



Building together

How engaging 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?

Creating shared value

Our business model is based on the shared value principle: 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.

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.

Measuring added 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 5. The method has not been applied for all projects but disclosed for projects where it has been 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 stakeholder 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.

Here are some concrete examples of what we have done in the Nordic region.

Person beyond diagnosis

(IHMİNEN DIAGNOOSIN TAKANA) 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 boards with patients, one patient need stood out: *wanting to be seen as a whole person and not just a disease.*

How we can help

This insight, fueled by inspiration from a Global internal event (Customer week 2023 in Parma), sparked the idea to create 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 in this training. 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

- 40 participants. Rating: 4.74/5, 100% would recommend to colleague.
- Based on feedback, a new event in 2025 is in planning.
- Patient journey impact score 2.1.

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. Treatment plans that are agreed and aligned with personal considerations may be easier to follow. High adherence brings better disease management and lower societal costs.

Business value

Positioning Chiesi as trusted advisor, showcasing patient centricity.

LHON patient brochure

SWEDEN



Background

Leber hereditary optic neuropathy (LHON) is a rare mitochondrial disorder which can affect persons of all ages and both genders and is most often seen in young males. It causes sequential and painless visual loss due to optic nerve degeneration. Most patients develop optic atrophy with profoundly impaired vision or near blindness, and severe negative impact on quality of life already within one year from first symptom.

How we can help

Chiesi and LHON Eye Society have the common goal to support persons living with LHON and their families by providing up-to-date information about living with the disease. As the knowledge

about LHON expands and the availability of visual aids and vision rehabilitation change, the existing brochure needed an update. Chiesi enabled the development of a new version via sponsorship to the LHON Eye Society.

Outcomes

In 2025, an up-to-date brochure will be available for distribution to vision centres, ophthalmology- and optometry clinics, and members of the patient organization. Relevant umbrella patient organizations in Sweden will also receive it.

Social value

Supporting patients and families with up-to-date information about the disease and available support in Sweden.

Improved knowledge help patients cope with disease and make adaptations to lead a functional life despite the chronic condition.

Business value

Improved disease awareness and understanding of disease progression may motivate users to follow treatment directions in line with documented optimal use.

COPD: How to get the best possible follow-up

NORWAY



Background

In Norway, a significant number of individuals with chronic lung disease do not receive regular follow-up care with primary care physicians or pulmonologists following their initial diagnosis. This can lead to missed opportunities for adjusting treatment, monitoring disease progression, and providing preventive care. It is also crucial for these individuals to understand what specific symptoms or changes to be aware of, such as increased breathlessness, cough severity or mucus production. Awareness of these warning signs can empower individuals to take early action, preventing symptom escalation and improving health outcomes.

What we can do

This project aims to increase awareness of the critical importance of follow-up care in managing COPD, and to bolster and enhance disease knowledge among people living with COPD.

The project was carried out in collaboration with the Norwegian association for asthma and allergy, NAAF, and included three distinct initiatives:

1. Awareness material: How to get the best Possible follow-Up? Think of this!
2. Podcast episode: COPD – How to live well with a chronic lung disease? Digital marketing in social media, NAAF newsletter and NAAF membership magazine in relation to the World COPD Day, November 20.
3. Arendalsuka. An engaging spirometry exhibit at the Arendalsuka event (an annual large political gathering), including distribution of COPD awareness material.



Measurable outcomes

- Number of spirometry tests performed at Arendalsuka: 50.
- Approximately 300+ brochures were distributed at the booth during Arendalsuka.
- Podcast episode and digital marketing: to be assessed.

Social value

- Lung health awareness.
- Improved access to health-promoting information for people living with COPD.
- Contribute to well-controlled patients (which could lower the social burden and improve quality of life for people suffering from COPD).

Business value

- Elevate Chiesi patient advocacy approach.
- Strengthen relation to NAAF and facilitate further collaboration with NAAF.
- Internal pride and feeling of shared responsibility – We Act!
- Promotion of the company Chiesi Nordic.



The Järva week

(THE JÄRVA WEEK) SWEDEN



Background

There is mounting evidence that low socio-economic status is linked to higher incidence of disease and poorer health. Available statistics indicate, among other things, a higher incidence of chronic obstructive pulmonary disease (COPD) in residential areas that are less well-off. Health equity gaps in COPD care also exist in high-income countries such as Sweden, in particular when it comes to diagnosing and accessing standard of care. High smoking rate, a major COPD risk factor, contributes to high probability of COPD.

One of these areas with low socioeconomic capacity is the suburb Järva, north of Stockholm. Here, a local enthusiast initiated Järvaveckan (Week of Järva), to counteract the sense of social exclusion from the rest of society and to bridge the gap between politicians and ordinary people. Järva week has developed into a meeting place for open conversations, sharing culture, music, food, exchanging ideas and perspectives and making connections for new job opportunities.

What we can do

We identified Järva week as an opportunity to improve disease awareness in a community where the degree of undiagnosed COPD is likely to be high. As the first pharma company to participate, Chiesi teamed up with the patient organization HjärtLung association and AstraZeneca to raise awareness about COPD and why seeking care early is important. Spirometry testing was offered at the open booth, we arranged a panel discussion about improving COPD care and video on display educated the visitors about COPD in four different languages, including Arabic and Somali.

Outcomes

- A total of 577 spirometry tests were performed, of which a full 20% had an FEV% <0.7, potentially indicating COPD or undertreated asthma, they were referred to care for further investigation.

- Patient Journey impact score: 3.4.

Visibility

LinkedIn posts, advertisement in Sweden's largest news paper Dagens Nyheter. Newsletter distributed to 1335 HCPs (opening rate 37%); two articles on www.chiesipro.se



The HeartLung-association also posted on their Facebook wall and shared an article in member newsletter.

Social value

- Improve awareness of COPD in a socio-economically challenged area.
- Contribute to early disease detection and access to care, leading to better outcomes for people living with COPD.

Business value

- Focus on health equity and acting for our community in accordance with Strategic sustainability plan 2023-2028.
- Collaboration with relevant stakeholders.
- Improved disease awareness may help symptomatic patients get a diagnosis and the possibility of a treatment.



Fabry patient advisory board

NORDIC



Background

Fabry disease is a rare lysosomal storage disorder with approximately 500 patients diagnosed in the Nordics.¹ The disease is a progressive multi-systemic disease involving multiple organs including heart, kidneys, and nervous system. The patient advocacy groups (PAGs) are small and rely on their member's spare time for doing patient advocacy activities.

What we can do

As a company working with Fabry's disease, we have the possibility to share and amplify the voice of the patient and their needs. To learn more, Chiesi Nordics organized the 4th Nordic patient advisory boards, with delegates from the PAGs in Sweden, Norway, Finland and Denmark. Helping patients prepare for their follow-ups with their physician was one need that was expressed. The patients typically have one 20–30-minute annual appointment with the treating physician, which is insufficient to cover all aspects of the disease. We received advise on potential collaboration project that were ranked in priority.

Outcome

A joint decision on what project(s) to move on with will be made early 2025.

Social value

Patient empowerment.

Business value

- Insights of how we can add value for both patients and healthcare.
- Can help us make important connections for improving focus on this disease area.
- Elevate Chiesi health equity focus.

¹ Estimate based on feedback from treating physicians in the Nordic countries (2024)

The Outreach Program

NORWAY



Background

The Sami people in Norway are acknowledged as both a minority group and an indigenous population, with their main presence in the northern Nordic regions. As an indigenous minority, the Sami have faced oppression over history, compromising land rights, resource management and preserving traditional Sami livelihoods like reindeer herding. Norwegian authorities are now making efforts to address Sami rights.

Finnmark, Norway's northernmost county with a significant concentration of Sami communities, is characterized by vast and sparsely populated areas. Consequently, due to their geographical remoteness and the distance to healthcare facilities, access to healthcare can be an issue. In addition to poor healthcare infrastructure, cultural and linguistic barriers, and socioeconomic factors may contribute to low access to healthcare.



What we can do

Aligned with the Chiesi strategy on health equity, The Outreach Program, carried out in collaboration with the patient organization LHL, has in 2024 focused on the Sami people in Finnmark, aiming to address health equity challenges related to

minority and geographical factors. Three events were organised in Karasjok, Vadsø and Alta, respectively, to facilitate this initiative. The events included free spirometry testing and educational meetings where a lung specialist and a user representative from LHL shared knowledge and experience from living with lung disease, either from personal or a relative's perspective.

Outcome

- Number of participants: Approximately 75
- Spirometry performed: Approximately 60
- Patient journey impact score 3.5

Social value

- Equal access to health care.
- Increase awareness around obstructive lung disease.
- Facilitate platforms where people living with lung disease can meet and exchange thoughts and experiences.
- Improve the care and life quality for people suffering from obstructive lung disease.
- Contribute to de-stigmatisation of COPD.
- Contribute to well-controlled patients (which could lower the social burden).

Business value

- Elevate Chiesi patient advocacy approach.
- Elevate Chiesi health equity focus.
- Insights from people living with obstructive lung disease.
- Internal pride and feeling of shared responsibility – We Act!
- To increase awareness around Chiesi as a company.



Webinar on Epidermolysis bullosa

SWEDEN



Background

Epidermolysis Bullosa (EB) is an inherited, rare and devastating tissue disorder. It is a disorder which causes skin fragility and blister formation. In severe cases multiple organs are affected, with scarring and shortened life expectancy.

There is no treatment that cures EB. The basic treatment for most forms of the disease is focused on wound care and protective dressings to prevent trauma that will cause new blisters/wounds.

Dermatology is a new therapeutic area for Chiesi. Finding important stakeholders for potential win-win projects is a necessary first step to leverage potential added value for patients.

What we can do

EB is a rare disease that most people is unaware of. We arranged a webinar that included impactful stories and expert insights to help explain EB to general public as well as healthcare professionals. We can also support the umbrella patient organization (DEBRA) to improve the prioritization of EB for dermatologists.

Outcome

- 69 registered participants, enabling access to recordings after.
- 38 unique live viewers + 1 dermatology clinic.

Social value

- Living with EB requires lots of adaptations in daily life, and having more understanding from the society makes it easier for those who are affected, as patients or family.
- Enabling the patient organization, DEBRA Sweden, to increase focus on EB.
- Collaborations between different stakeholders brings more perspectives and more holistic thinking.

“I had to add a mantra for myself when dressing my child’s wounds: it’s the disease’s fault and not mine”

A MOTHER DESCRIBING, DURING THE WEBINAR, THE CONSTANT PRESSURE OF DEALING WITH EB

Business value

The activity helped make connections with important stakeholders, from whom we can learn and potentially collaborate with on future projects. We also established relations with DEBRA Sweden and will continue to look for mutually benefiting projects to improve lives for those living with EB. The recording of the webinar is an asset that we can continue to use for improving disease awareness.

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

In order to address avoidable differences in health status, these must first be identified. As part of a retrospective study looking at prescription patterns and patients' characteristics across Denmark since 2016, we also address sociodemographic aspects of treatment: Is there a correlation between patient characteristics, prescribed treatment, patient journey and prescription pattern(s) in Denmark? Age, sex, region, municipality groups, educational

level, income, lung function, degree of disability on day-to-day activities due to breathlessness, smoking status and body mass index (BMI) are variables included in the analysis.

Outcome

Expected to be completed in 2025.

Social value

- Addressing social determinants of health is fundamental for improving health and reducing longstanding inequities in health.

Business value

- Gain insights on prescription patterns
- Improve our communication to improve the number of patients that obtain disease control.





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