

2 Redman Place Stratford London E20 1JQ

Email: cag@hra.nhs.uk

22 July 2025

Joanna Barry NHS England, Wellington House, 133-135 Waterloo Road, London, SE1 8UG

Dear Joanna Barry,

Application title: National Cancer Patient Experience Survey 2025

Methodology Pilot

CAG reference: 25/CAG/0080

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 03 July 2025. 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. The CAG request for the following changes to be made to the patient notification letter, and provided back to CAG within 1 month.
 - a. Ensure it is clear that the Secretary of State for Health and Social Care provided 's251' support on advice from CAG.
 - b. Where it reads "National Data Guardian opt-out", Remove the term 'quardian'.
 - c. Use the specific reference from the poster to the NDOO exemptions webpage
- 2. Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant <u>Data Security and Protection Toolkit (DSPT) submission(s)</u> has achieved the 'Standards Met' threshold. **Confirmed:**

The NHS England **23/24** DSPT review for **Picker Institute Europe & Greens Ltd** were confirmed as 'Standards Met' on the NHS England DSPT Tracker

This letter provides confirmation of final support, and all the above conditions are expected to be met within the stated timeframe. 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 22 July 2026 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 list of documents reviewed and approved at the meeting are as follows.

Document	Version	Date
CAG application from (signed/authorised) [CAG-section-251-form-non-research-applications_ CPES Pilot _CH JK NHSE_FINAL]		
Confidentiality policy [14. Picker Confidentiality Policy - June 2017]		June 2017

Data Protection Registration [12. NHS England - Data Protection Policy]	
Other [04. NCPES 2025 - Data flow for pilot]	
Other [05. NCPES 2025_Accessibility sheet]	
Other [06. CPES25_Pilot Sampling Instructions]	
Other [07. CPES25_Pilot Survey Handbook]	
Other [13. NHS England - Information Governance Policy]	
Other [16. Picker Data Protection and Processing Policy - External Version]	
Other [18. Picker Equipment Policy - January 2025]	January 2025
Other [19. Picker Information Governance - Sharing of PID]	
Patient Information Materials [01. CPES25_Pilot letters and SMS]	
Patient Information Materials [02. NCPES 2025_Questionnaire Pilot]	
Patient Information Materials [03. NCPES 2025 - Dissent Poster Pilot]	
Write recommendation from Caldicott Guardian (or equivalent) of applicant's organisation [NCPES 25 Pilot - Caldicott Guardian Letter (2)]	

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

Charlotte Miller 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 03 July 2025

Members present:

Name	Role
Professor William Bernal	CAG Alternate Vice Chair
Dr Tony Calland MBE	CAG Chair
Dr Sandra Duggan	CAG Lay Member
Dr Ben Gibbison	CAG Expert Member
Mr Anthony Kane	CAG Lay Member
Dr Harvey Marcovitch	CAG Expert Member
Mr Andrew Melville	CAG Lay Member
Dr Stephen Mullin	CAG Expert Member

Also in attendance:

Name	Position (or reason for attending)
Ms Katy Cassidy	HRA Confidentiality Advisor
Ms Rachel Katzenellenbogen	Approvals Specialist
Miss Charlotte Miller	Approvals Administrator
Dr Paul Mills	HRA Confidentiality Advice Service Manager
Ms Wangari Njiiri	Approvals Administrator
Ms Caroline Watchurst	HRA Confidentiality Advisor

Appendix A – Summary of Scope of Support

Summary of application

This application from Picker Institute Europe on behalf of NHS England is for the non-research purpose of management of health and social care to administer the National Cancer Patient Experience Survey 2025 Methodology Pilot. The purposes of the pilot is to test the use of a new methodology (involving text message reminders). This pilot will run alongside the main National Cancer Patient Experience Survey (NCPES) 2025 with the main survey acting as a control to understand the impact of the new methodology (a separate application has been submitted for the main NCPES – 25/CAG/0070). The reason for this pilot is to address falling response rates, reduce non-response bias and improve accessibility. The pilot will help ensure that the methodology for NCPES remains fit for purpose and continues to provide vital insight into experiences of care. By conducting a pilot before introducing any methodological changes to the NCPES, benefits can be maximised and risks can be minimised.

The 2025 pilot survey will mostly replicate the methodology used in previous iterations of the survey; Picker Institute Europe works with Greens Limited to mail initial questionnaires and then reminders (as required) to eligible participants following the above checks using name and address. The survey will be conducted by post, with two reminders (to non-responders only) as is the case with other national patient surveys. A standard questionnaire, covering letter and up to two reminder letters will be used. Patients will also be sent a link to complete the survey online should they prefer to do so. Changes to the above standard methodology include piloting a different letter for people aged under or over 75, and 2 different versions of SMS messages, one with the word cancer included and one without. Picker will send up to 3 SMS reminders to participants using Qualtrics platform (SaaS). Patient participation then proceeds on a consented basis.

A recommendation for class 1, 5 & 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	Approximately 7,300 adult patients (aged 16 and over), with a primary diagnosis of cancer, who have been admitted to hospital as inpatients for cancer related treatment, or who were seen as day case patients for cancer related treatment, and have been discharged in March 2025.	
Data Sources	 Electronic patient records at 45 participating Trusts in England 	
Identifiers	1. Name	
required by	2. Address inc postcode	
Picker from	3. telephone number (used by Picker to send SMS)	
Trusts	4. NHS number	
	5. date of birth	

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	2. 3. 4. 5. 6.	Sex ethnic group admission and discharge dates admission type ICD10 or ICD11 code speciality code referring ICB and site
Identifiers required for purpose of sending invitation letters (Picker to greens)	2.	Names Addresses Unique identifier