



2025

# Building together

How advocating for the patient perspective and engaging with patient organizations make us better at adding value – not just for us, but also for people living with diseases and for the society.

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# What is shared value?

## Shared value projects

In this document, you will find examples from Shared value-projects initiated in the Nordic region. Chiesi has adopted the *shared value principle*, a business strategy based on the belief that addressing societal and environmental challenges can create economic value. We aim to create economic value in a way that also creates value for society by addressing its needs and challenges. Success, for us, is making a positive imprint on the world.

The shared value projects aim to promote social sustainability and equitable access to welfare and good health.

## Our why: because we can

As a family-owned company, we think in terms of generations. This includes long-term sustainability of our operations. Our core business is delivering medicines to meet the needs of patients, and we reinvest 1/5 of the turnover in research and development to find new treatments for unmet medical needs. We also strive to do business in a way that also contributes to society. We actively look for opportunities to help solve societal challenges, social or environmental needs.

We want to be a positive force in society. Because we believe we can and should do what we can.

## Our "how"

We have embedded 9 of UN's global sustainability goals from Agenda 2030 in our strategic plan for the company. We look for win-win projects where we believe we can make a positive contribution to society.

### Sustainability is multidimensional

Sustainability can be divided into four dimensions – environment, governance social and economy. Chiesi's sustainability work includes all four dimensions.

The shared value principle permeates all our sustainability work and links very clearly to social and economic sustainability, by asking: How do we ensure that our actions create a positive and lasting impact?

You can learn more about our work in our sustainability report [here](#).

[www.chiesipharma.se/en/sustainability/sustainability-reports/](http://www.chiesipharma.se/en/sustainability/sustainability-reports/)

## Measuring shared value

To assess the potential impact of individual activities, Chiesi has developed a scoring system to rate the added value of our activities: Patient journey impact score. The scoring system has three major dimensions: impact on patient journey, innovativeness and health equity.

The efficiency of the solution is graded along with a score for intensity and priority of the need from a patient perspective. Maximum score is 100%. The method has not been applied for all projects but disclosed for projects where used.

## Patient journey

The patient's "disease journey" describes the different phases of the disease – from being a person at risk, to having the

disease, getting diagnosis, getting treatment and, if possible, an after-treatment phase. The patient metric constitutes 60% of the overall metric weight and includes metrics for how well it fits to actual needs and the generalizability of the solution (to disease stages, other diseases and stake-holder benefit).

### Innovativeness

New solutions may be needed to address unmet patient needs, so innovativeness is

important because this may help leverage the value we bring to our society (20% of the metric weight).

### Health equity

Solutions that address inequities within or between societies are given a higher score. Social determinants of health contribute to poorer health for vulnerable groups, leading to unfair - and avoidable - loss of health. We want to do what we can to address those inequities.



# BREATHiN

BETTER UNDERSTANDING OF OBSTRUCTIVE RESPIRATORY  
AIRWAY DISEASE TREATMENT AND HEALTH (DENMARK)



## Background

Even though asthma and COPD are common diseases in Denmark, it is less well known how they experience diagnosis and treatment, and what impact the disease has on daily life. While registry data can provide insights in prescription and healthcare utilization, it doesn't capture the patients' perspectives on disease control, inhaler technique or barriers to optimal treatment. By combining registry data with patient reported outcomes, we can better understand patients' needs.

## How we can help

With the financial support from Chiesi, Sanofi, GSK and AstraZeneca, Sygehus Lillebælt (Vejle Hospital, Department of Respiratory Medicine) and leading Danish pulmonologists was able to conduct the BREATHiN survey (Better understanding of obstructive RESpiratory Airway disease Treatment and HEalth: a nationwide INvestigative survey)<sup>1</sup>. By capturing real patient perspectives on diagnosis, treatment and daily life, we can identify barriers and improve care.

## Outcome

The projects combined information from the national prescription registry, identifying patients on treatment for asthma and COPD, with a nationwide electronic survey via e-Boks (a secure digital postbox platform). The survey was responded by almost 60 000 patients and rendered unique insights into treatment patterns and self-reported outcomes. Key

unmet needs unfolded, including inhaler misuse, comorbidity management and broader social determinants of health such as home care and pension-schemes. The insights will be collected in 3-4 scientific publications including a white paper for policy makers. Publishing in leading journals, e.g. European Respiratory Journals.

## Social value

BREATHiN provides clear clues on how to improve asthma and COPD care in Denmark. It highlights gaps between guideline-based treatment and real-life disease control and can be used to align future interventions with actual needs.

The white paper can serve policy makers with important insights on how to improve patient's experiences from healthcare as well as how to offer more equitable care.

## Business value

Chiesi is regarded as a trusted partner in real evidence generation in issues that matter to patients. This project strengthens collaboration with leading respiratory experts. Outcomes from BREATHiN helps us better understand health equity gaps.

## Reference:

1. Hansen KK, Pedersen LL, Løkke A, Hilberg O. BREATHEIN: Better understanding obstructive RESpiratory Airway disease Treatment and HEalth: a nationwide INvestigative survey in Denmark-a study protocol. *BMJ Open*. 2025 Aug 6;15(8):e099447

# The outreach Program

NORWAY



## Background

Social determinants of health, such as geography, culture, occupation and socioeconomic group may add to health challenges and unmet needs and inequities in the patient journey. In mining communities, many workers are exposed to occupational hazards such as dust inhalation, which increases the risk of poor lung health. In addition, as these communities may be located far from specialized care, this may further delay getting a diagnosis and proper care. Targeted interventions are needed to educate communities about when to seek care and to reduce the injustice in access to care.

## How we can help

We started the Outreach program to address health inequities in the mining communities, in Narvik, Porsgrunn and Notodden. The aim was to improve knowledge about lung disease and to recognize that breathlessness is a sign of illness. The events were also meant to break some social stigma around COPD. A person living with COPD talked about breathlessness, the importance of getting treatment and regular follow-up were presented – and discussed. Participants were offered spirometry tests, lung education with help of augmented reality glasses, inhalation training and could engage in conversations about living with lung disease.

## Outcomes

In total, 133 participants attended, whereof 47 underwent spirometry testing and 54 people attended AR sessions. The

events were also covered by local media.

Patient Journey impact score 71%.



## Social value

The events targeted the underserved mining communities, and improved access to care in remote areas. These awareness activities promote early recognition of COPD and aim to reduce stigma around breathlessness. By creating curiosity around lung health and enabling peer exchange and support, patient-centric care is strengthened, leveraging disease control. By engaging the local community, the stigma can be reduced.

*"I have had COPD for 40 years, but not until now do I know what it is".*

(93-year-old female participant)

## Business value

Demonstrates our commitment to health equity. Expanded awareness about Chiesi and our values. Partnership with civil society. Gaining insights into real patient needs and barriers to care. Contributing to society feels good and improves employee satisfaction.

# Fabry cookbook – a Nordic collaboration

DENMARK; NORWAY and FINLAND



## Background

In addition to symptoms involving brain, nerves, cardiovascular and kidneys, people with Fabry's disease frequently experience symptoms from the gastrointestinal tract. Roughly half of the patients experience at least one of the following symptoms:

Nausea, diarrhoea, cramps, bloating, constipation, vomiting, food intolerance, feeling full before finishing a meal.

Recent findings suggest that a diet low in FODMAP (Fermentable Oligosaccharides, Disaccharides, Monosaccharides And Polyols) can alleviate GI symptoms potentially impact quality of life.

## What we can do

By developing a cookbook for Fabry patients and their relatives, this patient group can be educated and inspired to help reduce GI symptoms. The cookbook can also be used as educational material for physicians and nurses who meet patients with Fabry.

In collaboration with patient organizations in Norway, Finland and Denmark, Chiesi is developing the Fabry cookbook with the expert help from dietitian Mette Borre, who is experienced in the Low FODMAP diet.



The cookbook will contain recipes low in FODMAP and have additional sections explaining GI symptoms in Fabry's disease and what a Low-FODMAP diet is. The cookbook will be made available in the major Nordic languages.

## Outcomes

Number of delivered cookbooks plus feedback collected from Patient Advocacy groups

## Social value

The gastrointestinal symptoms negatively impact the patients' quality of life and managing daily activities. With better knowledge of the interconnection between diet and gastrointestinal symptoms plus hands-on guidance, patients have a better chance of managing gastrointestinal symptoms.

## Business value

This project puts Chiesi as a leading stakeholder in Fabry's disease in the Nordics. The cookbook will also be a helpful resource in our information exchange with treating physicians and nurses as well as providing content for our patient web page RethinkFabry.

# The Järva week

SWEDEN



## Background

Low socio-economic status is linked to higher incidence of disease and poorer health, including higher incidence of chronic obstructive pulmonary disease (COPD). Despite Sweden's publicly funded care, some areas are disadvantaged in terms of access to care and diagnosing. High smoking rate, a major COPD risk factor, contributes to high probability of COPD.

The suburb Järva, north of Stockholm, is an area with low socioeconomic capacity. Here, a local enthusiast initiated Järvaveckan (Week of Järva), to counteract the sense of social exclusion from the society and to bridge the gap between politicians and ordinary people. Järva week has developed into a meeting place for cultural and political exchange.

## What we can do

To raise awareness about COPD and asthma, Chiesi participate for a 2<sup>nd</sup> time. Patient organizations *HjärtLung association* (HeartLung) and *Swedish Asthma and Allergy Association* joined us at an open booth where spirometry testing was offered along with information about asthma and COPD in several languages (Swedish, English Arabic and Somali).



In addition, Chiesi arranged two round table discussions on how to improve access to individualized medicine.



## Outcomes

A total of 1085 spirometry tests were performed, of which 20% had an FEV<sub>1</sub>% <0.7, potentially indicating COPD or under-treated asthma, they were referred to care for investigation.

Social media coverage: LinkedIn posts by Chiesi; Facebook post by HeartLung.

Emailing: included in HeartLung's newsletter to members (35 000) and in Chiesi's newsletter to healthcare professionals (n=1549).

Patient Journey impact score: 68%

## Social value

Improved awareness of asthma and COPD in an area with low socio-economic status.

The activity can contribute to early disease detection and access to care, leading to better outcomes for people living with asthma or COPD.

Enabling discussions concerning equal access to healthcare and individualized treatment.

## Business value

Focus on health equity and acting for our community in accordance with Strategic sustainability plan 2025-2030

Collaboration with relevant stakeholders.

Possibility to raise awareness about underdiagnosed diseases.

# Socioeconomic factors and influence on prescription: a registry study

SWEDEN



## Background

The risk of chronic obstructive pulmonary disease (COPD) is linked to socioeconomic status (SES), but it has not been known if SES impacts what treatments are being offered.

## What we can do

To explore whether drug prescriptions for COPD patients differ depending on SES or not, we initiated a registry study.

Data from patients with incident and prevalent COPD (age > 40 years), without an asthma diagnosis, visiting primary care in 2021–2022 were extracted from The Swedish National Airway Register (SNAR) and linked to Swedish National Health registries. Socioeconomic status was assessed by educational level and annual income.



## Outcome

Prescription patterns were associated with small, statistically significant differences, between COPD patients with low and high socioeconomic status. Triple therapy was more frequently prescribed to patients with

low socioeconomic status, and monotherapy with LAMA more often to patients with high socioeconomic status. The results are summarized in a scientific article published in the International Journal of Chronic Obstructive Pulmonary Disease.



## Social value

It is important to find out if patients are being offered different treatment options depending on socioeconomic status rather than health factors. This study also brings new leads for further studies as the treatment patterns may be linked to differences in burden of disease between groups.

## Business value

Understanding current unmet medical needs helps make better business decisions to ensure that those who would benefit from triple treatment have appropriate access to medicine.

# To live with COPD

DENMARK



## Background

Chronic Obstructive Pulmonary Disease (COPD) has a profound impact on everyday life and not “just” lung function. In meeting with patients in Denmark and the Nordic region, patients expressed a need for a reliable and practical information in lay language building on patient’s own experiences. Many patients reported feeling reduced to a diagnosis, struggling to navigate rights, treatment plans, and daily challenges. At the same time, HCPs expressed the need for a tool they could share with newly diagnosed individuals to support self-management.

## What we can do

In response, Chiesi partnered with nine people living with COPD to co-create a booklet “At leve med KOL” (Living with COPD). The patients co-authored text, reviewed images and ensured that the output reflected real life experiences and meaningful information.

## Outcome

The result was a booklet containing:

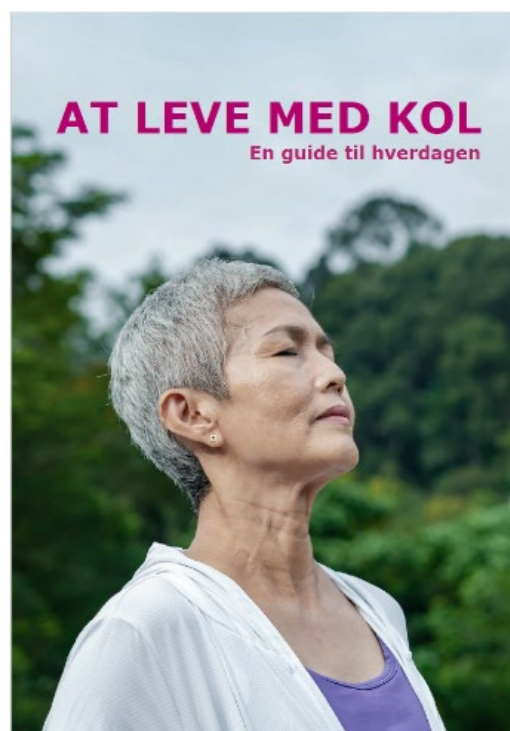
Basic facts about COPD including early warning signs; Patient rights and benefits in the Danish healthcare; practical tools for inhalation technique, self-help plans and annual check-up; advise on mental health, social life and work life; first-hand tips and reflections from other people living with COPD.

The booklet was finalized in 2025 and available digitally on the disease awareness site [www.omkol.dk](http://www.omkol.dk) and Chiesi’s site for healthcare professionals, [www.chiesipro.dk](http://www.chiesipro.dk) (for downloading or ordering physical copies). First edition printed in 3000 copies.

Patient Journey impact score: 59%

## Social value

Self-help plans, inhaler use, annual check-ups, rights and mental health tips are collected in a booklet, supporting patients self-management and adherence. Social factors like stigma and access to information are addressed. When individuals are empowered to better manage their disease this brings improved outcomes and lower healthcare costs.



## Business value

This initiative establishes Chiesi as a leader in COPD care and patient collaboration, offering healthcare professionals tools to improve patient engagement. It reinforces partnerships with patient organizations, boosts internal motivation, and supports health equity for vulnerable populations.

# Patient beyond diagnosis

FINLAND



## Background

Meeting with persons living with a disease can really bring interesting insights about their specific needs. In one Nordic and one Finnish advisory board with patients, one patient need stood out: *wanting to be seen as a whole person and not just a disease.*

## What we can do

This insight, fueled by inspiration from a Global internal event (Customer week 2023 in Parma), sparked the idea of creating an educational event to bring a more in-depth understanding of the multidimensional reality of being a patient. This training was offered to recently graduated doctors and medical students in grade 5 and 6. Academic credits were granted for the course.

## Training objective

Many medical students come from a privileged background, and the reality of public healthcare may come as a rude awakening that medical school does not prepare them for. This training aimed at bridging this gap and help them look for the person beyond the diagnosis. A specialist, a general practitioner, a nurse and a patient shared their experiences and perspectives.

The training objective was to improve the understanding of:

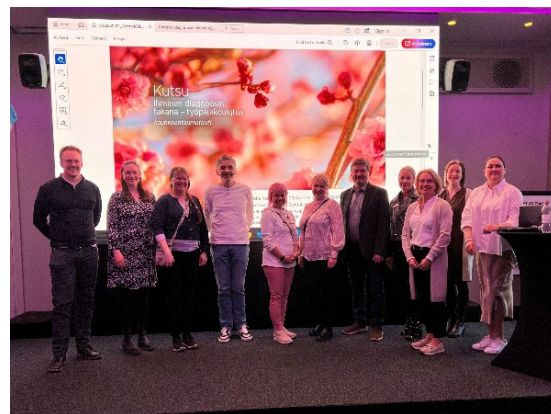
- The patient as a necessary part of the treatment team
- Aetiology of the disease and patient's treatment path

- How to consider patient needs in treatment plans
- Tools for open-minded patient encounters

## Outcomes

25 participants. Rating: 4.65/5, 70% would recommend to colleague.

Patient Journey impact score: 42%



## Social value

Improved understanding of disease and ability to listen to the patient perspective empowers patients to be more open and take a more active role as part of the treatment team. Agreeing with patients on treatment plans that are aligned with personal goals might make them easier to follow, bringing better disease management and subsequently lower costs for the society.

## Business value

Positioning Chiesi as trusted advisor, showcasing patient centricity.

# Oscillometry guide

DENMARK



## Background

To improve outcomes and prevent disease progression in COPD, early and accurate diagnosis is critical. Spirometry remains the cornerstone in lung function testing but has limitations in terms of detecting small airways disease and monitoring unstable asthma and not all patients can perform it. Oscillometry (FOT/IOS/AOS) is a supplementary technique that can provide valuable insights into lung function, requiring only normal breathing from patients. Using oscillometry as an additional diagnostic and monitoring tool in clinical practice has been a challenge due to the lack of a consolidated, practical clinical guideline in Danish.

## What we can do

Chiesi partnered with leading lung function experts and pulmonologists to create the first Danish Clinical Oscillometry guide. The guide provides a comprehensive yet practical overview of the clinical relevance, methodology, interpretation of oscillometry as well as its application in asthma and COPD. The guide is free and available on [chiesipro.dk](http://chiesipro.dk). By anchoring oscillometry knowledge in structured education, we aim to improve diagnostic accuracy, enhance treatment follow-up, and ultimately benefit patients with respiratory diseases.

## Outcome

The efforts resulted in the first ever Danish clinical guide on Oscillometry, launched February 2025. Designed as both a reference document and educational

tool, the guide is used in educational meetings with pulmonologists. It serves as a foundation for discussions on diagnosis, reversibility-testing a long-term monitoring.

Wide accessibility ensured via free download online. Used in hospital-based sessions with pulmonologists, sparking new interest in incorporating oscillometry in asthma and COPD care pathways.

It provides a reference text for respiratory specialists across Denmark.

Patient Journey impact score 62%

## Social value

By improving access to knowledge about Oscillometry in clinical practice, the guide can contribute to earlier diagnosis, more precise monitoring and subsequently

better disease control. Oscillometry can be used in patients unable to perform spirometry, a patient group risking misdiagnosis and underdiagnosis. For people living with COPD and asthma, this method may bring earlier intervention, more tailored treatments and better long-term health outcomes.

## Business value

Provides Chiesi with a share of voice in respiratory medicine by providing a reliable source for education and structured discussions with clinicians. It helps us stay connected with key opinion leaders and builds Chiesi's reputation as innovator in respiratory care.



# Prescriptriple

DENMARK



## Background

Social determinants of health are non-medical factors that can influence health outcomes and lead to unfair and avoidable differences in health status, even in a country where citizens have equal access to healthcare – in theory. Sociodemographic factors may influence patient journey, support given and treatment choices.



## What we can do

Chiesi sponsored the PRESCRIPTRIPLE study, using Real world evidence from Danish national registries to follow patients initiated on triple therapy in COPD. The study compared initiation patterns, adherence and outcomes for those using single inhaler triple therapy (SITT) vs multiple inhaler triple therapy (MITT), respectively. Access to different treatments was checked against patient characteristics, such as income, healthcare setting and smoking status.

## Outcome

Beyond its findings on clinical outcomes (data on file), the study revealed important insights into inequities in access to effective treatment, insights that go to the heart of Chiesi's commitment to health equity. The study showed that low-income patients

were more likely to receive multiple inhalers (MITT), while specialists adopted SITT sooner. SITT was associated with better adherence, fewer exacerbations or hospitalizations. Many patients continued smoking after diagnosis, indicating missed prevention opportunities. Seventeen percent received triple therapy in their first year after diagnosis, signaling a high disease burden and disease progression.

Patient Journey impact score: 68%

## Social value

The PRESCRIPTRIPLE study revealed that treatment inequities are linked to worse outcomes. To address gaps, healthcare professionals should be supported to prescribe treatments that are easy for patients to follow. Policy makers and payers should take socioeconomic barriers into account and include equitable prescribing practices and stronger integration of smoking cessation programs. Patient organizations play a key role in advocating for equitable access to effective treatments.

## Business value

Positions Chiesi as a scientific leader in highlighting and addressing health inequities in respiratory care. The study provides useful information when advocating for improved equity in COPD care, reflecting our vision to bring the most possible health for our pharmaceutical innovations.



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