



Understanding the experience of your child's transport to PICU

A chance to tell us about both your and your child's experiences

We would like to invite you and your child to take part in a research study. Before you decide if you would like to take part, we would like to explain what the study is about, and what joining the study will involve.

Please take time to read the following information. Please ask us about anything that is not clear, or if you would like more information. Talk to others about the study if you wish.

Study name: *Critically ill children and young people: do national Differences in access to Emergency Paediatric Intensive Care and care during Transport affect clinical outcomes and patient experience? The DEPICT study*

www.depict-study.org.uk

Aim of the study:

Children and young people who are very ill often need to be transferred to a specialist ward called a paediatric intensive care unit or a '**PICU**'.

Across the country we know there are differences in how quickly transport teams can reach sick children and how the transport is performed. This may be because the PICU is very far away from the hospital from which your child was transported, or may be because of how busy transport teams are.

The main aim of the DEPICT study is to understand whether these differences influence how children recover and how children and their families experience being transported to a PICU. We hope the results from our study will help to improve how NHS transport services are organised in the future and to better support families who use the transport services.

Why you are being invited to take part:

We are inviting you and your child to take part because your child was recently transported to PICU by a transport team. Over a period of 12 months, starting in early 2018, all parents of children transferred to one of 24 PICUs in England and Wales are being invited to participate in the study.

What will happen if you agree to take part in the study?

1) A short questionnaire now: while your child is in the PICU, we will ask you to complete a questionnaire (which should take about 10-15 minutes to fill in).

This questionnaire will ask about your experience before, during and after your child's transport. We also ask some questions about you and your family to help us understand your answers. You have the choice to fill out a paper copy of the questionnaire or you can fill it out on-line. We hope to collect around 800-1000 completed questionnaires. There are two (identical) questionnaires to complete in case your child had more than one parent / legal guardian present during the transport and you both want to tell us about your experience separately. You are also welcome to complete one questionnaire together if you prefer.

2) Two short (follow-up) questionnaires later: approximately one year after your child's PICU admission, the DEPICT research team would like to send you some questions to complete about your child, such as about their current quality of life.

Other information collected: If you consent, we will ask '**PICANet**', a national database to which your child's transport team will have submitted information about their transports, to provide us, the research team, with information related to your child's journey to PICU e.g. how long it took the transport team to reach your child and who

was on the team. Also with your consent, research team colleagues at Great Ormond Street NHS Hospital Foundation Trust would like to collect some information from your child's hospital notes.

Contact details and an invitation to chat:

Your contact details, which you supply, would be used to send the follow up questionnaires. If you are interested, we may also contact you 2-3 months after the PICU admission to invite you to chat about yours and your child's experience in an interview (and to invite your child, if they were able to remember at least some of their transfer to PICU and are old enough to speak to us – 5 years old and older).

Do we have to take part?

No, you do not have to take part. It is up to you to decide whether or not you want to take part. If you agree, you will be given this information booklet to keep and you will be asked to sign a consent form.

If you decide that you do not want to take part this decision will in no way affect the care your child receives. Your child's treatment is always what his or her doctors and nurses decide is best, based on their experience and preference.

Even if you agree to participate in the study, **you may withdraw your consent at any time.** You do not have to give a reason if you do not want to take part and it will not affect your child's care now or in the future. If you want to

complete the short questionnaires but do not want to be contacted about the interview you can indicate that on the consent form that we will ask you to sign.

What are the advantages of taking part in the study?

There may not be any specific advantages to you or your child from taking part in the study. However, participating in this research helps us to understand if there are ways we can improve the transport service, across the country, and to find new ways to support families in what can be a really difficult time.

What are the disadvantages to taking part in the study?

There are no particular risks or disadvantages to taking part in the study. Your child will get the same treatment whether you join the study or not.

By completing the questionnaire (and possibly the interview later) we are asking you to think about a very sensitive and difficult time and this may be upsetting. If this is the case, you can, if you want to, withdraw from the study at any time without giving us a reason.

If you would like to talk to someone about how you are feeling we can help arrange that for you.

Confidentiality of information:

Your identity and participation in the study will be kept confidential. Your contact details will be held securely at [name of hospital] and access will be limited to members of the study team based at [name of hospital]. Research data (anonymised i.e. without your personal information attached) will be stored for 15 years at GOSH after the end of the study.

What will happen to the results of the research study?

The results of the study will be used to inform NHS decisions about how to organise children's transport services in England and Wales and about any additional information or support needs of parents whose children are transported to a PICU.

We will share our results with colleagues by presenting the results at medical conferences and publishing in scientific journals. Any results presented or published will not contain information that could lead to the identification of participants.

We will also publicise the results of the study on the study website (www.depict-study.org.uk), through parent/patient groups and through social media (Twitter@DEPICT_Study). If you wish to find out about the results of the study we recommend that you visit our website where we will post study updates, and results when the study is completed.

Who is organising and funding the research?

The research is funded by the National Institute of Health Research (part of the NHS). All NHS research is reviewed

by an independent group of people, called a Research Ethics Committee, to protect your and your child's interests.

This study has been reviewed and given a favourable opinion by the Research Ethics Committee.

In case there is a problem

We do not expect there to be a problem. If you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study, then you may wish to contact the Chief Investigator, Dr Padmanabhan Ramnarayan (see contact details below)

The normal National Health Service complaints mechanisms are also available to you. Details can be obtained from the hospital or the Patient Advisory Liaison Service (PALS), contactable on 020 7829 7862

STUDY CONTACTS:

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Thank you for taking the time to read this information. Any questions please do ask. More details about the study can be found on our website:

www.depict-study.org.uk