 February 2025, to 01 August 2025, to allow the applicants time for data collection, analysis and linkage for the UK-ROX trial.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold **Confirmed:**

	The NHS England 23/24 DSPT reviews for **The Intensive Care National Audit & Research Centre (ICNARC) and NHS England** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 12 march 2025) Digital Health and Care Wales (DHCW) has a valid Welsh IG toolkit in place as confirmed by the Welsh Information Governance team. Due to the number of participating ICU's involved it is the responsibility of ICNARC, as controller, to ensure that these participating organisations meet the minimum required standard in complying with DSPTs, and take remedial action if they become aware of any that fall below this, or where any concerns are raised.
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed non substantial 14 February 2025**

2.9	**22/CAG/0103**	**Supporting the NHS Long Term Plan: An evaluation of the implementation and impact of NHS-funded tobacco dependence services**
	Chief Investigator:	Professor Eileen FS Kaner
	Sponsor:	Newcastle University
	Application type:	Research

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

The applicants have existing support to allow research staff at participating trusts to access confidential patient information in order to identify eligible patients and extract a pseudonymised dataset. Hospital records will be accessed to determine the number of smokers who have been offered and used tobacco dependence services and to calculate the cost of providing the service.

This amendment sought to amend the name of one of the participating sites, and data processors under 's251' support. Leicester Partnership NHS Trust is in fact titled Leicestershire Partnership NHS Trust.

This amendment also sought to remove Hull University Teaching Hospitals NHS Trust as a data processor. This Trust did not issue Capacity and Capability due to a lack of capacity in the team to deliver on research. Applicants confirm no data were collected or generated from this Trust:

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold: **Confirmed:** Due to the number of organisations involved it is the responsibility of Newcastle University, as controller, to ensure that participating organisations meet the minimum required standard in complying with DSPTs, and take remedial action if they become aware of any that fall below this, or where any concerns are raised about an organisation
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed non substantial 18 February 2025**

2.10	**24/CAG/0070**	**Alternative CErvical Screening study - ACES At Home: Can a urine test improve uptake in cervical screening?**
	Chief Investigator:	Professor Emma J Crosbie
	Sponsor:	The University of Manchester
	Application type:	Research

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This application is to identify if self-collected urine and vaginal tests could increase

uptake in cervical screening. Applicants will work with 20 GP practices across greater Manchester to identify potential participants through overdue cervical screening lists.

This amendment sought 's251' support to include The Maples Medical Centre as an additional GP practice in the study as a participating site, and data processor under 's251' support.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant organisation has achieved the 'Standards Met' threshold. **Confirmed:** Due to the number of organisations involved it is the responsibility of The University of Manchester, as controller, to ensure that practices hosting researchers meet the minimum required standard in complying with DSPTs, and take remedial action if they become aware of any that fall below this, or where any concerns are raised about a practice.
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed non substantial 27 February 2025**

2.11	**17/CAG/0184**	**UK collaborative clinical audit of health care for children and young people with suspected epileptic seizures (Epilepsy12)**
	Contact:	Niky Raja
	Data controller:	Royal College of Paediatrics and Child Health on behalf of joint data controllers HQIP and NHS England (for English data) and HQIP and the Welsh Government (for Welsh data)
	Application type:	Non-research

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

The original application covered the Royal College of Paediatrics and Child Health (RCPCH)'s management of the Epilepsy12 project under its previous contracts. The current contract runs until 31 March 2025, and RCPCH have recently been awarded a two-year extension under a new contract to deliver Epilepsy12 until 31 March 2027.

This amendment therefore seeks to extend the duration of 's251' support until 31 March 2027.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Secretary of State for Health and Social Care, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold **Confirmed:** The NHS England **23/24** DSPT reviews for **NHS England, Microsoft UK, Royal College of Paediatrics & Child Health and SysGroup PLC** were confirmed as '**Standards Met'** on the NHS England DSPT Tracker (checked 12 March 2025)

2.12	**24/CAG/0040**	**NHS Humber & North Yorkshire Integrated Care Board - Disclosure of combined commissioning data sets and GP data for risk stratification and population health management purposes to Integrated Care Boards and Data Processors**
	Contact:	Karina Ellis
	Data controller:	NHS Humber & North Yorkshire Integrated Care Board
	Application type:	Non-research

Present:

Name	Capacity
Dr Tony Calland, MBE	CAG Chair

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor
Dr Paul Mills	HRA Confidentiality Advice Service Manager

A CAG Officer previously reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This is a non-research application from Humber and North Yorkshire Integrated Care Board (ICB) for the purpose of population health management. Population Health Management involves using data to identify local 'at risk' populations to enable planning and targeting of interventions of the population to prevent ill-health and improve care for the local population. It allows commissioners to design appropriate care pathways for the population which can in turn reduce health inequalities and improve the health of the population. Support is in place for the flow of confidential patient information from GP suppliers to the population health supplier (North of England Commissioning Support Unit) and to link this information with national datasets through NHS number. Support is not required for the flow of national datasets as this is sent in a pseudonymised form.

This amendment sought to combine this population health management application with the risk stratification application for the same ICB (23/CAG/0118), as these are the same administrative datasets, and data flows, and this will ease the admin burden for the ICB and for CAG.

As a result, the new title for this application is: NHS Humber & North Yorkshire Integrated Care Board - Disclosure of combined commissioning data sets and GP data for risk stratification and population health management purposes to Integrated Care Boards and Data Processors

Confidentiality Advisory Group advice: *Fully supported*

The amendment requested was considered by Chair's Action. The Chair previously agreed with the Confidentiality Advice Team that this amendment should be processed to combine the applications.

The CAG Officer agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Secretary of State for Health and Social Care, subject to compliance with the standard conditions of support.

Number	Condition
1.	23/CAG/0118 is expired from the date of this letter, and all support for 23/CAG/0118 is now under 24/CAG/0040

2.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold **Confirmed:** The NHS England 23/24 DSPT reviews for **North of England Commissioning Support Unit** and **Microsoft Limited Azure**, were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 13 March 2025)

2.13	**23/CAG/0090**	**South London Registry of Cardiovascular Diseases' (SoLoR-CVD**
	Chief Investigator:	Dr Nilesh Pareek
	Sponsor:	King's College Hospital NHS Trust
	Application type:	Research Database

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

The Confidentiality Advice Team reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This application is for the creation of a research database collecting data on all patients admitted with cardiovascular disease (CVD), or seen in cardiology outpatient clinic at King's College Hospital NHS Trust (KCH) and Guy's & St Thomas' NHS Trust (GStT).

This amendment sought 's251' support to change the name of the study, from 'King's College London Cardiovascular Diseases Database' (KCL-CVD) to 'South London Registry of Cardiovascular Diseases' (SoLoR-CVD), as advised by NHS England.

The patient notification materials have been changed accordingly.

Confidentiality Advisory Group advice: *Fully supported*

The Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold **Confirmed:** The NHS England **23/24** DSPT reviews for **King's College Hospital NHS Trust, Guy's & St Thomas' NHS Trust & NHS England** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 27 March 2025)
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed non substantial 20 March 2025**

2.14	**22/CAG/0019**	**CUREd+: Centre for Urgent and Emergency Care Research Database - refresh**
	Chief Investigator:	Professor Suzanne Mason
	Sponsor:	University of Sheffield
	Application type:	Research Database

Present:

Name	Capacity
Ms Clare Sanderson	CAG Alternate Vice Chair

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

A CAG Officer reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This application updates and extends the CUREd Research Database (18/CAG/0126), to include more recent data and to extend the geographical area covered by the dataset. The CUREd Research Database refresh expanded the hospital data to cover all of England, updated the linked ambulance service data, added death registration data, reduced variation within the hospital data, reduced the amount of confidential patient information processed and retained by University of Sheffield, and will enable further research on a number of Urgent and Emergency Care (UEC) related topics.

's251' support is currently in place for the disclosure of confidential patient information (from patients in CUREd research database 2011 – 2017) from University of Sheffield,

and confidential patient information (from patients treated 2017-2023) from Yorkshire Ambulance Service (YAS) to NHS England in order to link to clinical datasets and disclose confidential patient information back to the applicant at University of Sheffield. There are also other elements to the support that are not relevant to this amendment.

The current cohort, data sources, and data items for linkage are as follows;

Cohort	Patient episodes of care between 1st April 2011 and 31st March 2023 Cohort A: Patients who 1) contacted or received care from the emergency ambulance service provided by Yorkshire Ambulance Service (YAS) NHS Trust, or 2) contacted the NHS 111 telephone triage service provided by YAS Cohort B: Patients who 1) received unscheduled care at a Walk-in Centre, Minor Injuries Unit, Urgent Care Centre or Emergency Department in England, or, 2) received inpatient or outpatient NHS hospital care in England, or 3) received care from Mental Health Services in England Approximate number of patients estimated as 80 million in Cohort B, plus additional minimal numbers in cohort A. (however the 80 million figure is based on number of unique NHS England (previously Digital) identifiers, and this may represent a lower number of individual patients)
Data sources	1. University of Sheffield - School of Health and Related Research (ScHARR) a. the YAS clinical data (999 and NHS111) extracted from CUREd Research Database", between 2011 and 2017 b. patient identifiers for the existing YAS cohort of patients from the CUREd database 2. NHS England (previously Digital) a. For cohort A: i. Medicines Dispensed in Primary Care data, ii. and address information iii. Demographic, and iv. Civil Registration – death data (ONS Mortality)

	b. For cohort B: i. Hospital Episode Statistics (HES); 1. Emergency Care Data Set (ECDS) 2. Accident & Emergency (A&E) 3. Outpatient (OP) 4. Admitted Patient Care (APC) ii. Mental Health Services Data Set (MHSDS) iii. Demographic, and iv. Civil Registration – death data (ONS Mortality) 3. Yorkshire Ambulance Service – (2017-2023) (cohort A) a. electronic Patient Records (ePR), b. Computer Aided Dispatch (CAD) and c. NHS111
Identifiers required for linkage purposes	1. Unique common pseudo-identifier 2. Name 3. NHS number 4. Date of birth 5. Postcode

This amendment sought support for various changes to data sources.

From each ambulance service, where they are available, applicants request the same data items that have been provided by YAS, (Unique common pseudo-identifier, Name, NHS number, Date of birth, Postcode) plus the provision of the 'gender' and 'sex' identifiers to NHS England for linkage. This amendment seeks support to include gender and sex in the data items disclosed to NHS England from YAS, and future ambulance services, and this is accepted by CAG as notification only, as these data items are not items of confidential patient information, and so the scope of 's251' support is unchanged.

The CUREd+ database is currently static, containing data up to March 2023, about patient episodes of care between 1st April 2011 and 31st March 2023, and for YAS from 2017-2023. This amendment seeks to widen the scope of the database, to being updated on an annual basis. This would mean adding one year's worth of data each year, and would comprise all of the data items currently in the CUREd+ database, from YAS and NHS England, and updated 'sex' and 'gender' fields for all past participants to be provided by all participating ambulance services to NHS England for linkage. Annual updates would be included for any new ambulance service added.

The updated cohort, data sources, and data items for linkage are as follows;

Cohort	Patient episodes of care between 1st April 2011 and present day (updated on an annual basis)

	Cohort A: Patients who 1) contacted or received care from the emergency ambulance service provided by either Yorkshire Ambulance Service (YAS) NHS Trust, or 2) contacted the NHS 111 telephone triage service provided by YAS Cohort B: Patients who 1) received unscheduled care at a Walk-in Centre, Minor Injuries Unit, Urgent Care Centre or Emergency Department in England, or, 2) received inpatient or outpatient NHS hospital care in England, or 3) received care from Mental Health Services in England Approximate number of patients estimated as 80 million in Cohort B, plus additional minimal numbers in cohort A. (however the 80 million figure is based on number of unique NHS England (previously Digital) identifiers, and this may represent a lower number of individual patients)
Data sources	1. University of Sheffield - School of Health and Related Research (ScHARR) a. the YAS clinical data (999 and NHS111) extracted from CUREd Research Database", between 2011 and 2017 b. patient identifiers for the existing YAS cohort of patients from the CUREd database 2. NHS England a. For cohort A: i. Medicines Dispensed in Primary Care data, ii. and address information iii. Demographic, and iv. Civil Registration – death data (ONS Mortality) b. For cohort B: i. Hospital Episode Statistics (HES); 1. Emergency Care Data Set (ECDS) 2. Accident & Emergency (A&E) 3. Outpatient (OP) 4. Admitted Patient Care (APC) ii. Mental Health Services Data Set (MHSDS)

	iii. Demographic, and iv. Civil Registration – death data (ONS Mortality) 3. Yorkshire Ambulance Service – (2017-present day) (cohort A) a. electronic Patient Records (ePR), b. Computer Aided Dispatch (CAD) and c. NHS111
Identifiers required for linkage purposes	1. Unique common pseudo-identifier 2. Name 3. NHS number 4. Date of birth 5. Postcode 6. Gener 7. sex

This amendment also sought support to widen the Data access to 'Approved Researchers' from NHS organisations and commercial NHS partners, widened from UoS staff and researchers designated as 'Visiting Academics' status by UoS. This data access is only regarding effectively anonymous data, the same as the original application access to data, which is the following and is effectively anonymous to researchers using it:

Identifiers required for analysis purposes	1. GP registration 2. Year of birth 3. Date of death – this is always modified for analysis 4. Output Area LSOA 5. Ambulance incident location postcode 6. Gender 7. Ethnicity 8. non-identifiable pseudonymised Unique Property Reference Number (UPRN) Effectively anonymous to researchers

Updated data flow diagram and patient notification provided.

Confidentiality Advisory Group advice: *Fully supported*

The CAG Officer agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold **Confirmed:** The NHS England 23/24 DSPT reviews for **University of Sheffield - School of Health and Related Research (8D715 – SHRR), Yorkshire Ambulance Service (RX8) and NHS England** were confirmed as '**Standards Met'** on the NHS England DSPT Tracker (checked 25 March 2025)
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed 11 February 2025**

2.15	**23/CAG/0046**	**Thames Valley and Surrey (TVS) sub national secure data environment (SNSDE) programme**
	Chief Investigator:	Ben Attwood
	Sponsor:	Oxford University Hospitals NHS Foundation Trust
	Application type:	Research Database

Present:

Name	Capacity
Dr Murat Soncul	CAG Alternate Vice Chair
Dr Malcolm Booth	CAG Expert Member

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

A Sub-Committee of the CAG reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

This application proposes to collect all primary and secondary care patient data into the Thames Valley and Surrey (TVS) sub national secure data environment (SNSDE) for the purposes of conducting medical research. 's251' support is in place to allow the disclosure of confidential patient information from primary and secondary care participating organisations who provide NHS treatment within the Thames Valley and Surrey area to Oxford University Hospitals NHS Foundation Trust into a

SNSDE and for the data management team at Oxford University Hospitals NHS Foundation Trust to access the SNSDE to check, link, de-identify, filter, and transform in the data processing environment, to produce a research database. The currently supported data sources are listed in the original outcome letter.

This amendment seeks ‘s251’ support to re-use data flows to the shared care record from both primary and secondary care providers to the SDE. This will effectively include an optional flow (for providers that can utilise it) of primary care data, and for summary data from some hospitals (admissions, discharges, transfers), from the shared care record (Graphnet) to the SDE at Oxford University Hospitals NHS Foundation Trust. The Thames Valley & Surrey Care Records Partnership, hosted by Frimley Health oversee the shared care record. The data processor is Graphnet. No additional information is contained within the Shared Care Record that is not available in the systems already approved under the original support. This is purely a change to simplify technical data flows, allowing a technical re-use of existing secure data feeds. This saves money, reduces the risk of managing multiple parallel feeds and supports the views of our patient and public community of practice. This addition enables Provider organisations a choice to utilise the existing secure shared care record data feeds. Data would flow from the Shared Care Record where the data processor (Graphnet) was instructed to do so by the controller of that data. There are a number of data flows that will continue to use the existing approvals as they are not collected via the shared care record, e.g. imaging reports. This change will overall reduce the flow of identifiers.

This amendment also seeks ‘s251’ support to update CAG that The TVS SDE now has a model of Joint Controllership for data held in the SDE between Provider Organisations and OUH as the Host for the TVS SDE. This in effect makes the SDE an extension of existing environments over which Provider Organisations retain control. Each Provider will sign the TVS SDE Provider Terms to agree to this approach. This change strengthens the role of partner organisations who are providing data to the SDE through the introduction of joint control between OUH and the contributing organisation for data held within the data processing environment. The data controller for the CAG application remains Oxford University Hospitals NHS Foundation Trust.

This amendment also seeks ‘s251’ support to include data from any other organisations that are commissioned by or outsourced by the NHS to provide services on their behalf (in addition to the NHS organisations that formed part of the original application) For example, NHS 111 services are provided by an ambulance service in some locations in TVS and by a commercial organisation in another location in TVS. These commissioning and outsourcing arrangements can change frequently therefore a definitive list of commercial organisations is not provided within this amendment.

This amendment also seeks ‘s251’ support to include data from 3 Integrated Care Boards: Buckinghamshire, Oxfordshire & Berkshire West ICB, Frimley ICB and Surrey Heartlands ICB. Although not specifically named in the original support, these ICBs are part of the Integrated Care Systems that are supported and named in the original outcome letter. The data to be included is patient data that is sometimes controlled by an ICB, such as:

- data related to assessment for NHS Continuing Healthcare, https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/

- Or ICS-wide quality and incident data such as PSIRF https://www.england.nhs.uk/patient-safety/patient-safety-insight/incident-response-framework/

The identifiers included are the same as supported in the original outcome letter.

This amendment also sought support to update the main contact for the application, as the SRO for the programme has changed from David Walliker to Ben Attwood.

The applicant advised that the Data Access Committee (DAC) has changed its name to Services and data Access Review Committee (SARC), and this is accepted as notification only as this does not change the scope of 's251' support.

Confidentiality Advisory Group advice: *Conditionally supported*

The amendment requested was considered by Chair's Action. The CAG Alternate Vice Chair was content to recommend support for this amendment. However it was noted that this amendment seeks 's251' support to include data from any other organisations that are commissioned by or outsourced by the NHS to provide services on their behalf, with the example of NHS 111 services provided by an ambulance service in some locations in TVS and by a commercial organisation in another location in TVS. These commissioning and outsourcing arrangements can change frequently therefore a definitive list of commercial organisations is not provided. A condition has been added to update CAG on the types of organisations, both that outsource services, and the types of organisations that provide the outsourced services, and an idea of how many organisations this concerns.

The CAG sub-committee agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Number	Condition
1.	Please update CAG on the types of organisations, both that outsource services, and the types of organisations that provide the outsourced services, and an idea of how many organisations this concerns, in 1 month.
2.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold **Confirmed:**

	The NHS England 23/24 DSPT review for **Oxford University Hospitals NHS Foundation Trust** was confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 17 March 2025) Due to the number of other participating organisations involved it is the responsibility of Oxford University Hospitals NHS Foundation Trust, as controller, to ensure that these participating organisations meet the minimum required standard in complying with DSPTs, and take remedial action if they become aware of any that fall below this, or where any concerns are raised.
3.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed 19 March 2025**

2.16	**20/CAG/0034**	**Detecting clinical deterioration in respiratory hospital patients using machine learning**
	Chief Investigator:	Dr Sherif Gonem
	Sponsor:	University of Nottingham
	Application type:	Research

Present:

Name	Capacity
Dr Tony Calland, MBE	CAG Chair

Also in attendance:

Name	Position (or reason for attending)
Ms Caroline Watchurst	HRA Confidentiality Advisor

A CAG Officer reviewed the above amendment in line with the CAG considerations in correspondence.

Summary of amendment request

The applicants have existing support for researchers from the University of Nottingham to access confidential patient information held in electronic and paper records at Nottingham University Hospitals NHS Trust, in order to extract an anonymised dataset for analysis. The purpose is to develop a new early warning score to detect when patients who are in hospital with respiratory problems are getting worse and may need extra treatment.

's251' support is currently in place for approximately 22,000 patients aged 18 years

and over who were admitted to Nottingham University Hospitals NHS Trust under the care of respiratory medicine services between 2014 and the present day.

This amendment sought to expand the cohort from purely respiratory patients to adult patients admitted under all specialties except for obstetrics, encompassing 1.8 million admission episodes. Data will be extracted for patients admitted up to 31st December 2024. Laboratory blood tests, venous/arterial blood gases and data on the type of tasks sent to clinicians will be included in the dataset (but no items of confidential patient information are collected, as per original support). This amendment will allow the previous results in respiratory patients to be extended to a much wider group of patients, increasing the generalisability of results and leading to broader patient benefit. The inclusion of laboratory blood tests and venous/arterial blood gases will enable applicants to improve the predictive accuracy of the models.

This amendment also sought to extend the duration of 's251' support from 30 June 2024 to 31 December 2027. This is to allow the applicant to complete the purposes of the application.

Confidentiality Advisory Group advice: *Fully supported*

The amendment requested was considered by Chairs' Action. The Chair asked for some minor alterations to the study poster, which the applicant made. The Chair was then content to recommend support.

The CAG Officer agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the standard conditions of support.

Number	Condition
1.	Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold: **Confirmed:** The NHS England 23/24 DSPT reviews for the **University of Nottingham and Nottingham University Hospitals NHS Trust** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 12 March 2025)
2.	Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed 11 March 2025**

3. ANNUAL REVIEWS SUPPORTED

CAG reference	Title
22/CAG/0160	National Prospective Cohort Study and Surveillance of

	Sympathetic Ophthalmia in the United Kingdom
22/CAG/0050	A Multi-Centre Randomised Controlled Trial of the Clinical and Cost Effectiveness of Pre-Hospital Whole Blood Administration versus Standard Care for Traumatic Haemorrhage
17/CAG/0184	UK collaborative clinical audit of health care for children and young people with suspected epileptic seizures (Epilepsy12)
24/CAG/0036	Can performing extra tests on non-diagnostic biopsy samples avoid the need for further invasive biopsies in people with suspected cancer of the lung lining?
21/CAG/0008	Clinical Practice Research Datalink (CPRD)
24/CAG/0003	Prescription Event Monitoring
23/CAG/0093	Natural Experiment of the impact of supervised Opiate Agonist Therapy (OAT) consumption on drug related harm and treatment outcomes
24/CAG/0023	Stroke and atrial fibrillation (AF) with a focus on prevalent and incident stroke and/or AF in one area of North West England, and associated clinical risk factors, multimorbidity, time trends, and outcomes, and development and evaluation of clinical risk models and dynamic changes in stroke risk
23/CAG/0147	Cheshire and Merseyside ICB: System Supplier processing of Confidential Patient Information to create a de-identified data mart for secondary uses
24/CAG/0013	Wessex sub national secure data environment (SNSDE) programme
24/CAG/0017	CRIS Linkage with the Police National Computer (PNC)
19/CAG/0001	National Respiratory Audit Programme (NRAP): children and young people asthma audit (CYPA)
ECC 8-05(f)/2010	A National Neonatal Research Database
24/CAG/0066	Geriatric Medicine, Care and the End of Life: Appreciating Clinical Uncertainty in the Acute Care of Older Adults
17/CAG/0081	UK Women's Cohort Study - HES

22/CAG/0010	The Integration and Analysis of Data Using ARtificial InTelligence to Improve Patient Outcomes with Thoracic Diseases (DART)
23/CAG/0108	NHS South West London ICB - Disclosure of combined commissioning data sets and GP data for risk stratification purposes to Integrated Care Boards and Data Processors.
23/CAG/0129	Disclosure of combined data sets and GP data for risk stratification purposes to Integrated Care Boards and Data Processors
23/CAG/0015	Flatiron Health UK Oncology Research Database v2.0
23/CAG/0031	Sentinel Stroke National Audit Programme (SSNAP)
22/CAG/0105	Improving patient outcome in the 'hot zone' during a major incident – a mixed methods medical research approach
21/CAG/0001	Optimum Patient Care Research Database (OPCRD)
23/CAG/0067	An evaluation of the clinical efficacy and risk profile of routine spinal operations performed in the National Health Service
24/CAG/0140	Royal Hospital for Neuro-disability (RHN) patients Database
24/CAG/0012	Pre-hospital Research and Audit Network (PRANA)
24/CAG/0011	Pre-hospital Research and Audit Network (PRANA)
16/CAG/0043	British Association of Dermatologists Biologic Interventions Register (BADBIR)
15/CAG/0127	Cellular immunity to herpesvirus infection: Studies with EBV and CMV
23/CAG/0024	National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH)
21/CAG/0007	National Neonatal Audit Programme (NNAP) data flow
22/CAG/0068	Childhood outcomes after perinatal brain injury: a population-based linkage study
17/CAG/0033	Prospective observational study of the long term hazards of anti-TNF therapy in rheumatoid arthritis
23/CAG/0038	National Audit of Inpatient Falls

22/CAG/0042	A long-term prospective cohort study on the effects of smoking and prophylactic aspirin on all-cause mortality in male British doctors.
19/CAG/0198	Evaluation of an aid to diagnosis for congenital dysplasia of the hip in general practice: controlled trial randomised by practice
CAG 6-06(a)/2014	Welsh Cancer Intelligence and Surveillance Unit (WCISU), Public Health Wales NHS Trust
23/CAG/0041	Management of patients with Chronic Liver Disease admitted to hospital as an emergency: MAP-CLD Social Science (CAG)
ECC 2-02(d)/2012	Resurrection of the Database of the Oxford Survey of Childhood Cancers (OSCC) as a Research Resource and its use to investigate Xray exposure
CAG 9-08(b)/2013	Linkage of readmissions to birth data
18/CAG/0002	Trajectories of diabetes related health measures and subsequent health and educational outcomes (STEADFAST)
24/CAG/0065	CSOR: Children's Surgery Outcome Reporting Research Database v1.0
17/CAG/0011	Pre-hospital Research and Audit Network (PRANA)
19/CAG/0084	Developing Diagnostic and Prognostic Algorithms Using Digital Pathology and Artificial Intelligence
CAG 9-08 (e)/2014	Diet, Lifestyle, and Biological Determinants of Health and Chronic Disease: A Prospective Population Study. EPIC-Norfolk
CAG 1-03(PR3)/2014	Next Steps previously known as Longitudinal Study of Young People in England (LSYPE)
22/CAG/0145	Safety and Efficacy of Managing acute heart failure care without hospital admission (SAFE)
24/CAG/0016	Collaboration on PiP Extremism Referrals (COPPER)
ECC 8-04 (b)/2013	Road Accident In-Depth Studies (RAIDS)
18/CAG/0126	Connected Health Cities: Data linkage of urgent care data (the research database later became known as CUREd: the Centre for Urgent and Emergency Research database)

22/CAG/0040	A Surveillance Study of Congenital and Hospitalized Neonatal Varicella in the United Kingdom & Portugal (NEOPOX)
20/CAG/0067	Learning Disabilities Mortality Review (LeDeR) (now called Learning from Lives and Deaths, people with a learning disability and autistic people – LeDeR)
19/CAG/0215	Small Area Health Statistics Unit Research Database

Minutes ratified in correspondence from

Dr Tony Calland, MBE, CAG Chair, Professor William Bernal, & Ms Clare Sanderson, CAG Alternate Vice-Chairs *11 April 2025*

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Signed – Chair *Date*

Ms Caroline Watchurst, HRA Confidentiality Advisor *09 April 2025*
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Signed – *Date*