How do you feel about using a ventilator at home? What’s important to you?

This survey has been put together to find out how people who use ventilators at home feel about the equipment they use, and the support that they receive at home.

The information from the survey will help healthcare professionals, working with the European Respiratory Society, develop new standards for best practice when prescribing and monitoring home ventilation.

The survey is anonymous so we will not ask for your name or to contact you, but if you would like to receive updates about this project please enter your email address at the end.

In this survey, home ventilation (HV) is defined as breathing that is assisted by a machine used in the home environment. It expects that although your medical condition is stable, your body cannot breathe well enough independently to maintain your health or life.

What is your diagnosis?

1. COPD
2. Overlap syndrome
3. Kyphoscoliotic
4. Neuromuscular diseases
5. SMA
6. ALS
7. Neurological disease
8. Other

1) You and your ventilator

How old are you? (use age ranges: under 35, 36-45, 46-65, 66-75, 76+)

a) How frequently do you use your ventilator?

- when needed
- under 12 hours
- only during the day
- only at night
- 12-16 hours
- over 16 hours
- 24 hours a day

b) What interface do you use? Mark all that you use.
• full-face mask
• mouth mask/mouth piece
• nasal mask
• pneumobelt
• have a tracheotomy
• other, what do you use?

c) If you use a nasal or face mask, has it been custom-made for you? Yes / No

d) If yes, do you feel that the custom-made mask is better than a standard mask? Yes / No. Please give reasons.

e) Do you have more than one ventilator?
If yes, how do you use the different equipment? Yes/no
If yes how do you use the additional one:
• Rescue Ventilator (to obviate maldysfunction)
• Travelling
• Airway clearance
• Others (please specify)

f) How long have you been using this ventilator for? Months

g) Does anyone help you use your ventilator at home? Please tick all that apply.
• partner/spouse
• relative
• friend
• support worker/ personal assistant
• a nurse/ home help team

h) Who does pay for ventilator?
• National Health Service (Hospital)
• Private Insurance
• Personal expenses

2) What matters most to you?

Please tell us how important the following factors of using a ventilator are to you: Very important/ Quite important/ Neutral/ Not very important/ Unimportant/ Not relevant

a) Daily life
• Mask comfort
• The noise from the ventilator
• Reducing dryness
• Reducing nasal secretions
• Doing the things you want to do whilst using ventilator
• Being able to speak/be heard when wearing a mask
• Not feeling claustrophobic
• Having a sense of independence
• Being able to travel with it
• How heavy it is
• How big it is
• Being able to use it on an airplane
• Being able to charge it from the cigarette lighter in car
• Having smooth, natural feeling, not ‘jerky’ breathing
• Being able to fall asleep easily and stay asleep whilst using the ventilator
• Being able to mount it on my wheelchair

[Box for comments]

b) Technical

• Auto-responds to my breathing
• Compensates for mask leaks
• Having a built-in/integrated humidifier
• Having alarms
• How much electricity it uses
• How much it costs to buy/rent
• Having an external power supply
• Having a battery with a long life
• Being able to operate the equipment yourself e.g. on/off buttons, alarm reset
• Being able to adjust the settings yourself
• Being able to clean the equipment easily
• Being able to change the tubing and filters easily
• Reliability
• Stability of settings
• Having long multi-tubed circuits
• Having disposable circuits

[Box for comments]

3) How good is your current ventilator and support?

a) Overall, how satisfied are you with your home ventilator? Very satisfied/satisfied/not entirely satisfied/not at all satisfied
b) Did you receive enough information and clear instructions when you started using the ventilator? Yes/ No. If no, what would you have liked to receive more information/guidance about?

c) How did the health professional give you information about the ventilator and make sure you understood? Mark all that were used.

- spoken information
- written information
- demonstrated using the equipment
- watched you using the equipment
- other, please give details

Do you use the ventilator as instructed? Yes/ Sometimes/ No. Please explain your answer.

d) Do you get enough support from health professionals? No support/ Too much support / Enough support/ Too little support. Please explain your answer.

e) Would you be happy for your health professional to monitor your ventilator remotely to make sure the settings are always (?)) correct and most comfortable for you? This is known as telemonitoring. Yes/ Maybe/ No. Please give reasons.

f) Do you receive enough support also from the manufacturers of the ventilator? This may be a home care company provided by the manufacturer. No support/ Too much support / Enough support/ Too little support

g) Do you know how to contact the Health Professional and or manufacturer/support team if your ventilator has a fault or stops working? Yes / Not sure/ No

h) Are you prepared in case of a mechanical or power failure? Mark all the ways you have prepared.

- Have a backup ventilator
- Have a second mask or cannula
- Backup power source e.g. extra batteries, generator
- Have a manual resuscitator
- Emergency plan
- Practice safety drills
- Emergency contact number for the manufacturer

4) Your recommendations

a) How could home ventilation be improved for you?

b) What key message would you like to give health professionals about home ventilation?

c) What would you say to others starting to use ventilation at home?

d) If you would like to receive updates or get more involved in this project please enter your email address
If you have any further comments or questions about this survey please email Sarah Masefield, European Lung Foundation (ELF), at sarah.masefield@europeanlung.org.