



Health Research Authority

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08 June 2023

Dr Marisa Mason
NCEPOD Chief Executive
Ground Floor Abbey House
74-76 St John Street
London
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Dear Dr Mason,

Application title: **The Child Health Clinical Outcome Review Programme
(CH-CORP)**
CAG reference: **21/CAG/0085**

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 (CAG) as set out below, has determined the following:

1. The amendment, to add the topic for this year's NCEPOD review, Juvenile Idiopathic Arthritis, is fully supported, subject to compliance with the standard conditions of support.

Amendment request

This application has 's251' support for a core methodology of data collection for The Child Health Clinical Outcome Review Programme (CH-CORP). Confidential patient information regarding all eligible cases is disclosed from participating healthcare providers to the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), a sample is selected, and confidential patient information is used to follow-up with clinicians involved in the patients care by way of questionnaire (completed online in pseudonymised format), and relevant copies of

extracts from the patient's case notes are also disclosed from treating clinicians to NCEPOD.

HQIP commission one topic each year. This year the topic is Juvenile Idiopathic Arthritis. The standard methodologies for retrospective case identification, sending of questionnaires to clinicians and anonymous case note review will be followed.

Confidentiality Advisory Group advice

The amendment requested was considered by the Chairs' action. The Alternate Vice-Chair was content to support this amendment.

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 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 21/22 DSPT review for National Confidential Enquiry into Patient Outcome and Death (NCEPOD) was confirmed as 'Standards Met' on the NHS England DSPT Tracker (checked 25 May 2023).

Reviewed documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
CAG0085_Juvenile Idiopathic Arthritis_Amendment-request_updated form		22 May 2023
JIA protocol_final		April 2023
JIA_Patient Information Leaflet_Child & Young Person		
JIA_Patient Information Leaflet_Parent Carer		
JIA_Poster		
NCEPOD JIA_Poster_Easy read		

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

Enclosures: Standard conditions of support



Health Research Authority

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.