



# Health Research Authority

2 Redman Place  
Stratford  
London  
E20 1JQ

Tel: 020 7104 8100  
Email: [cag@hra.nhs.uk](mailto:cag@hra.nhs.uk)

02 February 2021

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

Dear Ms King

**Application title:** National Cancer Patient Experience Survey 2019  
**CAG reference:** 19/CAG/0137

Thank you for your amendment request to the above non-research application, submitted for support under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process confidential patient information without consent. Supported applications enable the data controller to provide specified information to the applicant for the purposes of the relevant activity, without being in breach of the common law duty of confidentiality, although other relevant legislative provisions will still be applicable.

The role of the Confidentiality Advisory Group (CAG) is to review applications submitted under these Regulations and to provide advice to the Secretary of State for Health and Social Care on whether an application should be supported, and if so, any relevant conditions.

## **Secretary of State for Health and Social Care support decision**

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

The amendment, to extend the duration of confidential patient information arrangements until 31 August 2022 to allow a 2020 national Cancer Patient Experience survey to be administered on a voluntary basis, and to include the collection of ICD-11 codes, is supported, subject to compliance with the standard conditions of support.

## **Amendment request**

This application from NHS England set out the purpose of administering patient surveys to evaluate services provided to cancer patients in 2019. Support is currently in place to allow the disclosure of confidential patient information from participating NHS Trusts to Picker Institute Europe, to enable the 2019 patient survey to be distributed.

The National Cancer Patient Experience Survey is run on an annual basis and each year a separate application for support under Regulation 5 is submitted. However, the current pandemic placed unprecedented pressures on cancer services in 2020, which resulted in NHS England and NHS Improvement making the decision not to mandate the National Cancer Patient Experience Survey in

2020. However, it is recognised that there is value in learning from patients' experience of care during 2020.

This amendment is requesting support in the form of a duration amendment, to enable trusts to participate in the 2020 survey on a voluntary basis. Identifiers will be retained until 31 August 2022, at which point they will be deleted and support will no longer be required. The applicant has confirmed that data sources, data processes, and data flows remain the same as 2019 survey. A new application will be submitted for the 2021 National Cancer Experience Survey.

The applicants notified the CAG of minor amendments to the questionnaire to ensure that it remains appropriate to the way care delivery has changed during the pandemic. This includes the collection of the most recent version of the International Classification of Diseases, ICD-11 in addition to ICD-10, which was supported in the application. This is because Trusts are in the process of switching from ICD-10 to ICD-11. This is no more disclosive than original support.

The applicant also notified the CAG of a new way for Trusts to submit patient sample lists to a secure online platform. This is using the same data processor, and does not constitute a change in confidential patient arrangements,

The applicant has described the changes to patient notification materials as appropriate, which have already been displayed in Trusts.

An updated flow diagram and questionnaire have been provided, and the only changes to these are the changes described in this amendment.

### **Confidentiality Advisory Group advice**

The amendment requested was considered by Chairs action. The CAG chair confirmed that in these exceptional circumstances he was happy for an amendment to be submitted instead of a new application, and raised no queries.

### **Confidentiality Advisory Group conclusion**

In line with the considerations above, the CAG agreed that the minimum criteria under the Regulations appeared to have been met for this amendment, and therefore advised recommending support to the Secretary of State for Health and Social Care.

### **Specific conditions of support**

1. Confirmation of suitable security arrangements via IG Toolkit submission.  
**Confirmed – Picker Institute Europe (by check of DSPT tracker 22 January 2021) and Greens Limited (by check of DSPT tracker 22 January 2021) have confirmed 'Standards Met' grade on DSPT 2019/20).**

### **Reviewed documents**

<i>Document</i>	<i>Version</i>	<i>Date</i>
CAG amendment form		11 January 2021
CPES20_Questionnaire_V1 5_MB JK_12.01.2021_protect		12 January 2021
CPES20 - Data Flow Diagram		11 January 2021

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](mailto:cag@hra.nhs.uk)

Enclosures: Standard conditions of support

### **Standard conditions of support**

Support to process confidential patient information without consent, given by the Secretary of State for Health and Social Care, is subject to the following standard conditions of support.

The applicant and those processing the information will ensure that:

1. The specified confidential patient information is only used for the purpose(s) set out in the application.
2. Confidentiality is preserved and there are no disclosures of information in aggregate or patient level form that may inferentially identify a person, nor will any attempt be made to identify individuals, households or organisations in the data.
3. Requirements of the Statistics and Registration Services Act 2007 are adhered to regarding publication when relevant, in addition to other national guidance.
4. All staff with access to confidential patient information have contractual obligations of confidentiality, enforceable through disciplinary procedures.
5. All staff with access to confidential patient information have received appropriate ongoing training to ensure they are aware of their responsibilities.
6. Activities remain consistent with the General Data Protection Regulation and Data Protection Act 2018.
7. Audit of data processing by a designated agent is facilitated and supported.
8. The wishes of patients who have withheld or withdrawn their consent are respected.
9. Any significant changes (for example, people, purpose, data flows, data items, security arrangements) must be supported via formal amendment prior to changes coming into effect.
10. An annual review report is submitted to the CAG every 12 months from the date of the final support letter, for the duration of the support.
11. Any breaches of confidentiality around the supported flows of information should be reported to CAG within 10 working days of the incident, along with remedial actions taken / to be taken. This does not remove the need to follow national/legal requirements for reporting relevant security breaches.