

Home care ventilation of children and young people across Europe

Summary of key findings

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Survey- responses

16
responded

- Austria
- Belgium
- Czech Republic
- Denmark
- Estonia
- France
- Germany
- Ireland
- Italy
- Netherlands
- Norway
- Portugal
- Slovenia
- Sweden
- Switzerland
- United Kingdom

16 not
responded

- Armenia
- Croatia
- Cyprus
- Finland
- Greece
- Hungary
- Iceland
- Lithuania
- Luxembourg
- Malta
- Poland
- Romania
- Republic of Serbia
- Slovakia
- Spain
- Turkey

Is there a system for providing home care ventilation for children and young people requiring long term ventilation?

- All 16 countries responded there is a system, except for France- only non- invasive ventilation at home
- Services referred to as: hospital at home
home care
care at home

Who provides the service?

- Hospital provider



France
Norway
Sweden

Belgium
Denmark
Estonia
Netherlands
Portugal
Slovenia



Private
company

Austria

- Community provider

Italy
UK
Switzerland

- Other: Ireland- health service executive
Germany- medical aid and device company
Czech Republic- Ministry of health, insurance
company and Faculty hospital Brno

How is the service funded?

Health care system

- Austria
- Estonia
- Germany
- Portugal
- Slovenia
- Switzerland
- UK

Government

- Denmark
- France
- Netherlands
- Norway

Sweden- both

Belgium- Convention on Home Ventilation

Italy- Public Regional Funds

How long does it generally take to organize the discharge of the child requiring home care ventilation?

- Different in every country

from 3 days in France (non- invasive) or 1 week in Germany and Estonia to up to 12 months in Ireland

Some countries- the length is not defined, depending on patient and carers

Belgium, Netherlands

Depending on area patient live (city x small town)

Norway

Who teaches and prepare carers to care for their child on HCV

Nurses and doctors on PICU

- Austria
- Czech Republic
- Denmark
- Estonia
- France
- Germany

Italy
Slovenia
UK

Austria
Czech Republic
Germany

ventilator teaches
provider of ventilator

Community Nurses and doctors

- Netherlands
- Norway
- Portugal

as well in hospital

Other

- Ireland nurses on PICU and clinical nurse educators
- Sweden specialist nurses
- Belgium nurses on PICU and nurses and doctors of the sleep centers
- Switzerland Specialist nurses and advanced nurse in respiration

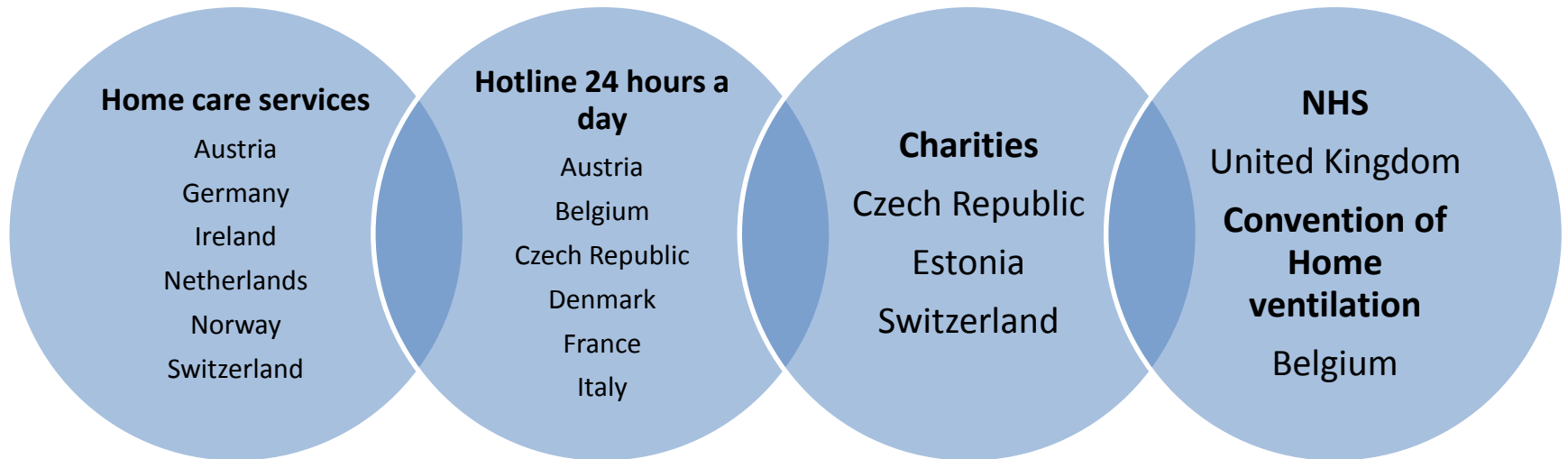
What competencies parents need to fulfil to care for their child on HCV

- Generally: ventilator operation
tracheostomy care
emergency responses

No competencies in Austria, Norway

Course in the care for child on HCV in Sweden

What support for carers is available?



Support for carers during the day

Depending
on child's
needs

- Italy
- Netherlands
- Norway
- Portugal
- Slovenia
- Sweden
- Switzerland
- UK

depending on the center

Various

- Austria
- Czech Republic
- Denmark
- Germany
- Ireland

3-4 or 6-10 hours a week

3 hours a week

multidisciplinary team available all day

8- 24 hours

4 hours a day 5 days a week

Not stated

- Belgium
- Estonia
- France

Support for carers during night

Depending on child's needs

- Italy
- Netherlands
- Norway
- Portugal
- Slovenia
- Sweden
- Switzerland
- UK

depending on the center

Various

- Austria
- Czech Republic
- Denmark
- Germany
- Ireland

rarely

no support

multidisciplinary team available 9 hours at night

8 hours

8- 10 hours 7 days a week

Not stated

- Belgium
- Estonia
- France

What financial support is provided for carers of the child on HCV

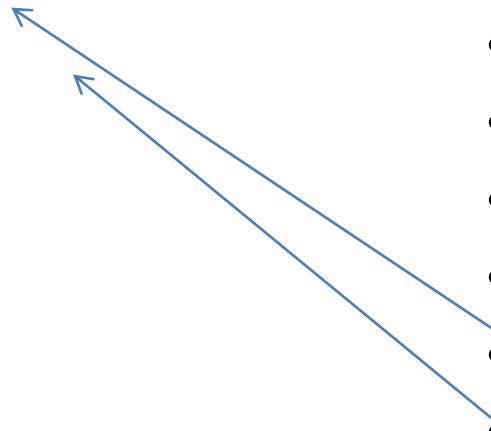
Government-carer allowance

- Austria
- Denmark
- France
- Ireland
- Italy
- Netherlands
- Norway
- Portugal

Insurance

- Czech Republic charity
- Estonia charity
- Germany
- Slovenia
- Sweden
- Switzerland
- UK

- Belgium via Convention of Home ventilation



In the case of an acute deterioration in the child's condition where would be the child generally admitted?

PICU

- Austria
- Czech Republic
- Estonia
- Germany
- Netherlands
- Sweden
- Switzerland
- UK

PICU or ward

- Belgium
- Denmark
- France
- Ireland
- Italy PICU/HDU/ward
- Norway
- Portugal
- Slovenia