

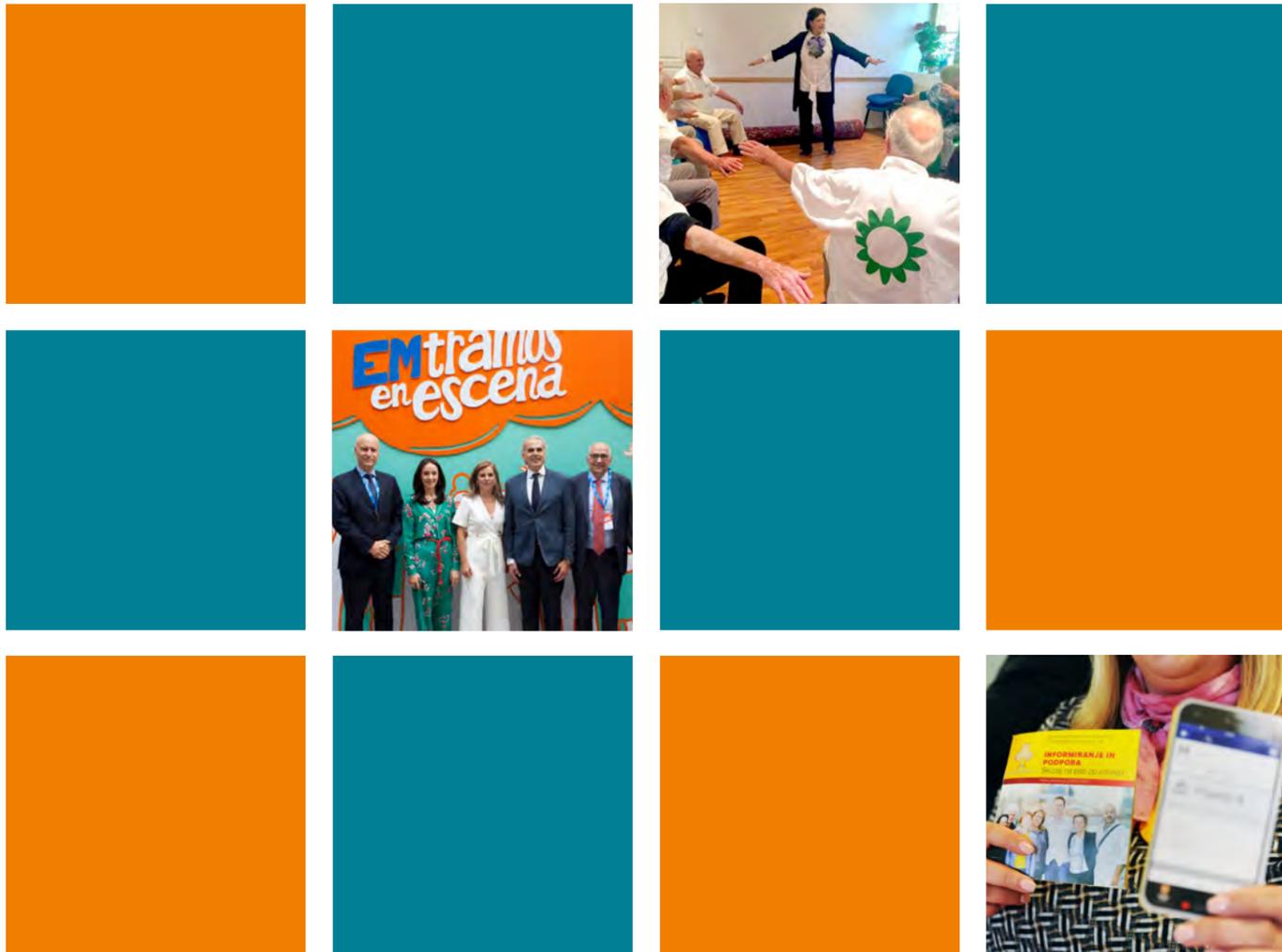


# HEALTH COLLABORATION GUIDE 2019



efpia

European Federation of Pharmaceutical  
Industries and Associations



# Foreword

Dear Colleagues,

**Health is our European success story. Over the last 50 years life expectancy across the region has grown by over a decade. Two out of three people living with cancer now live more than 5 years, deaths from cardio-vascular disease have tumbled, HIV has gone from a death sentence to a manageable disease and now 95% of people living with the Hepatitis C Virus can be cured with a 12 week course of medicine.**

But along with that success comes a number of challenges. An ageing population means increased demand on health services and increased prevalence of disease like neurodegenerative diseases, including dementia, cancer and diabetes. No one sector has all the answers but by working together, by connecting healthcare we can ensure a healthier future for Europe.

This means developing collaboration between patients and their caregivers, patient organisations, healthcare providers, regulators, policy makers, HTA bodies and life science companies.

Managing projects that include patient organisations and commercial organisations can be complex. They must be centred on patient benefit; they must be fully transparent with clear shared objectives and roles and responsibilities, transparent funding arrangements and well-defined outcomes while following key principles like mutual respect and trust. The EFPIA Patient Think Tank is committed to facilitating the patient being at the centre of these interactions through continuous dialogue and through supporting best practice in open and transparent collaboration.

With this idea in mind, the EFPIA Patient Think Tank published the first Health Collaboration Guide in 2016 to showcase best practice collaborations between patient organisations and industry, but also local authorities, governments, SMEs and other key actors in delivering healthcare. Now in its third year and bigger than ever before, the guide is designed to spark new ideas to develop collaborative projects that will continue to make a difference to patients across Europe.



Usman Khan Executive Director European Patients' Forum



Jean-Christophe Tellier President, EFPIA





*“Clinical Champions is sector leading, trailblazing and heralded as an example of how a charity and pharmaceutical company can work brilliantly in partnership. Its impact and profile will only increase year on year as our network of alumni grow and continue to learn from each other, making valuable improvements at scale across the country.”*

**Will Macleod**  
Head of Partnerships and Philanthropy,  
Diabetes UK



# Clinical Champions for diabetes

**Diabetes is one of the greatest challenges facing the NHS in the UK. However, solving this problem is complex. There is a lack of diabetes knowledge amongst non-specialists and decision-makers, leading to failings in diabetes care. People with diabetes are more likely to be admitted as an emergency, have longer hospital stays and are at a high risk while in hospital of clinical emergencies such as hypoglycaemia. Many of these episodes can be mitigated or prevented with care provision and delivery shaped and driven by knowledgeable and motivated agents for change.**

To address this, Diabetes UK and Novo Nordisk set up the Clinical Champions programme, in partnership with Ashridge Hult Executive Education. This aimed to capitalise on the specialist knowledge and experience of frontline NHS diabetes clinicians by empowering them to drive and accelerate change for the benefit of people living with diabetes. It also sought to develop stronger clinical advocates for diabetes to ensure it was not lost within the broader focus on long-term conditions and the ever-changing landscape of the NHS.

Clinical Champions are supported through expert leadership education and coaching from Ashridge Hult Executive Education and Diabetes UK, to complete a project with demonstrable improvements in service delivery and patient care. Since its establishment in 2014, 105 Clinical Champions from across the diabetes care pathway have been recruited and empowered with the skills required to deliver lasting change.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The programme has led to tangible improvements in diabetes care. An innovative pathway change in Northern Ireland redesigned specialist care and allowed the provision of a specialist diabetes clinic during dialysis sessions, ensuring quality care is received by those patients who are most at need and often the hardest to reach.

More than 18,000 people across Scotland can now access online diabetes education and use technology to monitor their diabetes. Patient engagement with young adult services improved by organising study days, peer support groups and family days directly with people with diabetes and their families. Other projects have brought patient benefits through improving safety, equity and educating other healthcare professionals.

To date, tens of thousands of patients will have directly benefitted, from the changes in diabetes care and service delivery instigated via the 105 Clinical Champions

## INNOVATIVE ELEMENTS OF THE PROJECT

The project managed to overcome industry distrust within the NHS, demonstrating that industry can work compliantly, transparently and successfully with a charity and with the NHS to deliver sustained positive change for people with diabetes.

Effective clinical leadership can be challenging in the NHS and this trailblazing partnership has successfully empowered clinicians to lead system change within the NHS to improve the lives of people living with diabetes.

## COLLABORATIVE ELEMENTS OF THE PROJECT

A grass roots approach was adopted to early development through collective programme creation by Diabetes UK, Novo Nordisk, Ashridge Hult Executive Education and the first cohort of Clinical Champions.

Regular partnership meetings maintain strategic priorities and there are regular formal and informal feedback sessions between partners. Diabetes UK programme managers keep in close contact with the Champions, ensuring regular communication and support.



# The Angels Initiative

**Every 30 minutes across Europe, a stroke patient who could have been saved dies or is permanently disabled. Not simply because of their stroke, but because they were treated in the wrong hospital. Treating acute stroke requires a multidisciplinary team which acts fast in line with stroke-unit protocols - to give patients the best chance possible of returning to the life they knew.**

The Angels Initiative aims to improve stroke care by building acute stroke networks, optimising treatment processes and sharing knowledge to set-up stroke ready hospitals.

The common goal is to improve care for as many people as possible who have suffered a stroke and thus save lives. Up to now the Angels Initiative has already established a community of more than 3,100 stroke-centres and 'stroke ready' hospitals in 95 countries worldwide including 37 European countries.

The main focus of the Angels Initiative is to guarantee a high standard of care for all patients with acute stroke, regardless of where they live. Our aim is to make sure that every patient admitted to a hospital that is part of the Angels Initiative will benefit from the care of a dedicated team of stroke specialists working every day to provide their patients with better outcomes.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Stroke is the second most common cause of death. 1 in 4 will suffer a stroke during their life time. If a stroke patient is treated in the wrong hospital they have a higher risk of dying or being permanently disabled. At the moment, for most stroke victims, this is a lottery. The 'Angels Initiative' is committed to change this. Their aim is that every patient has the same chance of access to a stroke-ready hospital that provides guideline-recommended treatments.

In the acute situation of a stroke, time is brain, because with every second the patient loses neurons. Therefore Angels hospitals focus on speed, as we know this has a major impact on improving outcomes. In Angels hospitals the patient pathway is standardized and optimized. By enrolling more than 3,000 hospitals in the Angels Initiative, we expect to impact close to a million patients each year.

### INNOVATIVE ELEMENTS OF THE PROJECT

The Angels Initiative realised that a healthcare issue cannot be solved through a single drug or therapy, nor by companies competing for the attention of the same community with similar applications.

A dedicated team of Angels consultants provides doctors, nurses and ambulance crews with the training and support they need to create and improve stroke treatment pathways and processes.

Consultants run assessments and simulations together with the hospitals, compare current processes with guidelines and best practices, and provide trainings and support for the hospital staff as well as process- and quality-monitoring.

Examples of these measures are checklists, which help to standardise processes and to limit unnecessary delays. The initiative also offers educational tools and programmes, equipment, support for pre- and in-hospital process optimization, a community platform for peer-to-peer exchange, and access to the world's leading stroke specialists.

### COLLABORATIVE ELEMENTS OF THE PROJECT

Angels form a key part of the ESO Quality Improvement project.

What makes the Angels Initiative different is its non-promotional nature, in the sense that it does not look at single elements of a disease. Instead, partners working together to address acute stroke treatment as a unit.

The Angels Initiative is run by Boehringer Ingelheim in partnership with the European Stroke Organisation (ESO), the World Stroke Organisation (WSO), the Stroke Alliance for Europe (SAFE) and many other national stroke societies and companies.



# KiDS and Diabetes in Schools

**In Poland, around 3 million people have diabetes. Obesity and diabetes prevention are one of Poland's key governmental priorities; over 20 percent of primary and secondary school students are obese or overweight. In addition, around 5% of the people living with diabetes, mostly children and adolescents, have type 1 diabetes, a life-threatening condition.**

The Podkarpacie region of Poland has one of the highest rates of obesity and overweight inhabitants (53.3 percent), and therefore faces elevated risks of diabetes. A health debate, supported by Sanofi in Podkarpacie in partnership with the University of Rzeszów, showed that diabetes prevention should be a priority for local health and administrative authorities.

At the same time, many parents of children with type 1 diabetes acknowledged that they encountered obstacles in schools with teachers having insufficient knowledge, leading them to be hesitant to support children with diabetes. Other children and their parents didn't understand the nature of the disease, risking discrimination and stigmatisation.

KiDS and Diabetes in Schools is a project to support children with diabetes. It is a global

educational programme, developed in cooperation with the International Diabetes Federation (IDF), the International Society for Pediatric and Adolescent Diabetes (ISPAD) and Sanofi. This initiative aims to build a supportive environment for children with diabetes and to help prevent type 2 diabetes through effective lifestyle choices. In the Podkarpacie region of Poland, in 2018, the project delivered training in 15 schools where at least one child was living in diabetes.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project helped change attitudes and thinking on diabetes in schools. Children with diabetes benefited from the creation of a friendly environment where they could address their therapeutic routine without being disturbed and without fear of stigmatisation and discrimination.

In addition, the school community, including all children, parents, teachers and other school staff, gained knowledge on diabetes. This included information on the daily challenges children with diabetes might face. In particular, teachers and other school staff learned how to deal with a child with diabetes.

In Podkarpacie, 1373 schoolchildren and their 40 teachers benefited from this training. In addition, 250 medical students were trained on diabetes and selected student-trainers were additionally equipped with presentation skills and methods for working with children.

## INNOVATIVE ELEMENTS OF THE PROJECT

Unlike standard educational material on diabetes, the KiDS toolkit was developed around a comic book, highlighting the life of a boy living with diabetes during his day to school. In addition, the KiDS programme not only targeted children and parents, like standard training on diabetes awareness, targeted teachers were also part of the training. This provides them with knowledge on diabetes epidemiology, medical aspects of diabetes and the practical side of diabetes treatment regimens in children and adolescents.

In addition, a wide range of public-private stakeholders were engaged in this project. The Minister of Education, the Mayor of Rzeszów, Podkarpacie School Inspectorate, Podkarpacie Region Sanitary Inspectorate, the Polish Diabetes Association and the Polish Federation on Education in Diabetology all granted their honorary patronages. The outcomes have been widely presented.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The project engaged a large number of stakeholders. A key milestone was the honorary patronage of the Minister of Education, providing the project with valuable visibility, as was the endorsement from the School Inspector in Rzeszów, enabling the selection of schools.

Well-established cooperation with the University of Rzeszów enabled us to secure support from the local authorities, health institutions and other bodies. It was also important to engage the local Polish Diabetes Association and Polish Federation of Education in Diabetology.



# NHS Wales Haematological Malignancy Data Solution

**Haematology services in Wales required an innovative and personalised data solution to be able to critically analyse the clinical outcome and patient preference data for patients with myeloma and ultimately all other haematological malignancies. Units need access to a database to register all patients at diagnosis with data covering their demographic characteristics, disease presentation/staging, diagnostic features, treatment plan, response to treatment and overall survival. Quality of life data may also be collected to justify the cost and burden of treatment and to demonstrate the impact of treatment over non-treatment from a patient perspective.**

Historically, data capture for cancer patients in Wales was via the Cancer Network Information System Cymru (CaNISC). This is ill-equipped to capture the nuances of haematological diseases. It is also unsuitable for capturing quality of life data or treatment response. Unscrutinised treatment with high-cost, potentially toxic drugs inevitably wastes resources and leads to ineffective treatment for some patients. Investment in data capture is urgently required to reverse this trend.

To address this, Janssen UK, the Welsh Government, NHS Wales and Myeloma UK partnered to co-create and implement an All Wales Haematological Malignancy Data Solution. This will capture Real World Evidence (RWE) to help improve patient outcomes

and build a value-based healthcare environment. The Welsh Government and NHS Wales wish to increase joint working with patient advocacy groups and industry. This will focus on delivering better outcomes for people in Wales by improving the efficiency and effectiveness of services in line with the principles of 'Prudent Healthcare'.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

As core contributors, patients can feed in valuable insights on their preferences and experiences, using appropriate data capture tools. This will inform future pathway decisions for themselves and others. Patients can have a more honest assessment of what to expect from treatment pathways based on RWE data.

The Patient Recorded Outcomes Measures (PROMs) data will be captured digitally, both in clinics and at the patient's home, on an All Wales PROMs platform. These insights will be used to improve the quality of one-to-one therapeutic engagement between the patient and healthcare professionals.

## INNOVATIVE ELEMENTS OF THE PROJECT

This is the first time the Welsh Government, NHS Wales, an industry partner (Janssen UK) and a patient advocacy group (Myeloma UK) have partnered on a long-term initiative with the core objective of improving patient outcomes.

It took an innovative, data-driven approach to capturing patient outcomes and, by working with health system and government leaders, ensured that the solution will be sustainable. The involvement of a leading patient group in developing PROMs was an innovative element of the initiative which will have long-term benefits to the patient community.

## COLLABORATIVE ELEMENTS OF THE PROJECT

This agreement between the Welsh Government, NHS Wales, Myeloma UK and Janssen focused on delivering better outcomes for patients by improving the efficiency and effectiveness of services. As signatories to a Joint Working Agreement, each stakeholder committed significant resource to the project in terms of funding, people and time.

In addition to the core stakeholder group, the initiative also involves collaborators from Cardiff and Vale Health Board, Cwm Taf Health Board, Aneurin Bevan Health Board, All Wales Toxicology & Therapeutics Committee (AWTTC), Public Health Wales, NHS Wales Informatics Service (NWIS), Wales Cancer Network (WCN), Digital Health Ecosystem Wales (DHEW) and Capitated Outcomes-Based Incentivised Care (COBIC).



# #EscuchaMisPulmones

## #ListentoMyLungs

**Idiopathic Pulmonary Fibrosis (IPF) is a rare, progressive disease, the cause of which is unknown. It is characterised by lung inflammation and fibrosis and affects over 7,500 people in Spain. Early diagnosis remains one of the greatest challenges for people with IPF. Diagnosing the disease at an early stage allows treatment to begin as early as possible, slowing its progression and improving quality of life.**

The #ListentoMyLungs campaign was created to increase awareness of the symptoms of the disease, particularly among primary care doctors. They are the first link in the health assistance chain and the first people that future patients meet. By listening to the internal sounds of the body with a stethoscope (a technique known as Auscultation) doctors can usually detect IPF, as the disease has a characteristic sound.

The campaign was organised by the Idiopathic Pulmonary Fibrosis Patients and Families Association (AFEFPI) and Roche to mark International Week of Idiopathic Pulmonary Fibrosis. It saw an information stand set up at the Plaza de la Independencia in Madrid, one of the busiest public spaces in the city, allowing people to hear the difference between a healthy lung and one damaged by IPF.

Hundreds of people received comprehensive information on the disease and its symptoms and shared their experiences on social media using the hashtag #EscuchaMisPulmones. On the same day, several experts addressed a press conference on IPF, providing more information on the disease and the needs of patients and their families.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This campaign benefited not only IPF patients but also health professionals involved in managing the disease, public administration and the public as a whole. Over 300 people visited the information stand in the Plaza de la Independencia to listen to the sound of lungs affected by IPF.

The campaign was spread using social media using the hashtag #EscuchaMisPulmones and was supported by videos and pictures. There was also a microsite with information about the disease, helping to raise awareness of the disease among the general public.

AFEFPI shared the message through its internal and external communication channels, amplifying the impact of the campaign by enlisting highly-motivated patients to spread the word. Over 20 different media outlets picked up on the campaign, reaching an audience of over 15 million users.

### INNOVATIVE ELEMENTS OF THE PROJECT

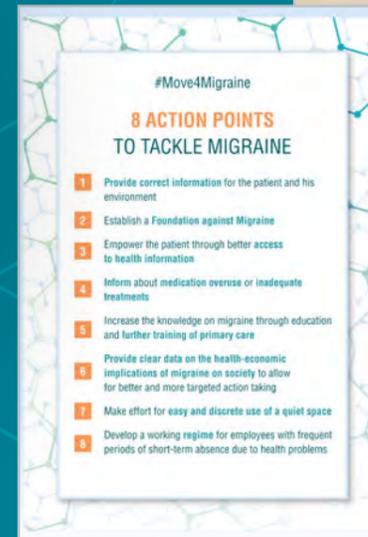
This was the first time that the public has been invited to listen to the sounds of a lung affected by IPF, to encourage early diagnosis of the disease. By giving the public this opportunity, the campaign offered a practical and memorable experience to the public, while emphasising the simple steps healthcare professionals can take to diagnose IPF.

The initiative brought information to the public using a wide range of channels, ranging from online media to engaging with people in central Madrid. The interactive nature of the campaign – on social media and at Madrid's Plaza de la Independencia – helped to ensure a high-impact event.

### COLLABORATIVE ELEMENTS OF THE PROJECT

The campaign involved the support of the Idiopathic Pulmonary Fibrosis Patients and Families Association (AFEFPI), ensuring participation of those most directly affected by IPF. Not only did this help to make the initiative meaningful to key stakeholders, it provided access to an existing network for disseminating communication materials.

This collaboration with patients' associations and healthcare professionals was aimed at building a project that everyone feels part of. The relationship established between both 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.



# #Move4Migraine platform

**Migraine can have a devastating impact on quality of life, affecting sufferers' social, family and working lives. The condition is estimated to affect around one in seven people, with approximately 2% of the population having chronic migraine.**

In addition to being a major burden for patients and their families, migraine carries a significant social and economic cost. Despite this, migraine remains overlooked and misunderstood in many European countries. Belgium is no exception.

The #Move4Migraine project aims to change this. As an independent, multidisciplinary platform, the initiative brings together patients and actors from healthcare, the employment sector and civil society, with the support of industry partners. Its goal is to raise awareness of migraine, to improve the patient quality of life and those most closely connected to them and, through a series of concrete actions, reduce the impact of migraine on society.

The first task for #Move4Migraine was to build a broad coalition including the main stakeholders in migraine community in Belgium. This coalition then worked to develop a 'Call to Action' including eight action points on policy, health and employment. The call to action was presented at a roundtable in the Federal Parliament, attracting 60 people from the healthcare, policymaking, civil society and employment sectors. A variety of media covered the event and reported on the action points. Tangible actions from the call to action are now in progress thanks to the platform.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The platform mapped the migraine related unmet needs of patients, caregivers, employers and other concerned parties. It has also published an advocacy brochure including a concrete 'Call to Action' with eight action points to tackle migraine that was presented to the Federal Parliament. Some members of Parliament committed to a political follow-up by informing the Minister of Public Health and Social Affairs of the initiative and by writing a resolution based on the 8 action points. #Move4Migraine is now in discussion with these members of Parliament to organize a hearing within the Commission of Public Health of the Federal Parliament.

Up to one million migraine patients in Belgium could ultimately benefit from the project if decision-makers are inspired to take action.

## INNOVATIVE ELEMENTS OF THE PROJECT

This ground-breaking initiative was built on innovation and designed for impact. The coalition driving the project brought together, for the first time, a broad range of actors with a shared vision and common mission. Never before has such a diverse and large coalition been assembled in Belgium to tackle migraine.

For many participants, this was a new venture in several ways. Significant preparatory work, time and effort was invested in ensuring this diverse group had clear and well-aligned objectives.

The coalition also brought together companies\* from the innovative biopharma and generic medicines sector, along with a medical device company. Multi-stakeholder initiatives can require fresh thinking from all parties, but goodwill and a common goal ensured that participants pulled in the same direction.

Not settling for only raising awareness, #Move4Migraine added a political dimension to its work. By setting out clear actions to improve the lives of people suffering from migraine, and engaging directly with key decision-makers, the project ensured its impact would be characterised by sustainability and longevity.

## COLLABORATIVE ELEMENTS OF THE PROJECT

Collaboration was the key ingredient in the #Move4Migraine platform. The project is built upon the active involvement of patients, neurologists, GPs, occupational physicians, pharmacists, sickfunds, employer and labor unions. Platform members worked together to devise eight concrete action items to recommend to public and health authorities, as well as patients, healthcare professionals and others. They collaborated on the promotion of the initiative and ensured buy-in from partners by taking decisions based on consensus.

In establishing an information platform for the general public, patients and healthcare professionals collaborated closely – ensuring that the content was both medically accurate and user-friendly.

This collaborative spirit drove the initiative from the beginning. While ensuring that the platform remained independent, #Move4Migraine is an outstanding example of how industry can support stakeholders in addressing major unmet needs.

\*First partners were Novartis, Eli Lilly, Cefaly and Sandoz, joined in 2019 by Teva and Allergan.



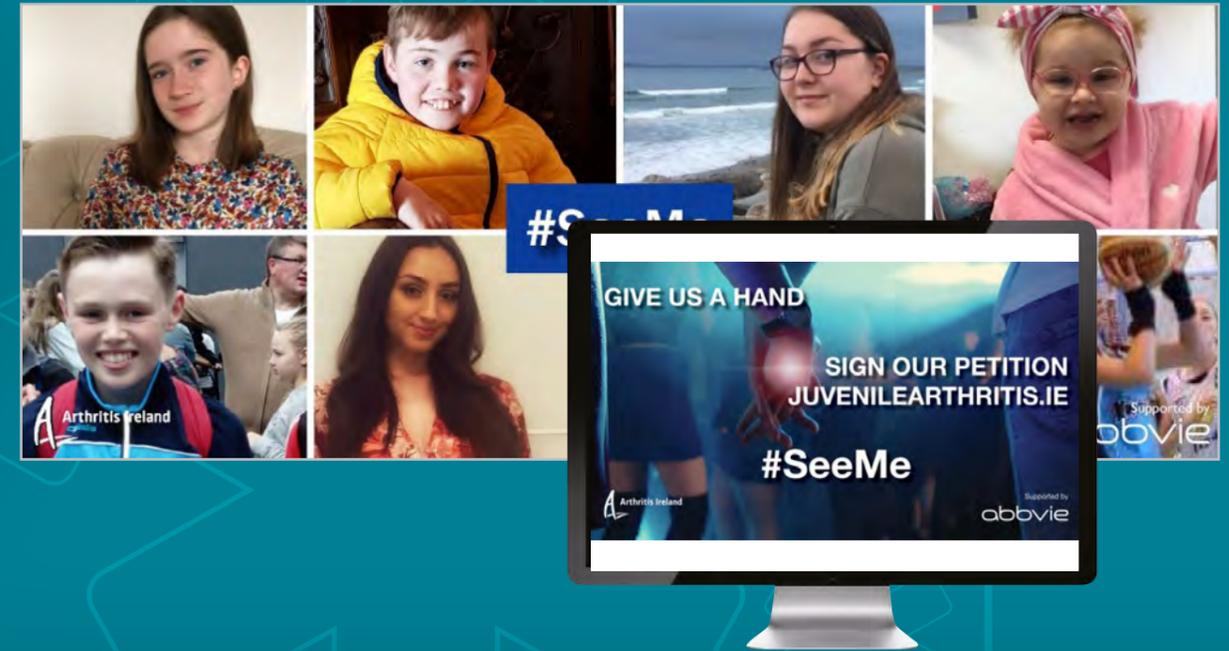
# #SeeMe

**Irish paediatric rheumatology is inadequately resourced. The model of care recommends six consultant paediatricians, but only two paediatric rheumatologist posts exist. Consequently, young people with Juvenile Idiopathic Arthritis (JIA) in Ireland face extreme delays in both accessing paediatric rheumatology services and in receiving treatment.**

The #SeeMe campaign was a multi-faceted advocacy and media campaign, run by Arthritis Ireland and supported by AbbVie. It highlighted the pressing need for the Irish government to fund additional paediatric rheumatologist posts for the 1,200 children in Ireland living with JIA. The key message was that JIA is an invisible disease, one that needed to be publicly acknowledged and immediately resourced because of its impact on those experiencing it.

The campaign had two key objectives. First, it aimed to increase the number of paediatric rheumatologists in Ireland. And, second, it sought to increase awareness and understanding of what it's like to live with juvenile arthritis – particularly invisible, chronic pain, - and how this impacts on life.

The initiative was successful: the Irish government agreed that an additional paediatric rheumatologist would be appointed in 2019.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Appointing an additional paediatric rheumatologist in 2019, whilst still well short of optimal resourcing levels, will increase capacity by 50 percent. The appointee will work with colleagues to address the significant existing waiting lists in paediatric rheumatology. This will have a huge positive impact on young people with JIA in Ireland seeking medical care.

The success of this campaign will have benefits for patients for years to come. Not only will today's patient population experience shorter waiting times, future patients should be treated far more quickly than had previously been the case. It may also inspire others to embrace advocacy and media campaigns to achieve meaningful change for patients.

## INNOVATIVE ELEMENTS OF THE PROJECT

The project created a unique campaign asset that spoke directly to young people and encouraged them to become involved in advocacy. This centred around a short music video featuring the hit song 'Take My Hand' by Irish band 'Picture This'. The video used visual effects to highlight flashes of joint pain with on-screen copy reinforcing core messages.

The campaign featured personal patient stories by involving #SeeMe Ambassadors, children and young people living with JIA willing to share their experience publicly.

There was also an infographic which was used to communicate key medical information about JIA and paediatric rheumatology services in a clear, accessible way.

## COLLABORATIVE ELEMENTS OF THE PROJECT

Project partners Arthritis Ireland and AbbVie have a shared goal of addressing the under-resourcing of paediatric rheumatology, improving the lives of children and young people living with JIA.

The campaign developed from open discussions between partners about the needs of patients and a joint commitment about taking action together. Through a series of meetings and phone calls, and reviewing similar campaigns from other countries, the details and goals of the initiative were refined. Regular contact was maintained throughout the project in line with a transparent collaboration agreement.

Both partners contributed their experience and expertise in health policy and paediatric rheumatology to develop and implement this successful campaign.



# 10 Thousand Steps Program



**Physical exercise has a positive impact on the quality of life and survival of men with prostate cancer. Research has found that men taking more than three hours of vigorous activity per week had a 49 percent lower risk of all-cause mortality and 61 percent lower risk of prostate cancer death.**

The 10 Thousand Steps Program aimed to support Hungarian patients living with prostate cancer to increase their physical activity. Its first objective was to create a comprehensive programme that encouraged men with prostate cancer to exercise more and educate them on the health benefits of physical activity. The second goal was to provide professional education for health care practitioners (HCPs) so that they would feel better positioned to deliver advice on physical activity to prostate cancer patients.

The Programme was co-created with active input from patient advocacy groups (PAGs), including the Hungarian League Against Cancer and the Heal With Us Association. Important contributions were also provided by experts in oncology, urology and physiotherapy, as well as prostate cancer experts from Janssen.

The programme produced videos of physiotherapy exercises, a patient brochure encouraging physical activity, and a brochure for HCPs with the scientific data supporting the programme. PAG digital campaigns, public outreach and email campaigns to HCPs helped to build programme awareness and encourage recommendation to patients.

Face-to-face meetings were organised with PAG events to educate patients and carers. Medical education was also vital. Leading experts presented the programme at national medical congresses, a continuing medical education event was hosted for physiotherapists, and the Janssen sales force shared details of the initiative at visits and roundtables.

## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The four video modules were viewed over 3,000 times, while the patient brochure was downloaded 800 times and 5,000 printed brochures were distributed to patients.

The communication campaign had more than 2,000 followers and achieved 180 articles and interviews in online, print and broadcast media, along with face-to-face events. The PAG educational events attracted more than 1,000 patients and carers.

The programme was also presented at six national medical congresses, while a CME-accredited physiotherapist event attended by 80 physiotherapists provided three lectures on prostate cancer and training on patients' exercise/movement needs.

All of these efforts combine to improve the likelihood that prostate cancer patients will learn about the value of physical activity – and put this knowledge into practice.

## INNOVATIVE ELEMENTS OF THE PROJECT

Most similar programmes simply focus on building awareness. The 10 Thousand Steps Program focused on improved therapeutic outcomes. Outpatient rehabilitation programmes are rare in Hungary and not accessible for all. Videos, printed materials and face-to-face events gave all patients the opportunity to benefit from dedicated exercises, particularly for those that could not reach and/or afford physiotherapists.

In addition, oncology/prostate cancer-related education of physiotherapists is not yet well-established in Hungary. Building capacity and highlighting their importance in the care of prostate cancer patients was an innovation in Hungary, one that should provide them with confidence for years to come.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The programme was cross-functional from its conception and was co-created by medical experts, patient experts and physiotherapists with patient benefit as the core aim.

By learning from individual expertise and collaborating to develop a wide-ranging programme, several issues were addressed. These include enhanced patient understanding of the importance and benefits of physical activity and the types and frequency of physical activity they should be doing.

In addition to these patient-oriented elements, the programme reached out to urologists and oncologists to enhance understanding and awareness of the available supporting materials, and of the importance of involving physiotherapists in the multidisciplinary team.

This approach ensured the initiative was truly multidisciplinary and patient-centred.



# Acting on Heart Failure

**Heart failure (HF) impacts approximately 60 million people worldwide, including at least 15 million adults in Europe. It is an underdiagnosed and poorly understood condition despite meaningful advances in disease management. Neither the general public, nor in many cases heart failure patients themselves, have a clear understanding of the diagnosis and management of this condition.**



While there are patient groups in Europe engaging in heart failure awareness days and activities, there has never been a coordinated effort across groups and countries. The 'Acting on Heart Failure' campaign aimed to unite city and town mayors from across Europe to pledge their commitment to raising awareness of heart failure. This took place during and after European HF Awareness days in May and involved local mayors publicly reading a statement about HF.

A total of 15 patient groups in 12 European countries implemented the campaign in 28 different cities, with 15 Mayors and 20 public representatives taking part.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This campaign gave a voice to those living with heart failure, through increased public awareness of the disease. A number of new patient advocates were identified as a result of this initiative. The Greek Caregivers organisation EPIONI joined iHHub (International Heart Hub) as a result of involvement, strengthening the network for patients and carers living with heart failure.

Engagement via multiple social media channels reached over 231,653 people. Eight countries achieved national print and broadcast coverage with a total potential reach of over 12.3 million people. Twelve countries achieved regional and local coverage with a total potential reach of approximately 1.5 million people.

## INNOVATIVE ELEMENTS OF THE PROJECT

This was a collaborative, multi-country patient group/industry initiative addressing the need for awareness and understanding of heart failure. The initiative was rolled out at local level through leveraging mayors and public representatives to take the message directly to the people in 28 European cities. These mayors and public representatives committed to help raise awareness of HF and call for local action to improve the lives of HF patients. The awareness raising centred on differentiating HF from other conditions, and informing people that onset can occur at any age.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The project involved key European patient groups that were involved from the outset. They advised on all elements of the campaign (strategy, logo, materials/resources). Novartis also worked globally and in four European countries (Germany, Spain, Portugal and Greece) to provide input on the initiative development.

Both iHHub and Novartis had project leads to provide coordination for the organisations involved. The Austrian Heart Foundation, ASBL/France, A.V.E.C./France, Herzschwache, Defibrillator (ICD) Deutschland, the Heartbeat Trust, Croi, AISC/Italy, ParSirdi, SNSA/Lithuania, Hart4Onderzoek, the Portuguese Heart Foundation and the Slovenian Heart Foundation all participated.

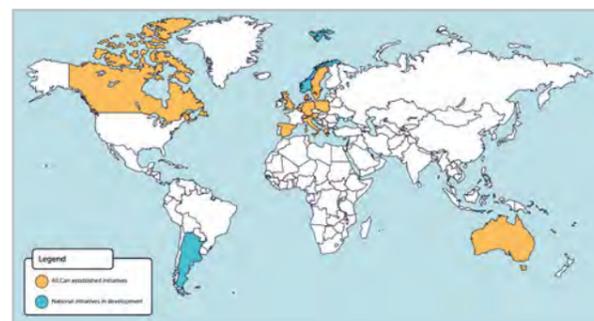


# All.Can

**The growing prevalence of cancer and rising pressures on healthcare budgets create a concern that healthcare systems won't be able to offer patients the quality of care they need to improve their outcomes. Up to 20% of healthcare spending is wasted on inefficient interventions. Identifying inefficiency in cancer care requires collaboration between a broad range of stakeholders. Together, we must ensure resources are allocated to where they make the greatest difference to patients; better use of resources means better outcomes for patients.**

All.Can is a multi-stakeholder initiative designed to improve the efficiency of cancer care by focusing on improving patient outcomes. It aims to identify and help implement concrete solutions to make cancer care more efficient, where efficiency is defined as focusing on what matters to patients. All.Can membership includes over twenty leading patient organisations, professional societies, provider groups, industry members and academics working in cancer both in Europe and internationally.

In 2018, All.Can conducted a survey of 4,000 cancer patients and carers in ten countries, asking where they encountered inefficiencies in care. Respondents provided valuable insights, and All.Can will be asking policymakers to consider these insights in policy, care planning and definitions of efficiency.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Understanding what inefficiency means to patients, and where there is the greatest need for improving efficiency, can help steer cancer care towards a more patient-centric path. Insights from the All.Can patient survey provide evidence for concrete recommendations to take to policymakers and other key stakeholders at EU and national level.

Patients live the reality of healthcare delivery, so have a unique perspective. To be true to the aim of delivering care focused on what matters to patients, it is essential that policymakers consider patient insights alongside economic and clinical data. This is not just about health system reform – it is also a question of how policies and societies need to adapt to adequately provide for people living with and beyond cancer. The All.Can patient survey revealed four key areas of opportunity for improvement in cancer care, and now these findings can be used to transform cancer care, improving the lives of current and future patients.

## INNOVATIVE ELEMENTS OF THE PROJECT

The project is genuinely multi-stakeholder in nature, involving stakeholders from all sectors, which is reflected in the diversity of its funders. Everyone has an equal say and all funding partners have an equal voice. This enables innovative discussions where all perspectives are heard.

Another innovative aspect of All.Can is in defining efficiency based on what matters to patients. Rather than focus narrowly on economic efficiency or viewing efficiency from the perspective of health professionals, payers or service delivery organisations, All.Can sees efficiency through a patient lens. This commitment to patient centricity is the guiding force behind the initiative and sets it apart from some other cancer projects.

All.Can has established an online efficiency hub, which collates examples from around the world of innovations and interventions that improve efficiency in cancer care. It aims to create a learning community around efficient practices and help organisations find and implement solutions to common issues.

## COLLABORATIVE ELEMENTS OF THE PROJECT

All.Can is driven entirely by its members, who are responsible for all major decisions. This is built into the organisation's Terms of Reference.

All work is conducted by working groups, open to all members. There are working groups for research, communications and stakeholder engagement, and national initiatives. These groups ensure that decisions on key aspects of the project are made jointly and with close input from members and that they reflect consensus from those involved at every step.

Publications are co-created and co-authored, taking a consensus-based approach to producing quality content. Regular calls to review progress, share best practice and develop common communications help to ensure this diverse group speaks with one voice to advance patient-driven policy changes at an international level.

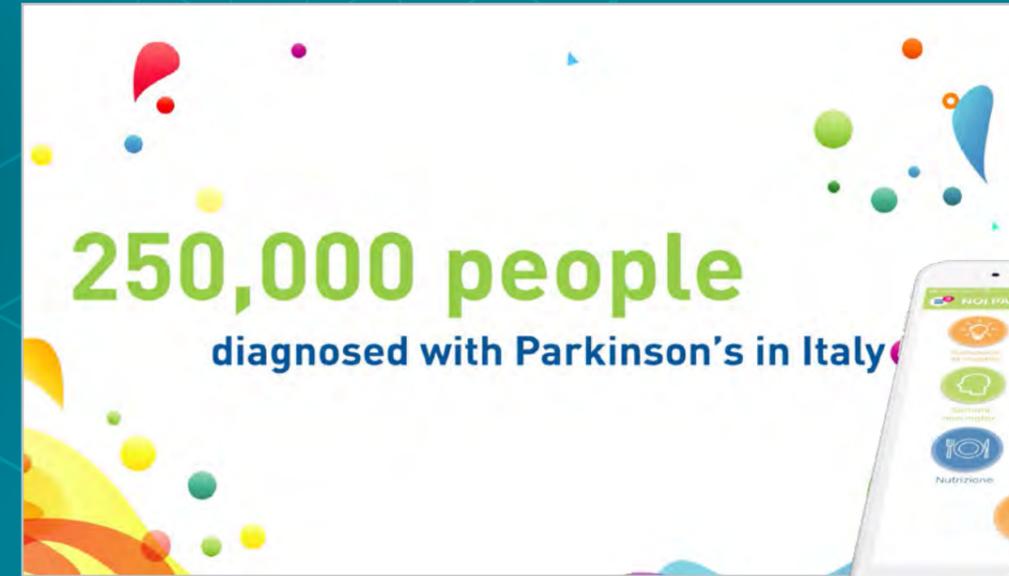


# NoiParkinson App

**Parkinson's disease is the second most common neurodegenerative disease in the world. Symptoms can vary from one patient to the next, but the most identifiable signs relate to movement (or motor) symptoms such as tremor. It affects more than 6 million people worldwide. The risk of Parkinson's increases with age.**

In Italy, the country with the oldest population in Europe, there are 250,000 people diagnosed with Parkinson's disease. They need daily support, guided by a team of healthcare professionals, to ensure that they have the highest possible quality of life.

The NoiParkinson App was designed to empower people living with Parkinson's disease and their carers. A multidisciplinary team of experts from the Parkinson Alliance for Better Life Solutions worked together with a group of patients to find insights and identify specific needs. Together, they reworked guidance and practical solutions to these challenges into a digital tool. The App offers free daily support, with instructions and videos to help understand the disease, therapies, rehabilitation, symptoms, nutrition and self-evaluation.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The goal of the project was to provide patients with a practical and measurable way to improve their knowledge and experience of Parkinson's disease. The patient population is large and growing, suggesting scope for growth in the impact of the project.

To date, 2,100 patients have downloaded the app. Of these, 87 percent continue to use the app and have stored it on their devices. Over time, use of the app is likely to continue, providing additional insights on what kind of information patients value most. This could provide opportunities to further refine and enhance the content on the app.

It is also expected that users will inform others in the Parkinson's community about the value of the app, further boosting its use.

## INNOVATIVE ELEMENTS OF THE PROJECT

The App provides a comprehensive digital tool, with everything you might want or need to know about Parkinson's disease in your pocket. Designed with input from experts and tested with patients and care givers, it uses existing technologies – mobile devices – to deliver well-packaged information in an accessible and convenient format.

Mobile apps can play an increasingly valuable role in improving the lives of people with neurological conditions, including Parkinson's disease. While this may be a new approach to engaging people with Parkinson's, the uptake and use of the app suggests patients appreciate this innovative tool.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The development of the app was an 18-month process (2017-2018) and required considerable collaboration between a diverse group of experts. Sixteen experts from different disciplines (neurologists, psychiatrists, psychologists and dieticians, gastroenterologists, specialist nurses, urologist) with experience in Parkinson's disease came together to define, agree and share what would have been the most useful content for patients and care givers.

Together, the experts identified unmet need in the Parkinson's community and established an expert board to share opinions and define content. They organized two of multidisciplinary workshops and defined an educational path to collect insights from a variety of specialists.

These medical specialists also worked with digital experts to develop and refine content for the app. By marrying the skills of digital app developers with the deep medical knowledge of Parkinson's experts, the group collaboratively produced a successful app.

asume un reto poco frecuente



# Asume un reto poco frecuente

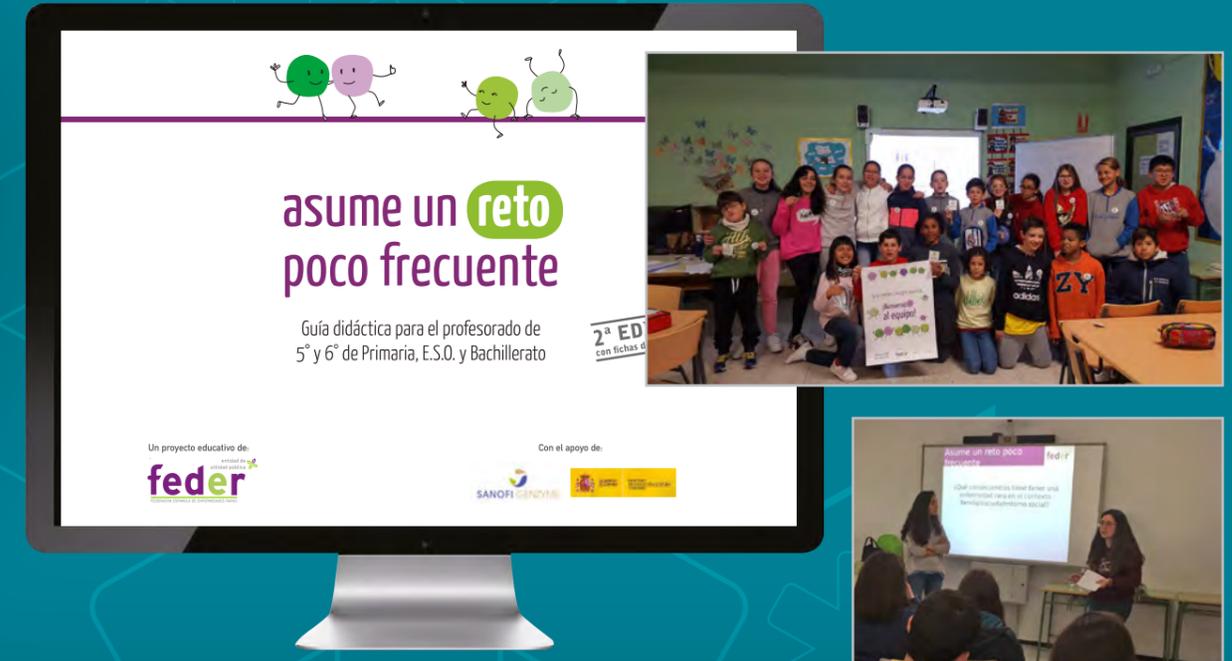
## Accept a rare challenge

**Rare diseases are, in summary, more common than many people think. While a disease or disorder is considered to be rare when it affects less than 1 in 2,000 people, there are between 6,000 and 8,000 rare diseases. In total, rare diseases may affect as many as 30 million EU citizens.**

Despite the diversity of these conditions, people with uncommon illnesses face similar challenges. In particular, they suffer from a lack of awareness among the public and health professionals, a slow and ill-defined diagnostic pathway, and a lack of treatment options. On a day-to-day basis, children with rare diseases may experience isolation and lack of understanding from teachers and classmates.

'Accept a rare challenge' is an educational awareness project designed by FEDER (the Spanish Federation for Rare Diseases) and Sanofi-Genzyme, with the objective of shedding light on rare diseases in schools and encouraging inclusion. The initiative involves an educational programme conducted through a series of activities for teachers and students. It is designed for those in primary and secondary education.

The activities, including quizzes, movies and flashcards, help raise awareness and interest in rare diseases. Since the start of this project in February 2014, 223 educational centres have joined the project, with more than 28,900 students taking part.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This initiative delivered direct benefits to people with rare diseases by enhancing knowledge and understanding among their peers and teachers. Students and educators also benefitted by developing deeper insights into the psychological consequences and real-life burdens of living with rare illnesses.

In addition, students learned that classmates living with rare diseases have many things in common with the rest of the group. In spite of the specific difficulties and needs that can accompany ill-health, all students shared similar dreams and concerns.

To measure the impact of the project, students completed questionnaires before and after activities. This allowed project leaders to track the evolution of students' knowledge and attitudes. Qualitative and quantitative information on teachers was also recorded.

By the end of the last school year (2018–2019) the initiative had been implemented in 223 educational centres, and continues to be offered at hundreds of schools in Spain.

### INNOVATIVE ELEMENTS OF THE PROJECT

This project addresses an unmet need in a proactive and collaborative way. People living with rare diseases report limited understanding of their needs in society. This is particularly challenging for younger patients who face social stigma and isolation in educational settings.

By engaging with teachers and school children, the initiative identified a practical and impactful way of educational consciousness-raising and diversity training aimed at increasing inclusion of groups with less-frequent diseases.

This was achieved using a methodology based on motivation, experimentation and research, cooperation and creativity. Each of these themes was addressed in training sessions and practical activities were undertaken in teams.

### COLLABORATIVE ELEMENTS OF THE PROJECT

The project brought together teachers, counsellors, school support staff, patients and other young people, with the support of Sanofi-Genzyme. By working with students, educators and industry, the initiative ensured a holistic approach to this complex issue. It helped to identify unmet needs and capacities of children affected by rare diseases, and fostered educational inclusion of young patients. This would not be possible for any one actor – industry, patient advocates or educators – working in isolation.

FEDER played a vital role in making the partnership work. It collaborated closely with Sanofi-Genzyme to deliver an effective initiative that met the highest ethical and legal standard. This guaranteed transparency while meeting the organisations' shared goal of improving the lives of people with rare diseases.



# Bladder Cancer Awareness Month 2018

**More than 175,000 people are diagnosed with bladder cancer in Europe each year. However, further work is needed to reduce the burden of the disease on patients. A crucial step in achieving better care for patients, is enhancing awareness of the condition and the treatment options. The Bladder Cancer Awareness Campaign focuses on educating, raising awareness and ensuring that bladder cancer is no longer a forgotten disease.**

Throughout May - recognised as Bladder Cancer Awareness Month – the campaign shared facts, statistics, information on risk factors and symptoms, and organised events across Europe, as well as running a multi-language social media campaign. This was all designed to raise the profile of bladder cancer and ensure better representation for the bladder cancer community in Europe and beyond.

The 2018 campaign’s ambition was to address the low level of disease recognition, helping to achieve a level of awareness and understanding in keeping with the disease’s position in the global Top 10 cancers. From the outset, it was acknowledged that making a breakthrough will take at least five years – 2018 was just the start.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Bladder Cancer is considered a neglected and virtually-forgotten disease. The patient community suffers a major disease burden, but does not receive the attention it deserves. The May 2018 Awareness Campaign was one of the first steps to reaching patients and the community.

Having organised a cross-border movement during May with a potential outreach of 22 million, the campaign managed to activate a huge part of the community. Patients, their families and friends spoke up, shared their stories and united to become a stronger community. Personal stories were shared in the media; clinicians and patients were highly visible; and connections were strengthened with patients communities in the US and Canada.

## INNOVATIVE ELEMENTS OF THE PROJECT

The campaign was based on simple messages and on often moving personal testimonies from individual patients. The campaign messages managed to engage two distinct audiences: those people with no knowledge and awareness of bladder cancer and those with a connection to the disease either as patients, family and carers, clinicians or other stakeholders.

The campaign’s third-party engagement strategy successfully reached new audiences through their networks, including the pharmaceutical industry, businesses, clinicians, hospitals as well as sports and social groups. The annual awareness activities for Bladder Cancer Awareness Month have evolved significantly from a small local campaign to the global movement of today.

The initiative has laid a foundation on which to build momentum for greater awareness of the disease and, ultimately, better outcomes for patients in the years ahead.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The major success of the campaign was achieved thanks to a strong engagement with the European Cancer Patient Coalition’s (ECPC) network organisations as well as partners, sponsors and individuals. This helped it reach audiences across Europe. Partners from the US and Canada have also adopted May as Bladder Cancer Awareness Month, giving the campaign a more global reach.

All partners, both industry and patient organisations, were able to become involved, providing ideas, insights, and hands-on support for delivering the campaign. Participants worked together towards the shared goal of doing what is best for patients with bladder cancer, as well as their families and friends.



# Brain Mind and Pain Patient-Centred Innovation Grant

**An estimated one in five people in Europe live with chronic pain. Pain can have a disruptive impact on people's lives, affecting their family, social and working lives. Addressing pain requires a deep understanding of the patient experience. This requires input from patients and patient advocates.**

The Brain, Mind, and Pain Patient-Centred Innovation (BMP) Grant, initiated by Pain Alliance Europe and supported by Grünenthal, aims to support patient-centred interventions designed to improve the lives of people living with chronic pain.

Normally, grants are given to scientific organisations based on a selection process led exclusively by healthcare professionals. The BMP Grant is unique. It empowers patients to select truly patient-centric projects for funding. Patient organisations are given a central role to ensure that the 'patient-centred' orientation of the grant, with support from scientific consultants from partner organisations.

This year, 20 projects from several European countries submitted entries for the 2018 BMP Grant. The jury, composed of patients' representatives, selected three projects which will be funded for the next 18 months. These were:

- MyBrainNet: a central platform for neurological brain diseases (Dystonia Europe);
- Master your pain: Improving access to personalized psychosocial treatment of pain due to rheumatic diseases (Groningen University);
- Reduce sensorial pain or stress in Autism Spectrum Disorder (ASPERGA Association).

The winners were announced at a ceremony in Brussels with Danuta Jazłowiecka, MEP, and all applicants were invited to attend.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Currently, there are 150 million people in Europe experiencing chronic pain – episodic, persistent, or variable – and they stand to benefit from the projects funded by the BMP Grant. The first BMP Grant saw many valuable projects apply for funding. The results of the selected projects will be available in June 2020.

The successful projects will offer online resources to people living with neurological brain diseases; enhance patient access to psychosocial treatment of rheumatic pain; and aim to reduce pain and stress for people with autism.

The Pain Alliance Europe will play an important role in ensuring that the results of these initiatives reach people living with pain. As an umbrella organisation with more than 400,000 members in Europe, it is well-placed to connect patients with new initiatives, tools and the latest scientific advances in pain management.

## INNOVATIVE ELEMENTS OF THE PROJECT

The BMP Grant is a unique concept in funding decision-making. It places patients in the driving seat, allowing them to decide on which projects are to be funded, ensuring that patient-relevant initiatives are prioritised.

BMP Grant formulates requirements to ensure that patient representatives are involved in the design, development and implementation of the proposed initiatives, not only as beneficiaries, but as partners, experts and decision makers.

The scientific organisations, the European Pain Federation (EFIC) and the European Academy of Neurology (EAN), provided advice as required to help identify the most innovative projects.

Together, patients and pain experts will apply this innovative decision-making model designed to improve the lives of people living with chronic pain.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The project was initiated by Pain Alliance Europe (PAE) and Grünenthal, with partner support from the European Pain Federation (EFIC), the European Academy of Neurology (EAN) and the European Federation of Neurological Associations (EFNA).

This brought together patients, experts and industry to give a holistic view of improving pain management in Europe. A Steering Committee was set up with representatives of all partner organisations. This group defined the process and criteria for selecting the winning projects.

All documents were reviewed and approved by the partner organisations to ensure that they complied with relevant regulations and used appropriate language. A website for the BMP Grant was developed to support the application process, with partners reviewing its content during development.

More information at <http://bmp-grant.eu/>



# BreastFit

**The incidence of breast cancer in women aged 20-49 has almost doubled over the past 30 years. It is often more common in women who are fully active in their professional, family and social lives. Around 30 percent of women develop advanced breast cancer (ABC). In about 5-10 percent of cases, this is diagnosed when the disease has already spread to other organs. These numbers could be dramatically reduced if women underwent regular preventive examinations.**

The aim of the BreastFit campaign is to increase systematic breast examination and education on prevention and the disease in both early and advanced breast cancer. The latest edition of the campaign targeted at men, supporting them in dealing with cancer when it affects the women in their lives – a mother, sister, wife or friend.

The third edition of the campaign, held in 2018, is also dedicated to women struggling with metastatic breast cancer. The need was identified by Fundacja OnkoCafe, whose volunteers meet patients and their relatives in their everyday work. Diagnosis, particularly of ABC, presents the patient and their relatives with a new, difficult situation that completely changes their lives and priorities. By increasing awareness of ABC, patients were empowered and made more visible to society.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

There are a number of benefits for patients and their caregivers: knowledge about prevention and the needs of metastatic breast cancer patients via leaflets, a reading list, a website, workshops provided by Onkocafe Foundation and psychological support.

The campaign and its messages reached numerous patients thanks to media coverage, social media impact, and the activities of all campaign partners. From 30 June until 20 September 2018, there were 271 articles with 5,882,122 media impressions, as well as 60,000 video views with 130 comments and 782 shares.

A total of 7,500 leaflets were issued focused on prevention, along with 3,500 guides for ABC patients which incorporated information on prevention and a caregiver guide. The website had 8,600 views while the YouTube video had 1639 views.

## INNOVATIVE ELEMENTS OF THE PROJECT

The method of building an audience for the topic of advanced breast cancer was innovative as it was not an immediately appealing for the media. To create media buzz, artistic photos of naked men were used to get the campaign noticed.

Another important element of this year's campaign was a video presenting stories of women with advanced breast cancer. A video entitled 'Invisible' was produced, showing that the challenges facing women with ABC often go unnoticed by society and the system.

There was also a calendar featuring 12 male athletes from Poland. All proceeds from sales of the calendar will go to women with ABC and their relatives.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The project attracted support from a range of organisations, including patient advocates, media organisations, and high-profile individuals, along with an industry partner. This ensured that the voices of women with ABC were heard and amplified in the media.

This broad cooperation brought a unique element to the campaign and provided access to media channels such as Multikino, a network of cinemas. Przelewy24, a payments company, facilitated online purchased of the calendar without any additional administration charges.

Support from the Patients Rights' Ombudsman and the First Lady of the Republic of Poland brought additional credibility and impact to the initiative.



# Certain Cancers can be Prevented

**The Human Papilloma Virus (HPV) is the leading cause of a number of anogenital cancers and diseases. Cervical, anal, vulvar and vaginal cancers, along with other frequent benign anogenital diseases, can be prevented through already available health prevention measures such as screening and vaccination.**

In Portugal, the HPV vaccine has been available through the National Immunisation Programme (NIP) for young girls since 2008. However, HPV is not restricted by gender or age, and all sexually active people are at risk of infection.

Education is the first step in creating willingness to adopt prevention measures. Although ten-year-old girls are being immunised in the NIP, HPV is also responsible for diseases in adult women and men. This project aimed to raise awareness of HPV and to address questions from people not included in the NIP.

Using the slogan 'Certain Cancers can be prevented - HPV does not choose age or gender', the project featured a website ([www.HPV.pt](http://www.HPV.pt)), a Facebook page and an online amplification strategy with digital influencers and YouTubers. The purpose was to engage and motivate people to talk to their doctor about the risks of HPV-related diseases and prevention measures, such as screening (for women only) or vaccination (for both men and women).



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

A better-informed population can make better-informed decisions. The ultimate benefit is the reduction of certain HPV-related cancers and diseases. The first step in achieving these health gains was to raise awareness among people of all ages and genders. There was a particular unmet need among those currently not benefitting from the HPV vaccination programme.

The success of the project was measured by assessing the number of users visiting the website and the Facebook community. The website has been accessed by more than 187,905 unique users, recording 244,635 visits. The Facebook page has 26,178 followers with a postengagement rate of 11.54 percent, meaning that the followers find the content helpful and meaningful. The number of followers of each digital influencer that partnered with the project is estimated at more than one million users.

## INNOVATIVE ELEMENTS OF THE PROJECT

The project relies on a fully digital ecosystem. It started with a website and Facebook page and is supported and disseminated by digital influencers to increase the reach and depth among the various target audiences.

On the Facebook page, there have been live streams with healthcare professionals – gynaecologists and paediatricians – taking live questions regarding HPV diseases, symptoms, treatments and prevention.

The website has had some updates. It now includes downloadable resources to motivate visitors to talk to their doctor and FAQs in video format, (also available on a dedicated YouTube channel). In the future more HCP's and digital influencers will be brought to the HPV conversation and the webpage visitors will have the possibility to subscribe to a regular newsletter.

## COLLABORATIVE ELEMENTS OF THE PROJECT

This initiative was a collaboration between LPCC (an anti-cancer organisation), APF (a family planning organisation) and MSD. All partners brought specific expertise to the development and execution of the initiative. LPCC had in-depth knowledge of general public cancer awareness campaigns, MSD contributed medical knowledge of HPV-related cancers and diseases as well as prevention measures, APF has a large network of influence among younger populations.

The partnership was formalised through a sponsorship agreement and regular meetings were held to share activity reports and revise content planning. This ensured active engagement of all parties and helped to deliver an impactful campaign informed by medical expertise and a deep understanding of the target audience.



# Crowd Ide@s

**More than 1,500 women are diagnosed with breast cancer each year in Sweden's Västra Götaland region. This is a devastating disease with a huge impact on women's lives as well as those of their loved ones. There is a significant need for psychological support for people affected by the disease. Patients and families experience need support in how to handle daily life and they often need someone to talk to.**

Crowd Ide@s is part of the solution to this challenge. Crowd Ide@s is a new 'way of working' (WOW) within the ecosystem of healthcare, academia, patients and the life science sector. A diverse group of partners established a steering committee and began working together to improve the care and lives of patients with breast cancer.



The collaboration proved highly productive. The group arranged an awareness initiative, a Facebook campaign, flyers, posters, rollups and promoted their work through the intranet of the steering committee. The project arranged workshops and local radio interviews, while a local newspaper published articles about the project. This work was supported through collaboration with the Sahlgrenska Innovation and Entrepreneur School, which provided support through Design Thinking methodology.

This was a new and exciting way of addressing a major problem. It engaged patients, families, friends, caregivers, doctors, nurses and citizens, and created valuable insights on how patients and their families experience the disease and their needs.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This was a person-centred initiative that listened to patients and their families, and responded with practical solutions designed to address their needs. The project asked patients, caregivers, healthcare professionals, nurses, families, friends and others to come up with ideas to improve and develop the care and lives of people affected by breast cancer. After six months, more than 200 ideas had been generated.

The initiative is implementing an app under the Crowd Ide@s umbrella in collaboration with the patient association, the healthcare system, the Västra Götaland region and Novartis. This will monitor patients' mental health and provide cognitive therapy for patients and their families. By providing a new tool to the patient community, the project added real value for people affected by breast cancer and addressed an unmet need identified by those affected by the disease.

## INNOVATIVE ELEMENTS OF THE PROJECT

Crowd Ide@s created a collective vision of healthcare in which stakeholders actively listen to the needs of patients, caregivers and families. This means that the full range of challenges arising along the patient pathway could be understood. It enabled stakeholder engagement on a level that goes beyond more traditional patient involvement efforts such as conferences or focus groups.

This innovative project tapped into the wisdom of the crowd to identify problems – and solutions – for a patient community in need of significant support. The methodology could inspire others to crowdsource answers to the biggest questions facing healthcare.

## COLLABORATIVE ELEMENTS OF THE PROJECT

This is a cross-sector collaboration with partners from all over the healthcare ecosystem: the local patient association, Johanna; the Sahlgrenska academy; the life science sector; and the healthcare system.

In addition, because the project used a shared funding model, it also shared ownership of the initiative. Partners collaborated with the students at the Sahlgrenska School of Innovation and Entrepreneurship, who helped to develop the ideas with colleagues at the Innovation platform. The patient organisation played a key role in this project and has been highly involved in all steps to move forward.

The initiative was built on a Steering Committee which ensured all partners had a seat at the table in developing and implementing the project. This group became a valuable new network upon which new collaborations can be built.



# Diagnosis Haemophilia - The story of an affected mother

**In Austria, there are 273 patients with severe Haemophilia A who need ongoing treatment. In total, there are 826 haemophilia patients registered with the lifelong chronic disease at varying levels of severity.**

Although haemophilia is often an inherited disease, more than 20 percent of people affected have no family history of it because the mutation in the FVIII gene is spontaneous. Therefore, the diagnosis, which usually comes when the child is aged around 8-12 months comes as a shock to the parents. To support families with this lifelong chronic disease, we wished to reassure parents that they are not alone, and that it is normal to feel a range of emotions after diagnosis.

The project featured a mother of a son with haemophilia telling her story about his diagnosis. For this, she drew pictures of their journey and wrote the accompanying text. She wrote about the stages of the disease and about how she coped with and accepted it, helping other parents with this diagnosis to understand that they are not alone. All her feelings are expressed in her drawings and writing.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project encouraged patients and their families to accept the disease and not fight against it. By reading about the experiences depicted in the booklet, parents of newly diagnosed patients could draw comfort from the fact that they are not alone in their journey. The drawings and text were published in booklet format and could be ordered from the website of Austria's haemophilia patient organisation. It was also made into an animated video that could be viewed on the site.

Success was measured by the number of booklets ordered, the number of times the video was viewed and time spent on the project website.

## INNOVATIVE ELEMENTS OF THE PROJECT

This is the first project by the haemophilia organisation/patient organisation in which personal experience has been used to reassure other parents facing similar experiences. The focus is on the emotional side, rather than the clinical side, of the disease and the project is directed at parents and families of patients, more than the patients themselves.

Supporting parents through this experience is vital and has knock-on positive effects for the patient. The distribution of the booklet and video through the patient organisation website ensured that the message reached its target audience.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The campaign was designed and executed in partnership with the Austrian Haemophilia Patient Organisation. This organisation put forward the mother/author at the heart of the campaign, Andrea Jäger. Shire, the Austrian Haemophilia patient organisation and Andrea Jäger worked together to create the booklet and video. All partners contributed to prompting the campaign, helping to amplify its impact.



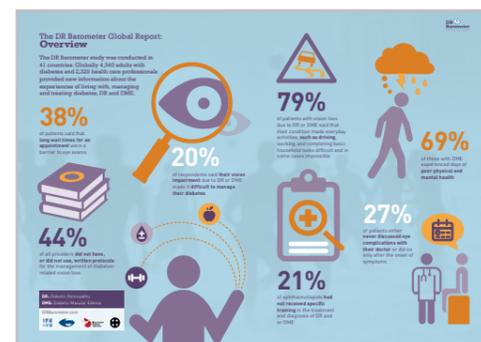
# DR Barometer Programme

**Vision loss is one of the most feared complications of people living with diabetes. Some 35 percent of people living with diabetes will go on to develop Diabetic Retinopathy (DR); of these, one in three are expected to develop diabetic macular oedema (DME), the leading cause of blindness in young adults in developed countries.**

The DR Barometer is the product of a unique collaboration of experts from the International Federation on Ageing (IFA), the International Diabetes Federation (IDF) and the International Agency for the Prevention of Blindness (IAPB), the Vision Academy, Bayer Pharma and GCI Health.

The programme, which seeks to improve the vision health of adults living with diabetes, was launched in 2016 with a study of over 7,000 adults with diabetes and providers in 41 countries. It identified serious gaps in awareness and education of diabetic eye diseases (DED) as well as pressing barriers to screening and treatment services at a country level.

To mobilise the study findings and address the gaps identified, the programme brought together key stakeholders in a global community to develop meaningful and sustainable interventions. The outcomes included publishing the study in important clinical journals; a pan-European advocacy workshop featuring over 60 experts and establishing the DR Barometer Communities of Practice, a growing multidisciplinary network of thought leaders and organisations.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Millions of people living with diabetes in Europe stand to benefit either directly or indirectly from this. First, the DR Barometer Programme gathers patient perspectives from the study conducted in 41 countries, around half of which are in Europe. These included findings from over 7,000 patients and health professionals that treat diabetes and its associated complications. This is important, because although capturing patients' views and opinions are crucial, it should be in partnership with the people that provide care, conduct research into new treatments and have the capability and the influence to change healthcare systems.

## INNOVATIVE ELEMENTS OF THE PROJECT

The size and scope of the DR Barometer Study was itself innovative, as is the way the DR Barometer programme has subsequently evolved. A unique element of the DR Barometer Programme is the Communities of Practice initiative, which aims to help improve vision health outcomes among people living with diabetes by encouraging communication and collaboration between disciplines. The DR Barometer European Advocacy Workshop was also groundbreaking in that it united a range of disciplines from 12 countries, including primary care physicians, diabetologists, ophthalmologists, patient groups and NGOs.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The DR Barometer programme was created through the understanding that collaboration is critical in improving patient outcomes. Since the inception of the programme, strong multidisciplinary and sectoral alliances have been formed. From the outset, the IFA, the IAPB, the IDF and Bayer have worked together to ensure all parties remain true to the programme's aims of optimum patient outcomes and putting the best interests of patients at the centre of activities. Join the DR Barometer Community [www.drbarometer.com](http://www.drbarometer.com)



# El cine se pone en pie por el cáncer renal -

## The cinema stands up for kidney cancer

**Kidney cancer is a virtually unknown disease in Spain, even though it affects one in every 100,000 people and causes almost 3,000 deaths per year. The lack of knowledge of the disease, as well as the risk factors, make it difficult to implement preventive measures.**

The goal of the campaign was to inform the Spanish population about kidney cancer and encourage early diagnosis. The first phase involved showing a short film in cinemas for a week. This was designed to be a call to action: all those who watched the film were meant to stand up for a few seconds in support of patients.

The second phase saw information stands at busy spots in Spain's main cities to spread awareness of the campaign and inform people about prevention, early diagnosis and symptoms of kidney cancer. Both phases of the campaign were related to the concept of 'time', as this is a cancer with a poor diagnosis and every minute counts for these patients.

The objectives of the project were to raise awareness of kidney cancer and show the importance of making the disease visible, to help people understand the disease in such a way that would help in early diagnosis, and to help society understand the challenges and limitations that these patients face.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The campaign was targeted at the general public and generated a great deal of conversation in offline and online media, radio, TV and social media.

There is no precise data on how many patients benefitted from this initiative, given that it was focused on both patients and the wider general public. However, we do know that the campaign reached over 5,000,000 people through the media campaign and over 115,000 people through the cinema and on-street marketing.

### INNOVATIVE ELEMENTS OF THE PROJECT

Phase one of the campaign, in which cinema-goers watched a short film and were encouraged to stand up in support of patients suffering from kidney cancer was a new and innovative way of raising awareness.

The second phase of the campaign was advertising on public transport in Spain, including stands in subway stations in major cities (Madrid, Barcelona and Seville) and at the hot spots of Spain's main cities. These combined actions completed an innovative 360° strategy which reached the target audience through different media and supports.

### COLLABORATIVE ELEMENTS OF THE PROJECT

Bristol-Myers Squibb collaborated with key opinion leaders from leading patient associations such as la Federación Nacional de Asociaciones para la Lucha Contra las Enfermedades del Riñón (ALCER) and scientific societies such as Grupo Español de Oncología Genitourinaria (SOGUG).

Through this worthwhile collaboration, our campaign reached key media outlets (both general and those specialising in covering health) and the general public.



# Embracing Carers™

**Almost everyone, at some point in their lives, will either receive help from a carer or act as a carer themselves. On any given day, carers are called upon to play the role of pharmacist, nurse, insurance agent, financial planner, cook or cleaner. There are as many as 100 million carers in Europe today – 20 percent of the EU population.**

The key aims of Embracing Carers™ are to empower carers to advocate for their own health and well-being and drive a call to action for support of carers worldwide, including within healthcare systems. In doing so, we can highlight the unmet needs of carers on a global and local level. By building connections and implementing real-life solutions, the initiative seeks to provide support to carers, who often do not know where to turn for help.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

While it's difficult to quantify precisely how many patients benefitted from the Embracing Carers™, awareness efforts have had a media reach of over 1 billion since inception reaching carers in 47 countries.

Additionally, by forging innovative collaborations with more than 20 organizations, we have supported new initiatives that help carers handle emotional stresses, financial burdens and work issues better. These collaborations have reached millions of carers in areas such as MS and Oncology.

## INNOVATIVE ELEMENTS OF THE PROJECT

Embracing Carers™ focuses on four areas for innovation.

First, support greater self-identification, as well as practical support and solutions, for carers.

Second, increase the number of stakeholders engaged in providing support for carers. We are collaborating with the International Alliance of Carer Organizations to ensure scale up and spread innovative practices from around the world.

Third, establish global policy best practice sharing and activation of specific support for carers.

Last, promoting carer-friendly policies on an international level, replicating successes and solutions at every opportunity.

## COLLABORATIVE ELEMENTS OF THE PROJECT

Embracing Carers™ is advised and supported by leading international carer organisations, ensuring that the aims of the initiative are aligned with, as well as recognised and respected by, international leaders in the area. This ensures that the initiative directly benefits the health and wellness of carers around the world.

Embracing Carers™ global advisors include Caregiver Action Network; Carers Australia; Carers UK; Carers Worldwide; Eurocarers; National Alliance for Caregiving; International Alliance of Carer Organizations and Shanghai Roots & Shoots, China.



# Epatite C Zero

## Hepatitis C Zero

**Hepatitis C virus (HCV) is an infectious liver disease. It is a major burden on infected patients, but in recent years new therapies have dramatically improved disease management. Raising awareness of these new treatment options is vital to enhancing outcomes.**

Epatite C Zero is an educational campaign on HCV prevention and management, targeting HCV patients, caregivers and the general public. The campaign is a collaboration between a leading Italian patient association (EPAC) and the Italian Foundation for the study of the Liver (FIRE).

It seeks to improve understanding of HCV symptoms and the risk factors for the disease; to communicate the fact that HCV can be treated and cured; to highlight how prompt treatment helps to avoid disease progression and prevent or manage complications; and to highlight the value of partnership (with doctors, patients and institutions) in fighting HCV effectively.

The campaign consists of a web-based series in five episodes, published and promoted on the EPAC Facebook page. The series focuses on the stories of five HCV patients and one doctor.

The initiative also hosted public educational meetings in Italian cities targeting patients, caregivers and others interested in HCV (academics, patients, HCPs and institutional stakeholders). An anonymous survey before the beginning of the public event tested awareness of HCV and provided correct answers and comments during the events.

The campaign was launched on September 2017 and ended on February 2019. To date, it has generated 80 million media contacts, more than 1.2 million page views and more than 6,000 interactions on social media.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The main benefit for patients, caregivers and non-patients is receiving clear information that is often lacking. It also provides patients with an opportunity to share their experience and ask experts for advice.

The first three events (in Turin and Padua) attracted more than 170 patients. The attendees interacted with the speakers, asking lots of questions both during the event and privately afterwards.

Social media activity was another barometer of impact. The web series saw more than 6,000 interactions with over 1,000 comments. It also served as a hook for people to get in touch with EPAC with questions after watching episodes.

### INNOVATIVE ELEMENTS OF THE PROJECT

The language used in the campaign was innovative and helped enhance its impact. HCV is explained through a simple, 'viral' approach, in order to engage the public and to promote further follow-ups with experts where necessary.

The collaboration between a patient association and a scientific society was also vital. This allowed the project to develop stories based on real-life experiences, which people could identify with easily.

### COLLABORATIVE ELEMENTS OF THE PROJECT

FIRE is the scientific supervisor of all content; prominent members of the Foundation joined local public events as lecturers. In addition, FIRE members inspired the character of 'the doctor' in the web serial. They collaborated with EPAC in building the story and in creating all the materials.

An EPAC Representative (the President, Vice President or both) takes part in the local events as lecturers. They also actively collaborate in collecting stories that could inspire both the main storyline of the web series as well as single stories. EPAC has promoted the web series on Facebook as part of the digital strategy.



# 'Expression of Hope Belgium', A(rt)wareness On Rare Diseases: From Pencil to Public

**Raising awareness of rare diseases can be critical in helping ensure people are diagnosed correctly and as soon as possible. Lysosomal Storage Disorders, or LSDs, are a group of rare genetic diseases caused by a problem with a particular enzyme in the body. There are over 40 diseases classified as LSDs, and while individually each of these diseases is relatively rare, together they affect one in about every 7,000 people.**

In 2006, Sanofi Genzyme Global launched the Expression of Hope programme, to give people affected by lysosomal storage disorders (LSDs) the opportunity to raise awareness of these rare genetic diseases.

In Belgium, "Expression of Hope" is a public awareness campaign on rare diseases using works of art made by patients affected by lysosomal disorders. It consists of an art exhibition showcasing 25 pieces of art travelling around hospitals and other health institutions in Belgium and Luxembourg. It includes a mix of photos, paintings and drawings made by adults and children affected by a lysosomal disease. Showcasing paintings and drawings of patients is proving an effective way of enhancing the

awareness of rare diseases involving hospital staff, visitors and the patient community.

At the start of the exhibition, there is an official opening for hospital staff, during which one or two physicians specialising in rare diseases give a presentation along with a patient, who explains the impact of the disease on their daily life.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Greater awareness increases the likelihood of a rare disease patient being diagnosed. Usually the physician makes the diagnosis, however the patient or their family can recognise certain symptoms or realise something is wrong. For someone with a rare disease, to be heard and to see an exhibition dedicated to their disease helps break the silence and can encourage them to talk about the disease.

Depending on the hospital size, between 1,000 to 10,000 people may visit the exhibition daily. The average duration of the exhibition is two weeks per hospital. In 2018, 11 different locations hosted the exhibition over 200 days.

## INNOVATIVE ELEMENTS OF THE PROJECT

Using art to increase awareness about rare diseases is a new concept. The exhibition provides information on the different Lysosomal Storage Disorders. However, the main innovation is in using the creativity of patients to both show how talented they are and to shine a light on their disease.

Each artist provides an emotional message alongside their artwork describing his or her own vision of hope. Despite their disease, they show people that there is always hope. This is a strong message for all of us, irrespective of health.

## COLLABORATIVE ELEMENTS OF THE PROJECT

Everything started from patients and patient organisations. Without patients, nothing would have been possible. The hospitals were very positive about our exhibition project and Sanofi Genzyme worked closely with their communication departments to ensure the smooth running of the exhibition.

In each hospital, during the exhibition, rare diseases specialists are involved, giving lectures, explaining what rare diseases are and creating awareness among their peers.

There is also the opportunity for some Belgian patients to (dare to) talk about their disease. The Expression of Hope Facebook page is creating a community and connecting people interested and involved in rare diseases.



# Female Oncological Prevention

Every year, 190,000 Italian women are diagnosed with cancer. Fortunately, six out of ten defeat the disease. However, prevention is the most powerful weapon to fight cancer. Some 40 percent of cancers could be avoided by adopting the correct lifestyle behaviour and by taking part in screening programmes and vaccinations.

**Un vaccino e un esame salvavita**

Esiste un pericoloso virus che si chiama **HPV** e che può insidiare il benessere femminile. È uno dei principali responsabili del tumore della cervice dell'utero e di altre malattie. Viene trasmesso durante i rapporti sessuali anche non completi. Per evitare i contagi esiste per fortuna un vaccino in grado di debellare l'infezione, in caso il corpo vada incontro al virus.

Quindi i virus non portano solo all'influenza... possono avere conseguenze ben più pericolose per la salute femminile?

Sì Fede, hai perfettamente ragione. **Circa l'8-10% dei tumori è dovuto a infezioni virali**, in molti casi prevenibili con le immunizzazioni. I vaccini sono dei presidi sanitari salvavita che possono prevenire efficacemente molte malattie tra cui il cancro.

**In tutta Italia è possibile vaccinare gratuitamente le ragazze a partire dai 12 anni di età; per maggiori informazioni bisogna rivolgersi all'Azienda Sanitaria Locale o chiedere al proprio medico. La somministrazione avviene per via intramuscolare, nel braccio, ed è composta da tre dosi (dopo la prima, altre due a distanza di 2 e 6 mesi) e non occorrono ulteriori richiami. L'immunizzazione si è dimostrata fondamentale anche per tutelare la salute dei ragazzi. Un terzo del totale dei casi di infezione da HPV riguarda infatti i maschi.**

The Female Oncological Prevention initiative is a communication campaign promoted by the Together Against Cancer Foundation, in collaboration with the Italian National Olympic Committee (CONI) and supported by an unconditional grant from MSD Italy. To provide the maximum impact, Italian Olympic Gold Medallist Swimmer Federica Pellegrini provided testimonials.

The project was created with the aim of informing and raising awareness among young women of female cancer prevention with a particular focus on screening programmes, lifestyle behaviours, anti-smoking programmes and vaccinations.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The benefit for young women and the general public was in becoming better-informed about the importance of female cancer prevention. They could learn about the value of screening programmes, improving lifestyle behaviours, anti-smoking programmes and vaccinations.

The results have been measured with several KPIs on message outreach, with the campaign and its prevention messages reaching millions of people. More than 30,000 leaflets were distributed. There were 177,000 views on Federica Pellegrini Instagram profile with 100,000 views on other channels along with 35 million views generated by media outreach. Finally, there were 13,000 social media views.

## INNOVATIVE ELEMENTS OF THE PROJECT

The Female Oncological Prevention campaign is an initiative based on a synergic and complementary usage of communication channels with a specific focus on digital communication.

The communication plan included several elements. Firstly, an educational booklet was published, with Federica Pellegrini and Francesco Cognetti, President of the Together Against Cancer Foundation, as the main characters. Booklets were distributed throughout Italy including in general practitioners' offices.

Secondly, a spot with Federica Pellegrini went viral on social media (YouTube, Instagram, Facebook). And finally, a national press conference was held at the Italian National Olympic Committee headquarters in Rome.

## COLLABORATIVE ELEMENTS OF THE PROJECT

MSD and the Together Against Cancer Foundation in collaboration with the Italian National Olympic Committee were inspired by a shared vision of saving and improving lives. The contribution of Federica Pellegrini served to increase the reach of the campaign by leveraging her existing audience.

The organisations, each one with its specific role, decided to commit together to creating educational campaigns that can have a real impact and make a difference, both in people's lives and in the health care system.



# Gritos a pleno pulmón

## Scream against Cancer

**Do you understand the causes, symptoms, prevention and diagnosis of lung cancer? A survey on behalf of Bristol-Myers Squibb among 1,023 Spanish people revealed that 62 percent of those asked admitted to not being well-informed about the disease. The results highlighted a lack of knowledge on the symptoms and severity of the disease and the groups at risk. This data was particularly striking given that in the next 20 years in Spain, increasing tobacco use means lung cancer occurrence will increase in both men and women.**

The idea behind Gritos a Pleno Pulmón (Scream against Cancer) was to encourage society to share a scream – ‘grito’ – against lung cancer and inform themselves about the symptoms and risk factors.

The objectives were to inform the public about lung cancer, risk factors, symptoms, prevention and early diagnosis. The initiative aimed to dispel myths about lung cancer, destigmatise the disease and educate society to seek medical attention. It also aimed to give visibility to lung cancer and encourage society to send solidarity and hope – a ‘grito’ to the people that fight to overcome it every day



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The campaign was directed at the general public but, by raising awareness, will have a positive knock-on effect on the patient community. The actions had a substantial impact on the target market as a consequence of the activities undertaken and may even help some people to identify symptoms earlier.

In total, the campaign impacted 17,760,814 people through traditional media (online and offline newspapers, magazines, radio and television), 7.2 million impressions in social media, and 20,070,697 million advertising impacts.

### INNOVATIVE ELEMENTS OF THE PROJECT

In the week of the International Day Against Lung Cancer, partners undertook a range of activities to increase the visibility of the disease and encourage members society to ‘shout’, through a photograph or video, as a sign of solidarity with the patients.

The campaign was rolled out in major Spanish cities. The messages were visible in the transport media of cities of Madrid, Barcelona or Valencia; media advertising and a campaign video-spot in multiple metro stations in Madrid.

### COLLABORATIVE ELEMENTS OF THE PROJECT

Patient associations, scientific societies, and industry came together to maximise the impact of the campaign and ensure its relevance to the target audience. In addition, partners collaborated with Spanish celebrities, including Marta Hazas, Javier Rey, Rozalén, David Otero, Ana Millán and Octavi Pujades, along with well-known Spanish journalists such as Manolo Lama and Mar Montoro.



# Haemophilia - Myths and Facts

**Some people with haemophilia believe if they cut their fingers or have any trauma they will bleed to death. This makes parents want to protect and wrap their affected children in 'cotton wool' in a bid to avoid potential trauma situations.**

In fact, those affected with haemophilia are completely normal and should be treated normally – their only problem is joint bleeding which could be prevented. Joint bleeding occurs in the space where two bones meet. In people with haemophilia, the most common areas to have joint bleeding include the elbows, knees and ankles. While these can be serious, it does not mean that people should avoid physical activity in order to minimise the risk of trauma or injuries, according to experts

The Myths and Facts project set out to address the anxieties and worries people have over how to deal with people with haemophilia. The ultimate goal was to improve understanding, awareness and acceptance, and improve the lives of those living with the condition.

**Gelenkschmerzen - Warum Prophylaxe wichtig ist**

Die **Gelenk** verbindet zwei oder mehrere **Knochen** miteinander. Gelenk und Knochen sind von einem glasigen Gewebe, dem **Knorpel**, überzogen, der für eine reibungslöse Bewegung sorgt. Knochen und Knorpel sind wiederum von einer mit Flüssigkeit gefüllten **Gelenkkapsel** umhüllt, welche als Polsterung dient.

Die Innenhaut der Gelenkkapsel hat feine, kleine Blutgefäße. Stürzen wir oder schlagen wir uns an einem Gegenstand an, so kann das die Blutgefäße verletzen und Blut tritt in die Gelenkhöhle ein. Das betroffene Gelenk schwillt an. **In dem Fall ist es wichtig, sofort den Faktor zu spritzen und den behandelnden Arzt zu kontaktieren.**

Je öfter eine Gelenkblutung auftritt, desto weniger ist die Innenhaut in der Lage auf die Verletzung zu reagieren. Die Blutgefäße werden noch feiner und anfälliger für neue Verletzungen. Das Eisen in unserem Blut kann unsere Knochen langsam zersetzen und macht die Knochen porös. **Das Gelenk wird unbeweglicher und starke Schmerzen sind die Folge.**

**Das muss aber nicht sein.** Heute gibt es eine Therapie, die das alles verhindern kann. Man weiß auch, dass das regelmäßige Spritzen des Faktors Gelenkschäden vorbeugt. Zwei bis drei Mal die Woche sollten wir den Faktor spritzen. Wenn wir viel Sport machen, dann auch mal mehr. Insgesamt wird auch das zur Routine – fast ein bisschen wie Zähne putzen.

**HÄMOPHILIE**

**ERWECKE SIE ZUM LEBEN!**

- plusApp downloaden und starten
- QR Scanner auswählen und Code scannen
- Handy oder Tablet über die gesamte Seite halten

Für die Demo, warum Matthias in Luftpolsterfolie eingewickelt ist

**MYTHEN & FAKTEN RUND UM HÄMOPHILIE**

**„Unser Sohn ist Bluter - Wir müssen Sicherheitsmaßnahmen setzen!“**

So denken Eltern, für die die Diagnose überraschend kommt... und sie haben die weitesten Vorstellungen!

Aber nicht nur unsere Eltern - auch Lehrer, Verwandte oder viele andere glauben, dass wir auf der Stelle verbluten, wenn wir uns schneiden. Sie wollen uns in Watte packen, weil jede Bewegung und jeder Sturz riskant sei.

Unabhängig davon können bei uns sportliche Aktivitäten aufleben. Gerade unsere Gelenke sind davon betroffen - am häufigsten die Kniegelenke, Ellbogen oder Fußgelenke.

**UNSERE GELENKE**

sind ziemlich komplex, Laufen, Springen, Schwimmen - all das ist möglich, weil unsere Gelenke beweglich sind.

In jeder Blutung werden diese mehr und mehr beschädigt. Die Folge sind Entzündungen und im schlimmsten Fall starke Schmerzen.

## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

By creating two 'slapstick' movies, two haemophilia-affected patients illustrated how they lived normal lives. People were able watch the videos by accessing a QR code.

In Austria, there are 272 severe Haemophilia-A patients requiring treatment; in total there are 826 patients with differing severities of haemophilia registered in the country. Success of the project was measured by the numbers of people downloading the QR code.

## INNOVATIVE ELEMENTS OF THE PROJECT

The project featured a printed flyer with augmented reality videos. By using a QR code scanner, the integrated videos could be seen using a mobile phone. This is the first flyer with augmented reality in the haemophilia care sector.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The content of the flyer and videos were made in cooperation with the Austrian Haemophilia Patient Organisation. The two protagonists in the video are actually boys with the condition. The project was completely undertaken by the Austrian Haemophilia Patient organisation which took care of the content and transparency.

# HUMMAN

Humanizando el Itinerario del Paciente con Mieloma Múltiple



## HuMMan Project

**In Spain, more than 2,500 cases of multiple myeloma (MM) are diagnosed each year; it remains an incurable disease. However, new therapies now mean survival rates of between seven and eight years. This has increased the prevalence of the disease; the time these patients spend in the health care system is also greater.**

In addition to their care from haematology specialists and support from primary care physicians, patients with MM may require care from other specialists. As there is no unified treatment protocol for the disease in the Spanish National Health System (SNS), doctors looking for the best treatment options for their patients, also face a difficult task.

To alleviate the physical and emotional stress that a patient may suffer during diagnosis and treatment of the disease, the Sociedad Española de Hematología y Hemoterapia (SEHH), in collaboration with Takeda, has launched the HuMMan project.

The main objective of the HuMMan project is to identify those needs not currently covered in the patient's journey and, by addressing these, allow for more humanised assistance. These actions are aimed both at providing patients and family members with good information. This will guarantee continuity and coordination between levels of care and actions that allow a better response to psycho-affective, psychosocial and quality of life needs.

### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project analysed the patient's journey, agreed on recommendations, identified priority lines of action that could be developed at a later stage, and disseminating the results of the initiative.

Every patient that has multiple myeloma stands to benefit from this project. It may also benefit health staff by establishing a more efficient and coordinated approach. Above all, addressing these different needs would improve the quality of life of MM patients.

Through various actions, it should be possible to provide the information that patients and relatives need on the disease and its phases. In addition, a unified protocol for patients with MM can contribute to an early diagnosis of the disease, as well better use of the appropriate treatment.

### INNOVATIVE ELEMENTS OF THE PROJECT

The most important and innovative element is that there has never been a unified protocol among all the hospitals of the National Health System (SNS) for treating multiple myeloma in every patient. This is a major step forward and will improve the lives of today's patients, as well as those diagnosed in the years to come.

Another benefit of the initiative is that this project relies on a multidisciplinary vision of the disease. Moreover, it incorporates the vision of both patients and their caregivers. This offers a more holistic and patient-centric approach. Finally, the project uses a methodology capable of guaranteeing quality outcomes.

### COLLABORATIVE ELEMENTS OF THE PROJECT

The project has the support of the pharmaceutical company Takeda, as well as the endorsement of the patient association Spanish Multiple Myeloma Community (CEMMP). Furthermore, it counts on the Advisory Committee led by the SEHH and a panel of experts.

This partnership ensures the right combination of technical experts while putting the patient voice at the centre of its work. Collaboration was essential to the innovative and ground-breaking work that led to a unified protocol for people with MM.



# IBD Toilet Card Campaign

**Inflammatory bowel disease (IBD) is a chronic disease with a high impact on quality of life. It can cause physical discomfort as well as carrying social stigma that can significantly impair patient confidence and curtail independence. However, it is an invisible disease and consequently there is little public awareness and understanding.**

This becomes obvious when IBD patients are out and about and ask for access to the toilet. When they experience that urgent need to go to the toilet cannot find one right away, they risk having a very embarrassing ‘accident’ in public. However, when they do find the toilet – in a store, a bar or a restaurant – they try to explain their condition and ask if they can use the bathroom. Sadly, too often the answer is ‘no’ – even when patients carry a ‘toilet card’ explaining that they have a medical condition.

The IBD patient advocacy groups (PAGs), with help from Takeda, decided that this was no longer acceptable and launched a campaign to ensure toilet access, either through a solidarity movement or by giving the toilet card legal status.



**13,490**  
mensen tekenden all

**Samen maken we IBD zichtbaar.  
Tekenen de petitie en maak de toilet pas afdwingbaar.**



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

All 30,000 IBD patients in Belgium and people in their environment benefit from greater awareness and understanding of their disease. Steps are now under way to launch a single toilet-card and to ask for solidarity from shopkeepers and the hospitality industry.

Public awareness of IBD was raised substantially, with 20 media articles as well as coverage on national TV and radio. Most articles focused on the burden of living with IBD, not simply the toilet access issue. Policymakers were also actively engaged and expressed their willingness to change the situation. There were also 13,000 signatures on an online petition.

## INNOVATIVE ELEMENTS OF THE PROJECT

The campaign used a ‘candid camera’ approach to highlight the real-world challenges faced by IBD patients. The video showed the barriers patients face when they ask to use the toilet in shops and restaurants.

It is difficult to get the attention of the general public and policymakers for an invisible disease such as IBD. Yet by highlighting a well-known, relatable situation (being denied access to a toilet), the project gained the public’s mandate. This was key to engaging policy maker and the hospitality industry.

As a direct result of the campaign, other patient organisations have reached out to the IBD patient groups and are now discussing how to continue with the campaign. This kind of collaboration, the coming together of patient advisory groups, is quite unusual.

## COLLABORATIVE ELEMENTS OF THE PROJECT

Takeda’s priority is to put the patient at the centre and ask how we can do more for them. With this in mind, strong relationships were established with patient advocacy groups. The company’s patient engagement manager regularly meets with PAGs to discuss specific issues and needs. Based on these insights, solutions that add value to patients’ lives are co-created.

The issue of low awareness and lack of understanding is always on top of the list of IBD PAGs. Following a brainstorming session, partnership came up with a project outline and asked a PR agency to help design a campaign.

From the start, the campaign was co-created with the PAGs at the centre and Takeda as a facilitator. PAG board members contributed to the production of a candid camera video and their spokespersons were interviewed by several journalists.



# Patient Advocate Advisory Council

**The advent of patient-focused drug development is changing medicine. It has brought into sharp focus the priority of establishing a systemic approach for engaging the patient voice in drug development. In 2016, Bayer launched a pilot programme in oncology called the Patient Advocate Advisory Council (PAAC) with the goal of designing and executing a programme where patients join clinical development teams as advisors.**

Through the first phase of the programme, a training platform was launched, additional PAAC members were recruited to expand the initiative's reach across the cancer community, and the team learned that patient advisors should be engaged as early as possible.

A critical success factor identified for the programme was having champions for patient engagement within the organisation, to ensure that activities are streamlined, standardised and advanced. This is particularly important given that patient engagement should be considered a long-term investment with sufficient and sustained dedicated resources.

The PAAC and Bayer team have committed to sharing learnings to advance opportunities for successful patient engagement in drug development throughout the oncology therapeutic landscape.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

To date, the pilot programme has yielded positive effects. There were important insights from the expert patient into crossover design considerations on the information provided to patients. In addition, they discussed the feasibility of capturing regular data from patients and in developing informed consent materials. During this process, there has also been progress on evaluating patient engagement in other study teams within Bayer.

The benefits will accrue first to patients that will be enrolled in Bayer Oncology clinical trials. In addition, lessons learned will benefit those patient communities – via the patient advocates – that participated directly in the PAAC and the pilot project.

## INNOVATIVE ELEMENTS OF THE PROJECT

This project successfully established patients as valued members of the Bayer clinical development team. This was a first for the organisation and represented relatively new territory for most drug development companies.

The PAAC team members identified inclusive mechanisms and processes within Bayer and supported the company in adopting this model more broadly, with the support of company leadership. Including the patient expert in the research team ensured that Bayer's research was better informed.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The PAAC is made up of leading patient advisory groups (PAGs) focused on supporting patients, caregivers and healthcare professionals in various cancers.

The European Men's Health Forum, Fight Colorectal Cancer, Friends of Cancer Research, Facing Our Risk of Cancer Empowered, WSCollaborative and Bayer teams, along with patient advocates and survivors, worked collaboratively to develop this pilot programme and the tools to help implement it.

**INDETECTABLES**  
WEBSERIE



# INDETECTABLES

**INDETECTABLES is a prevention campaign for HIV and other STIs, which also talks about stigma, discrimination and diversity using an innovative approach. Via the [www.indetectables.es](http://www.indetectables.es) website, it takes a fresh look at prevention presented with a hint of humour and involving candid everyday issues.**

Its main goal is to develop a unique prevention campaign talking about sexual health and diversity using fiction, like many other series our target group watches daily. They key audiences for the initiative are the LGBTBIQ community, young people, women, and the sexually active community members that need information.

The first season had five episodes: 'Me too', 'High risk', 'The evidence', 'Renew or die' and 'In the wall'. It attracted over 1,000,000 viewers online and at festival screenings. The project also provided daily information through social networks – Facebook, Twitter and Instagram – with more than 10,000 followers. It talks about HIV, but also other issues such as STIs, sexual and health rights, the LGBTBIQ community and HIV comorbidities.

The next World Aids Day will see the launch of a second series with five more episodes: 'Chenoas' fault', 'Bla Land', 'Always when I talk about', 'Volcanic' and 'Stigma'. The project has already planned the third season and is bringing in many new partners.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

In recent years, there have been no effective prevention campaigns for HIV or other STIs, while numbers of new infections in Spain are rising. In addition, there was new information - undetectable HIV means it is untransmissible. This information was not reaching those at higher risk, so we needed to bring these simple messages on prevention and diversity, to our target group.

More than 10,000 followers benefit daily through our 2.0 strategy and communication channels. The community is engaged not only in watching the series but in creating it: more than 80 community members are working on the production and on the project. As the series is accessible through schools and universities, more than 600 students have watched the series and discussed it.

### INNOVATIVE ELEMENTS OF THE PROJECT

There is no other project in the field of HIV and sexual health in the world like INDETECTABLES. It is the first series talking, unscripted, about issues such as HIV and sexual health. The format of the seasons is also innovative: five unconnected episodes, each with different filmmakers and actors, but with a common season goal.

The quality of the series, the campaign delivery as an online resource and the participation in film festivals, has also made it an educational tool at universities and schools.

### COLLABORATIVE ELEMENTS OF THE PROJECT

Apoyo Positivo develops programmes through co-creation and design thinking; the first meeting that led to the INDETECTABLES was the beginning of the idea to film easy and informative videos on these topics.

Janssen has always supported innovative projects and campaigns making them the first industry partner to approach; they have also made other audiovisual projects with NGOs in the past. A team was created with members from Apoyo Positivo, NGO and community members, Janssen and artists. Together, they discussed the themes of the episodes, the format and the content. Every detail was a collaborative process, making INDETECTABLES a common effort.



# Interdisziplinärer Schmerzdialog

## Interdisciplinary Pain Dialogue

**With about 40 percent of Austrians enduring pain, half of those chronic pain, the country needs a modern and accessible pain management service. However, access to adequate therapy is limited and waiting times are unacceptable, leading to the development of chronic pain.**

The aim of our Interdisziplinärer Schmerzdialog project was to establish a sustainable and productive cooperation between all stakeholders in the field of managing and treating pain. Pain, particularly chronic pain, is not widely acknowledged as an illness with affected persons often untreated or inadequately treated for years. The project aimed to create a dialogue between patients and relevant stakeholders on this condition, affecting around 3.6 million people in Austria.

The objectives were to implement a coordinated pain management scheme, including education and further training for medical professionals, raising public and professional awareness on the different effects and severity of pain. It included an emphasis on the gender and age components, and on creating a plan for a patient-centred network of pain centres.

During the project, relevant stakeholders – patient organisations, healthcare professionals and political actors – jointly developed concrete action plans and political initiatives to tackle this burden, which were featured in an action paper.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

By establishing new specialised pain centres, educational programmes and networks of political stakeholders, and by creating relevant legal frameworks, this initiative will improve therapeutic outcomes and decrease the number of patients with chronic pain.

The project also tracked approvals in federal states, national and regional administrations' initiatives, as well as activities of professional societies. Participants gathered epidemiological data on the occurrence of patients dealing the pain and their treatments.

All 3.6 million patients currently seeking pain-related treatments in Austria will benefit for this project. With increased awareness of the prevalence of pain in our society, health literacy will improve and further the prevention of pain-related diseases and effects.

### INNOVATIVE ELEMENTS OF THE PROJECT

The interdisciplinary aspect of the event was innovative. The workshop attendees, including representatives from politics, patient organisations as well as healthcare professionals, discussed the future of pain prevention and treatment without having pre-specified results. They focused their work on three areas: challenges, solutions and the development of an action plan.

Attendance was voluntary and unpaid. The desire to improve the situation for patients having to deal with pain in Austria served to unite the contributors and drove their ambition to create a valuable, realistic action plan.

### COLLABORATIVE ELEMENTS OF THE PROJECT

Each interdisciplinary working group developed an action plan examining the status quo and identifying ways to improve it. The results were discussed in the final presentation and panel discussion, then consolidated and published in the final action paper.

The working groups met in plenary sessions and small groups, with the help of relevant experts and members of patient advocacy groups. The written meeting records were shared with all participants for input. In the final action paper, every attendee and contributor to the project was named.



# The KOAN project

**In Spain, Inflammatory Bowel Disease (IBD) is expected to affect up to 170,000 people in the future. IBD also negatively impacts the patient’s personal and social life; indeed, up to three-quarters of patients say they have been depressed at some time due to their illness.**

Based on Takeda’s research, a White Paper document was developed that shows a 360-degree picture of the current situation in IBD care challenges in Spain. With this information, it was clear that the following questions needed to be addressed based on the opinions and insights of all stakeholders involved in IBD management. Firstly, what are the unmet care and social needs of IBD patients today according to this report? Secondly, what actions could deliver on these needs?

Takeda established the Koan Project in partnership with the Spanish Society on Crohn’s Disease and Ulcerative Colitis (GETUCCU), the Association of Crohn’s Disease and Ulcerative Colitis of Catalonia, the Spanish Society of Hospital Pharmacy (SEFH) and the Nurse Working Group on Intestinal Inflammatory Disease (GETEII). The project’s goal was to determine the unmet needs of Spanish IBD patients and to identify and implement actions to improve their disease management and quality of life. To achieve this, it was essential to have the highest degree of consensus among the professionals involved in managing the disease and to focus on patients’ needs.



### El paciente quiere...

- Rápido diagnóstico y tratamiento
- Trato personalizado
- Acceso a tratamientos innovadores
- Apoyo en el "papeleo"
- Estar informado (mi entorno y yo)
- Profesionales conocedores de mi enfermedad
- Poder compartir experiencias con otros pacientes
- Hacer vida normal
- Atención coordinada y continuada
- Tratamiento y atención simplificados

## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This is a project by and for patients. Unlike other studies that focus only on the clinical perspective, this addresses all aspects of IBD from the patient perspective, including the social and emotional. There are large areas where IBD patient care should be improved, particularly for those not treated in specialised units.

The project is based on the approach of solving unanswered questions on IBD, using focus groups, meetings and developing online surveys. So far, the project has engaged over 450 stakeholders, including patients, physicians, nurses, hospital pharmacists and managers from across different Spanish regions: Madrid, Catalonia and Galicia. Indeed, the need to define a unified care model across regions was found to be of paramount importance in order to deliver equality of care.

## INNOVATIVE ELEMENTS OF THE PROJECT

In Spain, no projects have addressed IBD in this overarching way, attending to the real needs of the patient (clinical and social) as identified by patients themselves and by the health professionals managing their disease.

To achieve this, the project reached a high level of consensus on the unmet needs of these patients and designed guidelines to implement programmes to improve their satisfaction. The role of nursing was also found to be critical as nurses play a fundamental role from diagnosis to treatment and follow-up.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The project included advisory committees formed from healthcare practitioners, patient advisory groups and policy makers. There was significant geographical collaboration across regions with multidisciplinary teams of managers and professionals from Catalonia, Galicia and Madrid.

There was also a validating team made up of representatives from the Spanish Society on Crohn’s Disease and Ulcerative Colitis (GETECCU), the Nurse Working Group on Intestinal Inflammatory Disease (GETEII), the Association of Crohn’s Disease and Ulcerative Colitis of Catalonia (ACCU Cataluña) and the Spanish Society of Hospital Pharmacy (SEFH).



# Life does not end after stroke

**Each year, 4,000 people in Slovenia experience stroke. This represents 0.2 percent of the national population. Among other measures to recognise stroke, a simple and easy to memorise algorithm has been developed for the general public to help react quickly and prevent devastating consequences.**

About 40,000 people in Slovenia today are stroke survivors - around 2 percent of the population - and live with stroke consequences. Many face permanent disabilities and, as a consequence, experience isolation from society and their families and face financial difficulties. In addition, many of these are among the younger, working population aged 50 and below.

There is no adequate national strategy on how to cope with these post-stroke consequences. A system with long-term comprehensive care would improve the lives of stroke survivors and their families. Approaching key stakeholders and policymakers can make a difference.

The aim of this project was to give hope to, and encourage, stroke survivors by equipping them to address the public and policy makers on the need for long-term measures to help stroke patients and their families. To facilitate this, Bayer collaborated with the Slovenian Heart Foundation (Društvo za zdravje srca in ožilja Slovenije) and the Society of Patients with Cerebrovascular Stroke of Slovenia (Združenje CVB Slovenije) by providing expertise on engaging with stakeholders.

This expertise enabled the associations to gain media traction to raise awareness of stroke and life post-stroke. They also organised a symbolic 'walk' to both raise awareness among policy makers and to give hope to stroke survivors and their families.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients felt empowered by sharing their stories and publicly demonstrating that life goes on after stroke. Through the organised 'walk', they appealed to policy makers to develop measures to improve health rehabilitation and the social, economic, and psychological status of stroke survivors and their families. They walked or used wheelchairs giving hope to stroke survivors and their families.

Over 250 stroke survivors and their families from all over Slovenia participated in the event through Ljubljana city centre. Many of them also had the opportunity to present their stories to the media and the wider public. The project generated more than €70,000 worth of media coverage and reached over a million readers.

## INNOVATIVE ELEMENTS OF THE PROJECT

The project was innovative by joining two large, well-organised patient associations together in a single voice, both of which Bayer has already cooperated with in the past. Both associations were active in their fields in encouraging and supporting patients and their families by running various activities related to prevention, education, coping with their disease, patients meeting other patients, sharing experiences, supporting each other and giving hope. However, they were lacking the experience of engaging with other important stakeholders, including the media and relevant government organisations. The project, with expertise from Bayer, aimed to fill this gap.

## COLLABORATIVE ELEMENTS OF THE PROJECT

By collaborating and working hand-in-hand, the two patient associations were able to make their voices heard. Objectives were predetermined by the patient organisations, which took over decision-making and asked for help on 'How To' and 'With Whom'. They came together with representatives from Bayer for one afternoon and brainstormed the right questions, how to approach and engage with the media and how to deliver their messages. Bayer also gave them guidance on which messages would resonate most with the public.



# Haemophilia Medical Theatre: My Challenges, My Victories

**Medical Theatre 'My Challenges, My Victories' is a play created and performed for young and adolescent haemophilia patients and those around them. The goal is to convey important messages and to open up the communication between parent, child, environment, and physician. The educational aspect was woven into a fun story about a young haemophilia patient, covering all the aspects of their daily life. The overarching message is that haemophilia patients can lead a perfectly normal life if they adhere to their treatment.**

Scientific literature and feedback from patient organisations and physicians show that around 20 percent of adolescent haemophilia patients do not adhere to their prophylactic treatment. In addition, other struggles like fear of self-injection, overprotective parents, and avoiding physical activity and sports impact the quality of life of the patient. With this play, specially created for haemophilia patients and their environment, Bayer and the Belgian patient organization AHVH wanted to address the above struggles, conveying important health related messages and aid the patients in coping with their disease.

The play was performed by three professional actors in four sessions, two in Dutch and two in French, at four different locations. The sessions were held around World Haemophilia Day to maximise haemophilia awareness. The productions were filmed and made available to patient organisations and physicians for educational use and were published on the haemophilia informational website of Bayer Belgium for patients to access.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Messages from the clinical setting are provided in an informal and fun environment. This reinforces them and allows them to stay with the patient longer. It also opens up conversations about the disease and the importance of treatment with parents and physicians. Ultimately, patients benefit from improved quality of life, health and understanding, and support.

Around 90 percent of the attendees were satisfied or very satisfied with the way haemophilia was illustrated. More than 80 percent learned something new during the play with the most important message being 'with haemophilia I am able to live a normal life'. In total, around 200 participants attended the four theatre sessions.

## INNOVATIVE ELEMENTS OF THE PROJECT

A theatre play, performed by professional actors, created an informal and fun setting where information and messages could be shared with younger patients. The idea of conveying messages this way was new to the haemophilia community and was appreciated by patients, family and friends, patient organization, and health care providers.

For 2019, a follow-up story has been developed, addressing other important messages with a similar approach. The new edition integrates further innovative aspects such as visual and multimedia effects, switching between live action and recorded fragments.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The project was co-created with input from all stakeholders in the haemophilia community. Bayer collaborated with 'The Medical Theater' company, who are specialized in bringing medical topics to the stage and screen. The playwright and director from 'The Medical Theater', set up face-to-face meetings with patients, the Belgian haemophilia patient organisation (AHVH), physicians, nurses and physiotherapists to collect stories and gain insights into the experiences, challenges and needs of the haemophilia community.

All the stakeholders were involved at every step of the writing and directing process, this to ensure the messages, story and specific situations were accurate, relevant and supported by all parties. There was further collaboration with the patient organisation and physicians in finalising and distributing the information on the play to all patients in Belgium and in managing patient registration and feedback collection.



# Mensajes del Corazón a la Cabeza - Messages from the Heart to the Head

**In Spain between 12,000 and 14,000 new cases of head and neck cancer are recorded each year, and it is expected that this will increase to 16,000 per annum over the coming years. Therefore, it is important to increase awareness of this cancer and its risk factors, since 75 percent of cases are caused by tobacco or alcohol consumption. Early detection is key, since timely diagnosis can stop these types of tumours in up to 75 percent of cases.**

Bristol-Myers Squibb, in collaboration with the Spanish Group of Head and Neck Tumours and Association of Cancer Patients, initiated the awareness campaign 'Messages from the heart to the head'. The objectives were to make head and neck cancer better-known to the public; communicate the risk factors of this kind of cancer; make society aware of this disease's severity; highlight the importance of early diagnosis in reducing new cases; and support patients who suffer from this disease.

In Phase 1, information stands were installed in Madrid's main shopping malls featuring a large screen, similar to a holiday postcard, for the audience to leave messages of support for the roughly 37,000 patients in Spain suffering from this kind of cancer. The actress Mayra Gómez Kemp, who also suffered from these tumours, attended the stands.

In Phase 2, a document was created, gathering all the supportive messages along with the experiences of head and neck cancer patients, including Mayra Gómez Kemp. This was distributed to different patient associations to provide support to sufferers.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The campaign encouraged people to share their support to patients and to educate themselves on the symptoms and risk factors. This helped the public understand the difficulties that patients suffer following treatment and helped to make this kind of cancer more visible across Spain.

These actions, in addition to supporting patient associations, generated a considerable interest in online and offline media, radio and TV, covering both the health-specialised and mainstream press. As a result, the campaign had the potential to reach a total media audience of 17,917,828 in Spain. In addition, more than 10,000 supportive SMS messages for patients were received.

## INNOVATIVE ELEMENTS OF THE PROJECT

One of the most eye-catching features of the project was the large screen in a holiday postcard format allowing the public share their supportive messages. This was combined with several information stands located in various Madrid shopping malls. The participation of Mayra Gómez Kemp in the campaign, telling different media outlets of her experiences as a patient, also helped the messages to stand out.

## COLLABORATIVE ELEMENTS OF THE PROJECT

Bristol-Myers Squibb partnered with the Spanish Group of Head and Neck Tumours and Association of Cancer Patients to develop the concept and create campaign materials. This ensured that the material was relevant to patients and the public. The collaboration with the well-known actress, singer and host Mayra Gómez Kemp was also vital to raising the profile of the campaign in a noisy media environment. She had suffered from tongue and throat cancer and managed to overcome it. Her participation was key in the campaign, talking about her experience as a patient, transmitting the importance of the general public knowing and understanding head and neck cancer and how it affects everyday life.



# Multilanguage Thalassemia Patient Brochures

**New migration patterns mean an increasing number of young patients with thalassemia in Switzerland in the last decade. These vulnerable populations originate from various countries, speak a range of languages and have diverse cultural backgrounds, making it difficult to incorporate them into healthcare systems.**

A solid understanding of one's disease, its consequences and the required therapy and follow-up is crucial, with the fundamentals already laid out at a young age. This is particularly true for vulnerable migrant patients, where access to appropriate healthcare may previously have been limited.

Creating a tool to overcome the language barrier effectively and simply was a core driver of this campaign. Partners felt that developing a multi-language communication tool and informative brochures would constitute an important aid to patients. The primary outcomes were illustrative, multilanguage, printed brochures explaining thalassemia, iron overload and therapies through age-appropriate design and content.

As a secondary outcome, a doctor-patient, play-based, attractive and intuitive communication tool was also created. It includes two sets of cards for healthcare providers with illustrations of key components of blood, elements of healthy and disordered haemoglobin physiology, as well as key words to help explain it all to patients and their families. They are available in Arabic, English, French, German and Italian.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Around 200-300 thalassemia patients are currently cared for in Switzerland (out of 7 million inhabitants), including children and adults. Those numbers have increased in recent years due to migration patterns. The brochures and cards should answer open questions, allow for further discussions, support patient therapy and help them cope with a lifelong condition.

Approximately 20-30 children will directly benefit from the brochures, while the playing cards can be employed with patients affected by other blood disorders. That number of patients is significantly higher at around 100-200.

### INNOVATIVE ELEMENTS OF THE PROJECT

The goal was to explain a complex disease using almost all visual elements, keeping any text to a minimum. The brochures and cards were intentionally created to be illustrative and self-explanatory. This is the first playing card set for haemoglobin disorders available to paediatric healthcare providers.

The playing card set for the doctor-patient interaction enables the physician to communicate with their patients in an individual, personalised way and to share information and assess the knowledge of their patients with a playful approach. The printed brochure is available in five languages (Arabic, French, English, German, and Italian) and further helps patients understand thalassemia and its care.

### COLLABORATIVE ELEMENTS OF THE PROJECT

Two paediatric haematologists from two leading academic hospitals in Switzerland were actively involved in devising the aims of the project, as well as in the project planning, design and development of the multilingual thalassemia educational material.

Both doctors have extensive experience in the treatment of children with thalassemia. The content was therefore built on their clinical input and expertise. Novartis provided financial support, but also ensured a collaborative environment.



# My time - Make moments valuable

**In Germany, there is a lack of specific information and activities about metastatic breast cancer (mBC) and a low level of public awareness. It is still considered a taboo topic due, in part, to the fact that there is no cure. This can leave patients feeling isolated.**

Now, new therapeutic options mean that patients are living longer with the disease and can spend valuable extra time on the things that matter to them and spend more time with their loved ones. This was the motivation behind the 'My time - make moments valuable' project. It aims to provide information about mBC as well as a platform for patients to share experiences. It also informs the wider public about the disease, the burden and the therapeutic options.



A key element of the project was regional patient events organised in cooperation with local breast centres and hosted by experts in psycho-oncology, social law and nutrition. Patients had the opportunity to ask open questions and to exchange insights with other women.

In addition, a Facebook campaign was created giving helpful tips and creating a community where patients can offer support to each other. The Facebook page continues to be a source of information on a wide range of topics such as training courses, self-care, returning to work and positivity. Brochures about relevant topics such as skincare, nutrition and movement etc., were also developed and distributed. A PR campaign was very successful in informing people about the project and increasing traffic to the Facebook page.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project fulfilled a number of unmet needs for patients. It provided them with fora to ask open questions, provided them with valuable information in the form of booklets and folders. It also created a platform to exchange ideas and form a community.

The two regional events attracted approximately 100 participants, while the Facebook channel boasts more than 17,000 followers, with an excellent interaction rate.

The PR campaign delivered more than 90 articles about 'My Time' and the topic of metastatic breast cancer, reaching an audience of approximately 1,300,000. There were more than ten experts involved at each of the events.

## INNOVATIVE ELEMENTS OF THE PROJECT

This was the first time Novartis Germany set up a Facebook channel. This presented an exciting opportunity to directly interact and communicate with patients and discover their wishes and needs. This is an ongoing benefit as the Facebook page continues to be operational and highly interactive. The Facebook campaign was rolled out in conjunction with events at regional level distributing expert help and advice to address all kinds of patient issues, both online and offline.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The project was a joint initiative from Brustkrebs Deutschland e.V., MammaMia - Das Brustkrebsmagazin and Novartis. The initiative was supported by a well-known German medical journal 'Senologie'. Each local event was organised in cooperation with a local breast cancer centre, with more than ten regional experts (per event) providing information on a variety of issues that affect patients, ranging from welfare entitlements to diet. All partner logos are represented on every piece of promotional material to provide maximum transparency.



# 'Men's Health: remain as healthy as possible for as long as possible'

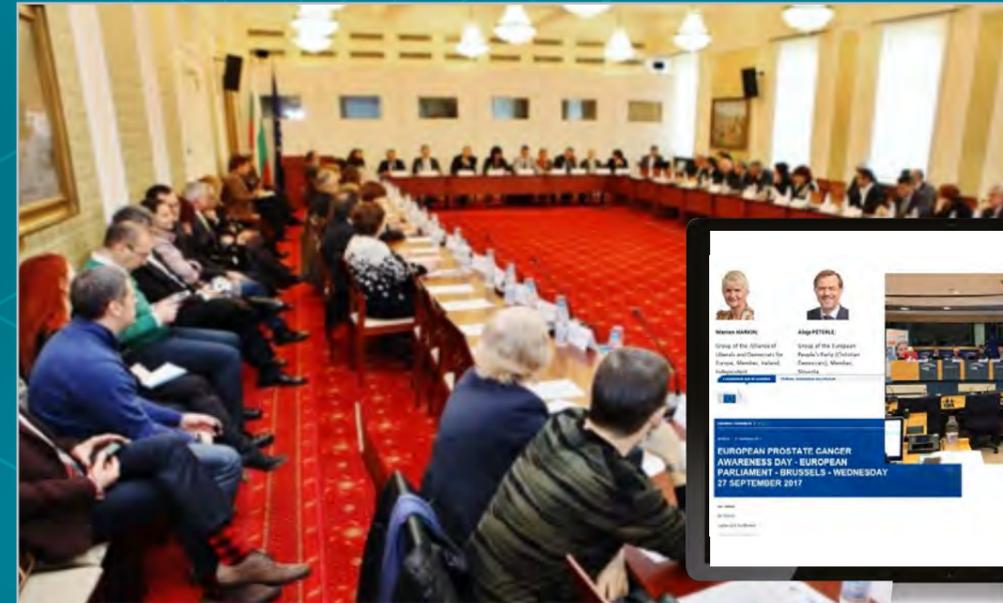
**There is low awareness among key stakeholders and policymakers about prevention, screening, diagnosis and early onset of prostate cancer treatment in Bulgaria.**

Following an event in the European Parliament on 27 September 2017 in support of European Prostate Cancer Awareness Day (EPAD), the Bulgarian Societies of Urologists and Oncologists, under the umbrella of the Parliamentary Healthcare Committee in Bulgaria, NGO Bulgarian Patients Forum and the Association of Research-based Pharmaceutical Manufacturers in Bulgaria (ARPharm) organised a debate in the Bulgarian Parliament on 5 October.

The main objective was to raise awareness among key stakeholders about the importance of compliance with the recommendations from the European Association of Urology (EAU), Europa Uomo, the European Cancer Patient Coalition and MEPs Against Cancer regarding early diagnosis and on-time treatment of prostate cancer.

The recent White Paper on Prostate Cancer by the EAU proved a valuable tool in the prevention, diagnosis and treatment of this disease. This was shared with Bulgarian health policymakers to ensure it reached all stakeholders.

A wide range of stakeholders attended the debate. The chairs of the two societies presented all topics covered during EPAD along with the current situation in Bulgaria. The event helped to highlight the challenges in prostate cancer diagnostics, cancer care inequality and follow up treatment, as well as the possibilities of addressing these by improving dialogue between stakeholders.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project led to increased dialogue between key stakeholders, as well as greater awareness about prostate cancer and the need for early diagnosis and treatment.

According to data from the Bulgarian National Cancer Registry 2014, there are 2,503 prostate cancer registered patients – 14.4 percent of all registered oncology patients. These patients will benefit from this project through an improvement in diagnosis, access to innovative treatments and equality of cancer care across regions.

### INNOVATIVE ELEMENTS OF THE PROJECT

The campaign is the first of its kind in Bulgaria. There had been no previous dedicated efforts to raise awareness among policymakers, payers and key stakeholders on the benefits of, and the need for, early diagnostics, on-time treatment and strict adherence to therapies. The campaign incorporates many innovative approaches to reaching the target groups.

The Scientific Societies initiated the project under the umbrella of the Parliamentary Healthcare Committee, which itself is an innovative approach for identifying and addressing problems in healthcare. It was truly innovative as it leverages the experiences, skills and pragmatic insights of NGOs in Bulgaria.

### COLLABORATIVE ELEMENTS OF THE PROJECT

The project owes its success to the collaboration between stakeholders who took on different roles in the project. Project preparation was carried out by HCPs, distribution by the Ministry of Health, the National Health Insurance Fund and the Parliamentary Healthcare Committee, and project management by NGOs and the pharmaceutical trade association, ARPharm.

It was launched as a response of the Parliamentary Healthcare Committee to the problem of low PCa awareness in the country. A group of experts was invited from both societies (oncology and urology). Each of the parties contributed to the detailed plan of activities, aimed at reaching the right target groups. Information was exchanged to ensure alignment on visuals and core messages between all stakeholders.



# Partners for Developing Patient Organisations

**A significant number of patient organisations (POs) in Slovakia work with limited resources. Despite representing thousands of patients, there is an important need to make the leaders better advocates and protect the rights of the patients professionally. We believe that empowering POs helps patients and the community as a whole. Capacity building, exchanging best practices and information, education and individual coaching, supports their work and mission.**

The intention is to make POs more professional and support their ambitions to become relevant partners for the healthcare stakeholders. The aim is to offer a comprehensive, continuous and effective education project developed precisely for the needs and limitations of PO representatives. Our key objectives are to enhance their capabilities (advocacy, leadership, organisation skills, adherence, etc.), to deliver better results for their patient communities. Monthly newsletters, face-to-face training, an annual national workshop, webinars, coaching and individual consultations are some of the key support tools. Experts from NGOs and trainers assure high quality, up-to-date education.

All activities reflect the real and evolving needs of POs. These are assessed regularly via questionnaires and face-to-face interviews. Cooperation between partners brings together exceptional skillsets, experience and expertise. The pharmaceutical company which serves as an 'idea maker', an agency with long-term experience of working with NGOs, the Patient empowerment organisation, the EUPATI National Platform Slovakia, Slovak umbrella patient organisation and academia representatives combine insights from their fields, maximising the potential of the programme.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

We have created a 'consultant on speed dial' for patient organisations; limited resources usually make working with a coach or the use of individual consultations by an expert unaffordable. Education in the local language is also a tremendous benefit. Lectures and topics may be available in English, but for most POs they are difficult to understand.

More than 30 patient groups participated in the programme, leveraging its impact to more than 20,000 patients within their membership. The metrics we used were the number and quality of campaigns, activities on social media, the size of the membership and new partnerships with corporations, medical societies, media, etc.

## INNOVATIVE ELEMENTS OF THE PROJECT

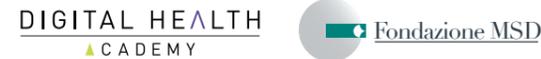
The programme is truly innovative in how it meets the patient organisations' needs. The project challenges traditional ways of delivering education and training.

We have designed an innovative service model that reacts to the needs of patient organisations and leverages experience, skills and insights from experts. The programme exchanges up-to-date information, research outcomes, new ideas and inspirations from abroad.

## COLLABORATIVE ELEMENTS OF THE PROJECT

This initiative was designed as a partnership ecosystem from the start. The idea of the project emerged within Sanofi. As there was a need to cover the complexity of the project and its execution, it was concluded that a professional partnership that leverages the work experience, network and backgrounds of all project partners was required.

New cooperation was established during the programme, with representatives of academia, the EUPATI National Platform Slovakia and the Slovak umbrella patient organisation. By bringing together new partners, the programme reached other patient advocacy groups and set the stage for stronger collaborations in future.



# Patient Digital Health Awards

**Over the past eight years, the Patient Academy of Fondazione MSD has supported patient empowerment initiatives, developing patients' skills in healthcare and digital innovation. It is now time for patients to use and capitalise on these competencies to become the main actor in the digital transformation of healthcare.**

The patient perspective is critical in understanding whether a digital innovation can be successful in dealing with disease needs. With this Patient Digital Health Award 2018, patients scout, evaluate and award the best digital innovation from their perspective.

A board of patient association representatives and digital experts was established to guide the project. An online survey was conducted through a patient association's website to collect insights on patients' needs for inclusion in the competition. The details of the competition call were defined through a combination of face-to-face and 'digital' meetings, before the opening of the competition in October 2018.

Top engagement and digital experts were involved in commissioning the project, while patient associates played an active role in driving social engagement. Preliminary results showed strong responses to the initiative. Excellent feedback was received from the patients involved.

Supplementary information here: <https://www.pdha.it>

## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

There were high levels of patient engagement in the survey. 40 Patient Associations were involved in the survey online, with more than 800 surveys completed; 30 patients' representatives from various therapeutic areas that answered to the call to action assessed 45 digital innovative projects and awarded the best 3 (and the best idea) in an official award ceremony last October in Rome.

The project benefited from high levels of social media engagement. This was reflected in positive feedback from participating cross-therapeutic areas. A network of patient associations was consolidated by this initiative enhancing the advocacy.

## INNOVATIVE ELEMENTS OF THE PROJECT

Digital innovations have enormous potential to catalyse change in the health sector. However, these innovations should be driven by a desire to improve patient outcomes and add value by addressing unmet need. To achieve this, it is essential that patients are key actors in the process.

This project was itself innovative in its approach. It was the first time in Italy (and Europe) that 30 patient associations have rewarded digital innovation based to their own views. Coming from different diseases with differentiated needs, organisations shared their efforts to become genuine lead actors in driving digital transformation.

## COLLABORATIVE ELEMENTS OF THE PROJECT

Collaboration was the essential ingredient of this project, as it is the joint nature that differentiates it from other initiatives involving patients. Some 30 different associations worked together, from the preliminary brainstorming phase to the final implementation.

Their insights were combined with input from digital and engagement experts working towards a common objective. This large and diverse group successfully partnered on areas of shared interest, independent of the specific disease their association represents. This was a significant achievement, helping to broaden the horizon of all participants, and drive collaboration in the field of digital health.



# Patients Focused Medicine Developments (PFMD)

**Despite increased awareness of the importance of including patients and patient input in health discussions, there has only been fragmented efforts to achieve more systematic and effective patient engagement (PE).**

The PFMD initiative, established in 2015, is an independent, non-profit global coalition of 32 members, including patient organisations and advocates, the pharma and health industry, academics and regulators working together to make patient engagement happen.

When PFMD was established, there were no global collaborative platforms dedicated to driving patient engagement forward, where all stakeholders could come and collaborate to build comprehensive solutions for advancing the patient engagement agenda. PFMD's goal is to improve global health by co-designing the future of healthcare for patients, with patients. Despite the growing understanding of the importance of patient engagement, there are no industry-wide standards on how it should be done.

PFMD is building a credible global framework for patient engagement with offline activities and tools, as well as a mapping and management tool, gradually growing its range of activities and tools to answer the needs identified by members and dedicated multi-stakeholder working groups. These, together with a global collaborative leadership platform and approach, are contributing to a systematic patient engagement and health ecosystem.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

There are tangible and concrete benefits of PE for patients and the wider healthcare ecosystem. Medicines developed in collaboration with patients reach the market more quickly and in a more cost-effective manner – achieving efficiency and saving money for the healthcare system.

Industry members are able to develop medicines in a way that considers the needs of the true end-user of the treatment. This translates into better outcomes for patients as their needs are being heard (and will be heard more systematically in the future) and increases the success of that treatment on the market.

PFMD membership ensures that the voice of the patient is represented on this important issue. It enables patient organisations to collaborate directly with other stakeholders in medicines development.

- [PFMD](#)
- [Synapse](#)
- [PE Quality Guidance](#)

## INNOVATIVE ELEMENTS OF THE PROJECT

The way PFMD is structured is innovative, particularly in allowing industry 'competitors' to sit at the same table to discuss and plan for common goals in a pre-competitive, neutral environment.

Many of PFMD's outputs are also very innovative, including, the SYNAPS E a mapping and management tool for patient engagement. This allows users to look for, or extract information in a structured way that they can use in their PE work. It is an innovative tool supporting and fostering patient engagement activities.

The Patient Engagement Quality Guidance is a tool to help determine why, how and when to involve and engage with patients from each stakeholder perspective has been released.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The PFMD alliance is based on shared value and collective impact. PFMD's unique governance structure takes an innovative approach to creating a robust, agile and credible alliance within a neutral not-for-profit structure. This gives all players an equal opportunity to voice their opinions, have an impact and participate in the PE environment.

The PFMD model allows industry players to work as collaborators rather than competitors. Together, they can advance patient engagement and reimagine the medicines development system in a way that achieves their common goals. This unique stepwise approach is evidence of an innovative collaboration where stakeholders are involved in relevant stages to advance projects.



# Prevention Campaign: The vaccine saves your life



**Human papillomavirus (HPV) is the most common sexually-transmitted infection. The absence of symptoms promotes its spread, as most of the individuals affected are unaware of the ongoing infection. It is not only responsible for cervical cancer, it can also cause vulvar and vaginal tumours in women, penile cancer in men, and anal, oropharyngeal and oesophageal tumours in both sexes.**

HPV-related cancers can be prevented through vaccination. Ensuring high uptake of the vaccine can significantly reduce the spread of the virus in the community – and saving lives in the process.

‘The vaccine saves your life’ is a cancer prevention and awareness-raising campaign for the HPV vaccine. It was carried out by the Italian Association for Medical Oncology (AIOM) with an unrestricted grant from MSD Italy. It aims - using an unequivocal message launched by renowned Italian tennis player Flavia Pennetta - of educating and informing all citizens about the real health risks to children and adolescents that can be prevented by vaccination.

To spread the strong educational message, the campaign used an integrated communication strategy, incorporating multiple channels to share the advertising spot filmed by the Pennetta.

## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

To spread the strong educational message, the campaign used an integrated communication strategy to promote a video testimonial by Flavia Pennetta – a household name in Italy.

The video was shown in 500 cinemas, on Repubblica TV and Corriere TV, and through regional broadcasters in Sicily, Campania, Lazio and Lombardy. It was also shared via Pennetta’s official Twitter and Instagram accounts which have a loyal following.

This allowed the advertising spot to reach a large part of the population: 10,000,000 TV and radio contacts; 8,100,000 total readership press and online; 50,000 views on Flavia Pennetta’s Instagram and Twitter account; 1,000,000 views on Facebook and Twitter; 651,000 contacts through cinemas; and 8,223 on TV in targeted regions.

## INNOVATIVE ELEMENTS OF THE PROJECT

The innovative element of the project was the use of a multichannel communication strategy, with a particular focus on social media. By harnessing the existing reach of a celebrity’s social channels, it maximised impact on Twitter and Instagram.

As the key feature of the campaign was a video, it was also important to reach viewers in cinema, through regional media and via national TV channels.

## COLLABORATIVE ELEMENTS OF THE PROJECT

Partnership between industry, medical professionals and a well-known sporting figure were key ingredients to the success of this initiative. Together, participants achieved what no single organisation or individual could achieve alone – a high-impact, scientifically sound campaign that resonated with a large target audience.

MSD and AIOM share a vision of saving and improving lives through cancer prevention. This is why both organisations, each with their specific roles, decided to commit together to educational campaigns that can have a real impact and make a difference both to people’s lives and to the healthcare system.



# Que el melanoma no nubles tus metas

## Don't let melanoma cloud your goals

**In Spain there is a stronger sun culture than in many other EU countries. Spanish people tend to be aware of how to prevent melanoma and protect themselves from the sun when they go to the beach or pool. However, there is a problem when it comes to protecting themselves while performing other outdoor activities, whether through work or outdoor sports.**

To address this, a campaign – ‘Que el melanoma no nubles tus metas’ – was undertaken in Madrid in July, a time of greater solar exposure and higher risk of this disease. The initiative was not designed to be a campaign focused on skin protection at the beach, but to educate this often ignored section of the population.

An informative workshop was organised directed at people such as athletes, mothers with young children, and outdoor workers. In addition, melanoma patients and specialists attended, both from the disease and outdoor sports sectors, to explain the consequences of melanoma and the importance of prevention and early diagnosis.

The objectives were to make the general public aware of what melanoma is and how to avoid it, particularly those people performing outdoor activities, as they face a greater risk of exposure. It aimed to inform the Spanish public of the risk factors; communicate the importance of prevention, early diagnosis and routine check-ups when dealing with melanoma; make the public aware of the experience of melanoma patients; and explain the ‘ABCDE’ method of identifying the common signs of melanoma.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The project focused both on today's patients and those at risk of becoming the patients of tomorrow. By raising awareness of prevention and early diagnosis, it aimed to reduce the overall burden of the disease.

The campaign reached a total audience in Spain of 16,822,466 through traditional media and approximately 160,000 people via social media. Social media users showed that the campaign messages of awareness, prevention and early diagnosis resonated with the public, giving visibility to the disease and to patients. A great number of users shared their own posts on the matter in their profiles, giving the hashtag greater visibility.

### INNOVATIVE ELEMENTS OF THE PROJECT

The most innovative aspect of this initiative was the use of influential people to help maximise the dissemination and impact of the message.

A video was developed to present the campaign, starring the international athlete Pablo Villalobos. In addition, an informative workshop was organised in the presence of two influencer athletes, Villalobos and Cristina Mitre. Cristina is President of Melanoma España and a cancer patient.

In addition, Bristol Myers secured the collaboration of the web bloggers portal Salud Esfera and Madre Esfera as well as Madrid's sport groups such as Madridsports.

### COLLABORATIVE ELEMENTS OF THE PROJECT

This project combined the expertise of industry with that of scientific societies and patient associations. Grupo Español Multidisciplinar de Melanoma (GEM), a professional scientific organisation, and Melanoma España, patients association, ensured that a holistic approach was taken to developing and executing the initiative.

In addition to key opinion leaders from the medical community, influential athletes and online personalities helped to generate attention and momentum during the campaign. Partnerships with media, bloggers and sports groups ensured that the message reached the target audience at a key moment during the summer months – when melanoma risk is at its highest.



# Roche in Neuroscience

**This initiative brings together a series of projects aimed at promoting knowledge of multiple sclerosis (MS) and eliminating the social stigma of patients suffering from the condition. It also gives them a voice to help increase their participation in decision-making about their disease. 'Roche in Neuroscience' has demonstrated and strengthened the perception of industry's ongoing commitment to research in this field.**

Several projects were conducted under this umbrella. These include 'RecogEMos tu Voz', a research project developed by Roche and Esclerosis Múltiple España (EME) to analyse the social and healthcare reality of the disease via the opinions, behaviour and attitude of 500 patients.

Through 'EMtramos en escena', Roche organised a seminar to communicate the company's debut in the neuroscience area and to present an ambitious project ('Conoce a EMET') that seeks to demystify multiple sclerosis and to offer consultancy on frequent areas of interest about the disease.

'Conoce a EMET' is a web-based project site with videos and information to ensure that patients and those around them can normalise the disease and live with it in the best way possible. Additionally, it attempts to contribute to making society aware of MS thus helping eliminate existing stigma.

EMET was created with this goal in mind, a monster representing MS that accompanies those suffering from the disease throughout their lives in different situations. Advice is included on the website on how to face up to these challenging situations.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

'EMtramos en escena' was attended by over 150 people, including patient associations representatives, healthcare professionals, government, media and the general public. Around 40 media outlets published stories reporting the initiative, reaching an audience of more than 2,200,000 people.

The website 'Conoce a EMET' managed to reach over 900 users. In addition, over 30 media outlets reported the results of the 'RecogEMos tu Voz' survey, reaching an audience of more than 37 million people. The three campaigns were widely reported on social media, with over 455,000 viewings.

In addition, various patients' associations circulated details of these initiatives on their internal and external communication channels.

## INNOVATIVE ELEMENTS OF THE PROJECT

The various initiatives in 'Roche in Neuroscience' include a number of innovative elements, both in terms of content and in the communication methods used. The 'Conoce a EMET' website provides an easy-to-access platform with clear, proven information about MS.

The seminar 'EMtramos en escena' also provides a meeting point for the different groups affected by the disease. Additionally, a discussion forum was created to give all of them a voice and to discover the current challenges in tackling the disease.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The project was delivered in collaboration with patients' associations and healthcare professionals. In devising and executing these initiatives, the opinions of these key stakeholders were sought, ensuring a spirit of cooperation and sharing ownership. These relationships were built on independence and mutual respect, with all partners working towards a shared goal.

The patient group, Esclerosis Múltiple España (EME), was particularly supportive of the 'RecogEMos tu Voz' survey, circulating it among patients and reporting the results.

„Túlélési ismeretek”  
szívinfarktust követően



# Survival Skills

**Hungary is in the highest quartile of EU countries for death from heart disease. ‘Survival Skills’ is an educational programme designed to help post-infarct patients avoid further heart attacks.**

The 365-day programme, run in collaboration with Sanofi Hungary, the Hungarian Society of Cardiology, the National Emergency Service and SZÍVSN – a local patient group representing cardiovascular patients – aimed to make post-infarct patient treatment more efficient inside one year.

The project established an educational programme targeting healthcare practitioners and patients, demonstrating the close link between high cholesterol and infarction, to draw attention to the importance of adherence to treatment and healthy lifestyle.

As a result of the project, 14 of Hungary’s 19 Invasive Cardiology Centres now have dedicated and educated HCPs that can educate post-infarct patients before they are discharged from hospital.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients were a central part of devising and delivering the project. Regular roundtables, scientific congresses and weekly patient advocacy group (PAG) educational meetings helped to reinforce the importance of the project and to communicate its goals.

A number of social media campaigns helped to reach patients and family members. Feedback was collected from at least 300 patients on the efficiency of campaign materials via the internet and social media. The Survival Skills Educational Pack is currently available in Hungary – from educated HCPs – for 16,000 post-infarct patients.

Of the Invasive Cardiology Centres in Hungary, four-fifths now have healthcare practitioners that can engage directly with post-infarct patients prior to their hospital discharge.

## INNOVATIVE ELEMENTS OF THE PROJECT

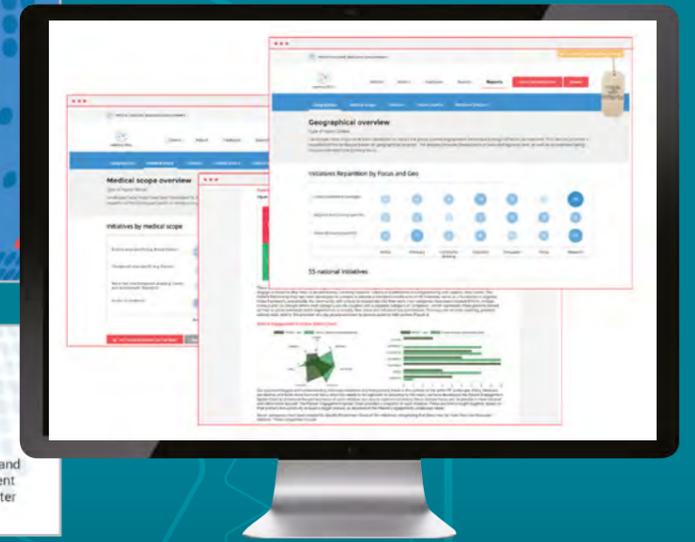
The initiative established a personalised programme based on unmet educational needs. It provides appropriate and accessible health information, helping demonstrate the connection between infarction and high cholesterol. The aim of the project is to ensure continuous follow-up to control the patient recovery process.

A digital version of the Survival Skills Educational Pack, as well as six educational videos, are available on the website of the Hungarian Society of Cardiology. It was spread digitally via Facebook and the news portal of the Hungarian Society of Cardiology, which played an important role in the project.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The project recognised the need for a common commitment to make post-infarct patient treatment more efficient during the first 365 days. Cross-functional collaboration was key. The programme was supported by a number of stakeholders for better access to, and communication with, patients that had recently suffered infarction, earning their commitment for improved cooperation.

The collaboration of Sanofi, the Hungarian Society of Cardiology, the National Ambulance Service and SZÍVSN led to an intensive cooperation on a national level between the government, the pharmaceutical sector and civil society.



# SYNaPsE - SYNergising Patient Engagement

**Meaningful Patient Engagement (PE) is essential for providing health solutions that achieve both clinical and patient-desired outcomes while improving drug development and delivering efficiency. The current approach to better PE is fragmented and thus produces fragmented results. Only an open and neutral, collaborative and comprehensive stakeholder platform can achieve common objectives.**

SYNaPsE - SYNergising Patient Engagement - is an online platform developed by the Patient Focused Medicines Development (PFMD) membership and network (patient organisations, pharmaceutical companies, HTA agencies, researchers and academia partners and others).

Launched in 2016, the objective of SYNaPsE is to manage and ensure that PE resources and tools are accessible to everyone in a single repository. It features PE initiatives, organisations, events and experts relevant to patient engagement, aggregated reports giving snapshots of the PE ecosystem across the globe, a growing repository of PE resources (including publications, white papers, videos and much more), and a Pledge to Patients campaign for culture change. All these functionalities are interlinked to make connecting and sharing PE knowledge easier.

SYNaPsE categorises and 'maps' PE initiatives and frameworks, organisations, experts and resources and will integrate all co-created tools that PFMD launched (such as the PE Quality Guidance), making the platform a truly dynamic single tool for planning, assessing, managing and sharing PE knowledge and activities within an organisation and across the ecosystem.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

By providing a fully-functional and sustainable platform, stakeholders can share information of their own PE activities and gain further knowledge about other initiatives. Only through sharing knowledge will the entire ecosystem benefit from higher quality engagement and involvement of the patient community, more impactful projects and better ways to measure results and impact.

As an ever-growing repository of resources for anything relating to patient engagement, SYNaPsE has become the place for learning more about PE. In 2017, there were 23,523 page visits; by June 2018, there were 46,937 visits.

- PFMD
- Synapse
- PE Quality Guidance

## INNOVATIVE ELEMENTS OF THE PROJECT

The most innovative element of SYNaPsE is the organisation-specific dashboard that enables users to manage their PE activities without expensive CRM tools. This is a powerful tool for both patient organisations and other stakeholders, allowing all patient engagement activities to be managed and shared from a single place.

The functionalities were co-designed and tested with members and other users ahead of launch and iteratively improved step-by-step. Collaboration to improve the tool is far faster than in any single company.

## COLLABORATIVE ELEMENTS OF THE PROJECT

All PFMD activities are co-created through joint decision-making with members and collaborators and involve frequent rounds of feedback. Openness and pre-competitiveness are in PFMD's DNA. When signing up for membership, organisations are committing to adopting and adapting the patient engagement framework developed by PFMD and to helping deploy it with all other stakeholders.

For SYNaPsE, the team proactively seeks user feedback by directly contacting users and supporting them. This ensures frequent connection to the end users – patients, industry and everyone relevant to the PE ecosystem.



# Global Patient Leadership Council

**Takeda Oncology’s Global Patient Leadership Council (GPLC) is comprised of ten well-respected patient advocates with a global perspective into the unmet needs of multiple myeloma communities. The council shares insights and feedback that directly inform education, strategy and empowerment efforts through a shared decision model. The GLPC provides a continuous forum for engaging directly from advocates on the most pressing issues and challenges faced by patients living with multiple myeloma, survivors, and their families.**

In February 2017 the first in-person advisory roundtable with key stakeholders was convened to produce a publication focused on solutions to the unmet needs of patients. It was moderated and supported by Takeda Oncology, in partnership with AONN+, the publishers of CONQUER and The Lynx Group, with ten advocacy leaders representing patient groups to form the GPLC.



In December 2017, based on roundtable findings, a white paper was published online and in CONQUER magazine, which provides a forum for cancer patients, survivors, and oncology team members. The paper focused on strategies and recommendations to empower patients, shared decision-making communication processes between patients and healthcare providers, and a compiled list of online and digital resources. It was published in French, German, Italian, and Spanish.

## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The White Paper aims to empower patients and caregivers through education, easy-to-employ tips, and information on resources.

There are concrete recommendations based on personal experience, or those of the patients they worked with, to assist readers on how to address these challenges.

There are examples of the resources available and details of how to access them.

The White Paper was delivered to nearly 13,000 patients, caregivers, patient advocates and cancer care coordinators (to share with their patients). CONQUER has had to reprint more copies to meet demand, specifically from France, Germany and the US.

## INNOVATIVE ELEMENTS OF THE PROJECT

By partnering with CONQUER, a multiple channel approach through digital and print ensured greater reach and durability of the outputs. The combined approach reached both digitally-savvy patients and their caregivers as well as those individuals that prefer traditional, printed materials.

The project was truly global in nature, given the diverse representation of the key stakeholders involved. Outputs from the GPLC are easily transferable between regions, particularly as it looks to expand.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The effort was collaborative and mutually beneficial for all stakeholders involved from the outset. The roundtable discussion was led by the patient advocacy groups. Every advocate reviewed and approved all follow-up items, papers, and next steps.

All stakeholders were directly involved with creating the White Paper based on the roundtable proceedings, social media promotion and outreach to the advocacy organisations they represented (e.g., Bloodwise, GEPAC, International Myeloma Foundation, Myeloma Canada, and Myeloma Patients Europe) as well as those they often partner with (Multiple Myeloma Awareness, Multiple Myeloma Research Consortium, Leukaemia & Lymphoma Society, Myeloma Crowd).



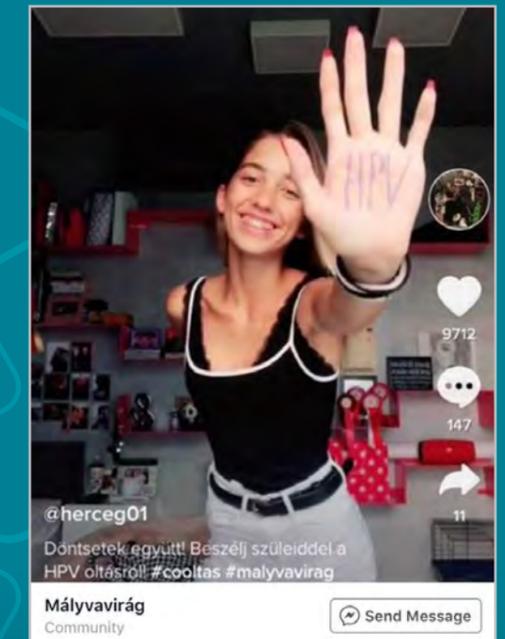
# Engaging teenagers in HPV vaccination on Musical.ly

**HPV vaccination can help to prevent cervical and other cancers. In Hungary, the HPV vaccine is financed by the Government at the age of 12 and parents can decide whether or not their children should have it. This campaign aimed to encourage teenagers to talk with their parents about the HPV vaccine and about the diseases it can prevent. This is the first step in a teenager's life for cervical cancer prevention, so their engagement is vital.**

The campaign has another element to motivate families to talk and encourage mothers to visit their doctors. Musical.ly ('TikTok') is a social media application widely used by young girls and boys in Hungary. Those that can do it well (measured by 'likes' and 'hearts') become influencers and are followed by thousands.

The Mallow Flower Foundation invited the three most popular teenage influencers in Hungary to make a video about HPV with a common hashtag: #cooltas ('cooljab'). They reached more than 60,000 girls and boys (the vaccination programme gives the opportunity to 50,000 twelve years old girls) in three days, with 600 comments added. Vaccination coverage data is coming in October. The project team reacted quickly to comments via Facebook and other PR activities. A press release was taken up by several media channels.

The initiative revealed that the girls are afraid of the pain of a jab, who talked about it with their family, and what the main HPV misconceptions are. This allowed the project to build on this information to organise an effective teenage programme in schools in the future.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The campaign reached around 1 million young people – the followers of the three influencers. In addition, it reached the families of the teenagers, generated more than 60,000 'likes' in three days and attracted more than 600 comments. It also achieved 27 online media appearances, was featured on five radio channels, 11 print publications, and was featured on the two most popular TV shows. The initiative also generated a two-minute article in the news on Mallow Flower Foundation's Facebook; some posts reached more than 50,000 people. The benefits accrued to 50,000 families with teenage girls, plus the 'minus one' age cohort (11-year-old girls).

## INNOVATIVE ELEMENTS OF THE PROJECT

The teenagers had never been asked about HPV vaccination before they were invited to use the programme. The project reached the target audience through their most popular and favourite platform. While the project team developed and deployed the idea, it was the teenagers that sustained the conversations, comments and opinions. This forum opened them up to a serious discussion, asking each other's opinion and showing how proud they were or what they were afraid of.

## COLLABORATIVE ELEMENTS OF THE PROJECT

The Mallow Flower Foundation wrote a two-page summary, then met with the sponsor to check whether the idea fitted their strategy and discussed potential benefits and risks. Then PR agency was selected and began contacting the parents and guardians of influencers. The team met with managers and influencers, explaining the history of the Foundation, HPV, cervical cancer and introducing the campaign plans. We then organised a meeting with the influencers, who made the video and chose the hashtag. This was important because we needed that age group to talk to a similarly-aged group – they understand each other best.



# Tous Aidants

## All Carers

**In France there are an estimated 2 million 'official' carers and 7 million 'unofficial' carers with no direct financial care allowance currently provided. As with many countries, the caregiving burden is particularly felt among the working population, representing up to 15 percent of the entire workforce. Janssen France posed the question – who cares for the carers? With this in mind, they set about improving the lives of this invaluable group.**

In 2017, Janssen France hosted a hackathon, challenging local caregiver groups, computer programmers and digital experts to collaborate intensively for 48 hours to find digital solutions – in this case, seeking solutions to support caregivers. Following the hackathon, a project called Tous Aiants – from digital start-up Coorganiz – was awarded €40,000 to develop an app providing a forum for caregivers to connect, share feedback on patient mood, and share calendars and distribute tasks between themselves.

To launch the app, Janssen partnered with Coorganiz, the Departmental Council of Hauts de Seine and Paris La Défense to take their message directly to France's workers. Using an 'Airstream' style caravan as a base, the team took over La Défense – Europe's largest purpose-built business

district – creating an oasis of calm in a bustling commercial environment, allowing volunteers to reach potential caregivers one-on-one.

Over three days, the team met more than 700 caregivers, hosted 60 welfare meetings, distributed over 2,000 flyers and were visited by five journalists.



### PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients benefit from their carer feeling better-supported and staying healthy and mentally well. By being able to reach out to other carers for support and more easily track the schedule and health of the person that they support makes their day-to-day role more manageable.

Quantitative and qualitative measurement of the impact on carers and the patients they care for can be collected through app usage. The app was downloaded by 1,000 individuals in the first month; and was subsequently made available in English, German, Spanish and Swedish.

### INNOVATIVE ELEMENTS OF THE PROJECT

Carers are an under-recognised, under-reached group in France and worldwide. This project was innovative for a number of reasons, including its recognition that almost everyone will become a carer one day. The project addressed both carers of patients and employees who care for relatives.

The 'hackathon' approach was highly innovative. Providing carer groups with access to programmers and digital experts was novel and allowed 21st Century ideas to solve long-standing problems. By bringing the 'Airstream' carer caravan to workers rather than hospitals, the project reached 'unofficial' carers or carers who had perhaps not realised that their role constituted that of a carer.

### COLLABORATIVE ELEMENTS OF THE PROJECT

By bringing a diverse group of people together in a 'hackathon', this project ensured that it was driven by collaboration from the outset. The users, developers, influencers, patients, employees, healthcare professionals, patient associations, caregivers' associations, a start-up company and a pharmaceutical company were all involved from the beginning. Together they tackled the question: 'what would we like to achieve?'

They have been committed to the project from the start and, by having this range of important stakeholders involved and aligned throughout the project, it has been a true and effective example of co-creation and collaboration.



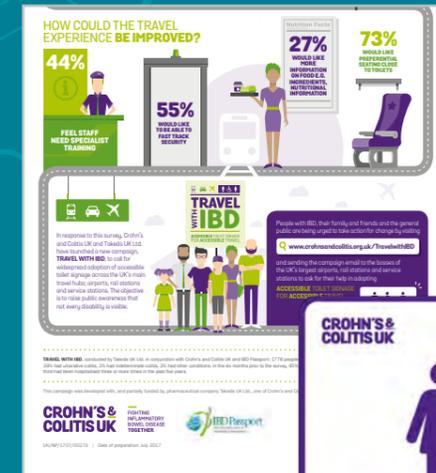
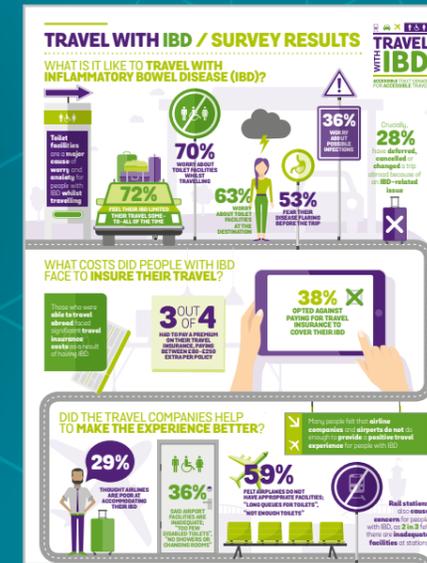
# Travel with IBD

**For people living with IBD, the sudden and uncontrollable need to use a toilet is particularly problematic. It can lead to episodes of public incontinence. Many also have a stoma bag and need space or privacy to change these comfortably. Despite this, patients in the UK regularly face the anxiety of being refused toilet access or being confronted over using a disabled facility just because they are living with an hidden disability. This is a particular concern for people when travelling.**

Takeda UK, Crohn's & Colitis UK and IBD Passport commissioned a survey of 1,776 respondents within the IBD community to understand their unmet travel-specific needs. This revealed a wide range of challenges; 28 percent deferred, cancelled or changed their trips because of their IBD. Over 50 percent of patients claimed they were subject to challenges and abuse simply for accessing the toilet facilities they required.

This was the basis for the 'Travel with IBD' campaign, mobilising the travel industry to act. The objective was twofold: to raise public awareness that not every disability is visible, and to encourage widespread adoption of new, non-statutory accessible toilet signage in the UK's main travel hubs.

The campaign run by Crohn's & Colitis UK in partnership with Takeda encouraged large numbers of people to email travel hub bosses and call for change. This built on the launch of the survey results, and saw the public send 50,464 emails to travel hub bosses and the campaign attract 2,789 supporters. This massively exceeded our target of 20,000 emails. As a result, 15 travel hubs committed to adopting accessible toilet signage while a further nine are in discussions to do the same.



## PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

In the UK, there are 300,000 people living with IBD. A follow-up impact survey of over 2,000 respondents conducted by Crohn's & Colitis UK found that 88 percent of respondents feel more comfortable visiting travel hubs now that the new signage has been installed. 87 percent thought the campaign has had a positive effect in tackling stigma and reducing isolation, while 68 percent stated that using disabled toilets would help. This suggests that a high number of patients could benefit from this campaign.

The collaboration has had a knock-on effect on availability of accessible signage in other venues, further benefiting patients across the UK.

## INNOVATIVE ELEMENTS OF THE PROJECT

Crucial to the campaign's success was having people living with IBD available to speak to the media. These were identified through the Crohn's & Colitis UK network. Including quotes from Olympian and Crohn's & Colitis UK ambassador, Siobhan Marie O'Connor, as well as Newcastle International Airport (an early adopter of the campaign) were valuable.

The campaign effectively mobilised large numbers of people to write to travel hub managers to urge them to implement much-needed changes. This exercise in people power delivered results that will improve the lives of patients.

## COLLABORATIVE ELEMENTS OF THE PROJECT

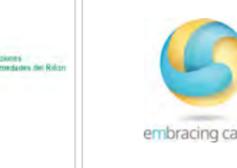
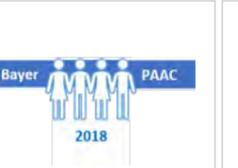
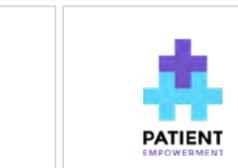
Due to separate existing projects, Takeda UK and Crohn's & Colitis UK identified the need to survey patients on their travel experiences, in collaboration with the support website IBD Passport. In implementing a solution to address the identified gaps, both Crohn's & Colitis UK and Takeda UK built a great working relationship that has since led to other projects utilising both organisations' strengths.

This collaboration helped to raise awareness of the campaign, and prompt action by patients, by leveraging existing networks of people with IBD.

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