

What is this study about?

NCEPOD is undertaking a study to explore the care of patients up to the age of 25 (before their 25th Birthday) receiving long term ventilation (LTV). LTV is defined as 'ventilation provided every day for 3 months (invasive and non-invasive) where the intention is/was to maintain the patient at home on continued ventilatory support (not home oxygen)'.

Information is being collected across the whole of the UK from areas of care where one or all of the following are provided:

- **Long term ventilation is initiated**
- **Settings where patients receiving LTV may be treated (specialist and non-specialist, acute sector and community care including respite)**
- **Emergency care is provided**
- **The hospital provides home ventilation**

Data collection methods include:

- **Parent/carer & patient views (questionnaires, interviews and focus groups)**
- **Clinician views (questionnaire and interviews)**
- **Case note review**

Who should complete this form?

Please complete this questionnaire if you work in one of the areas of care detailed above, and/or are or could be involved with this group of patients (this will include managers and commissioners of care). We are hoping to collect data from health and social care providers in both acute and community settings (including the ambulance service, residential placements and schools), and also commissioners.

All responses given as part of this study are confidential

Clinician interviews

As part of this study we will also be undertaking interviews to ask the services available for and care provided to patients receiving long term ventilation. If you would be willing to be contacted as part of the interview process please give your details below:

Name

Email address

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

1. What is your job role?

- Doctor Nurse Physiotherapist Occupational therapist Speech & language therapist
- Other allied health professional Paramedic Commissioner Social care provider
- Other (please specify)

2. If you are a CLINICIAN, please state your specialty (Free text)

3. Where do you work?

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

4. Please describe the locality:

- Mainly urban
- Mainly rural
- Mixed

5. Which type of setting do you work in? (Please tick all that apply)

- Acute hospital sector – LTV centre (LTV is initiated) Hospice or respite care
- Acute hospital sector – non-LTV centre (LTV is not initiated) Independent sector
- Community sector (residential/nursing home (including specialist care) Commissioning organisation
- Community sector (at home) Ambulance service
- Other (please specify)

6. What age groups do you care for/hold commissioning responsibility for, predominantly in relation to LTV?"

< 18 years

All ages

≥ 18 years

Other (please specify)

7a. In your opinion, how well do you think the healthcare services provided to patients on LTV in your area/hospital work?

1 (Not at all well)

2

3

4

5

6

7 (Extremely well)

Unknown

7b. Based on the above answer, please think about the healthcare services provided to your LTV patients and indicate:

Up to three things that go well

i)

ii)

iii)

Up to three things that could be improved

i)

ii)

iii)

8a. In general, how would you rate the effectiveness of other services in your locality, such as education, social care, voluntary care and independent services on the health and well-being of patients on LTV?

1 (Generally ineffective)

2

3

4

5

6

7 (Generally fully effective)

Unknown

8b. Based on the above answer, please indicate:

Up to three things that go well

i)

ii)

iii)

Up to three things that could be improved

i)

ii)

iii)

9a. In general, how would you rate equipment services for young people receiving LTV (for example ventilators, wheelchairs, ramps)?

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"/>

9b. Based on the above answer, please think about the equipment services that are provided in your area and indicate:

Up to three things that go well

i)

ii)

iii)

Up to three things that could be improved

i)

ii)

iii)

10a. What are the main problem areas with VENTILATORY equipment in your area of care? (Please tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Lack of standardisation of ventilator provided | <input type="checkbox"/> Storage of disposables |
| <input type="checkbox"/> Maintenance of equipment – in hospital | <input type="checkbox"/> Providing training required for use of LTV equipment |
| <input type="checkbox"/> Maintenance of equipment – in the community | <input type="checkbox"/> The maintenance of competencies of carers with safe use of ventilation equipment |
| <input type="checkbox"/> Community supply of disposables | <input type="checkbox"/> Out of hours support |
| <input type="checkbox"/> Other (please specify) | |

10b. Please give any further details including ways to improve equipment services:

11. Which aspects of care influence the quality of life for patients requiring long term ventilation in your area? e.g. specific social or clinical issues such as language problems, travel, access to school/employment opportunities:

12a. How would you rate the transition arrangements from paediatric to adult services in your locality for young people receiving LTV?

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"/>

12b. Based on the above answers, please indicate:

Up to three things that go well

- i)
- ii)
- iii)

Up to three things that could be improved

i)

ii)

iii)

12c. Are you/is your organisation responsible for the care of young people at the point of transition from paediatric to adult services?

Yes

No

Unknown

13a. How would you rate the overall commissioning arrangements for LTV services in your area in the last 5 years?

1 (Poor)

2

3

4

5

6

7 (Excellent)

Unknown

13b. When there are problems, broadly what did/do these relate to? (Please tick all that apply)

No problems

Delay in approvals by commissioning bodies

More than one commissioning body (e.g. local and specialist/national commissioners)

No formal commissioning arrangements

Health and social care overlap and/or disagreement in commissioning

Other (please specify)

13c. Where applicable, please give details of significant improvements/success with the commissioning of LTV services in your area

14a. What respite/short break care provision is available for people receiving LTV in your area? (Please tick all that apply)

	<18 years	≥18 years
Home care services	<input type="checkbox"/>	<input type="checkbox"/>
Residential or nursing care	<input type="checkbox"/>	<input type="checkbox"/>
Day care	<input type="checkbox"/>	<input type="checkbox"/>
Benevolent or charity funding	<input type="checkbox"/>	<input type="checkbox"/>
Bursaries or low cost holidays	<input type="checkbox"/>	<input type="checkbox"/>
Leisure discounts	<input type="checkbox"/>	<input type="checkbox"/>
Hospice	<input type="checkbox"/>	<input type="checkbox"/>
Acute hospital care	<input type="checkbox"/>	<input type="checkbox"/>

14b. How would you rate the availability of respite services where available?

	1 (Poor)	2	3	4	5	6	7 (Excellent)	Unknown
<18	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
≥18	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14c. Do you experience difficulties organising access to respite care?

- Yes
- No
- Unknown
- Not applicable

15a. In general, do all patients aged 0-24 have a lead consultant for LTV?

	Yes	No	Unknown
<18	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
≥18	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15b. Are you a lead clinician, or part of a lead clinical team for patients who are receiving LTV?

- Yes
- No
- Not applicable

15c. Do all patients have a personal care plan which includes ongoing input from a multidisciplinary team*? (*A multidisciplinary team is defined as a group of professionals from one or more specialties who make decisions regarding the treatment of patients. [NHS Data Dictionary. NHS digital. 2018.](#))

	Yes	No	Unknown
<18	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
≥18	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16a. In general, how do you assess the adequacy of ventilation once patients are on an established LTV programme? (Please tick all that apply)

- Clinical review
- Sleep studies
- Respiratory function tests (e.g. flow volume loops; thoracic compliance)
- NA – not part of job role
- Blood gas analysis/Non invasive monitoring of carbon dioxide (percutaneous, End tidal)
- Other (please specify)

16b. In general, how often does this occur post-discharge, when a patient is established on LTV?

For patients on invasive ventilation

- At least quarterly
- Only according to clinical need
- At least six-monthly
- Only when problems arise
- At least annually
- Other (please specify)

For patients on non-invasive ventilation

- At least quarterly
- At least six-monthly
- At least annually
- Other (please specify)
- Only according to clinical need
- Only when problems arise

17a. Do you feel that there is consensus between clinicians/care providers about managing risk at home (e.g. how to deal with common emergencies)?

- Yes
- No
- Unknown

17b. If NO, what problems has this lead to?

Many thanks for taking the time to complete this questionnaire