Confidentiality Advisory Group

Minutes of the meeting of the Precedent Set Review Sub Committee of the Confidentiality Advisory Group held on *20 October 2023* via correspondence.

Present:

Name	Capacity	Items
Dr Murat Soncul	Alternate Vice Chair	2.1 & 2.2
Dr Malcolm Booth	CAG Expert Member	2.1
Dr Sandra Duggan	CAG Lay Member	2.2
Mr David Evans	CAG Expert Member	2.1
Mr Umar Sabat	CAG Expert Member	2.2

Also in attendance:

Name	Position (or reason for attending)
Mr Dayheem Sedighi	HRA Approvals Administrator
Ms Caroline Watchurst	HRA Confidentiality Advisor

1. DECLARATIONS OF INTEREST

1.1	**23/CAG/0165**	**2023 Adult Inpatient Survey**
	Conflict:	CAG Member Mr David Evans declared an interest in this item (2.2) – He is conflicted with all non-research applications as his employment is in the same department as the CAG Non-research decision maker. The Precedent Set Review Sub-Committee agreed that they should not participate in the review of this application.

2. NEW PRECEDENT SET REVIEW APPLICATIONS FOR CAG CONSIDERATION

2.1	**23/CAG/0156**	**Development of Pathways for the Diagnosis and Management of Latent Tuberculosis Infection in Wales**
	Chief Investigator:	Dr Emma Thomas-Jones
	Sponsor:	Public Health Wales
	Application type:	Research

The Group reviewed the above application in line with the CAG considerations.

Summary of application

This application from Cardiff University (with the data controller confirmed to be Public Health Wales) set out the purpose of medical research that aims to develop new screening guidelines for Tuberculosis (TB) in Wales, for patients due to be immunosuppressed, by retrospectively reviewing existing data to determine what method would be most cost-effective and have the fewest problems related to antibiotic treatment (WP1). There are further aims relating to WP2, but this is out of scope for CAG support.

TB is an infectious disease. When a person becomes infected, they may either develop an active and infectious form of the disease, or their immune system can control it, such that it lies dormant until potentially 'activated' later. This is called latent TB infection (LTBI). Identifying and treating people with LTBI is crucial to preventing the spread of TB, and this is done with a blood test that measures how immune cells release specific chemical signal.

In WP1, Participants will be identified through Public Health Wales (PHW) databases containing retrospective LTBI screening data from the last 7 years. WP1 requires ‘s251’ support for the disclosure of confidential patient information (name, date of birth and NHS number), alongside IGRA screening test outcome and adverse treatment outcomes, from the LTBI Screening Database at PHW, and from the LTBI Screening Database at Oxford Immunotec Ltd (for which PHW is controller), to the applicant via a PHW laptop. Confidential patient information is necessary, as results of screening tests and adverse effects of antibiotic treatment may need to be accessed for clarification. This will only be done by the applicant, if data is missing, by undertaking checks using name, NHS number and date of birth, by accessing the Welsh Clinical Portal controlled by Digital Health and Care Wales (DHCW). The data will then be anonymised and disclosed to Cardiff University - Centre for Trials Research.

Confidential information requested

Cohort	WP1: approximately 20,000 patients of any age in Wales who have been screened for latent TB using an IGRA from 2015 – 2022

Data sources	1. LTBI Screening Database - Public Health Wales 2. LTBI Screening Database - Oxford Immunotec Ltd (Public Health Wales are controller for this data) 3. Welsh Clinical Portal – Digital Health and Care Wales (DHCW)
Identifiers required for linkage purposes	1. Date of birth 2. NHS number 3. Name - unclear
Identifiers required for analysis purposes	1. District level postcode Applicant states anonymous for analysis.

Main issues considered, discussed and outcomes

The CAG noted that this activity fell within the definition of medical research and was therefore assured that the application described an appropriate medical purpose within the remit of section 251 of the NHS Act 2006.

Having reviewed the application and considered the risks and benefits involved, the CAG was also assured that the proposed activity was in the public interest.

The Sub-Committee stated that although the patient and public involvement undertaken is limited, Members were content that it is proportionate to the proposed activity and relevant questions were explored.

The CAG was unclear at what point the confidential patient information would be deleted from the researcher's PHW laptop after undertaking the process of anonymising for analysis. The CAG requested that applicant clarify the retention period of confidential patient information on the researcher's laptop before it was anonymised. **(Action 1)**

The CAG noted that the applicant added 'Name' as part of identifiers required for linkage purposes on the data flow diagram, however inclusion of name was not stated in the CAG form. The CAG requested that applicant confirm whether full name was required for linkage purposes. **(Action 2)**

<u>Confidentiality Advisory Group advice:</u> Provisionally supported

The CAG was unable to recommend support to the Health Research Authority for the application based on the information and documentation received so far. The CAG requested the following information before confirming its final recommendation:

Number	Action required	Response from the applicant
1.	Clarify the retention period of confidential patient information on the researcher's laptop before it is anonymised.	
2.	Confirm whether full name is required for linkage purposes.	

The Group delegated authority to confirm its final opinion on the application to the Chair and reviewers.

2.2	23/CAG/0165	2023 Adult Inpatient Survey
	Contact:	Tamantha Webster
	Data controller:	Care Quality Commission
	Application type:	Non-research

The Group reviewed the above application in line with the CAG considerations.

Summary of application

This non-research application submitted by Picker Institute Europe on behalf of the Care Quality Commission, sets out the purpose of conducting the 2023 NHS Adult Inpatient Survey.

The Adult Inpatient Survey started in 2002 and falls within the NHS Patient Survey Programme (NPSP). The NPSP was initiated in 2002 by the then Department of Health, and is now overseen by the Care Quality Commission (CQC), the independent regulator of health and social care in England.

The 2023 Adult Inpatient survey will be the twenty-first carried out to date, and the fourth mainstage to be completed using a mixed method approach.

All eligible trusts (131) will be asked to conduct the survey, with preparations expected to begin in the autumn of 2023 and fieldwork expected to start from January 2024. Trusts will collect information of all eligible patients and, following suitability checks, will share confidential patient information with the coordination centre (Picker Institute Europe) and one of the approved contractors (Picker Institute Europe, Quality Health, Patient Perspective or Explain). The contractors will distribute questionnaires to patients using the approach detailed below:

	Mode of contact
Contact 1	Postal letter inviting the patient to take part online (and a paper questionnaire included for those over 80 years old)

Contact 1.1	Four days later an SMS reminder will be sent, including a direct link to the online survey
Contact 2	In week 2, a reminder letter will be sent to non-responders
Contact 2.2	Four days later an SMS reminder will be sent, including a direct link to the online survey
Contact 3	Final postal reminder sent, along with a paper questionnaire

Ahead of each reminder mailing, it will be necessary to remove all respondents who have completed the survey already, and to conduct a DBS or local check on the full sample. If anyone has requested to be opted out of further reminders, they should also be removed at these timepoints.

Confidential information requested

Cohort	Inpatients aged 16 years old or over who were discharged from acute and specialist NHS hospitals in November (and earlier for smaller trusts), having had at least one overnight stay in hospital. A list of reasons for exclusion, such as deceased patients and those under 16 years of age at the time of sampling, was included in the application. 1,250 patients per Trust
Data sources	1. Electronic patient records with acute and specialist trusts in England (131). 2. NHS England - NHS Spine Personal Demographics Service (PDSS)
Identifiers required for contact purposes	1. Name 2. Address fields including postcode 3. Mobile phone number 4. Patient unique identifier
Identifiers required for deceased check purposes	1. NHS Number 2. Full date of birth
Identifiers required for analysis purposes	1. Unique identifier (a three digit Trust code and 4 digital serial number related to sampled patient) 2. Postcode 3. Trust code 4. Year of birth 5. Gender 6. Ethnic category 7. Date of admission

	8. Date of discharge 9. Length of Stay 10. Treatment Function Code 11. ICD-10 Chapter Code 12. Treatment Centre Admission 13. Admission method 14. NHS Site code-Admitted 15. NHS Site code-Discharged 16. 'Decided to admit' date 17. Virtual ward indicator
Additional information	Trusts may also choose to collect additional sample variables outside of those detailed in the Survey Handbook. This can be valuable to trusts in enabling them to make greater use of their survey locally to target quality improvements. Sample and mailing data will be submitted by trusts to approved contractors in a single file. The file which contains both mailing and sample information will be split into separate files by the contractor before submitting only the sample information to the Coordination Centre for checking and approval. Please note that the Survey Coordination Centre does **not** receive any names or full addresses

Main issues considered, discussed and outcomes

The CAG noted that this activity fell within the definition of the management of health and social care services and was therefore assured that the application described an appropriate medical purpose within the remit of the section 251 of the NHS Act 2006.

Having reviewed the application and considered the risks and benefits involved, the CAG was also assured that the proposed activity was in the public interest.

The CAG noted that for the 2023 survey, Trusts would be provided with a communication toolkit to promote the survey in advance of fieldwork, as well as during fieldwork to promote the value, purpose and usefulness of the survey and how data would be used. The toolkit would consist of publicity posters, social media cards, infographics and website banners. The applicant has stated that copies will be provided to CAG once finalised. The CAG requested to see the full set of communication toolkit materials when ready, and advised the applicant to press Trust's to use the toolkit. **(Condition 1)**

<u>Confidentiality Advisory Group advice:</u> Provisionally supported

The CAG was unable to recommend support to the Secretary of State for Health and Social Care for the application based on the information and documentation received so far. The CAG requested the following information before confirming its final recommendation:

Number	Action required	Response from the applicant
1.	Security assurances for 2022/23 are outstanding for the following organisations. • Picker Institute Europe • Patient Perspective • Explain 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 CAG also set out the following provisional specific conditions of support in addition to the standard conditions of support.

Number	Condition	Response from the applicant
1.	Please provide the additional full set of communication toolkit materials that are being developed, as soon as they are ready, and confirm that Trust's will be strongly advised to use the communication toolkit.	

The Group delegated authority to confirm its final opinion on the application to the Chair and reviewers.

Dr Murat Soncul (Alternate Vice Chair)	01 November 2023
…….	……..
Signed – Chair	*Date*
Mr Dayheem Sedighi	30 October 2023
…….	……..
Signed – HRA Approvals Administrator	*Date*