



Health Research Authority

Skipton House
80 London Road
London
SE1 6LH

Tel: 020 7104 8100
Email: cag@hra.nhs.uk

11 December 2020

Peter Williamson
Insight and Feedback Manager
NHS England and NHS Improvement
Skipton House
London
SE1 6LH

peter.williamson7@nhs.net

Dear Mr Peter Williamson

Application title: Under 16 Cancer Patient Experience Survey 2020-2023
CAG reference: 20/CAG/0111

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 Advice Team as set out below, has determined the following:

1. The amendment, to allow the collection of patient's ICD-11 codes, in addition to ICD-10 codes, from participating NHS trusts, is supported, subject to compliance with the standard conditions of support.

Amendment request

The applicants have existing support to collect patients' ICD-10 codes from participating NHS trusts. The applicants are seeking to collect ICD-11 codes also.

NHS trusts are in the process of switching from the use of ICD-10 codes to ICD-11. Trusts must be using ICD-11 by 2022, however some trusts may have already switched over. The applicants are therefore seeking support to collect both codes to ensure that the correct patients are sampled and sent a questionnaire, and will also allow for comparisons of different cancer groupings at the reporting stage.

Confidentiality Advice Team advice

The amendment requested was considered by the Confidentiality Advice Team. It was determined that the proposed amendment would aid in ensuring that the correct patient group was included in the survey and was in the public interest.

Confidentiality Advice Team conclusion

In line with the considerations above, the CAT 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 provided from the IG Delivery Team at NHS Digital to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. See section below titled 'security assurance requirements' for further information. **(Confirmed – Picker Institute Europe has a confirmed 'Standards Met' grade on DSPT submission 2018/19 by check of the NHS Digital email dated 17 July 2019)**

Reviewed documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
P3313_ U16 CPES_Amendment Request_MB AT RH_27.11.20_v2.0_signed		27 November 2020

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

Kathleen Cassidy
Confidentiality Advisor

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

Email: 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.