

HEALTH COLLABORATION GUIDE 2017



Foreword

Dear Colleagues,

All partners in the healthcare equation agree that the patient should be at the heart of healthcare, from prevention and awareness, through research and development, regulatory and HTA decision making, to service design and outcomes measurement.

Realising this means developing collaborations between patients, patient organisations, healthcare providers, regulators, policy makers 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 objectives, transparent funding arrangements and well defined outcomes. The EFPIA Patient Think Tank is committed to facilitating the patient being at the centre of industry patient 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 second year, the guide is designed to spark new ideas to develop collaborative projects that, will continue to make a difference to patients across Europe.

Nicola Bedlington, Secretary General, EPF
Stefan Oschmann, President, EFPIA



ABOUT THE EFPIA PATIENT THINKTANK

The EFPIA Patient Think Tank provides a forum for an open exchange of ideas, information and perspectives between Patient Organisations and industry on topical issues impacting on patients.

The aim of the Patient Think Tank is to ensure that the patient voice is heard in the development of EFPIA policy and practice and to build trust and acceptance around transparent patient-industry dialogue and multi-stakeholder collaboration.

No subject is off the table and as a group we have discussed topics such as outcomes focused healthcare, medicines pricing, patient engagement in HTA, healthcare data and collaboration. The Think Tank is keen to take dialogue and debate beyond the membership of the group, through initiatives like the Health Collaboration Summit and the “Working Together with Patient Groups” rollout programme.

The Patient Think Tank has also initiated the Health Collaboration Awards to reward collaborative projects that have delivered patient benefit.

The aim of the awards is to share best practice and provide food for thought and inspiration to stakeholders considering developing multi-stakeholder projects that benefit patients. In addition to this, the Think Tank has also developed a white paper to underline the rationale for interactions between the pharmaceutical industry and Patient Organisations, suggest the principles on which these interactions should be based, outline the points of collaboration through the life cycle of a medicine.

As European Healthcare continues to face significant challenges it is critical that there is open dialogue between stakeholders. The Patient Think Tank plays an important role, providing a forum to share information, support best practice and exchange perspectives.



Together for Better Health, for us-by us

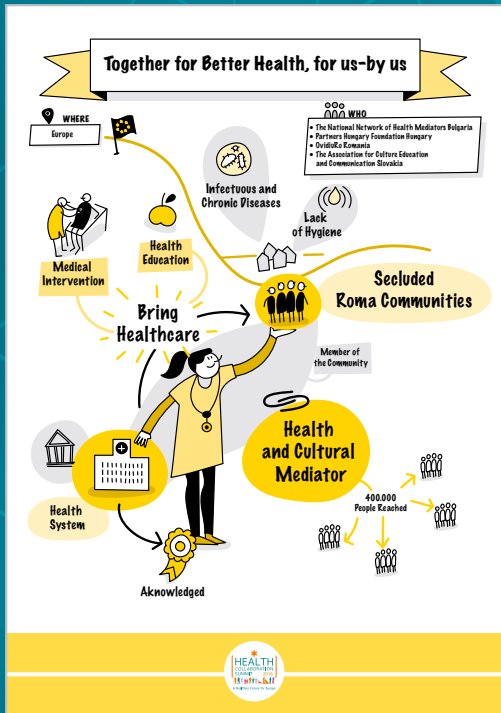
A significant number of Roma people in Central Europe live in geographically isolated communities, often characterized by a lack of infrastructure, hygienic amenities, and social and health services.

In 2012, GSK and four distinct NGOs from Bulgaria (National Network of Health mediators), Hungary (Partners Hungary), Romania (OvidiuRo) and Slovakia (ACEC), started a partnership to improve the health of those living in socially excluded and isolated Roma communities in Europe. "Together for Better Health", is supported by the GSK community partnership programme and the European Public Health Alliance. In September 2016, UNICEF joined the project.

Key to this programme are 'health or cultural mediators', individuals from Roma communities who receive training in basic preventative and curative healthcare, and who act as a link between the communities and the health system. One of the major success factors for health mediators is the fact that they often belong to the community for which they work. The other key component of the project is the education of Roma children and communities including health and hygiene.

Our main objectives are to share experiences and develop support materials for health and cultural mediators and teachers that work in secluded communities, to ensure that mediators are acknowledged and embedded in the national legal frameworks and to speed up sustainable access to available national and European funds. Leveraging the expertise and joint advocacy with the NGO partners already has led to policy changes. Local solutions have been developed from within the communities together with health and cultural mediators, healthcare professionals, teachers and local, regional and national authorities. All with a positive impact on the health and education for Roma people in the communities we work in.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

More than 400,000 Roma people have been reached so far. They received direct support in social and health issues, access to doctors and screening, (health) education, prevention, disease awareness, hygiene programmes and cultural integration. The activities and outcomes are measured by the mediators on a daily basis and by the NGOs involved. Joint measurements are now being developed to better inform national and EU policies. In Slovakia the Healthy Communities Programme was developed with the Slovak government, increasing the number of health mediators from 50 to over 300; In Romania “health caravans” are set up, with doctors and medical students traveling to secluded communities to provide check ups and referrals; In Bulgaria the number of health mediators increased and education further improved with positive social impact and in Hungary mediating programmes are set up. In all countries we successfully developed and run hygiene education projects in communities.

INNOVATIVE ELEMENTS OF THE PROJECT

The project is truly innovative as it leverages the experiences, skills and pragmatic insights of NGOs from different countries, supported by a key EU health NGO and by a company with the aim of making a direct impact on the lives of Roma people living in secluded communities. Most specifically, this occurs through empowering and employing people from those communities and supporting the (health and hygiene) education of children and adults. Our insights and experiences are used directly to improve the way that we provide support, as well to develop and provide materials to teachers, mediators and communities. Moreover we use our combined insights “from the field” to inform national policy development and funding to create sustainable networks of health mediators and (health and hygiene) education. The shared insights amongst the partners have already had a significant impact on national policies (recognition, funding, selection, education of health mediators) and legislation. We have provided input to the European Commission’s surveys and were participating in international conferences and platforms with the aim to direct policy and funding to the real needs of the secluded communities.

COLLABORATIVE ELEMENTS OF THE PROJECT

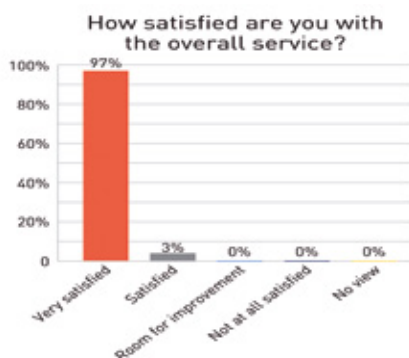
Experienced NGOs from different countries share and leverage their direct experience in helping Roma patients in secluded communities through health mediators and education, as well as finding ways to inform national policies and attract national and EU funding. These NGOs are supported in EU outreach and policy development by the EPHA. GSK provides structure, funding and national support, both managerial as well as in communication. Besides that, the program is supported by GSK Pulse Volunteers, dedicating 3-6 months full time to support the project. The programme is chaired by one of the NGOs in rotation for a period of nine months and supported by GSK. We have 3 virtual meetings per year through videoconferencing from GSK national offices and meet face to face once a year in one of the participating countries, to learn in practice by visiting secluded communities. We also hold events with national stakeholders, to share and inform pragmatic policy development. We also deploy common themes that are implemented simultaneously in all participating countries, amongst others, improving the hygiene situation, inspired by the GSK PHASE project, developed to improve hygiene in underserved communities around the world.



The Clatterbridge Cancer Centre **NHS**
NHS Foundation Trust

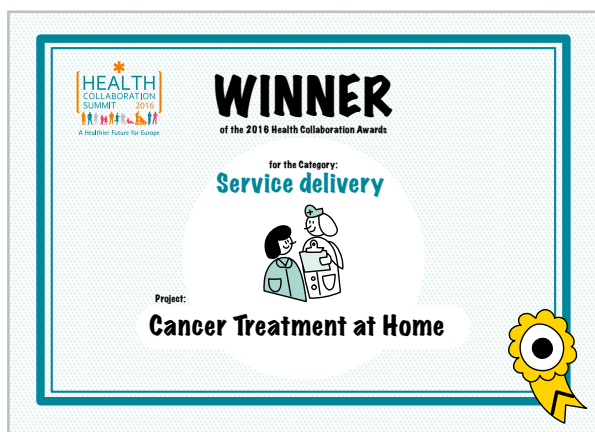
Cancer Treatment at Home

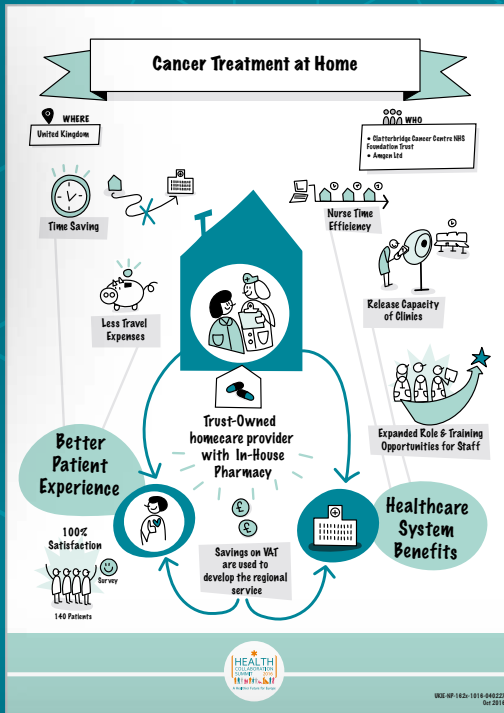
'Cancer Treatment at Home' is a pioneering service developed and run by the chemotherapy directorate of the Clatterbridge Cancer Centre NHS Foundation Trust (CCC). Serving a population of 2.3 million across Merseyside, Cheshire and the Isle of Man, the Trust is one of the UK's largest networked cancer centres.



Based specifically around the needs of the local patient population, 'Cancer Treatment at Home' enables patients with breast cancer to receive one or more of a number of identified therapies, in the comfort of their home. The service was unique in the UK, to be run in-house with support of a Trust-owned pharmacy. This allows the Trust to take advantage of the zero rate of VAT applicable to medicines supplied by a hospital pharmacy.

Objectives include: improving cancer patients' experience of care by offering independence and choice over treatment settings; reducing time spent travelling and waiting in clinics; and releasing capacity in day-case clinics.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The benefits of the service are substantial, with patient surveys consistently rating the service 100% for both patient satisfaction and patient needs being met. There are currently 112 patients enrolled, resulting in an estimated 1122 treatments episodes and associated clinic time saved in the seven months between 1st April and 31st October 2016. A VAT saving of £257,898 has been delivered over the same time period and the chemotherapy directorate is currently at 84.5% of its monthly CIP target for 'zero rated for VAT' medications.

Cancer Treatment at Home is benefitting patients by reducing the burden and expense of travel and alleviating anxieties around hospital visits. For patients preferring hospital treatment, clinical staff have noticed that freeing up clinic capacity has provided a calmer, more focused environment for treatment.

INNOVATIVE ELEMENTS OF THE PROJECT

Through the development of an innovative service model, Cancer Treatment at Home takes medications previously only delivered in hospital and enables them to be administered in a patient's own home. Some of these are complex medications and / or require regular monitoring but robust treatment protocols and clinical governance standards have ensured high levels of patient safety with zero patients reporting to triage or A&E due to problems following treatment.

The service model is unique in making innovative use of its in-house, wholly owned, out-patient pharmacy - PharmaC. This has delivered efficiencies savings that have been reinvested back into the service, allowing it to expand.

COLLABORATIVE ELEMENTS OF THE PROJECT

Collaboration with the pharmaceutical industry to obtain funding to support the implementation of the pilot scheme for Cancer Treatment at Home was a fundamental element in getting the service off the ground.

Amgen Ltd and CCC collaborated closely to ensure that patient satisfaction data was collated, financially supporting the use of iPads with the nursing team to allow them to record all their interventions whilst with the patient. The local Amgen Value Solutions Manager worked closely with the Chemotherapy at Home Senior Project Manager in sourcing relevant IT software to manage the scheduling of patients and hence maximize the nurses' time.

**VIVIR CON
EPILEPSIA** 

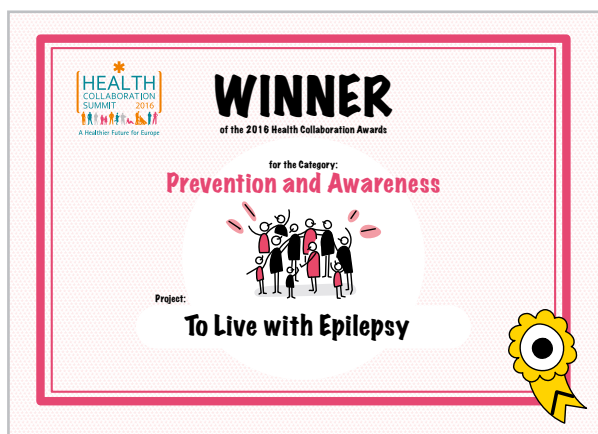


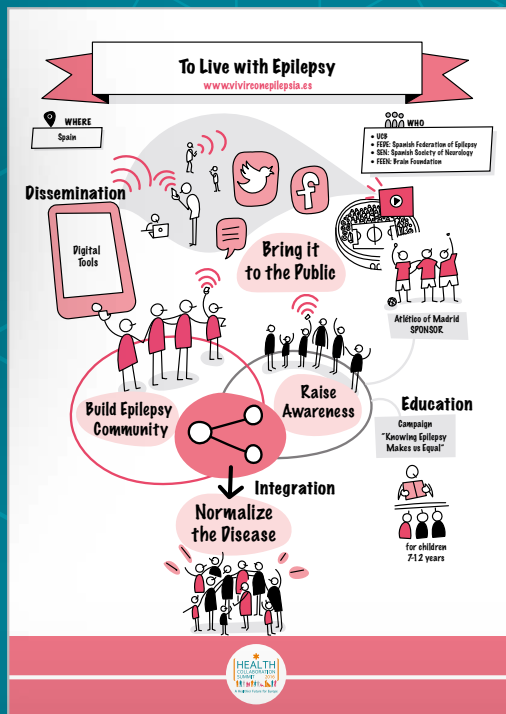
To live with epilepsy

In Spain, over 400,400 people live with epilepsy and each year more than 20,000 cases are detected. “Vivir con epilepsia” is a specially designed web-based project focused on epilepsy, aimed at enhancing knowledge of the condition and at sharing experiences amongst patients.

An epilepsy community has been created through a multidisciplinary approach to drive inclusiveness and enhance the quality of life of those who suffer from epilepsy.

The goals of the project have been to: establish a durable, coherent digital ecosystem, over the web, entitled ‘Living with Epilepsy’, which offers and disseminates comprehensive information on topics about epilepsy; create a digital community on epilepsy in which sufferers, carers/families can share experiences, be heard, followed and interact; show UCB’s commitment in this area through a non-branded project, aimed at improving patients’ quality of life; and set up a channel to offer support to the different epilepsy patient programmes that UCB is developing. Digital channels also included a blog, and outreach through social media to reach patients and healthcare professionals. Furthermore, an awareness campaign, “Knowing epilepsy makes us equal”, serves as a tool for schools to help reduce stigma among young people.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The main benefit for patients is the normalisation of the disease in the eye of the general public. The campaign wants to improve the day-to-day life of people who suffer epilepsy and fight against stigma and social exclusion. The website Vivirconepilepsia.es registered 66,608 visits, 54,074 unique users and garnered 105,853 page views. Regarding the awareness campaign "Knowing epilepsy makes us equal", this was downloaded over 700 times, received almost 1,300 page and registered more than 1,100 unique users who have seen part or all the campaign. There have been 1,260 visits to the video via Facebook and the hashtag #VivirconEpilepsia has secured 2,500,000 impressions in total, produced from 500 tweets from 316 different participants.

The majority of teachers praised the usefulness of the initiative in terms of knowing how to react during an epileptic attack and students have shown a great interest in the campaign, most of them changing their view of the disease and the stereotypes it has generated.

INNOVATIVE ELEMENTS OF THE PROJECT

The website "Vivir con epilepsia" offers new opportunities to increase knowledge about epilepsy. This is accompanied by a complete digital ecosystem (blog, Facebook and Twitter), with quality content, updated weekly.

The campaign "Knowing epilepsy makes us equal" is designed for children aged 7-12 years. The campaign offers an educational tool, such as a teacher's manual, and a storybook for children through which they are made aware about how to manage an epileptic seizure in a simple, but effective, way.

COLLABORATIVE ELEMENTS OF THE PROJECT

The pharmaceutical company UCB and the Spanish Epilepsy Patient Federation (FEDE), supported by the Spanish football champions league team "Atlético de Madrid", joined doctors, patients and the general public in several initiatives focused on reducing the stigma of epilepsy in Spain. The education campaign was approved through a compliance process, which respected and was in line with the principles of the EFPIA, Code of Practice on relationships between the pharmaceutical industry and patient organisations.

By directing digital communication over Social Media we showcased a transparent management of the content and offered direct participation in line with patients' needs. The digital communication process involved the departments of medicine, compliance and pharmacovigilance. All the communication experts involved in this project were taught and prepared by the pharmacovigilance department.

"At AbbVie, we believe our contribution needs to be more than just medicines. Working with the Hepatitis C Trust and Addaction was a recipe for success that we are looking to replicate in other areas, not only in the UK but globally. The South West Hepatitis C Partnership is an exemplar of what we can achieve when we work in a true partnership of equals, with focused goals and delivering outstanding tangible success for patients"

Len Gooblar

Head of Sustainable Healthcare, AbbVie

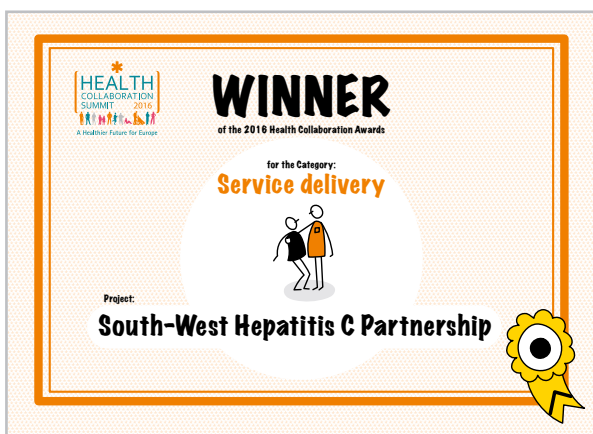


The South West Hepatitis C Partnership

People who inject drugs are at high risk of contracting HCV. The Hepatitis C Trust, Addaction and AbbVie have pooled their skills to pilot a unique approach to supporting people with a history of injecting drugs, into HCV testing and treatment.

A three-year pilot was rolled out across South West England, aiming to: identify what works best in empowering people to address HCV as part of their recovery journey; involve service users in testing the impact of peer education and buddying approaches; and upskill the Addaction team to confidently raise HCV issues with service users

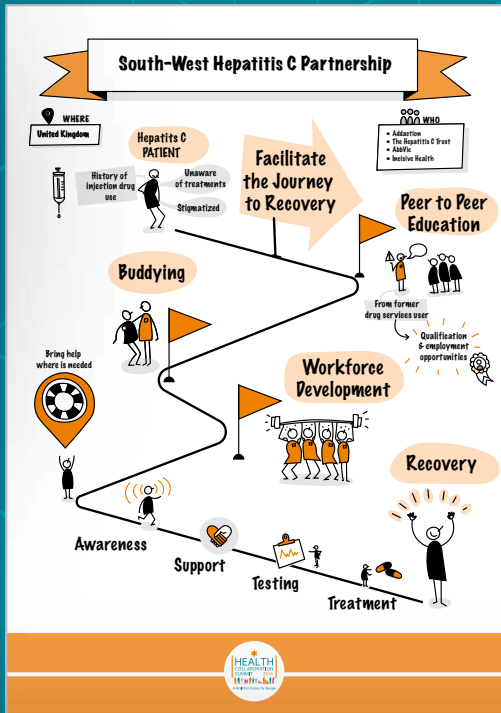
The pilot initiative comprised three key interventions: peer-to-peer education, training former service users as peer educators, to deliver talks to high-risk groups designed to reduce stigma and present facts around risky behaviours, testing and treatment; buddying, by training volunteers to provide one-to-one support to people going through testing and treatment; workforce development, including one-day training courses delivered by experts seconded from The Hepatitis C Trust to improve Addaction key workers' understanding of HCV.



"The elimination of hepatitis C as a public health concern is entirely achievable – if we can reach the people at highest risk. We are proud that Addaction's drug services are pioneering this through our South West Hepatitis C Partnership. We showed that through collaboration we can deliver the right support, in the right setting, to the people who need it, with great results."

Sam Downie

Director of Quality, Addaction



“Dealing with their hepatitis C can be the first loving thing that someone who uses drugs does for themselves. With peers by their side to provide information and support, service users were able to take this important step on their overall journey to recovery. But a peer-to-peer approach, recognising each other’s strengths, was also the key to our way of working as a partnership. Our expertise in hepatitis C, Addaction’s committed keyworkers and volunteers, AbbVie’s know-how – a powerful combination.”

Stuart Smith
Head of Drug Services, The Hepatitis C Trust

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Two independent evaluations were commissioned: an interim report for 2015, enabling partners to identify the elements securing most traction; and a final report due in late 2016. The peer-to-peer education programme, the pilot’s most successful segment, has reached almost 1100 people who use drugs or are in recovery – an average of 80 people each month. At least 85% of participants, when surveyed at the end of the talks, had taken in and retained all five key messages from the training and seven out of ten attendees felt that their knowledge of HCV had increased ‘a lot’ or ‘massively’.

INNOVATIVE ELEMENTS OF THE PROJECT

The project challenged existing models of delivering support to people with or at risk of HCV, demonstrating innovation through providing support closer to people who need it – the traditional structure for healthcare services meant that support could be difficult to access and was delivered by healthcare professionals with whom service users had no established relationships. The pilot enabled people who inject drugs to receive support and advice from local drug and alcohol services, from peers with relatable lived experiences or from Addaction’s key workers, whom they trust. It also succeeded in harnessing the energies of former drug service users – as former users of drug services, the peer educators and buddies could relate to and understand the perspectives of current service users. The reliance on peer educators to deliver the key messages, rather than healthcare professionals or patient support groups, ensured greater cut through with the target groups.

COLLABORATIVE ELEMENTS OF THE PROJECT

Project partners AbbVie, Addaction and The Hepatitis C Trust share an ambition to see hepatitis C eliminated in the UK. The partners each brought specific expertise to the creation and execution of the initiative. The pilot combined: The Hepatitis C Trust’s expertise in the virus; Addaction’s reach as a specialist drug service provider; and AbbVie’s knowledge of health and care systems. The partners worked with policy and communications consultancy Incisive Health to support the additional work to engage national and local stakeholders.

The project partners formalised their working relationships by putting in place a transparent contractual agreement. In line with the UK pharmaceutical industry standards, AbbVie’s support for the initiative has been clearly declared on all external materials relating to the pilot. To ensure input of all project partners could be fed into the annual planning and ongoing project management, regular meetings of the project partners were held with actions clearly minuted.

abbvie



NOVARTIS



AG Beipackzettel – Working Group Patient Information Leaflets

Patients need comprehensible, useful information on drug therapy that supports them in the safe and effective use of a medicine.

To meet patients' wishes and requirements for patient-friendly patient information leaflets (PILs), this group of representatives of patient and senior citizens' organisations and pharmaceutical companies have joined forces and created an innovative collaborative platform for all stakeholders. For years, this group has been a pioneer in working for easily comprehensible PILs, allowing interactive communication between the pharmaceutical industry, physicians, pharmacists and patients.

They all work together towards a common goal: clear, informative PILs that motivate patients to read them, because only PILs that are read and understood contribute to safe and efficient drug use.



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Gemeinsam erreichen wir mehr!

„Der Beipackzettel ist für mich als Patientin eine ganz wichtige Informationsquelle.“
In der AG Beipackzettel kann ich mich für eine verständliche Sprache und eine gute Übersicht einsetzen.“
Hildegard Kaltenstädler
Bundeselbthilfeverband für Osteoporose e.V. (BFO)

„Mir ist wichtig vor allem die Wirkungen eines Arzneimittels zu erfahren – ansonsten fällt es mir schwer, den Nutzen der Behandlung gegen die Risiken abzuwägen.“
Uta Kruk
Vertreterin einer Selbsthilfegruppe für Krebskranke Frauen

Der patientenfreundliche Beipackzettel
Stand der Information: August 2014 / BAGSO



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Every patient/carer stands to profit from the efforts of AG Beipackzettel, as each individual is confronted with the PIL.

AG Beipackzettel contributes to ensuring that standards set by authorities are patient-friendly. This includes:

- commenting on EU templates;
- supporting a translation of the “Excipients guideline”, improved and published by BfArM in 03/2015; and
- developing flyers for patients, which motivate them to read the PIL and to understand its structure, which is not self-explanatory.

Research work initiated by the group or some of its members is available publicly and makes another significant contribution towards improving the framework for the creation of patient-friendly, comprehensible PILs.

Approximately 100 PILs have been improved across companies (for products in a range of major therapeutic areas, registered via National, Mutual Recognition and Centralised Procedures – i.e. also PILs of EU widely registered products have been part of the project)

INNOVATIVE ELEMENTS OF THE PROJECT

The innovative nature of the project lies in the collaborative platform used to work on PILs. On the one hand, the collaboration across companies for the strategic common goal needs to be emphasised, but most of all it is the collaboration with patients that counts – nothing about patients without patients!

The work has started within the legal framework, but later embarked on efforts to influence the legal framework to improve conditions. This group always made the voice of patients heard, thereby allowing for patients’ needs could be discussed with authorities and politicians.

COLLABORATIVE ELEMENTS OF THE PROJECT

Patients were included to act as partners in the discussion, not simply as test subjects. Regular meetings were organised by participating companies and focus groups were established to discuss qualitative text analysis, rather than only employing a user test on key issues.

The group has also invited interested persons, among them the former Patients’ Ombudsmann of the German government, Wolfgang Zöller, to participate in working meetings and has maintained contact with his successor, Mr. Laumann.

The parties of the working group PIL adhere to the rules of the FSA code of conduct for patient organisations.



APO Summer School

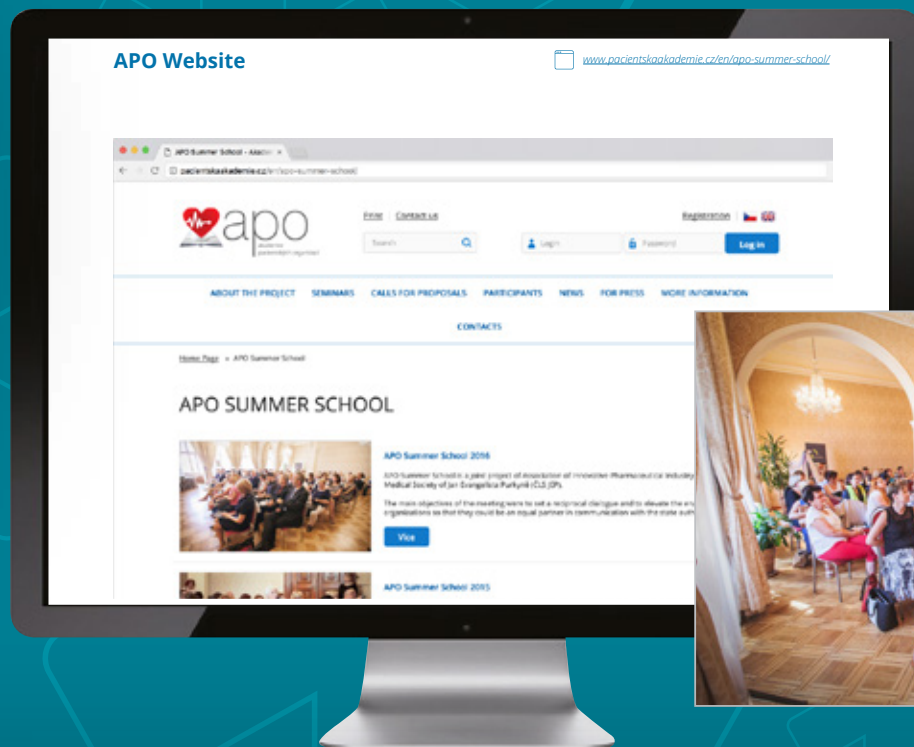
APO Summer School is a joint project of the Association of the Innovative Pharmaceutical Industry (AIFP), the Czech Medical Society of Jan Evangelista Purkyně (ČLS JEP) and more than 80 Czech patient organizations, which began in 2015.

One of the main aims has been to increase the erudition of patient organizations and to establish and encourage closer connection and cooperation between representatives of patient organizations and deputies of the Czech Medical Societies.

During the all-day events, each patient organization has a chance to join the round table with their counterparts from the Czech Medical Societies. Participating organizations have the opportunity to discuss current issues and to learn about medical professional societies, the latest treatment options and aftercare. Round tables are led by professional coaches and facilitators.

At the first annual APO Summer School in 2015, 12 round tables were organized on different therapeutic areas. The second annual APO Summer School in 2016, was linked to the discussion of the previous year. The main objectives of the meeting were to establish a reciprocal dialogue and to elevate the education level of patient organizations so they can act as equal partners in communications with the state authorities.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

More than 80 patient organizations from different therapeutic areas are involved in the project. About 120 participants attend the APO Summer School and provide information and services through their organizations to approximately one million patients and their families in the Czech Republic.

Benefits include setting joint strategies and establishing closer cooperation between patient organizations and the Czech Medical Societies in different therapeutic areas. Patient benefits are measured by the concrete outcomes from the discussions at the round tables and follow-up in a real world environment. Individual groups of patient organizations and Czech Medical Societies continued the discussion and collaboration from the previous year at the second annual APO Summer School in 2016.

INNOVATIVE ELEMENTS OF THE PROJECT

Impartial professionals facilitate interactive discussion between representatives of patient organizations and deputies of the Czech Medical Society at the round tables at APO Summer School. The representatives of patient organizations are well prepared to enter into a fully-fledged debate – based on APO training – on coaching, negotiation, as well as communication and presentation skills. Impartial professionals, in cooperation with patients, present the outcomes from individual round tables. Outputs and conclusions are summarized in written form for the next collaboration and for use in the future.

COLLABORATIVE ELEMENTS OF THE PROJECT

APO Summer School is a joint project of Association of Innovative Pharmaceutical Industry and the Czech Medical Society umbrella ČLS JEP. The main aim of the project is collaboration between patient organizations and the Czech Medical Society.

The deputies from Ministry of Health accept the invitation to attend the interactive debate every year and show their support for the project. Representatives of the innovative pharmaceutical industry and other patient umbrellas also attend the event. Representatives of patient organizations from other EU countries have also participated actively in the APO Summer School to speak about the advantages of collaboration between patients and professionals – as a means of provided best practice from abroad. A high number of mentions in the Czech media shows the importance of the project APO Summer School.



Butterflies under protection

According to the Polish National Cancer Registry from 2011, each year up to 2,500 Poles may be diagnosed with thyroid cancer. Although in 90% of cases the prognosis for treatment is positive, for those diagnosed it is still cancer - a life-threatening disease.

Starting in March 2015, and initiated by the Polish Amazons Social Movement, 'Butterflies under protection' is the first campaign in Poland that provides reliable information about thyroid cancer. The campaign was implemented with the support of an educational grant from Sanofi Genzyme and involves the Projan Foundation as a partner.

Providing practical knowledge about thyroid cancer therapy and its consequences offers significant support to people who are diagnosed with the condition. The most important element of the project is a guide for patients, which is available via the project website www.motylepodochrona.pl. The guide and information leaflets about the campaign also are distributed by medical centers in Poland in printed form.

The website collects the stories of patients who share their own experiences with the disease. The campaign directs not only internet activities, but

also seeks to organise meetings for patients, during which everyone may obtain information about thyroid cancer and its treatment, by talking with endocrinologist, a nurse and a patient.

The campaign also focused on building awareness of the prevention of thyroid cancer. That is why, over the past two years - in May and September – free and open preventive examinations of the thyroid have been offered. In September 2016, we launched the first office for thyroid ultrasound checkups.

The campaign also produced the film "Let's talk about thyroid cancer," which shows the disease from the patient's perspective. This material may become the next source of support for people who have just received a diagnosis. It is also a way to draw doctors' attention to the impact that thyroid cancer has on every patient.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The 'Butterflies under protection' campaign is the first project in Poland that allows easy access to comprehensive information on thyroid cancer. All the information and materials related to the campaign and thyroid cancer can be found in one place: on the website of the organisation Polish Amazons Social Movement at www.motylepodochrona.pl.

Patients may take the opportunity to participate in informative meetings about thyroid cancer. During the meetings they can talk about thyroid cancer and its therapy with an endocrinologist, nurse and a patient. In the first meeting, held in March 2016, 20 patients took part. Activities carried out under the campaign are communicated in the media - so far the media have published more than 80 publications.

Every month, the website is visited by about 2,000 users. Guides for patients are also supplied to 12 medical centres throughout the country. So far a thousand guides and 10,000 leaflets with information about the campaign have been distributed to the medical centres. 20 patients took part in the first informative meeting about thyroid cancer.

INNOVATIVE ELEMENTS OF THE PROJECT

The biggest innovation of the campaign focuses on the subjects, which are aimed at providing practical knowledge about how to prepare patients for therapy, as well as offering information on innovative methods of dealing with the effects of thyroid cancer.

Information about the campaign and thyroid cancer are supplied to patients in a printed form and via the website and social media. There is also a plan to create the first Facebook group in Poland on thyroid cancer, which patients struggling with the condition will be able to join, regardless of where they live. They will be able to share on social media their experiences and tips related to the treatment of thyroid cancer.

COLLABORATIVE ELEMENTS OF THE PROJECT

As part of the campaign 'Butterflies under protection' has established cooperation with 12 leading medical centres across Poland that provide the thyroid cancer treatment.

The campaign provides objective content to patients in accordance with the latest medical knowledge. The information provided to patients contains includes available treatments and ways to mitigate the effects of the disease. Each of the partners in the campaign has defined clearly the scope of their activities under the project, which is visible to the audience of the campaign.



Városmajori
Szív- és Érgyógyászati
Klinika



Cardiovascular Prevention Labyrinth

The highest standardised mortality rates for ischemic heart Disease in 2013, were seen in Lithuania, Latvia, Slovakia, Hungary and the Czech Republic (deaths per 100,000 population exceeded 350 in all of these countries in 2013).

The aim of the Health Labyrinth CV Prevention Labyrinth is to increase the Hungarian public's awareness about the prevention of cardiovascular diseases. The programme sets aside 1.5 to 2 hours to learn about CV risk factors in an interactive way, and offers an opportunity for immediate consultation about them. The cardiac risk status of programme participants is portrayed in a "CV tree of life".

Most information/awareness-raising programs focus on screening (blood pressure, blood glucose, BMI, Cholesterol), but those interested rarely receive comprehensive information about other areas that support health promotion, such as stress management with yoga, lifesaving reanimation exercises , a healthy diet, family tree, etc





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

After registering 178 persons (125 females and 53 males), blood pressure and body weight/body fat measurements were taken, with subsequent risk factor stations. From the 82 completion logs received, results were obtained from 45 high-risk (29 females and 16 males) and 37 healthy (24 females and 13 males) or adequately medicated patients. Our youngest visitor was a 4-year-old girl, while the oldest one was a 78-year-old lady.

The programme offered patients on-site risk assessment of fatal cardiovascular events from European regions by scoring them: on the basis of blood pressure, gender, smoking and cholesterol levels. It further provided the ability to plan a “do-it-yourself” personal and family health map, as well as stress and relief management via yoga exercises.

Opportunity was offered to ask questions immediately from the association’s patient advisors and from medical students. Daily exercise including learning exercises from a physiotherapist and healthy cuisine was an option, with recipes and an opportunity to try these in practice.

INNOVATIVE ELEMENTS OF THE PROJECT

The programme offered a novel, holistic approach to reducing CV risk factors, through quadrilateral cooperation. It furthermore focuses on the provision of information of importance both at an individual and community level at the same time.

The project was so successful among public that as a regular program it is available 3-4 times during the year organized by SzívSN patient association announced on their website.

COLLABORATIVE ELEMENTS OF THE PROJECT

The event was organised by the Hungarian Society of Cardiology (MKT) under the title ‘- Our hearts’ day’ and was a full-day event, during the first Health Labyrinth prevention program was implemented by graduate volunteers, patients and appropriately-trained volunteer medical students of the SZÍVSN patient organisation in Budapest on September 25, with the support of Sanofi-Aventis Zrt.

The programme has been monitored continuously, starting from the birth of the concept. After learning about the details of the programme, our priority in terms of support was to ensure wider cooperation. Also important was a need to provide information concerning the importance of the programme both at individual and community level at the same time. The Hungarian Society of Cardiology (MKT) operates together with the Cardiovascular Section of the National Patient Platform (NBF) and with our voluntary patient organisation



#Di_Capacitados

During the last 50 years, considerable progress has been made in improving the medical outcomes of people with schizophrenia but much less has been done to improve their social outcomes.

In 2014, the Janssen team witnessed first-hand how the lack of awareness and understanding among the general population in Spain was negatively impacting individuals with schizophrenia. The team committed to changing the public's thinking and #Di_capacitados was born.

The team knew that a wide-reaching communications campaign would be critical to increasing the awareness and understanding of schizophrenia. Working closely with its PAG partners across Spain, Janssen developed ideas and found a range of individuals with schizophrenia willing to share their stories.

Working with 10 individuals to learn more about their goals, challenges and support networks, the team gathered a series of powerful and personal video testimonials, taking viewers inside the lives of individuals with schizophrenia to demonstrate that recovery – and a return to normal life – is possible.

What started as a collection of short testimonial-style videos later evolved into a 90-minute award-winning documentary featuring 14 patient stories.

#Di_capacitados: The Documentary premiered on 5 October 2015 at Cinema Palafox in Madrid, Spain, and was attended by an invited audience of 1,000 people, including the 'stars' – the individuals involved in the making of the film. It was subsequently shown at a further 16 cinemas across Spain, collectively viewed by more than 6,000 people and attracting extensive media interest. In addition the documentary was screened at the Goya Awards, shown on television and has been viewed over 3 million times on YouTube.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

#Di_capacitados helps individuals with schizophrenia across Spain by ensuring that their positive stories are heard by the wider community. It raises awareness and seeks to dispel myths associated with schizophrenia, in order to reduce the associated stigma.

By turning the camera on individuals, the power of #Di_capacitados: The Documentary lies in the openness and honesty of those sharing their personal experiences. This not only helps to unburden them from the stigma related to their condition, but also demonstrates that patients can regain their lives and live with schizophrenia.

Individuals who participated in the campaign have explained the positive impact the film has had on how they view their condition as well as how it has altered attitudes in their own communities towards schizophrenia.

The #Di_capacitados project aimed to benefit all patients living with schizophrenia in Spain: approximately 400,000. Janssen is currently developing a national survey in Spain, aimed at measuring the true extent of the impact of the documentary on individuals with schizophrenia as well as the general public.

INNOVATIVE ELEMENTS OF THE PROJECT

The Janssen team's use of the film medium allows it to take viewers inside the individuals' day-to-day and intimate experiences of living with schizophrenia to increase empathy and understanding. Evolving the video testimonials into an award-winning documentary helped increase national awareness of schizophrenia and the stigma surrounding the illness.

By sharing the documentary through mainstream cinemas, Janssen ensured this important film received more attention from the wider community and general public. This elevated the campaign beyond website and social media engagement, and encouraged social interaction and media coverage by staging an official premiere, which served as a catalyst for further awareness across Spain.

COLLABORATIVE ELEMENTS OF THE PROJECT

Through a combination of personal contact, transparency, openness, honesty and respect, the Janssen team developed strong working relationships with eight patient groups during the development of #Di_capacitados.

In addition, the Janssen team collaborated with:

- a video production company, to ensure that the testimonials were brought to life in a highly emotive and impactful way;
- the Spanish cinema network, to ensure the story would reach the widest and broadest national audience; and
- the psychiatric medical and research community, to highlight the clinical aspects of schizophrenia and confirm that recovery, and a normal life, is possible for those living with the illness.

The campaign was endorsed by the psychiatric medical and research community via a number of leading associations including: Sociedad Española de Psiquiatría (Spanish Society of Psychiatry); Fundación; and Española de Psiquiatría y Salud Mental (Spanish Foundation of Psychiatry and Mental Health).



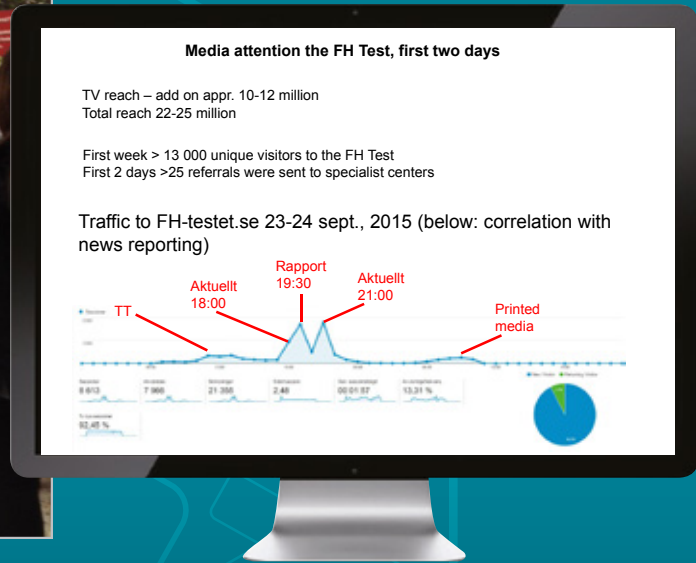
The FH Self-Diagnosis Test

Familiar hypercholesterolemia (FH) is a highly underdiagnosed disease that is silent/ asymptomatic and, if untreated, deadly. A common scenario of an untreated person with FH is a cardiac infarction or stroke at a fairly young age. It is estimated that about 50,000 people have FH in Sweden but only 2,000 have received an FH-diagnosis.

This project's aim was to raise awareness about FH and increase the diagnosis rate through a web-based self-diagnosis tool for the public, as well as to offer a possibility to get direct referral to an FH-specialist, if FH is suspected. A series of questions was developed for the public, the answers to which formed the basis of a diagnosis of "possible FH" or not. The patient organisation "FH Sverige" found the self-diagnosis tool very interesting and took charge of the project.

Aside from evaluating the test, they also made sure the questions were accessible and available on the internet. The patient organisation also appreciated the possibility of getting a referral to a specialist directly if the test resulted in "possible FH". The web-based FH Test was successfully launched in Sweden on the international FH Day, with the help of massive media attention. The media attention helped raise awareness about FH and drive traffic to the Test. Within a year, the FH Test has facilitated a potential 50 percent increase in the number of people with an FH diagnosis in Sweden. Additionally, the FH Test has provided data to benefit FH research.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The main patient benefit was getting 271 people with a possible FH diagnosis into the healthcare system and under treatment – potentially saving and/or extending their lives as well as their undiagnosed relatives.

The media attention surrounding the launch helped increase awareness of FH amongst potential sufferers and drive traffic to the online FH Test (and to more information about FH). Its accessibility and ease of use (getting rid of “road blocks” to getting a proper diagnosis) is appreciated. Within the first two days there were about 13,000 visits to the online test and in the first year, 3,283 tests were completed, with over 271 cases of suspected FH referrals to experts downloaded. If all these people have confirmed FH and their relatives are screened for FH, the FH Test may be responsible for increasing diagnosis from approximately 2,000 in Sweden to 3,000 – a rise of 50% in one year.

INNOVATIVE ELEMENTS OF THE PROJECT

This is the first self-test for FH in Sweden, representing a vehicle for those at risk for FH and providing direct pathway to an expert within the healthcare system through the self-referral feature. The FH Test is also a great tool for the patient organisation and the network of FH experts to refer people to.

Aside from the FH Test, an animated film was developed to explain FH and its effects, and a road show that screened the public for cholesterol was devised. This provided an additional opportunity for media attention, along with face-to-face information and discussions about FH with the general public.

The FH experts who developed the questions also wanted to take the opportunity to collect data for research, resulting in the FH Test featuring the option to share answers to benefit FH research. More than 80% of the people opted to say “yes” to this within the first year.

COLLABORATIVE ELEMENTS OF THE PROJECT

The FH Test brought together key stakeholders of FH. It was a collaborative effort between Sanofi, prominent researchers/FH experts at two university hospitals in Sweden, a company specialised in self-evaluation tests and the FH patient organisation. Sanofi acted as coordinator of the project.

Finding passionate and driven cardiologists was key to help develop the questions for the self-test. They needed to have the same drive and wishes as the patient organisation in terms of finding a better way to reach and diagnose FH. From start to finish, it took about a year of close collaboration for FH Test to take form and to launch it.



Health Ecosystem Solution: Risk Sharing Agreement + Patient Support Programme

A lack of patient engagement with a new drug can lead to worse clinical outcomes and poor adherence to treatments. This could also affect the physician-patient relationship.

In several regions, UCB has developed a risk-sharing agreement for Cimzia, its anti-TNF, indicated for rheumatoid arthritis, spondyloarthritis and psoriatic arthritis. Included is a commitment just to pay for the patients who respond at week 12 – when the product has demonstrated a predictability point for a clinical decision – moving from the concept of pay-for-product to pay-for-value.

The next step with our Health Ecosystem Solution Project is to link the concept to “Pay for Value of the Scheme” to provide services “beyond the pill”, with a nurse support programme at home, to maximise the patient experience during these first 12 weeks. The aim of the programme is to demonstrate that a better-trained and educated patient can lead to better health outcomes and also savings for the system when dealing with chronic diseases.

One of the main objectives of the programme has been to measure the “value” for all stakeholders. Several interviews have been conducted to decide the outcome that better reflects the impact of the programme. Finally, three outcomes were selected: clinical outcome (DAS28); patient activation measure (PAM); and patient satisfaction (NPS).

Health Ecosystem Solution

Risk Sharing Agreement
+
Patient Support Program



 Inspired by patients.
Driven by science.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Extra home nursing support was provided during the first three months of treatment, consisting of: home delivery (if needed); device training at home (subcutaneous device); optimal treatment, disease information and healthy habits counseling; a home check list (medicine storage, first aid kit, ergonomics and caregiver relationship); preparing next doctor's visit; a programme that offers the opportunity to the nurse to see and help patients in their environment, which is not often possible in hospital.

The programme has three impact measures: patient satisfaction (NPS); clinical health outcome (DAS28); patient activation measure (PAM), related to the grade of autonomy and knowledge of patients about their disease that impact on health system resources.

INNOVATIVE ELEMENTS OF THE PROJECT

We link the concept of efficiency (guarantee the best health outcomes in clinical real world practice) to the Pay for Performance Scheme, to move forward in providing not just the "Product" but also "Services", and provide real word data to ensure paying only for health value outcomes.

All the content of the project has been develop for HCP's. The project has been carried within the framework of an observational study measuring the impact and value for all stakeholders, and may be replicated afterwards for more patients. It provides evidence incorporating innovative interventions (home delivery, nurse at home, educational program etc.), which really impact a patient living with a chronic disease.

COLLABORATIVE ELEMENTS OF THE PROJECT

For this project we have co-created with HCPs, scientific society, and patients' advocates. It involved: the pharmaceutical company UCB; a group of nurses from the National Rheumatologist Society; the National Pharmacist Society; specialist nurses from all the hospitals involved; a multidisciplinary study coordination group, consisting of a rheumatologist, pharmacist, nurse and a patient as an advocate.

The co-creation with HCPs and Patients was just at the beginning. Pharmacovigilance was undertaken throughout, and endorsement from the Rheumatologist National Society was gained and an ethical committee was accepted.



ÖSTERREICHISCHE
APOTHEKERKAMMER



ÖSTERREICHISCHE
ÄRZTEKAMMER

Hepatitis Awareness Campaign

This is an annual campaign to raise awareness on Hepatitis A&B infection. This year the focus was on Austria and unvaccinated people aged between 16-69.

The aim of the study was to identify reasons for not getting vaccinated against Hepatitis A or B and barriers to vaccination. Despite Hepatitis A and B being acknowledged as being dangerous, willingness to get vaccinated lies at only 14%.

Results showed that 64 % believe there is no or little risk of getting infected with Hepatitis A or B in Austria. As it is still seen as a “travel disease”, we sought to create awareness of the risk of infection in Austria.





Einstellungen zu Hepatitisimpfung in der nicht geimpften Bevölkerung

Studiennummer 5264, November 2015

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The net coverage of the awareness campaign in the media was 83 % (print) and 3.7 million ad-impressions online. In fact, the combined awareness approach, dating back until 2006, showed an increase in vaccination coverage over the years (increase of coverage of approximately 4 % from 2014 to 2015 – data for 2016 not yet available).

The project resulted in the provision of several services for the lay public, including: a price reduction of hepatitis vaccines; the provision of several information materials on hepatitis A and B; ensuring easy access to information on the disease and the vaccine via a common approach with all stakeholders; and the creation of broad awareness. The combined awareness approach showed an increase in vaccination coverage of approximately 4% from 2014 to 2015.

INNOVATIVE ELEMENTS OF THE PROJECT

To reach the greatest coverage in terms of creating awareness, an innovative multichannel approach was used: creating awareness through a combination of digital, print and out-of-home measures; involving stakeholders to achieve a common appearance vis à vis the lay public in order to gain trust, credibility and to show the importance of disease prevention, not only when travelling, but also on the domestic front, in Austria.

COLLABORATIVE ELEMENTS OF THE PROJECT

We cooperated with patient organisations and medical chambers, holding a press conference with GSK to present a joint front to reduce hepatitis A & B infections in Austria. We exchanged information during the creation of the campaign in order to ensure alignment on visuals and core messages between all stakeholders. We shared medical knowledge for the creation of lay public material and supported each other in ensuring the adequate price-reduction of vaccines – achieved following negotiations between Chamber of Pharmacists and GSK. The Chamber of Pharmacists and the Chamber of Physicians sent out information about the campaign to their respective members, requesting support for this topic.



abbvie

MİMAR SINAN
GÜZEL SANATLAR
ÜNİVERSİTESİ

romaturka

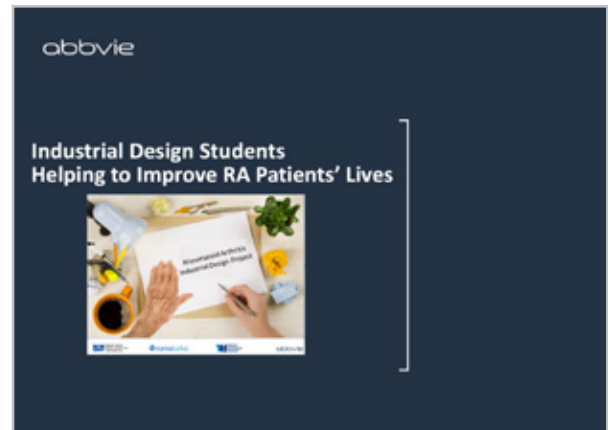
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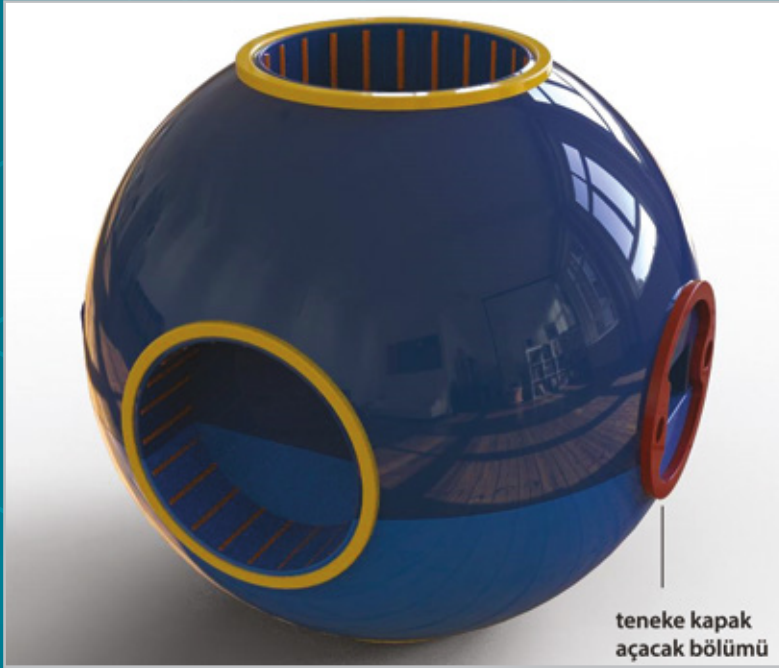
Industrial Design Students Helping to Improve RA Patients' Lives

Some 12 million people in Turkey, constituting 22.5% of the population aged 15 and above, have a difficulty in mobility that impacts their daily lives.



With this project we aimed to attract attention to Rheumatoid Arthritis (RA) patient's life and differentiate AbbVie with its patient centric approach creating innovative solutions for patients by collaborating with nontraditional partners. RA Industrial Design Project was designed to highlight the challenges faced by rheumatoid arthritis patients in their daily lives and increase awareness about the disease and importance of early diagnosis.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

More than 80 solutions were designed to make the daily lives of RA patients easier. These included a bottle/can opener, nail clipper, toothpaste opener, showerhead unit, power socket pedal, ergonomic spoon, bag carrier, pen/pencil holder, toothbrush cover. The four winning and eight secondary designs were selected by an expert panel and were announced on 12 October World Arthritis Day at a press conference, followed by an exhibition cocktail reception for all stakeholders. The prototypes of all the designs were exhibited at the National Rheumatology Congress on 29 October 2016. These efforts have empowered patients by involving them through all the process, from sharing their needs/challenges, design solutions, to selecting the designs for their daily needs, thereby making them feel they are real partners. The project has reached an estimated 70,000 RA patients, helping to increase patients' independence, communication with their surroundings and their self-esteem.

INNOVATIVE ELEMENTS OF THE PROJECT

The RA Industrial design project is the first ever in Rheumatoid Arthritis to make the daily lives of RA patients easier in Turkey, and brings together all stakeholders with an interest in every aspect of disease. We helped to empower the patients and improve their self-esteem/mood, making them feel they are real partners and involving them through all the processes, including sharing their needs/challenges and design solutions, and then voting for the best of them. With this Industrial design project AbbVie, Turkey has played a pioneering role as a highly focused biopharmaceutical company for all key stakeholders (including a university, physicians' association, patient association and patients), leveraging unique expertise in rheumatology. This has had an impressive impact in terms of a collaborative and sustainable approach, placing patients at the centre of everything we do.

COLLABORATIVE ELEMENTS OF THE PROJECT

We established trust and partnerships with a variety of stakeholders (Mimar Sinan Fine Arts University Industrial Design Department, Rheumatology Society of Turkey and the Patient Association) by building esteem with disease state expertise and patient centricity. We introduced effective cross-functional collaboration by creating the All for One AbbVie culture (including its communications/patient relations, commercial and medical departments). This project was based on the Pharma 3.0 business model, partnering with non-traditional partners to improve health-related outcomes and using a holistic approach in line with regulations governing the relationships between the pharmaceutical industry, physician and patient organisations.



Make Sense Campaign

The Make Sense campaign is a pan-European project run by the European Head and Neck Society (EHNS), to drive awareness of head and neck cancer (HNC).

The project addresses a number of unmet needs in HNC, including: disease awareness and understanding, HNC signs and symptoms education, emotive support for patients, and partnerships with governmental bodies and organisations, including the European Cancer Patient Coalition (ECPC) and industry, to increase the importance of this deadly disease and ensure better patient outcomes.

The objectives of the campaign, include:

- Raising awareness and understanding of head and neck cancer among the general population so they can recognise the signs and symptoms;
- Helping the general public to engage in a meaningful conversation about the role HPV plays;
- Aiding primary care staff in improving the standard of care and early diagnosis rates.

The campaign centres on an awareness week, the third week in September, where all participants and stakeholder execute activities; each day has an identified theme to address the unmet needs in head and neck cancer. Throughout the years, the EHNS and ECPC have partnered to deliver activities to move the needle on appropriate care and health resources across Europe. Joint activities work to: raise awareness of the role multi-disciplinary teams can play in successfully treating head and neck cancer, and position head and neck cancer as a global health priority among policy/political representatives.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The most direct activity to help patients is the early diagnosis day clinics, which take place around Europe on the Wednesday of the awareness week. Physicians involved in the campaign, volunteer to open their clinics and invite the general public to attend a free screening for HNC. In addition, patient leaflets are developed and shared, and the campaign website provides additional helpful information for anyone looking to find out more about HNC. Through increased awareness, screening activities to identify patients earlier, and improved awareness of optimal treatment practices among healthcare providers, the organisers are confident that people have detected their head and neck cancer early.

From 2013 to 2016 (4 awareness weeks) more than 23,000 people have been screened in 313 clinics open to the public across Europe, with a referral rate of 8.5-30%. In 2015 alone, the messages from the campaign reached approximately 5,010,260 people across Europe, and in 2016 over 13,000 patients were screened.

INNOVATIVE ELEMENTS OF THE PROJECT

The campaign has evolved significantly since its inception and employs a multi-channelled approach through traditional and social media, and live events, including: youth education sessions at local schools and universities; the launch of the “Uniting Voices” virtual choir, bringing together voices from around the world in solidarity with sufferers; education at Global and European wide congresses to discuss the benefits of multidisciplinary care and other aspects of HNC; early diagnosis day clinics to encourage people who might not otherwise visit a doctor to drop in for a screening at a local clinic; EU parliamentary activities to raise awareness of rare cancers, including HNC; and media and educational materials

COLLABORATIVE ELEMENTS OF THE PROJECT

The campaign has a Secretariat responsible for the budget and coordination of all activities, and an EHNS Steering Committee has been set up to ensure input and sign off on all activities and materials. The Secretariat coordinates and connects all campaign participants, including the sharing of materials and resources. The EHNS Steering Committee retains the final decision-making power for the direction of the campaign.

All partners, both industry and patient organisations, provide ideas, insights, and hands-on support in the delivery of the campaign, with a shared goal of doing what is best for patients with HNC. Partners are able to put forward suggestions and have them validated on their merit within the broader campaign – meaning that if/when an activity is implemented, everyone knows it is for the good of the entire campaign. Also, for transparency reasons, all the logos of industry partners are made visible clearly on the website and all printed materials (2016 industry partners included Merck and Boehringer Ingelheim. The 2017 campaign saw the addition of Norgine and Bristol-Myers Squibb).



Министерство на
Здравеопазването



National Campaign 'Vaksinko'

Low awareness among parents about prevention afforded by vaccines included in Bulgaria's immunisation calendar, and about the safety of vaccines, has led, in part, to increasing anti-vaccination sentiments in society.

In response, the National Campaign "Vaksinko" aims to raise awareness among parents about the importance of compliance with the mandatory and recommended immunisation calendar of the Republic of Bulgaria, inform them about the safety of vaccines and stress the importance of obtaining information from reliable sources, whilst highlighting the risks among children and the community where immunisation is not undertaken. Other key priorities include supporting the expansion of the immunisation calendar, providing support to address challenges associated with the provision of required doses to cover the needs of the Bulgarian market and improving dialogue between all stakeholders.

A broad range of stakeholders attended the debate on vaccines. The event helped to outline the challenges in healthcare and the possibilities to address them through improving dialogue between stakeholders. A Facebook page with publications on the subject was viewed over 500 000 times and was accompanied by events that reached out to over 5 000 children, as well as future and current parents. A website offers up-to-date, reliable information, and provides a platform for feedback. It has been visited over 15,000 times by some 9,000 individuals. Media partnerships also contributed to the visibility of the campaign, with publications seen over 3,000,000 times. Promotional events included participation in health exhibitions, video clips with parents, and the distribution of 100,000 brochures and 15,000 posters to target groups.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

According to a survey, 99% of those familiar with the initiative find it useful and have received new information, and over 70 % think that the campaign must continue and target wider coverage. The events were attended by many pregnant women who wanted advice on whether and how to get their children vaccinated, which testifies to the credibility of the campaign and the need to conduct such initiatives. We also received many calls and emails in which parents thanked us for the initiative.

INNOVATIVE ELEMENTS OF THE PROJECT

The campaign was initiated by the Consultative Body to the Council of Ministers "Partnership for Health," which in itself is an innovative approach to identifying and addressing problems in healthcare through an active dialogue between all stakeholders. The campaign is the first of its kind in Bulgaria and until it was initiated, there had not been any dedicated efforts on behalf of the institutions to raise awareness within the community about the benefits of and the need for strict adherence to the Immunisation Calendar and its expansion. The campaign incorporates many innovative approaches to reaching the target groups, such as Facebook, which allows for a very precise targeting of the audience. It also included an event aimed at parents and children during which bacteria and cultures were observed under a microscope and hands were checked under UV light. These interactive approaches not only provided feedback but also provided an opportunity for learning through playing.

COLLABORATIVE ELEMENTS OF THE PROJECT

The campaign owes its success to the effective collaboration between all stakeholders in terms of preparation (doctors), distribution (Ministry of Health), management (NPO) and funding (GSK, MSD, Sanofi and Mylan).

The campaign was launched with a decision of the Consultative Body to the Council of Ministers "Partnership for Health" in response to problems related to vaccines in the country. As a Secretariat of the Partnership, NPO set up a group of experts who created a consortium of four pharmaceutical companies, the Bulgarian Paediatric Association, the National Association of General Practitioners in Bulgaria, the Bulgarian Red Cross, and departments to the Ministry of Health. Each of the parties contributed with insights and detailed plan of activities, aimed at covering all the target groups.



No to Diabetes!

The International Diabetes Federation estimates that there are 387 million people with diabetes worldwide, which corresponds approximately to 8.5% of the adult population. In 2035, this figure is set to reach 592 million. The 2014 OCDE Health Report marks Portugal as the European country with the highest diabetes prevalence – about 13% of the population aged between 20 and 79.

No to Diabetes! is a project lead by Associação Protectora dos Diabéticos de Portugal (APDP) designed to show how local government structures, local regional and national health structures, and civil society in general, as well as individuals, can organise themselves and collaborate in the fight against diabetes. The project has the following objectives: to prevent 50,000 “high risk” people from developing diabetes in the next 5 years, by intervening through a specific prevention plan, aimed at health promotion and healthy lifestyles; and to identify, over the same period, 50,000 people who aren't aware they have diabetes, promoting their inclusion in the National Health System, for adequate control and follow-up. The project has a national scope and intends to involve municipalities representing 80% of the adult population in Portugal over 5 years.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

We know that interventions that lead to individual behaviour changes, can result in healthy lifestyles, and reduce or significantly delay the development of type 2 diabetes. The Finnish diabetes prevention study (Lindstrom & Tuomilehto, 2003) demonstrated that this can be achieved by: reducing weight by more than 5%; reducing fat intake to under 30% of daily energy needs; reducing saturated fat ingestion to below under 10% of daily energy needs; consuming fibre to an amount of at least 15 per 100 calories; and practising physical activity at least 4 hours per week. As a result of the project, 50,000 high-risk individuals won't develop diabetes and 50,000 people who are unaware of their status will be diagnosed.

INNOVATIVE ELEMENTS OF THE PROJECT

We employed an integrated approach, identifying diabetic and pre-diabetic population and screening 25% of the adult population aged between 20 and 79 in each participating municipality, through the introduction of a risk evaluation questionnaire (FINDRISK). We included a follow-up of high-risk individuals to health units, with each identified high-risk person referred, within a month, for diagnosis confirmation. Diabetes prevention managers were trained in communitarian intervention programmesto coordinate locally existing resources, organize screenings and lifestyle changes' initiatives.. Also in place is a prevention educational programme designed for the promotion of health and healthy lifestyles (nutrition and physical activity), which consists of group education sessions delivered by healthcare professionals or via a web-based platform that will receive de abovementioned identified people.. Finally we have instituted a follow-up of the people that participated in the prevention educational programme.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project is based on the broad participation of local health and governmental organisations and structures, as well as general society, which aims to encourage society to adopt healthy lifestyles, through the promotion of health and disease prevention attitudes. The main objectives of the project have been determined through dialogue between a Steering Committee, a Monitoring Committee and an Executive Committee. These committees include independent scientists, health authorities, funding agencies, representatives from municipalities, and scientific societies. This mix brings together issues of policy-making, scientific evidence, and needs assessment. The agreed-upon actions are then executed by APDP, in close communication with local health administrations and municipalities.



On-line advisory center 'I know My Medications'

The AIFP (The Czech Association of Innovative Pharmaceutical Industry) project 'I know My Medications' is a free on-line (<http://www.aifp.cz/cs/online-poradny/znam-sve-leky/>) advisory centre, which helps patients who are taking several different medicinal products – prescription or OTC medications – to understand their medications, identify potential interactions and multiple uses of the same molecule, and to point out specific food and herbs that should be avoided to increase the effectiveness of the treatment.

It is a consultancy service, but complements, rather than replaces the physician's professional advice, providing additional information to patients who wish to know more. Their questions are answered by students of the Faculty of Pharmacy in Hradec Králové town, Charles University Prague, while more complex questions are responded to following consultation with healthcare professionals.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients are informed about medications they are taking, about potential interactions of used drugs, about side effects of specific food and herbs that cause decrease in the effectiveness of the treatment. This online advisory centre is anonymous, no personal data are collected, but all questions and answers are archived. Each positive find is counted as a benefit for Czech patients.

With safety the key issue, patients sent in over 31,000 questions from June 2014 to July 2016. More than 8% of the questions concerned serious interactions (3rd degree: a life-threatening contraindication; the administration of both medications should be avoided; or it is necessary to change the dosage or to monitor certain laboratory tests and symptoms). Some 10% of all answered questions found a multiple usage of the same molecule.

INNOVATIVE ELEMENTS OF THE PROJECT

The Czech medical system is not interconnected (a no electronic prescriptions system), therefore there is a possibility, that a greater amount of drugs are used, unwanted interactions between drugs, which may cause side effects. There is also pointless multiple uses of the same molecule. This project could be perceived as the first step in an interconnected implementation process system. The project also places more responsibility on Czech patients and increases awareness about drug interactions, where no proper system has yet been established.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project was put together by healthcare professionals, students, researchers, patient organisations and industry. The pre-launch phase (June to August 2014) involved collaboration with patient organisations. Patients were informed in a focus seminar, through electronic communication and via social media (patient Facebook page). The official launch of the project was held in August, at a press conference. The press conference was attended by more than 30 journalists, including television journalists. The updated brochure is available on the AIFP website. As the project has very sensitive content, no personal data have been collected, all questions were taken anonymously and answers are sent directly to the recipients' email.



Patient Summit 2015 'Social Entrepreneurship Bootcamp'

The 'Social Entrepreneurship Bootcamp' is a 48-hour intensive training, which offers participants the opportunity to develop, as a team, the concept and design of new entrepreneurial initiatives or to redesign existing initiatives, defining their business models and implementation plans.

The aim has been to (re-)build sustainable models to solve root social problems. After the "Bootcamp", we introduced appropriate follow-up for the implementation of the various projects. Our aim with Patient Associations is develop projects in order to be: more active, more professional, develop projects w/impact on patients/public in general, obtain recognition by the official and political entities, give empowerment, less dependence on Pharmaceutical Industry.

In terms of outcomes we intend to: train participants for the development of new forms of revenue generation within their organisations, notably through the design and development of sustainable initiatives and their impact on society; promote the "mindset" of business as a force for good in non-profit organisations through a set of examples and tools; provide tools that support participants in overcoming the main challenges and constraints of operation of their organisations; and create a strong link between peers, while establishing contacts and networking.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

We measured the “success” of the project via a survey that was delivered at the end of the “Bootcamp”. That had the objective of evaluating some points related to the preparation of the meeting, teams, methodology, social institute of entrepreneurship team and global results. The evaluation ratio was (1 to 5) and the final results recorded a minimum of 4.3 in 5 and a maximum 4.9 in 5. According with the patient associations was the first time that patients associations were involved on this type of innovative training. Patients Associations represented some 18,000 patients as associated members.

INNOVATIVE ELEMENTS OF THE PROJECT

In terms of innovation, the methodology we used was based on a methodology for creating Social Entrepreneurship projects, developed by IES-Social Business School, including all phases of training, through which a project with a high social impact can be created. This was used as a tool for training action, and has been implemented in about 8 universities in Portugal and Mozambique, forming the basis of some of the Institute for Social Entrepreneurship’s programmes. This innovative methodology has the objective of supporting patient associations to understand the key concepts underlying social entrepreneurship, supporting the (re-) construction of sustainable models – which have helped resolve problems of society since its origin – and, finally, providing a set of practical tools that enable participants to develop ideas that evolved during the “Bootcamp” or other future ideas.

COLLABORATIVE ELEMENTS OF THE PROJECT

This project was developed in partnership with the SBI-SBS (Institute for Social Entrepreneurship and Social Business School “), a unique entity in the development of Social innovation project, the establishment of a network of partnerships with different entities from Government agencies and Foundations on a network of entrepreneurs increasingly damp throughout the territory.

The Patient Summit “Bootcamp” was made up nine teams, each with specific input from AbbVie and all of them with external affairs, public affairs, and market access members. Without the presence and contribution of these members, it would not have been possible to achieve the objectives. The members that participated were: Fernando Bastos - External Affairs & Market Access Director, Joana Dias - Senior Patient Relations & SHI Manager, Goreti Silva – KAM, Pedro Almeida – KAM, Rita Almeida – Head of KAM, Sara Farinha - Market Access & Value Proposition Manager, Sofia Borges - Market Access & Value Proposition, Sandra Pedro (ex KAM).



PeSsOa - burden of psoriasis in Portugal from the patients' perspective

Although psoriasis is a chronic disease – with many associated comorbidities – and has a high impact on patients' quality of life (QoL), it is the social and economic impact on patients and healthcare systems (HS) that is frequently undervalued.

The PeSsOA study aims to generate data on the burden of psoriasis in Portugal from the patient perspective. The main objectives are to characterise the Portuguese psoriasis population, evaluate the impact on patients' QoL social and day-to-day activities, quantify the direct and indirect economic burden and describe patient access to healthcare and the use of health resources.

This study was developed to create disease awareness and strength the advocacy of different stakeholders (health authorities, patients, physicians). The PeSsOA questionnaire was created by a representative sample of psoriasis patients in Portugal, stratified by age. The publication of study results will contribute to improved knowledge of psoriasis its impact and the characterisation of patients.





Estudo
Pessoa
VIVER COM PSORÍASE

Colabore neste estudo, para sabermos mais sobre como é viver com Psoríase.

Participe Agora
www.psoportugal.pt

Um estudo:

NOVARTIS | PSO PORTUGAL | ASSOCIAÇÃO DE FARMÁCIAS

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The study analysis includes questionnaires from 564 patients. More patients will benefit from this study through results communication during the annual meeting of PSOPortugal and activities with local media.

The study results will contribute to a better understanding of the impact of psoriasis from a patient's perspective, identifying needs and aspirations and then using this information in clinical practice to incorporate patient objectives in the treatment decision. Study results will be presented for the first time at the annual PSOPortugal meeting (Oct 2016) and at ISPOR, 2016 in Vienna and the publication plan also includes the presentation at national congresses (Portuguese society of dermatology – SPDV and rheumatology – SPR) and international congresses (EADV). This plan also includes the submission of 4 scientific papers, to national and international journals. PSOPortugal will also present study results to the National Assembly within the scope of activities related to the international day of Psoriasis. PSO Portugal will communicate study results through national lay media to increase psoriasis awareness. All this will help to disseminate information and thereby benefit patients.

INNOVATIVE ELEMENTS OF THE PROJECT

This is the first national study with a focus on the evaluation of patient perspectives in terms of the impact of psoriasis on QoL and daily activities. The recruitment of patients through the patients' association and social media also allows the involvement of different sets of patients from those normally included in studies undertaken in a hospital setting. PSOPortugal contributes to creating data on the reality of psoriasis in Portugal.

COLLABORATIVE ELEMENTS OF THE PROJECT

This project is the result of an innovative partnership between academia (FFUL), a patient association (PSOPortugal) and the pharmaceutical industry (Novartis). Physicians were also included in the project with PSOPortugal representatives, allowing clinical input during the protocol and questionnaire development, data analysis and publication. The patient association disseminated information throughout the patient community.

All partners participated actively in the definition of the study objectives, methodology and the construction of the study questionnaire. A critical analysis of results, communications and publications has also been developed by all partners. Novartis signed a protocol with PSOPortugal and a contract with FFUL, which includes a definition of responsibilities.

P.S. Mam SM
KAMPANIA OSÓB ZE STWARDNIENIEM ROZSIANYM

SANOFI GENZYME

P.S. I have MS

Multiple sclerosis is one of the most common, chronic, neurological diseases, affecting up to 45,000 people in Poland.

Insufficient access to knowledge about MS and a lack of support in arranging sufferers' lives remains problematic. Moreover, there are still plenty of negative stereotypes about the disease (e.g. MS means a wheelchair, MS means a disability and life at home), which promote uncertainty and fear.

“Campaign P.S. I have MS” was designed for people newly diagnosed with MS. The main goal of the campaign is to support patients and their relatives in designing their lives with the disease. By combating MS stereotypes, providing education about MS and motivating people to live an active life, the campaign spreads the message: “MS does not define your whole life”.

kocham,
marzę,
działam...

P.S. Mam SM

Bo choroba nie jest całym życiem

KAMPANIA OSÓB ZE STWARDNIENIEM ROZSIANYM

Dowiedz się więcej o SM

Poznaj rzeczywiste osoby żyjące z SM

Dołącz do Grupy Pozytywnych

Pokaż co dla Ciebie robisz. Udzielaj się zdjęciami na fb.com/NeuroPozytywni oraz swoją pasję i zamiar #PSMamSM

Inspiruj i dołącz do kampanii

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ORGANIZATOR:
Fundacja NeuroPozytywni

PARTNERZY:

with a SMile
bigam z uSMiechem

Polski Związek o Złoty

Kampania realizowana jest przy wsparciu grantu edukacyjnego firmy **genzyme**



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

We publish inspiring stories about people with MS, who despite illness and difficulties realise their passions. All the stories are included on the campaign website. Following on from this, we organise thematic meetings on Facebook, led by people with MS. These meetings are an opportunity to share experiences and inspirations. There is an education section on the campaign website where we publish content about different aspects of the disease. We have also prepared a series of short videos explaining the most. In cooperation with a graphic artist who also has MS, we have created campaign post cards. People could write inspiring wishes on them and sent them to patients via e-mail or social media. All these elements serve to educate patients and put their minds at ease in terms of living with MS. We have about 6,000 followers on NeuroPozytywni profile on Facebook and more than 2,000 followers on the Facebook group NeuroPozytywni.

INNOVATIVE ELEMENTS OF THE PROJECT

According to surveys, more than 40% of consumers say that information found via social media affects the way they deal with their health. 90% of respondents from 18 to 24 years of age have also said they would trust medical information shared by others on their social media networks.

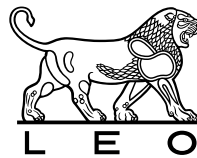
In response to this, we run communications activities via social media. Examples include online chats, hosted by MS patients for MS patients. These involve dozens of patients with MS who share their experiences and tips for daily life. There is also a dedicated folder on the campaign website where patients can post their stories and passions to motivate others. At the end of October we are going to run first video meeting on FB with a neurologist.

COLLABORATIVE ELEMENTS OF THE PROJECT

The campaign is run with one of the biggest patient organisations – Foundation NeuroPozytywni and sponsored by Sanofi Genzyme. The Foundation is engaged in each stage and delivers the knowledge about what is important for patients and ideas how to communicate with them. Thanks to it campaign responds to the real patients' needs and expectation and has very positive social reception.

There is regular communication between the Foundation Neuro Pozytywni and Sanofi Genzyme, with clearly specified duties for each partner. Sanofi Genzyme supports the campaign not only financial, but also on the basis of merit. Representatives of patients are furthermore engaged in creating process.

iMed Comms



Psoriasis Academy – engaging and empowering people

Nonadherence to treatment is a barrier to quality care for people living with psoriasis, preventing them from achieving the best possible results from their treatment. Several renowned experts in the field of psoriasis acknowledge that communication is the key to better treatment adherence; informed and engaged people stand a better chance of managing their psoriasis effectively.

Psoriasis Academy is a global educational programme focused on improving consultations and dialogue between people living with psoriasis and their healthcare practitioners (HCPs). With a syllabus centred on doctor–patient communication, it seeks to position people with psoriasis as partners in the care process. To drive the global adoption of a patient-centric approach to psoriasis care, LEO Pharma collaborated with a multidisciplinary global faculty consisting of leading experts within the field of psoriasis, psychodermatology, patient communication and adherence, nursing, and patient representatives. Together they have designed a programme that not only focuses on raising awareness of the impact of poor adherence, but also equips physicians with communication strategies. These strategies are acquired through a combination of plenary sessions, case studies, patient profiling exercises and role-play activities.

The inaugural Psoriasis Academies in 2015 were structured as “train-the-trainer” meetings. Throughout 2016 the delegates have actively cascaded their learnings and the content to national levels, reaching more than 1600 HCPs from 27 countries.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patient-centric communication can positively impact patient knowledge, self-efficacy, decision-making, adherence and self-care, ultimately improving treatment outcomes and quality of life. Psoriasis Academy provides the resources and tools for dermatologists to tailor their communication to the individual patient and delegates practise communication techniques using case studies. In a survey among delegates from the inaugural academies, 86% of respondents rated the utility of Psoriasis Academy content as “good” or “outstanding.” Delegates have further reported that they “have improved relationships with [their] patients; “can encourage [their] patients to be more trusting” and that “there is more satisfaction and patient engagement with treatment.”

On the 19th November 2016, representatives from more than 21 countries attended a Psoriasis Academy World Summit to share their experience and learning from implementing the programme at a national level. Consequently, several work streams have now been put in place. These include integration of patients into the programme, programme validation, seeking consensus on how to demonstrate benefit to patients, and expanding the programme to other skin diseases.

INNOVATIVE ELEMENTS OF THE PROJECT

International research across seven countries provided the basis for four patient profiles. These distinct profiles underpin a major part of the educational programme, providing insight into the information needs, challenges and best ways to communicate with particular patients, while allowing HCPs to practise how to tailor their communication style to their patients’ needs. Using effective adult learning principles that employ a combination of role-playing activities, interactive exercises, plenary sessions, discussions and poster sessions, a unique environment has permitted HCPs to practice communication techniques that they can use in their daily clinical practice. This approach and focus on communication provides an innovative educational programme that supports HCPs in influencing behavioural change and improving patient outcomes.

COLLABORATIVE ELEMENTS OF THE PROJECT

The expertise and resources of multiple stakeholders in the clinical, pharmaceutical and medical communications industry have been vital in developing and delivering the early phase of the Psoriasis Academy programme. This global faculty is driving the development of the syllabus and has now expanded to include representatives of the International Federation of Psoriasis Associations who represent the global patient voice. Ashfield Healthcare Communications (part of UDG Healthcare plc), provides ongoing medical communication support, using effective adult learning principles to make content engaging and interactive. A cross-functional team from LEO Pharma, encompassing commercial, medical affairs, research and development, and their networks of local affiliates, also supports the faculty. Delegates from the inaugural academies have established national steering groups, working to increase the reach of the Psoriasis Academy by sharing their learnings with other HCPs at a national level and collaborating with local psoriasis initiatives.

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Česká republika

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PRŮVODCE z.ú.**
Váš průvodce labyrintem
českého zdravotnictví



Public campaign 'Rheuma Challenge'

The patient organisation League Against Rheumatism, Czech Republic, and the Medicine Advisor Institute have joined with Pfizer and AbbVie to improve access to modern biological treatment of rheumatoid arthritis (RA) for Czech patients.

The organisers have established a special campaign to raise public awareness of public and stakeholders about the rheumatoid arthritis, limited access to modern treatment for RA patients and recommendations of the European and Czech medical experts (EULAR, Czech Society for Rheumatology).

The project was underpinned by consistent media campaign that ran from 2015 to 2016, with a press conference held on 7th October 2015, the main theme of which was on-time treatment of RA. The event was attended by specialists, patients and journalists. 12 short thematic videos (facebook, youtube campaigns) were created, in which Czech celebrities tried to perform daily tasks (e.g. tooth brushing, opening a bottle) in special gloves simulating joint damage from RA.

The White Paper was published in the form of a patients' position document, containing comprehensive information on disease, treatment and current challenges. This was accompanied by "10 Recommendations" leaflet for patients with RA, which set out brief instructions on how to live with the condition. A beneficial theatre performance, organised by the League Against Rheumatism, which was designed to draw attention to the challenges experienced by Czech RA patients, complemented these written documents.





PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The campaign successfully raised awareness about the challenges of daily life experienced by RA patients as well about barriers to access to modern medicines. Patients also benefited from the unique and rare position document – the White Paper – with verified and updated information about the disease, its incidence, symptoms, diagnosis and treatment options, as well as from the “10 Recommendations” leaflet for patients with RA, a set of brief instructions on how to live with RA.

During the campaign patients obtained and presented data that strengthened their case for support for the “disease burden cost,” as well as data on the economic and social costs to society as a whole of the illness, in cases where intervention is either not timely nor effective.

INNOVATIVE ELEMENTS OF THE PROJECT

We involved social media and young people in the campaign and the effective, technical element of the gloves, which helped to portray and emphasize the difficulties that people with RA experience in daily life. RA is most often a disability of joints of the hands. Therefore, the special gloves, developed by the scientists from The Institute of Technology, Georgia, USA, became a symbol of the campaign. These gloves can limit finger movement as well as hand grip strength via metal strips and so authentically simulate the symptoms of the disease. The gloves cannot, though, simulate the pain.

COLLABORATIVE ELEMENTS OF THE PROJECT

An important aspect of the project, crucial for collaboration, was a central motto: “The patient at the centre of interest.” Each project stakeholder knew its role and was identified with the main goal of the project. As a result, we managed to create a broad coalition for change, involving the non-profit sector, academics, clinicians, experts, as well as government and commercial subjects. The project enjoyed multi-source financing, supported by businesses, government (via public tender with transparent terms) and by the NGO sector. The project report, including all financial details, were published.



Shared Skin Initiative

Dermatological conditions come with negative consequences related to appearance, which cause low self-esteem and, in some cases, may force patients to change their lifestyle to the extent that they cannot attend work or school.

The Shared Skin Initiative will allow us to feel closer to patients with dermatological conditions and, by putting ourselves in their skin, empathise with those who suffer from them. The goal of this initiative is to raise employee awareness of dermatological conditions and help society understand the emotional impact of these diseases.



Initially, five Almirall employees agreed to become part of this unique experience – without knowing what their role would be, including Almirall’s Chief Executive Officer. Subsequently, they underwent a blind two hour makeup session, and without seeing how they looked like, they went out to the street to interact with strangers. This is where the real challenge began for them, feeling both stares and people trying to avoid eye contact. They experienced the hurdles that patients have to overcome in their daily lives: the participants were confronted with the stares of the general public, alongside others who were desperate to avoid their gaze. Having faced the general public, the participants then came face-to-face with a mirror, discovering that the makeup had simulated a dermatological disease. Firstly, they reacted with surprise, yet sadness and confusion quickly followed, amongst a range of other strange feelings.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Thanks to this initiative, patients have felt understood from the emotional and psychological perspective. In many cases, dermatological patients can feel isolated due to their disease. However, by effectively “putting on the skin” of the patients and sharing some of their experiences, it enabled them to realize that they are not alone. The results can be measured by the impact that the Shared Skin Initiative had on Almirall’s employees themselves, alongside the fact that the company decided to share the scheme across the globe, publishing two videos across social media.

INNOVATIVE ELEMENTS OF THE PROJECT

This project contained a range of innovative characteristics, such as the initial idea of creating this campaign. One of the most original elements is the willingness of Almirall’s employees to participate without knowing what the initiative would entail, or the consequences it would have.

Another original element was the make-up session and participants’ public engagement on the street without being aware of their own appearance. By recreating the visible symptoms of various dermatological conditions, the participants gained valuable insight into the emotional consequences that sufferers encounter on a daily basis.

COLLABORATIVE ELEMENTS OF THE PROJECT

The collaborative elements begin with the international commitment of Almirall to its patients. Moreover, the cooperation of the company’s employees facilitated the success of this initiative, in which they essentially “shared” the skin of patients suffering from severe dermatological diseases.

Our experience and liaisons with patient associations helps us to understand the high impact that skin conditions can have on the quality of life of patients. However, the Shared Skin initiative aims to involve Almirall’s employees directly in recognising the impact of these diseases themselves. Creating first-hand awareness amongst employees can help them to gain a deeper understanding of these conditions in order to improve their daily work in a pharmaceutical company, like Almirall, with a strong focus on improving lives of Dermatology and Aesthetics patients.



Societal Impact of Pain (SIP)

Pain imposes a huge burden on both individuals and society. The enormous costs arising as a consequence of pain and disability from pain mean that all European Governments and EU institutions need to act urgently to address the issue, and lessen all aspects of this burden.

Costs to society relate to those in healthcare, social systems, economic factors and employment. It is clear that the societal impact of pain should be on the policy agenda across Europe, and in order to address this issue, the “Societal Impact of Pain” (SIP), an international multi-stakeholder platform, was established in 2009.

SIP aims to raise awareness of the impact that pain has on our societies, health and economic systems. It provides a stage for discussion on pain policy and related matters to healthcare professionals, pain advocacy groups, politicians, insurances, health authority representatives, regulators and budget holders. Information about national initiatives and best practices within Europe are shared during annual SIP symposia and as well on the SIP website and via regular newsletters.

During the SIP symposium in May 2016, specific policy recommendations addressing the societal impact of pain (SIP) were produced. Together with the Road Map developed in 2012, and the recommendations of the Council in 2014, the 2016 recommendations provide politicians with concrete points on which to act.

The scientific framework of the “Societal Impact of Pain” (SIP) platform is under the responsibility of the European Pain Federation EFIC®. Cooperation partners for SIP 2016 and 2017 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). Grünenthal GmbH is responsible for funding and non-financial (e.g. logistical) support.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patient representatives have been involved in the multi-stakeholder initiative SIP from the very beginning. Patients are seen as relevant and equal partners and are actively involved in all meetings with MEPs and other politicians to emphasise the needs of the patients. More than 300 international and national pain advocacy groups, scientific organisations and authorities have been endorsing the aims of SIP so far and most of them are representing the interests of the patients. Potentially, about 100 million patients suffering from chronic pain in the EU will benefit from the success of the “Societal Impact of Pain” initiative.

INNOVATIVE ELEMENTS OF THE PROJECT

SIP is seen as a role model of a multi-stakeholder platform in Europe that focuses clearly on the needs of patients. Antonella Cardone, Fit for Work Global Alliance, the Work Foundation Alliance, UK, attended SIP for the first time: “What really impressed me of the whole event was how successfully the organisers managed to bring together over 200 experts and stakeholders with a wide range of experience, from research and academia, clinical and rehabilitation, to patients and policy makers. More than 20 MEPs played an active role during the 2-day symposium. Their presence was not symbolic. They were clearly committed to help address the issue of pain as a societal burden and find solutions together.”

COLLABORATIVE ELEMENTS OF THE PROJECT

The collaboration between European Pain Federation EFIC® and Grünenthal GmbH as well as other partners has been established for many years. All involved parties are seen as equal partners in SIP and contribute actively to the initiative at national and European level. By sharing best practices and data from all European countries in multi-stakeholder meetings, via the website and newsletter, the initiative is growing continuously and receiving further endorsement and support.

SIP materials and initiatives have to be approved by all involved partners to ensure that there is an aligned approach how to address the Societal Impact of Pain in Europe. The collaboration of the SIP partners is made fully transparent on materials, website and in meetings.



Top-Talk about psoriasis within a satellite symposium at European Forum Alpbach

The WHO publication* defines psoriasis as a disease without lobby and without credit of burden. 70% suffer with co-morbidities, 28% have no self-confidence and depression is the most common complication – patients need the understanding of their environment otherwise they stop working, stop social life and cost more and more money for the Health care system. Even relatives suffer.

The project consisted of a multi-stakeholder discussion based on the WHO publication for psoriasis, aimed at finding solutions to raise awareness regarding disease burden and the public impact of unmet needs of people with psoriasis powered by Celgene Austria**.

A major outcome was the message to stakeholder groups raising awareness of the disease, as well as increased awareness for all people that psoriasis is a non-communicable disease and concrete actions to strengthen the resolve of patients.



*WHO Library Cataloguing-in-Publication Data
Global report on psoriasis.
1.Psoriasis – epidemiology. 2.Psoriasis – prevention and control. 3.Public Health. 4.Skin Diseases.
I.World Health Organization.
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PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

We expect articles about the WHO paper and the needs of these patients to be published in major newspapers of Austria. The patient organization now has contact with many new stakeholders, awareness is higher, health insurance funds are aware of unmet needs, and projects will be discussed to help people with psoriasis. Measuring is ongoing and is instituted through talks with relevant stakeholders, PR articles, patients coming to the self-help groups as a result of having seen the articles.

INNOVATIVE ELEMENTS OF THE PROJECT

The European Forum Alpbach was the background platform for this Health Talk. This has been the first time that Psoriasis as a chronic disease was discussed, based on a WHO publication, with different stakeholder groups and the self-help group PSOR Austria enjoyed a convincing voice among these stakeholders.

COLLABORATIVE ELEMENTS OF THE PROJECT

Partners included Chamber of Employment (in order to have a representative who is aware of daily life issues for sufferers), health insurance funds (to discuss direct and indirect costs), dermatologists (to offer expert opinion on treatment), a self help group (to show real life evidence of burden of disease), psychologists from health insurance funds (to highlight needs and problems), Dr. John (Sven Malte John, University of Osnabrueck, Germany, co-author of the WHO Publication), a General Practitioner, the Main Association of Health Insurance Funds, a patient ombudsman, and the president of the chamber of pharmacists.

The self-help group for Psoriasis*** in Austria was able to address the needs of patients and the most important stakeholders in the system listened to them and discussed solutions, with the media in attendance, after which the outcomes were published. The collaboration between different stakeholders was documented and will continue to make progress. The Vice-President of the Austrian self-help group participated in the discussion and was able to discuss with the author of the WHO paper, Dr. John, the implications for Austrian patients.

WC ASAPP

1 out of 400 Belgians suffer from chronic inflammatory bowel disease (IBD) such as Crohn's disease and ulcerative colitis. Where the condition is not controlled, symptoms include diarrhoea (up to 20 times a day), abdominal pain and cramping, fever and fatigue and weight loss. Leaving home for work or pleasure becomes a significant challenge and there is a growing need to ensure fast and easy access to toilets – the latter being the number one issue identified by patient associations.

The aim of the WC ASAPP project has been to “co-create” with patients to address this issue through the development of a patient friendly app that helps to offer encouragement and support easy access to toilets for patients with Crohn's and colitis disease. The main objectives were to: understand user needs – this included defining the typical user experience and analysing the key gaps; establishing the most appropriate ideas for sufferers – based on technical feasibility, business requirements and mostly user needs, in order to prioritise the different features of the app; develop a prototype of the full solution; and validate the solution with potential users.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Success has been measured in terms of the number of app users: 5548 via the website; 3360 through use of android operating systems and 1755 through iOS. The most significant benefit was the ability of patients to gain access to and use toilets effectively and easily.

INNOVATIVE ELEMENTS OF THE PROJECT

A pre-defined process for optimal digital tool development was followed, enabling: a prioritisation approach – by using agile techniques; rapid go-to-market – through smart collaboration; cost-effective solutions capable of meeting user needs; and a crowdsourcing validation process via its users – the app will identify more and more toilets with useful information.

COLLABORATIVE ELEMENTS OF THE PROJECT

Patient involvement was key throughout each step of the journey, either through the patient associations or social media. The name of the app was actually generated through patient engagement over social media. An IBD bike tour was also organised with the patient associations to promote the app, and a press conference was held for publicity purposes.

One of the key issues was securing engagement and input from the patient associations right from the beginning of the process, in order to understand their needs from the outset, through to developing the solution and validating it.



Working Together, Roadmap for Sustainable Healthcare

AbbVie, in partnership with Philips, the European Patient Forum, and the European Steering Group for Sustainable Healthcare has created a “Do Tank” across 21 European countries, establishing strong multi-stakeholder partnerships and working groups – including policy makers, healthcare professionals, patient organisations, NGOs and academia – to develop concrete pilots to address health systems sustainability.

These are being implemented at local level to address key patient access barriers, with a view to scaling them up for the benefit of patients and healthcare systems on a broader level. More than 30 pilots have been launched, which highlight a very concrete approach to finding and implementing sustainable solutions.

In 2015, a pan-European White Paper on Sustainable Healthcare was published, including all 30+ country-specific pilot projects and the 18 policy recommendations to policy makers both at EU and Member State level. Going forward, AbbVie and the European Steering Group will focus on driving one of the key policy recommendations: ensuring crossministry collaboration and joint projects. The collaboration

between different Ministries such as Health, Social Welfare, and Employment, is essential for the achievement of various policy goals, as well as for the maximization of value to patients, health systems and society. AbbVie and the European Steering Group will build upon the case of the successful Early Intervention project in Spain, which highlights that one euro of investment generates eleven euros of return. AbbVie and the European Steering Group will work with experts and partners to develop practical tools and frameworks to help different countries and regions to replicate and scale up Early Intervention as a good practice around cross-ministerial joint projects and collaboration.

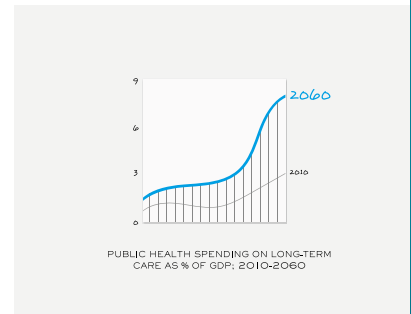
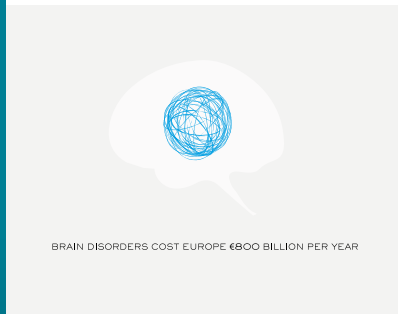
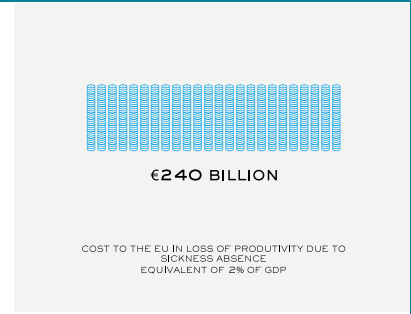
ACTING TOGETHER: A ROADMAP FOR SUSTAINABLE HEALTHCARE

How to continue to provide high quality and universally accessible health services in a financially sustainable way in Europe.

RECOMMENDATIONS AND CALLS TO ACTION



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PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

As the Sustainable Healthcare initiative covers 21 countries in Europe and beyond, numerous patients have and will benefit from this initiative either directly or indirectly.

Accordingly, among the pilot projects that have been completed to date, key measurement outcomes include: significant increase in health system efficiency through elimination of wrong referrals and reduction in patients' waiting time; increased rates of people remaining/or returning to work through a reduction in temporary/permanent work disability; and improved patient-HCP dialogue through patients being able to take better control of their health and medical conditions.

INNOVATIVE ELEMENTS OF THE PROJECT

The Roadmap for Sustainable Healthcare is the first cross-border multi-stakeholder "Do-Tank" at EU and at Member State level. Breaking the status quo of publishing papers and reports, Roadmap for Sustainable Healthcare has stepped to create and implement innovative pilot projects that lead to a paradigm shift in healthcare, from acute care to preventive care, from hospital to community and home care.

COLLABORATIVE ELEMENTS OF THE PROJECT

The Roadmap for Sustainable Healthcare is a truly multi-stakeholder collaborative initiative. At EU and Member State level, individual pilot projects have resulted from collaboration and work between stakeholders from governments, social insurers, healthcare professionals, patient organisations, academia, non-governmental organisations and the pharmaceutical industry. All the initiatives have been centered on providing improved quality of care for patients and improved efficiency for the healthcare systems.

All the partners and multi-stakeholders participated in regular meetings, discussed key issues, and together agreed on the common goals, roles and responsibilities, expected outcomes, funding process, as well as clear communication and governance structure. Depending on the subjects, additional external experts have also been consulted to obtain their insights to support the development and implementation of the pilot projects

Our project partners and contributors

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