

Home care ventilation of children and young people across Europe

Summary of key findings

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Survey- responses

19
responded

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

13 not
responded

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

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

- In all 19 countries responded there is a system providing HCV
- Services referred to as: hospital at home
home care
care at home

Who provides the service?

- **Hospital provider**



- **Community provider**



- **Other:** Ireland- health service executive

Germany- medical aid and device company

Czech Republic- Ministry of health, insurance company and Faculty hospital Brno

Iceland- hospital provider, community provider, specialized home care and support institution of professionals

★ Belgium- mostly by university hospitals or revalidation center for children

★★ Netherlands- Home Care Ventilation Centers for children and young adults

How is the service funded?

Health care system

- Austria ✨
- France
- Portugal
- UK

Government /insurance, taxes/

- Croatia
- Denmark
- Estonia
- Germany
- Ireland ✨
- Italy
- Netherlands
- Norway
- Slovenia
- Sweden
- Switzerland
- Turkey

Belgium- Sleep centers with the Convention on Home Ventilation

Czech Republic- Insurance companies and charities, parents are involved

Iceland- both

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 2 days in France (non- invasive) to up to 12 months in Ireland. Most countries within 1-6 months

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

Hospital staff

- Austria
- Belgium _p
- Croatia _p
- Czech Republic _p
- Denmark
- Estonia _p
- France
- Germany
- Iceland
- Ireland
- Italy
- Norway
- Slovenia
- Switzerland
- Turkey _p
- UK

Primary Nurses and doctors

- Portugal

Austria
Czech Republic
Germany

Provider of vent. device provides technical teaching

Other

- Belgium- nurses and doctors of sleep centers or PICU
- Iceland- the heads of specialist childrens' nurses
- Netherlands- members of home care ventilation center
- Sweden- specialist nurses
- Switzerland- specialist nurses for respiration and clinical nurse specialist for HCV

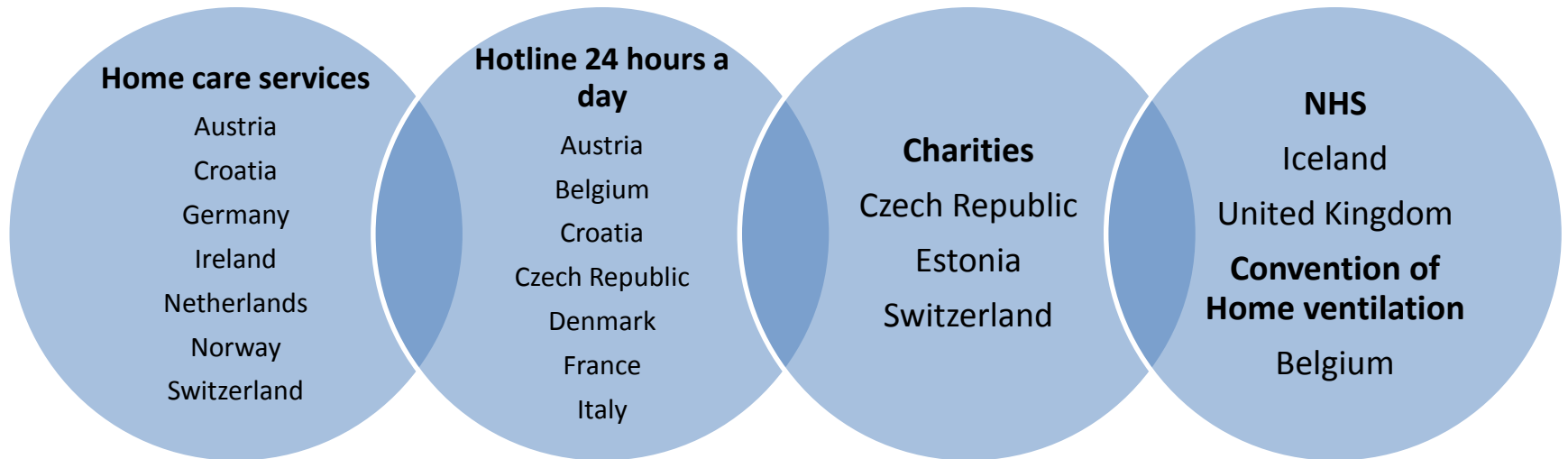
What competencies parents need to fulfil to care for their child on HCV

- Generally: ventilator operation
tracheostomy care
emergency responses

No competencies in Austria, Czech Republic,
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

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

depending on the center

Various

- Austria 3-4 or 6-10 hours a week
- Czech Republic 3 hours a week
- Denmark multidisciplinary team available all day
- Germany 8- 24 hours
- Ireland 4 hours a day 5 days a week
- Turkey no support

Not stated

- Belgium
- Estonia
- France

Support for carers during night

Depending on
child's needs

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

depending on the center

Various

- Austria
- Croatia
- Czech Republic
- Denmark
- Germany
- Ireland
- Turkey

rarely
no support
no support
multidisciplinary team available 9 hours at night
8 hours
8- 10 hours 7 days a week
no support

Not stated

- Belgium
- Estonia
- France

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

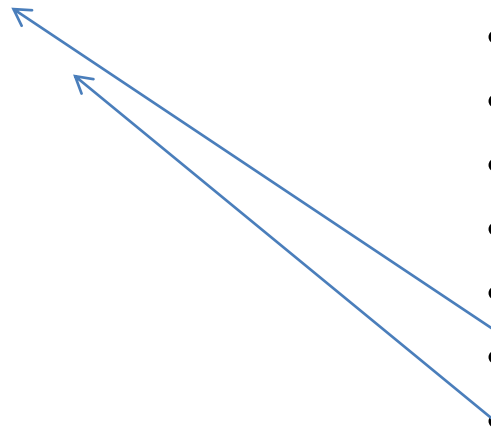
Government-carer allowance

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

Insurance

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

- Belgium via Convention of Home ventilation
- Croatia- not stated
- Turkey- no special support



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
- Croatia
- Denmark
- France
- Iceland
- Ireland
- Italy PICU/HDU/ward
- Norway
- Portugal
- Slovenia
- Turkey