

The DEPICT Study Privacy Notice

Data Linkage study: work stream A

(To be made available on the DEPICT website: <https://depict-study.org.uk/>)

This privacy notice explains how we use any personal information we hold about your child.

What is the DEPICT Study?

DEPICT (Differences in access to Emergency Paediatric Intensive Care and care during Transport) is a research study. It is funded by the National Institute for Health Research (Health Services and Delivery Research Programme, ref: 15/136/45). The Chief Investigator is Dr Padmanabhan Ramnarayan and the Study Sponsor is Great Ormond Street Hospital NHS Foundation Trust. The data linkage study (work stream A) is being led by the University of Leicester.

The DEPICT study is a mixed-methods study. This privacy notice relates to work stream A, which uses routine data sources to investigate the impact of timeliness of access to care on the outcomes of children who are transported by specialist paediatric transport services. The data sources are the: Paediatric Intensive Care Audit Network (PICANet); Intensive Care National Audit and Research Centre Case Mix Programme (ICNARC CMP); Hospital Episodes Statistics (HES); Patient Episodes Data for Wales (PEDW) and Office of National Statistics (ONS). These data sources hold information about the following:

- **PICANet** dataset (based at University of Leeds and funded by the Healthcare Quality Improvement Partnership or HQIP) holds data about children admitted to paediatric intensive care, including the care and treatments they receive
- **Intensive Care National Audit and Research Centre (ICNARC)** dataset holds similar information to PICANet, and we will use it to find out about children who receive care in adult intensive care units
- **Hospital Episodes Statistics (HES)** datasets contain information on hospital episodes that take place in hospitals and in outpatient appointments in England
- **Patient Episodes Data for Wales (PEDW)** dataset holds information on hospital episodes that take place in hospitals and in outpatient appointments in Wales
- **Office of National Statistics (ONS)** holds information about the date and cause of death of individuals in England and Wales

The data controllers for work stream A of the DEPICT study are [Great Ormond Street Hospital](#), and the [University of Leicester](#). For contact details for these organisations please refer to the end of this privacy notice.

What information is being collected?

No additional data beyond that already held by the data sources (see above) is being collected for the purposes of this work stream of the DEPICT study.

Data has been collected by PICANet and ICNARC for several years for inclusion in their audit and programme. Both these organisations have Section 251 support (approval from the Confidential Advisory Group) to collect data without patient consent. Identifiable data (NHS number, gender, postcode and date of birth) will be sent by PICANet and ICNARC separately to NHS Digital using a secure file transfer system. The data will then be linked to HES and ONS mortality data by NHS Digital. Once linked, the identifiable data will be removed from the linked dataset leaving a pseudo identifier and the HES and ONS data. This will make the final dataset pseudonymised meaning that there is less risk of identifying individuals within the pseudonymised dataset alone however if it is combined with other information it could be made identifiable. Therefore, workstream A of the DEPICT study take extra care when handling your data and do not have access to any of the identifiable data from the PICANet and ICNARC datasets.

The pseudonymised dataset will be sent securely to the DEPICT workstream A study team based at the University of Leicester by NHS Digital once it is complete

Ethics and Legal basis

The DEPICT study has ethical approval (REC reference: 17/LO/1267) and Section 251 (CAG) support (reference: 17.CAG.0129) to undertake linkage between the data sources in the described way. The DEPICT Study is using Article 6(1)(e) and Article 9(2)(j) from the General Data Protection Regulation (GDPR) as our legal basis for processing data.

Why are we using this information?

We are linking these data sources to allow us to investigate and understand the longer term impact of care received during paediatric intensive care transport. For more details on the work of the DEPICT study, including the other work streams, please visit the DEPICT Study website (www.depict-study.org.uk).

Where is the data held and for how long?

The linked dataset will be stored on the secure servers at the University of Leicester. No data will ever leave this location. It will be retained until May 2025, five years after study completion, to allow us the time to generate reports, publications and respond to queries about the DEPICT study. After this time, the data will be destroyed.

Sharing data with other organisations

The DEPICT workstream A study team will only have access the pseudonymised dataset. The PICANet and ICNARC data, which does contain identifiable information (NHS number, gender, postcode and date of birth), will be passed directly to NHS Digital without involvement of the workstream A DEPICT study team.

The DEPICT team will not share the linked dataset with any third parties.

Contact details for Data Controllers

University of Leicester

University of Leicester, University Road, Leicester, LE1 7RH

The data protection officer at the University of Leicester can be contacted via: Information Assurance Services (ias@le.ac.uk)

Great Ormond Street Hospital

Great Ormond Street, London, WC1N 3JH

www.gosh.nhs.uk

The data protection officer at GOSH is: Anna Ferrant (your.data@gosh.nhs.uk)

Further details

You have the right to complain about the way your data is being used; please direct your complaint to the [Information Commissioner's Office](#)

The workstream A DEPICT team do not have access to your personal data. If you would like to access, amend, erase or opt out of your personal data being used, you must contact the PICANet or ICNARC teams directly.

PICANet: <https://www.picanet.org.uk/patients-and-families-information/>

ICNARC: <https://www.icnarc.org/About/Information-Standards/Information-Security/Privacy-Policy>

Further information about the DEPICT study can be found in the website: www.depict-study.org.uk