



PICANet clinical audit and research database opt out policy for children, young people and parents

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 and Leicester.

You (child / young person) or the child you care for can opt out of having your personally identifiable information stored by PICANet. If you wish you can also stop your data being included in approved research projects. This document tells you how to do this.

Paediatric critical care (PCC) units collect information during your child's admission. PICANet use this information to find out the best treatment and care for children. This will enable organisations to plan and continue to provide high quality services in the future. You can find out more information about what PICANet does with the data collected from our website (www.picanet.org.uk/), posters and information leaflets.

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

Personally identifiable information that PICANet collects and stores includes:

- Name(s)
- Date of birth
- Health record identifier number (e.g. NHS number/ case note number)
- Address and postcode

If your healthcare was provided in Republic of Ireland, we do not receive name, address or health record identifier number. Only an encrypted hospital identifier is received.

If your healthcare was provided in Northern Ireland, we do not receive name or address. Only a partial date of birth and encrypted health record identifier are received.

How do I request that my/my child's personally identifiable information are removed from 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 personally identifiable information are removed before being sent to PICANet.

Any 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 you/your child included in PICANet, please call us directly at PICANet on 0113 3438125 or email picanet@leeds.ac.uk.

PICANet will remove the identifiable information within 25 working days of your request and let you know once this has been done.

Please note that your anonymised information will remain in the PICANet database for audit (non-research) and approved research purposes.

How do I opt out of PICANet clinical audit?

As described above you can ask for you/your child's personally identifiable information to be removed. Please note that anonymised information will remain in the PICANet national clinical audit dataset for non-research purposes.

What if I have applied via the National Data Opt-Out (in England) not to have my/ my child's health data used for research and planning?

The National Data Opt-Out is not applied to PICANet data received from English PCC services for non-research purposes. PICANet have received permission from the Health Research Authority Confidentiality Advisory Group for England and Wales not to apply the National Data Opt-Out which relates to information about an individual's health care provided in England. This application was made as an amendment to our existing approval 21/CAG/0090. Permission was granted because the absence of even one child's data can lead to inaccurate conclusions.

However, if you or your child do not want any of the data to be included in secondary uses, such as approved research purposes, you can follow the opt out process below.

How do I opt out of the PICANet research database?

This section does not apply to you if you/ your child has been admitted to a Level 2 Paediatric Critical Care unit. Data collected from these units are not included in research.

What if I have applied via the National Data Opt-Out (in England) not to have my/ my child's health data used for research and planning?

PICANet applies the National Data Opt-Out to the processing and/or release of data received from English hospitals where the purpose is for secondary uses, such as approved research projects. Therefore, you do not need to contact PICANet if you have set a National Data Opt-Out. This will mean that your child's data will not be included in any approved research projects.

If you have not set a National Data Opt-Out and/or you are considering opting out of all data being included in the PICANet research dataset, we encourage you to speak to the nurse or doctor caring for your child. They 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 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 (Dr Hari Krishnan and Professor Mark Peters) with whom you can discuss this with and request to opt out.

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

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

Please note that if you wish to withdraw your data 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 Dr Hari Krishnan and Professor Mark Peters 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 providing that your personally identifiable information has not been removed from the clinical audit dataset. Please let Dr Hari Krishnan and Professor Mark Peters know.