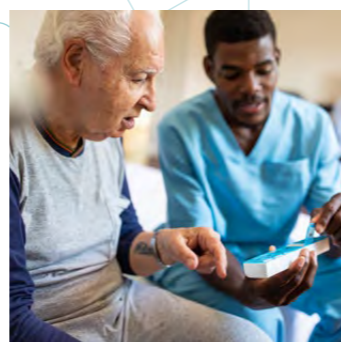




efpia

European Federation of Pharmaceutical
Industries and Associations

CONNECTING HEALTHCARE GUIDE 2021



Foreword

Dear Colleagues,

Some problems are too great to solve alone. Today's healthcare challenges are complex and require the skills and perspectives of diverse stakeholders. If there was any doubt about this, the COVID-19 pandemic has illustrated the value – indeed, the necessity – of partnerships and collaboration.

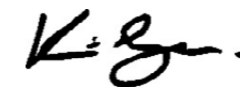
The most striking example can be seen in the millions of doses of COVID-19 vaccines being administered across Europe. Public and private researchers, regulators, healthcare providers and policymakers, with the vital support of patients and the wider public, helped to develop several safe and effective vaccines in record time. The patient voice remains central as our thoughts now turn to supporting high rates of vaccine uptake.

Partnership is also the key to unlocking solutions to the challenges that we must solve together in the years ahead, including those that stem from an ageing population and rising rates of non-communicable diseases. By working together, healthcare stakeholders can ensure that their priorities are reflected in how services are planned, funded and delivered.

The EFPIA Patient Think Tank aims to put patients at the centre of these conversations. By sharing best practices in open and transparent collaboration, we hope to showcase what can be achieved when partners pool their energies and work towards a shared goal.

As you explore this, the fourth Connecting Healthcare Guide, we hope you find inspiration. These projects bring together diverse coalitions of stakeholders that came together to make a difference to patients across Europe. Along with healthcare actors, the contribution of local authorities, civil society organisations and technology companies shows that no player has a monopoly on good ideas or solutions. Indeed, sometimes new partners can be found where we least expect. Provided the principles of transparency, trust and mutual respect are followed, we must remain open to fresh insights from wherever they may come and to working together.

The pandemic may have disrupted services, prompting creative ways to deliver care, but it has also led us all to embrace new collaborative tools. As we seek to move past the worst of the COVID-19 crisis, let's ensure that we keep the best of what we have learned and continue to work side-by-side to improve the lives of patients in Europe.



*Elisabeth Kasilingam,
Acting Executive Director,
European Patients Forum*



*Nathalie Moll, Director
General, EFPIA*





International Map of Axial Spondyloarthritis (IMAS)

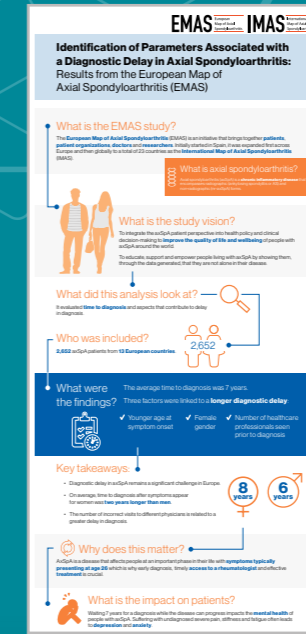
Axial spondyloarthritis (axSpA) is a chronic inflammatory disease that can lead to chronic, life-long pain, structural damage, and disability. In addition to its huge physical impact, the psychological stress axSpA places on patients, can disrupt every aspect of the person's life, including mobility, sleep, work, and relationships.

Physicians often do not consider the complete patient experience during their conversations with patients; interactions are focused on the clinical symptoms and immediate solutions. There is a clear need to change this cycle. Ensuring that patients report how axSpA is impacting their life will enable rheumatologists to improve care and adapt the way the disease is managed for that patient.

The International Map of Axial Spondyloarthritis (IMAS) brings together patients, patient organisations, clinicians and researchers around the world to generate insights into the real-life experiences of people living with axSpA. IMAS uses a survey developed together with all stakeholders to evaluate how patients experience their disease from a physical, psychological and

social perspective and how they are managed within healthcare systems.

Incorporating the patient's perspective into clinical practice facilitates shared decision-making between patients and physicians, which improves disease management, increases patient participation in their care, ensures greater therapeutic adherence, and generates better physical and psychological health outcomes.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

With over 4,000 participants so far, IMAS is the largest ever survey of people living with axSpA. The results capture their experiences, fears and hopes, giving an understanding of the patient's reality which is not currently reflected in clinical studies. The findings are being discussed with patient and rheumatologist leaders worldwide to help inform clinical decision-making, shorten diagnostic delay and ensure patients are optimally managed.

IMAS findings have been shared at key international rheumatology congresses with 48 scientific abstracts and presentations to date. Additionally, seven articles have been published in high impact, peer-reviewed rheumatology journals, directly reaching researchers and clinicians who manage the care of people living with axSpA. IMAS results continue to be discussed at patient organisation meetings, activating patients to be part of the conversation that changes the course of their disease.

INNOVATIVE ELEMENTS OF THE PROJECT

Initiated by patients for patients, IMAS was uniquely designed to unite the medical and patient communities around a common purpose: generating and disseminating robust evidence on the axSpA patient experience to enable truly patient-centred care.

Through IMAS, the axSpA patient community has the opportunity to play an integral role in identifying areas for improvements in their care. One key area that was identified through IMAS is the significant impact that axSpA has on mental health. This insight was used by the international patient organisation and IMAS partner, ASIF, to form key campaign messages and the overall theme for World AS Day 2020.

To bring the IMAS data to life, an interactive artistic sculpture exhibit highlighting patient quotes and data was launched at EULAR 2019 to engage rheumatologists to pledge support for their axSpA patients by writing messages directly on the spine sculptures.

COLLABORATIVE ELEMENTS OF THE PROJECT

IMAS started in Spain through a pilot initiative led by Professor Marco Garrido-Cumbrera, a Spanish axSpA patient representative working at the Health and Territory Research (HTR) group of the University of Seville, supported by the Spanish Federation of Spondyloarthritis Associations (CEADE), medical experts, and Novartis Spain.

Together with ASIF, the University of Seville and Novartis, the survey was then expanded to 13 European countries. In Europe, it was overseen by a Pan-European steering committee made up of patient representatives from ASIF, Agora, CEADE and nine axSpA experts, including rheumatologists and psychologists.

The survey is now being further expanded to include a total of 28 countries worldwide across Europe, North America, Latin America, Africa and Asia Pacific. The collaboration is grounded in mutual value and with a clear common objective.



The Dreamcatcher – the future belongs to dreamers

Rheumatic disease is the collective name for a variety of autoimmune conditions affecting the joints. Symptoms include stiffness, swelling and pain, making it difficult to move, while fatigue is also common. In Europe, over 120 million people live with rheumatism of some kind.

A survey by the Swedish National Organisation for Young Rheumatics found that 50 percent of young people with rheumatic disease feel that the healthcare system does not enable them to fulfil their dreams. Important life decisions, such as career choices or starting a family, often take a backseat to disease management.

Almost four in ten say they would like greater influence over their medical treatment. Patients and providers lack a tool to support structured patient conversations that look beyond symptoms to focus on future goals.

The Dreamcatcher aims to address this gap. It is an innovative digital tool that enables young people with rheumatic disease to express their future ambitions and, with the support of healthcare providers, make these dreams come true. This flips

the traditional model of care on its head. Rather than focusing on symptoms and limitations, the Dreamcatcher prioritises health and possibilities – enabling a more patient-centred approach. Using behavioural design, nudging and social tools, the Dreamcatcher sets goals, facilitates follow-up, and puts the patients’ wishes at the heart of the patient-healthcare provider relationship.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Dreamcatcher makes patients the co-creators of their own care. Based on real insights from patients and healthcare providers, this digital tool shifts the focus to health and empowerment, while making efficient use of time and healthcare resources.

The Dreamcatcher improves interaction with healthcare providers and makes clinic visits more meaningful. By sharing advance information about the patient’s progress and what they find important, the provider can more easily determine what type of specialists are needed to help them reach the goal – such as physical therapists and dieticians.

In addition, the Dreamcatcher is designed to allow users to share their dreams with others in a social Dream Collective. Not only is the tool of practical benefit to users, but it also has great potential to connect and inspire the patient community.

INNOVATIVE ELEMENTS OF THE PROJECT

The Dreamcatcher is a digital tool built using open-source code. Through a partnership with Upstream Dream, the company behind an app called Genia that targets patients with cystic fibrosis, data can be shared directly with health teams, quality registries and researchers when the patient approves it.

Following a pilot phase, the initiative will begin measuring increased physical activity and self-realisation with the help of the Dream Scale, adapted from the familiar ten-point VAS Scale used to estimate pain and fatigue. A Minimum Viable Product (MVP) will be developed, as well as a web application on Upstream Dream’s technical platform.

COLLABORATIVE ELEMENTS OF THE PROJECT

The Dreamcatcher is a unique collaborative project between patients, healthcare providers and the pharma industry. It gathers a variety of organisations and individuals from the public and private sectors to jointly learn, improve and develop a practical tool.

To ensure that the project captures the needs of stakeholders, in-depth interviews and workshops with patients, doctors, researchers, medical experts, health app manufacturers and several health care units were conducted. To co-design the Dreamcatcher with patients, we also participated in youth camps and conferences, organised by the Swedish National Organisation for Young Rheumatics.

The project is characterised by collaboration, openness, and a whole new type of partnership. We believe this can inspire others to curiously explore and experiment together, in order to move society forward.

BREAKING DEPRESSION



Breaking Depression

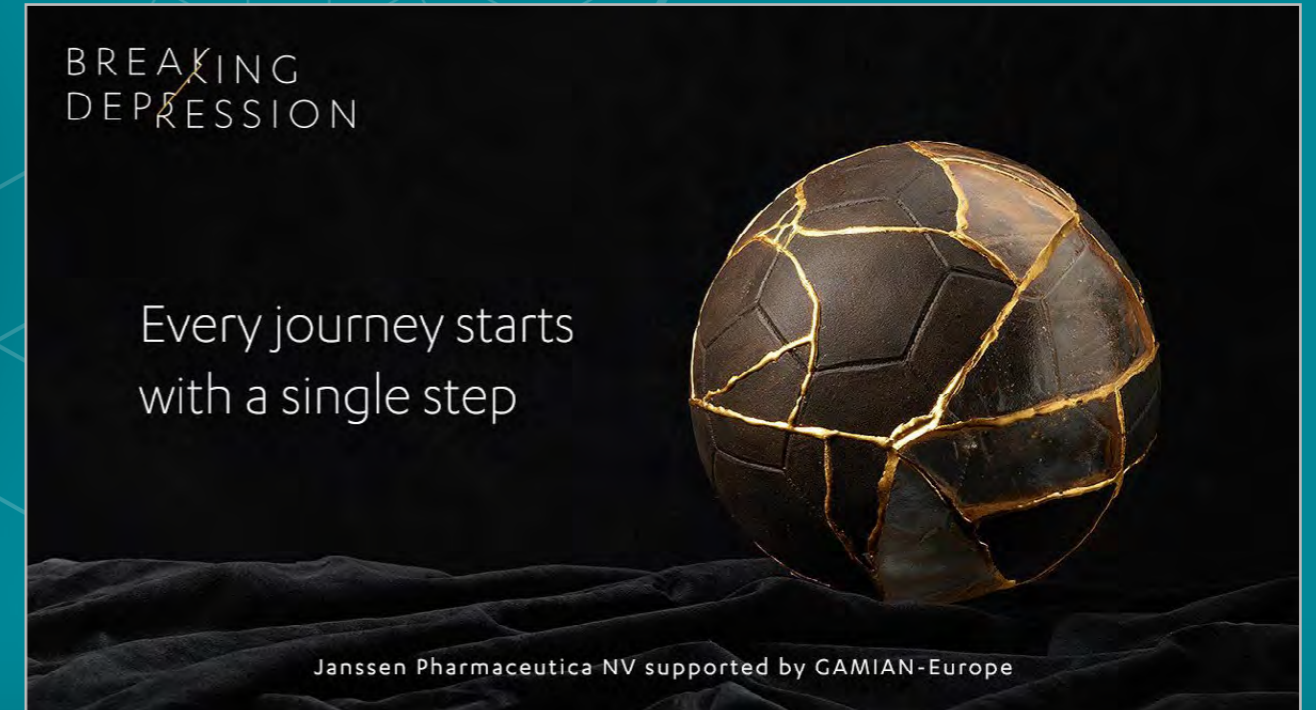
Major Depressive Disorder (MDD) is one of the leading causes of disability worldwide and one in four people will be personally affected by depression in their lifetime. Despite this, 75% of people diagnosed with depression will not receive timely and appropriate care. Stigma and common misconceptions about depression can prevent people from opening up about how they are feeling.

Patients often feel broken and beyond repair. Breaking Depression is a pan-European disease awareness campaign which aims to improve understanding of MDD and encourage more open and honest conversations about depression to make sure we are all able to better care for our loved ones and ourselves.

The creative concept behind the project stems from the ancient Japanese art of kintsugi. Translating as 'golden joinery', it involves repairing broken objects with gold lacquer, treating the breakage and repair as part of an object's history, rather than something to conceal. The process is analogous to managing MDD: by respecting the cracks and realising the repair process is complex and takes time, we can help people to get the right support.

Working with two artists, eight works of art were created, inspired by stories from people living with MDD, revealing that with time, care and patience, people with MDD can begin to heal.

The stories were shared via a dedicated website (www.breakingdepression.eu), a social media campaign, advertising and at art installation at a medical congress, ensuring a high impact on diverse audiences.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

By focusing on patient experiences, the campaign changed the conversation on MDD. Insights from in-depth phone interviews with psychiatrists, combined with social listening and patient group research, allowed partners to map out exactly what needed to be done.

The campaign reached 45 million people in its first nine months – far exceeding the initial target. 40,000 people became Breaking Depression advocates through Instagram and the project website. A survey of conference delegates who saw the art installation at a congress found that 82% rated the concept as having 'high resonance'.

A 'making of' video was viewed more than 640,000 times on YouTube, Instagram and Twitter. In addition, there were 2.2 million impressions with 12,292 engagements via POLITICO Europe's website and social media channels, along with Janssen EMEA's social channels.

INNOVATIVE ELEMENTS OF THE PROJECT

The project was highly creative, engaging artists to communicate patient stories built on the concept of kintsugi. Audiences were segmented with dedicated campaigns tailored to each target group.

The soft launch of Breaking Depression was held at the European College of Neuropsychopharmacology (ECNP). To gain the professional community's support, an installation was created, unveiling eight art pieces alongside patient stories and a 'making of' video.

To create an immersive experience, we followed the delegates' journey with digital advertising at the airport, bus shelters and in nearby hotels, supplemented by paid and organic social posts, to maximise reach and engagement.

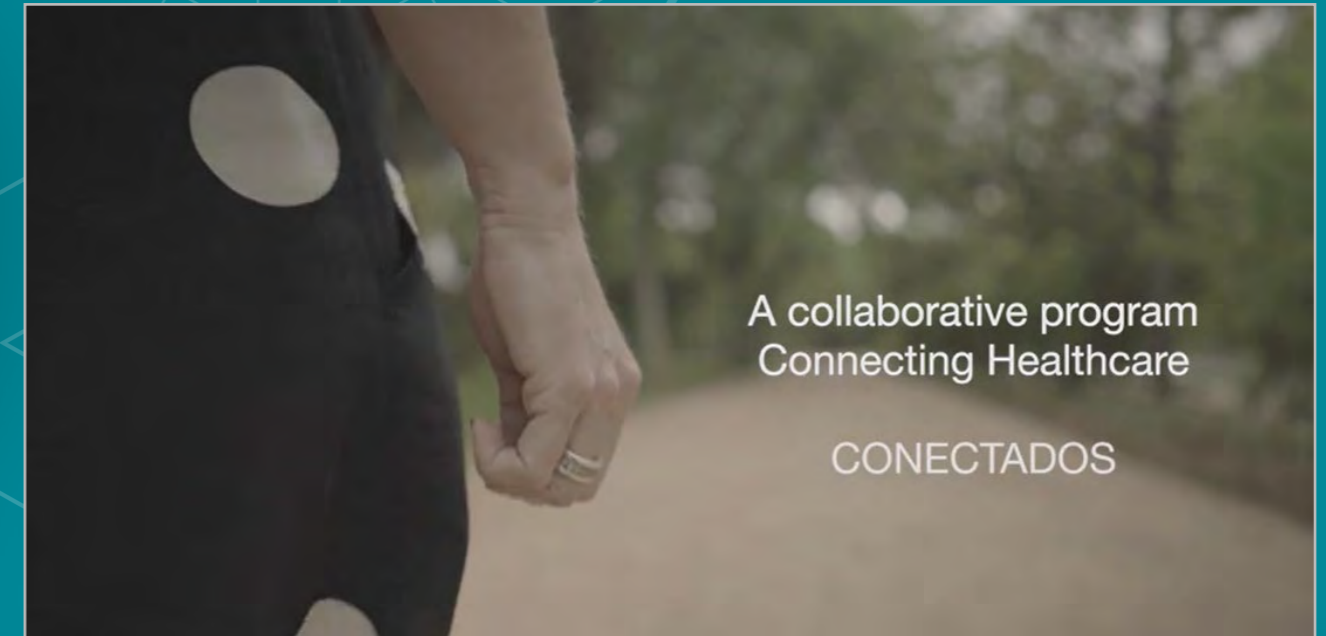
The hard launch was held on World Mental Health Day, with the unveiling of a website and social media campaign.

COLLABORATIVE ELEMENTS OF THE PROJECT

Janssen took a collaborative approach to all aspects of Breaking Depression. Working with a patient-driven mental health advocacy group, GAMIAN-Europe a public affairs agency, a media partner and two artists, a unique partnership was developed.

All materials and assets were produced with input from patient advocates to ensure appropriate language and resonant content. Clear and frequent communication was to the fore throughout the collaboration, helping to build a project which provides a foundation for further expansion.

What united everyone involved is the belief that collaboration is the best tool to help break miseducation and misconceptions, break stigma and ultimately break depression.



Conectados

Diagnosis with chronic lymphocytic leukaemia (CLL) has a profound impact on people’s lives. They fear the consequences of the disease and can struggle to take in all the information provided by clinicians. Patients often face mental health as well as quality of life challenges, and, additionally, adherence to treatment can be an issue. COVID-19 has exacerbated the isolation patients feel when dealing with their condition.

Conectados is a Janssen programme delivered by AEAL, a patient organisation. The campaign targets patients who are currently on, or about to start, oral treatment and their caregivers. Patients are informed about the project by their haematologist. Conectados, which means ‘Connected’ in Spanish, connects patients to a psycho-oncologist who discusses a range of issues with them, including motivation, nutrition, exercise and wellbeing. Patients receive information in the form of structured worksheets developed by the company and psycho-oncologists with the advice of haematologists.

The project offers emotional support and continued telephone assistance. It aims to increase adherence to medication and to enhance the relationship

between patients and physicians. Since the beginning of the programme, there has been an increase in participation of 95% each year. The haematologists have noticed an improvement in the communication, quality of life and state of mind of participating patients. 100% of the participating patients have communicated their satisfaction and interest in continuing with the programme.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The programme empowers patients by increasing their knowledge of disease and allowing them to take more control of their life. It provides patients and their relatives with psychological support at a key moment in their lives.

By improving adherence to treatment, the programme has the potential to enhance clinical outcomes which would have a positive impact on survival and quality of life.

Psycho-oncology support is a valuable tool for helping patients fight the loneliness and isolation that can accompany a diagnosis. Due to the COVID-19 pandemic, there has been an increased need for psychological support during the lockdown in Spain, proving the value of the project in the daily lives of patients. The programme has also increased the amount of information given to patients about safety measures against COVID-19. More than 500 patients have enrolled in Conectados.

INNOVATIVE ELEMENTS OF THE PROJECT

The programme brings psychological support closer to the patient. Using telecommunications, services can be provided to patients anywhere, anytime. This increases access to the support service for patients, saving them from traveling to clinics to see the psychologist. During COVID-19, this is especially valuable – cancer patients are at increased risk if infected with the SARS-CoV-2 virus and are reluctant to visit hospitals unless it is necessary.

The project is delivered by a patient organisation, helping to build trust with patients. In addition, the programme is recommended to patients by their doctor which adds to its credibility. While this may not be a common approach for an industry-supported initiative, it helps to ensure strong uptake by patients.

COLLABORATIVE ELEMENTS OF THE PROJECT

Janssen coordinated with the patient organisation in the creation of the project. In addition, feedback was also secured from the national medical societies (SEHH and GELLC) – both of which endorsed the initiative.

Close coordination with haematologists in all participating hospitals played a vital role in linking the programme to the patient journey. Clinicians referred patients to the project, ensuring that it was integrated into their care. Other healthcare professionals, including pharmacists and nurses, were also engaged and helped to register patients to the programme.

Throughout the project, there was continuous engagement between the patient organisation, healthcare professionals and Janssen. All information about the initiative was published online, ensuring transparency regarding the launch, development and endorsement of the programme.



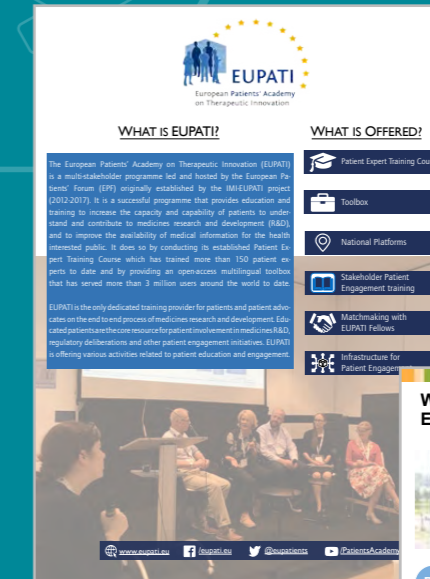
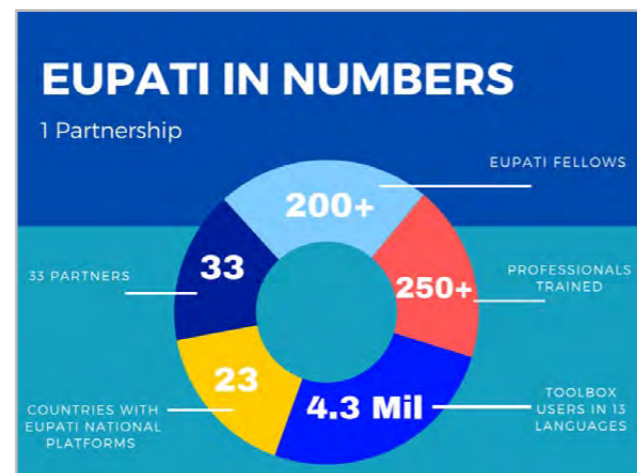
EUPATI

EUPATI was launched in 2012 as a flagship project of the Innovative Medicines Initiative (IMI) and was led by the European Patients' Forum (EPF) as a multi-stakeholder programme from 2017 until August 2020. Today, EUPATI is an independent Foundation with 33 partners. It has built a strong brand, demonstrating a sustainable future for the initiative.

The EUPATI online Toolbox on medicines' R&D has reached over 4.3 million users since its launch in 2016. It is available in 13 languages. This demonstrates the impact of EUPATI not only in Europe but also globally.

The goal of EUPATI is to bring patient engagement to the discussions of all stakeholders, to ensure that treatments are as effective as possible for the end users. To that end, EUPATI's main focus is on providing training and information to patients, patient advocates and the lay public about the tools and processes behind medicines R&D. This is achieved through the three main pillars of EUPATI: the Toolbox, the Patient Expert Training Course, and the EUPATI National Platforms Network.

The Patient Expert Training Course has over 200 graduates. EUPATI has also extended its portfolio to offer training about patient engagement to industry, academia and other stakeholders.



Number of articles in the toolbox	Number of videos in the toolbox	Number of presentations in the toolbox	Number of webinars in the toolbox	Number of images in the toolbox	Number of factsheets in the toolbox	Number of video interviews in the toolbox	Number of documentary in the toolbox	Number of infographics in the toolbox	Number of glossary items in the toolbox	Number of acronyms in the toolbox
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PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

EUPATI has reached millions of people worldwide. The EUPATI Toolbox has 4.3 million users. It contains 1,463 articles, 254 presentations, 97 videos, 5 webinars, 246 images, 160 factsheets, 25 video interviews, 1 documentary, 148 infographics, 4708 glossary items and 2695 acronyms.

Since the launch of the EUPATI Patient Expert Training Course, more than 200 patient experts have graduated and a further 60 trainees have been enrolled. In 2020, the online modules of the course became openly accessible on demand to anyone wishing to study at their own pace. Through 23 EUPATI National Platforms (ENPs), the initiative is increasing the number of individuals who benefit from the training.

INNOVATIVE ELEMENTS OF THE PROJECT

EUPATI has been a game changer for patient education and patient engagement in medicines R&D. By bringing together all stakeholder groups, it continues to be one of the key drivers of change at a pan-European level.

Through dynamic collaboration, it has empowered European patient advocates to become leading actors in R&D, while enabling academia and industry to intensify their patient involvement work. Regulators have also started to enhance the role of patients in the regulatory process.

Collaboration has been the cornerstone of EUPATI's business model, involving stakeholders in driving the initiative and in creating content for training courses.

COLLABORATIVE ELEMENTS OF THE PROJECT

EUPATI is a public-private partnership which exercises a truly multi-stakeholder approach in all of its activities and decision making. The EUPATI Foundation is governed by a Board of Trustees, with representatives from different stakeholders (patient representatives, industry, regulators, academia) and a EUPATI Board elected by the Sustaining Partners' Assembly.

The EUPATI Board is co-chaired by a patient and an industry representative who work together with representatives from the EUPATI National Platforms, patient organisations, academic/non-profit organisations and industry partners. This multi-stakeholder approach is also reflected in the way all EUPATI training and materials are co-designed and co-delivered. EUPATI's 33 partners are drawn from across the industry, patient organisations and NGOs.



BREATHLESS: Redefining severe asthma care globally

Approximately 34 million people around the world live with severe asthma (SA), a distinct form of asthma with a serious impact. SA patients can face long delays of up to seven years to receive their diagnosis. Once diagnosed, these individuals experience additional challenges to accessing the specialist care and treatments needed to manage their condition.

The PRECISION programme seeks to challenge the existing approach to SA care. It has created the first ever SA Patient Charter, which sets out a blueprint for how governments and healthcare providers should reassess national approaches to deliver meaningful care improvements. This was followed by the publication of a Global Quality Standard for Identification and Management of Severe Asthma.

Despite this work, there is still a gap in policymakers' understanding of the real burden and impact of SA as a distinct condition, and of the specialist needs of patients. BREATHLESS – an emotive documentary-style film – aimed to tackle that misconception, improve policymaker awareness and pave the way for care improvements.

The film was endorsed by the Global Allergy and Airways Patient Platform (GAAPP) which organised a screening via a Facebook Live event with 12 patient advocacy groups from ten countries. Policy briefings ensured that the message reached key decision-makers. The content has been viewed by over 2.5 million people worldwide.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Partnering with GAAPP on the development, launch and dissemination of the documentary ensured engagement with the broad global respiratory community. A policy briefing to support patient advocacy engagement with policymakers was downloaded more than 800 times. Through events in eight countries, more than 400 policymakers engaged with BREATHLESS.

The initiative has helped to build a supportive environment for policy change, leading to updates and reforms in Germany, the UK, Japan and Canada. Each policy is at a different stage of implementation but has the potential to benefit an estimated 190,000 patients. Taken together, these changes show signs of growing momentum towards improved recognition of the needs of people with SA.

INNOVATIVE ELEMENTS OF THE PROJECT

The project was supported by a combination of an emotive piece of content with smart micro-targeting strategies, to successfully communicate compelling messages to a very specific and often hard-to-reach audience of respiratory health policymakers.

The film, produced by an award-winning independent documentary filmmaker, aimed to disrupt the status quo in SA by breaking the conventional norms of disease awareness content. The documentary used the experiences of three real patients to tell their story of the impact of living with this devastating disease and how their life can be transformed with access to specialist care.

The final documentary was launched to coincide with the European Respiratory Society's annual congress. All content was provided with subtitles in five languages to ensure maximum usability and reach across the globe.

COLLABORATIVE ELEMENTS OF THE PROJECT

The PRECISION programme is a multi-disciplinary, global programme working to ensure patients with severe asthma routinely receive the right care, at the right time, in the most appropriate setting. It is funded by AstraZeneca, but the policy group sets its own agenda and has oversight of key initiatives.

The conception and realisation of BREATHLESS happened in collaboration with the Improve Access Taskforce of the PRECISION programme, of which GAAPP are a core member. Working in close collaboration with GAAPP helped to identify three powerful SA patient stories from different countries, and to make them internationally relevant. Endorsement by GAAPP helped the documentary to reach more than 26,000 people, building advocates and empowering local initiatives.



'Don't tick off the tick. Tackle tick-borne encephalitis' educational campaign

Tick-borne encephalitis (TBE) is a viral disease that can have serious neurological consequences. It is spread by a simple bite from ticks – small parasites found in forests in several central and eastern European countries.

In severe cases, TBE causes permanent disability and can be fatal. Between 150 and 350 cases are recorded in Poland every year, although this may be an underestimate. Despite its potential severity, awareness of TBE is low in the Polish population.

The spread of myths and online misinformation about the disease and vaccination further complicates public knowledge on the topic.

An educational initiative, highlighting the risks of the disease and its potential prevention through vaccination, was launched in 2018 with the support of medical experts, academic centres, and trusted institutions. 'Don't tick off the tick. Tackle tick-borne encephalitis' educational campaign set out to improve public awareness and reduce the impact of the disease and to provide credible and reliable information on TBE prevention.

At the heart of the campaign was the launch of a National TBE Awareness Day, supported by an online information hub, social media channels and outdoor information centres.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The educational activities and awareness day met with great interest from the public, as well as the media, which are constantly looking for reliable information on tick-borne diseases and the risks associated with ticks.

In 2018 and 2019, as a result of the campaign, nearly 800 articles appeared in opinion-forming media, including national daily newspapers, breakfast TV shows, radio programmes, and influential online channels.

The campaign website became the highest-ranked site in Poland when people searched for information about ticks, while the Facebook page attracted 7,600 fans. The total reach of the campaign was close to 30 million people – or almost 80% of the population.

All of this translated into a meaningful change in public awareness: in 2019, knowledge of TBE in Poland increased by 18% compared to the previous year.

INNOVATIVE ELEMENTS OF THE PROJECT

The campaign changed the conversation on TBE in Poland through a range of innovative initiatives. By organising the country's first National TBE Awareness Day, it helped to make the disease – and its prevention – a permanent feature of conversation at the beginning of tick season in Poland.

Designating a 'Green Month of TBE' helped to focus attention on ticks in areas where the public is at higher risk. Educational materials appeared in parks and forested areas to reinforce the key messages circulated through the media. 'Tick Tents' were created to provide the public with practical knowledge about the disease.

The use of social media as a communication tool, and collaboration with a range of influential voices, were a novel component of TBE communication in Poland, while the use of social research to evaluate the project ensured the impact of these innovations were measurable.

COLLABORATIVE ELEMENTS OF THE PROJECT

Partnerships were key to ensuring credible communication from experts about TBE. Working with campaign partners, including patient advocacy groups, infectious disease specialists and health organisations, the campaign established itself as a reliable source of information.

Together, participating organisations developed a compendium of knowledge about ticks, the risks of TBE and how to prevent the disease. This became the backbone of the information shared on the website and social media channels, as well as interactive materials prepared for the public – including animations and infographics.

Engagement with journalists through media briefings, a series of meetings with biologists, and the circulation of an emotionally resonant patient story, combined to deliver a high-impact campaign underpinned by collaboration.



Access to health, access to life!

More than 800,000 people have diabetes in Romania, equivalent to 12.5% of the population. An estimated 3,440 children live with self-monitored type 1 diabetes. The diabetes epidemic in Romania is growing as overweight and obesity become increasingly common in younger people. Medical, social, emotional, nutritional, and hereditary factors all have a role to play.

'Yes, I can too' is a patient-driven initiative designed to raise awareness of diabetes and promote physical activity. Working with partners, the campaign organised educational events and mobile blood glucose testing in rural areas, along with interactive sessions on healthy eating and outdoor exercise.

The initiative aimed to help people recognise the signs of illness, how to access services and manage diabetes. Under the banner 'Access to health, access to life!' the campaign brought a traveling clinic to schools in more than 22 Romanian areas which can be hard to reach. Students, teachers and parents were offered glucose, weight and height measurements, free of charge.

By emphasising diet and physical activity – notably cycling – it highlighted the value of prevention and management of chronic disease.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

More than 1,200 students, along with 300 teachers, parents and citizens from 22 communities, benefited from the mobile campaign. 25 information sessions were each attended by at least 50 people.

The initiative raised awareness of diabetes, healthy behaviours and preventative measures, as well as treatments. People with diabetes were identified through glucose testing and offered support and equipment to ensure correct management of their condition. This reduces their risk of complications that are associated with diabetes when the disease is not well treated.

The wider community also benefited from sports and outdoor programmes, including cycling, which helps to improve overall fitness and wellbeing.

INNOVATIVE ELEMENTS OF THE PROJECT

The initiative brought educational and medical services to regions which are often underserved. By combining nutrition, health and exercise in a school-based setting, the campaign offered a unique service to people with diabetes, their families and communities.

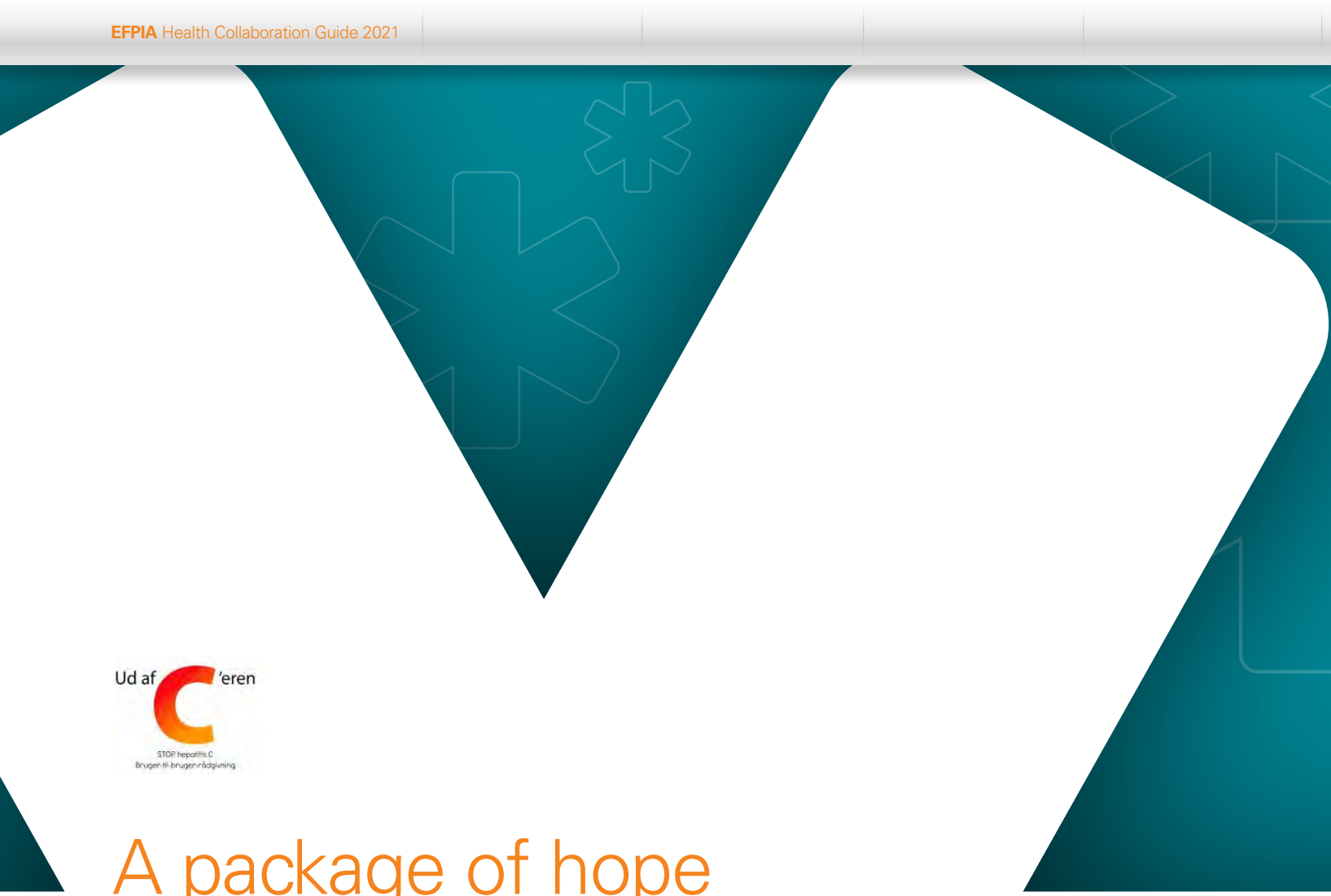
Using data from glucose tests performed during school visits, partners are developing a database to allow follow-up with those in need of support or guidance in diabetes management.

The project is also helping to connect community volunteers with resources that allow them to support local campaigns through fundraising and civic involvement. Ongoing connections between communities and nutrition clinics will support continued education on diabetes and autoimmune disorders.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project brought together a diverse group of actors to support outreach to rural communities. These included a diabetes NGO, a nutrition clinic and a petrochemical company. A high-profile nutrition expert, nurses and people with diabetes helped to ensure the content was of high quality and relevant to the audience.

In addition, links were developed with the Ministry of Education, local authorities and the media. Together, participants agreed to focus on delivering better outcomes for patients by improving the efficiency and effectiveness of information campaigns. Stakeholders contributed significant time, resources and expertise to make the initiative a success.



EASL
The Home of Hepatology

A novel hepatitis C intervention in Denmark to test and treat people who inject drugs

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INTRODUCTION
Providing testing and treatment for hepatitis C (HCV) for people who inject drugs (PWID) is a key component in eliminating HCV. Reaching this population with health care services can be challenging. Combining point-of-care testing with peer support and counselling has been shown to be effective. However, treatment also needs to be more accessible.

AIM
To investigate if a mobile van equipped with rapid detection tests for HCV antibodies and RNA could test and link PWID to care and treatment in a hospital.

METHOD
In Copenhagen, Denmark, a peer-led mobile service providing counselling, anti-HCV testing (In-Tech™), and linkage to standard of care was equipped with a point-of-care HCV-RNA finger-prick test (Xpert HCV Viral Load Finger-Stick Point-of-Care Assay, Cepheid). All clients were eligible for testing but only those with a legal residence in Denmark could be referred for treatment. Eligible HCV-RNA+ individuals were offered assisted referral to a fast-track hospital clinic for treatment, and peers provided assistance as needed.

RESULTS
From 1 May to 31 October 2019, a total of 304 anti-HCV tests were performed, and 42 individuals were found to be HCV-RNA+. In addition, six individuals with known HCV infection contacted this service to be linked to care. Of the 48 individuals with possible chronic HCV infection, 24 (50%) were evaluated at the hospital clinic and by 15 November 2019, all had initiated treatment with direct-acting antiviral therapy. The main reasons for not being evaluated were being in the country illegally (n = 10, 42%) and being lost to follow up (n = 9, 33%). Two died before being linked to care and two ended up in prison. Among those initiating treatment, 14 were connected to drug treatment services and could be treated while receiving opioid substitution therapy. The peer-led service assisted all treated with inter- and communication with the hospital nurse, collecting medicine, and accompaniment to follow-up visits.

CONCLUSIONS
A peer-led mobile service can engage PWID in HCV testing and treatment. We identified being an illegal migrant as a major cause for not accessing care. This poses a challenge for HCV elimination in Denmark, in part due to the risk of onward transmission, and is a health threat to the individual.

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Brugernes Akademi's mobile van in Copenhagen

Finger-prick test

Gene Xpert inside the mobile van



A package of hope

Denmark supports the UN's goal of eliminating Hepatitis C and has made access to injection equipment a legal right. However, in practice, effective initiatives to promote this right and eliminate Hepatitis C have been limited.

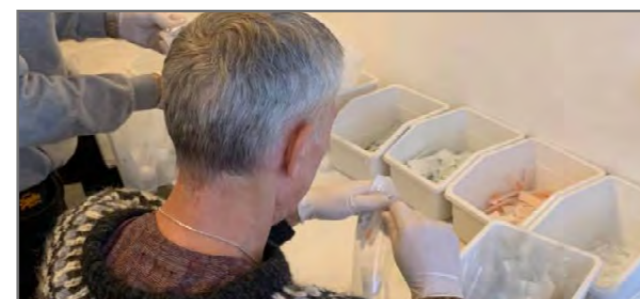
Denmark supports the UN's goal of eliminating Hepatitis C and has made access to injection equipment a legal right. However, in practice, effective initiatives to promote this right and eliminate Hepatitis C have been limited.

Out of the C (Ud af C'eren) is a project delivered by The Users Academy – a not-for-profit organisation committed to helping drug users. The campaign launched an anonymous postal service to provide clean injecting equipment to substance users. The package also includes materials with information about the campaign, prevention of contagion and the right to treatment for Hepatitis C.

The packaging work is done by a group of users who benefit from tax exemptions designed to support the most vulnerable groups in society. The project fosters patient empowerment in two

ways: by giving users a sense of pride through meaningful work, and by enabling substance users to reduce the spread of infection while also reminding them to get tested.

The project has had a strong impact, distributing 20,000 pieces of injection equipment around Denmark in its first three months. The beneficiaries included private individuals as well as public houses and hospital wards. Nurses working in social care at the Regional Hospital in Horsens even made an 'unboxing' video to help spread the word online.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The aim of the project is to connect with a hard-to-reach patient population, urging them to get tested, while providing clean and safe injection equipment for contagion prevention. In 2020, 51 individual citizens received materials by post, along with a further 41 institutions and public houses who are in close contact with users.

Patients have benefited in several ways: through free and anonymous access to injection kits; through information about Hepatitis C and the right to care; by advancing the goal of eliminating the disease; and by providing work for people who use drugs.

INNOVATIVE ELEMENTS OF THE PROJECT

The biggest challenge in eliminating Hepatitis in Denmark is reaching patients. Drug users sometimes live chaotic lives and may have limited faith in healthcare services. By working with the Users Academy, this initiative benefited from insights from an organisation run primarily by former drug users.

Not only do they understand the habits of drug users, the Users Academy has the respect of the target community – this is a radical shift away from using experts and key opinion leaders in an attempt to connect with drug users.

Out of the C is a new and effective way to approach potential patients while preventing contagion. It also demonstrates to decision-makers how collaborations can make an impact in hard-to-reach groups.

COLLABORATIVE ELEMENTS OF THE PROJECT

The Users Academy has established itself as a legitimate partner for the Danish healthcare system, testing dozens of users for Hepatitis C every week. When a test is positive, the NGO helps the user through their treatment. The organisation is an ideal leader for this initiative, given the trust they have built within the system and with drug users.

The partnership was underpinned by a contract which was available online, in the spirit of transparency and openness. The agreement was developed in line with Danish legislation and the relevant industry code of ethics.



explore

#ExploreForCancer

#ExploreForCancer

Advances in immunotherapy offer promising and innovative treatments for cancer. However, this is not widely known to the public. A survey in France shows that 50% of respondents do not know what immunotherapy is and only 11% associate it with oncology treatment.

#ExploreForCancer was an educational and societal approach to explaining how biopharma companies, patient associations and public research institutes work together to discover revolutionary treatments that save the lives of cancer patients. It was devised by Bristol Myers Squibb in partnership with the Curie Institute and the Corasso Association which represents head and neck cancer patients.

The initiative aimed to enhance public knowledge of immunotherapy while raising the profile of cancer patients. Short YouTube videos were used to provide insights into the daily lives of patients, to deliver information on cancer risk factors, and to explain how the immune system works.

The construction of a large dome on the Place of Saint Lazare Station was the centrepiece of the initiative. Visitors to the dome had a chance to meet patients and learn more about the disease and treatments. Every time a person passed under the dome, and for each mention of the hashtag #ExploreForCancer on social networks, BMS donated €1 to a fundamental research programme (up to €100,000).

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The initiative resulted in a €100,000 donation to the Curie Institute in support of cellular research. The total number of visits and uses of the hashtag exceeded 156,000 – significantly beyond the target.

Through the project, the patient association engaged with more than 2,000 people under the dome, giving them an opportunity to explain their condition to a new audience. Their testimonies were also featured in YouTube videos, helping to get their message to the public and validating their stories.

Along with raising the profile of patient advocates, the wider patient community may ultimately benefit from the research funded through the initiative.

INNOVATIVE ELEMENTS OF THE PROJECT

The project featured a large structure constructed at Saint Lazare Station in the heart of Paris. The dome provided an immersive experience to deepen public understanding of immunotherapy. Inside the dome, visitors could experience an interactive 3D experiment, using a virtual immune system to fight cancer.

Visitors also had the chance to meet scientists and patients; to test their knowledge through a quiz; and to take home artistic illustrations featuring cancer prevention messages. In addition to the live event, the digital content was disseminated around France via social networks.

COLLABORATIVE ELEMENTS OF THE PROJECT

The initiative was built on a novel experiment in partnership between BMS, the Curie Institute and the Corasso Association – representing private industry, public research and patients.

The partnership was presented to the public with full transparency. From the outset, these relationships were conducted in close consultation with medical regulatory, and legal teams to ensure an exemplary collaboration.



Timely treatment of lung cancer in Sweden

Lung cancer patients experience long delays both from their first symptom to hospital referral, and from referral to treatment. Symptoms of lung cancer can be diffuse and difficult to recognise. Some symptoms may be neglected due to the stigma and prejudices related to lung cancer. According to patients, several visits to primary care units are often required before they are referred for further investigations.

This project, led by the Sweden's Lung Cancer Association, was designed to improve early detection and timely treatment of the disease. It also aimed to strengthen alliances with public and private partners.

By increasing awareness of lung cancer symptoms, enabling early detection, and decreasing referral times for treatment, the project aimed to improve outcomes.

Through articles in national newspapers and televised discussions, the project highlighted gaps in lung cancer care. Dedicated members in the Lung Cancer Association have reached out to the industry, resulting in several roundtable discussions, and seminars on the topic. A website for patients and their families was created to help improve knowledge of the disease and of patient rights.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The initiative had a real and lasting impact on patient care. So far, it has resulted in a change in regional guidelines on how to handle patients with suspected lung cancer. The project activated several important stakeholders that will continue to work to improve lung cancer care in Sweden.

Early detection of lung cancer is now higher on the agenda of policymakers and service providers. It has been a priority topic for several meetings organised by authorities and other cancer patient advocacy groups.

The impact of better diagnosis and care is significant. Approximately 4,000 new lung cancer patients are diagnosed in Sweden each year and about 11,000 Swedes are living with a lung cancer diagnosis.

INNOVATIVE ELEMENTS OF THE PROJECT

The project engaged new partners to help find solutions. These included patient groups and service providers, the pharmaceutical industry, as well as technology companies such as Microsoft. The outcome of this novel collaboration is still in development, it is hoped that innovative solutions will emerge.

As one part of the project, the focus has been on driving the lung cancer agenda, focusing on better and timely care, and engaging partners to work towards a shared agenda.

COLLABORATIVE ELEMENTS OF THE PROJECT

This collaboration featured a number of sub-projects: some were delivered by the Lung Cancer Association alone; others featured industry partners; and some had several contributing stakeholders.

For example, the Zero Vision Cancer initiative is driven by regional cancer centres, public innovation funds, the pharmaceutical industry and others.

Initiating partners for "Early detection of cancer in primary care using a risk-evaluation tool with support from AI" included the Lung Cancer Association, regional cancer centres, a primary care organisation, Microsoft, and MSD



Patient Hackathon

Improving the lives of patients is the shared goal of stakeholders across the healthcare ecosystem. To co-create solutions that meet the real needs of patients, it is vital to put them in the driving seat.

The Patient Hackathon was a two-day event where up to 120 participants came together to develop innovative solutions. Contributors included patients, developers, designers, entrepreneurs, healthcare professionals and other talented people – all of whom were passionate about improving the healthcare journey of patients and their caregivers.

Together, this diverse group of people worked intensively on challenges defined by patients. Their aim was to create innovative projects, break down traditional boundaries between disciplines and organisations, build new healthcare innovation networks, and generate public attention on issues that matter to patients.

The Patient Hackathon delivered 19 rough prototypes for innovative patient-centric solutions that are applicable, replicable and scalable in healthcare contexts. Some of these advanced to healthcare incubators and have received valuable input from a selection of experts and jury members.

This collaborative approach benefited participants and, ultimately, their innovative ideas have the potential to positively affect the lives of patients.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The Patient Hackathon produced 19 innovative solutions that address the needs identified by the patient community. Each project will be further developed and will potentially benefit all relevant patients.

50 participants in the Patient Hackathon were patients or representatives of patient organisations. Participants were inspired and energised by the experience: 76% gave a satisfaction rating above 8/10.

The event had an impact beyond those present at the meeting. #PatientHackathon was the most used hashtag in Belgian healthcare on 18 February – even more popular than COVID-19 or coronavirus which were trending at the time.

INNOVATIVE ELEMENTS OF THE PROJECT

The hackathon format is increasingly used by communities and organisations to boost technology-driven innovation, collaboration and start-up inspired business and design capabilities.

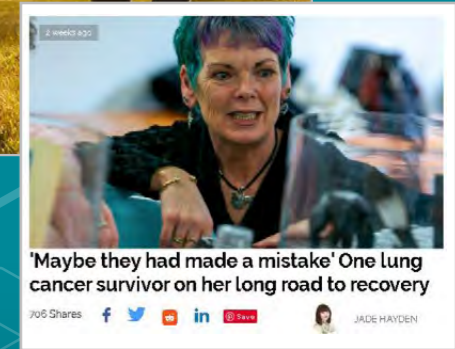
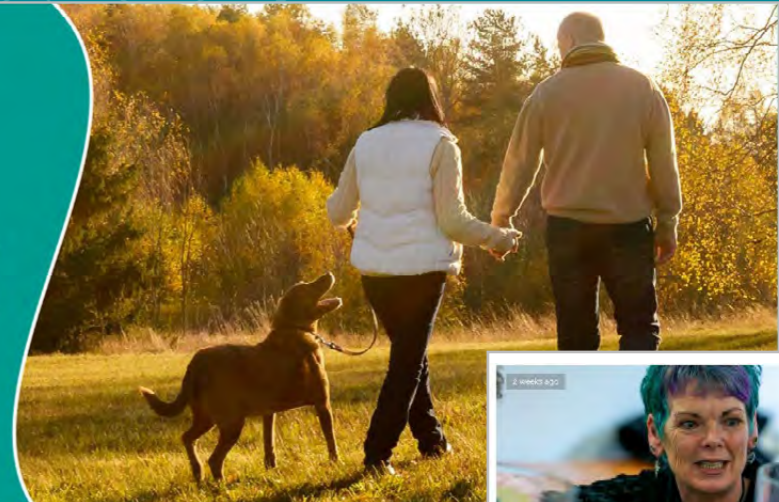
The Patient Hackathon was the very first hackathon driven by patients for patients. All challenges were developed and selected by patients, and patients were in the driving seat in each of the hackathon teams. All projects were pitched by patients to ensure that everything started and ended with the patient.

COLLABORATIVE ELEMENTS OF THE PROJECT

The Patient Hackathon was an opportunity for a unique collaboration between all stakeholders in the patient ecosystem: patients and patients organisations, caregivers, healthcare professionals, hospital management, insurers, think tanks, incubators, students, entrepreneurs and policymakers.

These stakeholders collaborated as partners or sponsors of the event, as participants and as team members, as jury members and as experts. There was no hierarchy: participants were all on the same level, united by their willingness to improve patients' lives.

Pfizer did not impose any limitations on the selection of topics, ensuring the initiative was patient-driven at all times. Partnerships with HackBelgium ensured the project had practical hackathon expertise, while collaboration with Esperity brought connections with patient networks.



Making Moments Matter

Lung cancer kills thousands of people annually in Europe, but early diagnosis and medical advances can help patients gain precious extra time. However, there is a stigma associated with lung cancer.

According to research conducted by MSD and the Marie Keating Foundation in 2018, 27% of respondents believed non-smokers with lung cancer should have their treatment prioritised over those who smoke, and 17% believe health insurers should not cover lung cancer patients who smoked. 34% agreed lung cancer patients face stigma from the public.

Making Moments Matter aimed to raise awareness, challenge stigma, give a voice to lung cancer patients, and highlight the importance of extra time for people with the disease. It was first run in Austria in collaboration with Lungenkrebsforum, a small lung cancer patient organisation, and subsequently launched in Ireland with the Marie Keating Foundation.

Making Moments Matter saw patients and families tell the stories of significant moments in their lives since being diagnosed with lung cancer or losing a loved one. Working closely with an artist who was also a cancer survivor, each patient crafted their own 'memento jar' to help tell their personal story, contributing tokens that illustrate the preciousness of these extra moments, and how much they mattered to them and their loved ones. The memento jars were shared at launch events and art galleries.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

In Ireland, a total of six patient advocates created memento jars which were unveiled at the launch event of the awareness campaign. The advocates' stories, accompanying a campaign video featuring the jars and quotes from patients, were published on the Marie Keating Foundation website.

Media coverage included 10 strong pieces covering the campaign and showcasing patient case studies, and more than 100 pieces of social media content across all platforms. The initiative helped patients by combatting stigma and putting a human face to the disease. In addition, it gave a voice to a patient community that is too often overlooked.

INNOVATIVE ELEMENTS OF THE PROJECT

The innovative element of the project was the 'memento jar' concept. This idea was developed by MSD Austria to focus on long-term survival and better quality of life of lung cancer patients. The jars with the souvenirs convey emotional patient stories without violating the privacy of the patients.

The concept was then adapted for the Irish context. The memento jars were a powerful visual depiction of the impact of lung cancer and the importance of sharing special moments with loved ones following a diagnosis. The jars, combined with a press release and speeches at the launch events, highlighted the value of making more moments matter through early diagnosis, intervention and treatment.

COLLABORATIVE ELEMENTS OF THE PROJECT

In Austria, the campaign was delivered with the support of Cake, a marketing agency. By interviewing attendees at a small meeting of Lungenkrebsforum, the campaign generated awareness of the patient group. Using a website and Facebook page, along with distributing flyers at hospitals, the patient group succeeded in attracting larger numbers to its regular meetings.

In Ireland, the project was developed in partnership with the Marie Keating Foundation with the support of Reputation Inc, a PR company. The project began with a brainstorming session between the partners to plan the campaign, before the Foundation recruited patients via a national advertising campaign. In line with best practice under the industry code, the campaign was co-sponsored by another pharmaceutical company, Bristol-Myers Squibb.



Dikaioma mou!

My rights

People diagnosed with cancer can face considerable challenges in finding information about their condition and accessing healthcare. It can be complicated to navigate the health system, understand the treatment options, and know how to ensure their patient rights are met.

Dikaioma mou (My rights) was devised by KEFI, a cancer patient organisation based in Athens. The campaign aimed to provide information on cancer patients' journeys, patient rights within the healthcare system, along with all necessary disease-related information.

The project provided a complete repository of cancer information within an easy-to-navigate webpage. From symptoms and diagnosis to insurance and patients' rights, it addresses the information needs of all cancer patients and their families. The primary focus began with lung cancer – the cancer with the highest mortality rate in Greece – and expanded to other cancer types, including breast and pancreatic cancers.

By providing valuable information, the campaign ensures patients are well informed, helping them to avoid delays in diagnosis and treatment. The initiative ensures that patients do not feel unduly anxious or alone on their journey through the healthcare system.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Dikaioma mou was launched through an interactive digital press conference, open to the public and media, ensuring patients are aware of the website. The direct benefits were measured by tracking visits to the site on a monthly basis.

In addition, a questionnaire was shared with registered members and patient groups to identify patient benefits of the information provided.

The inspiration for creating Dikaioma mou came from a series of calls, e-mails and discussions that KEFI had with Greek cancer patients who highlighted information gaps. KEFI believes that all cancer patients in Greece will be eligible to benefit from this project.

INNOVATIVE ELEMENTS OF THE PROJECT

The innovative aspect of this project lies within its novelty: there has never been a complete cancer-related information repository to address all patient needs and worries. The website provides a rounded, informative and practical patient guide in easy-to-understand language.

Beyond disease information, the project focused strongly on legal, ethical and financial elements of living with cancer. This wide-ranging approach helped to reduce the stress and logistical burdens patients face on a daily basis.

COLLABORATIVE ELEMENTS OF THE PROJECT

Dikaioma mou is an initiative run by KEFI, under the auspices of the Hellenic Society of Medical Oncology (HESMO), and with the support of MSD Greece and Bristol-Myers Squibb Greece.

Throughout the delivery of the project, KEFI worked closely with partners to depict accurately the lung cancer patient journey. In addition, industry supporters highlighted sources of high-quality information, based on requests from the patient association. Throughout the project, KEFI was in the driving seat, hosting regular meetings with all participating parties.



The REMUS report: counting the costs of musculoskeletal diseases

Musculoskeletal disorders affect more people and impose higher costs on society than other major health conditions. That is among the key findings of a report by Menon Economics, commissioned by the Norwegian Rheumatism Association with pharma company partners.

Norway spends around 255 billion kroner (€24.5bn) a year caring for people with rheumatic diseases and musculoskeletal disorders – approximately 45 billion kroner (€4.3bn) more than is spent on cancer and four times as much as spending on obesity. However, with relatively simple measures – including earlier diagnosis, cost-effective treatments, and closer follow-up, billions of kroner could be saved.

The report was commissioned with the aim of improving patient care and to highlight the socioeconomic impact of rheumatic diseases, including rheumatic arthritis, psoriatic arthritis, and ankylosing spondylitis. The project highlighted the need to develop and implement a national clinical pathway for rheumatic diseases to ensure all patients benefit from optimal, cost-effective care.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Delay in diagnosis, treatment and follow-up lead to negative outcomes for patients. Optimising care can reduce the impact of musculoskeletal diseases on individuals and society.

This report highlighted geographical differences, based on registry data. Best practice measures were proposed to reduce these observed differences, improve the referral process, and improve timelines for treatment escalation and follow-up.

More than one million of Norway's 5.2 million population are living with musculoskeletal disorders. By putting these issues in the spotlight, and communicating the findings to the media, health authorities and policymakers, the report has the potential to enhance patient outcomes.

INNOVATIVE ELEMENTS OF THE PROJECT

This extensive project builds on material from a wide range of sources. The project partners are not aware of any previous reports that offer such a comprehensive view of rheumatological conditions in Norway.

The impact of this unique report is amplified by its strong consortium representing patients, academics and industry. The project could inspire other countries to look closely at the socioeconomic cost of these conditions and explore ways to improve care.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project was initiated by the Norwegian League Against Rheumatism, a patient organisation, and delivered in cooperation with AbbVie, Pfizer and Novartis. By working together, partners achieved more than would have been possible if they had acted alone.

The pharmaceutical companies took part in the project team meetings and provided cross-functional resources and co-funding. All parties took part in the discussions and planning of the project from the beginning to end. Together, they defined the research, set the terms of the analysis, developed potential measures to address the findings, and communicated the results to decision-makers.



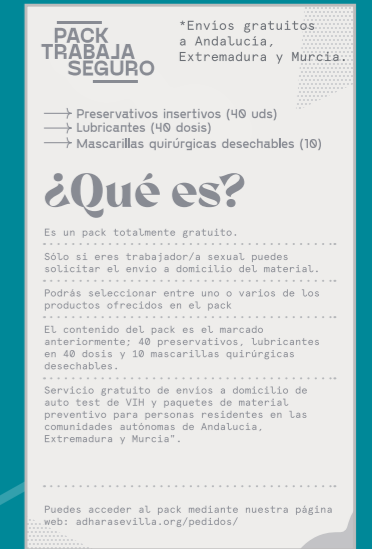
Strengthening community responses to HIV during the COVID-19 crisis

The biopsychosocial needs of people living with HIV (PLHIV) and related co-morbidities must be addressed in a holistic manner. In so doing, special attention should be paid to at-risk populations such as men who have sex with men (MSM), migrants/displaced individuals, sex workers, transgender people and women.

This is more challenging during the COVID-19 pandemic as social distancing is required to preserve the health of staff and clients of HIV services. Existing services which provide testing and preventative care, must be reimagined to ensure continuity as well as protecting public health.

This project adapted its support services, as well as the distribution of HIV treatment, and allowed service users to order self-testing kits and latex barriers online. Helplines were provided for sex workers and migrants who need legal advice, while video and online platforms were used for educational and peer services for people in detention.

The value of this modified service has been clear as the pandemic required several periods of restrictions. The goal throughout this crisis has been to reshape supports to those in need – even in the face of a pandemic.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This project is targeted at hard-to-reach populations. These include sex workers, people for whom it is difficult to keep regular appointments, those in rural areas, and people receiving PrEP who faced disruption to their treatment due to the pandemic.

The target populations, totalling approximately 9,000 people, are in the Andalusia, Extremadura and Castilla La Mancha regions. The consortium is tracking and measuring the reliability of services, capacity to deliver prompt care, and is working to address any gaps in patient needs.

INNOVATIVE ELEMENTS OF THE PROJECT

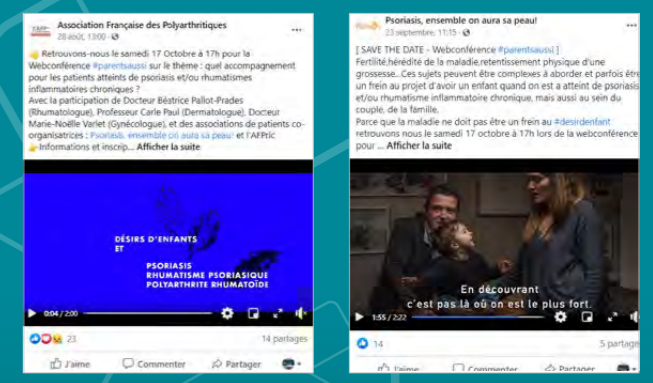
The COVID-19 pandemic demands rapid and reliable responses to continue delivering vital services to vulnerable populations. The option of ordering self-testing kits online helps to bring services to those in need. In addition, sex workers and migrants can order a box containing testing kits, preventative material and face masks delivered to their door. This is done with maximum confidentiality.

In the process, people ordering online can complete the EURO COBATEST survey which will allow the collection of epidemiological data. Users are offered the possibility of counselling and referral for care.

COLLABORATIVE ELEMENTS OF THE PROJECT

Adhara is a patient-led organisation for PLHIV and viral hepatitis which promotes education, prevention and awareness on blood-borne infections and STIs. It is well established in this field and has strong connections with key partners, including health authorities, NGOs, and international organisations such as EATG and the International Committee on the Rights of Sex Workers (ICRSW).

This project was conducted in close collaboration with Consejería de Salud de Junta de Andalucía and the city government. Collaboration agreements are in place with the three public hospitals, the STI centre, and one private hospital, as well as two industry partners.



A l'Origine

For some patients with inflammatory chronic diseases such as rheumatoid arthritis, psoriasis or psoriatic arthritis, starting a family can be difficult subject. It raises a range of personal questions, but patients rarely share these with healthcare professionals (HCPs). For their part, HCPs rarely mention delicate subjects such as patients' sexual life, family planning and fertility. However, recent therapeutic innovation makes this life project a real possibility for some patients.

The A l'Origine aims to answer the questions that couples have about starting a family, helping them to better prepare for the arrival of a baby. The programme seeks to open a dialogue on this emotional theme. It uses the real personal experiences of patients, with the support and generosity of healthcare professionals operating in different therapeutic domains (dermatology, rheumatology and gynaecology) throughout France.

Testimonies of families shared through the programme act as a conversation catalyst, enabling HCPs to open and facilitate discussions with families. The ultimate goal is to empower couples to plan for the future they want. This programme was supported through a website (www.alorigine.com) and social media campaign that served as an accelerator to engage patients on family planning. The hashtag #parentsaussi was created and widely used throughout the campaign.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

By opening the door to private and complex conversations, the programme was beneficial to patients and relatives willing to start a family. Videos were developed to ease communication for HCPs and patients.

The communication plan was built with the support of patient advocacy groups and used their networks to maximise impact in the patient community. The website recorded more than 1,200 active users in the first two months of the project, with 30% of traffic coming from Facebook. Users spent more than three minutes on the site, visiting four pages per session, suggesting strong engagement with the content.

INNOVATIVE ELEMENTS OF THE PROJECT

The programme was a creative response to the findings of a survey which showed a lack of information for women of childbearing age living with inflammatory diseases. The survey suggested that new approaches were needed to help patients and physicians engage on this sensitive topic.

Testimonies from couples provided unique insights into their journey to becoming parents. Patient associations and physicians supported by Catalpa (a communications agency) played a vital role in developing these resources. The project partners are also working on shorter video clips suitable for social media.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project benefited from the input of patient associations, physicians, a communications agency and an industry partner. The collaboration was evaluated by UCB to ensure compliance, while contracts were signed setting out the responsibilities and obligations of each party. HCPs generously offered their time free of charge. Details of the collaboration were published online.

By bringing patients and physicians together, the project ensured that its outputs would be relevant to the target audience. Together, this consortium addressed an unmet need in the patient community.



National Congresses of the Spanish Diabetes Federation

The Spanish Diabetes Federation (FEDE) has held its National Congress annually since 2017 with the support of a diverse group of partners. In its first three years, this innovative meeting for patients with diabetes was held in Madrid, Seville and Toledo, respectively.

The Congress is conceived as a space that encourages debate, collaboration and analysis of the latest advances in diabetes and its management. It aims to strengthen and unite diabetes advocates in Spain, facilitating patient empowerment.

In addition, the event also helps to build capacity among the patient advocacy community and to train attendees in good practices and adherence. In the first three years, a total of 1,500 people attended the Congresses which were broadcast live, with the contents made available online afterwards.

To make this ambitious project a reality, a large financial investment is required. Supporters provide a range of resources including financial, human resources, equipment and materials. Thanks to strong coordination and communication between partners, with the vital support of a technical secretariat, the Congress has been a success.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients are the main beneficiaries of the event. Up to 70,000 people – the number of members of FEDE and its associations – stand to benefit from the knowledge shared by those who attended and watched the event online.

Every year, the community of Congress attendees becomes a more cohesive and empowered group. Attendees leave the event inspired to launch projects and initiatives that change the lives of people living with diabetes in their communities.

Patients' views are considered in the design and planning of each edition, and their satisfaction is a key indicator of success after the event. More than 1,500 patients have benefitted directly from the Congresses.

INNOVATIVE ELEMENTS OF THE PROJECT

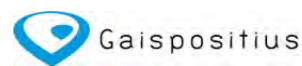
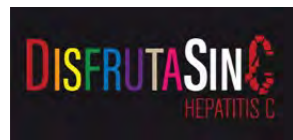
The National Congress of the Spanish Diabetes Federation is an innovative event as it is the first major diabetes patients' meeting in Spain. Never before have people with diabetes organised a meeting on this scale.

In contrast to other diabetes events which focus on diabetes in scientific terms, the FEDE National Congresses take a patient-centred view of diabetes and patient care. It is an event created by patients for patients.

COLLABORATIVE ELEMENTS OF THE PROJECT

Collaboration is intrinsic to the Spanish Diabetes Federation, and the dominant feature of the Congresses has been partnership. The event brings together non-profit entities and scientific societies, private sector companies and public administration.

The event has attracted six major industry partners, offering financial and in-kind supports which are essential to the success of the Congress. These partnerships are built on ongoing dialogue between companies and associations, ensuring that the event meets the Federation's vision of a patient-driven Congress.



Disfruta sin C

Hepatitis C is a serious viral infection. In recent years, there has been an increase in hepatitis C cases among men who have sex with men (MSM). Since early 2000, outbreaks of acute HCV infection have been reported among certain groups of MSM with HIV. This higher incidence observed in HIV-positive MSM could be explained by both a greater susceptibility to HCV infection due to biological issues and increased risk behaviours.

The aim of Disfruta sin C (Enjoy without C) is to reduce the number of new hepatitis C cases in MSM at high risk of HCV infection. The project, launched in Barcelona by Grupo de Trabajo sobre Tratamientos del VIH (gTt-VIH), Stop Sida and Gais Positius, seeks to identify and research MSM; to raise awareness of HCV; to promote sexual health and safer drug use; to test and treat those at risk. In the second phase of the project, its extension to Madrid is planned.

The project built a website which offers interactive content on the transmission, prevention and reduction of risks associated with HCV. Users can take a test to identify risky practices based on the HCV-MOSAIC risk score. The site also provides information on HCV testing in Catalonia. In addition, the organisations Stop Sida and Gais Positius offer rapid HCV testing to MSM populations who meet the screening criteria set by the local Department of Health.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project provides clear, reliable and science-based information on hepatitis C transmission in the context of chemsex, and also suggests individualised risk and harm reduction strategies, including the possibility of one-on-one consultations with health workers from the three participating organisations.

In addition, the Disfruta sin C website provides access to an online risk assessment, as well as a list of community health resources. The aim of the project is to achieve a reduction in the number of HCV infections, contributing to the WHO's goal of eliminating hepatitis C by 2030.

INNOVATIVE ELEMENTS OF THE PROJECT

This is the first campaign aimed at 'micro-elimination' of Hepatitis C in MSM in Catalonia. Its key tool is a digital resource that offers a test to identify risky practices by asking a few simple questions about sexual behaviour.

That webpage links to the Center for Epidemiological Studies on HIV/AIDS/STIs in Catalonia, so that MSM can submit an online request for a self-testing kit for HCV. Once the sample has been collected, it is sent to the reference laboratory and the results are made available online.

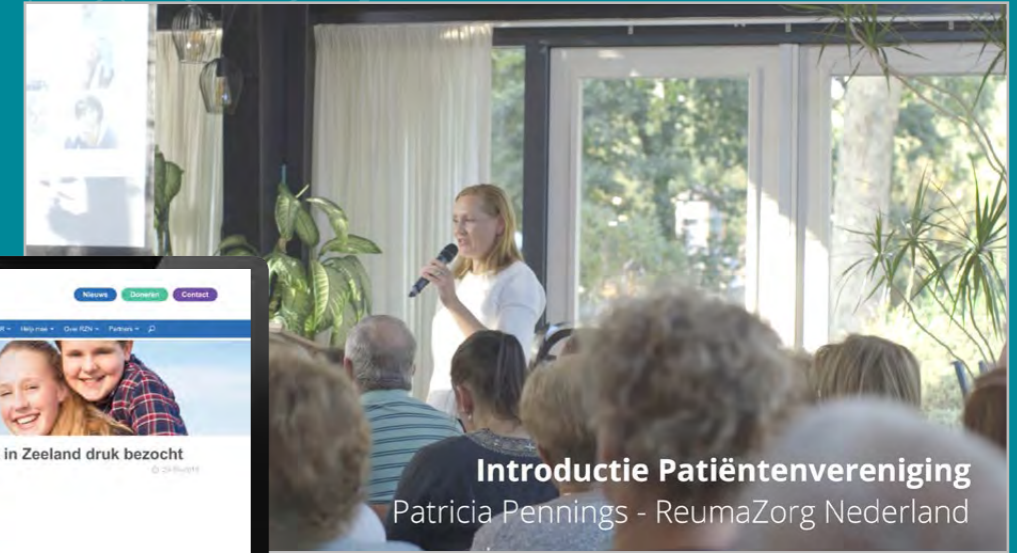
The project also includes an awareness and street education campaign in the main nightlife venues and on relevant dating apps.

COLLABORATIVE ELEMENTS OF THE PROJECT

Three organisations with extensive experience in the development of information and interventions related to hepatitis C are collaborating on the project. Coordination has been achieved through face-to-face meetings to develop website content and an activities calendar.

In addition, the project coordinates with other agents involved in public health in Catalonia and has the support of three industry partners. Disfruta sin C falls within the framework of activities included in the Plan for the Prevention and Control of Hepatitis C in Catalonia, set by the Department of Health.

Reuma Inspiratie Avond



RA Inspiration meetings

Rheumatoid arthritis (RA) is an inflammatory condition affecting the joints. RA can affect both sexes but is more common among women. It causes pain and swelling in the joints, often limiting patients' movement and leading to fatigue. In addition, it can sometimes damage other parts of the body including the skin, eyes, lungs, heart and blood vessels.

RA can have a profound impact on people's lives, but patients sometimes feel 'invisible'. They need clear, accurate information on how their condition can be treated, and how they can improve their quality of life.

The RA Inspiration meetings, organised by a professional patient communication expert, provided patients with a safe and accessible way to discuss this with one another. The seven events were a collaboration between a patient organisation, local hospitals, and industry partners. The aim was to give patients high quality information on treatments and living with RA, and to connect them with patients in their own region. Attendees were provided with information on the latest medical insights on treating RA, the role of shared decision-making, and the impact of arthritis on work. Patients often run into difficulties returning to work or applying for jobs and, as a result, they may fear discussing their condition with employers.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The evening events helped patients understand the latest treatment options for people living with rheumatoid arthritis. Patients were empowered to take an active role in their own care and to know how shared decision-making works.

At the meetings, patients benefited from the support of their fellow patients and healthcare professionals who took the time to discuss issues that matter to patients. Patients also learned about supports available to those keen to maintain their working life.

The information helps patients in their daily lives and to prepare for consultations with healthcare professionals. In total, 667 participants attended the meetings and provided positive feedback to evaluation questionnaires at the end of the evening.

INNOVATIVE ELEMENTS OF THE PROJECT

The partnerships between local hospitals, a patient organisation and pharmaceutical companies, managed by a patient communication expert, ensured a mutually beneficial relationship that delivered vital information to patients. The patient organisation had an opportunity to introduce themselves to a new group of RA patients and to deepen their connections with the hospital.

For the hospital rheumatology department, it was a chance to engage with patients in a new way, while Novartis and Pfizer deepened their knowledge about what matters to patients. The two industry supporters also strengthened their relationships with healthcare professionals and the patient organisation.

COLLABORATIVE ELEMENTS OF THE PROJECT

The events were developed collaboratively with the industry and patient partners who shaped the programme for the evening event. Hospitals were invited to host the meetings and the participation of the rheumatologist was secured.

The partnership was conducted in line with legislation on presenting information to patients. Dutch regulations on this are designed to prevent the sharing of promotional content, and only the patient relations managers of industry partners were permitted to attend. Details of the sponsorship of the evenings are included in the transparency register.

Together, partners in this project connected patients to the information they need to improve their quality of life.



Hack4Health: Lung Cancer

Lung Cancer is one of the deadliest forms of cancer – approximately 25% of patients are alive five years after their diagnosis. MSD has, through several projects, identified key challenges in the treatment of lung cancer in Norway.

However, no single organisation can solve these challenges alone: collaboration is essential as many of the barriers to better care are specific to the patient journey. To provide a forum for collaboration, a hackathon was organised, bringing together 50 participants from 22 organisations.

Attendees from the IT sector, physicians and nurses from university hospitals, tech start-ups, patient organisations, consulting companies and the pharmaceutical industry worked together for 48 hours to identify innovative and practical solutions to help lung cancer patients.

The Hackathon concluded with a pitching competition between cross-industry teams. Each team presented their idea in front of a jury which comprised representatives from the public and private sectors. The winning team was rewarded with access to 50 hours of specialised consultancy support to further develop and realise their concept.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The solutions devised during the event were highly patient-centric. One of the ideas, Fit4Fight, is now close to launch. It was developed by medical and IT professionals from four different organisations. The Fit4Fight solution focuses on pre-habilitation to prepare patients for the difficult treatment journey ahead. The concept of pre-habilitation has proven to have an effect on optimising patient outcomes and reducing waste.

Fit4Fight targets patients and their caregivers, giving it strong potential to benefit the entire population affected by lung cancer. One of the participants, who is an active member of the Norwegian Lung Cancer Group (for clinicians), is now looking into how pre-habilitation can be implemented as a routine practice nationally before a patient undergoes surgery.

INNOVATIVE ELEMENTS OF THE PROJECT

The challenges to be overcome during the event were, by their nature, not possible for a single actor to solve in isolation. Neither the industry, healthcare experts nor patients could do it alone due to the complexity of the problems.

The collaborative arena enabled by the hackathon, and the cross-functional teams it created, ensured a highly innovative environment for testing new ideas. This provided a forum to bring together completely different set of skills, competences and perspectives. The results of two intensive days will be felt for years to come.

COLLABORATIVE ELEMENTS OF THE PROJECT

The entire project was highly collaborative in nature. Unlike some projects, where one actor kick-starts the process with a predefined idea and concept, this initiative was built from scratch by a diverse group. In addition to holding several physical and digital touchpoints a week, the organisers established digital boards for transparency and also utilised communication channels such as Slack throughout the project.

While it was driven by MSD Norway and the Lung Cancer Association, five organisations were involved in the planning phase while participants from 22 organisations worked together during the event.

Even after the hackathon, the winning team – consisting of participants from four different organisations – continue to work together. Their partnership ultimately led to the development of solutions that will benefit patients and the healthcare system.



 Banques Alimentaires



Tackling food insecurity and diabetes together during and after COVID-19

Diabetes is proven to be a high-risk factor for severe forms of COVID-19. In addition, lockdowns designed to reduce the spread of COVID-19 have a negative impact on people with diabetes – reducing opportunity for exercise while exacerbating social isolation and increasing consumption of junk food.

People living in precarious situations face additional challenges during the pandemic, often struggling to maintain a balanced diet. A survey by the National Food Bank in France showed that those living on the street and/or people who struggle to address their basic needs are at additional risk of diabetes (13%) and obesity (more than 20%).

Diabetes patient advocates and food banks, supported by an industry partner, have come together to address food insecurity and type 2 diabetes. Through a three-year €500,000 project backed by Novo Nordisk, partners have devised a diabetes prevention and food education project delivered through food banks. It is both a short-term response to the COVID-19 crisis and a long-term support to prevent diabetes among at-risk populations.

Through this initiative, food banks purchased masks, hand sanitiser and fuel, enabling them to continue to provide vital services. The Diabetes Patient Federation provided screening sessions in several regions; patient experts delivered training at food banks; a traveling education truck offered advice on balanced nutrition; and volunteers prepared and delivered meals at food banks.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Precarious patients are more affected by chronic diseases such as diabetes. However, they face additional pressures during the pandemic as some services are curtailed.

The project prioritises people with special health needs by delivering fresh food, vegetables and fruit. It identifies people who have not yet been diagnosed with diabetes, helping them to access testing and care.

Food is provided for free and food banks help to break social isolation while also sharing advice on nutrition and cooking. Prevention sessions help to raise awareness and inspire healthy behaviours. Approximately 20 sessions are envisaged in the first full year of the programme, potentially benefiting hundreds of people.

INNOVATIVE ELEMENTS OF THE PROJECT

The project innovates in several ways. It is the first cooperation of this kind between food banks, a patient association, a scientific society and a healthcare company. The project combines the twin targets of tackling food insecurity and health issues.

In addition to increasing the total number of meals provided to vulnerable people, the initiative is adapting the meals to meet the unique needs of individuals. This is a change of paradigm from the traditional approach.

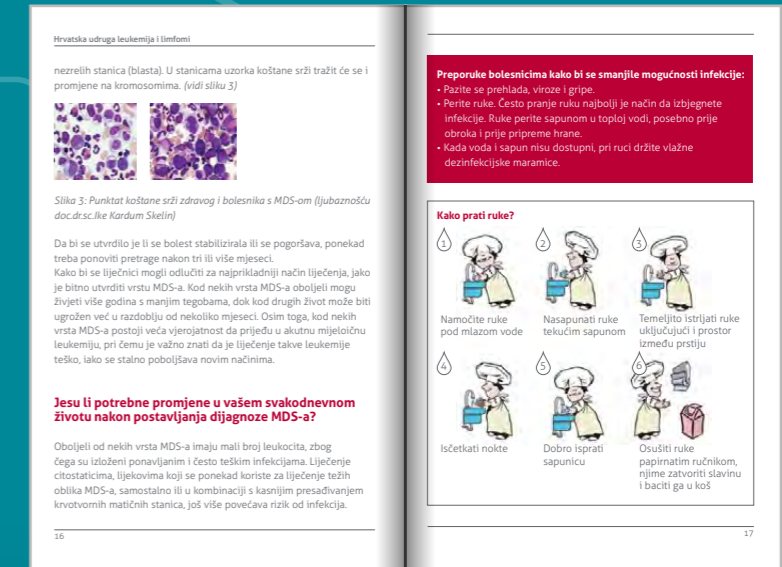
The project addresses the immediate crisis posed by the pandemic but also looks beyond the acute COVID-19 period. It is a long-term project with a three-year commitment from partners to change services for people challenged by diabetes and food insecurity.

COLLABORATIVE ELEMENTS OF THE PROJECT

From the very beginning, a patient association, a food aid NGO, a scientific society and a healthcare company have worked together to develop this project. Regular meetings take place with all actors to ensure constant alignment and transparency in the decision-making process.

A key feature of the initiative has been the active role played by all parties. The Diabetes Scientific Society has launched a working group on precarity and diabetes; patient experts from the National Diabetes Patient Federation are training food bank volunteers on this issue; and a joint publicity campaign has been launched.

Together, this diverse group of active partners is engaging the public and private sectors in the fight against diabetes, obesity and food insecurity.



Health Through Knowledge

Patients facing cancers of the blood, such as leukaemia and lymphoma, need support and information, along with timely treatment. Advice on everyday issues – such as what to eat, what to wear or whether to go out in the sun – are important to patients’ quality of life but may not be addressed by specialist doctors.

At the same time, patients, their families, and primary care staff need information on the signs and symptoms of disease, as well as diagnosis and access to treatment. To ensure acceptance and reduce stigma, it is also important that the wider public has greater awareness of these diseases.

This campaign aimed to inform society about haematological cancers through public lectures and media reports. Working with the Croatian Association of Leukaemia and Lymphomas (HULL), a series of three public events and workshops were organised to raise awareness of the disease, help patients cope with diagnosis, and educate patients about treatments.

Each event featured lectures from Croatian haematologists, psychiatrists and other experts, and were attended by 40 visitors plus 10 representatives of institutions and media. Media coverage helped to shape public opinion on these diseases and their treatment.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The direct beneficiaries of Health Through Knowledge were the 120 people who participated in lectures and workshops. More broadly, the 500 members of HULL, as well as their families and health professionals, benefited from the deeper understanding generated by the three events.

The events helped to share knowledge about these diseases, to clarify and explain treatment options, and to offer supports and information about patients’ rights. Details of clinical trials of new therapies were also addressed, along with discussions on the alignment of regulations across the EU.

Ultimately, the campaign promoted the idea that knowledge empowers patients and that patient associations are equal stakeholders in advancing treatment of cancer.

INNOVATIVE ELEMENTS OF THE PROJECT

The innovative elements of the project Health Through Knowledge lie in the awareness that information, support and cooperation can overcome numerous problems in the treatment of patients with haematological cancer.

Contrary to the outdated belief that treatment decisions are made by clinicians on behalf of their patients, the campaign presented patients as active participants in their care. Indeed, without their input, treatment cannot be successful.

The Health Through Knowledge project has managed to overcome distrust and ignorance and bring about a sustainable change in relation to haematological patients with oncology diseases. The initiative contributed to a shift in attitudes, strengthening patients’ role in their own treatment.

COLLABORATIVE ELEMENTS OF THE PROJECT

The Health Through Knowledge project brought together all the key stakeholders in the fight against these haematological diseases. Working together, healthcare professionals and patients can create a supportive environment for disease management. Empowering the patient as a partner in care is the ultimate form of collaboration in this field.

The three events focused on collaborative efforts to raise awareness of chronic myeloid leukaemia, lymphoma and myelodysplastic syndromes. Working closely with HULL, an established patient advocacy group, ensured that the patient voice was heard in the development of the project. Together, event organisers and participants helped to address the information needs of patients and enhance public knowledge.



Entrénate en Diabetes

Train Yourself in Diabetes

As diabetes is a chronic condition, it is important for people to self-manage their disease. To do this, people with diabetes need high quality information and training, along with a strong commitment to self-management. Increasing health literacy and knowledge of diabetes care among patients and their caregivers is vital to enhancing the quality of life of people living with the condition.

Entrénate en Diabetes is an educational programme for people who would like to learn more about the management of diabetes. The project offers a series of 30-second videos designed to help people improve diabetes control, learn the importance of foot and mouth care, how to detect hypoglycaemia, and how to contribute to having a healthy life with a balanced diet and physical activity.

The videos are available on YouTube and on the websites of MSD and FEDE, a leading diabetes patient organisation. The videos were developed together with different stakeholders involved in the management of diabetes type 2, including physicians and nurses. They have been reviewed by the patient organisation to ensure patients' perspectives and needs are met by the video content. In its first five months, more than 2,000 people have accessed Entrénate en Diabetes.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

In Spain, there are around 2.5 million people living with diabetes mellitus type 2. All of them can potentially benefit from this educational programme.

The impact of the programme will be measured in two ways. Quantitative measures (number of views, number of viewers reached, number of physicians prescribing this educational program) and qualitative KPIs (feedback from patients, caregivers, patient organisations and diabetes scientific societies) will be assessed.

The programme aims to empower people living with diabetes, giving them the skills that they need to manage their own health. Armed with this information and knowhow, they can take greater ownership of their disease and share responsibility for diabetes management with their clinician.

INNOVATIVE ELEMENTS OF THE PROJECT

The innovative elements of the project are its unique video training programme for people with diabetes. The resources are available 24 hours a day, 365 days per year via any digital device – smartphone, tablet or PC.

The videos are short, highly visual, and easy to understand. They cover the most important needs reported by people living with diabetes and their healthcare professionals (doctors and nurses). Topics are divided into two groups: self-care (hypoglycaemia, mouth and feet healthcare, healthy diet) and myths around the disease (carbohydrates & fruits, diabetes patients' denial and daily medication).

COLLABORATIVE ELEMENTS OF THE PROJECT

The project took a collaborative approach from the beginning, led by MSD Spain and FEDE (the Spanish Diabetes Federation). First, the partners reviewed the patient journey for people with diabetes, based on input from patients, scientific societies and healthcare professionals.

A specialised team developed the content and video scripts which were then reviewed by the patient organisation to ensure the language and visuals were appropriate. All content was reviewed by the MSD scientific team. FEDE and MSD collaborated closely in the dissemination of Entrénate en Diabetes. This ensured that the videos reached as many people as possible.

The project was reviewed by the FEDE Board of Directors and the MSD Compliance, Legal and Medical Review teams. All details of the partnership were disclosed in an annual transparency report.



Patient Academy

Patients are the reason the pharmaceutical industry continues to develop new medicines. Involving patients as equal partners throughout the product life cycle of medicines is essential.

The Patient Academy established by Vifor Pharma provides a forum for two-way dialogue between employees and patients to shape company strategy. The initiative brings together patient experts from priority therapeutic areas – iron deficiency, nephrology, and cardio-renal – to educate employees on disease burden, patients’ unmet needs, and on the patient journey.

As a result, patients are central to all company programmes from R&D and patient access to disease awareness and patient support programmes. The project is about more than simply deepening understanding or providing disease area education to staff, it is about empowering people to think about how they can better serve patients by changing their ways of working.

Patient organisations have worked with the company’s HR department to ensure that even at the recruitment stage, patient-centricity is at the forefront. This continues throughout the company, helping to inform clinical trials, patient surveys, and support programmes.

The patient voice remains crucial to the future of medical innovation, including in response to the COVID-19 pandemic. Through the Patient Academy, Vifor can ensure that whatever they co-create is for patients and by patients.

VIFOR PATIENT ACADEMY PARTNER REFERENCES

Pumping Marvellous:
"Developing the rationale, concept and seeing tangible activity around the Patient Academy is so refreshing. It needs a special culture to embrace these departures from hereditary processes. This is a "Think Tank" concept that actually achieves influence. For too long the Life Sciences industry has talked to the people they treat, now they are working with those people and building sustainable value to the most important stakeholder, the patient", Nick Hartshorne-Evans, Founder of Pumping Marvellous

Vasculitis International
"It was amazing to see to what extent our patient input was taken into account", Wil Vergoossen - GPA patient - The Netherlands

Thalassaemia International Federation (TIF)
"Understanding what our patients need is the driving force of any successful research program. By talking with researchers we hope to make the future of our children longer, brighter and painless", Panos Englezos, President of TIF and parent of a thalassaemia patient

30 SEPTEMBER 2020

VIFOR PATIENT ACADEMY PATIENT REFERENCE

"It is finally happening, and it is amazing; we are moving from being in the room to being at the table. And now we need to strengthen our voice", Sarah H., chronic kidney disease patient

30 SEPTEMBER 2020

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients participating in the Academy offer a unique and invaluable perspective to the company’s teams and clinical pipeline, making their voice heard and suggesting improvements that will better-serve patient needs. They are recognised as a primary stakeholder and a key partner.

As the Patient Academy increases disease awareness within the company, Vifor’s work is increasingly geared towards meeting the needs of patients. More than 20 patients or patient group representatives have already contributed to the initiative in areas such as heart failure, kidney disease, vasculitis and beta thalassaemia. Within one year, this number quadrupled, and the goal is to grow even further across all therapeutic areas.

INNOVATIVE ELEMENTS OF THE PROJECT

The Patient Academy stands out from other similar initiatives through its goal to shape the entire company strategy. Patient input cascades from Corporate Senior Leadership to national General Managers and beyond. Employees are trained by patients on how to develop patient-centric, innovative, and life-changing solutions, and on best practices to incorporate the patient voice along the product lifecycle.

Patients also have a key advisory role in the recruitment process, helping to shape interview questions. In addition, all new senior leaders must speak with patient representatives within their first three months at Vifor, and all participants in the company’s leadership programme will hear from patient representatives.

COLLABORATIVE ELEMENTS OF THE PROJECT

Through the Patient Academy, the company has worked with the Thalassaemia International Federation to shape an early clinical trial programme for beta thalassaemia; developed a quality-of-life survey together with heart failure patients; and held a webinar with chronic kidney disease, heart failure and ANCA vasculitis patient representatives on the impact of COVID-19. The relationship with partners complies with the EFPIA code and the company has developed a tool for patients to explain how best to engage while supporting the Academy.

To alleviate the risks associated with COVID-19 for the most vulnerable patients, Vifor established a grant programme worth CHF 200,000 – allocated on a national, regional or local level – to support initiatives that specifically address the evolving challenges faced by patients, caregivers and patient groups. The programme will continue as long as COVID-19 represents a threat to patients who are particularly at risk for infection and complication. Again, Patient Academy input was vital.



Be a Mom with MS

Multiple sclerosis (MS) affects more than 2.3 million people worldwide. It impacts twice as many women as men, with most people diagnosed between the ages of 20 and 40 years. Patients often have questions about the impact of their diagnosis on their plans to start a family.

According to the 'Women with MS 2018' report, 37% of women with MS in Europe give up on motherhood due to concerns about caring for children and how their condition might affect pregnancy. However, while MS may have an impact on reproductive health, it has no significant effect on the ability to conceive, carry a baby to term or on foetal development.

Be a Mom with MS was a Polish initiative by Merck and two major MS patient organisations: the Polish Multiple Sclerosis Society and 'MS – fight for yourself'. The project was a series of half-day workshops for MS patients who are planning a family. Hosted by patient advocates, the events aimed to provide proven medical knowledge on family planning in MS.

Participants had the opportunity to meet experts in family planning and MS, including a neurologist, a gynaecologist, a psychologist, an MS nurse and a midwife, as well as connecting with other women and mothers with MS.

More than 100 women with MS attended and 22 articles on the topic were published in local media. Recordings of the meetings were made available on patient organisations' websites. The initiative was commended by the MS International Federation.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project addressed an unmet need in the MS patient community. It offered patients a chance to learn from experts, to ask questions, and to exchange experiences with other people living with MS, including mothers.

The project initially benefited more than 100 patients, as well as their relatives, who attended events in Poznan and Warsaw. The publication of videos from the workshops ensured an even wider impact. In addition, two webinars were held on the same topic, reaching around 1,000 MS patients through live streaming on a website and Facebook.

The project also inspired the production of a series of brochures on family planning topics with the support of the Polish Multiple Sclerosis Society. The topics addressed were: 'Trying for a baby', 'I'm pregnant', and 'I'm a mom'.

INNOVATIVE ELEMENTS OF THE PROJECT

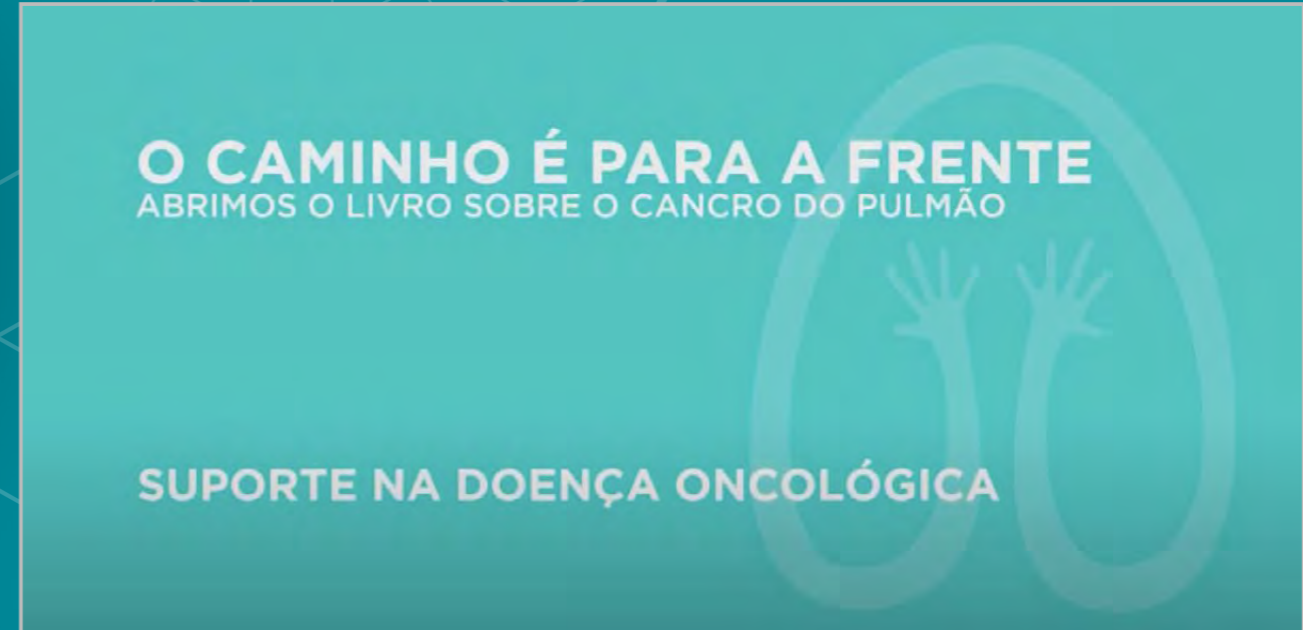
This is the first and only initiative in Poland dedicated to family planning for women with MS and their relatives. The expert panel ensured a multidisciplinary approach to sharing information from neurology and gynaecology to psychology and midwifery. The events addressed questions on available therapies and MS management during pregnancy and childbirth, as well as breastfeeding and the early months of parenthood.

The format of the workshop itself was also innovative, creating a safe environment for patients and their loved ones to voice any concerns they have regarding family planning. Bringing patients together with peers provided a unique opportunity to hear from other MS patients on their personal experiences of pregnancy and motherhood. Patient stories – and testimonials from their children – were a valuable addition to expert explanation.

COLLABORATIVE ELEMENTS OF THE PROJECT

This initiative was a collaboration between key Polish patient advocacy groups and Merck. Together, partners identified a significant unmet need for information on pregnancy and motherhood. All three organisations prepared and conducted the workshops based on insight and concerns gathered from MS patients. Collaboration between the industry, patients and a multidisciplinary group of experts was vital to the success of the workshops.

The relationship was conducted in the spirit of mutual respect, aiming to provide up-to-date information on the disease and treatment in a non-promotional way. Regular meetings and calls were organised to prepare the initiative, as well as a focus group to learn about patients' fears and questions on this topic. This also helped to prepare experts for questions they may receive during the event. Activities were in compliance with applicable laws and codes, ensuring that high-quality and compliant material was shared with the audience.



The Way Forward

Lung cancer kills more people worldwide than any other form of the disease. In Portugal, 5,800 new lung cancer patients are diagnosed annually. This diagnosis often comes when the disease is already at an advanced stage. In addition to the physical impact of having cancer, and the psychological challenge of coping with this diagnosis, many patients also suffer stigma as the disease is associated with tobacco consumption.

All of these factors, along with low health literacy in the general population, contribute to a passive attitude to the disease. This has harmful consequences and should be addressed.

This project aimed to empower lung cancer patients and their caregivers by giving them accurate information and promoting communication between patients, health professionals and patient associations. Together, partners hope to equip patients to be proactive and play a central role in the health system.

Patients and caregivers need information based on evidence. However, it is important that medical facts are explained in an accessible way. First-person video testimonies by patients can validate the experience of other patients, help to address specific obstacles they face, and give them hope for the journey ahead. Messages from healthcare professionals can also provide information, hope and support in the fight against lung cancer.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The initiative provided a reliable and up-to-date source of free information about lung cancer. It addressed the central issues and skills needed to fight the disease. Testimonials from experts and patients offer people with lung cancer the information they need to engage with the health system.

By sharing experiences between peers, the videos help patients to begin taking a more active and positive approach to their care. In a country with low health literacy levels, and a disease with a poor prognosis despite new therapeutic approaches, it is important to improve patient communication.

As a national association for lung cancer patients (PULMONALE), the project leader and industry partner were well placed to ensure these messages reach the target audience through websites, social media and TV.

INNOVATIVE ELEMENTS OF THE PROJECT

All content was created in video format with the voluntary participation of patients and health professionals. The patient organisation leading the project successfully involved patients, helping them to speak publicly about their own experience with the disease. This is rare given the stigma and shame that is reported by lung cancer patients.

The videos covered a range of topics which have not been widely addressed in the past: early diagnosis, the patient journey, active patient participation, new therapeutic approaches, clinical trials, support and palliative care.

COLLABORATIVE ELEMENTS OF THE PROJECT

The implementation of the project was achieved through a collaboration between the lung cancer association in Portugal and MSD. Together, partners analysed the topic to be addressed, the technical support required to produce videos, and a strategy for disseminating the results through the media. Partners in the project joined forces in a transparent way to advance the quality of life of these patients.

This project benefited from the participation of individuals and organisations that play a role in the journey of lung cancer patients. These include patients, caregivers, doctors, nurses and psychologists. By collaborating with a wide range of stakeholders, the initiative offered a holistic view of patient-centred lung cancer care.



Get breathless for pulmonary hypertension

Pulmonary hypertension (PH) is high blood pressure in the vessels that supply the lungs. It can cause serious damage to the heart, potentially leading to heart failure. While rare, it is more common in women and can occur at any age.

To raise awareness, the Bulgarian Society of Pulmonary Hypertension Patients organised World PH Day, together with the National Patients' Association in Bulgaria and PHA Europe. The patron of the event was the Mayor of Sofia and, in support of patients with the disease, the National Palace of Culture was lit up in in blue – the colour of the campaign.

Bulgarian musician and actor, Orlin Pavlov, joined the online campaign by broadcasting a live performance on Facebook. Several well-known actors also supported the initiative with video messages which were made available on social media channels.

Members of the public were encouraged to participate in high-energy activities at home during the lockdown in solidarity with PH patients. A social media campaign using the hashtag #BlueLips provided an opportunity to raise awareness and show support. A seminar entitled 'COVID-19 and pulmonary hypertension: Life with(out) restrictions' attracted more than 100 participants. It featured presentations from leading experts in cardiology, respiratory medicine and psychology.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The campaign offered training for PH patients in advocating for their rights and social inclusion. It helped patient groups to raise awareness, conduct research, deliver educational material and to connect with other patient advocates.

More than 120 patients with PH, along with their carers and family members, were involved in the project. A survey was developed specifically for women with PH as the disease is much more common in women (80% of patients). Over 30 different media outlets picked up on the campaign, reaching an audience of over 1 million users.

In addition, the project partners organised a fundraising campaign to support patients who must pay for portable oxygen concentrators.

INNOVATIVE ELEMENTS OF THE PROJECT

This was the first online campaign conducted by the Bulgarian Society of Pulmonary Hypertension Patients. Despite restrictions imposed due to COVID-19, the campaign found innovative ways to raise awareness by engaging high-profile figures from politics and entertainment. Turning a building blue was a creative and striking way to gain attention.

The initiative also inspired the first survey specifically focused on women with PH. The results provided a basis for a brochure offering practical advice for female patients. The handbook was also informed by expert input along with input from patients and their families. It provides essential information on the disease and its management, as well as advice on pregnancy and family planning.

COLLABORATIVE ELEMENTS OF THE PROJECT

The campaign brought together three patient organisations with the support of an industry partner (Pfizer). It benefited from the input of patients and their families, helping to make the initiative meaningful for key stakeholders.

The active participation of health professionals, including experts in respiratory medicine, cardiology, psychology, nutrition and rehabilitation ensured a fruitful and multidisciplinary collaboration. In addition to partners in the health sector, engaging a senior politician, a singer and actors helped widen the appeal of the campaign.

Project partners and health professionals were determined to create an inclusive campaign, offering practical support for people with PH who often suffer in isolation. By working together on this initiative, relationships between stakeholders were strengthened.



HPV: It's up to everyone

Approximately 75-80% of sexually active people will become infected with human papillomavirus (HPV) at some point in their life. This sexually transmitted infection is the most common among young people in Spain and causes cervical cancers. Cervical cancer is the fourth most prevalent in Spanish women between the ages of 15 and 44.

It is also responsible for 90% of anal tumours, 70% of vaginal tumours, 40% of penile and vulvar tumours, and between 5% and 70% of oropharyngeal cancers. In addition, HPV causes 100% of anogenital warts.

This campaign aimed to generate social awareness of the importance of HPV and its prevention. The project ran a street marketing campaign in the Metro of large cities (Madrid, Barcelona and Bilbao) and in urban buses (Madrid and Barcelona). A campaign also ran in the Capitol Cinema for two weeks.

In addition, simultaneous press conferences were held in Madrid and Barcelona, along with media sessions in Seville, Almeria and Malaga. A social media campaign helped to increase the reach of the message, using the hashtag #EIVPHesCosaDeTodos.

A dedicated website was developed featuring information on HPV. An estimated 2,500 HPV posters were placed in hospitals and health centres, and talks were held in universities, as well as awareness-raising meetings with experts. This multimedia campaign aimed to reach a wide cross-section of the public online and in public spaces.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The impact of the campaign was significant. It was supported by 28 medical/scientific organisations whose endorsement added credibility to the initiative. Social media reach was particularly strong: the topic was trending on Twitter where it had 4.6 million impressions.

More than 8 million people saw the campaign on the Metro, while a further 20 million were exposed to the marketing messages on buses. There were 500,000 views of the cinema campaign and thousands of unique visits to the website.

Patients benefited from the project through the widespread public awareness it created. The wider public would also benefit if measures were taken to reduce the transmission of this common virus.

INNOVATIVE ELEMENTS OF THE PROJECT

The street marketing campaign on the Metro and city buses ensured that the public encountered the messages in their daily lives. Press conferences in several major cities helped to maximise the reach of the project through a range of online and offline media.

The social media strategy was very effective, helping to connect with a large number of people on platforms commonly used by the target audience – notably Twitter and Instagram.

In addition, physical events and posters placed in hospitals and health centres, along with a website, ensured that the public was exposed to high-quality information in several online and offline spaces. This multimedia approach was highly innovative.

COLLABORATIVE ELEMENTS OF THE PROJECT

The campaign was built on a broad collaboration with a diverse group of stakeholders. The initiative was launched by MSD and included more than 20 partners.

These included medical and scientific organisations, hospitals and healthcare institutes, and cancer patient advocacy groups.



Scratch beneath the surface

Atopic dermatitis is the most common type of eczema and affects over 1.5 million people in the UK. The burden of this condition is often underestimated, and many patients find numerous aspects of their life severely impacted, including their work, sleep and relationships.

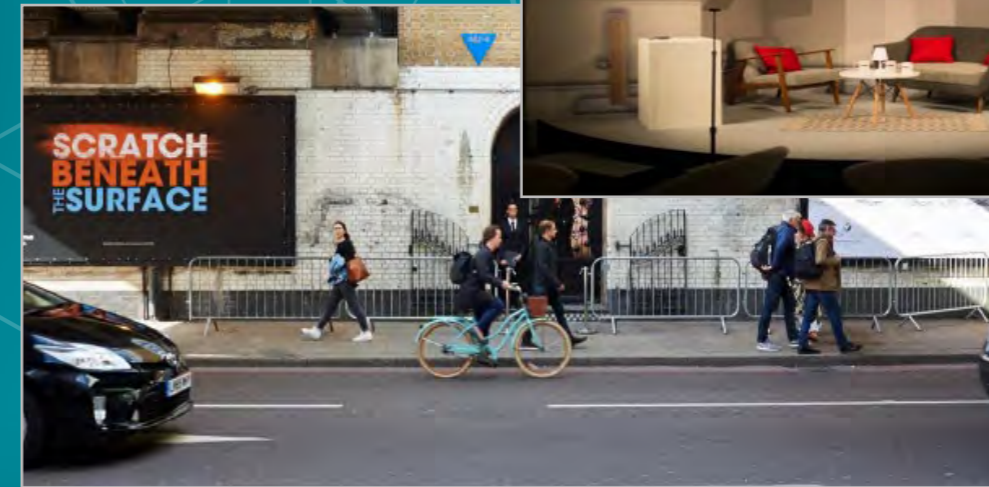
Sanofi UK and Allergy UK worked in collaboration on a national campaign with the joint aim of raising awareness of atopic dermatitis and helping people living with the condition to access the most appropriate support for them.

The campaign was rolled-out nationally with a targeted launch in London, bringing together multiple stakeholders, offering varying perspectives on the condition, and shedding light on the broader impact of atopic dermatitis.



Through social media and the campaign microsite, patients found a platform to share their experiences and access information to help them manage their condition. The microsite received over 1,400 new visitors in the first six months. Patient bloggers were a critical channel for reaching patients; there were over 500 engagements through their social media posts and content sharing.

The national media campaign, including radio interviews of healthcare professionals, had a broad reach (>3.5m) and ultimately helped to raise widespread public awareness of atopic dermatitis and facilitate a more supportive and understanding environment for patients.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients benefitted not just through the campaign outputs, but also through having the opportunity to share their own experiences and to be listened to.

A patient survey and qualitative panels allowed over a hundred people living with the condition to share their experiences and ultimately steer the direction of the campaign. The campaign provided patients with a platform to meet others facing similar challenges and to feel heard.

Allergy UK's patient case study videos, Twitter and Facebook posts, which were aimed at the atopic dermatitis community, totalled more than 2,000 views and engagement. The microsite hosted a suite of education materials including an ABC of atopic dermatitis. The national media campaign was designed to create a better understanding of the disease and facilitate a more supportive environment in the UK.

INNOVATIVE ELEMENTS OF THE PROJECT

The London launch event took attendees on an interactive, immersive journey starting at the skin's surface and then going deeper to explore how the condition can impact a patient's life. Using novel techniques such as live skin projection mapping and theatrical performances, it delivered information in a non-traditional way, with expert speakers providing a third-party perspective. The innovative skin mapping technology projected the disease onto a human body, introducing the pathophysiology of the disease.

Following this, a theatre style presentation led the audience through the "Scratch Beneath the Surface" house, where each room represented a different aspect of the disease. Actor performances based on the insight gained from the patient survey highlighted different aspects of the disease, including sleep, work and lifestyle, as well as discussing disease management.

COLLABORATIVE ELEMENTS OF THE PROJECT

This campaign was a true partnership, and the approach and content reflected this collaborative relationship throughout. Allergy UK and Sanofi worked together to create the patient survey to better understand the reality of those living with atopic dermatitis. Allergy UK shared it on their social media channels to reach the patient community.

To ensure the patient voice was reflected in every stage, Allergy UK also identified patients for the qualitative panels, the case studies videos, and speakers for the launch event.

Throughout the campaign, Sanofi and Allergy UK both shared content on their media channels to drive traffic to the campaign microsite. Allergy UK reviewed all content to ensure it reflected patient needs, and the right tone and messaging were used. Sanofi ensured the campaign complied with industry codes.



Metastatic Breast Cancer Awareness Month

Although breast cancer is frequently discussed in the Hungarian media, the focus is usually on the importance of early recognition, screening and treatment. Metastatic breast cancer (MBC) is rarely spoken about.

However, in Hungary about 30% of patients diagnosed with early-stage breast cancer face recurrence, and about 5-10% of the patients screened already have metastases. MBC is a taboo topic in Hungary. This campaign aimed to break the silence through a dedicated Metastatic Breast Cancer Awareness Month.

The campaign featured a talk-show event with approximately 500 people in the audience. Participants in the discussion included a patient, the relative of a cancer patient, an oncologist and an onco-psychologist.

The event was accompanied by a carefully planned communications campaign disseminated through the media partner, talk-show panel members, and the patient group. Through YouTube and strong media coverage, patients' personal messages reached tens of thousands of people, and the event itself generated an active social dialogue about living with metastatic breast cancer.

Together with the biggest breast cancer alliance in Hungary, and one of the country's most significant and influential online magazines, Pfizer ran a month-long awareness raising campaign to initiate a social dialogue on the topic. The aim was twofold – to send a strong and visible message to patients that they are seen and cared for, and to educate the public.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The initiative focused not only on patients but their loved ones and on wider society. By encouraging an open conversation on MBC, it aimed to enhance patients' quality of life.

Articles written by the speakers were published to highlight additional aspects of living with the disease. These pieces reached almost 64,000 people and directed readers to the website of the breast cancer association where they could find more information on MBC. In addition, the website and Facebook posts reached a further 750,000 people. More than 30,000 people watched the recorded event on YouTube.

The campaign successfully grabbed the attention of both the general public and breast cancer patients, sparking a social dialogue on a taboo topic.

INNOVATIVE ELEMENTS OF THE PROJECT

Talking about an incurable disease in a talk-show format is unusual, but also highly effective. The campaign was built on encouraging messages to and from MBC patients, families and carers, covering as many aspects of living with the disease as possible. The aim was to look further than the mere disease and grasp the human side of it from various angles.

Participants in the conversation were diverse, ensuring a lively and engaging event. They included an acrobatic diver who lives an active life after diagnosis, breast cancer survivors and family members, and experts in oncology and psychology.

COLLABORATIVE ELEMENTS OF THE PROJECT

Pfizer Hungary worked together with the biggest Hungarian breast cancer patient association – Egészség Hídja Összefogás a Mellrák Ellen – and one of the most significant and influential online magazines for women, WMN.hu.

For the event itself, partners also invited experts and representatives of patient groups or healthcare services to cover all aspects of an MBC patients' lives. Before and after the talk-show, the audience had an opportunity to meet and engage with the guest speakers and representatives of the patient association group.

Pfizer Hungary initiated the awareness campaign, but the details were developed in close collaboration with the partners. This enabled the campaign to strike the right balance between talking openly about the challenges without seeming insensitive.

Invisible signs

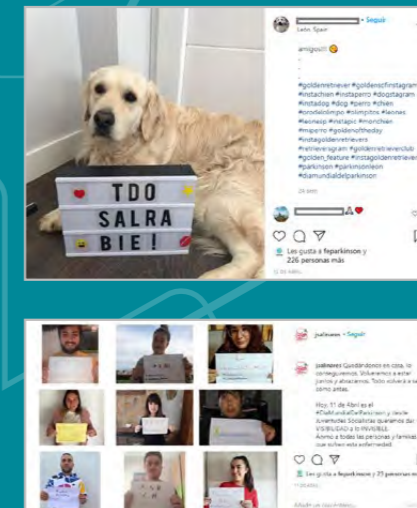
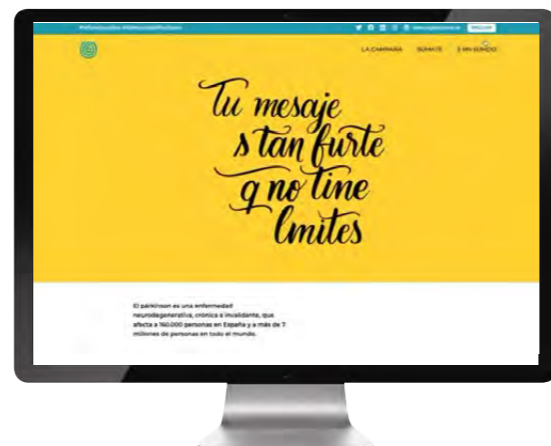
Parkinson's disease (PD) is a neurodegenerative, chronic and disabling disease that affects 160,000 people in Spain and more than 1 million in Europe. It is a progressive condition which becomes more complex over time.

Tremor is one of the best-known symptoms. However, there are many other symptoms which are often more disabling. They include sleep disorders, depression, impulse control disorder, and cognitive impairment.

These 'invisible signs' affect the quality of life of people living with PD and some of them generate communication problems – including handwriting disorders – which put the person in a vulnerable situation.

This project, developed by the Spanish Federation of Parkinson's Disease, highlighted how the disease can affect the simple daily task of writing. It aimed to capture public attention, raise awareness of symptoms of the disease, and tackle stigma. The campaign materials included three videos, posters and social media assets, toolkits, a brochure and a website in English and Spanish.

Held on World Parkinson's Disease Day, the campaign received widespread attention on social media channels (Twitter, Facebook, Instagram and LinkedIn). The hashtags #señalesinvisibles and #diamundialdelparkinson were trending topics in Spain on Parkinson's Day, helping to directly reach 288,119 people. In addition, more than 4,000 views of the campaign videos on YouTube.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

People living with Parkinson's continue to encounter barriers to social integration, due to the widespread ignorance of the disease. That is why the 'Invisible signs' aimed to give visibility to the way PD affects everyday life.

The campaign was focused on empowering people with PD and encouraging them to express themselves. 'Your message is so strong it has no limits' was a key message of the campaign.

The project was directed to the 13,000 people living with Parkinson's disease, through the 67 local Parkinson's disease associations that are members of the Spanish Federation of Parkinson's Disease (FEP). Ultimately, the campaign was shared nationally and internationally, reaching nearly 300,000 people.

INNOVATIVE ELEMENTS OF THE PROJECT

'Invisible signs' set out to attract as many partners as possible to maximise its impact. More than 100 companies, public institutions, research centres, scientific societies and patient associations removed letters from their logos on behalf of people living with PD. This was an eye-catching and unique way to convey our message on the importance of communication.

These diverse partners also shared a range of key messages designed to empower patients, remove fear, and encourage others to listen.

Finally, the COVID-19 pandemic, declared prior to the launch of the campaign, forced a complete rethink of how the project would be delivered. Actions that had been planned for several months had to be rapidly adapted to comply with the national lockdown while striving to maximise impact.

COLLABORATIVE ELEMENTS OF THE PROJECT

'Invisible Signs' was a collaborative project from the very beginning. The idea to raise awareness came from the daughter of a person with PD who reached out to FEP. Together, the idea was developed and further expanded with the support of local PD associations.

The idea was pitched to the General Assembly of the European Parkinson's Disease Association (EPDA) and its members were invited to join. The lettering studio "Vasito de Leche", run by the grandchild of a person with PD, helped to design the campaign graphics pro bono and a publicity agency also offered their services free of charge.

More than 100 companies and organisations, including six sponsors from the pharmaceutical sector, joined the 'Invisible Signs'.



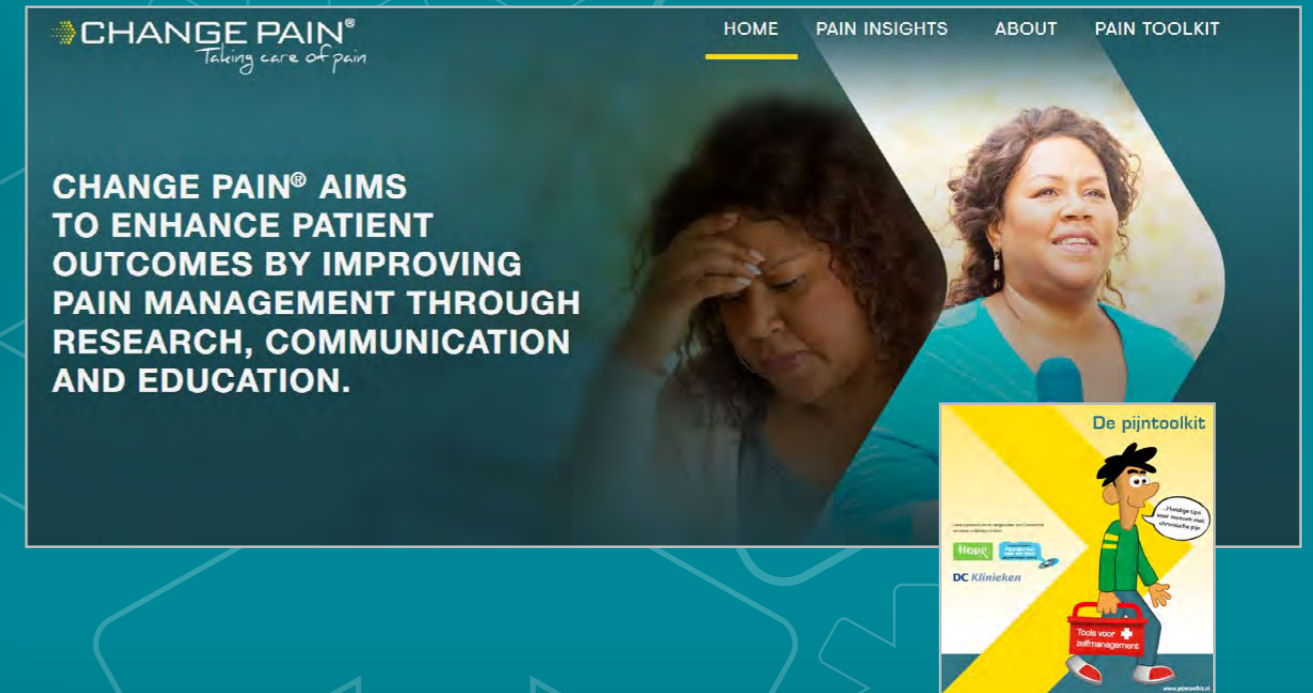
Change Pain

Research on the global burden of disease has highlighted the importance of chronic pain when considering how long patients live with disability. A 2019 patient survey revealed the stigma of chronic pain and its impact on patients seeking support from healthcare professionals – and on the treatment they receive. Despite its impact, there is substantial evidence that chronic pain management remains woefully inadequate, and many patients are affected by psychological and social factors that lead to decreased quality of life.

The CHANGE PAIN initiative was established by Grünenthal in 2009, with scientific and clinical advice from the European Pain Federation (EFIC). An updated website, www.CHANGE-PAIN.com, was launched in June 2020. In addition to educational content, it offers a wide range of practical tools for multidisciplinary pain management teams. The new site includes a dedicated section for patients with chronic pain.

Originally designed to support the education of multidisciplinary healthcare professionals, the project now provides information and practical tools for supported self-management of pain. Input from patient representatives was sought while designing the materials for patients.

The key points to address when educating patients about chronic pain include overcoming stigma and seeking support; finding a suitable healthcare professional; learning to manage pain; and reaching a point of acceptance regarding the patient's new life. This process can take several years, but it can be supported with information and by knowledgeable healthcare professionals.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

CHANGE PAIN provides helpful information and tools to support the education of patients and healthcare professionals. One example is the Pain Toolkit initiative, which was developed by Pete Moore. It is available in multiple languages and has been transformed into a patient support email programme and coping toolbox.

Until February 2021, the Pain Toolkit has reached around 1.775 patients in Europe, and it is now expected that many pain patients countries will also benefit from this programme. Pain Alliance Europe (PAE), which has more than 450,000 members, is supporting the CHANGE PAIN initiative in reaching a broader community of pain patients in Europe. In Europe, more than 150 million people suffer from chronic pain*, suggesting the need for these resources – and potential patient benefit – is significant.

INNOVATIVE ELEMENTS OF THE PROJECT

CHANGE PAIN provides concrete tools for patient education which are disseminated in a digital format. This enhances the potential impact of these materials, going beyond traditional communication methods.

For example, the content in the Pain Toolkit was transformed from a brochure into a patient support email programme and coping toolbox. Once participants have subscribed for free, they receive an email twice per month that contains useful pain self-management tips for how to manage and take back control of their pain and their lives. The information is shared using videos, infographics and pictures, as well as downloads that feature additional educational material.

COLLABORATIVE ELEMENTS OF THE PROJECT

The content of the CHANGE PAIN website was created with guidance and input from a multinational, multidisciplinary CHANGE PAIN steering committee. The Committee's members include pain specialists, general practitioners, nurses, physiotherapists, and patient representatives. In addition, the patient section of the site was developed based on valuable insights from several patient representatives. Patient organisations and healthcare professionals are helping to raise awareness of this content among patients.

CHANGE PAIN has been endorsed and supported by the European Pain Federation (EFIC) since it was established in 2009. As of 2020, it is also endorsed by the European Society of Regional Anaesthesia & Pain Therapy (ESRA) and by Pain Alliance Europe (PAE), an umbrella organisation that represents more than 450,000 pain patients in 19 countries.

*<https://www.sip-platform.eu/resources/details/sip-thematic-network-2018-joint-statement> last accessed May 2021



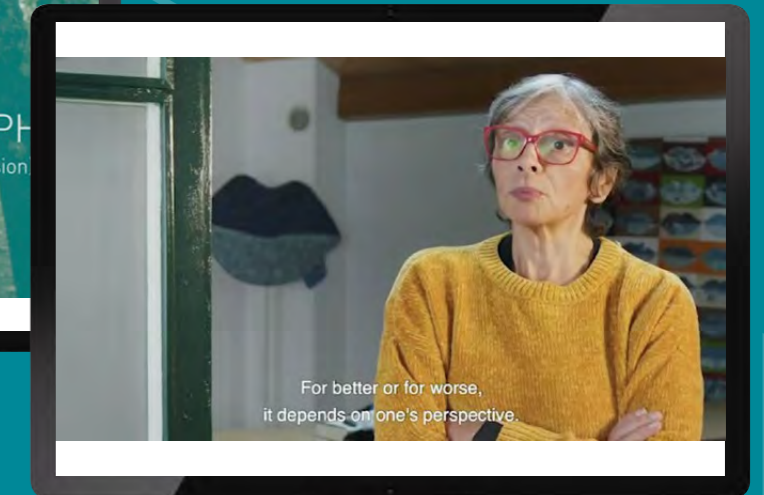
Pulmonary hypertension: a rare disease that cannot be anonymous

Pulmonary hypertension (PH) is a rare, progressive and serious condition that affects more than 25 million people worldwide. This invisible disease has a major impact on people's quality of life. It is possible to live with PH, but daily activities, such as taking care of children, working or exercising can be a huge challenge for patients.

There are a growing number of therapeutic options that provide a better quality of life. However, PH takes an average of 2.5 years to be diagnosed and, without medical intervention, the mortality rate is high. Primary care providers (PCPs) typically play a key role in diagnosing PH but high patient volumes and the lack of specificity of the disease's symptoms are a challenge.

To address this, MSD in partnership with APHP, developed a video to raise disease awareness and understanding of what it is like to live with PH. This video was created to increase knowledge of the symptoms of the disease and to illustrate how an accurate and early diagnosis can be made in specific treatment centres for this disease.

This campaign, together with a more focused preventive effort, is an important step towards improving outcomes in PH treatment in Portugal and abroad. An English-subtitled version of the video has also been produced and can be adopted by any country.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The video benefits patients by increasing awareness of the disease, reducing the time to diagnosis and curtailing disease progression.

To maximise the impact of the video, it was shared on social media, with journalists, and posted on a website with information about the disease to raise awareness. It was also disseminated in reference centres for PH, in public and private hospitals, clinics and other healthcare facilities all over the country.

The project's success will be measured by the increased number of patients referred to treatment centres and the disease stage at the time of diagnosis.

INNOVATIVE ELEMENTS OF THE PROJECT

This is the first video to actively encourage Portuguese primary care providers to diagnose PH early. The content was displayed on the screens of the hospitals or clinics and health professionals can view it on their own smartphones while they visit their LinkedIn page.

By giving them this opportunity, the campaign emphasises the simple steps healthcare professionals can take to diagnose PH. Potential patients will also be reached by watching the video while they are waiting for their appointments in the hospital or scrolling through their Facebook or Instagram pages. The initiative uses a wide range of interactive channels to ensure high impact.

COLLABORATIVE ELEMENTS OF THE PROJECT

The campaign involved the collaboration of Associação Portuguesa de Hipertensão Pulmonar (APHP), MSD Portugal and healthcare professionals from all Portuguese hospitals. Meetings between APHP and MSD Portugal were established every month to define the action plan as well as the responsibilities and duties of each partner.

This collaboration between patients' associations, healthcare professionals and pharma industry were aimed at building a project that everyone feels part of. The relationship established between these groups is based on independence and respect, to the benefit of all. The project helped to strengthen relationships which provide a platform for future collaboration in areas of shared interest.



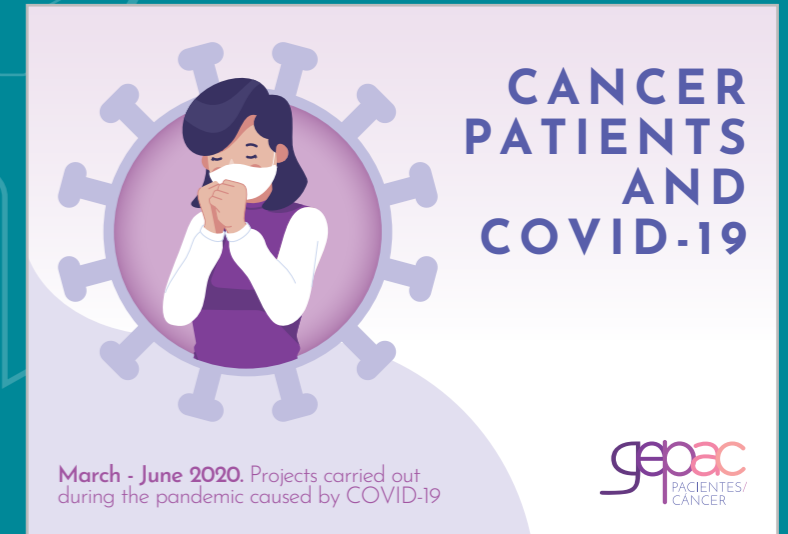
COVID 19 & Cancer

In the early stages of the SARS-CoV-2 pandemic, there was limited information about COVID-19 infection in people with cancer. Some data suggested an increased risk of complications, mainly in those receiving chemotherapy or surgery in the month leading up to infection. Despite this, the data were fuzzy, which increased concern among patients – particularly at times when face-to-face clinic appointments were discouraged.

For patients and their families, having access to medical information in easily understandable language is vital. This project, launched by the Spanish Group of Cancer Patients (GEPAC), aimed to address patient concerns regarding cancer treatment during the pandemic, prevention measures, what to do in case of COVID-19 infection, and emotional issues arising from self-isolation.

The project was endorsed by 28 scientific societies. Through a dedicated online hub, patients could find information on the disease and links to the websites of scientific societies. In addition, two webinars were organised to address doubts patients may have, and to discuss legal issues that patients face.

To tackle the emotional aspect of living with cancer during the pandemic, a team of psycho-oncologists published a guide for patients and families. This was disseminated online, and video summaries were made of each chapter. In addition, a study was conducted to understand the needs of patients.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The objective of the project was to provide patients with tools to help them rise to the challenges they face, including anxiety and stress.

To evaluate the impact of the campaign, the number of website visits, attendees and views of the webinars, downloads of the guide, and participants in the study were measured. By the end of August 2020, there had been more than 3,000 visits to the website, almost 500 attendees at the first webinar and 127 views of the second.

These initiatives ensured that patients benefited from the campaign in several ways, through practical supports and insights from experts in oncology, psychology and law.

INNOVATIVE ELEMENTS OF THE PROJECT

New technologies were used to provide cancer patients with comprehensive care during the pandemic.

A team of psycho-oncology experts, in close coordination with the organisation's medical committee, helped to address concerns that patients had about cancer, COVID-19, nutrition and physical exercise, without forgetting the emotional impact that patients have suffered during the pandemic.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project, led by GEPAC, was made possible through the collaboration of the Presidents of the Spanish Society of Medical Oncology (SEOM) and the Spanish Society for Haematology and Haemotherapy (SEHH), along with a team of psycho-oncologists and other medical professionals.

In addition, the project was endorsed by numerous scientific societies, which ensures that rigorous and reliable information was provided to patients. All formal collaborations were made possible by agreements signed with organisations and by collaboration with sponsoring entities.



We join forces, increase support

The COVID-19 pandemic and resulting lockdown have had a major impact on society. After the initial shock of a novel virus spreading around the world, it quickly became apparent that SARS-CoV-2 infection is especially dangerous for cancer patients.

It poses two specific threats: people with cancer are at elevated risk of developing severe COVID-19, and cancer treatment has been severely disrupted due to safety concerns in hospitals.

SARCOMA, the Polish association supporting people with sarcomas and melanomas, reached out to other patient organisations to develop a project that would restore patients' trust in the safety of treatment. By delivering personal protective equipment (PPE) to 94 cancer and haemo-oncology centres across Poland, it helped to make cancer care safer.

Each consignment of PPE included disposable surgical masks, FFP2 particle filtering half masks, protective suits, protective aprons and helmets. The campaign was supported by Bristol Myers Squibb, and successfully delivered essential equipment within weeks of the outbreak of the pandemic.

Patient organisations continue to educate and reassure patients about safety during their hospital visits, while oncologists urge patients not to discontinue vital treatment. Together, we are working to minimise the impact of the pandemic on vulnerable patients.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The main goal of the project was to bring PPE to cancer centres. SARCOMA, working with partners, coordinated the purchase of high-demand equipment and ensured its delivery to 94 hospitals.

This had the twin benefit of making cancer care safer for patients and staff, while also offering reassurance to patients. The campaign not only reduced the risk of infection, but also addressed the risks associated with disrupting treatment for life-threatening diseases.

INNOVATIVE ELEMENTS OF THE PROJECT

The initiative was unconventional in that it focused on meeting a sudden need for PPE and also involved an unprecedented partnership between patient groups.

SARCOMA has a strong track record in supporting people with sarcomas and melanomas. For example, the organisation runs the annual Onco-Run for charity, educates the public about prevention, and supports cancer awareness.

The insights gained from working with the cancer community helped SARCOMA to understand the value of uninterrupted access to therapies and diagnostics. Protecting vulnerable patients, and the medical staff who care for them every day, was the key priority as the pandemic unfolded.

COLLABORATIVE ELEMENTS OF THE PROJECT

'We join forces, increase support' is a joint action of five patient organisations. Initiated and led by the Sarcoma Association, partners include Carita Foundation, OnkoCafe – the Better Together Foundation, the Hope Oncological Foundation and the Polish Amazons Social Movement. The campaign was supported by Bristol Myers Squibb, ensuring that it had the resources to address an urgent unmet need in the cancer community.

Participating organisations signed donation agreements with all hospitals. Equipment for hospitals met all the standards in force in Poland, helping to ensure that patients and staff had access to high-quality PPE.



CONOCEii – game-based learning initiative for IBD

Crohn’s disease and ulcerative colitis affect more than six million people worldwide and the prevalence of inflammatory bowel disease (IBD) continues to grow in many countries. People with Crohn’s disease and ulcerative colitis need access to high-quality, engaging sources of information.

CONOCEii is an educational game aimed at patients and their families or friends. This innovative digital tool was developed with input from patients and healthcare professionals. It provides a game-based learning environment offering information about symptoms, lifestyle, nutrition, exercise and sexuality – answering key questions facing patients diagnosed with IBD.

To play the game, patients log in to the website with a username and select their disease (either Crohn’s disease or ulcerative colitis). They then answer a series of challenges on various topics relevant to the daily life of patients with IBD. These include diet and nutritional guidelines, travel advice, healthy lifestyle habits, physical exercise, motherhood and more.

Once patients have answered the questions correctly, they can proceed to take on more challenges. The game, supported by MSD, was co-created with a patient organisation (ACCU) and a scientific society (GETECCU).



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This project improves knowledge of IBD, supporting communication between doctors and patients. As all the content shared during the game is verified by the patients’ organisation (ACCU) and the scientific society (GETECCU), it offers a high-quality source of information.

The project empowers people living with Crohn’s disease or ulcerative colitis. By giving them knowledge of their condition, they are better equipped to manage their health and to engage with health professionals.

More than 2,500 people accessed the webpage between July 2019 and September 2020, with a total of 490 using the game-learning tool.

INNOVATIVE ELEMENTS OF THE PROJECT

CONOCEii is an innovative alternative to educating patients and families about Crohn’s disease and ulcerative colitis. It offers an easily accessible digital tool based on game-learning. It is the first such game in Spain in this disease area.

The gamified approach makes information easier to remember and requires users to complete challenges before progressing to the next step. The game is responsive and can adapt easily to various mobile devices.

COLLABORATIVE ELEMENTS OF THE PROJECT

The topics addressed in the game were selected by the patients’ organisation (ACCU) and the scientific society (GETECCU). The questions and answers were co-created by ACCU and GETECCU. All content was reviewed by the MSD scientific team with the input of the patient association.

This project was endorsed by ACCU, GETECCU, MSD Compliance, MSD Legal and MSD Medical Review. ACCU and MSD signed a framework contract establishing the nature of the relationship and the governance, all based on the principles established by EFPIA and Spanish Farmaindustria. All collaborations with GETECCU and ACCU are disclosed annually in the transparency report that is published on the company’s website.



HPV vaccination for all

The human papillomavirus (HPV) is the most common sexually transmitted infection (STI), impacting a large majority of the population. HPV is responsible for 90% of all cervical cancers but also for cancer of the vulva, vagina, penis and anus, as well as genital warts.

Despite the fact that many young girls are now vaccinated, HPV continues to circulate in the population for a number of reasons. These include a lack of information about protection and screening, stigma around STIs, and inequality of access to HPV vaccines. Boys are not yet offered vaccines in all parts of Europe.

The 'Vaccination for all' project assembled a HPV coalition to address this. It aims to sensitise political and scientific decision-makers about the need to vaccinate girls and boys, and to provide trustworthy information about HPV for the public. Activities focused in particular on the French-speaking part of Belgium where vaccine uptake rates are particularly low.

The campaign was launched in 2018, engaging with the public and politicians on HPV recommendations and reimbursement. A dedicated website was created as a centre of reference for young people, parents and health professionals. The benefits of vaccinating boys were highlighted throughout the initiative. Online and traditional media (including radio), as well as a conference, brochures, videos and pharmacy advertising, were used to reach a diverse cross-section of the population.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This long-term multi-stakeholder collaboration and multi-channel effort has contributed to an important policy change to the vaccination programme in Belgium and addressed an inequality in healthcare.

In 2019, Wallonia ordered 3.5 times more HPV vaccines than in the previous year which clearly indicates the success of the HPV coalition campaign. In addition to vaccination, the region invested €1.5 million in cervical screening, helping to reduce the burden of cervical cancer in the years ahead.

Young people, parents and healthcare professionals now have a central resource for all HPV and vaccination-related information, leading to better health literacy, proactivity in screening and, consequently, earlier diagnosis.

INNOVATIVE ELEMENTS OF THE PROJECT

The project stepped away from the traditional messaging style and format of public health awareness campaigns. Young people are best placed to reach other young people and so they were given an active role in developing material for the initiative.

Colourful posters, catchy slogans and humorous cartoons were displayed at original spots such as toilet doors. This innovative thinking helped to ensure the success of the campaign. By using a long-term, multi-channel and multi-stakeholder approach, and co-creating content with the target population, the initiative took a unique approach to achieving its goal.

COLLABORATIVE ELEMENTS OF THE PROJECT

The coalition involved a large number of diverse stakeholders who were identified and brought together in dialogue by O'YES, the leading patient organisation. Patient representatives and academic experts jointly built a multi-layer action plan, with close involvement of the target population. By assembling a strong coalition, their voices were heard by authorities and politicians.

Materials were developed in close collaboration with young people, for young people. In addition to the active coalition members, other parties were identified to help in disseminating the messages and distributing materials through diverse channels, such as pharmacies and local city councils.

Central to this coalition was the partnership between MSD and O'YES which was established through approximately 15 face-to-face meetings ongoing contacts.

VIH-DA.pt



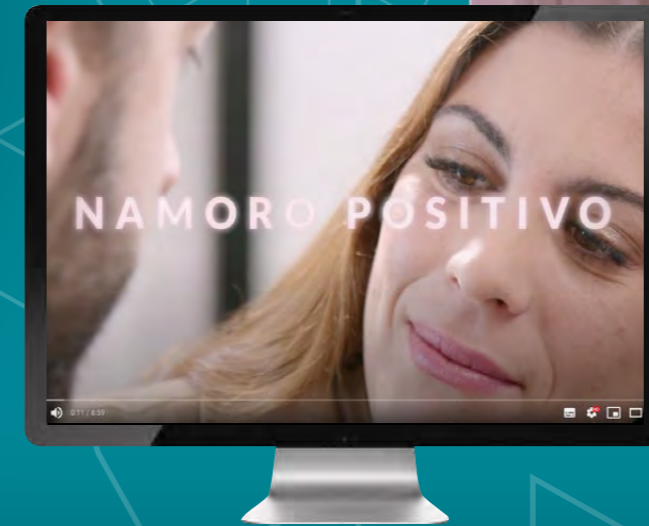
VIHDA.pt

Portugal has among the highest rates of HIV in Europe. While the number of infections has fallen over the past decade, almost 1,000 new cases were recorded in 2018. More than half of those affected were late presenters.

Investment in preventative and risk reduction measures, along with screening and education, are essential. There is strong evidence that health literacy contributes not only to health promotion and disease prevention, but also to the effectiveness and efficiency of health services.

VIHDA.pt aims to promote health literacy, allowing people to make informed health decisions. The goal is to support Portugal in hitting national HIV targets and helping Europe to become HIV-free. In particular, the campaign targets the new generation of adolescents and young adults, providing them with information on HIV, its prevention and its treatment.

The content of the VIHDA.pt portal was developed by a HIV patients' association, medical societies and MSD. Material was designed to empower people living with HIV by dispelling myths and providing high-quality information; to share the message that 'undetectable = untransmittable' and support adherence to treatment; and to develop the website into a valued resource for the community.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The website is a repository of information about HIV infection, including diagnosis and screening, and how to live with HIV. It is an easily accessible resource that can address questions that patients or the public may have. Approximately 40,000 people in Portugal are living with HIV.

The project aims to reach this community but also to educate the general population about the disease. In this way, it helps to improve understanding, address stigma and reduce discrimination.

In addition to answering frequently asked questions, it features explanatory videos on topics including sexuality, family planning and medication.

INNOVATIVE ELEMENTS OF THE PROJECT

The portal aims to advance health literacy and medical education by meeting the needs identified by stakeholders. Several aspects of the project make it unique in comparison to existing alternatives in Portugal. The site is designed with two distinct areas: an open access area directed to the general population and a restricted area for healthcare professionals.

The site offers a complete range of information organised in four sections: About HIV, Living with HIV, HIV & The Body, and Clinical Practice. The video library provides a repository of short informational videos developed with healthcare professionals. These 'micro learning' resources address key issues in HIV.

COLLABORATIVE ELEMENTS OF THE PROJECT

VIHDA.pt is a project that engages several stakeholders in a joint effort to build a platform for health literacy. It has the support of three scientific societies and five patient organisations. The HCPs involved build and review content that they consider important for their HIV patients. The seal of medical societies scientifically endorsed the portal.

At MSD, several internal departments work together to ensure the success of this initiative. With a broad coalition of external partners, a valuable and credible resource has been developed which continues to serve the needs of the HIV community and the wider public. These partnerships are conducted in a transparent manner at all times.



Sveučilište u Zagrebu

International Council of the Patient Ombudsman

Person-centred and evidence-based medicine play an important role in ensuring optimal treatment outcomes. While Europe's healthcare systems are diverse, all are covered by the European Charter on Patients' Rights.

The European Patient Ombudsman Award for best practice in medicine is a project with a mission to promote patient rights, reduce complaints, and build confidence in the doctor-patient relationship by supporting effective communication. The project aims to enhance active patient participation in diagnostic and therapeutic decisions.

Potential winners of the award are encouraged to strive for patient satisfaction and safety, with applications to be evaluated by experts. Partners from academia, professional societies and international organisations work together to manage and communicate about the initiative.

The process is led by the International Council of the Patient Ombudsman with partners including the Croatian Association for the Promotion of Patients' Rights; the University of Split School of Medicine, Croatia; the University of Zagreb, Croatia; University of Padova, Italy; and Cochrane evidence-based medicine. Together, this diverse coalition manages the project and evaluates all candidates and their work, before awarding this prestigious honour.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project brings multiple potential benefits to patients by supporting person-oriented medicine. This initiative involves a significant number of patients, particularly those who avail of specialised hospital care. In particular, the focus is on inpatient care rather than outpatient or community-based services.

Each EU Member State has more than 100 professional medical societies covering various specialties. Each of these provides expert care to thousands of patients every year – all of whom could benefit from evidence-based patient-centred care.

INNOVATIVE ELEMENTS OF THE PROJECT

Inspired by the increase in patient complaints regarding healthcare providers over the last year, this project aims to improve products/ services offered to patients. Medical innovation can include increasing knowledge and transforming existing business models to better serve changing needs.

Big data and other technologies are fuelling a wave of health innovations around the world but the role of human rights in modern medicine is still not recognised to a satisfactory level.

This project focuses on the disconnect between human rights and the provision of patient care.

COLLABORATIVE ELEMENTS OF THE PROJECT

This multi-partner project brought together NGOs, international organisations, and universities in Croatia and Italy to enhance the integration of patient rights into medical care. Together, partners mobilised the medical community, the human rights community, patient advocates, and other stakeholders.

Transparency was at the heart of these partnerships. The initiative is listed on the EU transparency register and is committed to the highest standards of openness. All partners work to advance the objectives of the project for the good of patients and the health system.



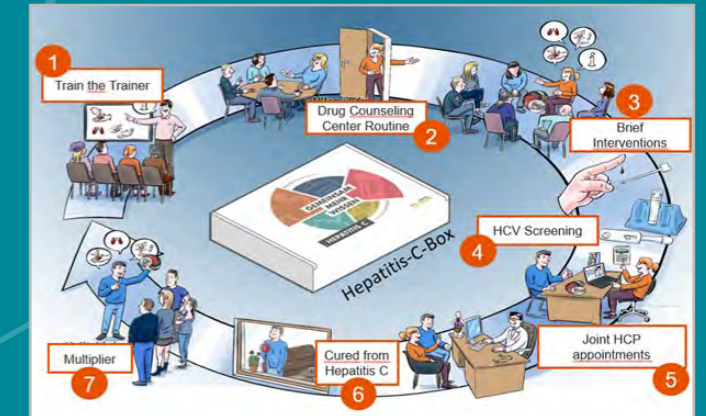
Hepatitis-C Awareness: Shared Knowledge is better knowledge

Hepatitis C is a liver disease caused by the hepatitis C virus (HCV) which can cause both acute and chronic illness. Although infection can lead to liver cancer, it is now curable if diagnosed early. What is missing is a consistent screening strategy and greater awareness of the disease and its transmission.

Many people are unaware that they are infected because hepatitis C can be asymptomatic. In Germany, 52% of people who inject drugs (PWID) have chronic HCV. This high-risk population group is well-suited to screening programmes.

In this project, a standardised approach was developed to raise awareness and educate PWID on HCV. A central element of the approach is AbbVie Care's Hepatitis C Box, which was developed in cooperation with the association for innovative drug self-help (VISION e.V.). The Box is designed to provide high-risk groups with basic knowledge on hepatitis C, ways of transmission, and information about diagnostics as part of a brief intervention.

In Germany, more than 200 drug counselling centres are now using the Hepatitis C Box on site. Together, they are making an important contribution to the WHO HCV Elimination 2030 target. The Box has also been translated into the English language for use in Canada.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients and people at risk of hepatitis C benefit from awareness and education on HCV, routes of infection and access to testing. The benefit is measured by the number of participants and the number of interventions provided. Together with events, like health awareness days, many high-risk patients benefit from this multi-stakeholder initiative.

Within one year, almost 12,000 people can be reached by one intervention per month. As the prevalence of HCV is high, with 52% of PWIDs affected, there are potentially more than 6,000 individuals who could have a chance of being cured thanks to this intervention.

INNOVATIVE ELEMENTS OF THE PROJECT

These materials are especially developed to meet the needs of the target community. A central element of the project is a quiz, which enables interaction and discussion about ways of infection in a way everybody can follow. A board game with playing cards offers an interactive and engaging way to communicate about a vital health issue.

In addition, the Box includes posters which feature information about opportunities for testing and the potential for curing hepatitis C. A guideline on how to set up the brief intervention, a presentation, and more detailed information is provided to help counselling centres to begin using the material immediately.

COLLABORATIVE ELEMENTS OF THE PROJECT

The standardised approach to raising awareness was developed through cooperation between VISION e.V. and AbbVie. The project is also supported by JES, a national network of former and current drug users.

Together, these organisations were well-placed to understand the needs of the target community, to develop a brief intervention, and to engage with counselling centres who were essential to the success of the project. A group of experts from these centres provides feedback and shares best practices, helping to ensure the sustainability of this initiative within the community.



El Destino de Dialberto

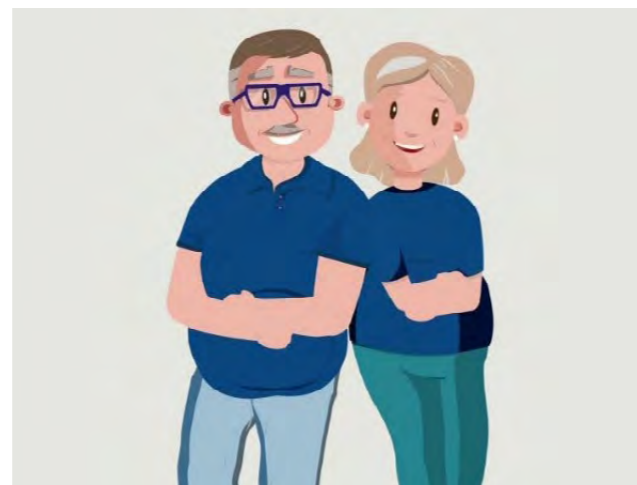
Dialberto's Destiny

The prevalence of diabetes in Spain continues to grow, resulting in 400,000 people being diagnosed each per year. More than 80% of people with type 2 diabetes suffer or have suffered a cardiovascular event, such as a myocardial infarction or stroke.

There is a lack of information regarding diabetes and its potential complications. Dialberto's Destiny is an awareness project which aims to highlight cardiovascular risks associated with type 2 diabetes. The target audiences include patients and their relatives, highlighting the role of diabetes control in managing long-term health.

The website attracted 30,000 visits while more than 500,000 people were reached via Facebook posts. The project was seen by a further 1.3 million through TV and 161,000 on YouTube. Digital promotion in shopping centres helped to extend the reach in Madrid and Barcelona.

In consultation with medical and patient advocates, the initiative launched a website featuring information on diabetes and cardiovascular disease, along with tips and recommendations for leading a healthy lifestyle. In addition, the website has an interactive game where the patient can choose between two options – one recommended, one not recommended – and see how these decisions affect the health and appearance of the on-screen character.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This campaign aims to help patients, families, caregivers and the general population to make the most appropriate decisions to improve their lifestyle. The goal is to prevent the onset of type 2 diabetes or avoid complications associated with the condition.

Thanks to the interactive game, patients can associate lifestyle habits (diet and exercise) with diabetes and cardiovascular disease. In addition, the campaign website has information on diabetes, diabetes and heart and healthy living habits adapted to all audiences, so that it can be easily understood by all ages and profiles.

In Spain there are more than 6 million people living with diabetes. This campaign is aimed to impact all of them and also other Spanish speaking patients and relatives living overseas. In total, 6,608,619 people were reached through various channels.

INNOVATIVE ELEMENTS OF THE PROJECT

The online game is the key innovative element of the project. It supported by the virtual ambassadors – a Dialberto and Dialberta – whose digital personas face a range of lifestyle and health choices.

The interactive game can be played on laptops or any mobile devices, increasing its accessibility. A multimedia campaign, including social media posts and information provided in commercial centres, ensured a highly engaging project.

COLLABORATIVE ELEMENTS OF THE PROJECT

Novo Nordisk initiated the project which earned the support and participation of 10 non-profit scientific societies and patient associations in Spain. All partnerships adhered to EFPIA and Farmaindustria codes of practice, with details of the relationship made public. These partnerships helped to shape the project and to disseminate the promotional campaign.

All the content of the website and interactive game were produced in collaboration with partners to ensure appropriate language and imagery. Partners agreed to endorse all advertising materials and supported the project on their social networks, including Facebook and Twitter.

Linha Pulmão

Lung Line

Lung cancer can cause increased levels of anxiety, depression, feelings of guilt and stigmatisation. People with lung cancer can feel lost, confused and lonely. Often patients and their loved ones do not understand what is happening and need support to face the disease, to make decisions about treatment, and to find new ways of living.

Lung Line – an information helpline – was created to answer the need to empower lung cancer patients and their families. The objective is to give accurate information and to support the person with lung cancer and their family/friends.

Information is provided on the disease and treatment, institutions or treatment centres, and the rights of patients and caregivers. This service is available between 9am and 6pm, with calls charged at local rates, whether made from fixed or mobile phone lines.

The project is delivered by a team of specialised technicians and psychologists trained in the area of oncology. They are equipped to inform callers about risk factors associated with lung cancer, to clarify symptoms, and to discuss diagnosis and staging, treatments, palliative care, prognosis, smoking cessation, oxygen therapy and screening.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Lung Line addresses an unmet need among the lung cancer patient community. It provides information and support at a crucial time in a patient’s journey. Better knowledge about their disease offers patients more confidence in making informed decisions with their healthcare professionals.

An average of 520 calls are answered per year from patients, family members and the general public. Female callers account for 60% of calls. However, while supportive information is of value to callers, precise patient benefits cannot be measured directly as our service does not monitor the people who call.

INNOVATIVE ELEMENTS OF THE PROJECT

This project is a help line that provides information on lung cancer. While this is not innovative in itself, Lung Line is novel in the sense that it empowers lung cancer patients in a new way.

The Portuguese League Against Cancer has a generic helpline open to people with all types of cancer. However, this project addresses the specific needs of lung cancer patients who are living with a disease where mortality rates are high and for whom diagnosis can trigger significant anxiety.

COLLABORATIVE ELEMENTS OF THE PROJECT

This project involves the cooperation of several professionals, including psychologists, a legal team, social support services and therapists. Lung Line is the gateway to a multitude of free services provided by the Portuguese League Against Cancer.

This service is operated by an outsourcing call centre with supervision and training by the Portuguese League Against Cancer. Staff follow a best practice manual and are provided with specific training by a pulmonologist to equip them with the knowledge to answer questions that may arise. Calls are recorded for quality and legal purposes.



FRAME

Fragility fractures are a burden on health systems across Europe. Italy currently spends €9.4 billion on fractures and is expected to spend close to €12 billion by 2030. The International Osteoporosis Foundation says Italian healthcare is facing a public health emergency, with 560,000 cases of fractures due to fragility in 2017 alone. This may be an underestimate as many vertebral fractures are only partially diagnosed or not recorded.

Fractures can cause complex disability and have an enormous impact on quality of life. During the COVID-19 emergency, hospitalisation itself carries additional risk. Fracture risks could be managed with specialist, preventative care. Approximately 75% of patients do not receive drug treatment after a fracture. Following a fragility fracture, the risk of suffering a subsequent fracture within a year increases by a factor of five. These common fractures translate into more than 700,000 days of work lost – a significant economic impact, in addition to the cost of care.

FRAME is an alliance built by 18 patient and citizen advocacy associations. Together, this diverse coalition is working to change the lives of people who suffer fragility fractures. With the support of six scientific societies and two professional associations, FRAME aims to engage with policymakers, regions, and regulatory agencies/payers; and to define treatment guidelines and an optimal care path.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

FRAME aims to improve the lives of patients by encouraging the adoption of new health policies, management models and initiatives that prevent and fight fragility fractures. A national group of policymakers, known as a parliamentary intergroup for fragility fractures, is helping to bring the voice of patients to high-level decision-making.

Seven Italian regions are developing policies to improve outcomes for patients affected by fragility fractures, a care pathway has been developed, a panel of experts has been assembled to draw up treatment guidelines, and engagement with the medicines regulator has begun.

INNOVATIVE ELEMENTS OF THE PROJECT

FRAME is an example of connected healthcare starting from the citizen's perspective. It shifts the focus from patient-centricity to patient engagement; citizens are no longer just recipients of care but are central actors in a modern model of healthcare.

The initiative is helping to break down silos between stakeholders and therapeutic areas, including in the world of patient advocacy groups. All players are participants in this active dialogue, including patients, industry, professional bodies, policymakers, scientific societies, and the Ministry for Health.

COLLABORATIVE ELEMENTS OF THE PROJECT

This initiative addresses the needs of various stakeholders by identifying common values and objectives. All members are part of a broad coalition dedicated to advancing dialogue on fragility fractures in Italy.

Based on the diverse experiences of coalition members, several key priorities were identified to underpin the spirit of the collaboration. FRAME continues to work towards involving stakeholders and engaging any necessary expertise; there is no single leader; democratic principles apply; and FRAME is not a legal entity. This approach allows the group to hold stimulating meetings, share experiences and identify areas of common interest.



In Italy, 23 million people – almost 40% of the population – suffer from at least one chronic disease. Only 50% of those strictly follow medication advice prescribed by their doctor. This can have a detrimental effect on patients’ health, increasing the risk of seizures in epilepsy patients and the development of motor symptoms in people with Parkinson’s disease. It also costs the health system an estimated €11.4 billion per year.

The lack of availability of medicines in pharmacies is among the reasons for this low rate of adherence. The SiCura programme is designed by UCB to provide fast and free support for patients in urgent need of their medicines. The service provides timely information on where to find the nearest pharmacy in which their prescribed medication is in stock.

To avail of this initiative, people call a toll-free number that is open from Monday to Saturday for 10 hours per day. They describe their situation and receive, within one hour, the address of a pharmacy where they can collect their prescribed UCB medicines. If no pharmacy currently has the product in stock, the SiCura operators liaise with local pharmacies and the UCB direct-to-pharmacy service to ensure delivering within 24 hours.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The SiCura programme ensures that all epilepsy and Parkinson’s disease patients treated with UCB products can access the medication they have been prescribed. Patients can request monthly reminders to refill their medicines – an option taken by 58% of service users.

In its first five months, the programme assisted more than 800 patients. Almost 3,000 requests were received, with one in four coming from people who had run out of medication on the day they were in contact with SiCura. Feedback from patients, doctors and stakeholders has been extremely positive, with an average satisfaction rating of 4.93 out of 5.

INNOVATIVE ELEMENTS OF THE PROJECT

SiCura is the first patient support programme to provide medicines information to patients based on availability in their locality. The management software, basing on the information provided by patients, automatically gathers data about the pharmacies located in that area, optimising the research process.

The project was initially conceived as a home delivery service, but this faced high levels of bureaucracy and delays in accessing medicines. By rethinking how the service can meet the needs of patients most efficiently, SiCura was redesigned to offer an easier and faster solution.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project is the fruit of co-creation by a team of UCB’s internal stakeholders and an external partner, PharmaPrime. This start-up has the expertise in digital projects and customer relationship management required to deliver the project.

This unconventional patient support programme involved 22 people, 13 departments and required a full year of cross-functional teamwork. Patients, healthcare professionals and the scientific community played an important role in raising awareness of SiCura among patients with epilepsy or Parkinson’s disease.

#hoysípuedo



#HoySíPuedo

Today I can

More than 2.5 million people in Spain suffer from an autoimmune disease. Seven out of ten patients are women, many of childbearing age. This can pose additional challenges. One in seven women with an inflammatory rheumatic disease says their condition affects their plans to start a family.

Lack of information often leads women with rheumatic disease to feel unprepared to make decisions about their treatment and pregnancy. Disease activity can also be a limiting factor: only 25% of women become pregnant while their disease is active rather than in remission.

Patients often express frustration with their disease on social media, focusing on things they cannot do – including having children. This campaign took a positive approach, highlighting what is possible rather than what is challenging. It began in 2018 under the name #HoySíPuedo (#TodayIcan) and evolved to #Túhaceshoysípuedo (#YoumakeTodayIcan) in 2019.

The objective was to connect with patient associations and the Spanish Society of Rheumatology around the unmet needs of women with autoimmune diseases. A key message of the campaign was that patients do not need to choose between controlling their disease and having children. The initiative prompted the creation of an expert group that devised a checklist for caring for female patients with rheumatic disease.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project generated awareness of family planning options for women with autoimmune diseases. This empowers patients to engage in shared decision-making with their health professionals.

The total number of people reached through social media, newsletters and advertising was 6.35 million of which 5.5 million were women of childbearing age. Instagram influencers helped to ensure impact among the target audience, while healthcare professionals were also reached on Twitter.

The impact of this initiative spread beyond Spain to Brazil and Portugal where the campaign was replicated. It also helped to inspire a Europe-wide campaign, featuring global tennis star Caroline Wozniacki, using the hashtag #Advantagehers.

INNOVATIVE ELEMENTS OF THE PROJECT

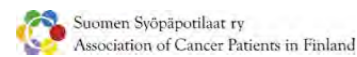
This was the first multi-stakeholder educational health project to tackle the unique unmet needs of women of childbearing age living with autoimmune diseases. Using a range of social media channels, including Instagram influencers, it reached a younger population with relatable and inspiring content.

By creating hospital-level guidelines, developing a new medical course in autoimmune diseases, establishing an expert group, and inspiring international campaigns, this initiative ensured a strong impact on the field.

COLLABORATIVE ELEMENTS OF THE PROJECT

Partners collaborated as a team throughout the project. All milestones for #HoySíPuedo were co-created with the Spanish Rheumatology Society, six patient associations and UCB. Videos and brochures were made by patients and nurses. A review committee, comprising two nurses and two physicians, provided an additional layer of review of all content.

A working group was created, with representatives from each stakeholder, to ensure all participants had input on the project. Weekly alignment meetings were held, and materials were shared using a cloud-based folder.



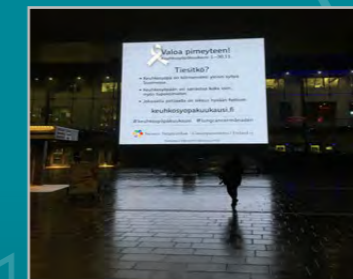
Valoa pimeyteen

Light into darkness

Lung cancer is the third most common cancer in Finland. However, despite its prevalence, there have been few developments in recent years in terms of improving treatment outcomes. Lung cancer patients feel they are not always heard within the healthcare system or in media coverage.

This campaign aimed to bring light to the darkness experienced by people with lung cancer. A white reflective ribbon was chosen as a symbol for this initiative which was launched in November – the darkest month of the year in Finland. The project builds on the metaphor of bringing a flash of brightness to patients by shining a light on the stigma they face.

The aims were to raise public awareness of lung cancer, the harmful stigma it carries and the need to improve the status quo; to call on politicians and healthcare professionals to address the need for improvement; to create traditional and social media publicity to challenge current lung cancer narratives; and to use patient insights and stories, supported by data, to make the case for action. As a result of this campaign, several articles were published in the Finnish media, including primetime TV news and leading newspapers. Numerous high-profile politicians, including government ministers, wore the white ribbon in the national parliament.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

By sharing their stories on social media, patients were able to address the perceptions that people have of lung cancer patients and highlight topics that are important to them. In addition, by engaging with Finnish politicians, the project has the potential to ignite real change and improvement for lung cancer patients' treatment outcomes.

Several patients and patient advocates were directly involved in the campaign. Some took part in a survey or attended events, while others gave interviews to the media. Patients had an opportunity to have their voice heard and to share their views on how lung cancer care can be improved.

INNOVATIVE ELEMENTS OF THE PROJECT

The project was patient-centred from the very beginning, involving patients in planning the campaign and making white ribbons by hand. The campaign name came from a lung cancer patient advocate. Grassroots patient activity was central to the initiative, along with the expertise provided by industry sponsors. This broad approach helped to connect us with politicians, health professionals and journalists.

Events were held in Helsinki and at a university hospital in the north of Finland. More than 200,000 people were given white ribbons at the public meeting in Helsinki. All of this was made possible thanks to the unique collaboration with patient advocates.

COLLABORATIVE ELEMENTS OF THE PROJECT

The campaign and its activities were planned by the Association of Cancer Patients in Finland, with two industry sponsors – MSD Finland and AstraZeneca Finland. The survey conducted during the initiative was created in collaboration with patients and patient advocates. Campaign material was created by the patient advocacy group with input and approval from all sides. The campaign benefitted greatly from the industry sponsors' networks and experience in governmental and public affairs.

The Association was primarily responsible for content creation for the campaign. All materials were reviewed by industry partners' ethical review processes as well as a patient advocate.



Fight COVID-19 & Lung Cancer

The COVID-19 pandemic has affected our lives, routines and habits. It has also had a negative impact on people with lung cancer – a patient group with a high risk of morbidity and mortality if infected with SARS-CoV-2. The combination of immunosuppression, advanced age and high prevalence of chronic lung disease and cardiovascular comorbidities, makes patients especially vulnerable.

However, the aggressive nature of lung cancer leaves no room for delay in treatment and support for patients. It is vital that people with lung cancer continue to receive the best possible medical and emotional care.

Pulmonale – the Portuguese Association Against Lung Cancer – has been working to adapt its support services for patients and caregivers. Due to safety issues arising from the pandemic, digital platforms play a key role in connecting with those in need. These platforms include the patient association website and social media channels such as Facebook and Instagram.

The campaign to fight COVID-19 & lung cancer (Luta Contra A COVID-19 & Cancro Do Pulmão) aimed to provide information about infection with SARS-CoV-2. It offers support by addressing patients' questions and concerns, aiming to empower patients to deal with the pandemic.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

By developing a dedicated Q&A about COVID-19, this initiative addressed an urgent unmet need among the lung cancer community. It provided free online psychological support and specialised telephone consultations delivered by healthcare professionals. Webinars featuring patients and physicians were organised, along with the creation of a forum for sharing information.

The patients' association leading this project is the only group supporting this vulnerable patient population. More than 5,800 new lung cancer cases are diagnosed each year in Portugal. The campaign had a strong reach on social media channels, including among the association's 5,000 Facebook followers.

INNOVATIVE ELEMENTS OF THE PROJECT

The project used a range of digital tools to support people with lung cancer at a particularly challenging time. Patients and their families had a wide range of concerns when the pandemic began, adding to their existing worries about living with an aggressive form of cancer.

Lung cancer patients should be active agents in the management of their own disease. The initiative sought to empower patients to reduce their risk of contracting COVID-19 and to shape their care.

COLLABORATIVE ELEMENTS OF THE PROJECT

This digital initiative involved patients and health professionals who voluntarily participated in the project. Novartis provided support to cover the expenses associated with the production of webinars.

The collaboration was simple and transparent, with the patient organisation retaining creative control over all material and the webinar.



Assessment of users' quality of life in CASCO programmes

Comite AntiSIDA Coruña (CASCO) was founded by people suffering from AIDS or living with HIV. Its mission is to support others affected by HIV/AIDS to regain their dignity and to overcome social exclusion.

While people with HIV/AIDS are living longer due to advances in antiretroviral therapy, quality of life issues remain a challenge. CASCO is dedicated to social integration and has always worked closely with the most disadvantaged people in society in a spirit of solidarity.

A range of programmes and interventions are offered by CASCO to advance social integration and inclusion, including for those at risk of homelessness. To determine the effectiveness of these supports, this initiative used the GENCAT scale to evaluate quality of life, taking account of the age and nationalities of users.

The results show that individualised programmes and foster homes have a significant impact on quality of life. In addition, there is a significant relationship between the perception of improved quality of life and the age and nationality of the user.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Eight dimensions of quality of life were evaluated: emotional well-being, relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. Using the GENCAT scale, these elements of quality of life were assessed in 48 people who are homeless and who applied for specific intervention programmes.

By rigorously evaluating the impact of these interventions, CASCO can continue to improve its services, ensuring its resources are used to meet the needs of people living with HIV.

INNOVATIVE ELEMENTS OF THE PROJECT

The project focused on individualised intervention programmes targeting homeless people living with HIV. There is an urgent need to address housing and social inclusion in marginalised groups.

CASCO seeks to do this in an effective and efficient manner using the resources at its disposal. Reflecting on the impact of these programmes is an important element of ensuring quality services are offered to those in need.

COLLABORATIVE ELEMENTS OF THE PROJECT

CASCO's work is conducted in collaboration with national and local authorities, including the Ministry of Health, Ministry for Social Policy and Coruña City Council.

Specific grants are used to implement the various social and health programmes evaluated by this project. These collaborations ensure a holistic approach to meeting the complex needs of vulnerable people living with HIV.



Doctor-Patient Dialogue

Patients, people with disabilities, relatives, caregivers and the organisations that represent them play an increasingly active role in Spanish society. They want to make decisions jointly with healthcare professionals and health authorities in order to advance patient care.

Doctor-Patient Dialogues is a direct response to that need. It is a platform allowing patients' voices to reach healthcare professionals and health authorities, as well as fostering partnerships.

In May 2019, the Farmaindustria Foundation and SomosPacientes.com launched a new project: Doctor-Patient Dialogue. This initiative offers first-person insights from doctors and patient representatives through video discussions on the challenges posed by particular diseases.

The format, language and tone of voice used in these exchanges offer a comprehensive, open and up-to-date insight into each disease in just a few minutes. Dialogues on breast cancer, multiple sclerosis and rheumatoid arthritis have explored issues relating to these conditions.

The initiative's objective is twofold: to give a face to those fighting against a disease and to raise awareness of the progress being made regarding diagnosis, treatment, and other health-related psychosocial issues.

The project strengthens connections between medical organisations and respective patient organisations, in turn connecting them both with the research-based industry, media platforms, and ultimately with society.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The Dialogues allow patients to access verified and up-to-date information regarding their illness; to become acquainted with their doctor's point of view; to help overcome the stigma that may still be associated with living with (often chronic) diseases; to raise awareness and understanding in society regarding the reality of the disease; and to make useful information available through a variety of communication channels.

Each Dialogue is approximately 12 minutes long, with 3-4 micro-videos that are compiled from the videos' content for circulation on social media platforms. A press release is published for each episode, with both partner organisations promoting the videos on their websites and social media channels.

INNOVATIVE ELEMENTS OF THE PROJECT

For the first time, Spain is publicly placing both doctor and patient on the same level, sharing the spotlight while they each discuss their particular concerns and points of view about a certain disease – whether they agree or not.

Moreover, the audiovisual format allows for familiar language to be used, helping the videos reach a wide audience while at the same time making them very appealing for patient organisations, medical societies, pharmaceutical manufacturers and the media. The project offers society a first-hand glimpse into the reality that Spanish patients live.

COLLABORATIVE ELEMENTS OF THE PROJECT

Each Doctor-Patient Dialogue is made with the participation of a representative from the main patient organisation for a particular disease as well as the corresponding scientific and medical societies.

To date, the project has been carried out in collaboration with the Spanish Rheumatology Society (SER) and ConArtritis; the Spanish Neurological Society (SEN) and Multiple Sclerosis Spain (EME); and the Spanish Medical Oncology Society (SEOM) and the Spanish Breast Cancer Federation (Fecma).

The Doctor-Patient Dialogues are produced with funding by the Farmaindustria Foundation and those participating in them do so 100% pro bono. Furthermore, the initiative is communicated with total transparency and in coordination with the participating organisations.

#anchiomamma



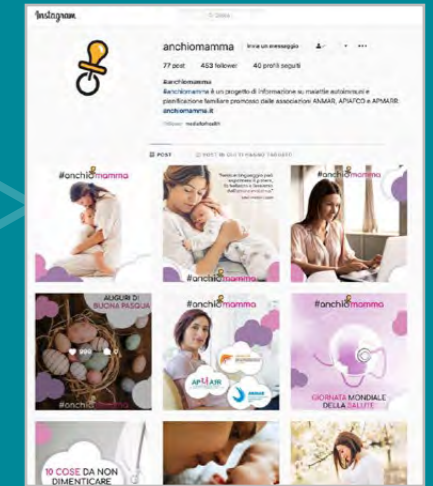
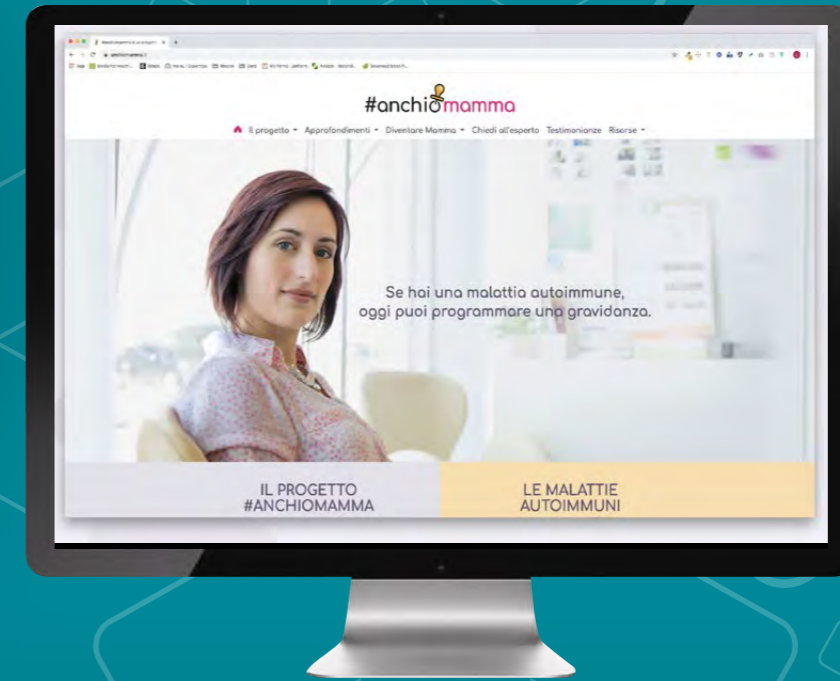
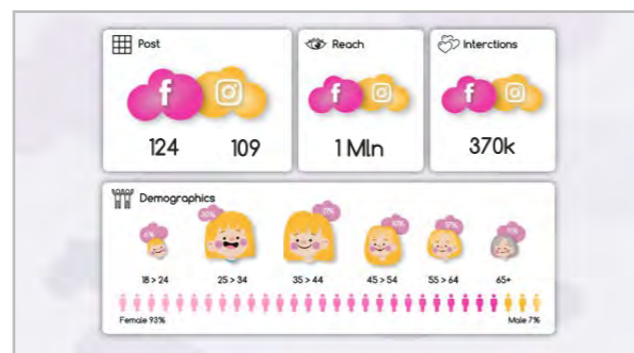
#anchiomamma

Rheumatological and dermatological diseases often affect women of child-bearing age. For this specific patient population, the burden of disease can dramatically impact family planning. Female patients suffering from rheumatic or dermatological diseases delay pregnancy and report having fewer children than they might otherwise have wished.

There is a clear need to create awareness on this topic, not only among patients and the medical community, but in the general population as well. Misconceptions on how these conditions affect motherhood must be addressed if female patients are to make informed decisions about their health and family planning options.

A digital awareness campaign, #AnchioMamma, was launched in May 2019 to create awareness among patients and the general population about motherhood and autoimmune diseases, and to provide patients with clear and complete information. It was promoted by three patient associations (ANMAR, APIAFCO and APMARR) and delivered by Media For Health, a communication agency, with the support of UCB.

Five physicians with expertise in rheumatology, dermatology and gynaecology ensured high-quality information was made available through the project website and social media channels (Instagram & Facebook). More than 100,000 people accessed the website, with social media posts reaching 600,000 people.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

In Italy, 5 million people are affected by rheumatic diseases and about 2 million people are living with psoriasis. It is estimated that 11,500 of these are female patients of childbearing age with rheumatological and dermatological conditions. There are many myths about the impact of these diseases and medications on conception and pregnancy.

The project provided reliable information to female patients and the wider population, helping to address misconceptions around motherhood and chronic inflammatory diseases. It gave patients the opportunity to ask questions of medical experts and to connect with others facing similar challenges. Empowered patients are better placed to control the impact of the disease on their daily lives.

INNOVATIVE ELEMENTS OF THE PROJECT

This was the first time that three patient associations worked together to develop a project on this topic. While their members are diverse, they share some key concerns about family planning.

Together, partners built a website to improve awareness and allow patients to seek answers from experts. By providing clear and factual information, the project supported patients in taking an active role in engaging with their physicians.

The initiative used social media channels to reach a large audience of more than 600,000 people, including many who are directly affected by chronic inflammatory conditions.

COLLABORATIVE ELEMENTS OF THE PROJECT

This awareness campaign on autoimmune diseases and family planning was initiated by three patient advocacy groups: PMARR, ANMAR and APIAFCO. To ensure a professional and targeted campaign, they sought the support of a communications agency. MediaForHealth was hired to develop a strategic communication plan and to manage the project.

The three patient groups worked closely with the agency and five physicians with expertise in rheumatology, dermatology and gynaecology. All content was discussed by this key group at regular meetings. UCB agreed to support #AnchioMamma as the main sponsor but did not take part in the decision-making process.



Lilac Week – Women’s Health Week

Every year more than 2,700 women in Croatia are diagnosed with breast cancer and more than 850 women die from it. Cervical cancer is the second most common cancer in women. It is almost 100% preventable and treatable but kills 109 women every year. Ovarian cancer is the deadliest cancer in women. Of the 425 women diagnosed every year, 319 succumb to the disease.

In light of this devastating data, Lilac Week – Women’s Health Week aims to raise awareness of the importance of prevention, timely diagnosis and treatment of cancers that affect women. Led by NISMO SAME, a patient advocacy group, the project focused on preventative tools such as free HPV testing in six hospitals and mammography. Both services were offered without GP referral.

Through a multichannel communication plan, it used social media, educational leaflets and informal gatherings of experts, patients and those who wanted to educate themselves. The project webpage features interviews with leading experts in breast cancer, ovarian cancer, cervical cancer, endometrial cancer and HPV.

The slogan of Lilac Week is ‘Put Yourself First!’ The initiative is held during the week in which World Ovarian Cancer Day takes place and is also close to Mothers’ Day. Lilac Week has run for three years and is the only initiative of its kind in Croatia.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The main benefit was increased awareness among the broader public, especially women who might be affected by these diseases. In addition, free HPV testing was offered for one week, along with free mammography for one day. A total of 836 women were tested for HPV, of which 123 were positive. The majority of women who came to get tested had not had a gynaecological examination in more than three years.

The project made a strong impact in the media in Croatia and beyond. The website had more than 3,000 visits per day while 350,000 people were reached on social media.

INNOVATIVE ELEMENTS OF THE PROJECT

One of the innovative elements was Lilac Coffee. This informal gathering of experts, including psychologists, psychiatrists, and oncological specialists, gave the public an opportunity to educate themselves, ask questions or just share experiences.

More than 100 people attended gatherings with experts. This aspect of the campaign was so innovative that other PAGs have launched similar initiatives in Croatia.

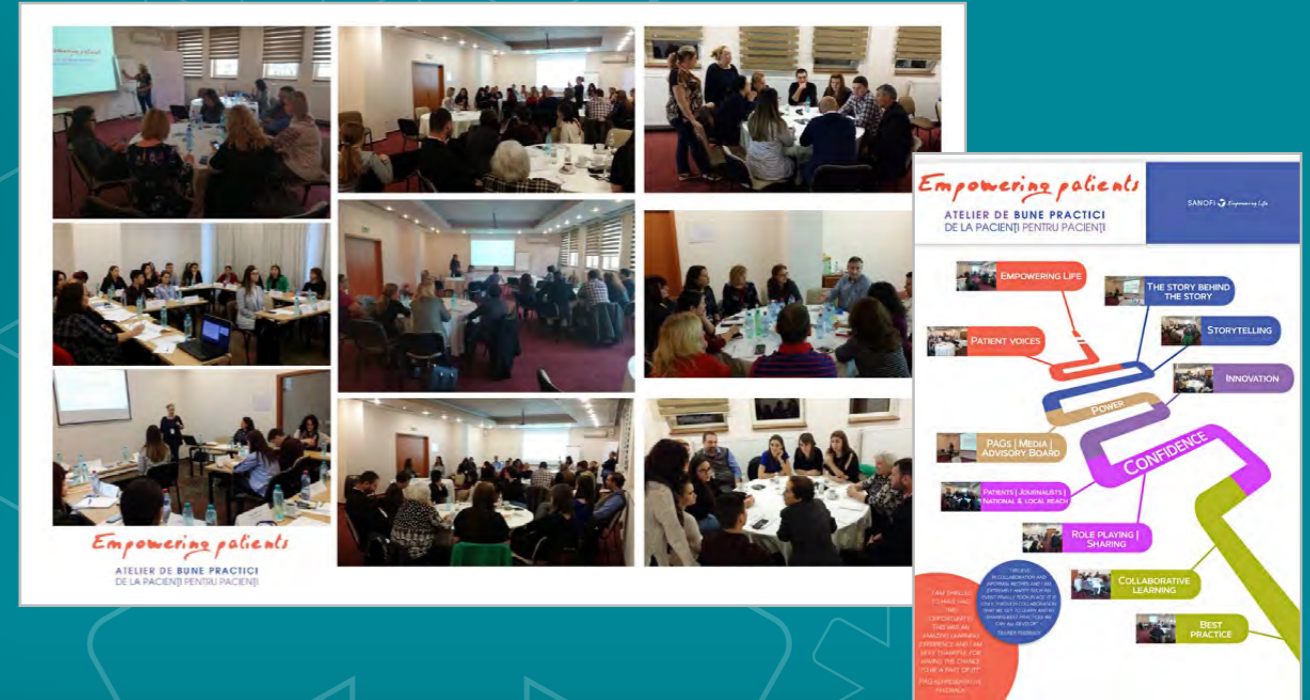
The provision of free HPV testing and mammography without referral was also highly innovative. It ensured easy access to screening services for women who may be at risk of cancer.

COLLABORATIVE ELEMENTS OF THE PROJECT

Six Croatian hospitals and three Institutes of Public Health, along with Roche Croatia, and Nismo Same collaborated to deliver the project. Partners worked towards the common goal of saving lives and preventing the effects of disease. Prompt and regular exchanges of information enabled ongoing communication between stakeholders and ensured transparency.

The project was highlighted by all partners through their websites and social media channels, ensuring a broad reach. The strong and diverse coalition made it appealing to journalists. The initiative was covered on a leading TV show, as well as on radio, online portals and in print media.

Empowering patients
ATELIER DE BUNE PRACTICI
DE LA PACIENTI PENTRU PACIENTI



Empowering Patients Programme

The Empowering Patients Programme is a platform for sharing best practices between Patient Advocacy Groups (PAGs) in Romania. It aims to build capacity among PAGs by connecting small patient associations with larger PAGs. The initiative also links PAGs of all sizes with journalists and industry experts.

Participating PAGs were selected based on their needs and development potential. The presidents of four high-profile PAGs provided training to representatives of 12 smaller PAGs during an intensive workshop programme.

At the same time, 15 young journalists from local and national media outlets attended workshops with modules delivered by experienced health reporters. Joint sessions brought PAGs and journalists together, giving the media representatives opportunities to learn about patients' needs, while PAG members gained valuable insights on how best to communicate with the public. A session on ethics and interactions with the pharmaceutical industry was offered to patients and journalists by an industry association.

The initiative led to the launch of a best practice guide for PAGs. This was developed in collaboration with the leaders of four patient groups. It will be shared with the wider patient community and with the media. Not only has the programme resulted in the developing of valuable resources, but it has provided a networking opportunity that will help to build capacity.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Capacity building among the PAG community helped to create a critical mass of empowered patients to speak on behalf of patients. Participants in the programme appreciated the opportunity to interact with the presidents of established PAGs and to learn from their vast experience.

By networking with other patient advocates and engaging with journalists, participants developed new contacts and skills that will help them to communicate their message to the public. Some of the 12 participating PAGs are umbrella organisations with multiple members, such as the Coalition of Organisations for People with Chronic Diseases which has 19 members.

INNOVATIVE ELEMENTS OF THE PROJECT

This innovative programme was the first of this kind. By using established patient advocates to train others, the project ensured the messages were delivered by trusted voices – a feature greatly appreciated by participants. Trainers had the skills and experiences that participants need to take their campaigning to the next level.

The inclusion of journalists made the project unique, while the development of a best practices guide, launched through a webinar, will add to the long-term impact of the initiative.

COLLABORATIVE ELEMENTS OF THE PROJECT

The Empowering Patients Programme is a multi-stakeholder initiative led by Sanofi's Romania Public Affairs and Communication Departments. It was launched following an Advisory Board Meeting which explored the needs of the patient community in Romania and the potential format of events that would address existing skills gap.

Four well-known patient advocacy groups delivered training to PAGs. The trainers included representatives of patients with rare diseases, autoimmune disorders and an association of mothers. The Romanian Association of International Drug Manufacturers, as well as partners from three highly regarded media outlets in Romania, helped to ensure that workshops were led by a broad-based coalition.



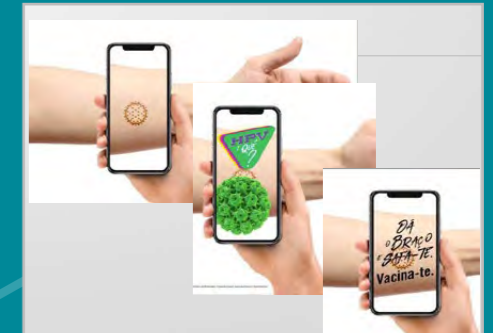
HPV e Quê?

Approximately 80% of the sexually active population – male and female – has already had contact with the human papillomavirus (HPV). There are more than 120 types of HPV which cause a range of cancers, including cancers of the cervix, vagina, vulva and penis.

As the infection can be asymptomatic, it spreads easily. Raising awareness of prevention among people aged 15 to 24 is vital. This project aimed to reach that target population – a group which has low knowledge of HPV and often reacts negatively when faced with messages on sexual health. There is also a persistent misperception that HPV is solely an issue for women.

HPV e Quê? was created in partnership with several scientific societies and patient advocates. It featured a roadshow that brought a highly technological and musical campaign to schools around Portugal. The Portuguese League Against Cancer (LPCC), with the support of a popular rapper, teachers and doctors, helped to instil positive messages about vaccination among younger people. The rapper, known as Waze, wrote a song about HPV entitled 'O Inimigo' (the enemy) which helped to give a voice to the campaign.

The project aimed to increase health literacy and knowledge of HPV, to introduce the National Vaccination Plan, and to highlight the need for boys to be included in HPV vaccination.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project reached more than 4,500 students in 30 schools. The positive impact of the campaign was measured in terms of preventive measures taken by students – either through increased adherence to vaccination or by increased knowledge about the virus and the diseases it can cause.

Wider population benefits will be reflected in the lower number of people infected with HPV in future. By promoting prevention, the campaign has the potential to reduce the risk of illness in the years ahead. From 2018 to 2019, Portugal ordered 16% more HPV vaccines. By 2019, 95% of young women were vaccinated – the highest rate for three years.

INNOVATIVE ELEMENTS OF THE PROJECT

During the roadshow, 'tattoos' were distributed to students. They contained an augmented reality (AR) marker which, when read by an app, displayed a virus molecule with important information on HPV. This gave users a realistic experience of how the virus affects the body.

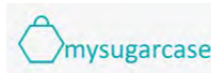
A virtual reality quiz also offered an immersive experience in which students could see the virus floating around them. Engagement was high, thanks to the innovative nature of the virtual reality (VR) quiz and the appealing prizes.

The project was also inventive in its use of direct, informal language and partnership with a musician who could speak directly to the audience through song.

COLLABORATIVE ELEMENTS OF THE PROJECT

The support of MSD, a patient group, scientific societies, the Ministry for Health, a youth organisation, a family planning association, and a digital partner ensured that the campaign had the backing of a broad coalition. Not only did this guarantee the quality of the content, it also enhanced the credibility of the campaign.

In particular, by partnering with a high-profile rapper, HPV e Quê? had the right message – and messenger – to connect with a hard-to-reach population.



#Dedoc° Voices

Dedoc° believes in the value patient advocates bring to scientific congresses. This inspired the creation of #dedoc° voices, a programme granting diabetes advocates free access to Europe’s leading diabetes conferences. The initiative provides a dedicated platform for people with diabetes, healthcare professionals, researchers and industry leaders to meet and exchange views.

The #dedoc° voices pilot programme funded 23 diabetes advocates to attend the Advanced Technologies & Treatments for Diabetes (ATTD) conference in Madrid and helped more than 50 advocates join the 2020 European Association for the Study of Diabetes (EASD) virtual event. These #dedoc° voices drove more than 15% of overall Twitter traffic on the official conference hashtag #EASD2020, at an event in which more than 20,000 people participated.

People with diabetes view the Diabetes Online Community (DOC) as a trusted source of information, turning to blogs and social media groups for information and advice. Including these key opinion leaders in conferences ensures that they are well informed and that medical experts hear their views.

The #dedoc° voices programme is run by the community, for the community. While pharma and medtech companies contribute and fund it through a non-commercial partnership agreement, there is no direct relationship between any patient advocate and industry partner. Advocates are thus fully funded, but truly independent in everything they do. Find out more at: www.dedoc.org/voices



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The #dedoc° voices programme is establishing the patient voice as an important stakeholder at scientific conferences. It has already formed a strong community of patient advocates who find a common identity and mission in reaching out to the DOC and sharing their knowledge in the true spirit of #dedoc°.

The group of 50 #dedoc° voices at EASD 2020 generated more than 2,500 tweets, Facebook posts, Instagram stories and blogposts in more than a dozen languages. By using plain language, they have helped to make the content of scientific conferences accessible to people with diabetes around the world. The hashtag #dedoc° generated more than 3.5 million Twitter impressions within one week of EASD.

INNOVATIVE ELEMENTS OF THE PROJECT

This was the first time that EASD has been so widely accessible to patient advocates. Participants with diabetes provided unprecedented first-hand information to their peers, further extending the reach of the event.

By working with EASD to partner with #Dedoc° Voices, and by broadcasting a virtual #docday° via Facebook Live, this initiative created value far beyond the actual conference. The #docnight° meeting, held on Zoom after the end of the official conference, offered opportunities to anyone who wished to meet, share ideas or just listen in. More than 200 people took part, with the meeting remaining open for five hours due to strong demand.

COLLABORATIVE ELEMENTS OF THE PROJECT

The initiative brought together conference organisers, alongside several industry supporters, and outreach partners from the diabetes online community. The programme and selection of participants was co-created with senior #dedoc° advocates from Europe and beyond. Partners also helped to craft a morning newsletter published at the start of each day of the conference.

Successful applicants to the EASD #dedoc° voices programme joined a closed Facebook group where they were welcomed by the first cohort of #dedoc° voices from ATTD in February 2020. The programme was managed through Slack, G-Drive and Zoom. Rather than rely on hard governance rules, the group was self-organised and members conducted themselves in a positive and collaborative spirit.



**Il tema di quest'anno:
PARTECIPAZIONE
DELLE ASSOCIAZIONI
PAZIENTI
AI TRIAL CLINICI**



People – not just Patients

Enabling patients to play an active role in healthcare decision-making improves the quality of health systems, making services more suited to the needs of users. *Persone Non Solo Pazienti* (PNSP) aimed to equip 16 patient advocacy groups (PAGs) with the skills needed to engage with researchers, health professionals and authorities.

Since 2015, it has provided training courses on issues ranging from communication and HTA to access to medicines and patient pathways. The initiative has published a declaration promoting the effective participation of patients in decision-making processes and, in collaboration with Bocconi University of Milan, developed recommendations on improving the involvement of PAGs.

In 2019, the initiative focused on patient participation in clinical trials. PNSP explored how patients can help to shape the design and conduct of clinical trials; surveyed PAGs to understand their needs; and published an ethical toolkit for patient involvement in trials.

The document set out principles and values that should underpin patient input in R&D. For example, PAGs can contribute to defining the profile of the therapy to be developed, the needs of patients beyond drug efficacy, and patient relevant outcomes.

The overarching goal of the project is to ensure that PAGs' voices are heard and understood by institutional and scientific communities. The outcomes of the initiative were shared widely through its diverse network of partners.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project gauged satisfaction through regular surveys of PAGs. The results showed the value of PNSP to patient advocates. By bringing patient insights to decision-making processes and clinical trial design, the quality of research and service delivery can be enhanced to ensure they meet patients' needs.

The project has grown year on year, retaining the support of 16 PAGs, as well as the funding and resources needed to deliver its work. Patient groups active in the fields of oncology, haematology, neurology, rheumatology and genetic diseases are direct beneficiaries of the initiative, but the wider community also benefits from the development of a more patient-centred system.

INNOVATIVE ELEMENTS OF THE PROJECT

The patient community often speaks with different voices across a variety of disease areas. PNSP has empowered PAGs representing patients with various pathologies to have 'one voice' directed towards the scientific community and institutions.

'The Declaration of Principles & Values – an Ethical Toolkit for the Participation of PAGs in Clinical Trials', is one of the first sets of guidelines of its kind in Europe. It provides patient-led policy guidance for stakeholders and is a valuable advocacy tool for patient representatives.

COLLABORATIVE ELEMENTS OF THE PROJECT

Collaboration is at the core of the PNSP project. Since 2015, the open and active cooperation of 16 PAGs has been the driving force behind the initiative. The Roche Foundation has been a leading partner from the beginning, with Roche Italia serving as an industry partner. Italy's National Research Council (CNR) has been a key scientific partner since 2019.

Together, this group comes together to plan activities, choosing a different theme every year. Depending on the focus of each annual campaign, additional experts are invited to contribute their knowledge and expertise. The Roche Foundation guarantees transparency regarding the collaboration with PAGs.



MuSC

Infection with SARS-CoV-2 poses significant challenges for the therapeutic management of patients with multiple sclerosis (MS), both in terms of ongoing therapies and for the commencement of new treatments.

Early in the COVID-19 pandemic, it was unclear whether immunosuppressive therapies, the mainstay of treatment for MS, would confer protection or additional risk for patients infected by the novel virus. There was an urgent need for data on which to base clinical decisions.

To collect information on the relationship between MS and COVID-19, a user-friendly, digital tool was developed known as MuSC-19. The initiative was led by a diverse group of partners in Italy – the first European country to be severely affected by the pandemic.

The Italian Neurology Society, the University of Genoa, the Italian MS Federation and Roche worked together towards the shared goal of gathering data to evaluate the course of COVID-19 in patients with MS. This provided opportunities to chart the clinical course of illness and assess the influence of disease-modifying treatments. The platform was developed in just 10 days in response to a crisis situation. It allowed real-time data extraction, with information from the platform shared with all participating centres through a weekly newsletter. The tool has helped Italy's community of neurologists to make clinical decisions during these challenging times.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This initiative supported neurologists in caring for their patients and making informed clinical decisions during stressful circumstances. It also helped to inform protective strategies. By collecting specific information on COVID-19 cases in patients with MS, it helped to build evidence to evaluate risk factors for COVID-19 infection and severity, including immunosuppressive therapies taken by MS patients.

Initial data were published in an academic journal in April 2020 and further publications are foreseen. The MuSC-19 registry is the largest cohort of COVID-19 cases in MS patients worldwide. The MuSC-19 registry currently includes 1,378 patients with confirmed or suspected COVID-19 from 90 Italian and 59 international sites, representing 23 countries.

INNOVATIVE ELEMENTS OF THE PROJECT

The software used in this project is a web application that allows data collection in a systematic and structured manner. It is user-friendly and accessible from any device with a web browser, and it can be used in online and offline mode to facilitate data entry by HCPs involved in the MuSC-19 registry.

The software was pre-configured according to the needs and interests of the Italian Society of Neurology and epidemiologists from the University of Genoa. By developing this digital tool, stakeholders ensured effective and accurate collection of data to inform clinical practice.

COLLABORATIVE ELEMENTS OF THE PROJECT

This digital platform was a genuinely collaborative effort, involving several teams within Roche. Company personnel worked closely with Italian epidemiologists and neurologists to set up the platform modules for COVID-19 and MS data.

Roche Global Medical Affairs reached out to the Italian MS community to offer support to the MuSC-19 study. Rapid collaboration with neurologists and epidemiologists happened within 24hrs.

In a spirit of collaboration and in the context of a global pandemic which was putting severe pressure on health services in Italy, a valuable data collection project was built. Data collection and ownership remains independent of Roche.

Our project partners and contributors

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