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03 November 2021

Peter Williamson
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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 Advisory Group as set out below, has determined the following:

1. The amendment, to include the ICD-O-3 4 and the ICD-O-3 morphology code, to give participating trusts the option to use an online sampling checker platform and to send the survey type, trust name and site name to Greens Ltd, is fully supported, subject to compliance with the standard conditions of support.

Amendment request

The applicants have existing support to allow the disclosure of confidential patient information from NHS Principal Treatment Centres (PTCs), delivering children's cancer care and treatment in England, to Picker Europe Ltd, in order to facilitate the Under 16 Cancer Patient Experience Survey 2020-2023. The fieldwork for the first iteration of the Under 16 Cancer Patient Experience Survey (U16 CPES) 2020 is complete, and the planning for the 2021 survey is underway.

The applicants are seeking to amend the data items to include the ICD-O-3 4 and the ICD-O-3 morphology code, in addition to the ICD-10 and ICD-11 codes. This change to include the ICD-O codes will enable applicants to improve the way cancer grouping is presented to trusts at a national level.

The applicants also seek to use a new online sampling checking platform. Trusts will still be able to submit their patient sample lists using the secure file transfer platform (FTP), as with the first wave of the U16 CPES survey (2020) that ran this year. However, the applicants would also like to provide trusts with the option of using a secure online sample checking platform. This platform is hosted by Picker Institute Europe and performs a number of automatic checks on the sample list, thus improving checking accuracy and reducing the amount of time trusts need to be engaged with questions about their samples. This platform is in use across other national patient experience surveys, including the National Cancer Patient Experience survey, and the NHS Staff Survey, with positive feedback being received from trusts.

The applicants also seek to send the survey type, trust name and site name to Greens Ltd to improve the efficiency of the survey mailings. This will allow the Patient Reference Number to be shortened, improving efficiency as survey recipients need to refer this number when making queries about the survey and reduce the quality checking time needed between sending the patient sample list to Greens and mailing out the surveys.

Confidentiality Advice Team advice

The amendment requested was considered by the Confidentiality Advice Team. The CAT agreed that the revisions made would lead to more efficient running of the survey, which was in the public interest.

Confidentiality Advisory Group 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:

Confirmed – Picker Institute Europe and Greens Ltd has a confirmed 'Standards Met' grade on DSPT submission 2020/21 by check of the NHS Digital email dated 28 October 2021)

Reviewed documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
Amendment request form		28 September 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

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.