

What is this study about?

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

Information is being collected across the whole of the UK, and as part of this project we are asking patients and parent carers for your views, because it's you who really know how services could be improved to help you and other people receiving LTV.

Who should complete this survey?

Please complete this survey if you are the child or young person OR the parent carer of a child or young person who is receiving or who has received long-term ventilation. If you are a parent carer you may also wish to help the child or young person to complete the questionnaire as well as completing one yourself.

ALL RESPONSES GIVEN AS PART OF THIS SURVEY ARE CONFIDENTIAL

Background information

We recognise that different families will have different experiences and will feel better able to answer some questions than others. Where you are unable to answer a question, please tell us this by marking your response as 'unknown'

1a. Are you:

- A parent carer
- A child or young person who receives LTV

1b. If you are a PARENT CARER are you completing the questionnaire:

- For yourself
- For the child or young person you care for

2. Where do you live?

- Northern England
- Midlands and Eastern England
- London
- South East England
- South West England
- Wales
- Scotland
- Northern Ireland
- Offshore Islands
- Other

3a. If you are a child or young person receiving LTV, how old are you?

3b. If you are a parent carer, how old is your child or young person receiving LTV?

4. Who delivers most of your/your child or young person's care?

- Child health
- Adult health
- Both child and adult health
- Unknown

5. How is ventilation provided?

- Invasive ventilation (with a tracheostomy)
- Non-invasive ventilation (usually via a mask)
- Unknown

6. How long have you/your child or young person been receiving LTV?

We would like to get your views on how much you were included at the point when a decision was made to begin Long-Term Ventilation. When you look back to this:

7. How well do you/your child or young person feel you/they were included/involved in the decision to provide LTV?

- Poorly included/involved
- Included/involved some of the time
- Fully/well included/involved
- Unknown
- Not applicable

8. At the time ventilation started, were you aware of the impact this would have on you/your child or young person's life?

- Yes
- No
- Unknown

9. If there were things that you didn't understand, how could this have been improved? (Please specify)

10. Were there things that you would have liked to have more information about? Please tell us what these are?

11a. Do you have/does your child or young person have: (Please tick all that apply)

- A lead consultant(s)
- A named community worker that acts as a lead nurse
- An agreed personal care plan

We would like to know about the health services you/your child or young person currently receives.

12a. How would you rate the overall quality of the LTV care you/your child or young person receives?

1 (Poor) 2 3 4 5 6 7 (Excellent) N/A

12b. Based on the above answer, please think about the LTV care you received in the last year, and please tell us about:

Up to three current things that go well and why you think that is

i)

ii)

iii)

Up to three current things that could be improved and if possible how you think this might happen

i)

ii)

iii)

The overall availability of health services and how easy it is to get them

13a. Do you feel that you get the full range of HEALTH services needed to help you/your child or young person keep well?

- Yes
- No
- Unknown

13b. If NO, please give examples of where there are particular HEALTH services where you have problems:

14. What care does your GP provide? (Please tick all that apply)

- Appointments for routine/simple health problems and advice
- Urgent care (first source of advice when you are unwell)
- Other (please specify)

15. Do you feel overall that services for you/your child or young person are well coordinated?

- Yes
- No
- Unknown

16. Have there been any problems with the funding of you/your child or young person's services?

- Yes
- No
- Unknown

Emergency healthcare

17a. Do you/your child or young person have a written plan which you can refer to and use in case you need urgent help (sometimes called an escalation plan or emergency health care plan)?

- Yes
- No
- Unknown

17b. If YES, do you know who to contact?

- Yes
- No
- Unknown

18a. Have you had help to prepare you in dealing with common urgent healthcare situations at home?

- Yes
- No
- Unknown

18b. If YES how would you rate your confidence in dealing with urgent situations?

1 (Low)	2	3	4	5	6	7 (Very high)	Unknown
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19a. Have you ever had any problems accessing emergency healthcare in relation to LTV?

- Yes
- No
- Unknown

19b. If YES, please give details:

Support services

When you have a less urgent concern about long-term ventilation and need to discuss it with someone:

20a. Is there an online and/or telephone support services?

- Yes
- No
- Unknown

20b. Are these available all of the time?

- Yes
- No
- Unknown

Psychosocial support

1 (Poor)

2

3

4

5

6

7 (Excellent)

Unknown

N/A

21c. Please give any further detail in relation to your answers:

23a. Did you/your child or young person have access to any respite/short break care provision in the last year?

Yes

No

Unknown

23b. If YES what was the duration of this? (Please specify)

24. Have you/your family in the last year had a holiday away from home?

Yes

No

Unknown

Communication

25a. Please rate how well you think the team providing LTV care for you/your child or young person communicate with EACH OTHER:

1 (Poor)

2

3

4

5

6

7 (Excellent)

Unknown

25b. Please give more detail:

26a. Please rate how well the team providing LTV care for you/your child or young person communicate with YOU/YOUR CHILD OR YOUNG PERSON:

1 (Poor)	2	3	4	5	6	7 (Excellent)	Unknown
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26b. Please give more detail:

Transition (moving to be cared for by adult based services)

27a. Have you/your child or young person moved from children's to adult care or have started planning to do so?

- Yes
- No
- Unknown

27b. If YES, were you/are you prepared?

- Yes
- No
- Unknown

27c. If YES, were you/are you well informed about the process of moving to adult services?

- Yes
- No
- Unknown

27d. If YES, did you/are you experiencing any problems with the move to adult services?

- Yes
- No
- Unknown

27e. If YES, please give details:

Overall

28. What do you think could happen/be changed to make LTV care easier for patients and their carers?
(Please specify)

Thank you for taking the time to complete this questionnaire