



PICANet clinical audit and research database opt out policy

Paediatric Intensive Care Audit Network (PICANet) is an international database of paediatric intensive care in the United Kingdom and Republic of Ireland run by the Universities of Leeds & Leicester. The information we collect helps us learn what works best to help very sick children so that we can give every child in critical care the best healthcare possible. You can find out more information about what PICANet does with the data collected from our PICANet posters and information leaflets.

This document provides further detail about how you (child / young person) or the child you care for can opt out of having your identifiable personal information stored by PICANet and/or if you wish to prevent your data being included in approved research projects.

What personally identifiable data would PICANet store about me/my child?

Personally identifiable data that PICANet collects and stores includes:

- Name(s)
- Date of birth
- Date of death (if applicable)
- Health record identifier number (e.g. NHS number)
- Address and postcode
- Hospital identifiers (e.g. case note number)

We do not receive name, address or health record identifier number for data from Republic of Ireland. Only an encrypted hospital identifier is received.

We do not receive name or address for data from Northern Ireland. Only a partial date of birth and encrypted health record identifier are received.

How do I request that my/my child's data is de-identified in the PICANet database?

If you do not want information which could identify you or your child included in PICANet, please tell the nurse or doctor caring for your child. They will make sure your child's information is de-identified before being sent to PICANet.

Your decision will not alter the care your child receives in this or any other hospital.

If you have left hospital and decide that you do not want information which could identify your child included in PICANet and would like to withdraw any information, please call us directly at PICANet on 0113 3438125 or email picanet@leeds.ac.uk.

PICANet will de-identify the data within 25 working days of your request and let you know once the process is complete.

How do I opt out of PICANet?

Clinical audit

For the clinical audit dataset, please note that currently, you can ask for you or your child's confidential information to be de-identified as per the process outlined in the previous section. Please note that anonymised information will remain in the PICANet national clinical audit dataset for non-research purposes.

However, if you or your child do not want any of the data to be included in the research dataset and used for approved research purposes, you can follow the opt out process below.

Research

If you are considering opting out of the research dataset, we encourage you to speak to the nurse or doctor caring for your child who can provide an information leaflet about PICANet for your consideration. The leaflet links to our website (www.picanet.org.uk) where you can find out more.

If you or your child decide that you do not want any of their data to be included in the research dataset and used for approved research purposes please contact the Nursing or Medical Leads for your local PICU or the Chair and Deputy Chair of PICANet's Clinical Advisory Group (Professor Mark Peters and Dr Hari Krishnan) with whom you can discuss this with and request to opt out.

Professor Mark Peters
Tel: 0207 813 8213
Email: mark.peters@ucl.ac.uk

Dr Hari Krishnan
Tel: 0121 333 8754
Email: hari.krishnan2@nhs.net

Please note that if you wish to withdraw your records from the PICANet research dataset you will have to inform the PICANet team of each care event. Any subsequent care events that you wish to remove from the research dataset will require you to follow the process outlined above again.

How long will this process take?

As soon as you have confirmed in writing or email to Professor Mark Peters and Dr Hari Krishnan that you wish to opt out of the research dataset, a member of the PICANet team will contact you to confirm the outcome within 25 working days of receiving the request.

What if I want to opt back in?

You are able to opt back in at any time. Please let Professor Mark Peters and Dr Hari Krishnan know.