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
  - Croatia
  - France
  - Norway
  - Sweden
  - Turkey

• 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
  - 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

Private company
Austria
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
- Croatia
- Czech Republic
- Denmark
- Estonia
- France
- Germany
- Iceland
- Ireland

**Primary Nurses and doctors**
- Portugal

**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?

- **Home care services**
  - Austria
  - Croatia
  - Germany
  - Ireland
  - Netherlands
  - Norway
  - Switzerland

- **Hotline 24 hours a day**
  - Austria
  - Belgium
  - Croatia
  - Czech Republic
  - Denmark
  - France
  - Italy

- **Charities**
  - Czech Republic
  - Estonia
  - Switzerland

- **NHS**
  - Iceland
  - United Kingdom
  - **Convention of Home ventilation**
    - Belgium
## Support for carers during the day

<table>
<thead>
<tr>
<th>Depending on child’s needs</th>
<th>Various</th>
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</table>
| • Croatia  
• Iceland  
• Italy  
• Netherlands  
• Norway  
• Portugal  
• Slovenia  
• Sweden  
• Switzerland  
• UK  | • 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 |
| depending on the center | |

<table>
<thead>
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<th>Not stated</th>
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| • Belgium  
• Estonia  
• France | |
Support for carers during night

Depending on child’s needs
- Iceland
- Italy
- Netherlands
- Norway
- Portugal
- Slovenia
- Sweden
- Switzerland
- UK

Various
- Austria: rarely
- Croatia: no support
- Czech Republic: no support
- Denmark: multidisciplinary team available 9 hours at night
- Germany: 8 hours
- Ireland: 8-10 hours 7 days a week
- Turkey: 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
- Estonia
- Germany
- Slovenia
- Sweden
- Switzerland
- UK

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

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

<table>
<thead>
<tr>
<th>PICU</th>
<th>PICU or ward</th>
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<tbody>
<tr>
<td>Austria</td>
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