

The DEPICT Study Privacy Notice

Questionnaire and interview study: work stream B

This privacy notice explains how we use any personal information we collect about you / the child you care for.

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.

What information is being collected?

Personal information is being collected as part of the DEPICT Study in work stream B (questionnaires and interviews work stream). In this part of the DEPICT Study:

- Parents/legal guardians of children transported for intensive care across England and Wales in 2018 will be approached by a research team at their child's intensive care unit (the 'local site research team') to consent for their participation in the DEPICT Study and complete a transport questionnaire. Parents/guardians will be asked to provide written consent to share their child's and their personal data (information that could identify that person e.g. child's name, NHS number, parents' name and preferred contact details, e.g. email address or phone number) with the DEPICT Study team based at Great Ormond Street Hospital in London. Local sites will transfer personal data to the DEPICT Study team using a secure system (such as NHS.net email or similar).
- Parents/legal guardians who participate in interviews (or who consent for their child/young person's participation in an interview) will be asked to give permission for the interview to be audio-taped. Audio recordings may contain personal data.
- NHS staff (clinicians and service managers) across England and Wales will be approached by the local research teams to consent for their participation in the DEPICT Study. They will be asked to provide explicit written consent for the DEPICT Study team to collect their personal data (name, preferred contact details, e.g. email address or phone number).

Why are we collecting this information?

- Personal data collected from parents/guardians will be used by the DEPICT Study team based at Great Ormond Street Hospital to contact them to discuss participation in detailed

interviews about their/their child's experience of the transport to intensive care. With their consent, we will also contact parents/guardians 12 months after their child's intensive care admission to seek their participation in completing questionnaires about their child's quality of life.

- Personal data collected from NHS staff will be used by the DEPICT Study team based at Great Ormond Street Hospital to contact them for participation in detailed interviews.

- Audio recordings of interviews with parents/guardians and children/young people will be used to describe transport experiences. Audio recordings of interviews with staff will be used to describe their experience of working for or with transport services.

For more details on what information is being collected as part of the DEPICT Study and to find out more about why we are collecting this information, please visit other pages of the DEPICT Study website (www.depict-study.org.uk).

Where is the data held and for how long?

- All personal data collected by the DEPICT Study team will be stored in secure servers at Great Ormond Street Hospital and access to the data will only be available to authorised study staff. Personal data will only be stored for 6-12 months after the research study completion (May 2020).

- Digital files of audio recordings of interviews will be stored securely at Great Ormond Street Hospital. They will be transcribed by an external company called Take Note (www.takenotetyping.com) which has a confidentiality agreement in place with Great Ormond Street Hospital. Transcribed notes (which will have identifiable information removed) will be stored on secure servers at Great Ormond Street Hospital for a minimum of 15 years. Similarly, parent transport questionnaires (without any identifying information) will be held securely.

Sharing data with other organisations

We will not share your personal data with any other organisations without your explicit consent. All research data will be analysed and published only in aggregated and anonymised form.

How can I access the information you hold about me?

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. If you wish to withdraw consent and do not want for your personal

data to be included in the data collection, please contact our Data Protection Officer whose name is Anna Ferrant and you can contact her Your.data@gosh.nhs.uk

What to do if you wish to make a complaint about how we have handled your data

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) Post: Wycliff House, Water Lane, Wilmslow, Cheshire, SK9 5AF, web: <https://ico.org.uk/concerns/> Phone: 0303 123 1113