## If you would like to know more about PICANet you can:

Talk to the doctors and nurses

Or

Email <u>picanet@leeds.ac.uk</u>
Call 0113 343 8125

Visit our website at www.picanet.org.uk

Or

Call our **Research Nurse**, **Dr** Lyn Palmer, on

0116 252 5414

Or write to Lyn at:

slp60@leicester.ac.uk

Or by post at:

PICANet
Department of Health Sciences
College of Life Sciences
George Davies Centre
University of Leicester
University Road
Leicester
LE1 7RH

#### **Principal investigators:**

Professor Elizabeth Draper
PICANet
Department of Health Sciences
College of Life Sciences
George Davies Centre
University of Leicester
University Road
Leicester, LE1 7RH

Professor Richard Feltbower
PICANet
School of Medicine
University of Leeds
LIDA, Worsley Building
Leeds, LS2 9JT

### www.picanet.org.uk



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# Paediatric Intensive Care Audit Network



Information Leaflet for families and carers of children admitted to paediatric critical care

#### What does PICANet do?

PICANet is a project helping to continually improve how we treat and care for very sick children in paediatric critical care (PCC).

PCC units collect information during your child's admission. We 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.

#### **How is PICANet funded?**

Funding is provided by the National Clinical Audit & Patient Outcomes Programme administered by the Healthcare Quality Improvement Partnership (HQIP) for England, Welsh Health Specialised Services Committee, NHS Lothian – University Hospitals Division, The Royal Belfast Hospital for Sick Children, National Office of Clinical Audit Ireland (NOCA), and HCA International.

#### How is information collected?

A member of staff records information about your child's condition or illness from their medical notes which is then sent to the PICANet database.

#### What information is collected?

Personal details, like name and date of birth, help us to follow your child's critical care journey and treatment including admission to other PCC units. We can use your postcode to help plan future PCC services in a geographical area.

#### Will the information be safe?

We send and receive all information in a very safe way and the University of Leeds store this confidential information in a secure electronic environment. Noone can see the information, unless it is their job to do so. For further information please see the PICANet Privacy and Fair Processing Statement on the PICANet website www.picanet.org.uk.

#### What are the benefits of collecting data?

PICANet's international data collection ensures a UK and Ireland-wide overview of paediatric critical care as well as national and local views, including critical care referral and transport services. During the past few years, we have shown that over 19,000 children are admitted to the PICUs in the United Kingdom and Ireland each year and there are over 5,000 transports to PICU annually.

As well as writing reports and informing planning of children's critical care for the future, PICANet supports quality improvement at national levels by providing data and specialist input into reports and reviews. PICANet can monitor the impact of the COVID-19 pandemic nationally. PICANet is able to report on patient characteristics, treatment, and outcomes of confirmed COVID-19 cases.

On a more local level, each PCC can review their own data collected within PICANet. Regular reports to each unit by PICANet allows identification of potential risk factors. This allows each unit to minimise complications and drive improvements in clinical practice to reduce mortality and physiological impact.

## Does my child have to be included in the clinical audit database?

Yes. You don't need to do anything for your child to be included. The National Data Opt-Out is not applied to clinical audit data received from English paediatric critical care services. This is because the absence of even one child's data can lead to inaccurate conclusions.

## Does my child have to be included in the research database?

No. PICANet applies the National Data Opt-Out to the research database for data received from English hospitals. 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 BUT do not want any of the data about your child to be used for approved research purposes please contact PICANet.

## Can I opt out of my child's personally identifiable information being included in PICANet?

Yes. If you do not want information included which identifies your child, please tell the nurse or doctor caring for your child or contact PICANet (details provided overleaf). Your child's anonymised information will remain in the PICANet database for audit (non-research) and approved research purposes.

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

For more information please see the PICANet clinical audit and research database opt out policy on our website.

