

PICANet Patient Privacy Notice and Fair Processing Statement.

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

What data are being collected?

PICANet collects data on every child and young person referred or admitted to a Paediatric Intensive Care Unit (PICU) in the UK and the Republic of Ireland. The data are sent to us over a very secure web application by each PICU or specialist transport team on a regular basis. Data are collected for each individual for the whole period of their PICU stay and also about what happened to them if they had a critical care transport (this means a specialist team of nurses and doctors travelled in an ambulance to pick them up and take them to a PICU). PICANet has permission to also collect personal identifiers of children or young people admitted to or referred for Paediatric Intensive Care without taking explicit (written) consent from the children or their carers. This was granted by the NHS Health Research Authority Confidentiality Advisory Group. A summary of the entry for PICANet is available on the register of approvals on the [HRA website](#) (PICANet was first approved in 2002 and its reference is: PIAG 4-07(c)/2002). The personal identifiers include name, address, date of birth and health record identifier number (e.g. NHS number)*.

* We don't receive name, address or health record identifier number for the Republic of Ireland or Latvia

What are the data being used for?

We collect this data for clinical audit, research and service evaluation and planning to improve the care given to children and young people admitted to PICU. Each year we produce a report on activity and outcomes for paediatric intensive care in the UK and Ireland. No personal information will ever be made public in any report or publication.

Where are the data held and for how long?

All of the data is held at the University of Leeds in a highly secure environment. As we are an audit, we keep this data permanently so we can check on what has happened in the past. We do remove personal identifiers from our data base once an individual is older than 18 years and has not been in PICU for the last five years.

Sharing data with other organisations

PICANet may share data held on its database with 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. Very occasionally, personal data may be processed by an authorised third party such as NHS Digital, again, only with the necessary regulatory permissions. They have very high levels of security and will keep these data very safe.

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 report. Data collected in English NHS paediatric intensive care units and specialist transport teams are controlled by the Healthcare Quality Improvement Partnership and all requests go through their Data Access Request Group. More details about the HQIP data request process can be found at: <http://www.hqip.org.uk/national-programmes/a-z-of-nca/audits-and-data-gov-uk/>.

What if I don't want information about me or about the child I care for included?

If you do not want information that would identify you or the child you care for included in PICANet, please tell the nurse or doctor in the paediatric intensive care unit. Alternatively, you can contact PICANet by telephone or email (details provided below) and we will ensure that your personal

identifiers are taken off the database. You are free to request this at any time and any decision request removal of your or your child's identifiers will not alter the care you receive in this or any other hospital. You also have the right to request access to and to request to rectify information held about you or the child you care for.

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Who is responsible for the data?

The **Data Controller** for data collected in English NHS PICUs and transport teams is:

Healthcare Quality Improvement Partnership

6th Floor, 45 Moorfields,
London,
EC2Y 9AE
(Charity Reg No. 1127049)
Data Protection Officer: Sasha Hewitt (E: data.protection@hqip.org.uk)
Data controller registration number provided by the Information Commissioner's Office: Z1780946

The **Data Controller** for data collected in private PICUs and PICUs and transport teams in Scotland, Wales, Northern Ireland and the Republic of Ireland is:

University of Leeds

Leeds
LS2 9JT
Data Protection Officer: David Wardle (T: +44(0)113 343 4452, E: d.wardle@adm.leeds.ac.uk)
Data controller registration number provided by the Information Commissioner's Office: Z553814X

Who processes the data?

The **Data Processors** for all data are:

University of Leeds

Leeds
LS2 9JT
Data Protection Officer: David Wardle
T: +44(0)113 343 4452
E: d.wardle@adm.leeds.ac.uk

University of Leicester

University Road
Leicester, LE1 7RH
Data Protection Officer: Parmjit Gill
T: +44(0)116 229 7945
E: pg170@le.ac.uk

What is the legal basis for processing the data?

The data are needed to carry out a task in the public interest to ensure high standards of quality and safety of healthcare. *

What if I have concerns about the way the 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/>

* General Data Protection Regulation:

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.

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.