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21 December 2023

Jenny King Chief Research Officer Picker Europe Buxton Court 3 West Way Oxford OX2 0JB

Dear Ms King,

Application title: CAG reference:

Urgent and Emergency Care Survey 2024 23/CAG/0179

Thank you for submitting a **non-research** application under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 ('section 251 support') to process confidential patient information without consent.

This application was considered at the Confidentiality Advisory Group (CAG) meeting held on 07 December 2023. This outcome should be read in conjunction the <u>minutes</u> of this meeting.

Confidentiality Advisory Group advice and Secretary of State for Health and Social Care decision

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.

The Secretary of State for Health and Social Care, having considered the advice from the Confidentiality Advisory Group as set out in the minutes, has determined the following:

• The application is <u>conditionally supported</u>, subject to compliance with the <u>standard</u> and specific conditions of support.

Please note that the legal basis to allow access to the specified confidential patient *information without consent is now in effect.* A summary of the scope of support is provided in Appendix A.

Support provides a lawful basis to allow the information to be processed by the relevant parties for the specified purposes without incurring a breach of the common law duty of confidence only. Applicants must ensure the activity remains fully compliant with all other relevant legislation.

Specific conditions of support

- 1. Please provide detailed feedback on the outcomes the questions about using confidential patient information without consent, and linkage with ECDS (added to the cognitive questioning research) to CAG for review. This should be provided to CAG within 3 months.
- 2. Update the patient notification materials as follows and provide to CAG for review:
 - a. Include the information in the cover letter 3 that people receiving the paper questionnaires are informed that they can opt out of the survey by returning the questionnaire blank in the envelope provided to the freepost address.
 - b. Include the process of patient Opt-Out in Letter 2.
 - c. This should be provided to CAG within 3 months.
- 3. Please clarify whether it's possible to include a unique link in the SMS as an alternative way for patients to Opt-Out. This should be provided to CAG within 3 months.
- 4. 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.
- Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant <u>Data Security and Protection Toolkit (DSPT)</u> submission(s) has achieved the 'Standards Met' threshold. **Confirmed:**

The NHS England **22/23** DSPT review for **Patient Perspective Ltd**, **Picker Institute Europe**, **Quality Health Ltd and Explain Market Research Ltd** was confirmed as 'Standards Met' on the NHS England DSPT Tracker (21/12/2023)

As the above conditions have been accepted or met, this letter provides confirmation of final support. I will arrange for the register of approved applications on the HRA website to be updated with this information.

Maintaining CAG support: Reporting requirements

Please note the following guidance on reporting requirements in order to maintain CAG support for the duration of the activity.

- Annual review report: It is your responsibility to submit an annual review report every 12 months for the entire duration that confidential patient information is being processed without consent. The next annual review should be provided no later than **21 December 2024** and preferably 4 weeks before this date. Further guidance and the annual review form is available on the <u>IRAS website</u>.
- Notifying amendments to the scope of CAG support: Guidance on submitting CAG amendments and the amendment form is available on the <u>IRAS website</u>.

- **Notifying the end of activity:** Guidance on notifying the end of activity and the end closure report form is available on <u>the IRAS website</u>.
- **Register of supported applications:** It is a statutory requirement to publish all supported applications to process confidential patient information without consent. Supported applications are published on the <u>HRA website</u>.

Approved documents

The list of documents reviewed and approved at the meeting are as follows.

Document	Version	Date
CAG application from (signed/authorised) [23.CAG.0179_UEC24_cag section 251 form non research applications_SUBMITTED]		
Confidentiality policy [Confidentiality Policy - Picker - June 2017 - V1.2]	1.2	01 June 2017
Covering letter on headed paper [UEC24_Draft Coverletter 1_Type 1_V1.0_PROTECT]		
Covering letter on headed paper [UEC24_Draft Coverletter 1_Type 1_V1.0_PROTECT]		
Covering letter on headed paper [UEC24_Draft Coverletter 2_Type 3_V1.0_PROTECT]		
Covering letter on headed paper [UEC24_Draft Coverletter 2_Type1_V1.0_PROTECT]		
Covering letter on headed paper [UEC24_Draft Coverletter 3_Type 1_V1.0_PROTECT]		
Covering letter on headed paper [UEC24_Draft Coverletter 3_Type 3_1.0_PROTECT]		
Other [UEC24_Data flow chart - post codes V1.0_PROTECT]		
Other [UEC24_Draft Questionnaire_Type 1_V1.0_PROTECT]		
Other [UEC24_Draft Questionnaire_Type 3_V1.0_PROTECT]		
Other [UEC24_Draft Sample declaration form for in-house trusts_V1]		
Other [UEC24_Draft Sample declaration form for trusts using a contractor_V1]		
Other [UEC24_Draft Sample declaration form for trusts using a contractor_V1]		
Other [UEC24_Draft Sampling_spreadsheet_1_V1]		
Other [UEC24_Draft Sampling_spreadsheet_2_(For in_house trusts)_V1]		
Other [UEC24_Draft Sampling_spreadsheet_2_(Using approved contractor)_V1]		
Other [UEC24_Draft Survey handbook_V1.0_PROTECT]		
Other [UEC24_Information flowchart_V1]		
Patient Information Materials [UEC24_Dissent poster_Type 1_V1.0_PROTECT]		
Patient Information Materials [UEC24_Dissent poster_Type 3_V1.0_PROTECT]		
Patient Information Materials [UEC24_Dissent poster_Type 3_V1.0_PROTECT]		
Patient Information Materials [UEC24_Multilanguage sheet_V1]		
Patient Information Materials [UEC24_SMS Guidance_Type 1_V1]		
Patient Information Materials [UEC24_SMS Guidance_Type 3_V1]		

Write recommendation from Caldicott Guardian (or equivalent) of applicant's organisation [Caldicott Guardian recommendation letter	
FINAL]	

Please do not hesitate to contact me if you have any queries following this letter. I would be grateful if you could quote the above reference number in all future correspondence.

Yours sincerely

Dayheem Sedighi HRA Approvals Administrator

On behalf of the Secretary of State for Health and Social Care

Email: cag@hra.nhs.uk

Included:

List of members who considered application Summary of scope of support

Confidentiality Advisory Group meeting 07 December 2023

Group Members:

Name	Profession	Present	Notes
Dr Joanne Bailey	CAG Expert Member	Yes	
Professor William Bernal	Alternate Vice Chair	Yes	
Dr Malcolm Booth	CAG Expert Member	Yes	
Dr Tony Calland MBE	CAG Chair	Yes	
Mr. David Evans	CAG Expert Member	Yes	
Dr Ben Gibbison	CAG Expert Member	Yes	
Mr Andrew Melville	CAG Lay Member	Yes	
Professor Sara Randall	CAG Lay Member	Yes	

Also in attendance:

Name	Position (or reason for attending)
Ms Emma Marshall	HRA Confidentiality Specialist
Dr Paul Mills	HRA Confidentiality Advise Service Manager
Mr Dayheem Sedighi	HRA Approvals Administrator

Appendix A – Summary of Scope of Support

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 Urgent and Emergency Care Survey 2024 (UEC24). The 2024 Urgent and Emergency Care Survey will be the tenth carried out to date, 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. Any outputs provided will be anonymous. This statistical dataset is used for a wide variety of purposes, with the ultimate aim of supporting the improvement of patient experience in England.

The CQC have commissioned the Survey Coordination Centre (SCC) at Picker to manage and coordinate the survey programme. All eligible trusts (123 plus 3 pilot organisations) will be asked to conduct the survey, with preparations expected to begin in July 2023 and fieldwork expected to start from April 2024. Trusts will collect information of all eligible patients and, following suitability checks, will share confidential patient information with the SCC (Picker Institute Europe) in the form of post code only, 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 (URL/QR code)
Contact 1.1	3 working 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 (URL/QR code)
Contact 2.2	3 working days later an SMS reminder will be sent, including a direct link to the online survey
Contact 3	Final postal reminder sent (no URL/QR code), along with a paper questionnaire
Contact 3.3	3 working days later an SMS reminder will be sent, including a direct link to the online survey

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.

The methodology for the 2024 survey is slightly changed from the 2022 survey, to include a small number of non-acute providers as a pilot, to submit type 3 samples, to include more Urgent Treatment Centres (UTCs). Findings from this pilot will inform a potential national rollout to all independent providers and NHS community trusts providing Type 3 services in the 2026 survey.

Other changes proposed for the 2024 survey relate to the mode of data collection- a mixed mode design of online and paper self-completion questionnaire, which was previously supported as part of a pilot (21/CAG/0174), push to web approach, change in sampling information provided, and the timings of the sample, fieldwork and reporting phases. Also for 2024 - NHS number is additionality requested to be sent to the SCC, for linkage with Emergency Care Data Set (ECDS).

Support is requested to allow the disclosure of confidential patient information from NHS trusts to one of the approved contractors for the purpose of sending out questionnaires for the Urgent and Emergency Care Survey 2024, and for disclosure of postcode and NHS Number to Picker Institute Europe (SCC) for analysis purposes. As part of this process, the approved contractors will run deceased checks using the NHS Spine Personal Demographics Service (PDSS), using confidential patient information.

Support is also requested to allow the disclosure of confidential patient information from Picker Institute Europe (SCC) to NHS England, for the purposes of linkage to Emergency Care Data Set (ECDS) and for the flow of data back.

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

Confidential patient information requested

The following sets out a summary of the specified cohort, listed data sources and key identifiers. Where applicable, full datasets and data flows are provided in the application form and relevant supporting documentation as this letter represents only a summary of the full detail.

Cohort	People aged 16 and over who attended a Type 1 emergency department in February 2024 or a Type 3 urgent care department in February 2024. Trusts can sample back to January 2024 if required to fulfil sample.
	Total sample size for trusts submitting a Type 1 sample = 1250 patients.
	Total sample size for trusts submitting a Type 1 and Type 3 sample = 1,530 patients (950 Type 1 patients and 580 Type 3 patients).
	A further 3 organisations participating in the Independent Providers and NHS Community Trusts pilot will only submit a Type 3 sample. The sample they submit will be 1250 patients.
	The Sampling Instructions will ask trusts to exclude:
	 deceased patients children or young persons aged under 16 years at the date of their attendance at the emergency department any patients who are known to be current inpatients planned attendances at outpatient clinics which are run within the Emergency Department (such as fracture clinics)
	 patients without a UK postal address patients attending primarily to obtain contraception (e.g. the morning after pill), patients who suffered a miscarriage or another form of abortive pregnancy outcome whilst at the hospital, and patients with a concealed pregnancy
	- any patient known to have requested their details are not used for any purpose other than their clinical care

	 any patients who were admitted to hospital via Medical or Surgical Admissions Units and therefore have not visited the emergency department Any attendances at Walk-in Centre's Any attendances at Type 3 departments not wholly managed by the sampling trust (or organisation). Patients who attended or were streamed to a separate Same Day Emergency Care unit (i.e. were not treated in the A&E department or Urgent Treatment Centre). 	
Data sources	 Electronic patient records within all eligible acute Trusts in England (123 trusts) Electronic patient records within 3 non-acute organisations; Independent Providers and NHS Community Trusts included in the pilot. These are: Partnership of East London Cooperatives (PELC) Malling Health Derbyshire Community Health Services NHS Foundation Trust 	
	 NHS England - NHS Spine Personal Demographics Service (PDSS) – DBS checks undertaken by approved contractors NHS England - Emergency Care Data Set (ECDS) – linkage undertaken centrally by SCC 	
Identifiers required for contact purposes	 Title (Mr, Mrs, Ms, etc.) Initials or First name Surname Address Fields including postcode Mobile phone number Patient unique identifier. This code is printed on the covering letter as part of the online log-in details and the questionnaire itself. 	
Identifiers required for deceased checks	 NHS Number Full date of birth 	
Identifiers required by SCC for analysis purposes	 Trust code Patient unique identifier Full Postcode - to use to map to deprivation index Year of birth Gender Ethnicity Department Type Designated UTC Time, Day, Month and Year of Attendance NHS Site Code Sub-ICB codes Mobile Phone Indicator 	

	 13. NHS Number – for linkage to ECDS 14. Chief Complaint 15. Diagnosis codes 16. Acuity 17. Person Score
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. Please note that the Survey Coordination Centre does not receive any names or full addresses, except the patients postcode and NHS number