



Title	Is Neonatal Screening for Cystic Fibrosis Recommended in Belgium?
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Aim

To answer the following questions: What is the evidence supporting neonatal cystic fibrosis (CF) screening in terms of benefits and harms? Is CF newborn screening (NBS) cost effective? What organizational, ethical, legal, and budgetary aspects are to be considered when introducing CF NBS in Belgium?

Conclusions and results

Implementation of a CF neonatal screening program in Belgium could help avoid a potentially long, painful, and costly diagnostic odyssey and will improve height and weight gain in children diagnosed early. CF NBS could also benefit pulmonary status and reduce the therapy burden, but this is not based on RCT data. The beneficial effects on survival may have become undetectable given the improvement in care. The benefits of CF NBS override potential harms only if several quality criteria for screening are strictly followed. The budget impact of implementing CF NBS is small compared to the annual budget expenditures to reimburse CF DNA tests.

Recommendations

- Immediately after diagnosis, children with CF should have the highest level of affordable care, as improvements in the quality have dramatically impacted on survival.
- Quality of care in CF centers should be audited regularly and should be brought to a uniformly high level. This should be a requirement for CF centers to keep their funding.
- Implementing local CF NBS programs without evaluation of patient outcome should be avoided.
- Public funding of two largely overlapping screening programs should be questioned (CF NBS program and large-scale opportunistic CF carrier screening of future parents).

The decision to implement CF NBS depends on the bal-

ance of benefits and harms. To limit potential harms, CF NBS should be implemented only if certain conditions are met (see full report).

Methods

A multidisciplinary team including pediatricians in charge of CF care, scientists, and experts in neonatal screening, ethics, and legal issues carried out the project. Additional external experts in CF NBS and preventive care representatives from two communities in Belgium regularly reviewed the progress of the project. Systematic literature reviews focused on the effectiveness and cost effectiveness of CF NBS. Organizational, ethical, legal, and budgetary aspects were covered based on additional data collection, published data, and analyses of the Belgian CF registry at the Institute of Public Health.

Further research/reviews required

- Evaluate the integration of the PAP test into the screening algorithm.
- Study the best practice for CF patient follow-up, including the respective roles of CF specialist centers, pediatricians, and GPs.