



PICANet Patient Privacy Notice and Fair Processing Statement

Paediatric Intensive Care Audit Network (PICANet) is an international database of paediatric critical care in the United Kingdom and Republic of Ireland run by the University of Leeds and the University of Leicester.

This statement explains how we use any personal information we collect about you (child / young person) or the child you care for.

Contents

What data are being collected?	1
What are the data being used for?	2
Our legal basis for processing the data	2
Where are the data held and for how long?.....	3
Sharing data with other organisations	3
How to request that your/your child's personally identifiable information are removed from the PICANet database	4
Does the National Data Opt-Out in England apply to PICANet?	4
How to opt out of the PICANet research database	4
Who is responsible for the data?	5
What if I have concerns about the way personal data are processed?	6

What data are being collected?

PICANet collects paediatric critical care (PCC) data. We run the National Paediatric Critical Care Audit (NPCCA) and data are collected for every child and young person referred, transported or admitted to a Paediatric Intensive Care Unit (PICU) in the UK and the Republic of Ireland.

Some PICUs provide Extra Corporeal Membrane Oxygenation (ECMO) treatment and data are collected if there is a referral to an ECMO centre made for a child or young person and/ or a child is admitted to PICU for an ECMO assessment, admitted to PICU already receiving ECMO, or is placed on ECMO during their PICU admission.

Data are also collected on children and young people admitted to a designated NHS level 2 paediatric critical care unit (sometimes called a High Dependency Unit) in England.

The data are sent to us over a very secure web application by each participating unit or specialist transport team on a regular basis. Data are collected for each individual for the whole period of their critical care unit stay. Data are also collected about what happened to them if they had a critical care transport to PICU (this means that a specialist team of nurses and doctors travelled in an ambulance to pick them up and take them to a PICU).

What are the data being used for?

We collect this data for clinical audit, research, service evaluation and commissioning purposes (which means the continual process of planning, agreeing and monitoring services). These help to improve the care given to children and young people admitted to PCC. Each year we produce a report on activity and outcomes for paediatric intensive care in the UK and Ireland. No personal or identifiable information will ever be made public in any report or publication.

All data, except from data collected from the Level 2 PCC units and the ECMO Admission and Referral data, are also part of the PICANet research database. PICANet supports high quality research in the areas of paediatric intensive care, specific conditions affecting children and young people accessing paediatric intensive care services, epidemiology of critical illness, and public health. Following a rigorous data request process, and providing the appropriate research ethics approvals and legal bases for data processing and sharing are in place, baseline data can be provided for research studies and clinical trials to extend the available knowledge with a view to ultimately providing benefits to patients.

Our legal basis for processing the data

PICANet has permission to collect personal data including identifiers and special category data of children and young people referred, transported and admitted to a PICU and/or admitted to a level 2 PCC unit without taking explicit (written) consent from the children or their carers. The personal identifiers include name, address, date of birth, and health record identifier number (e.g. NHS number)*. Special category data include ethnicity and data concerning health.

* We do not receive name, address or health record identifier number for data from Northern Ireland or the Republic of Ireland.

Throughout the UK, the disclosure of confidential information is lawful under the Common Law Duty of Confidentiality. This is because the work of ensuring high standards of quality and safety of healthcare is in the public interest. Our lawful basis for processing personal data from the UK and Republic of Ireland is Public Task as set out in Article 6 of the General Data Protection Regulation (GDPR):

- Article 6 (1) (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

The Data Protection Act 2018 legal basis is, Schedule 1(1)(3) 'public health' underpinned by Health and Social Care Act 2021 Part 1 section 2.

PICANet has the following support to process confidential patient information without consent for both non-research and research purposes under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 ('section 251 support' of the NHS Act 2006) for data collected in England and Wales:

- The clinical audit activity falls within the management of health and social care services in the public interest. Therefore, the Health Research Authority and The Secretary of State for Health and Social Care, on advice from the Confidentiality Advisory Group, an advisory body which provides independent expert advice on the use of confidential patient information without consent in England and Wales, has provided support for PICANet to process confidential patient information without consent for non-research purposes.
- The medical research database is approved by a research ethics committee and contributes to medical research in the public interest. Therefore, the Health Research

Authority, on advice from the Confidentiality Advisory Group, has provided support regarding research purposes.

Summaries of the approved non-research and research applications for PICANet are available on the register of approvals on the [HRA website](#). The references are: 21/CAG/0090 (non-research) and 21/CAG/0098 (research).

For the participating organisations in Scotland, local and Caldicott approvals are in place and approval from the NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP). The reference is 1819-0107 Feltbower.

A Data Access Agreement for personal identifiable data is in place between PICANet and Belfast Health and Social Care Trust for data from organisations in Northern Ireland.

The legal basis set out in GDPR for processing special categories of personal data is:

- Article 9 (2) (i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy.

For the research database, the legal basis set out in GDPR is:

- Article 9 (2) (j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

Where are the data held and for how long?

The University of Leeds hold all data in a highly secure environment. The University of Leeds and the University of Leicester process all data, including confidential personally identifiable data, in highly secure environments. As we are an audit, we keep this data permanently so we can check on what has happened in the past. There are some data that we collect which we do not need to keep permanently. We follow the UK General Data Protection Regulation's data minimisation and storage limitation principles. For example, these data are collected, processed for the necessary purposes and then deleted from the database once an individual is older than 18 years and has not been in paediatric critical care for the last five years: Case note number and Address (house number/name, street, county and country).

N.B. Case note number is retained for data from Northern Ireland or the Republic of Ireland.

Sharing data with other organisations

PICANet may share data held on its database with commissioners, executive agencies of government e.g. the UK Health Security Agency (UKHSA), researchers, other audits, or other healthcare providers in order to help improve patient care. We will NOT share personal identifiers (such as name, address, date of birth or NHS number) with anyone else unless the appropriate legal, ethical, and security arrangements are in place to keep your personal details safe and secure. PICANet regularly share data from the NHS PCC providers in England with NHS England for commissioning purposes. Very occasionally, personal data may be processed by an authorised third party, but again, only with the necessary regulatory permissions and data security measures in place.

We have a rigorous process of assessing the merit of requests for data and information and publish details of these requests each year in our annual State of the Nations Report. Data collected in English NHS paediatric intensive care units and specialist transport teams are jointly controlled by the Healthcare Quality Improvement Partnership (HQIP) and NHS England and all requests go through the HQIP data access process. For more information on English NHS data sharing for uses outside of the NPCCA programme, please see: [NCAPOP Privacy Notice – HQIP](#).

How to request that your/your 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.

You do have the right to request access to and to request to rectify information held about you or the child you care for.

Does the National Data Opt-Out in England apply to PICANet?

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. This application was made as an amendment to our existing non-research approval, 21/CAG/0090. Permission was granted because the absence of even one child's data can lead to inaccurate conclusions.

PICANet applies the National Data Opt-Out to the processing and/or release of data received from English PCC services for secondary uses, such as approved research projects. This means that, where a National Data Opt-Out has been set, data will not be included in any approved research projects. For such projects, the National Data Opt-Out is extended by PICANet to all data included from private PCC services in England to ensure compliance with the National Data Opt-Out.

Please note that Data collected from Level 2 Paediatric Critical Care units and the ECMO data collection are not included in research activities. Therefore, this and the following section do not apply.

How to opt out of the PICANet research database

If you have not set a National Data Opt-Out and you are considering opting out of the PICANet research dataset please see the PICANet clinical audit and research database opt out policy available on our website (www.picanet.org.uk/) for full details.

You are free to withdraw your/your child's data from the research database at any time. Any decision will not alter the care your child receives in this or any other hospital.

Who is responsible for the data?

NHS England is joint Data Controller with the Healthcare Quality Improvement Partnership for all data collected in English NHS PICUs, transport teams and Level 2 PCC units for the National Paediatric Critical Care Audit.

Healthcare Quality Improvement Partnership

Healthcare Quality Improvement Partnership Ltd.
128 City Road
London
EC1V 2NX
(Charity Reg No. 1127049)

Data Protection Officer:
E: data.protection@hqip.org.uk

Data controller registration number provided by the Information Commissioner's Office: Z1780946

The NHS Commissioning Board (NHS England)

NHS England London
Skipton House
80 London Road
London
SE1 6LH

Data Protection Officer: Carol Mitchell (E: england.dpo@nhs.net)

Data controller registration number provided by the Information Commissioner's Office: Z2950066

The University of Leeds and the University of Leicester are joint data processors for the data collected in English PICUs, transport teams and NHS Level 2 PCC units.

The joint Data Controllers and Data Processors for data collected in PICUs and transport teams in Wales and Northern Ireland are:

University of Leeds

Leeds
LS2 9JT

Data Protection Officer: Rebecca Messenger-Clark
E: dpo@leeds.ac.uk

Data controller registration number provided by the Information Commissioner's Office: Z553814X

University of Leicester

University Road
Leicester, LE1 7RH

Data Protection Officer: Parmjit Gill
T: +44(0)116 229 7945
E: dpo@leicester.ac.uk

Data controller registration number provided by the Information Commissioner's Office: Z6551415

The joint Data Controllers and Data Processors for data collected in Scotland are the University of Leeds and the University of Leicester (details above) and Lothian Health Board and Greater Glasgow and Clyde Health Board:

Lothian Health board

NHS Lothian
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG

Data Protection Officer:
T: +44 (0)131 465 5444
E: Loth.DPO@nhslothian.scot.nhs.uk

Data controller registration number provided by the Information Commissioner's Office: Z5757124

Greater Glasgow Health Board
NHS Greater Glasgow & Clyde
J B Russell House, Gartnavel Hospital
1055 Great Western Road
Glasgow
G12 0XH

Data Protection Officer: Stewart Whyte
T: +44 (0)141 278 4774
E: Data.Protection@ggc.scot.nhs.uk

Data controller registration number
provided by the Information
Commissioner's Office: Z8522787

The joint Data Controllers and Data Processors for data collected in Republic of Ireland are the University of Leeds and the University of Leicester (details above) and the Royal College of Surgeons in Ireland through the National Office of Clinical Audit:

National Office of Clinical Audit
2nd Floor, Block B, Ardilaun House
111 St Stephens Green
Dublin 2, D02 VN51

Data Protection Officer: Brid Moran
T: +353 1 4028577
E: dpo@noqa.ie

The joint Data Controllers and Data Processors for data collected in private PICUs are the University of Leeds (details above) and HCA International Limited:

HCA International Limited (HCA UK)
2 Cavendish Square
London
W1G 0PU
E: DPO@hcahealthcare.co.uk

Data controller registration number provided by the Information Commissioner's Office:
Z5688794

[What if I have concerns about the way personal data are processed?](#)

If you wish to raise a complaint about how we have handled your or your child's personal data, please contact the Data Protection Officers (above) who will investigate the matter. If you are not satisfied with our response or believe we are processing the data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

<https://ico.org.uk/>