Guidance for parents/carers of newborn babies being transported with breathing difficulties

Study title:

NeoVISOR: Prospective study to identify risk factors predictive of death, requiring Extracorporeal Membrane Oxygenation (ECMO) or cardiac disease in neonates referred to UK neonatal and paediatric transport services with respiratory failure -

We know this leaflet may reach you at a very difficult time. You do not need to read it now, or do anything at all. Decisions resulting from the below information can be made at any time in the coming weeks.

What Is This Study About?

Evelina London Children's Hospital is running a national study to learn more about newborn babies who have trouble breathing.

Being in the study will not change how the doctors and nurses care for the babies.

We will only use information that doctors and nurses already record about your baby.

If you don't want us to use your baby's data, you can say no and this leaflet explains how to opt out.

What are we trying to do?

Some babies with breathing problems need to go to special hospitals for extra care.

Sometimes, they need to be moved again to get a higher level of help, like a treatment called ECMO.

ECMO is a machine that adds oxygen to the baby's blood outside the body and then puts it

back in.

We want to find out early which babies might need this extra help. That way, they can get the

right care faster and avoid them being moved more than once.

How will the study work?

Babies will still get normal care but after they are moved to a specialist hospital, we'll look at the information already collected by medical staff

We will use secure & safe computer systems to keep the data.

The data will be linked to data stored on other big NHS databases to learn what happened to each baby.

The data is already routinely collected by the NHS so we will not require you to complete a Consent Form.

If you do not want your baby's information used, you can:

- scan the QR code and fill in the short form
- tell any member of the team caring for your baby
- email the study team: james.diviney@nhs.net
- register a National Data Opt-out at www.nhs.uk/your-nhs-data-matters