

## *Topic Expert Group: Follow-up and continuing care*

### **Respiratory outcome**

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#### *Target group*

Infants born very preterm or those infants with risk factors (see Follow-up & continuing care), parents, and families

#### *User group*

Healthcare professionals (including general practitioners), neonatal units, hospitals, health services, and follow-up teams

#### *Statement of standard*

Respiratory health is evaluated as part of a follow-up care programme.

#### *Rationale*

Infants born very preterm or infants with risk factors are at increased risk of respiratory morbidity, especially an obstructive airway disease, as compared to full term infants. (1–3) Respiratory symptoms occur most frequently during the first two years (4) but persist through school age and into young adult age. (5–9) At school age, asthma medication is prescribed in up to one third of children born very preterm. (5,8,10) Respiratory disorders, including wheezing during respiratory infections, has been shown to be the most common reason for rehospitalisation in very preterm infants. (11–13)

Those born smallest or most immature or with more severe pulmonary problems during the first hospitalisation (having a diagnosis of bronchopulmonary dysplasia (BPD)) are more likely to have later respiratory and cardiovascular problems. (7,10,12,14–16) There are no published studies assessing the efficacy of routine lung function tests in the follow-up of very preterm infants. However, knowing the increased risks it is important to provide clinical respiratory surveillance for all high-risk infants to identify those who need more detailed tests or intervention. In particular, infants with neonatal bronchopulmonary dysplasia should be followed closely to identify those children needing treatment. In addition, their cardiovascular risk should be kept in mind in adulthood, because of a small increase in the risk of ischaemic heart diseases. (16)

Health promotion is important for this group, in particular, parents and families should avoid passive and active exposure to tobacco smoke and where possible environmental pollution (6,9,11,15–21) and they should protect themselves and the whole family with appropriate vaccinations. A reduced exercise capacity is reported in very low birthweight infants and BPD survivors, but a physical activity programme could improve exercise tolerance, exercise capacity and flexibility in preterm children. (22,23)

#### *Benefits*

##### *Short-term benefits*

N/A

### Long-term benefits

- Improved identification of individuals who require further diagnostic tests or treatment of respiratory conditions (consensus)
- Reduced risk of rehospitalisation (24)
- Reduced school absence (25)
- Reduced number of days of restricted activity (25)
- Reduced emergency room visits (25)
- Improved respiratory health (consensus)

### Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents, family and children and adults born preterm		
1. Parents and families are informed about and invited by healthcare professionals to attend follow-up programmes including respiratory assessment. (1,2)	A (High quality) B (High quality)	Patient information sheet
2. Parents and children get recommendations for healthy life style and vaccinations by healthcare professionals. (1,2)	A (High quality)	Patient information sheet
3. Parents receive individual advice regarding day care attendance. (26)	B (Low quality)	Patient information sheet
For healthcare professionals (including general practitioners)		
4. A unit guideline on follow-up including respiratory care is adhered to by all healthcare professionals.	B (High quality)	Guideline
5. Training on the appropriate referral and treatment for high-risk infants with respiratory disease and about health promotion including cessation of household smoking is attended by all responsible healthcare professionals. (12,17,18)	A (High quality) B (High quality)	Training documentation
For neonatal unit, hospital, and follow-up team		
6. A unit guideline on follow-up including respiratory care is available and regularly updated.	B (High quality)	Guideline
7. Symptomatic individuals are referred to appropriate paediatric respiratory services for longer term surveillance.	B (Moderate quality)	Clinical records

8. Training on the appropriate referral and treatment for high-risk infants with respiratory disease and about health promotion including cessation of household smoking is ensured.	B (High quality)	Training documentation
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#### For health service

9. A national guideline on follow-up including respiratory care is available and regularly updated.	B (High quality)	Guideline
10. RSV immunisation is available for the infants with high risk for hospitalisation. (27–30) Its use should be suited to the local resources as the cost-effectiveness and long-term benefits are still unclear. (31)	A (High quality) A (Low quality)	Audit report, guideline

### *Where to go – further development of care*

Further development	Grading of evidence
For parents and family	
N/A	
For healthcare professionals (including general practitioners)	
N/A	
For neonatal unit, hospital, and follow-up team	
<ul style="list-style-type: none"> <li>Implement the evidence-based practices about lung protective treatment strategies (see Medical care &amp; clinical practice). (31–33)</li> </ul>	A (High quality)
<ul style="list-style-type: none"> <li>Benchmark and make available respiratory outcomes up to adulthood against similar services. (34)</li> </ul>	B (Low quality)
For health service	
<ul style="list-style-type: none"> <li>Increase awareness of adverse effects of tobacco use and environmental pollution on respiratory health. (18–20)</li> </ul>	A (High quality)
<ul style="list-style-type: none"> <li>Include follow-up information on an electronic healthcare card.</li> </ul>	B (Low quality)
<ul style="list-style-type: none"> <li>Increase adult physicians' awareness about the long-term consequences of preterm birth.</li> </ul>	B (Moderate quality)

### *Getting started*

#### Initial steps

##### For parents and family

- Parents and families are informed by healthcare professionals about the importance of respiratory health, avoiding exposure to tobacco smoke and promoting a healthy lifestyle.
- Parents are informed by healthcare professionals about potential signs of respiratory problems.

#### For healthcare professionals (including general practitioners)

- Attend training on the appropriate referral and treatment for high-risk infants with respiratory disease and about health promotion including cessation of household smoking.

#### For neonatal unit, hospital, and follow-up team

- Develop and implement a unit guideline on follow-up including respiratory care.
- Develop information material about the need for respiratory assessment as part of follow-up programme and of recommendations for healthy life style for parents.
- Support healthcare professionals to participate in training on the appropriate referral and treatment for high-risk infants with respiratory disease and about health promotion including cessation of household smoking.

#### For health service

- Develop and implement a national guideline on follow-up including respiratory care.
- Develop ways to keep track of high-risk infants including e-health applications.

### Source

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Second edition, September 2022

### *Lifecycle*

3 years/next revision: 2025

### *Recommended citation*

EFCNI, Lehtonen L, Leemhuis AG et al., European Standards of Care for Newborn Health: Respiratory outcome. 2022.

