

We want to improve the quality of care for future patients on long-term ventilation. Are you a parent/carer or patient on LTV? If so...read on!

We are currently working on a study to explore the quality of care received by young people on long-term ventilation (LTV) aged 0-24. We will produce a report for clinicians and other professionals about how to improve their care and guidance for patients and families on what care you should expect to receive.



Part of the project will be asking **patients, parents & carers** their views, because it's **YOU** who really know how services could be improved to help you and other people receiving LTV.

The National Children's Bureau are running a series of focus groups on our behalf, and helping us distribute an online anonymous survey to help gather your views on what happens, what works, what doesn't and what a better service would look like.

The online survey can be found on our website or by following the link here: https://www.surveymonkey.co.uk/r/NCEPOD_LTV_Survey

Another part of the study will involve us asking the LTV departments at hospitals across the UK, Guernsey, Jersey & Isle of Man for a list of all LTV patients aged between 0-24 over a 2-year period (the information will be sent password protected and will include NHS number/ hospital number and DOB but will not include names and addresses).

We will then randomly select cases for a detailed (anonymous) review by clinicians. For each case we'll ask the clinician various questions and then we will review case notes and other reports (all of which will be destroyed at the end of the study in November 2019).

More details on the study can be found here:
<https://www.ncepod.org.uk/ltv.html>

All patients, relatives and carers can opt out of identifiable information being used in this study. If you'd like to opt out please contact us on the details below:

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