

HEALTH COLLABORATION GUIDE 2016





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 established the Health Collaboration Awards in 2015, to reward and acknowledge the value of such collaborative projects, not only between patient organisations and industry, but also local authorities, governments, SMEs and other key actors in delivering healthcare.

The Health Collaboration Guide seeks to highlight the projects that applied for this award in October 2015 to showcase best practice collaborations that have benefitted patients across Europe. We hope the guide will spark new ideas to develop collaborative projects that, will continue to make a difference to patients.

Nicola Bedlington, Secretary General, EPF
Andy Powrie-Smith, Director of Communications, EFPIA
EFPIA Patient Think Tank Co-Chairs

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. Our aim is not to create common positions, but to ensure that the patient voice is heard in the development of EFPIA policy and practice and give industry members the opportunity to discuss aspects of medicines research and development with the patient organisation community.

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 the annual Health Collaboration Summit. The event brings together patient organisations, policy makers and industry leaders from across Europe, to discuss key healthcare topics. The emphasis is on giving a voice to different perspectives from a board range of stakeholders and ensuring an interactive debate.

As part of the Summit the Think Tank also hosts the Health Collaboration Awards for 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.

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



COGWEB – Network

Nervous system disorders are associated with major cognitive and motor deficits, and are responsible for the highest disability rates and global burden of disease worldwide, estimated to reach 14.7% by 2020.



COGWEB is a tool that enables the implementation of customised programmes for cognitive training. As it is based on an online platform, it is equally accessible to healthcare professionals or patients wherever an internet connection is available. This feature allows for a variety of uses in a number of environments, which may vary from a strictly clinical setting to the comfort of the patient's own home. It has also been designed for use in a variety of pathologies by people of various ages.

The aim of the COGWEB-Network project is to boost patient access to high quality, supervised, cognitive training. This resulted in the implementation of a nationwide, collaborative multi-organisational translational network aimed at dissemination of sustainable web-based cognitive training methodologies in Portugal.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Usability testing was undertaken by 80 patients/caregivers, using the web-based cognitive training platform (COGWEB). All patients and their caregivers offered a positive evaluation of the cognitive training tool. 39% mentioned the need for further face-to-face coaching from a relative or health care professional. Only 4% were not interested in performing the exercises at home.

A real world cohort study in 45 patients/caregivers followed in a "memory clinic" setting with relevant disease groups. Here, patient adherence and intensity of training over long periods of time were evaluated. At six months the compliance rate was 82.8% and the average training intensity was 6 hours/week. Patients with dementia trained more intensively (444.6 minutes/week).

Finally, a network implementation study took place on the potential for dissemination of practices and operative procedures in a network of centres in the context of the Portuguese Health System. In the first 12 months, 68 professionals from 41 centres adhered and 298 patients gained access to training.

INNOVATIVE ELEMENTS OF THE PROJECT

This work explores an innovative line of research, envisioning sustainable technological solutions to improve the treatment of cognitive deficits in very large and growing populations. The aim was to promote more intensive treatments under remote monitoring, and through it improve clinical decision-making and increase access to healthcare.

The research project integrated low-cost technologies with common, clinical operative procedures developed within a memory clinic.

The innovative nature of the project is better demonstrated by the publication of three original scientific articles in #1 the Journal in Medical Informatics and #2 Health systems innovation research: Journal of Medical Internet Research.

COLLABORATIVE ELEMENTS OF THE PROJECT

Partners included: Alzheimer Portugal – Casa do Alecrim; Novartis Farma – Produtos Farmacêuticos, S.A.; neuroscience start-up company, Neuroinova, Lda; and other organisations and stakeholders, including university based centres (clinical and basic research), major hospitals, outpatient memory clinics, rehabilitation clinics, day care centres, schools and adult learning institutes.

A translational network concept was devised from the start. To our knowledge this project represents the first collaborative network dedicated to cognitive training research and implementation.

Clinical actors and institutions in the field of cognitive impairment assessment, diagnosis and treatment in Portugal were invited to join the COGWEB network.

The continuous increase in the number of trained centres and professionals, since 2012, allows us currently to reach 10 new patients per day in very diverse clinical and social settings.

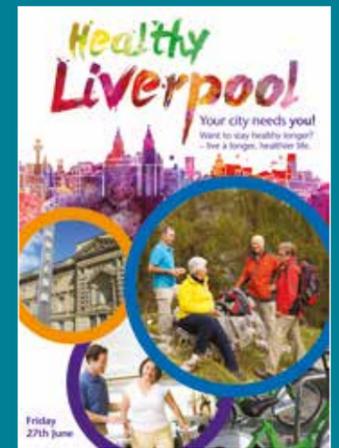
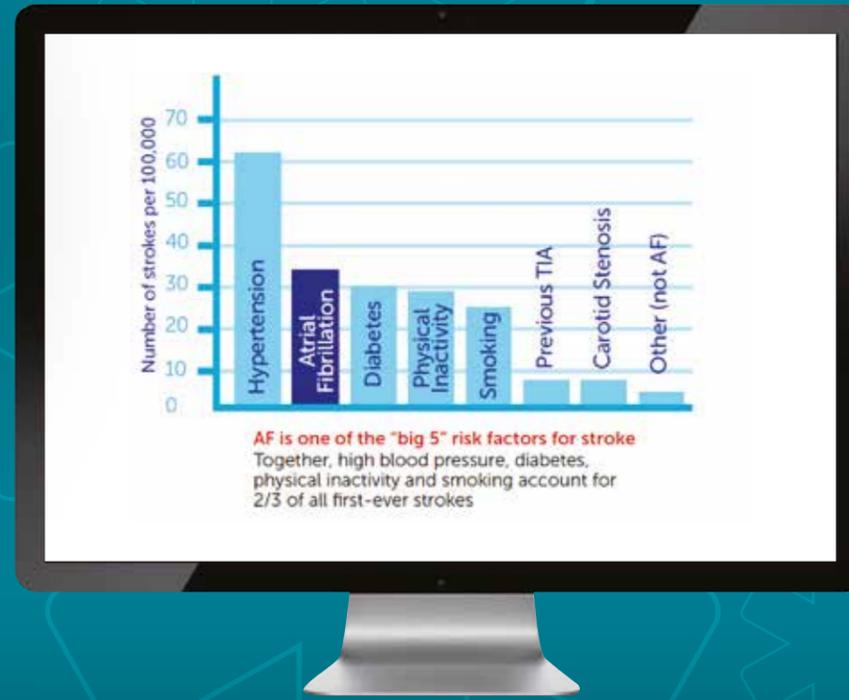


Know Your Pulse

Stroke occurs approximately 152,000 times a year in the UK – that is one every 3 minutes and 27 seconds – and costs the UK's NHS £4.6 bn. During the Year of the Brain 2014, the European Brain Council (EBC) launched a series of UK events to raise awareness of Atrial Fibrillation (AF)-related stroke, raising public awareness about prevention and seeking improvements to the clinical treatment of irregular pulses detected in primary and secondary care settings.

"Know Your Pulse" events were held to educate and inform the public and to generate publicity ensuring more opportunities to share the AF message.

A clinical event (part of the UK International Festival of Business 2014) was also hosted to inform, educate and inspire clinicians on the subject of AF-related stroke, identifying gaps in clinical service provision in primary and secondary care and establishing how these could be addressed.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Through the "Know Your Pulse" events, an increase in awareness of AF-related stroke and how to prevent it was generated amongst the public. At the same time, many people were checked ad hoc for AF-related stroke.

The UK International Festival of Business 2014 clinical event was successful in informing, educating and inspiring clinicians on the subject of AF-related stroke, which will have a consequent effect on the level of care offered to stroke patients. New collaborations were also formed, looking at the patient pathway, leading to better health outcomes by combining research and education.

Patient benefit was aligned to approximate attendance levels and assessment of impact. At the Healthy Liverpool event, random exit polls of attendees were conducted to obtain qualitative feedback. During the "Know Your Pulse" events, 379 evaluations were completed and 99% of attendees found the information they received useful.

INNOVATIVE ELEMENTS OF THE PROJECT

Partnerships with the local football clubs' outreach teams and health organisations achieved higher public prominence than by just a "health" message alone. Moreover, the Healthy Liverpool event at the city's World Museum during a school holiday enabled the AF message to be relayed to the public in a "fun" environment. This event took the health messages outside of the traditional hospital and healthcare settings.

The handheld AliveCor ECG devices used in the campaign generated considerable public interest. The AliveECG App includes an accurate and FDA-cleared AF Detector.

COLLABORATIVE ELEMENTS OF THE PROJECT

The prevention of AF-related Stroke project was managed by a diverse collaborative partnership that worked together to improve the outcomes for patients through achieving heightened public awareness of prevention. The partners leading the events were principally Liverpool Health Partners (LHP) and the North West Coast Academic Health Science Network (NWC AHSN), who collaborated closely with AliveCor, Liverpool City Council (Liverpool CC), Liverpool Clinical Commissioning Group (Liverpool CCG) and the EBC.

The multi-disciplinary clinical event identified gaps in provision and discussed how to improve clinical treatment for better patient outcomes, by combining presentations from specialist providers, GPs, CCG and patients' perspectives.



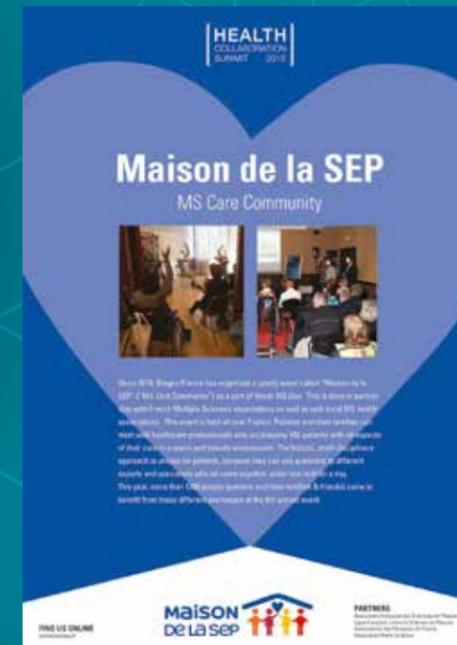
Maison de la SEP

Since 2010, Biogen France SAS has organised a yearly event called “Maison de la SEP” (“MS Care Community”) as a part of World MS Day. This is undertaken in partnership with French multiple sclerosis associations, such as: AFSEP, La Ligue, APF, Notre Sclerose and Association des Aidants, as well as with MS health associations that work at local level.

The event is held all over France – in 2015, it was present in 9 different cities. This allows for patients, their families and friends to meet with professionals, including neurologists, nurses, psychologists, rehab professionals, social workers, and sophrologists, who accompany MS patients in all aspects of their care, in a warm and friendly environment.

Maison de la SEP strives to provide patients, their families and friends with concrete answers about a specific condition, to help improve quality of life and facilitate the patient’s independence through plenary Q & A sessions and workshops on physical activity, practical matters and relaxation.

Maison de la SEP was founded on 3 needs: the fundamental need to complement and broaden the information about quality of life that patients receive during their consultations with neurologists; the need to have practical information that is often difficult to obtain on one’s own; and the need for a multi-disciplinary approach (involving neurologists, nurses, rehab therapists, psychologists and sexologists) when tackling MS.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

This year, more than 1,200 people (patients, their families and friends) came to benefit from these different exchanges at the 6th annual event. More than 110 professionals (health and other) participated as well. The aim is to allow patients to lead the fullest possible lives.

We measured patient benefit through issuing a feedback form for patients, their families and friends as well as gaining feedback from patient advocacy healthcare organisations.

Demand for another event the following year (2016 will be the 7th edition!) also provided encouraging evidence of success.

INNOVATIVE ELEMENTS OF THE PROJECT

The holistic, multi-disciplinary approach we adopted is unique for patients, because they can pose questions to different experts and specialists who all come together under one roof for a day. No subject is off limits (for instance, patients and their loved ones appreciate the sex-related workshops).

COLLABORATIVE ELEMENTS OF THE PROJECT

Every year, Biogen France SAS signs a partnership agreement with patient associations and healthcare networks in each of the cities that participate in Maison de la SEP.

Biogen France SAS funds Maison de la SEP in its different locations and coordinates logistics for the event. Biogen draws up the programme and shares it with patient associations and healthcare networks for refinement. Then, they contact panellists locally, based on the agreed programme.

Rare Disease UK

Run by Genetic Alliance UK, Rare Disease UK (RDUK) is a national campaign for people with rare diseases and all who support them, and provides a unified voice for the rare disease community, capturing the experiences of patients and families and raising the profile of rare diseases across the UK. It seeks to bring about lasting change, offering better health and quality of life to individuals and families affected by rare diseases.

Among other things, RDUK aims to raise awareness for rare conditions within the UK and Europe and ensure patients affected by rare conditions have equitable access to health and care services. The campaign has worked to influence the development and the implementation of the UK Strategy for Rare Diseases, ensure that rare diseases are viewed as a public health priority by the UK government and NHS, and bring together and mobilise the rare disease community through its membership.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Between November 2008 and November 2015, we held 22 parliamentary Rare Disease Day events across the UK, enabling patients to meet a range of stakeholders with an interest in rare diseases as well as a parliamentary representative.

In 2012, we held a series of activities to support our members and all of the rare disease community across the UK in making their own consultation response. Our evaluation of the events showed that 100% of those who gave feedback agreed that the stakeholder engagement events helped them to better understand the details of the rare disease plan under consultation.

In 2014, we established the Patient Empowerment Group (PEG) to ensure the patient voice is properly informed of, and effectively represented in, the discussion and development of the implementation of the UK Strategy for Rare Diseases.

We have also undertaken a number of quantitative and qualitative reports to understand the experiences of patients affected by rare diseases. Through RDUK's website and social media channels we have also helped to develop a community of patients.

INNOVATIVE ELEMENTS OF THE PROJECT

In order to remain relevant and proactive, we have utilised a number of innovative tools. We ran contact campaigns and encouraged our members to directly contact their local parliamentary representative, providing template letters. There were also webinars and briefing documents provided, representing a powerful drive to empower members to respond to the UK Strategy for Rare Diseases consultation. This included: 4 webinars, viewed over 400 times; and briefing documents, downloaded 1,346 times. We also ran 4 innovative events across the UK, attended by 250 people.

In 2015, our social media presence increased exponentially and we utilised this to good effect. Our Rare Disease Day Facebook poster was our most successful to date and reached almost 60,000 people.

COLLABORATIVE ELEMENTS OF THE PROJECT

Rare Disease UK is the only project in the UK that brings together all stakeholders with an interest in rare diseases. Our membership of 270 patient organisations is the largest alliance of patient organisations that we are aware of in the UK. By working together we can keep rare diseases high on the political agenda.

We work with all stakeholders in the rare disease community to benefit patients and families affected by rare conditions. We are politically neutral and independent of commercial interests. Any collaborative work we carry on must abide by Genetic Alliance UK's Ethical Collaboration Policy



Университет
за пациенти



Национална
ПАЦИЕНТСКА ОРГАНИЗАЦИЯ

University for Patients

In the past, patients received training rarely about their condition and how to comply with treatment. Failure to adhere leads to faster disease progression and insufficient results. The lack of treatment adherence and proper management of chronic diseases causes serious financial expenditures in all of Europe.

The University for Patients programme is a long-term initiative of the National Patients' Organisation (NPO) of Bulgaria. The original programme model was developed by the Spanish Patients' Forum, funded by the Catalan government and was replicated by the NPO since 2012.

It is the largest national training programme of its kind, which aims to develop certain skills for patients to help them manage their chronic diseases more efficiently. Training modules target patients, healthcare specialists and volunteers in the healthcare system.

Each disease model is integrated into an individual faculty, which has its own principles of conduct.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients with chronic diseases improve their control over their condition, aided by training from a medical professional. This reduced the possibility for disease progression.

The programme allows for patient-friendly access to disease information, using additionally the patient as an expert to train other patients. This introduces more hands-on experience and relevant opinions on how patients with a chronic disease can live a quality life.

Each faculty ensures that the patients receive educational information materials created especially for them, participate in training in their disease area and are able to share experiences with patients with similar conditions.

As this is a long-term campaign constant monitoring and evaluation is needed to ensure the patients' satisfaction and treatment outcome.

A specialist at a call centre works with patients and other stakeholders, including the medical personnel, to ensure that patients: enjoy effective collaboration with doctors; they comply with the therapy; and have access to their medicines. Follow-up is undertaken on a regular basis.

INNOVATIVE ELEMENTS OF THE PROJECT

The project allows for the integration of different stakeholders in the process of managing chronic diseases, including: specialists; nurses; patients; and industry. It promotes the continuity of patient care and stresses adherence to therapy.

A novel peer-training method allows for patients to be advised and trained by other patients with the same disease.

A set of educational and informative print materials is also being developed for every faculty of the university and is provided for free to patients.

COLLABORATIVE ELEMENTS OF THE PROJECT

In essence, we managed to bring together different stakeholders who usually don't tend to work together closely when it comes to patient empowerment, such as NGOs, the pharma industry and medical facilities and specialists. Partners have expertise in their own field, so effective coordination by us as a leading organisation was essential.

A number of medical stakeholders are partners in the initiative, including state-owned national hospitals, disease-specific professionals, general practitioners and nurses. Furthermore, it is supported by pharmaceutical companies, including Novartis, Astra Zeneca, Abbvie, GlaxoSmithKline, Amgen, Sanofi Aventis, Sanofi Pasteur, Roche, Boehringer Ingelheim and USB.



CONNECTED

The project, organised by the Madrid Lupus Association (Amelya), in collaboration with UCB, aimed to create a better understanding of what is important for patients in the treatment of their chronic disease and to improve their quality of life. It worked on the premise that patients need to be informed and connected with other patients.

The first step was the organisation of an online meeting of patients to ascertain their needs. Almost 200 people attended from a range of countries. The announcement of this event was disseminated via a number of channels: emails to patient associations in Spain, Portugal and Latin America; information leaflets for rheumatology services at hospitals; a viral campaign for CONNECTED patient videos on YouTube; representations on Twitter and Facebook, under the hashtag #PacientesConectados; and RSS feeds via UCB and patient organisations' accounts.

The meeting was interactive and bidirectional. Questions preselected from patient associations about the topic "how to improve communications between patients and healthcare professionals" were sent to the audience via an interactive voting system. Based on these answers the round table of expert patients offered feedback and recommendations.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

It became clear that informed and empowered patients would play a valuable role in managing chronic diseases in the future. The role of the patient is expected to evolve, with patient organisations and medical professionals set to train patients to become disease advocates.

The responses of patients were subject to analysis. 41% of patients said they would appreciate increased closeness and empathy on the part of their healthcare professional. Moreover, a number of patients sought more time with their doctor.

Almost 60% of patients said they consulted the internet after discovering symptoms or receiving a diagnosis. 96% said they would appreciate their doctor recommending website channels and would welcome new communications channels.

On the basis of a satisfaction survey that was sent at the end of the activity, 93% of participants said they would like to take part again in this type of online forum. 89% had a positive assessment of the interactive format and 78% said they would act on the recommendations that were issued.

INNOVATIVE ELEMENTS OF THE PROJECT

It was the interactive online format of the meeting that constituted the innovative element of this project, with a view to enhancing patients' quality of life. This also included a round-table encounter with a famous basketball player acting as caregiver and three expert patients. This was important to add value for patients, who shared their own experiences and recommendations.

COLLABORATIVE ELEMENTS OF THE PROJECT

The #PacientesConectados project was approved via a compliance process, which respected and was in line with the principle of the EFPIA Code of Practice on relationships between the pharmaceutical industry and patient organisations.

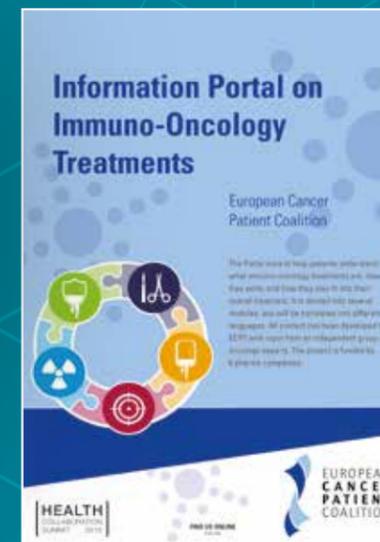


ECPC Information Portal on Immuno-Oncology Treatments

The European Cancer Patient Coalition (ECPC) and the oncology research community, supported by industry, have established jointly an Information Portal, to disseminate scientifically-accurate, patient-friendly information on immuno-oncology treatments to European cancer patients, through an online learning platform. There is currently little adequate, actionable, easily available information on immuno-oncology therapies for European patient advocacy groups, general practitioners (GPs) and policy-makers, and this Portal is intended to address that need.

The ECPC Portal differs from other dissemination tools, as it focuses on three key audiences: European cancer patients; GPs; and policy-makers. The Portal will also act as a pan-European advocacy hub, providing European cancer patient advocacy groups with advocacy tools and information on cancer immuno-oncology treatments and cancer immunotherapies more generally. It will present information in a graphically-pleasing, easy-to-read way. Developed in consultation with industry partners, the content will be produced by ECPC and reviewed by clinical experts.

For more information on the Portal, please visit: <http://iop.ecpc.org/>



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The science of immuno-oncology is evolving rapidly and many questions remain unanswered, making it difficult for patients to understand fully the pivotal importance of new treatments. This leads to a knowledge gap that can harm the capacity of patients to win the fight against cancer, as new treatments become available.

The Portal benefits individual cancer patients by providing appropriate information that can improve their understanding of the role immuno-oncology treatments could play in their care. It has a role in educating cancer patient advocates and general practitioners, both key contact points for cancer patients seeking information and advice.

The initiative has already been welcomed warmly: the presentation of the Portal during the ECPC 2015 Annual General Assembly not only stirred interest among patients present, but was also praised as an ideal tool to access more information on a topic often misunderstood by expert patients and patient advocates.

INNOVATIVE ELEMENTS OF THE PROJECT

The Portal is the first European interactive information source on immuno-oncology treatments, designed by patients for patients. The support of the scientific reviewers in developing the Portal has been critical to ensure that all content is scientifically robust and usable by clinical audiences.

The Portal also examines the introduction of innovative therapies from the point of view of policy-makers – a critical audience to 'get on board' in recognising the potential of immuno-oncology treatments for patients and helping facilitate patient access to them.

COLLABORATIVE ELEMENTS OF THE PROJECT

Industry support has been vital in realising the Portal, with the costs of the project divided equally between six partners. Industry partners are updated regularly on the progress of the project. They also have the opportunity to review the content, to ensure that it is clinically valid, entirely non-product related and non-promotional and thereby adheres to their own compliance rules as funders of this initiative.

The drafting of the content is coordinated by the ECPC Office, in collaboration with an external medical writer. The content is revised by both ECPC Board Members and a panel of experts from academia.



Society of Volunteers Against Cancer - AgaliaZO

The Society of Volunteers Against Cancer-AgaliaZO, through the nation-wide informational programmes that it implements, aims to stimulate the public conscience about the importance of prevention and pre-symptomatic control. Our message is that prevention saves lives, and that the primary weapon against cancer is early detection.

At the same time, through the dissemination of information, we aim to demystify cancer, thereby reducing the stereotypes of fear and discrimination associated with the disease and the patients. The work we do is very important, as we replace processes and the infrastructure of the welfare state, which is unable to function properly due to the severe economic crisis in Greece.

We already have 40 years of experience in the struggle against Cancer, with targeted and organised campaigns, including: awareness campaigns for the prevention/early diagnosis of all forms of cancer; psychosocial support of cancer patients and their families; financial support of impoverished or uninsured cancer patients; and advocacy for cancer patient rights.

For this campaign, in January-February 2014, we created an awareness campaign for the prevention/early diagnosis of cervical cancer. This was followed by an awareness campaign for the prevention/early diagnosis of prostate cancer from February-November 2014. Simultaneously running was an awareness campaign for the prevention/early diagnosis of skin cancer and malignant melanoma, which ran from June-July 2014.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Apart from raising public awareness of the importance of prevention – early diagnosis of the 3 types of cancer through lectures, promotions, distribution of printed material, radio and TV spots etc. – all campaigns included free pre-symptomatic screening sessions. The number of people screened (2000 for the Cervical Cancer Campaign, 2000 for the Prostate Cancer Campaign and 700 for Skin Cancer – Melanoma) in conjunction with the number of those referred for further tests due to high probability of being symptomatic (85, 124 and 110 respectively), provided us with the best quantitative indication of patient benefit.

INNOVATIVE ELEMENTS OF THE PROJECT

In the case of the Campaign for Prevention-Early Detection of Cervical Cancer, the innovative aspect was approaching the widest audience possible, through ticketing and pamphlet distribution in the public subway, department stores and fitness clubs. Equally important were the information lectures to secondary education students and their parents.

The innovative aspect of the other two campaigns was organising lectures and diagnostic screenings in remote areas, where residents have very limited or no access to medical care, and including the participation of firefighters in one of the campaigns.

COLLABORATIVE ELEMENTS OF THE PROJECT

- a) Awareness Campaign for Prevention-Early Detection of Cervical Cancer: we collaborated closely with ECCA (European Cervical Cancer Association) and the Hellenic Society of Obstetrics & Gynaecology.
- b) Awareness Campaign for Prevention-Early Diagnosis of Prostate Cancer: we collaborated with the Hellenic Urological Association and the Hellenic Fire Service.
- c) Awareness Campaign for Prevention-Early Diagnosis of Skin Cancer and Melanoma: close collaboration with the Hellenic Society for Melanoma Study and the "Andreas Syggros" Hospital of Cutaneous & Venereal Diseases.



EMPower – Evaluation of MS impact on patients and caregivers

There has long been a lack of data in Portugal about the impact of multiple sclerosis on quality of life and its social/psychological impact on patients and caregivers. It was clear for the Multiple Sclerosis Society of Portugal (SPEM) that their goals related to advocacy and policy-making influence required increased knowledge of the community itself. By generating patient-based evidence from their pool of associates – around 3000 – SPEM could build stronger arguments to support their needs.

The project 'EMpower', a Patient Reported Outcomes Study, was developed to: raise public awareness of the impact of MS on patients' quality of life and on their caregivers; strengthen advocacy activities with health authorities; and generate data for publication, contributing to improved knowledge of the reality of MS in Portugal.

In order to implement the project, a scientific committee of neurologists was engaged to endorse and validate the assumptions and content of the study. The aim was to capture the insights from patients using validated PRO study methodologies and transform this data into treatable, meaningful information, useful for the community and healthcare decision makers.

EMpower is now a reference that can be used to support decision-making investments associated with social payments, early access to treatments, caregiver needs and the overall social and economic burden of MS.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

For the first time ever, we have data showing the burden of disease on patients and informal caregivers, which is actually owned by a patient group.

500 patients and 100 caregivers (SPEM associates) participated in the study. Early results were presented at SPEM's Congress, on National MS Day, and generated media and public attention with regard to the community's needs. The first publication of the results – in poster form – was launched at a local congress in April 2015, and there are now four manuscripts in development, with a targeted publication by the end of 2016.

The presentation of final results, accompanied by a debate is being planned for National MS Day. At this session, and with a new government in place, partners intend to stimulate a discussion around investment in the NHS and Social Services regarding MS patients and their caregivers.

INNOVATIVE ELEMENTS OF THE PROJECT

We transformed a medical situation into a community social subject, through an innovative partnership with a patient group, academia and the pharmaceutical industry.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project was co-developed by Sociedade Portuguesa de Esclerose Múltipla (a patient group) and the Pharmacy Faculty of University of Lisbon (FFUL-Academia) with the support of Novartis (Patient Relations and Health Economics & Outcomes Research teams).

FFUL is responsible for all the study methodology and developed the study protocol according to SPEM's identified goals. Novartis, through its HE&OR team, offered advice on data collection that could be further leveraged with health authorities to support better patient outcomes.

Implementation of the study was carried out by FFUL and SPEM. Novartis supported the research costs financially by contributing with a grant to FFUL. All partners participated actively in the development and implementation of the communication plan in order to leverage disease awareness and policy-making discussions around MS.



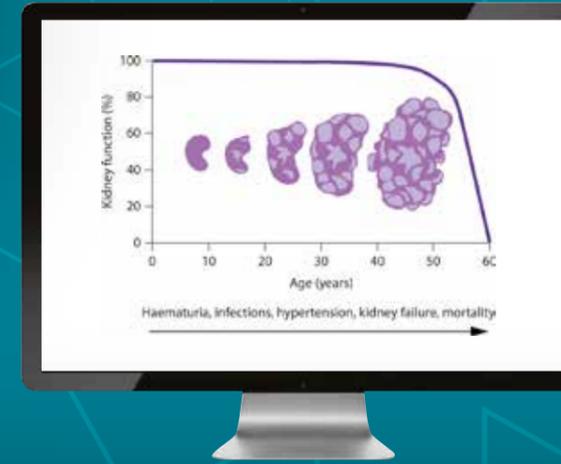
European Autosomal Dominant Polycystic Kidney Disease Forum

The European autosomal dominant polycystic kidney disease (ADPKD) Forum (EAF) is an independent, multidisciplinary, international faculty of ADPKD experts who are dedicated to improving the health and quality of life of people with ADPKD.

The EAF was created to drive European policy change by:

- (i) raising awareness of ADPKD and all its implications for patients;
- (ii) recommending strategies to improve ADPKD care at EU level; and
- (iii) encouraging and facilitating collaboration between people involved in ADPKD management, including policy-makers, healthcare providers, payers, patients, and industry.

To date, the EAF Faculty has produced two publications: "Translating science into policy to improve ADPKD care" and "Brussels Declaration on ADPKD" and is now focusing specifically on a model for 'tiered ADPKD care', increased research collaboration (that involves patients) and the creation of workshops to build capacity and advocacy for patients.

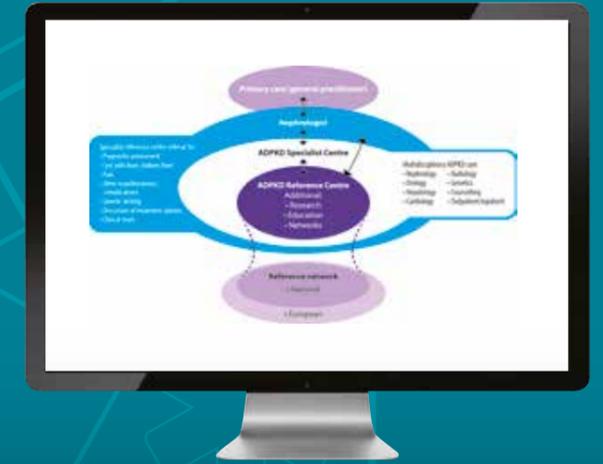


PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The EAF outputs are freely assessable to all patients in multiple languages, with over 5,000 reports being accessed.

Recently, the EAF faculty hosted a roundtable event (January 2016) that brought together European societies to discuss the need for coordinated multi-specialist ADPKD care, develop the multidisciplinary/tiered care model proposed in the EAF Report and explore how such a model might be implemented and adapted nationally. Implementation of any of these recommendations will further benefit patients

Ultimately, the EAF aims to provide inspiration and establish a new paradigm for patient engagement in transforming healthcare for less common, rare and inherited conditions.



INNOVATIVE ELEMENTS OF THE PROJECT

Patient co-chair: Ensured that the patient voice and role in decision-making was always present.

Clinical diversity: A range of clinical specialisms (nephrology, hepatology and genetics) sat alongside patient advocates to support collaboration and insightful, action-based outcomes.

International support: The Faculty engaged wider consultation, with PKD International, a global alliance of PKD patient groups, the Patient Network for Research and Health (EGAN), and endorsement was sought from international patient organisations.

Perhaps more importantly, the EAF is a working example of how patient involvement can impact policy and set the directional travel required for rare diseases (and indeed others).

COLLABORATIVE ELEMENTS OF THE PROJECT

The EAF initiative has been a collaborative effort between patient advocates, clinicians (from a range of different specialties including nephrology, hepatology and genetics), Interel and Otsuka Pharmaceutical Europe Ltd. This unique composition has brought together a range of different skill sets and specialisms. Specifically project managers, medical writers and individuals with experience of policy change to ensure insights and knowledge from disease-specific individuals could be captured efficiently to deliver the first of the EAF outputs in less than 12 months.



European Patient Clinical Trials Steering Committee in Psoriasis

There is critical need and tremendous value to incorporating the patient perspective in a protocol design for a clinical trial in psoriasis. This allows the capture of patient-relevant aspects and is essential to establishing whether a planned trial will be unduly burdensome. The European Patient Steering Committee was established to provide patient organisations' input into study design / study concepts of clinical trials in psoriasis to be conducted in Europe.

The project had a series of aims. It was devised to gain insights on patient-relevant end points to be incorporated in future clinical trials with secukinumab, which will be conducted in Europe in patients with moderate to severe psoriasis. It sought to explore the needs related to patient-relevant aspects and gather inputs for the implementation of a clinical trial, compared with real-life clinical practice. Finally, it looked to identify areas of improvement for psoriasis patients that can be addressed by future clinical trials with secukinumab.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

By interacting with psoriasis patient organisations in Advisory Boards the study sponsor aimed to share draft study designs/concepts and future development plans. The project looked at assessing and co-developing with patient organisations new tools to be used for investigation in future clinical trials.

A study protocol was designed taking into consideration the expectations of patients in terms of improvement of the skin conditions, aiming for maximising the benefits of their treatment, while fully preserving with safety. Another study protocol was designed incorporating PROs (Patient Reported Outcomes), measuring several aspects of quality of life that were selected based on inputs from both representatives of patient organisations and clinicians. By using patient community inputs to identify and address the highest priority of unmet need, the study protocol has become of greater relevance, introducing patient ownership and commitment to the programme's success.

INNOVATIVE ELEMENTS OF THE PROJECT

One out of three meetings held within the framework of this project was conducted via a webex with a view to facilitating the participation of patient organisations.

Questionnaires that were created with a view to exploring quality of life of patients suffering with psoriasis will be administered via a digital tool, such as an iPad.

Moreover, the precise concept of incorporating the patient perspective in a protocol design for a clinical trial is in itself revolutionary and will change the way in which seeking therapies to combat psoriasis is addressed.

COLLABORATIVE ELEMENTS OF THE PROJECT

The very foundation of the European Patient Steering Committee is its aim to provide patient organisations' input into study design/study concepts of clinical trials in psoriasis.

EUROPSO and national patient organisations therefore selected representatives to participate to the Patient Steering Committee. In terms of governance of the project, each meeting was regulated through the contract established between industry and patient organisations.



Figueira Improvement Project

Cardiovascular diseases (CVD) remain the leading cause of premature death across Europe, including in Portugal. There are several modifiable risk factors that can be identified, linked to lifestyle, such as smoking, poor diet, physical inactivity and alcohol abuse, as well as several chronic diseases.

The Figueira Improvement Project recognises the role of education as a “therapeutic environment”, acknowledging that the empowerment of patients allows them to assume responsibilities, remain informed and help doctors to define therapeutic targets and appropriate strategies to achieve better results.

Its principle objectives are to improve knowledge of: nutrition and balanced diet; the benefits and contraindications relating to exercise; dangers of tobacco; dyslipidemias; hypertension; and type 2 diabetes mellitus (DM2). It aims to change lifestyles by: reducing salt intake; increasing exercise; reducing / stopping tobacco use; reducing fat intake; and reducing the consumption of fast-absorption carbohydrates. Finally, it seeks to enhance the diagnosis and the correct disease

management of people with cardiovascular risk factors and associated diseases.

The project will last for six months with monthly sessions about health education, nutrition, exercise, smoking, dyslipidemia, hypertension (HTA) and DM2. Each session will be divided in exhibition component and interactive component (dance and cooking shows and gym workouts).

The target population is the resident population in the municipality of Figueira da Foz, in Coimbra district, Portugal.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

What is sought is an overall improvement in identifying cardiovascular risk (CVR) and thereby improving management of the condition.

In relation to the first set of objectives, the degree of knowledge and changing lifestyles will be assessed through questionnaires before and after the 6-session programme.

The CVR will be calculated in the first and last session using SCORE (40-65 years) and the relative risk table (65 years) based on: blood pressure; measuring capillary total cholesterol value; a survey interview about smoking habits and chronic conditions that influence CVR (diabetes, complications of diabetes, chronic kidney disease, cardiovascular events or established CVD); measuring capillary blood glucose; measuring waist circumference; and calculating the body mass index.

The risk of DM2 is calculated using a scale that patients contribute to via a survey. Finally, a card will be handed to each participant with the recorded changes found, to enable proper guidance by the participant's family doctor.

INNOVATIVE ELEMENTS OF THE PROJECT

There are various leagues of friends in hospitals but in primary healthcare it is far from common to find one in which users are willing to cooperate with health facilities in order to improve the quality of care and the population's quality of life. There are some published quantitative assessments of the CVR resulting from intervention in the area of health education, but there are no studies carried out in Portugal designed to assess knowledge and lifestyle changes, which may be the result of these kind of interventions.

COLLABORATIVE ELEMENTS OF THE PROJECT

This project involves a set of patients from USF Buarcos and members of the League of Friends of USF Buarcos, working in partnership with USF Buarcos in health promoting activities, among other actions.

Within the project, the relationships between AstraZeneca, healthcare professionals and patients will be developed according to the EFPIA HCP Code and AstraZeneca's Standard Operating Procedure about Local procedures related to the Global Ethical Interactions Policy and will not cover any promotion of AstraZeneca's products.



for HER

For HER is the first Pan-Hellenic overarching, patient-centric campaign for women’s cancer (ovarian, cervical and breast cancer) that addresses a diverse audience, including: healthcare professionals; patients; the general public, Roche employees; and the media.

While it was designed by Roche Hellas, it was also founded on strong partnerships, which were the basis of the campaign’s success and holistic approach. The basic aim of the campaign, which involved a wide range of events, was to transmit the valuable message that prevention and early diagnosis can save lives. The “for HER” campaign is designed to increase awareness of how precious life is and emphasise that we should take care of the women in our lives. It also seeks to underscore that cancer can be defeated, if it is detected at an early stage, and that with existing, innovative treatments therapeutic solutions are available.

The specific objectives of the campaign were to: increase awareness of the various types of women’s cancers and the importance of early diagnosis; create a network with different stakeholders to improve the outreach of our messages; empower patients already living with the disease by designing a series of activities with the main message, “Live your life and not your disease”; and encourage the participation of Roche employees as ambassadors of the campaign.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

It is estimated that the campaign has reached over 180,000 women. In terms of raising awareness, this is a significant figure.

We have also received valuable feedback from our partners during face-to-face meetings regarding the effectiveness of the programme. They communicated that breast cancer survivors were very grateful for the events organised for them.

An analysis of the campaign from a media perspective shows that the press conference was attended by 30 journalists and created 10 print clippings in local newspapers and magazines, as well as 55 online clippings in local sites and portals. It furthermore gave rise to one special feature video on a medical portal and two radio interviews in addition to two TV mentions.

INNOVATIVE ELEMENTS OF THE PROJECT

“for Her” is the first holistic campaign that has engaged and affected many different stakeholders under the same message and branding. The demonstration of the awareness video, via cinemas, was by far the most innovative aspect of the project.

COLLABORATIVE ELEMENTS OF THE PROJECT

Under Roche Hellas’ holistic approach, we managed to secure essential partners, including: Alma ZoisPanHellenic Association of Women with Breast Cancer; the Association of Cancer Patients, Volunteers, Friends and Physicians - K.E.F.I., which focuses as well on gynaecological cancers (ovarian and cervical); and Women for Oncology, an NGO of women oncology professional who participate in many educational events. Journalists were also partners in the effort to spread the message of prevention and early diagnosis.

Through regular bi-weekly meetings between the various partners and the project team, we held extremely productive brainstorming sessions and set clear timelines so that we can ensure the best deliverables.



Getting to Know Epilepsy Makes Us Equal

Around 65 million people worldwide are affected by epilepsy, including 6 million in Europe and 400,000 in Spain, who face, on a daily basis, the social stigma still present in the society.

In order to minimise the social stigma, especially among children, the campaign has been rolled out in roughly 3,750 courses in public, private and partially public-funded schools in Spain, reaching over 63,000 children.

This campaign included a football player from the Atlético de Madrid's first team Jesus Gámez, who shot a video with children who suffer from the disease, offering a parallel view between how to act if you witness an epileptic seizure and how to face a penalty kick, as well as a press conference highlighting epilepsy during Atlético de Madrid's match with Almería on 21 February 2015. The aim was to bring more social acceptance to the condition, to discuss the potential positive benefits of sport on the condition and to offer information on how to deal with epileptic seizures.

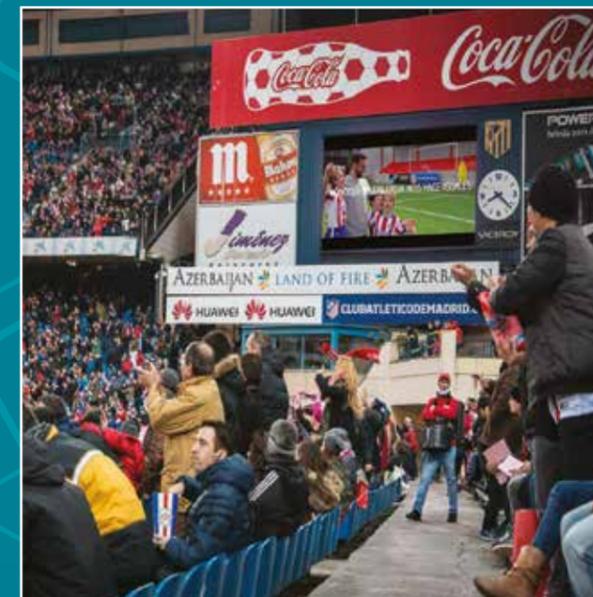
Gámez promoted the campaign to tens of thousands of his fans on Facebook and Twitter. He furthermore appeared at a press conference before the match, alongside representatives from the Atlético Madrid Foundation, the Spanish Epilepsy Patients Federation (FEDE in Spanish), a neurologist, three children with epilepsy and J. Sobrino, MD of UCB Iberia.

The event attracted journalists from high profile newspapers, radio and television channels. The press event was also attended by children, who took part in a drawing contest organised by UCB, in the schools where the campaign was implemented.

UCB and FEDE are working with schools, patients and doctors to increase understanding of the disease and welcome the support of AtléticoM.



Jesús Gámez, football player, with children with epilepsy at the recording of the video.



Stadium of Atlético Madrid at the soccer game, with the video of the campaign at the screens.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Patients benefited from efforts to make people more socially aware of epilepsy and its effects on patients. It increased understanding, particularly in terms of how young people see epilepsy. In essence, we added value to the patient's cause, by addressing social stigma; integration; education; and "normalisation" of the disease. We emphasised that the majority of children with epilepsy can lead normal lives and practice sports in the same way as their classmates.

We have measured the effectiveness of the campaign by analysing media coverage on national and regional TV channels, as well as in the general and sports press.

- National & regional TV channels
- Both general & sport press

An estimated 44,053,000 persons reached with the campaign through mass media.

The success meant more than 44 million people impacted the campaign, helping the social integration of epilepsy patients.

This campaign has received two Awards:

Award 2015 - Publifestival
Category: Best Social Health Awareness Campaign – 18 June 2015

Award Best Ideas "Diario Médico" 2015
Solidarity Category: Specialised press in Spain.

INNOVATIVE ELEMENTS OF THE PROJECT

The football team's input was novel, this being the first time Atlético Madrid has ever joined forces with a pharmaceutical company. The highly effective social media campaign was also part of our innovative approach.

COLLABORATIVE ELEMENTS OF THE PROJECT

Pharmaceutical company UCB and the Spanish Epilepsy Patient Federation (FEDE), supported by the Spanish football champions Atlético Madrid (AtléticoM), joined doctors, patients and the general public across a number of initiatives aimed at 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.

The joint UCB/El Atlético campaign, under the slogan "Getting to know Epilepsy Makes us Equal", concluded with a UCB-produced video that was shown in a stadium full of 55,000 spectators. The short video starred team player Jesús Gámez and three children living with epilepsy. It was shown at a match between El Atlético and Almería teams.

This initiative has also open doors for future collaborations with the Atlético of Madrid Foundation or other Sport entities with the aim to normalise epilepsy.



HCSA Folkemode Denmark Hiv Denmark AIDS Foundation and GSK



In Denmark, HIV patients have experienced obstacles to obtaining normal health insurance and some banks refuse to provide property mortgages to loan takers without life insurance.

HIV patients are often requested to make late appointments with dentists. Moreover, in many cases, HIV patients experience severe discrimination and are often forced to pay an incremental cleaning fee. Hiv-Danmark and the AIDS-Foundation have challenged these and many other examples of stigma and discrimination of HIV patients during many years. In 2015 Hiv-Danmark and the AIDS-Foundation initiated a project with GSK. The partnership focuses on prejudice and stigma surrounding HIV and on raising awareness that well-treated HIV is not contagious. It also focuses on obstacles that HIV patients meet in daily life. All the activities culminated in an event at the "People's Meeting" a political "festival" attended by over 100,000 people.

Representatives from Hiv Denmark addressed two hurdles an HIV patient faces on a daily basis, aimed at changing perceptions and the process of: access to dental treatment for ordinary conditions; and access to health and life insurance with the same conditions as other patients with a chronic disease.

The debate at the People's Meeting focused on insurance and dentist visits for HIV patients and representatives from the dentists and insurance associations participated actively. Both representatives acknowledged there was an issue with current standards and said a revision of standards for HIV patients was necessary.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

After the People's Meeting, the AIDS Foundation and HIV-Denmark have worked to keep focus on the main issues of the debate:

- the Danish Dentist Association has informed all members about the hygiene rules from the Danish Health Authorities, urging equality for all patients including HIV patients
- new contact has now been established with the Danish Insurance & Pension Association in order to normalise life for people living with HIV; there is ongoing dialogue to ensure equal access to insurance and pensions
- to avoid discrimination of all patients due to an HIV diagnosis

From ongoing dialogue between the patient organisations and the two associations we know that procedures have been changed. New positive stories have been shared at by the patient organisations.

INNOVATIVE ELEMENTS OF THE PROJECT

For the first time ever, a political festival (the People's Meeting) has been used as a platform to increase awareness of the fact that well-treated HIV is not contagious. The platform from which we were able to convince both the chairman of the Danish Insurance & Pension Association and the Chairman of the National Dentist Association that they should participate in the panel discussion on these vital, yet complex, topics.

COLLABORATIVE ELEMENTS OF THE PROJECT

The cooperative efforts that were linked with this meeting were initiated via a workshop to identify the key topics that should be taken up. Based on the outcomes from the workshop, an agency was appointed which was given responsibility for logistics around the meeting. To ensure transparency and to avoid conflict of interest, all those involved in the meeting had to sign a conflict of interest form. They all furthermore received a zero-fee contract relating to the agreement.



IO NON SCLERO

Projects and dreams do not stop for Multiple Sclerosis

In Italy some 75,000 people live with multiple sclerosis. MS sufferers are often young, as the disease appears between the ages of 20 and 40.

Online conversations and observations by the National Observatory on Women's Health have showed that for many sufferers, MS was not stopping them from living their lives and they were still pursuing projects and planning their futures. These insights generated the need for a project aimed at encouraging patients and their families to "unveil the real face" of MS.

The project launched in September 2014, with a six-episode web series, showing that life does not end with a diagnosis. The campaign objectives were to: raise awareness of MS; give a voice to patients; generate societal support; create a public movement to renew focus on MS; and show that the disease cannot stop projects and dreams.

The web series was supported by a website, a Facebook page and Yahoo! Italy, with a homepage endorsement and video. Additionally, in November 2014, the campaign landed in over 400 cinema screens around Italy, with the distribution of informative postcards. An online initiative also engaged patients and caregivers and encouraged them to submit their projects and dreams.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The aim was to create community engagement and participation by patients and their families, both in online conversations and in real stories.

This engagement caused a spontaneous shift from fiction to reality, as patients and caregivers submitted online their true projects and dreams and became the protagonists of the campaign with their own stories. These stories were also featured, together with messages and comments posted by the community on Facebook, in the e-book published recently on the website. The campaign gave MS patients the opportunity to share experiences and it altered the tone of voice surrounding MS. It helped people to feel they are not alone and that they can live full lives, despite diagnosis.

The greatest measurement of patient benefit was to hear directly from people with MS and their families about how happy they were to finally see a realistic, but optimistic reflection of their futures.

INNOVATIVE ELEMENTS OF THE PROJECT

The project offers a unique and novel approach to dealing with MS in the sense that the various strands ignited a spontaneous conversation among both patients and caregivers. This has helped to shed new light on MS and alter the tone of the conversation around the disease.

By focusing on the stories of individual patients and their families, we brought home to others the direct experiences of living with the disease and yet enjoying fulfilling lives.

The online conversation was monitored constantly and moderated by a supervising team that made sure they acknowledged and respected all of the community policy requirements.

COLLABORATIVE ELEMENTS OF THE PROJECT

Our project was promoted by the National Observatory on Women's Health (Onda), with the endorsement of the Italian Society of Neurology and an unrestricted grant from Biogen Italy. It drew in a variety of stakeholders, including patients and their families, and was backed by the internet technology company Yahoo! Italy.



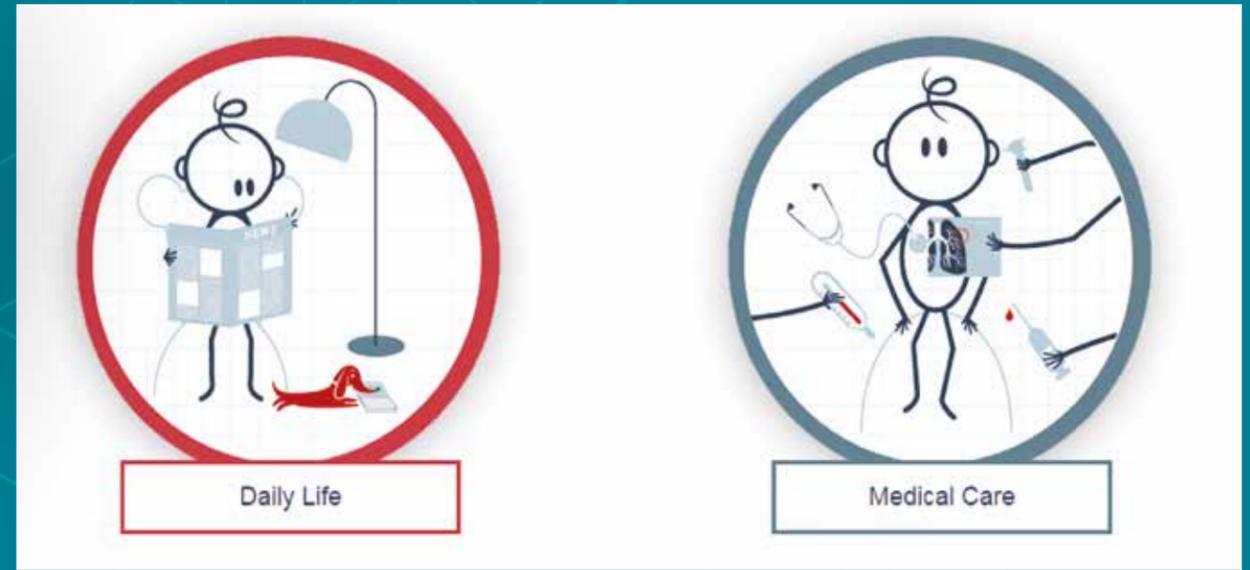
Lung Cancer: We're Listening

People living with lung cancer, lung cancer survivors and carers are impacted by lung cancer in different ways. In 2013, the Global Lung Cancer Coalition (GLCC) and Boehringer Ingelheim started a long-term collaboration, with the aim of better understanding the daily impact of lung cancer on the lives of patients and carers.

The objectives of the 'Lung Cancer: We're Listening' campaign were to: establish the single most important challenge faced by patients and carers, including medical and psychosocial issues; and to identify and address current gaps in lung cancer care and support on a global basis.

The campaign was driven by a simple, web-based anonymous questionnaire. Lung cancer experts from the GLCC identified 200 specific and globally-relevant challenges related to medical and psychosocial topics, and patients and carers were asked to identify their most challenging, in respect of either 'Daily Life' or 'Medical Care'.

Subsequent sub-categories were presented via illustrations, and with small text descriptors, to help the individual isolate their most difficult challenge related to lung cancer. Once an individual challenge was identified, questions regarding the individual's ability to cope, the availability of information and the level of support required were also asked.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Understanding truly the impact of lung cancer on both patients and carers is the key to providing tailored, valuable support that can have a positive effect on an individual's experience of living with lung cancer – and this is where the campaign really delivers.

Over 700 individuals answered the questionnaire and the data were presented to the lung cancer community at the World Congress of Lung Cancer 2015 and at the 2015 European Respiratory Society International Congress. The results showed that 'daily life' challenges represent more of a burden to lung cancer patients and their caregivers than the 'Medical life' challenges associated with their care.

In addition they highlighted that more than 50% of patients and carers struggle to cope with challenges of living with lung cancer, and a more holistic approach to lung cancer care should be adopted to ensure patients and carers receive the support and information they need.

The results have reaffirmed the ongoing work of the GLCC and continue to influence the care and support programmes they provide.

INNOVATIVE ELEMENTS OF THE PROJECT

"Lung Cancer: We're Listening" used a simple illustration-led survey, which, by its very design, helped patients and carers to identify easily their single greatest challenge related to the disease.

Each individual challenge was illustrated, and was designed to be culturally sensitive as well as to overcome potential language barriers. The survey was translated into 11 languages and was multiple-choice to enable fast but accurate completion of the questionnaire.

COLLABORATIVE ELEMENTS OF THE PROJECT

A taskforce team within the Global Lung Cancer Coalition designed the survey and established the 200 specific challenges featured in the campaign. Boehringer Ingelheim provided sponsorship to fund the research and provided support via digital and communications agencies to run the survey and communicate the results.



Roche Hellas Lymphoma Campaign

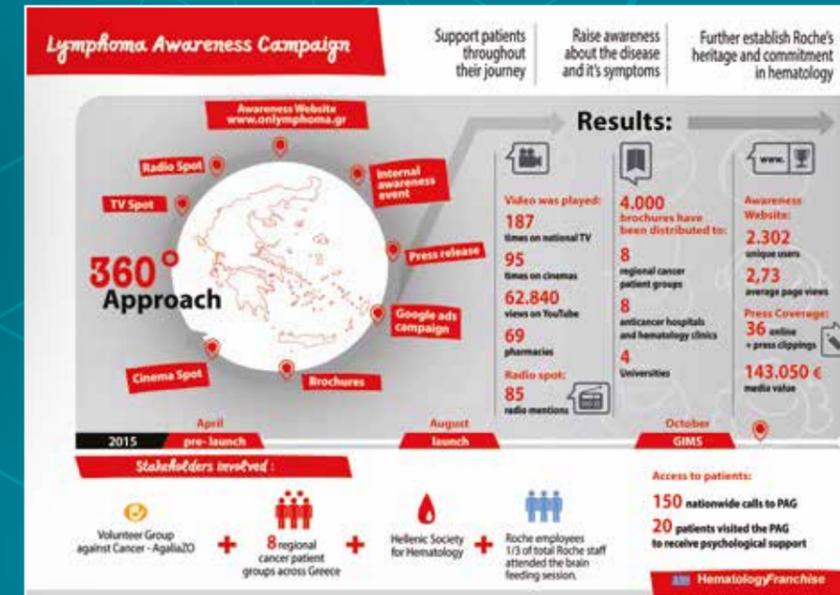
As awareness of lymphoma and its symptoms is very low, Roche Hellas decided to build a Lymphoma Awareness Campaign, aimed at supporting patients, raising public awareness about the disease and helping to clear up any confusion about its symptoms.

In order, however, to better understand what it is like to live with the disease, the challenges facing patients and their families, we partnered with the patient group "AgaliaZO".

The campaign focused on three key objectives: engaging stakeholders from the healthcare community; creating informative material with a broad geographical reach and wide accessibility; and adopting a tailored approach to address the needs of all our audiences. Specific target audiences included patients; caregivers and the general public (including younger age groups that can act as pressure groups).

The project started on 1 August 2015, and is ongoing. It includes a TV advertisement, played 186 times on National Television and 95 times at cinemas. This has also registered 8,996 views on YouTube and has been shown in 69 pharmacies as well as on the websites of patient groups.

This was furthermore accompanied by a radio advertisement, which was broadcast on national radio stations. We have also launched an online portal (<http://www.onlymphoma.gr>) and three awareness brochures, tailored to our three target groups: regional cancer patient groups covering 7 out of 9 geographic regions of Greece; 8 anticancer hospitals and hematology clinics in Athens; and the 4 largest (by enrollment) Athens-based universities. Finally, we hosted an internal awareness event aimed at employee engagement.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The campaign was launched on 1 August 2015, so any public benefit at this stage has been estimated from the reach that has been achieved through the multiple tools used to communicate our messages.

We are collecting valuable patient feedback through our strategic ally, the Volunteer Group against Cancer, AgaliaZO, and its eight collaborating patient groups across Greece. They have been receiving queries and comments about the campaign throughout this period.

INNOVATIVE ELEMENTS OF THE PROJECT

Since 2012, there have been no recorded awareness campaigns in Greece about lymphoma.

We employed a variety of innovative approaches in this project, blending traditional campaign methods – to create a sustained, organised effort together with the patient group and reach older populations – with social marketing and social movement principles – to generate bottom-up energy and harness younger people.

Furthermore, we introduced tools that enabled a geographical spread across Greece, in order to reach rural areas that are not exposed to disease awareness initiatives.

COLLABORATIVE ELEMENTS OF THE PROJECT

Our strategic partners included the volunteer Group against Cancer, AgaliaZO, eight regional cancer patient groups across Greece and Roche Hellas employees.

To implement a successful campaign that would benefit patients, care givers and the general public, we recognised at an early stage the importance of partnering and engaging with a number of different stakeholders. The campaign was built on successful collaboration, through which we managed to approach the project holistically, acquiring insights and expertise from the patient perspective, as well as that of the business and healthcare communities.

My PD Journey

This is a unique, multi-stakeholder project for people with Parkinson's in Europe, led by the European Parkinson's Disease Association (EPDA). Patients often do not receive a personalised approach to individual treatment and care, one that is tailored to their individual needs and preferences. We aim to create a sustainable environment that ensures people with Parkinson's receive optimal and timely access to appropriate diagnosis, treatment and care throughout the progression of their disease. The initiative involves the entire Parkinson's disease community, including European umbrella healthcare organisations, high profile European Parkinson's specialists, people with Parkinson's, carers and members of the multidisciplinary healthcare team, among others.

The project is based on three strategies: understanding the different hurdles that negatively impact treating the progression of Parkinson's; developing solutions that contribute to a comprehensive and individualised management of Parkinson's; and implementing the My PD Journey solutions.

Three concrete projects are being carried out in 2015/16. The European Inventory, a research project, aims to identify where gaps exist in current Parkinson's care pathways and highlights national examples of good practice that could be replicated in other regions. We are also creating a

completely new and easy-to-use composite scale for people with Parkinson's. Finally, we are building national coalitions of Parkinson's stakeholders across Europe.

My PD Journey also has developed a series of EU and national policy recommendations and actively is engaged with policymakers at all levels to ensure these recommendations are adopted and implemented.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

My PD Journey's goal is to influence positively how services are provided currently in the care pathway in relation to the management of Parkinson's disease. Through a series of different projects, we aim to improve the lives of people with Parkinson's.

More specifically, the composite scale currently is being tested and measured in a second validation study all across Europe. The first results were made available in February 2016. Once it is adopted it will be measured on the basis of scrutinising its use within health services around the world.

In addition, the My PD Journey national coalitions that are being established currently will each focus on different pilot projects that address the needs of their own unique national healthcare systems. Each of these pilots will have their own measurable outcomes.

INNOVATIVE ELEMENTS OF THE PROJECT

The pan-European nature of the My PD Journey projects outlined above incorporates the European inventory, the composite scale and national coalitions, each aspect of which is innovative.

In particular, the composite scale is entirely new – the scale takes into account how the disease affects individuals differently. As a result, patients' care plans can be tailored better to suit their individual needs.

The national coalitions, meanwhile, are innovative, as they encourage multidisciplinary and interdisciplinary co-operation and interaction to effect change.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project entails a range of cooperative interactions between various stakeholders. The My PD Journey European Strategic Committee (ESC) is chaired by the EPDA. The committee provides strategic oversight, ensuring effective implementation of the initiative's work programme and includes representatives from the European Parkinson's Disease Association (EPDA) and the My PD Journey Parkinson's Specialist Panel, represented by its chair and vice chair.

The project also harbours a Parkinson's specialist panel, working groups and national coalitions, as well as a secretariat, to provide strategic oversight.

Roche Hellas Patient Group Educational Programme

Roche Hellas shares an interest in helping patients understand and manage their disease/condition, including having timely and equitable access to the treatment they need. To this end, Roche Hellas designed an overarching educational programme for patient groups.

The basic aim of the programme was to provide patient group representatives with the necessary tools and information to become more empowered and active advocates. To accomplish this, we announced a comprehensive training programme that included seminars on topics that are of key importance for patient groups nowadays, such as Clinical Trials, Healthcare Technology Assessment, Shaping Health Policy, and Alternative Means of Fundraising etc. The programme also included practical workshops to equip them with skills that aimed to increase their confidence during their everyday tasks as advocates for example, communication skills, advocacy skills, emotional intelligence skills and an introduction to basic management principles in order to optimise their efficiency.

Last but not least, we introduced an advisory board targeting psychologists and social workers in an attempt to map the main issues patients face, as well as encouraging experience exchange among participants.

In more detail, the programme was launched with individual mini training seminars addressed to the members of the board of directors of patient groups, which were tailored to their needs, followed by the advisory board for psychologists and social workers. It concluded (for 2015) with the implementation of a two-day advocacy workshop addressing 14 patient groups across different disease areas from Greece and Cyprus.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Questionnaires were used to measure the levels of awareness in each topic before and after the mini training seminars, using a scale from 0-5. The results showed that awareness on a variety of challenging topics (Clinical Trials, Healthcare Technology Assessment etc.) had indeed increased encouragingly.

In addition, at the end of each mini training session, multiple-choice questionnaires were distributed to ensure that the basic terms and key points had been digested. 76% of all questions were answered correctly. Finally, following the completion of all activities, feedback was requested from all participants in order to co-decide the topics of upcoming seminars and workshops focusing on the patient groups' needs.

INNOVATIVE ELEMENTS OF THE PROJECT

Roche Hellas is the first pharmaceutical company in Greece to organise and implement an all-year-round educational programme, focusing on fostering active learning and developing advocacy skills.

Both the short training seminars and the advisory board included pioneering elements, such as following a tailored approach when drafting the agenda of each seminar as well as organising a patient-centric advisory board focusing on the psychological impacts of cancer – an aspect that is often overlooked.

Finally, the two-day advocacy workshop was the highlight of the series of activities implemented as part of the overall educational program since for the first time in Greece 14 patient groups across different therapeutic areas were invited to discuss and address key topics via an interactive agenda that aimed at experience-based learning and building rewarding and lasting relationships.

COLLABORATIVE ELEMENTS OF THE PROJECT

Our partners in this effort were internal and external. Internal contributors were colleagues from the Medical Affairs and External Affairs departments. Suitable presenters for the sessions were selected according to experience and based on their communication and presentation skills. These included medical managers, health economics managers, biologists and clinical trials executives who ensured that each topic was presented in a way that was understandable and easy to digest. External partners included patient groups from other disease areas (best practice sharing presentations), as well as other contributors that assumed various topics according to their expertise, such as health journalists, public policy academics, and fundraising specialists from other NGOs.



aBC App

Studies have shown that sufficient physical activity increases the performance and quality of life for many patients with advanced breast cancer.

Therapy Management for advanced Breast Cancer (aBC) patients is not so easy because of their physical condition. A cross-functional team of Novartis Oncology in Germany therefore thought pro-actively about ways to improve the patient outcome in therapy.

Studies have shown that sufficient physical activity increases the performance and quality of life for many patients. So one of the first projects within the campaign was to develop a brochure about 'Physical Activity'. Patients are mobile, not only at home but also outside this setting, even with aBC, and this encouraged us to develop an App, so that they could train on a regular basis, even if constantly out and about. Moreover the App contains the additional opportunity of a motivational element of a ZEN-garden. The animated elements motivate patients to train regularly.

While developing the App, Novartis involved the patient organisation 'mamazone' for the final adjustment of all the functionalities. In the end, this involvement not only leads to a better product but also to a broad acceptance of the App within the patient community.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

After introducing the App into the German market, the success was astonishing. High momentum: patients hearing about/recommending the App to each other (e.g. via Facebook, reviews in magazines of patient organisations), not only in Germany, but also in other European countries. Patients in Belgium, for example, have asked Novartis for this App in Flemish and French. In the meantime, Novartis decided to launch the App in a variety of languages in different countries.

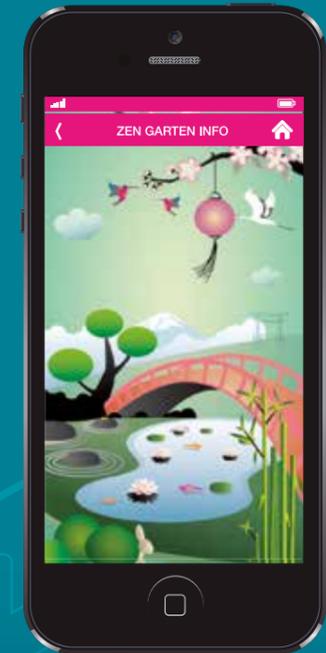
The App received sensational feedback from physicians, patient organisations and patients, in the first 3 months the App was downloaded 573 times; after 12 months there were 1060 downloads. Patients are still sharing/recommending the App among/to each other.



INNOVATIVE ELEMENTS OF THE PROJECT

Several tutorial videos have been adapted to disease progression status and types of metastases. In addition, the App has a motivational element of a ZEN-garden (e.g. animated elements motivate patients to train regularly).

Moreover, through a Patient-AdBoard the project has benefited from elementary patient insights for a final adjustment to all functionalities within the App. The involvement of the Faculty of Sports (University Cologne, Dr. F. Baumann) was also crucial to its overall success.



COLLABORATIVE ELEMENTS OF THE PROJECT

From the beginning we have witnessed close cooperation with the patient organisation "mamazone" in the development process. It was very useful to involve patients and the patient organisation from the beginning of the project (conceptual phase) and not only to undertake a review of a "final product" with them. Furthermore, their involvement was crucial to our overall success, because the acceptance of this tool has been increased enormously. After using the App, patients have been sharing/recommending the App with/to each other (e.g. via Facebook, reviews in magazines of patient organisations).

Pancreatic Cancer Europe

Pancreatic cancer is currently the 4th highest cause of cancer-related death, and is set to be 2nd by 2020, if no action is taken. It is the only cancer with increasing mortality in both sexes, and it also has the lowest survival rate of all cancers.

Pancreatic Cancer Europe is a multi-stakeholder platform represented by academics, physicians, politicians, patient groups, journalists and industry, which works for the overall purpose of reducing the burden of pancreatic cancer and improving care for patients. This mission is pursued through working towards the improvement of awareness and diagnosis and an increased prioritisation of pancreatic cancer in research and politics at local and EU level.

Pancreatic Cancer Europe was formed after a Call to Action, launched in July 2014, by four Members of the European Parliament: Philippe De Backer, Françoise Grossetête, Philippe Juvin and Daciana Octavia Sârbu. The Call to Action sought the establishment of a mechanism to address the main gaps surrounding this forgotten, yet serious fatal disease. However, Pancreatic Cancer Europe operates independently, with Celgene and Baxalta providing the financial support in 2016.

The diversity of the Pancreatic Cancer Europe stakeholders, as well as their geographic spread and their high level of engagement, results in speedy agreement among members, especially on strategy and priorities. Leveraging stakeholder experience in other cancers has allowed speedy consensus development and communication of best practices.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Late diagnosis of pancreatic cancer is common due to a range of medical factors, including a low awareness of symptoms, particularly among doctors. One of the main aims of Pancreatic Cancer Europe is to encourage earlier diagnosis and timely referral of patients to specialists. Therefore, Pancreatic Cancer Europe has engaged in and launched several political activities, such as events in the European Parliament or the participation in the MEPs against cancer (MAC) meeting to push for a higher recognition of the need to take political action on pancreatic cancer.

Pancreatic Cancer Europe has created a website, pancreaticcancereurope.eu, to share relevant information for the benefit of patients and other stakeholders. This includes information on key patient groups and their contacts, medical societies and reference centres to allow best practice sharing between countries and offer support to national groups in raising awareness and providing information to patients. Finally, there is a lack of national patient registries and systematic, harmonised data collection that could help better understanding of the disease, the development of more efficacious diagnosis and treatment strategies. In order to close these gaps, Pancreatic Cancer Europe supports the communication around the work relating to a widespread collection of real world data through harmonised registries across Europe.

INNOVATIVE ELEMENTS OF THE PROJECT

Pancreatic Cancer Europe is the first platform gathering medical practitioners, researchers, patients, policy makers and industry to address this disease.

The high level of expertise of our platform members and the size and organisation of the platform have also enabled us to deliver a substantial and concrete outcome.

Through the commitment of active Members of the European Parliament, the platform is politically-driven to act at policy and political level.

Another innovative aspect of the project is the capacity of platform members to translate the documents elaborated in multiple languages and to disseminate them at national level, under the heading of the platform. The medical or advocacy expertise of platform members from Sweden or the UK can hence benefit patients and doctors in a number of other European countries.

COLLABORATIVE ELEMENTS OF THE PROJECT

PCE is endorsed by key EU stakeholder organisations active in the field of cancer and gastroenterology. It also gathers multiple national patient groups and medical associations who work together, aiming for the prioritisation of pancreatic cancer on the EU and national policy agendas.

The diversity of the Pancreatic Cancer Europe stakeholders, as well as their geographic spread and their high level of engagement, results in speedy agreement among members, especially on strategy and priorities. Leveraging stakeholder experience in other cancers has allowed speedy consensus development and communication of best practices.



QIC Diabetes

Since 2010, the UK's NHS has aimed to make savings of £20 billion by 2015, of which the central pillar is efficiency savings. Therefore, best practice examples of programmes and initiatives that improve patient outcomes can be recognised, shared and implemented across the UK to deliver the efficiency savings as needed, without reducing quality or scope of service.

Quality in Care (QIC) Diabetes aims to recognise, reward and disseminate good practice in diabetes care. It demonstrates the benefits and adaptability of entrants' initiatives to a wider healthcare audience, including presenting at the annual Diabetes UK Professional Conference. Further dissemination opportunities include webinars, newsletters, workshops and the communication channels of QIC Diabetes' partner Sanofi and our programme supporters.

Entries are invited from the NHS and other healthcare systems, the private sector, patient organisations and the pharmaceutical industry. Entries are welcomed from within the UK.

The implementation of the QIC programme is split into three phases: the identification of good practice; the celebration of the most successful improvements in patient care; and the dissemination of good practice and implementation support.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The credibility and continuity of the QIC programme undoubtedly has provided a platform for healthcare professionals, allied healthcare professionals and healthcare organisations to showcase their excellent work. This shows that they have been able to offer the same or better standards of care whilst delivering huge efficiency savings.

Each entry to the awards required a robust submission to demonstrate the quality of the programme. The evaluation and results section requires entrants to report the results of each objective, demonstrate how the success was measured and detail the future impact on the initiative for people with diabetes. There is also a requirement to detail how the project is innovative or pioneering, how the project has been measured in terms of impact and how easily the project can be adapted to other diabetes services or centres. This last section is key to facilitating the dissemination of projects.

In summary, each project is assessed for a robust measure of patient benefit which can be seen on the website listing of finalists, and there are also measures indicators for dissemination of best practice through the website.

INNOVATIVE ELEMENTS OF THE PROJECT

Quality in Care was innovative in terms of its structure and aims. This was the first programme to bring together a wide array of stakeholders (healthcare professionals, academics, industry, charities, patient organisations, patients and carers) to identify good practice, celebrate the most successful improvements in patient care and then share this with the wider community and offer support to implement.

COLLABORATIVE ELEMENTS OF THE PROJECT

The QIC programme is intrinsically collaborative, is funded by Sanofi and has the support and active participation of a number of diabetes charities, including the Association of British Clinical Diabetologists, Children & Young People's Diabetes Network, Diabetes UK, Diabetes In-patient Specialist Nurse UK Group, Diabetes Research & Wellness Foundation, Primary Care Diabetes Society, Training, Research and Education for Nurses in Diabetes UK and Young Diabetologists and Endocrinologists Forum. The judging panel includes recognised academics, clinicians, patient bloggers, nurses and commissioners working in diabetes.

abbvie



Quality of Life and Needs of Patients with Autoimmune Diseases

Healthcare systems around the world increasingly are becoming interested in strengthening the role of patients in managing their own care. The cost of not including patients in decision-making processes is estimated to be almost €100 billion per year for arthritis alone.

This project focuses on improving treatment and decision-making processes through patient empowerment in Slovakia in the field of autoimmune diseases. The project contributes to offering patients an improved level of information and enhances their ability to participate actively in the treatment process.

The project aims to improve the availability and dissemination of accessible and user-friendly information on the efficacy and safety assessment of healthcare services, including the provision of medicines, their risks and benefits, and their economic implications (including HTA), in a format useful to patients. It also looks to improve the capacity of “patient experts” and well-informed patients, to provide objective, credible, understandable and accurate information to the wider patient community and the public.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

Only educated patients can be empowered patients – those who are able to contribute to the actual decision-making process that leads to an improvement in their treatment.

The results of this participative, patient-reported outcomes study (of psoriasis, rheumatoid arthritis and psoriatic arthritis) will make it possible to explain to rheumatologists and the wider professional public, the experiences, knowledge and the needs of patients with autoimmune diseases. This should lead to an improvement in communication between patients, doctors and other health personnel, resulting in a better consideration of the needs and feelings of patients in the treatment process.

Individual benefit for the patients include a better understanding of and ability to cope with the disease and thus to improve their quality of life, resulting in gaining access to treatment.

INNOVATIVE ELEMENTS OF THE PROJECT

This is a concrete national project on how to move towards a better sustainability of healthcare and good access to quality health care. Innovation comes in the form of creating “patient experts” and well-informed patients in patient organisations in order to provide objective, credible, understandable and accurate information to the wider patient community and public. Furthermore this project involves a novel approach that will provide expert and academia-based patient education, including in the field of HTA.

COLLABORATIVE ELEMENTS OF THE PROJECT

The project linked patient organisations, represented by the League against Rheumatism in Slovakia and the Association for Patient Rights Protection in Slovakia, with a pharmaceutical industry partner in the form of AbbVie Slovakia. The agreement was signed in Bratislava on 4 October 2015.

It has permitted the education of patient association representatives and patients on HTA, healthcare policies and quality of life – mainly in cooperation with academia. Ultimately, patients will partner physicians in making individual treatment decisions.

The project also enabled cooperation with experts from the ISPOR Chapter of Slovakia, the Slovak agency for health technology assessment, the Slovak Medical University, the National institute for rheumatic diseases, the League against Rheumatism and the Association for Patients’ Rights Protection in Slovakia.

SM24.pl portal

The SM24.pl portal was designed for patients with multiple sclerosis to create a comprehensive and reliable source of information about the disease, as well as supporting patients and their loved ones in terms of the possibilities of coping with MS symptoms.

The overall aim of the portal is to provide specific tools, such as expert advice and multimedia tool that can be used individually by patients, thus aiding them in coping with the disease on an everyday basis.

Each thematic section was prepared in cooperation with experts from various fields: neurology; psychology; physiotherapy; speech therapy; sexology; neuropsychology; and law. The portal enjoys the patronage of the most important Polish patient organisations involved in supporting MS patients: the Polish Multiple Sclerosis Society; the NeuroPozytywni Foundation and the Urszula Jaworska Foundation.

It includes a materials such as: disease information; expert advice on how to deal with MS symptoms; training videos on individual rehabilitation; speech-improvement exercises; advice on coping with stress; an e-learning course on the principles of nutrition and dietary tips; examples of diet plans; cognitive games; and a simulation of MS symptoms.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The primary goal of the portal has been to respond to the needs of patients. For that reason, ongoing contact with patients is of key importance to the project. It is the patients who determine the direction in which the platform is developed and indicate topics that are important to them or which they think should be elaborated upon.

All multimedia materials, such as instructional videos or e-learning materials are first shown to patients and assessed by them. In its year-long existence, the portal has managed to win over patients who, thanks to their commitment to developing the portal, became its natural ambassadors. That is why opinions expressed by patients and patient institutions, which are the portal's patrons and experts who cooperate with us, are the most credible measure of patient benefit.

Additionally, portal statistics show a steady increase in interest in the platform, particularly when its content is updated with new materials. The contact form available on the website makes it possible for anyone to express their opinion, suggest new topics etc.

INNOVATIVE ELEMENTS OF THE PROJECT

To help patients with different levels of MS symptom severity navigate through the site, the portal was equipped with voice-guided navigation, the possibility of adjusting font size and has been made available as a high-contrast version, as well as a mobile version. On the website, apart from traditional, written content, patients can also find multimedia materials including: instructional videos on rehabilitation; and speech exercises that they can perform by themselves at home. Other tools were created with enhancing cognitive functions in mind.

COLLABORATIVE ELEMENTS OF THE PROJECT

The portal has been created in cooperation with three patient organisations, of which each is an equally important partner. In order to align the interests of each party and at the same time facilitate project management, individual thematic sections included on the website have been distributed among the three organisations. The partners have agreed upon the division of responsibilities on the basis of their engagement in a given subject matter or their specialisation.



SROI Project

The negative effects of psoriasis are not experienced by sufferers alone because they also have an adverse impact on society, the economy and the national health system as a whole. The problem is that there is currently a gap in the Spanish NHS in terms of understanding the severity of the disease.

SROI is a multi-stakeholder project, the aims of which are to: generate patient evidence; and demonstrate the beneficial economic and social impact of increasing investment in psoriasis in order to increase the standard of care. Specifically, it looks to identify the impacts of clinical care, healthcare assistance and economic and social factors on patients suffering with psoriasis. It furthermore seeks to quantify the social return on investment (SROI) in both the current and ideal approaches to treating the condition.

The overall goal of the project is to reach a consensus amongst a group of representative stakeholders on an optimal psoriasis management model for the Spanish National Health System by means of a comparison between the present model and the proposed new standard of care.

A principal outcome would be the delivery of a position paper that would facilitate a collaborative dialogue between the patient interest group Acción Psoriasis and other stakeholders with a view to improving the standard of care.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

SROI will measure the changes to the system and see how they are relevant to people or organisations that are using it or contributing to it. It should be able to tell the story of how these changes are being made by measuring social environmental and economic outcomes. It will use monetary values to represent each of these elements. This enables a ratio of benefits to costs to be calculated.

In this specific project we will be measuring the number of contacts made in order to discuss the results of the project with key decision makers who are in the field of psoriasis. We will also measure the number of commitments made for the next steps that are implemented and that are connected to promoting change and thereby delivering a better standard of psoriasis care.

In the long term we aim to measure the number of specific KPIs and to evaluate any evolution in daily clinical management and practice, and improve psoriasis care and quality of life for patients.

INNOVATIVE ELEMENTS OF THE PROJECT

This is an innovative, multi-stakeholder project based on social return on investment methodology. The methodology includes a direct patient voice. We have also implemented a survey to measure the social burden and have secured the participation of over 1150 patients. The project has been promoted by patient organisations and has secured the input and support of leading professionals in the field of healthcare management and geopolitical distribution.

COLLABORATIVE ELEMENTS OF THE PROJECT

Regular meetings were held between Acción Psoriasis, members of the scientific committee and Novartis to follow up and deploy the project. We have also implemented a publication communications plan to share the results from the project in order to increase impact. The collaborative project enjoys full transparency and will be communicated to the surveillance unit at Farmaindustria.



Steps

The campaign focused on the support and development of the Moscow-based Social-Psychological Centre for HIV positive people and those close to them. The main goal has been to provide social and psychological support to HIV-positive people, both newly-diagnosed and those with the experience of living with HIV, their relatives and others in their proximity, living in Moscow and the Moscow region.

The social support centre works 7 days a week, with services including: self-support groups for different social groups of people living with HIV; psychological therapeutic groups; groups on treatment adherence; round tables and discussion clubs with doctors/medical specialists, lawyers, social services and other specialists, dealing with issues that HIV-positive people face or may face; individual psychological counselling; individual peer-to-peer counselling; individual counselling by non-medical specialists; social support and/or case management for those in need; and medication delivery for people with limited transportation.

The campaign's key objectives are to: encourage HIV-positive people who don't turn to medical support, to attend AIDS-centres; increase information and the knowledge level among HIV-positive people concerning the disease, its therapy and care; increase treatment adherence in HIV-positive people who start or continue taking antiretroviral medicines; and create a "friendly and safe place" for HIV-positive people that is free of stigma.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

From a quantitative perspective, the projects succeeded in raising the number of people trained/counselled, overall awareness and the number of people who brought a friend to the centre. It also complied with the "key objectives" as set out above.

In terms of a qualitative assessment, feedback forms were prepared, distributed and then analysed by the centre's volunteers and further feedback information was sought within the area of social media.

We were able to verify that: a minimum 50 people a week made visits/calls to the centre; at least two ongoing self-support groups were established; and a minimum of 10 patient schools a year offered group counselling.

Success was also achieved with the dissemination of informational materials for HIV-positive people, relatives and doctors (100,000 brochures, flyers and leaflets a year delivered). Individual 'peer-to-peer' counselling recorded 880 consultations and a new partnership programme was set up with state/commercial institutions, allowing for a minimum of six new partnerships a year.

INNOVATIVE ELEMENTS OF THE PROJECT

The centre that was established under this project is unique due to the wide number of services it offers and the fact that it is the only one in Russia (there are very few in Europe). A key innovative aspect is the incorporation of this model into the list of AIDS-centre services for all vulnerable groups and groups at high risk of HIV, offering 100% tolerance and zero level of stigma.

COLLABORATIVE ELEMENTS OF THE PROJECT

Partners included: "Steps" Charity Foundation; the all-Russia public organisation "Community of People living with HIV"; and "Janssen", a pharmaceutical division of Johnson & Johnson. Janssen has long supported this programme as a social project, enjoying collaboration with two other non-commercial partners.

This partnership is an effective operational model that is ready, has already been copied across Russia and CIS countries and will be supported by the state in the future.



‘Together it’s easier’

In 2014, the International Diabetes Federation (IDF) stated that there are 387 million diabetes sufferers in the world, which means that 1 in every 12 people has the disease. The latest Report of the National Diabetes Observatory says that in Portugal diabetes affects some 13% of the population aged between 20-79 years – about one million people.

“Together it’s easier” is a national training programme for people with type 2 diabetes (DM2). It aims at improving lifestyles, in terms of nutrition and physical activity. It also employs dynamic methodologies, including motivational interviewing and a Change Behaviour Model, to improve quality of life and diabetes control.

The programme highlights the importance of active methods as a fundamental tool in group training, because the impact of sharing among peers allows for better performances, autonomy and wellbeing. It takes place over 6 months, with 6 educational sessions in groups of maximum 10 people. During the sessions, participants share their experiences and choices related to behaviour changes, providing interactive learning.

All sessions are addressed to people with DM2 and their relatives, guided by a facilitator and focused on motivation, physical activity, and healthy nutrition. At the end there is a final assessment to evaluate the evolution of the participants.

The pilot programme took place in 2011, in APDP, with 11 trainers, 21 groups, 150 patients, and after that the trainers have trained healthcare providers (HCPs) from healthcare units all over the country.

PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

The 2011 pilot programme involved 150 patients with T2DM. At the end of the programme, results showed statistically significant reductions relating to weight loss – 3.7kg (p-value < 0.01) and mean abdominal perimeter lost – 4cm (p-value < 0.05).

Participants filled in satisfaction questionnaires and answered the question: “What have I gained by participating in this course?” Results of the qualitative analysis included: positive statements concerning quality of life/wellbeing; an improvement in positive attitude/self-esteem; increased acceptance of disease state; acknowledgement of changes to lifestyle; and a boost to motivation.

INNOVATIVE ELEMENTS OF THE PROJECT

This project uses as educational models Motivational Interviewing and the Change Behaviour Model, allowing group facilitators (HCPs) to use strategies to help participants to improve their behaviour changes according to their own interests and needs. After the proven success of the 2011-2014 Programme, new features were added, namely a website with a database that allows the patients to see clinical data introduction by healthcare professionals trained all over the country.

Since 2015, the training programme for HCPs is web-based, in a b-learning format, including a previous e-learning course, plus one-day face-to-face training session.

COLLABORATIVE ELEMENTS OF THE PROJECT

A Scientific Commission was created in Portugal, with representatives from stakeholders, including: patients associations; scientific societies; the health ministry; healthcare professionals and the pharmaceutical industry. Together they outlined, discussed, monitored and approved all the trainers’ training programmes and patient-sessions’ content, implementation and results.

This project furthermore includes partnerships with national relevant institutions in the diabetes area, such as the oldest diabetes association in the world (APDP) and the Portuguese Society of Diabetology (SPD) and is accompanied by an unrestricted grant from Novartis Portugal - under the auspices of the National Diabetes Programme.



Urticaria 'In the First Person'

Chronic urticaria has a low prevalence and people affected by the disease are often misdiagnosed as having a non-controllable disease that could have a serious impact on their quality of life and their overall wellbeing. A national, Spanish group of entrepreneurial patients therefore created the PAG Association of People Affected by the Chronic Urticaria (AAUC) as a point of contact for patients looking for advice and support.

The project is built around the framework of a robust website, a call centre and a variety of social media channels, all aimed at facilitating contact. The blog has been designed with a view to being all-inclusive and to collect a range of views from patients, their relatives and doctors. The project as a whole is geared towards discussing: how UC affects social life or work; how the disease was diagnosed; the environment in which patients are living with the disease; and living with the disease throughout pregnancy and beyond.



PATIENT BENEFIT FROM THE PROJECT AND HOW IT WAS MEASURED

A major focus of the project was on allowing patients space in which to empathise with each other and share their experiences with those in a similar position. AAUC has come across patients who are suffering in isolation and who, as a result, may fall into depression, driven on by social rejection and misconceptions of the disease.

AAUC offers a window of hope to UC sufferers, allowing them to share their experiences "in the first person" as well as their concerns, in an environment of privacy and respect. AAUC has now reached over 1800 followers on Facebook, with a further Twitter following of almost 650.

It is not easy to measure the benefit in terms of figures, but the blog has reached an audience of around 4000 users and the project has proved that it offers a platform on which patients, their relatives and medical professionals can feel comfortable about sharing their issues in a way that has not been seen before.

INNOVATIVE ELEMENTS OF THE PROJECT

It is the comprehensive participation of urticaria patients, their relatives and medical professionals in a way that has never before been seen, that highlights the innovative nature of this project. The various sections of the AAUC project (website, blog, forum etc.) are fast-growing and allow for an effective diffusion of the AAUC mission objectives.

COLLABORATIVE ELEMENTS OF THE PROJECT

The collaborative nature of the project, which focused on co-operation between patients, their relatives and doctors, was well supported by a grant to the AAUC from Novartis, which has published its support on www.novatis.es/sobre-novartis/Novartis-con-lospacientes.

The collaboration was supported by the Code of Practice Surveillance Unit of the national pharmaceutical industry association, Farmaindustria.

Read more about AAUC here:
www.urticariacronica.org/ Urticaria,
In the First Person project page:
enprimerapersona.urticariacronica.org/

Our project partners and contributors



