



Features

The Dutch National Program for Respiratory Research

See Online for Dirkje Postma's podcast on the Dutch National Program for Respiratory Research

For the WHO statistics see http://www.who.int/healthinfo/global_burden_disease/projections/en/

For the ERS White Book see <http://www.erswhitebook.org/chapters/the-burden-of-lung-disease/>

For more on the effects of climate and meteorological changes on respiratory disease see *World Allergy Organ J* 2015; 8: 25.

For more on the Netherlands Respiratory Society see <http://www.nrs-science.nl>

Respiratory diseases have a huge personal, societal, and economic impact. The main three—ie, chronic obstructive pulmonary disease (COPD), lung cancer, and respiratory infections—are all in the WHO top 10 leading causes of death worldwide, causing 8.1 million deaths annually. Collectively, these three diseases have outranked death rates from ischaemic heart diseases in 2012 (7.5 million deaths). Furthermore, there is a huge burden of asthma from childhood to old age, and preterm birth also affects the lungs. Rarer, but increasingly prominent, respiratory diseases, such as cystic fibrosis, obstructive sleep apnoea, pulmonary hypertension, and interstitial lung diseases, are examples of chronic diseases that have a major impact on patients, their families, and society. The burden of

respiratory disease is high; one in 18 white European people suffers from a chronic respiratory disease, and this number is expected to increase because of climate and meteorological changes.

One of the main reasons for the prevalence of respiratory diseases is that the respiratory system interacts with the environment more directly than most other organs of the body. Therefore, respiratory research has traditionally been interdisciplinary. The linking of these interrelated disciplines has provided better understanding of the origins, presence, and prognosis of respiratory diseases, but results have been insufficient to prevent, cure, or stop the progression of most of these diseases.

The Netherlands Respiratory Society (founded in 2009) has therefore initiated the development of a National Program for Respiratory Research entitled *Lungs Lasting a Lifetime*, to strengthen collaborative efforts in the Netherlands and improve the outlook for affected patients. The National Program for Respiratory Research is a clear example of how various groups in one country are collaborating to improve research.

The process started with a bottom-up procedure (internal assessment) of inviting Dutch experts in basic and clinical research in 12 respiratory disease areas: allergy, asthma, bronchopulmonary dysplasia (and primary ciliary dyskinesia), cystic fibrosis, COPD, interstitial lung disease, infection, intensive care, lung transplantation, lung cancer, pulmonary hypertension, and sleep apnoea. Relevant data for the defined areas were collected, SWOT analyses (strengths, weaknesses, opportunities, and threats) were done, and relevant publications from both Dutch research teams and international collaborative research groups from the past 5 years were ranked. Additionally, promising areas for research results with impact in each area were identified by patients and incorporated into the assessment.

Each of the working groups also identified opportunities for challenging collaborative research with the other 11 areas, providing an opportunity for breakthroughs by transdisciplinary research, and identified such opportunities both within and outside the respiratory field.

All 12 research areas were blindly assessed by 86 international experts for several research and organisational aspects (external assessment). All reports were analysed in parallel to identify missing links and were subsequently discussed with the 12 working groups, which consisted of professional or scientific associations, patient associations, charities, governmental organisations, pharmaceutical groups, and industrial organisations. The outcomes were used to

Panel 1: Six goals on the road to tomorrow's respiratory science

- Draw attention to the current status and developments in the field of lung research.
- Develop a programme for national training and support of young researchers.
- Cross-talk and inspiration between different areas of respiratory research and other related areas of research.
- Encourage and promote innovative research.
- Activate existing and new opportunities of national biobanks for respiratory diseases.
- Evaluation and update of the National Program for Respiratory Research with new opportunities for research in the Netherlands every 3 years.

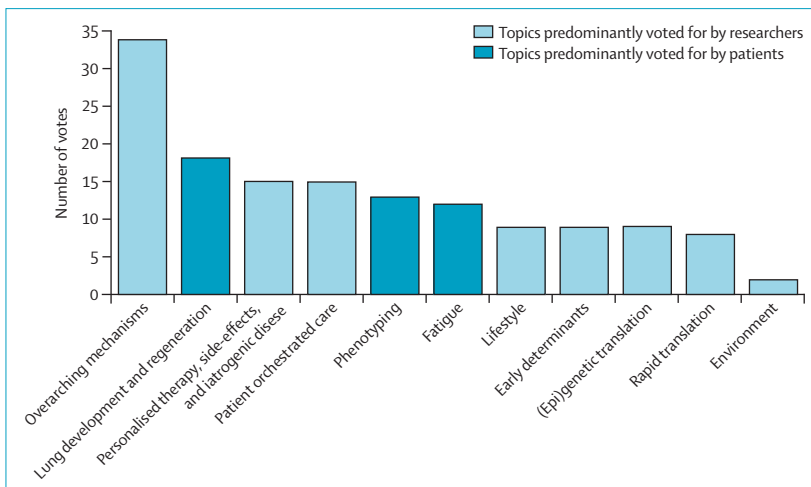


Figure: Outcome after the first part of the *Lungs Lasting a Lifetime* conference
Data are the number of attendants (researchers and patients) that voted for each topic.

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build taskforces that aimed to achieve six goals towards research success (panel 1), which were purposely based on opportunities and missing links in the research network necessary to stimulate high-quality, result-oriented research. To achieve this goal, collaboration between all above-mentioned players in research is essential.

Progress and plans of each of the six taskforces are published and continuously updated on the website. As an example, taskforce number 2 has pinpointed the need to train a generation of young, medical and basic researchers to tackle aspects from basic science to translational and clinical research, and who are capable of supporting and developing future innovations. The aim is to attract the most talented individuals to the respiratory field to pioneer the ground-breaking, innovative techniques needed to underpin future treatments not only for respiratory diseases, but for many other disorders.

The taskforce for innovative research organised a 2.5-day meeting to define research priorities. After introductory lectures focusing on opportunities, strengths, and gaps in knowledge of five disease areas, and with the outcomes of the 12 SWOT analyses, patient priorities, and international ratings in mind, mixed working groups of patients (n=15), and basic and clinical researchers (n=45) discussed three questions: (1) What are the main questions regarding lung health? (2) Which questions can provide solutions for multiple diseases? (3) As a consequence, which areas of research should be focused on during the coming 5–10 years?

After merging, discussion, and voting, a list of research areas was collectively defined. On the final day, additional brainstorm sessions were held with representatives from European Respiratory Society, Dutch Royal Academy of Sciences, Lung Alliance Netherlands, Lung Foundation Netherlands, Dutch universities, Dutch public-private top sectors in research, ZonMw (governmental research organisation), and Nefarma (association for innovative medicines in the Netherlands), and basic and clinical researchers. The final prioritisation areas based on the outcome of day 1 (figure) were opportunities for cross-talk and inspiration in research, effect of research for patient and society, and possibilities for promising research to be implemented in existing and foreseeable, international and national research programmes. Finally, a discussion evening was organised for everyone interested, which resulted in agreement of five priorities for respiratory research in the Netherlands (panel 2).

At a time when respiratory research is on the verge of major breakthroughs, research funding is facing large budget cuts worldwide. Financial support is central to maintaining excellent research, which calls for creative measures such as prioritisation of research and strengthening of collaborations. In the Netherlands, a

Panel 2: Five priorities for research in the Netherlands and their relevant impact

- Overarching disease mechanisms. Impact: new therapies by cross-talk in research.
- Phenotyping and monitoring. Impact: patient-tailored diagnosis and treatment (P4 medicine: predictive, preventive, personalised, and participatory).
- Regenerative medicine. Impact: reduction of tissue damage, cure.
- Reduction of fatigue in patients with lung diseases. Impact: lower burden of disease (patient) and increased societal participation (society).
- Early determinants and detection. Impact: sustainable health, evidence for lifestyle recommendations.

focused and broadly supported National Program for Respiratory Research was developed by a bottom-up procedure, in order to strengthen visibility and quality of respiratory research. We are currently mirroring our research priorities with EU Horizon 2020 priorities. The research priorities of the Netherlands and EU overlap, which could encourage effective European collaboration. Respiratory research now receives attention from the health-care sector and research sector, ranging from university academics to general practitioners and basic scientists to patients. Together, we in the Netherlands can now take the next steps in research towards better management and treatment of respiratory diseases and invites other countries to join in.

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DSP reports grants and consultancy work from AstraZeneca, GlaxoSmithKline, and Chiesi; grants from Genetech and Roche; and consultancy work for Boehringer Ingelheim, TEVA, and Takeda, outside of the submitted work. PSH reports grants from Boehringer Ingelheim and Galapagos, outside of the submitted work. PJW, BNM, G-JB, MNH, and PJS declare no competing interests.

For more on the **National Program for Respiratory Research taskforces** see <http://www.nationaal.programmalongonderzoek.nl/en/npr/>

For the **list** see <http://www.nationaal.programmalongonderzoek.nl/en/the-beginning/>

For more on **budget cuts and research funding** see **World Report Lancet 2015; 385: 1381–83.**