



Health Research Authority

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30 November 2023

Peter Williamson
NHS England Project Lead
NHS England
Quarry House
Leeds
LS2 7UE

Dear Mr Williamson,

Application title: 23/CAG/0164
CAG reference: Under 16 Cancer Patient Experience Survey 2023-2026

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 09 November 2023. This outcome should be read in conjunction with the provisional support outcome dated 20 November 2023, the [minutes](#) of the CAG meeting date 09 November 2023, and the [sub-committee minutes](#) of November 2023, available within 2 weeks of month end).

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 fully supported, subject to compliance with the [standard](#) 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. 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 **22/23** DSPT reviews for **Picker Europe Ltd & Greens Ltd** were confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 27 November 2023)

As the above conditions have been 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 **30 November 2024** and preferably 4 weeks before this date. Further guidance and the annual review form is available on the [IRAS website](#).
- **Notifying amendments to the scope of CAG support:** Guidance on submitting CAG amendments and the amendment form is available on the [IRAS website](#).
- **Notifying the end of activity:** Guidance on notifying the end of activity and the end closure report form is available on [the IRAS website](#).
- **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 [HRA website](#).

Approved documents

The final list of documents reviewed and approved are as follows.

<i>Document</i>	<i>Version</i>	<i>Date</i>
CAG application from (signed/authorised) [P-101876_U16CPES2023-2026_CAG-S251-form-non-research-application_TD_AT_MB_FINAL]		
Confidentiality policy [Picker Data Protection and Processing Policy - External Version V1.3]	1.3	
Confidentiality policy [Confidentiality Policy - Picker - June 2017 - V1.2]	1.2	
Corporate Level Security Policy (CLSP) [ISO27001 Certificate to 31102025]		
Corporate Level Security Policy (CLSP) [ISO20252 2023 Certificate to 19032026]		
Corporate Level Security Policy (CLSP) [2. QA & ISMS Part 2 ISO 20252 2019 - December 2022 - v1.0]	1.0	

Corporate Level Security Policy (CLSP) [1. QA & ISMS Part 1 ISO27001 v4.23 NP MC]	4	
Data Protection Registration [DPO Registration Certificate - Z4942556 - to August 2024]		
Other [P3313-01_U16 CPES_2022_Questionnaire_8-11Children_FINAL]		
Other [Under 16 CPES 2023_P-101876_Sampling Instructions_BJ AT_v1.3]	1.3	
Other [P3313-01_U16 CPES_2022_Questionnaire_0-7parents_FINAL]		
Other [P3313-01_U16 CPES_2022_Questionnaire_12-15Children_FINAL]		
Other [P-101876_U16CPES2023 Survey Handbook_AT_CH v1.1]	1.1	
Other [U16 CPES - Data Flow Diagram]		
Patient Information Materials [U16 CPES Dissent Poster]		
Patient Information Materials [P3313-01_U16 CPES_Third mailing letter_V1.1]	1.1	
Patient Information Materials [P3313-01_U16 CPES_First mailing letter_V1.1_CW]	1.1	
Patient Information Materials [P3313-01_U16 CPES_Second mailing letter_V1.1_CW]	1.1	
Write recommendation from Caldicott Guardian (or equivalent) of applicant's organisation [20231004 U16 CPES Caldicott Guardian letter SIGNED]		

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

Caroline Watchurst
Confidentiality Advisor

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

Email: cag@hra.nhs.uk

Included: List of members who considered the application
Summary of scope of support

**Confidentiality Advisory Group meeting attendance
09 November 2023**

Members present:

Name	Capacity
Dr Patrick Coyle	CAG Vice Chair
Dr Murat Soncul	Alternate Vice Chair
Dr Joanne Bailey	CAG Expert Member
Dr Malcolm Booth	CAG Expert Member
Dr Sandra Duggan	CAG Lay Member
Dr Ben Gibbison	CAG Expert Member
Dr Rachel Knowles	CAG Expert Member
Dr Pauline Lyseight-Jones	CAG Lay Member
Dr Stephen Mullin	CAG Expert Member
Professor James Teo	CAG Expert Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor
Ms Emma Marshall	HRA Confidentiality Specialist
Dr Paul Mills	HRA Confidentiality Advice Service Manager
Mr Dayheem Sedighi	HRA Approvals Administrator
Ms Flora White	HRA Member Support Administrator (Observer)
Ms Rachael Maddocks	HRA Member Management and Development Specialist (Observer)

Appendix A – Summary of Scope of Support

Summary of application

This application from NHS England set out the purpose of conducting a survey into the experiences of patients under 16 years of age receiving treatment for cancer.

The National Cancer Patient Experience Survey (CPES), commissioned and managed by NHS England, is one of the ways that patient experience data for cancer patients in England is captured. The results of these surveys are used to help commissioners, providers and national policy makers to identify priority areas of improvement for services. The application supports the implementation of the NHS Long Term Plan, which recognises the importance of good patient experience alongside other outcomes. The plan specifically references obtaining patient experience feedback from children.

Picker will provide NHS Trusts (PTCs) with detailed sampling instructions to compile a sample of patients, a patient declaration list and a template in which to organise their data. Each participating NHS Trust will extract confidential patient information for the survey sample, taken from the Patient Administration System (PAS) and transfer a list of eligible patients to Picker. Picker will check the sample and create a single master file containing the mailing information (patient name and address), trust code, site code, trust name, site name, survey type, and unique reference number for each patient. This file will be securely transferred to Greens Ltd who will then mail out questionnaires to the home address of patients, addressed 'to the parent/carer of [patient name]'. An anonymous code will be used to track who responds so that two reminders can be sent to non-responders, with 2-3 weeks between mailings and any opt-outs removed. PECS Data Services Limited (PECS) will record the responses received, but this will be under patient consent.

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 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	All children aged under 16 at the time of their care and discharge, with a confirmed primary diagnosis of cancer or a non-malignant brain, other central nervous system or intracranial tumour, who are aware of their diagnosis and have received NHS care and/or treatment for their cancer or tumour in England within a recent twelve-month period (e.g. Jan 1st – Dec 31st 2023 for the 2023 survey).
Data sources	1. NHS Principal Treatment Centres (PTCs)
Identifiers required for linkage purposes	1. Name 2. Address 3. NHS number 4. Sex

	<ul style="list-style-type: none"> 5. Ethnic group 6. Date of birth 7. Discharge date 8. Patient classification 9. ICD10 code or ICD11 code 10. ICD-O-3 site code 11. ICD-O-3 morphology code 12. Specialty code 13. Site code 14. Trust code
Identifiers required for analysis purposes	<ul style="list-style-type: none"> 1. Postcode
Additional information	Confidential patient information for analysis will be held with consent as the legal basis.