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

16 not responded
- Italy
- Netherlands
- Norway
- Portugal
- Slovenia
- Sweden
- Switzerland
- United Kingdom
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

- 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?

<table>
<thead>
<tr>
<th>Health care system</th>
<th>Government</th>
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</thead>
<tbody>
<tr>
<td>Austria</td>
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<tr>
<td>Estonia</td>
<td>France</td>
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<tr>
<td>Germany</td>
<td>Netherlands</td>
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<tr>
<td>Portugal</td>
<td>Norway</td>
</tr>
<tr>
<td>Slovenia</td>
<td>Sweden- both</td>
</tr>
<tr>
<td>Switzerland</td>
<td>Belgium- Convention on Home Ventilation</td>
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<tr>
<td>UK</td>
<td>Italy- Public Regional Funds</td>
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</table>
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

**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
traceostomy care
emergency responses

No competencies in Austria, Norway
Course in the care for child on HCV in Sweden
What support for carers is available?

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

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

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

- **NHS**
  - United Kingdom
  - **Convention of Home ventilation**
    - Belgium
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: 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

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  rarely
- Czech Republic  no support
- Denmark  multidisciplinary team available 9 hours at night
- Germany  8 hours
- Ireland  8-10 hours 7 days a week

Not stated:
- Belgium
- Estonia
- France

Not stated.
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?

<table>
<thead>
<tr>
<th>PICU</th>
<th>PICU or ward</th>
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<tbody>
<tr>
<td>Austria</td>
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<td>Netherlands</td>
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<td>Sweden</td>
<td>PICU/HDU/ward</td>
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<td>Switzerland</td>
<td>Norway</td>
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<td>UK</td>
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