



Best practices on Chronic Patients and Organizations' Empowerment

Brussels, May 12-13 / 2014



INTRODUCTION

Chronic illnesses, which affect more than 80% of people over 65, are the primary cause of mortality in Europe (86% of all deaths). 70% to 80% of healthcare costs are spent on chronic diseases, which corresponds to 700 billion in the European Union, and this number is expected to increase in the coming years (Reflection Process on Chronic Diseases, Interim Report, 2012).

As mentioned in the EU Health Work Programme 2013: "Patient empowerment is a core value of a modern patient-centred health system as advocated by the Council conclusions on common values and principles in European Union health systems (2006/C 146/01). However, the concept of patient empowerment is not clear, and patient empowerment is often perceived only as the use of eHealth tools. There are also concerns that an empowered patient may represent an increased cost for the health system."

But empowered patients are a resource and not a cost!

The essential role of citizens' organisations in the empowerment of individual patients with chronic diseases and their families is often underestimated. Patients with chronic diseases do not only have to cope with the medical aspects of their condition, but also with the social, relational and psychological impacts of their disease, which often have as much weight as the disease itself on the quality of their lives. The added-value of citizens' organisations consists in a global approach to patient empowerment, supporting, informing and training patients to help them face the many difficulties of their daily lives. This global approach is necessary to make patients strong enough to collaborate with their doctors on an equal footing, helping them personalize the care, participating actively in the management of their disease, and using health services more effectively.

On one hand, there is a general concern about the increased costs that shall derive from the pressure exercised by associations of patient with chronic diseases on health institutions, because their main objective is supposed to be increased access to and better reimbursement of innovative and expensive treatments and drugs. On the other hand, they play a decisive role in the development of a modern patient-centred health system. Therefore, the empowerment of patient organizations should be considered as an added value, because they become actual partners in the health policy, sharing with the institutions the responsibility of finding the best balance between the interest of patients and the sustainability of the system. This shall be achieved through the creation of networks and alliances, which allow the identification of common objectives and goals. This includes the development of a global and long-term perspective, which goes beyond the single chronic diseases and reflects the general interest of patients.

Patient empowerment does therefore have two different but complementary dimensions:

1. Improvement of a person's capabilities to effectively self-manage his/her chronic disease;
2. Enhancement of patient groups' capacities to participate efficiently in health policies.

In both cases, citizens' organisations – which include self-help groups, associations of patients with a chronic disease, networks and umbrella organisations - play an essential role. Patients' org. educate and support individual patients and their families, while networks and umbrella organizations contribute to build their capacities to participate in the policy-making.

Active Citizenship Network (ACN) has decided to gather and share during the 8th celebration of the European Patients' Rights Day 2014 (dedicated to: "The role of citizens' organisations in the empowerment of patients with chronic diseases") the following best practices (BP) of different citizens and patients' organisations, coming from a wide range of EU countries on:

-empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.

-empowerment of patients' organisations by the creation of national or European networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.

The BP come from 17 different Countries (Belgium; Bulgaria; Cyprus; Finland; France; Germany; Georgia; Italy; Latvia; Macedonia; Malta; Netherlands; Portugal, Romania; Spain; Switzerland; United Kingdom) and the sources are:

-experiences brought by the members of the Associations involved in the ACN Network and in the Organization involved in the Conference of the 8th European Patients' Rights Day 2014.

-some of the 40 BP "active involvement of active ageing citizens in the health policy" collected in the framework of 6th EPRD (2012) (www.activecitizenship.net/files/take_action/active_ageing_eu_policy.pdf).

17 of 28 BPs concern the **empowerment of individual patients**, 3 of 28 concern **the empowerment of patients' organisations**, 8 of 28 relate to both the aspects analyzed.

The kind of subjects involved in the BPs are, of course, civic organizations but most of them includes the participation/promotion by public institutions, universities, health insurance, international networks, university hospitals, scientific societies, foundations, industries etc.

Best practice N.1

CONTACT DETAILS

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Short description of the organization/public institution

GUDEAS is the MA representing people with diabetes and HCPs from Georgia. GUDEAS is IDF full member since 1994. Education of people with diabetes and HCPs is one of the main priorities of the organization. Since 2007 , I was the member of the IDF-E Board and as the board member participated in the creation of the European CMap Education Tools .

DESCRIPTION

Title of the BP.	
Implementation of the CMap education Tools in the EECs and training of Facilitators. Conversation Maps	
Policy Field:	<input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.
	<input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice	<input checked="" type="checkbox"/> Public Institution(s) National Centre for Diabetes Research <input checked="" type="checkbox"/> Civic Organization(s)
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	<p>Georgian Union of Diabetes and Endocrine Associations; International Diabetes Associations of the Ukraine, Charity Organization for Disabled and People with Diabetes. UMID- Tashkent, Uzbekistan, IDF-Europe</p> <p>X Other Subjects involved</p> <p>World Welfare Foundation, Georgia; Red Cross Georgia.</p>
Did you directly experience the BP above mentioned?	X Yes
Location	Tbilisi, Georgia; Kiev, the Ukraine.
Term	2010 -2014
Objectives	To implement CMap Education Tool in EECs and to train Facilitators to carry out patient education
Outcomes Impact on participants	<p>190 HCPs from EECs were trained, 190 CMap Education Tools were handed out to trained Facilitators. It means that around 90 Education Centres/Diabetes Schools are using CMap education Tool in EECs.</p> <p>CMap Education %Tools are also used for training of nurses, medical students and interns, as well as PCDs in diabetes (at the moment in Georgia)</p>
Resources	The 1-st 2010 training for EECs HCPs and trainings in the Ukraine were carried out under the financial support of Eli Lilly (one of the 3 partners of the CMap Tool Program), trainings in Tbilisi, Georgia were financed in the framework of the WDF Grants. Trainings were prepared by 2 certified Expert Trainers based on the slides and presentations of Healthy Interactions, a Canadian company, that produces CMap Tools.. ALL trainings are carried out by 2 Expert Trainers.

ANALYSIS

Development of the BP	<p>It was the IDF-E program. Under the support of the Office and the Board of IDF-E and Barbara Eihorst from H3althy Interactions contacts with the MAs from EECs were established and the first group of HCPs were selected. At first a 2-day training curriculum (training from 9am till 6pm) was written and presentations and small group activities (metaploans, role-plays, working in couples and triples)) were prepared (E.Shelestovq, ET, and Liana Tsutskiridze, ET).In 2012 and 2013 3 initial trainings were carried out in the Ukraine. After that, a 1-day training was prepared. Main attention during the trainings is paid to small group activities and only 2hrs/a day are presentations. In 2013 a 2-day training was carried out in Georgia. Repeated 1-day trainings will be carried out in Georgia and the Ukraine in 2014 (dates to be fixed). Together with IDF we are working on the assessment phase.</p> <p>Implementation of the CMap Education Tools: CMap Education Tool is an</p>
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	<p>excellent educational tool for carrying out education in the countries, regions with the limited financial and human resources. The idea to create CMap Education Tool for European Region of IDF was aimed exactly for the Eastern European Countries, where patient education is being carried out for more than 20 years, though there is always lack of resources to print education materials for people with diabetes. The set makes it easy to carry out education in any place, for any population even if people do not or cannot read.</p> <p>Training of the Facilitators. A 2-stage training program was prepared (1-st stage – a 2-day initial training, min. in 6 months - 2-nd, 1-day repeated training). First training for 21 HCPs from 7 Eastern European countries (EECs) – Armenia, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Ukraine and Uzbekistan was carried out in 2010.</p> <p>In 2012 in close co-operation with the International Diabetes Association of the Ukraine training of Facilitators was initiated in the Ukraine. In 2012-2013 around 140 HCPs from various regions of the country were trained and now are using CMap Education Tool in their everyday practice. The program is in progress.</p> <p>In the framework of the WDF Project Facilitators for 9 Centres located in 3 various regions of Georgia were trained. It is planned to train more Facilitators in the framework of another WDF Project.</p> <p>As a result of the discussions with UMID-Tashkent, a Charity Organisation for disabled and people with diabetes, it was decided that in 2014-2015 identical training (i. in the framework of the Project that has started in Uzbekistan Facilitators for 6 pilot regions will be trained.</p>
Did you meet any obstacles?	<p><input checked="" type="checkbox"/> Yes:</p> <p>At the beginning and with the dates of the Ukraine trainings - operational obstacles, sponsoring company (Moscow Head Office for the Eastern European region) blocked our activities, It took time to settle everything down..</p> <p>Support of Healtyi,, IDF-E and IDF-GI, discussions with Eli Lilly,US, co-operation with National MAs. And their strong support for the program.</p>
Factors enabling the process	Everything mentioned in the box above. Especially strong support we received.

EVALUATION

Reproducibility:	Is it possible to reproduce and implement the BP in other situations and places
Innovativeness:	Innovative solution: implementation of a new, effective, interactive method of patient education that does not require much finances.
Added value:	Using the BP it was helpful instead in approaching needs in already experienced way in several EECs
Appropriateness:	The BP enables an efficient management of the needs in training the

	trainers and practicing interactive patient education that is very important in the highlight of the Global NCD preventive strategies.
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Best practice N.2

CONTACT DETAILS

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Short description of the organization/public institution

The Belgian Foundation Against Cancer (Fondation Contre le Cancer/Stichting tegen Kanker) is the national cancer organization in Belgium, covering both the Flemish (Dutch speaking) and the Walloon (French speaking) side and whenever needed the German speaking part (minority group in Belgium). The main focus of the Belgian Foundation Against Cancer is progress in the fight against cancer. We, firstly, invest in scientific cancer research. We are in fact the largest philanthropic funding organization for oncological research in Belgium. Secondly, the Belgian Foundation Against Cancer is involved in the organization of different practical projects in the field (ex. Relay for Life, beauty treatments for patients, physical activity for patients, telephone helpline to stop smoking, psychological coaching, financial aid...) to help patients and their relatives in their daily lives. Last but not least, we constantly aim at providing valid, up to date and above all understandable information to patients on medical, prevention, economic and psychosocial topics. We are currently developing a Cancer Information Service to optimize this process even further. This all in order for patients and their families to be able to get access to the best possible care and to live a healthier life before, during and after cancer.

DESCRIPTION

Title of the BP	
Social Guide: Cancer in the Everyday Life (60 practical information cards)	
Policy Field:	<input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.
	<input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) <input type="checkbox"/> Civic Organization(s) <input checked="" type="checkbox"/> Other Subjects involved social workers, patients and relatives
Location	Belgium (available in Flanders, Brussels and Wallonia)
Term	Published 2014 in printed form and online form (ongoing) (Dutch and French)
Objectives	To offer a systematic, comprehensive and above all manageable overview of all the existing benefits and services which are available for cancer patients in Belgium, we developed a social guide consisting of 60 information cards which can easily be consulted. The cards contain information and tips and tricks on the health insurance system, administration within the hospital setting, domestic help, tax benefits, mobility problems, education, transportation issues, palliative care,... information which is necessary but often scattered and hard to find. The printed version was developed for social workers and the online format was developed for patients and relatives.
Outcomes Impact on participants	The social guide gathers all existing information which is otherwise scattered and not always easy to find for social workers, patients and relatives. The guide was developed to facilitate the empowerment of patients by informing them of their rights and the benefits or services which they can apply for.
Resources	The social guide was funded by the Belgian Foundation Against Cancer and developed by our social department in close collaboration with patients and social workers. The guide was distributed in printed form to our network of social workers and is available for online consultation/download at our site.

ANALYSIS

Development of the BP	Social workers and patients informed us about the need for structuring information on rights and benefits for cancer patients. In collaboration with social workers and patients we developed a tool (print + online) to try
Did you meet any obstacles?	<input checked="" type="checkbox"/> Yes: It soon became clear that legislation and benefits almost constantly change, this especially in the complex Belgian context. The printed version was therefore almost immediately out of date. Therefore we also created an online tool which is easily updatable at minimal cost and which can be downloaded in a print friendly format.

EVALUATION

Reproducibility:	Yes, the guide (print + online) could be reproduced in other countries and for other pathologies.
Innovativeness:	The guide aids at disseminating information which should in fact already be known by all social workers, patients and relatives if they want to be able to have access the best possible care and services (practically and financially) but reality in the field demonstrated that this is, more often than not, not the case. In this respect the guide can be considered an innovative tool.
Added value:	We experienced that social workers and patients find it hard to know all existing benefits and services. The information is often scattered and it is not always clearly mentioned that cancer patients can apply. The guide gathers all information, clearly indicates the conditions in which cancer patients can apply for specific benefits and formulates tips and tricks which warn people for certain problems which may occur during the illness. Given the fact that the guide is available in print and in an online version (in which specific cards can be printed separately), it is easy to work with and available for a maximum of people.
Appropriateness:	Yes, we received a positive response from the social workers who consider it to be a helpful tool. The challenge will be to keep the printed version up to date or to promote consulting the online version.

Best practice N.3

CONTACT DETAILS

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Short description of the organization/public institution

IDF Europe is the European chapter of the International Diabetes Federation (IDF). We are umbrella organization representing 69 diabetes organizations in 47 countries across Europe. We are a diverse and inclusive multicultural network of national diabetes associations, representing both people living with diabetes and healthcare professionals.

DESCRIPTION

Title of the BP	
National Diabetes Youth Camps	
Policy Field:	<p><input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p><input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<p><input checked="" type="checkbox"/> Civic Organization(s). National, regional and local diabetes associations (NGOs/ patient groups)</p>
Did you directly experience the BP above mentioned?	<p>x No, the BP was led by: Numerous patient organizations across Europe including: the Cyprus Diabetes Association, Portuguese diabetes association, Serbian Diabetes</p>

	Association etc.
Location	Countries all across Europe; Cyprus, Portugal, Serbia, Belgium, Italy, Ukraine, Lithuania to name a few.
Term	Usually during summer time; ranging from one day, to a weekend, to 1-2 weeks.
Objectives	The objectives of these youth camps are to help young children, adolescents (type I) and adults (type II) learn how to manage their diabetes by learning for example how to do carbohydrate counting, how to check their blood sugar levels, when to administer insulin etc. diabetes education is a continuous process and so these camps are extremely valuable to those living with diabetes in order to improve the management and control of their diabetes.
Outcomes Impact on participants	Improved diabetes management and control, better nutrition habits, physical activity uptake etc.
Resources	Group leaders, instructors, medical team including a diabetologist, diabetes specialist nurses, diabetes treatment medicines and devices (although participants obviously bring their own regimens to the camp). Good facilities to host the camp and various activities, relevant equipment, financial resources to fund the camps.

ANALYSIS

Development of the BP	Sport activities, games, workshops etc. National, regional, local diabetes associations, volunteers, parents do all of the work in preparing the camps for the children/ adults.
Factors enabling the process	Teamwork, friendship

EVALUATION

Reproducibility:	Yes, take up and adapt and implement
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Best practice N.4

CONTACT DETAILS

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Short description of the organization/public institution

The Belgian Foundation Against Cancer (Fondation Contre le Cancer/Stichting tegen Kanker) is the national cancer organization in Belgium, covering both the Flemish (Dutch speaking) and the Walloon (French speaking) side and whenever needed the German speaking part (minority group in Belgium). The main focus of the Belgian Foundation Against Cancer is progress in the fight against cancer. We, firstly, invest in scientific cancer research. We are in fact the largest philanthropic funding organization for oncological research in Belgium. Secondly, the Belgian Foundation Against Cancer is involved in the organization of different practical projects in the field (ex. Relay for Life, beauty treatments for patients, physical activity for patients, telephone helpline to stop smoking, psychological coaching, financial aid, ...) to help patients and their relatives in their daily lives. Last but not least, we constantly aim at providing valid, up to date and above all understandable information to patients on medical, prevention, economic and psychosocial topics. We are currently developing a Cancer Information Service to optimize this process even further. This all in order for patients and their families to be able to get access to the best possible care and to live a healthier life before, during and after cancer.

DESCRIPTION

Title of the BP	
Policy Field:	<p><input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p><input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.</p> <p>For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) <input type="checkbox"/> Civic Organization(s) <input checked="" type="checkbox"/> Other Subjects involved Several physical therapists, sport coaches, volunteers, ...
Location	Belgium
Term	Ongoing project (started in 2006)
Objectives	Raviva/ Rekanto is the physical activity program of the Belgian Foundation Against Cancer. Participation in physical activity and recreational sports is one of the first things which patients drop when being confronted with the disease, although it has been demonstrated by research that it has several positive effects (physical, mental, social benefits and even effects on recurrence and survival). Originally developed to address fatigue related to a cancer treatment, the program has further developed into an important physical and psychosocial activity for cancer patients in Belgium which is aimed at reintegration and rehabilitation. Trough participation in specially adapted physical activities, ranging from soft (yoga, tai chi,...) to intensive sports (aqua gym, fitness, ...), patients are coached and supported to take on a more active, confident position in life in general. Patients can choose to participate in group or solo activities in different regions in the country. The activities are developed and coached by physical experts who have all also received a special training from the Belgian Foundation Against Cancer which prepares them to deal with the specific oncological setting (ex. physical, social and psychological limitations).
Outcomes Impact on participants	Different studies have demonstrated several positive effects of physical activity and Raviva/Rekanto was developed with these studies in mind. Positive psychosocial effects in light of overall quality of life where mentioned by participants. The Belgian Foundation Against Cancer has been the first to organise physical activities for cancer patients in Belgium. Only recently the Belgian government has started to investigate how to implement oncorevalidation as a process by organizing pilot projects within selected hospitals. As a foundation we continue to monitor this development and try to act as complementary stakeholders.
Resources	The Belgian Foundation Against Cancer has funded this project. The coaches work as volunteers and the practical costs are covered by the Foundation. Now we are also looking into collaborations with hospitals, fitness centres and sport clubs. As the government becomes more involved in the oncorevalidation project we will have to monitor how we can be of use and provide added value.

ANALYSIS

Development of the BP	The Belgian Foundation Against Cancer firstly developed a pilot project in Flanders and then in Wallonia. Now Raviva/Rekanto is one of the strong projects of the Foundation covering the whole country and its popularity is still growing.
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<p>Did you meet any obstacles?</p>	<p>■ Yes:</p> <p>Participants are very content with the program, which is available to them free of cost for 1 year. However, most participants want to participate more than 1 year as they develop a strong group feeling. For financial and philosophical reasons (the aim is reintegration in normal life as fast as possible), this is however not possible. We also see that the vast majority of participants are breast cancer patients and woman, a fact which has created a stereotype amongst patients and health professionals: they believe that Raviva/Rekanto exists exclusively for breast cancer patients and women. We are now trying to counter this stereotype with new forms of communication.</p>
<p>Factors enabling the process</p>	<p>Cancer patient's general need to be able to take the first step towards an active life after a life changing diagnosis in a safe and understanding environment.</p>

EVALUATION

<p>Reproducibility:</p>	<p>The benefits of physical activity within a context of chronic disease are well demonstrated. The Raviva/Rekanto project can be reproduced in another context. A multi-pathological context could also have benefits as this could possibly facilitate rehabilitation in the wider, normal population in which chronically ill people are more and more present.</p>
<p>Innovativeness:</p>	<p>At the start Raviva/Rekanto was the only existing physical activity program for cancer patients in Belgium.</p>
<p>Added value:</p>	<p>The project demands continuous evaluation and adjustment. Our initial intention was tackling fatigue, but we have come to realize that the program does more than only that. Therefore, we have made some alterations to the program on to go and will continue to do so.</p>
<p>Appropriateness:</p>	<p>It is hard to convince people who are tired and ill that being physically active will make them feel better. However, people who start the program are motivated to be active and look back at their original participation as a liberating thing (ex. being too self-conscious after treatment to go to a regular swimming-pool, taking the first step to be active in public again).</p>

Best practice N.5

CONTACT DETAILS

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Short description of the organization/public institution

These organizations are registered in the public interest for the protection of patient rights in Bulgaria. Members of these organizations are patients with chronic diseases. I was a patient representative in the National Health Insurance Fund. We participate in many workshops with the Ministry of Health and the Committee of Health, Bulgarian Parliament.

DESCRIPTION

Title of the BP	
Round table for patients with chronic diseases	
Policy Field:	<p><input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p><input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<p><input checked="" type="checkbox"/> Public Institution(s)</p> <p>Ministry of Health Health Committee University Hospital</p> <p><input checked="" type="checkbox"/> Civic Organization(s)</p> <p>Other patient groups of patients with chronic diseases</p>
Location	Sofia, Bulgaria
Term	May 2013
Objectives	Round Table for patients with chronic diseases presented different problems. We discussed the access to medicines, treatment in hospital, Organ Donation and Transplantation.
Outcomes Impact on participants	The benefits are: the institutions heard our problems and later they offered solutions. Patients from the whole country were able to discuss their problems. Patients need emotional and psychological support.
Resources	The place for the roundtable was provided by University hospital. Patients themselves organized the event

ANALYSIS

Development of the BP	A new roundtable in October 2014
Factors enabling the process	help of the media

EVALUATION

Reproducibility:	Yes
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Best practice N.6

CONTACT DETAILS

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DESCRIPTION

Title of the BP	
Chance for life	
Policy Field:	<input type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.
	<input checked="" type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice	<p><input checked="" type="checkbox"/> Public Institution(s)</p> <p>Ministry of Labour and Social Policy; Ministry of Health; Bulgarian Healthcare Commission; Expert National Medical Commission; Labour Expert Medical Commission; Territorial Expert Medical Commission; Bulgarian National Council of People with Disabilities;</p> <p><input checked="" type="checkbox"/> Civic Organization(s)</p> <p>Association of Women with Cancer and Adherents; Bulgarian Cancer Association; Confederation for Health Protection</p> <p><input type="checkbox"/> Other Subjects involved</p>
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Location	Varna, Bulgaria
Term	July 2007 – May 2010
Objectives	<p>After the fifth year of their disease, cancer patients in remission, in Bulgaria had no right to a disability pension according to the Labour Expert Medical Commission (LEMC) regulation. A period of five years is not enough to achieve complete cure (not counting the cases where the disease had complications). So the goal of our initiative was to change the law in force and give the right to the cancer patients to be reevaluated for occupational disability according to the requirements of LEMC. Most “cured” cancer patients had difficulties finding a job, due to their diagnose and a very high percentage were left unemployed with no income, hence many could not pay their health insurance, which means inability to obtain proper health care while in remission. Moreover, the psychological aspect of this unfortunate situation had huge impact with often physical consequences. We started our initiative with the aim to change the reality for those people and bring hope where it was highly needed</p>
Outcomes Impact on participants	<p>The changes, concerning the disability percentage of patients with cancer are reflected in the new ordinance on medical expertise, which was published in the State Gazette - 36 of May 14, 2010. From 17 May 2010, all cancer patients were entitled to undergo LEMC examination after the fifth year of their illness and if they do not have other concomitant medical problems to be acknowledged 50 degree of permanent disability. This fully covered our demands and is a successful ending of the initiation.</p> <p>This voluntary project managed to present the activities of patient organizations for people with cancer outside the capital and helped out to emerge us from the isolation we were in. Moreover, fighting for our cause helped us enormously to gain and improve our experience in the contacts with both - media and institutions. For some of our volunteers it became the very time to appear at the public stage. Having been so active was not let unnoticed. Public figures and institutions no longer neglect us, they are now willing to react faster to questions, requests and other issues when approached. We believe this to be a huge advantage for us and the whole society, not only now but also for the future. This was proved by very recent problems which we had and were solved almost immediately due to our experience to recognize the issue, know how to deal with it, know whom to turn to and of course, the will to be heard from the other side.</p>
Resources	<p>The initiation and implementation of the initiation was supported by 73 volunteers. The main costs - technical support by the subscription, postage and telephone charges were all covered by donors’ contributions. The trips to Sofia were all personally paid by each one of us. The only financial support we received was at the National Meeting at 11.10.2007 financed by the Municipality of Sofia, which took over the costs of all 128 participants for food, accommodation and rentals of halls.</p>

ANALYSIS

<p>Development of the BP</p>	<p>Our initiative was launched with an official letter to the Ministry of Labour and Social Policy and the Ministry of Health; publicity was given by press conferences, participations in electronic and print media. A subscription was started and spread all over the country. In 2007 we initiated a National Meeting – roundtable, where the subscription was officially given to the representatives of the institutions. Members of the Parliamentary Health Commission were approached by letters, meetings were held with them and with the President of the National Assembly. In October 2008, we participated in a roundtable, with first item on the agenda - occupational rehabilitation of cancer patients. There followed contacts with letters, meetings and discussions with members of commissions. In 2009 a reminder of our cause was sent to the institutions in Bulgaria and in 2010 an informal meeting was held with the Prime Minister Mr. Borisov. Our voice was heard, the State policy changed!</p>
<p>Did you meet any obstacles?</p>	<p>The lack of funding for this initiative was a huge obstacle, because we could not afford to be frequently and for a long period of time close to the institutions that are located in the capital. The communication with them was difficult and sometimes practically impossible. Despite the many calls for meetings we made, it was hard to always ensure their presence. We cannot ignore the difficulties encountered in collecting signatures for our cause. Many cancer patients did not dare to put down their names out of fear or shame it will be known they are sick and preferred to remain anonymous. Due to all that, the biggest obstacle turned out to be the extensive period of time it took us to bring the initiation to a successful ending.</p>
<p>Factors enabling the process</p>	<p>Due to the cooperation with the media, the community of cancer patients took its place among our fellow citizens and got sympathy and support. Only until recently, cancer was a word not spoken out loud. The publicity made it possible for our voice to be heard, we were no longer just an official letter but people with faces. In the very beginning the cause was supported by the Municipality of Sofia and the Confederation for Health Protection which was a huge recognition for us.</p>

EVALUATION

<p>Reproducibility:</p>	<p>The way we all worked together is not specific for our initiative. It can easily be extended to other frameworks of the public space, different causes with other dimensions and goals, not only in our country, but also abroad.</p>
<p>Innovativeness:</p>	<p>The initiative succeeded to persuade the institutions to make highly needed changes in the existing regulation concerning the LEMC decisions for cancer patients. A solution, to a very serious and in some cases even lifesaving problem, was found.</p>
<p>Added value:</p>	<p>The continuous and close cooperation with the media and other NGOs created a relationship of trust, which helped not only to give publicity to the problem, but also to engage as many people as possible.</p>

Appropriateness:	The establishment of public relations with the institutions and their optimization contributed enormously to the problems of the cancer patients be solved in most effectively, competent and in our eyes appropriate way.
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OTHER INFORMATIONS
http://varna.bgcancer.org/english/chanceforlife.html

Best practice N.7

CONTACT DETAILS

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Short description of the organization/public institution

Universal Patients' Rights Association (UPRA) is founded in 2002 with the initiatives of the Platform for Patients' Rights (including 14 patient organizations and the Cyprus Turkish Medical Association). Board members are elected people and they are the representatives of those Associations. So, UPRA is not a member based association, as UPRA accepts all the members of those supportive associations as its natural members. UPRA recognise patients' rights and encourage the use of patient rights within society which are determined under European Charter of Patients' Rights, supports patients and their relatives in the case of violation of their rights, informs and raises awareness within society, involves in policy making and implementation of the health policies, organizes advocacy and awareness raising campaigns, ensures cooperation and solidarity with the public, private and civil sector. Currently, UPRA is putting its efforts for supporting "the implementation process of the results of the Health Workshop" which was led by the Health Ministry together with the other civil society organizations that they work at the health field. Also UPRA has been conducting a legislative campaign for acceptance of the European Charter of Patients' Rights.

DESCRIPTION

Title of the BP "My Journey Through Diabetes"

Policy Field:

X empowerment of individual patients: information, support and capacity-building of people with diabetes and as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.

X empowerment of patients' organisations by the creation of Cyprus Turkish Diabetes Ass., Platform for Patients' Rights, Universal Patients' Rights Ass., Platform for Smokefree Island (conducted legal campaigning for smoking regulation between 2007-2008), which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.

For example: courses in self-management, integration of hospital/community

	services, involvement of chronic patient associations in the organization of services, etc.
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Actors of the Best Practice	<p><input checked="" type="checkbox"/> Public Institution(s)</p> <p>North Cyprus Health Authorities, Department for Social Security under the Ministry of Internal Relations, members of Turkish Cypriot Parliament,</p> <p><input checked="" type="checkbox"/> Civic Organization(s)</p> <p>Non -profit, non- governmental CSOs such as Dietitians Ass, Nurses Ass. Medical Ass., patient organizations such as Heart Association</p> <p><input checked="" type="checkbox"/> Other Subjects involved</p> <p>National Media, Private Sector, Municipalities, Primary and Intermediate Schools, Universities, Employers Associations, Teachers Union, Police Academy, Public..</p>
Did you directly experience the BP above mentioned?	<input checked="" type="checkbox"/> Yes
Location	North part of Cyprus
Term	November 1994 –March 2010
Objectives	Empowering people with diabetes and their relatives, raising awareness, advocacy and lobbying, networking, policy involvement.
Outcomes Impact on participants	<p>Patients and their relatives increased the level of knowledge and skills in diabetes management. Patients and their Relatives changed their negative attitudes to positive regarding living with diabetes. Less prejudism through people with diabetes. Increased public awareness in recognising the symptoms of diabetes and prevention of diabetes through lifestyle changes. Increased benefits for people with diabetes in getting free drugs and evidence based treatment for free of charge.</p> <p>Increased quality of life for people with diabetes and their relatives..</p> <p>Politicians and decision makers in the north part of Cyprus recognised the importance of the fighting for diabetes after the results of the public survey showing %13 prevalence of diabetes in the adult population and 35% obesity.. (Health Ministry conducted “scientific survey in diabetes prevalence in North Cyprus” twice at those period.) According those results, the new health policies and initiatives came on.</p>
Resources	<p>*Having skills and networking ability of the local health professional (Doctors, nurses, dietitians etc.) for diabetes educations that provided, having support of the diabetes civil society organizations of Turkey for the access to scientific info and exchanging experiences.</p> <p>*Having funding from UNDP for children diabetes camp, funding from a Bank for conducting the childhood obesity survey in North Cyprus. Funding form Nicosia Municipal Authority to building and refurbishing a Diabetes Center.</p> <p>*International Medical Firms operating in diabetes fields in Turkey provided free medical devices and training materials.</p> <p>*Teachers Union provided funding for printing a guide book called</p>

	<p>"Children with diabetes at school" for teachers and school staff.</p> <p>* A Public Bank provided funding for a Childhood Obesity North Cyprus Survey .</p> <p>*Ministry of Health provided room at the biggest state hospital for Podiatry Clinic and Bank of Teachers Union provided funding for refurbishment of the room and for the medical devices.</p> <p>*Members supported our fundraising events.</p>
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ANALYSIS

Development of the BP	<p>*1994-First "Diabetes" Symposium organized by Ass. for public and the media.</p> <p>*1995- Association campaigned for "free Insulin" for all citizens and campaign was succesfull.</p> <p>*1996-By the initiative of Cyprus Turkish Diabetes Association, first diabetes survey in the country conducted by the Ministry of Health to see where we are.</p> <p>*1996-First time Diabetes Camp for Children with diabetes organized by Ass. and became annual event.</p> <p>*1996-Symposium called"Attention Diabetes" organized by Ass. , for launching survey results, raising awareness and national diabetes policy implementation.</p> <p>1997- Advocacy and lobbying conducted; Glukometer and strips became free of charge for people with Type 1 diabetes, 80% reimbursement in strips for the people with Type 2 diabetes.</p> <p>1997- First "Living with Diabetes" Meetings conducted in the rural areas in the five regions.</p> <p>1997- Association started "diabetes trainings" for the relatives of the children with diabetes, those trainings repeated annually.</p> <p>2000-First time "Diabetes Camp" organized by Ass. for the people with diabetes.</p> <p>2005-First country survey in childhood obesity conducted by the Ass.</p> <p>2007-2009"EU funded "childhood obesity- lifestyle changing" project conducted by the Ass. collaborating with the Dietition Association, Health and Education Ministries.</p> <p>2009-First Podiatry Clinic opened in North Cyprus by the Association.</p>
Did you meet any obstacles?	<p>x Yes:</p> <p>Lack of time, finance, human resources at the beginning.</p> <p>Personal obstacle was my increased responsibilities on top of my professional and home life.</p> <p>Lack of spirit of volunteerism.</p> <p>Ignorance</p> <p>Attitude of "public has no power to change the situation"</p>
Factors enabling the process	<p>Diabetes has high prevalence in Turkish Cypriot population. Therefore, it was an advantage when searching for new supporters, allies, sponsors. Plus president had diabetes, many politicians and ministers had diabetes.</p>

EVALUATION

Reproducibility:	YES
Innovativeness:	Yes, specially people with type I diabetes started to use new medical technologies. Health Ministry decided not to use some medicines.(such as animal insulin and some oral anti diabetic tablets). Insulin syringes turned to insulin pens. Type 1 diabetes people has free access to Insulin Pumps if advised by the endocrinologist. The tradition of diabetes management turned to patient oriented team work. Innovation brought increased quality of life to people with diabetes and their relatives.

OTHER INFORMATIONS

As a mother of a son with diabetes and a single parent woman, my “Best Practice” in my whole life is the unexpected but incredible journey through diabetes. My son had diabetes at the age of 5 in 1992. At that time, I was a working mother with no civil society experience. Managing diabetes was very, very difficult for me because of lack of knowledge, lack of diabetes materials and lack of health professionals. Then, I met mothers of the children with diabetes and people with diabetes. We were 37 of us, got together and established Cyprus Turkish Diabetes Association. I was the leader of the Association for 16 years. At this period, I met many people and had new friends for life, having learned so many new things, practiced many experiences, learned team working and increased my skills through civil society capacity building trainings (such as Self Managing Leadership, Advocacy and Lobbying, Networking, Volunteer Management, Strategic Planning etc.) funded by European Bodies. Apart from this, the most important part of those years, I have learned how to change disasters to opportunities in my life. Since then, I am an activist for civil rights.

Best practice N.8

CONTACT DETAILS

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DESCRIPTION

Title of the BP	
Experience-Based (EB) Education Initiative	
Policy Field:	<p>X <u>empowerment of individual patients</u>: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p>X <u>empowerment of patients' organisations</u> by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<p>X Public Institution(s) The Ministry of Education, the Finnish National Board of Education, 24 Teaching Units (TU) of the social and health care sector</p> <p>X Civic Organization(s) 25 Civic Organisations, stakeholders of various disease and handicap groups</p> <p>X Other Subjects involved 250 Experience-Based (EB) educators from the participating organizations</p>
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Location	A nationwide initiative implemented at localities providing social and health care education. The localities currently participating are Helsinki, Turku, Pori, Vaasa, Kemi-Tornio, Oulu, Kuopio, Joensuu and Lappeenranta. Finland
Term	2008 - 2011
Objectives	<p>Patients should be heard when designing, implementing and evaluating health care services. Experience-Based educators are chronic patients, disabled persons, or their family members, trained as educators at schools of the social and health care sector. They have years of experience of coping with the condition. During lessons, EB educators share their experiences or otherwise participate in teaching. EB education provides an opportunity to learn about living with a disorder or disability and about things a severe condition or disability brings to a family member's life. Future professionals will gain a deeper understanding of their work, as EB knowledge complements scientific and clinical knowledge, bringing a human and holistic perspective to the daily lives of patients/disabled persons. The goal of EB Education Initiative is to establish EB education as part of vocational education in the social and health care sector and to create a co-operation model for implementing EB education.</p>
Outcomes Impact on participants	<p>A standard for training EB educators has been created during the initiative and 125 EB educators have been trained. The project website has e.g. a nationwide EB educator database for teachers with information of all EB educators. The Ministry of Education has appointed a contact person and TU's have been approached for launching the initiative. There is action at nine localities and it is being launched at one locality. The aim is to involve key units in the initiative by the end of 2011.</p> <p>Experience-Based education has had many positive effects. Firstly, a meaningful form of activity has been created for people suffering from chronic conditions, disable people, and their family members in organizations in which their Experience-Based expertise is put to a new influential use. Teaching Units have acquired a new method to supplement teaching. A new, active mode of co-operation has emerged between organizations and teaching units, giving rise to other co-operation projects as well. For students Experience-Based knowledge has provided a new perspective to meanings of illness / disability. Knowledge provided by an EB educator has supplemented, and made tangible, the knowledge acquired from other teaching.</p>
Resources	<p>The initiative has funding from RAY allowances to organizations of the social and health care sector. The initiative has had a part-time project manager, secretary and assistant. The initiative has been steered by a management team of organizations' representatives, and co-operation has been run by a network of organizations' contact persons. Regional steering groups have been responsible for EB education in TU's. The groups have had representatives from TU's, organizations and EB educators.</p>

ANALYSIS

<p>Development of the BP</p>	<p>Patients have always been involved in the training of health care professionals, if sporadically. The goal of the EB educator initiative is a systematic use of Experience-Based educators meeting uniform competence criteria. Negotiations have been held with the Ministry of Education about making EB education a part of the basis of curricula. Negotiations are in progress, but the Ministry of education has appointed for the initiative a contact person who has recommended the use of EB educators for Teaching Units. Headmasters of TU's have been approached with an information package and requested to appoint a contact person. Contact person negotiations have been arranged either in TU's or for representatives of TU's in a region. EB education has been presented at these events, and stages of launching the initiative have been explained. If interest for the initiative has arisen, a regional steering group has been appointed to launch and co-ordinate the EB education.</p>
<p>Did you meet any obstacles?</p>	<p>In principle, attitudes towards EB education have been positive. There may have been prejudice about the nature of knowledge conveyed by the EB educators and whether they really can be beneficial for teaching. After teachers have observed the activity and heard presentations by EB educators, the suspicions have dissolved. The initiative has not yet spread to the extent one might have expected based on the positive attention. This is probably due to two factors: Teaching Units have tight time resources. Introducing new modes of operation is challenging; it is difficult, for example, to find time for meetings with so many other issues competing for attention. The starting point in the EB education initiative has been that an EB educator is an expert like other teachers and that at least expenses, such as travel expenses, should be compensated. Many TU's have felt that budgets are so tight that there are no assets available for expense compensation, let alone rewards.</p>
<p>Factors enabling the process</p>	<p>Experience-Based education has existed in Finland before the initiative, but project funding has made wide-ranging nationwide co-operation and development work possible. As teachers and students have had a chance to observe EB education in practice, the good experiences have facilitated the spreading and introduction of the initiative.</p>

EVALUATION

<p>Reproducibility:</p>	<p>It is possible to model EB education and apply it also to other teaching contexts, to other actor groups, and in other countries. The information needed for launching EB education can be found on the project website and is freely utilisable.</p>
<p>Innovativeness:</p>	<p>Regional EB education steering groups can offer organizations and teaching units a new type of co-operation platform for increasing Experience-Based knowledge in social and health care education</p>
<p>Added value:</p>	<p>Co-operation is the key for ensuring that students acquire systematic Experience-Based knowledge about illness and disability. Organizations have contacts to competent EB educators and teaching units can make</p>

	room in their curricula for EB knowledge.
Appropriateness:	A project network integrates nationwide policy-making action and local action co-ordinating practical implementation. Interaction between the levels is needed for the initiative to be as effective and productive as possible.

Best practice N.9

CONTACT DETAILS

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Short description of the organization/public institution

IDF Europe is the European chapter of the International Diabetes Federation (IDF). We are umbrella organization representing 69 diabetes organizations in 47 countries across Europe. We are a diverse and inclusive multicultural network of national diabetes associations, representing both people living with diabetes and healthcare professionals.

DESCRIPTION

Title of the BP	
La formation des Bénévoles Patients Experts (AFD – French Diabetes Federation)	
Policy Field:	<p><input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p><input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.</p> <p>For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) <input checked="" type="checkbox"/> Civic Organization(s)
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	.Fédération Française des Diabétiques (AFD) (French Diabetes Federation) <input type="checkbox"/> Other Subjects involved
Did you directly experience the BP above mentioned?	<input checked="" type="checkbox"/> No, the BP was led by: Fédération Française des Diabétiques (AFD) (French Diabetes Federation)
Location	France – The project spreads year by year in all regions of France
Term	ongoing course
Objectives	This project has an aim to develop and implement a training programme for volunteers to become Expert Patients. Those volunteers, once trained, are able to lead people suffering from diabetes to find their own solutions to improve their quality of life without interfering into the medical treatment.
Outcomes Impact on participants	A study in progress has revealed that the development of this programme of peer training and support has had 3 effects: <ul style="list-style-type: none"> •On the volunteers trained: they have improved their quality of life by updating their knowledge of diabetes and by helping others. An external perspective on their daily life with the disease has helped them to manage their own diabetes and improve their quality of life. •On the people receiving support: the evaluation is based on criteria of improvement of the quality of life. 75% have positively modified their relationship with diabetes. •On the development of the AFD's local associations: an increase in the number of members, development of the AFD's other activities, recruitment of new volunteers.
Resources	At the head of the federation, 3 employees are coordinating the project daily, from the training of the Experts Patients until the implementation by the association's members. Today, more than 30 of the AFD association's members are leading this activity. Our main financial partners are the French National Health Insurance Fund and the French Ministry of Health.

ANALYSIS

Development of the BP	La formation de Bénévole Patient Expert comprend 5 sessions de formation + une validation pratique :
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	<div style="display: flex; flex-direction: column; align-items: center;"> <div style="display: flex; align-items: center; margin-bottom: 20px;"> <div style="text-align: center; margin-right: 10px;"> <p>Bénévole Actif</p> </div> <div style="border-left: 1px solid black; border-right: 1px solid black; padding: 0 10px;"> <ul style="list-style-type: none"> • Logiciel d'autoformation « Connaissance diabète » • Journée du Bénévole Actif </div> </div> <div style="display: flex; align-items: center;"> <div style="text-align: center; margin-right: 10px;"> <p>Bénévole Patient Expert</p> </div> <div style="border-left: 1px solid black; border-right: 1px solid black; padding: 0 10px;"> <ul style="list-style-type: none"> • Formation « Accueillir et mener un accompagnement » • Formation e-learning sur le diabète et la précarité • Formation « Animer un groupe de rencontre entre patients » • Validation pratique </div> </div> </div> <p>Firstly, the volunteers increase their knowledge of diabetes (by use of a dedicated self-study CD-ROM, taking around 10 hours). Then they are trained to lead peer support groups for patients (5 days of training).</p> <p>Once trained, the volunteers lead patient-to-patient support groups. The spirit of these groups is to allow people receiving assistance to find out for themselves the answers to their questions concerning life with the disease, by benefitting from the views, the knowledge and the experience of their peers.</p>
<p>Did you meet any obstacles?</p>	<p><input type="checkbox"/> Yes:</p> <p>This training has been evolving during the last 7 years. From the beginning, as an organization ruled by patients and volunteers mainly, the AFD has aimed to demonstrate the importance of the peer to give support and mainly in front of sceptic's health professionals.</p>
<p>Factors enabling the process</p>	<p>Our 200 trained volunteers.</p>

EVALUATION

<p>Reproducibility:</p>	<p>Yes, for any long term disease.</p>
<p>Innovativeness:</p>	<p>Yes – this is low tech innovation</p>
<p>Added value:</p>	<p>Yes – in addition to the traditional doctor/nurse education</p>

Best practice N.10

CONTACT DETAILS

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Short description of the organization/public institution

For 125 years, the AOK is the largest health insurance in Germany for safety and comprehensive medical illness. The AOK serves about 24 million people - nearly a third of the population in Germany. Around 53,900 employees in 1,250 offices guarantee an efficient service. With about 35 percent market share is the market leader in the AOK health insurance.

And: The AOK is more than one health insurance. It has established a comprehensive health management. This means that a consistently implemented quality management is associated with an increased efficiency of care. What this means for policyholders. Optimal care at competitive premiums from insured employers and elected officials in local governments perceive the interests of members and their employers. This self-insured management ensures efficient and realistic design of health insurance. The AOK Federal Association represents the interests of the umbrella organization the AOK community.

DESCRIPTION

Title of the BP	
Healthy Ageing	
Policy Field:	<p><input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p><input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.</p> <p>For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) . <input type="checkbox"/> Civic Organization(s) X Other Subjects involved AOK Niedersachsen
Location	Hannover. Lower Saxony
Term	01/12/2003 – 01/12/2007
Objectives	<ul style="list-style-type: none"> - Preventive home visits to promote autonomy and engagement - Individual interventions (case management) to improve the quality of life and to improve networking between regional offers in the field of health promotion and social care
Outcomes Impact on participants	<p>The following information was presented by the project manager and is based on interviews with 272 older participants:</p> <p>Overall 98% of the clients were satisfied or very satisfied with the home visits.</p> <p>10% criticized the low frequency of the home visits.</p> <p>Only 8% were not satisfied with the long intervals of the home visits.</p> <p>Over 14% of the clients have more contact to other people.</p> <p>About 11% have been activated successfully; they take part in different activities more frequently now. Nearly 20% of the clients changed their nutritional habits towards healthy nutrition and over 34% improved their fluid balance (prevention of dehydration). Almost 26% refreshed vaccinations and about 30% visited their family doctor. After the intervention about 16% of the clients reported that they move more often; 17% said that they are in a good mood. Compared to the beginning of the project improvements in the quality of life have been achieved for most participants. Compared to the control group the participants had a better health status that means less myocardial infarction and strokes, less fractures, less drug consumption, less admissions to hospitals or nursing homes, less need of care and a lower mortality (compare Fischer, Perschke-Hartmann & Trautner, 2006,3).</p>

ANALYSIS

Development of the BP	<p>The programme "Healthy Ageing" of the AOK Lower Saxony has two aims: on individual level the health status and the quality of life of older insureds should be improved and their independence should be kept. To realise this aim selected older insureds received preventive home visits by a multi-professional project team. On systematical level the programme tends to improve networking between regional offers in the field of health</p>
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promotion and social care.

The preventive home visits included a comprehensive geriatric assessment and the development of an individual assistance plan for the insureds. The project team informed their clients about different themes e.g. healthy nutrition, physical activities and local offers (e.g. PC-classes, choir, walking, aqua gymnastics or meditation). Furthermore the clients were informed about improvements/adaptations of their living space in order to prevent falls. The consultants also tried to motivate and activate their clients to take part in local offers and activities. Additionally individual target agreements were set up for each client in order to assure their participation and efforts.

OTHER INFORMATIONS

<http://www.aok.de/bundesweit/index.php>

Best practice N.11

CONTACT DETAILS

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Short description of the organization/public institution

LILA - Italian League for the Fight against AIDS - is a non-profit HIV/AIDS organisation founded in 1987. It is a federation of 15 associations (local units) of both HIV positive and HIV negative operators, volunteers and professionals, which operates in many Italian regions through its local units. The national coordination team has implemented a structure organised in the following areas of intervention: information, prevention, health care/HIV treatment, harm reduction strategies targeted to at-risk population (drug users, sex workers, prisoners), solidarity and assistance, defense of human rights. Furthermore, LILA’s national coordination team supports the development of social and sanitary policies and coordinates the activities of its units at regional, provincial and municipal level.

LILA promotes and defends the right to health care, is committed to affirm principles of solidarity and stands against any form of violation of human, civil and citizenship rights of people living with HIV and AIDS (PLHIV). LILA also works in partnership with other Italian and European NGOs as well as with the major Italian institutions. LILA participates to the National AIDS Commission within the Ministry of Health, and to other commissions related to health issues, drug use and infective diseases. Since its foundation, LILA has chosen neither to ask for nor to receive any grant from pharmaceutical corporations in order to maintain its independence.

DESCRIPTION

Title of the BP.	
Implementing UNAIDS Greater Involvement of People Living with HIV (GIPA) Policy	
Policy Field:	<p><input type="checkbox"/> <u>empowerment of individual patients</u>: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients’ organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p><input checked="" type="checkbox"/> <u>empowerment of patients’ organisations</u> by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.</p>

	For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.
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Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) <input checked="" type="checkbox"/> Civic Organization(s) LILA Onlus – Lega Italiana per la Lotta contro l’Aids (Italian League for Fighting Aids) National Organization, as well as local offices. <input type="checkbox"/> Other Subjects involved
Location	The Policy has been implemented throughout the National Organization (Coordinating Committee), as well as inside the several local branches of the Federation (currently 15) operating in Italy.
Term	The process began in 2000.
Objectives	<p>At the individual level, involvement can improve self-esteem and boost morale, decrease isolation and depression, and improve health through access to better information about care and prevention.</p> <p>Within organizations, the participation of people living with HIV can change perceptions, as well as provide valuable experiences and knowledge.</p> <p>At the community and social levels, public involvement of people living with HIV can break down fear and prejudice by showing the faces of people living with HIV and demonstrating that they are productive members of, and contributors to, society.</p>
Outcomes Impact on participants	After the full implementation of the UNAIDS-GIPA Policy, the entire Federation has reached a high degree of involvement and empowerment of People Living with HIV (PLHIV), so that – for example – the current Coordinating Committee is composed of 4 PLHIV (out of 6 members), including the Chair.
Resources	Consistent resources have been invested in the implementation of this policy, both in efforts and economic means. The main point of the expenses has been creating growth processes (in terms of formation and empowerment) for PLHIV in the association: individuals initially getting in touch with LILA Onlus because of a personal need are involved in self-help groups (often moderated by specifically trained PLHIV), then are given the opportunity to participate in empowerment initiatives, as well as following appropriate training courses about activism and treatments.

ANALYSIS

Development of the BP	<p>Beside the above-mentioned training and empowerment processes, the main activities towards the effective implementation of UNAIDS-GIPA Policies in LILA Onlus may be resumed as following:</p> <ul style="list-style-type: none"> - Organize and establish common ground with other organizations and networks of people living with HIV, and demand a place at decision-making tables. - Ensure that the GIPA Principle is a living and practised concept within
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	<p>organizations and that new, inclusive and diverse leadership, such as female, young people and other vulnerable population leadership, is nurtured.</p> <p>- Encourage professionals, particularly people living with HIV, to become involved by offering their skills and services to organizations and networks of people living with HIV.</p>
Did you meet any obstacles?	<p><input checked="" type="checkbox"/> Yes:</p> <p>Cultural obstacles: mainly related to the environment surrounding the Association and its activities.</p> <p>Intrinsic obstacles of any training activity (natural dropout rate, individual difficulties...)</p> <p>Obstacles related to the common lack of economic resources, occasionally leading to the loss of management/operational positions originated by this empowerment path.</p>
Factors enabling the process	<p>GIPA is a Principle/Policy actively and worldwide suggested and promoted by the Joint United Nations Programme on HIV/AIDS (UNAIDS), and the participation and contribution of people living with HIV is unanimously considered as one of the best examples of global progress in public health.</p>

EVALUATION

Reproducibility:	<p>Since its initial formulation, in 2001, UNAIDS GIPA Policy has been implemented in several Associations and Organizations in the world.</p> <p>The implementation of a comparable policy in other bodies dealing with different pathologies or conditions, although - at the moment - not so frequent, would certainly be desirable.</p>
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Best practice N.12

CONTACT DETAILS

Name and Surname	Ugo VIORA
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Phone number	+393351372113

Short description of the organization/public institution

ANMAR is the Italian association of patients with Rheumatic deceases and works in all the country with regional independent associations. According to EULAR PARE committee, ANMAR operates some international programs to empower people with rheumatic diseases, to help them in their life and work, to inform people about all problems which make our life so difficult and to represent rheumatic people in national and international policies and contests. ANMAR works side by side with EULAR and SIR (Italian Society of Rheumatologists) and organizes workshops and meetings to develop knowledge and scientific news. Now we are working on performing a Diagnostic, Therapeutic and Assistential Pathway in Rheumatoid Arthritis on a National level: this work may allow all Italian people to undergo the best therapy as soon as possible and in time to achieve the best results.

DESCRIPTION

Title of the BP	NOI: the Italian way to explain T2TconTAct and to work on it
Policy Field:	<p><input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p><input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<p><input checked="" type="checkbox"/> Public Institution(s) SIR</p> <p><input checked="" type="checkbox"/> Civic Organization(s) All regional patients association representing ANMAR</p>
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	<input checked="" type="checkbox"/> Other Subjects involved Volunteers, hospital attendants
Location	All Italian regions.
Term	May 2013 ; still working
Objectives	To explain what is T2T program, to grow up people knowledge and awareness.
Outcomes Impact on participants	The booklet helps people with Rheumatic diseases and their families to know what they can ask to the physician to be sure to fully understand treatment they will undergo, if it is really correct for their illness and if it will provide them benefits and improve their quality of life. It will also learn them what they have to do to reach goals they have arranged with their physician.
Resources	Carrying-out the initiative we used money provided by a sponsor (to edit the booklet), all our volunteers (distributing booklet in consulting rooms and hospital departments) all our meetings, some press conferences and some presentations in scientific congresses.

ANALYSIS

Development of the BP	Training to physicians o T2T program Publish the booklet Press conference to present the program and the booklet Distributing and explaining session Benefits Evaluation (still pending)
Factors enabling the process	All actors seem to be interested in the program. Cartoons – made just for the program – made it intelligible even by children and oldest people.

EVALUATION

Reproducibility:	It is possible to reproduce and implement the BP in other situations and places
Innovativeness:	The first results seem to allow us to say that the BP sorts benefits we purposed to reach
Added value:	Looking at the interest our approach to T2T generated in all the events in which we presented it, it is reasonable to say it is an helpful instrument to use.
Appropriateness:	We think it is quite appropriate: now we are printing the fourth edition of the booklet

OTHER INFORMATIONS

To see all cartoons we designed just for the program, please go to
http://www.youtube.com/user/anmarassociazione?feature=results_main

Best practice N.13

CONTACT DETAILS

Name and Surname	Dace Likanse
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Short description of the organization/public institution

Patients' Ombud Office of Latvia - a well-known and reliable partner both for patients and for health care services. Patients' Ombud Office as an independent and professional instrument, mediator and counselor in patients' rights, communication and legislation in health care system. We render an effective complaint handling management to resolve the problems and concerns of clients and to provide comprehensive feedback to staff and management in order to improve health care services in general. Basic aims is to inform patients about their rights and duties in health care system, and how to reach their needs in the provided system, inform medical professionals about patients' and their own rights and duties, to promote not only first rate medical services, but also a good communication between staff and patients; facilitate positive and effective communication and collaboration between health care personal and patients, collaborate with local and international health care organizations to exchange experience and to improve health care quality in hospital and country in general and promote person's health, well-being and patients' rights as a priority in individual and national system of values.

DESCRIPTION

Title of the BP	
Patients' and health NGOs' Support Centre of Latvia	
Policy Field:	<p>X <u>empowerment of individual patients</u>: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p>X <u>empowerment of patients' organisations</u> by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) <input checked="" type="checkbox"/> Civic Organization(s) <p>Patients' Ombud office of Latvia was created this centre in February, 2013 as new initiative in field of patient empowerment in Latvia. Partner organizations are "Health Projects for Latvia" and "Pulmonary hypertension association" , as well as Latvian cancer society „Dzīvības koks” , Latvia Hemophilia Society, Latvian cystic fibrosis Society e.tc.</p> <input type="checkbox"/> Other Subjects involved
Location	<p>Centre is open for every patient or patients' organization in Latvia, central office is located in Riga, regional units currently are located in cities Valmiera and Cesis.</p>
Term	<p>Creation of centre started in September, 2013, official opening ceremony was held February 26th.</p>
Objectives	<p>The aim of centre is to improve the Latvian health care system at in order to be understood, safe, effective and available for any patient, irrespective of the addition circumstances.</p>
Outcomes Impact on participants	<p>Full support for:</p> <ul style="list-style-type: none"> - patient organizations and non-governmental organizations working in the field of health care; - patients who receive health care services in Latvian and other EU countries; - medical staff; - health care system makers, organizers. <p>Participation in health care organizations and improve the quality of political papers, active monitoring of the health care system in order to prevent a deficiency.</p>
Resources	<p>There' s need to raise funds for centre to be operational, attract several consultants in field of patients right and volunteers also. Centre was created on base of Patients' Ombud office of Latvia and start-up financing was attracted through the European Economic Area funding.</p>

ANALYSIS

Development of the BP	<p>Consultations on patients' rights / obligations and other health system issues for patients and patients' organizations / health NGOs, patient satisfaction surveys and qualitative research, involvement in health policy making, public opinion of health care problems e.tc.</p>
Factors enabling the process	<p>Positive effect could be achieved by better collaboration with health care providers and state institutions – Ministry of Health, Health Inspection e.tc.</p>

EVALUATION

Reproducibility:	Centre was created as the main supporter in health care in Latvia. Is expected to be active all around the state.
Innovativeness:	Centre is innovative practice in Latvia, it works by innovative approach, to pay attention from punishment to analysis of health care errors.
Added value:	As indicated above, centre was created on base of Patients' Ombud office of Latvia, previous experience in field of patient right allows to create a more stable and stronger operations. Centre employs knowledgeable and well-trained staff in advance.
Appropriateness:	The new, innovative project is based on efficient management, democracy and participatory practice. All functions of centre are subordinated to these principles.

OTHER INFORMATIONS

Contacts: Patients' and health NGOs' Support Centre of Latvia, Brivibas street 97, 3rd floor, Riga, LV-1001, tel.: (+371) 28646268. **Contact person:** Dace Likanse, Manager of Support Centre.

Best practice N.14

CONTACT DETAILS

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DESCRIPTION

Title of the BP	
Steering Committee for Advancement of Healthcare	
Policy Field:	<input type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.
	<input checked="" type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice	<input checked="" type="checkbox"/> Public Institution(s) Ministry of Health and other public institutions (Health Insurance Fund, Ombudsman, etc.) <input checked="" type="checkbox"/> Civic Organization(s) Over 30 CSOs active in field of healthcare and professional associations <input type="checkbox"/> Other Subjects involved
Location	Skopje

Term	July 2009 - March 2010
Objectives	To open a comprehensive, wide-stakeholder debate on the reforms in healthcare, in the key segments: financing of healthcare, organizational management, legislation in healthcare and patients' rights.
Outcomes Impact on participants	<p>Almost 300 contributions were produced and numerous other documents collected, all available through a ground-breaking Website that relies on advanced tools of social networking. The Secretariat compiled a draft Green Book with 400+ densely printed pages.</p> <p>Much clearer idea of the capacities, possibilities, strengths and weaknesses of the healthcare actors, and ideas for future involvement in improvement of healthcare policy. Establishment of various contacts and networking opportunities.</p>
Resources	Regular meetings of the Committee and 5 Sub-Committees, that were chaired by members of the Committee, submissions of ideas by all involved stakeholders and production of summarized reports of each sub-Committee.

ANALYSIS

Development of the BP	Almost 300 contributions were produced and numerous other documents collected, all available through a ground-breaking Website that relies on advanced tools of social networking. The Secretariat compiled a draft Green Book with 400+ densely printed pages
Did you meet any obstacles?	After the completion of the process, seeking of funding for the implementation of proposed ideas was seen as a challenge.
Factors enabling the process	Overwhelming interest by all involved stakeholders to participate in the process.

EVALUATION

Reproducibility:	Highly reproducible
Innovativeness:	This kind of process has never been initiated in Macedonia before, in any other sector.
Added value:	Much clearer idea of the capacities, possibilities, strengths and weaknesses of the healthcare actors, and ideas for future involvement in improvement of healthcare policy. Establishment of various contacts and networking opportunities.

Best practice N.15

CONTACT DETAILS

Name and Surname	Mary Vella
Organization	Arthritis and Rheumatism Association (ARAM)
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Short description of the organization/public institution

ARAM association is made up of 300 members and is led by a committee of 7 members all suffering from a chronic condition and run on voluntary basis. The association has been established since August 2007. On national level it is a member of MEUSEC and Malta Health Network. On International level it forms part of Agora an organization which is a Platform for the Southern countries in Europe. It is a member of European league of people with Arthritis and Rheumatism in Europe-EULAR. The main objective of our association is to educate, support and raise awareness about arthritis and rheumatoid conditions and any other musculoskeletal diseases.

To improve quality of life for people suffering from RMDs by organizing seminars on various topics led by Professionals in the field. Organize Physical activities for improvement of health through exercise. Both ground exercises and Therapy pool exercises. Organized walks are on the agenda starting in May. Work in collaboration with the Government Health Promotion and disease Prevention directorate of the Ministry for Health to establish Self-Management courses run both by the Patients and by professionals. Attend Conferences both international and on national level to gain more knowledge how to guide members of the association. Campaign for equal rights and treatment for people with RMDs both local and international. We organize roadshows to educate and raise awareness throughout the island. To establish a young active group for young people suffering from a chronic condition

DESCRIPTION

Title of the BP	
Self-Management Courses	
Policy Field:	<input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.
	<input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact

	<p>on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>
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Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) <input checked="" type="checkbox"/> Civic Organization(s) Arthritis and Rheumatism Association <input type="checkbox"/> Other Subjects involved
Did you directly experience the BP above mentioned?	<input checked="" type="checkbox"/> Yes
Location	The Project is now being implemented in Malta
Term	January 2014-October 2014
Objectives	The project will empower the patients to self-manage their care.
Outcomes Impact on participants	The patients will be able to learn how to lead a better life despite their Chronic Condition
Resources	<p>Human resources to receive training and disseminate this knowledge to the patients on a national level.</p> <p>Financial resources to cover training, hiring of facilities to give out training sessions, refreshments during these sessions and all the necessary hand-outs and notes.</p> <p>The expense for the initial training of the key-leaders was sponsored by Agora a Platform for southern countries in Europe which was launched in MALTA two years ago.</p>

ANALYSIS

Development of the BP	<p>The identified 2 key-leaders receive training in Amsterdam. This training was brought about through our contact with our partners in treatment project in Amsterdam.</p> <p>Following this training the trainers will be facilitating 6 training sessions of 2.5hours each to members of ARAM.</p> <p>Following this training to the patients by patients this course will be then followed by further training jointly by patients and health professionals.</p>
Factors enabling the process	On international level - Collaboration with AGORA – Organisation of Southern Countries who sponsored and organised through Partners in

	<p>treatment Project - Train the Trainees in Amsterdam.</p> <p>On the national level - Good will from members of ARAM and collaboration with the Health Promotion Unit – Ministry of Health Malta.</p>
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EVALUATION

Reproducibility:	This training can easily be delivered in different countries and it is a method which is already being implemented in various European Countries and can then further be adapted to other chronic diseases.
Innovativeness:	Yes the fact that patients themselves are empowered in decisions about their own treatments and care plans.
Added value:	The program was already developed and thus it is already tried and tested and did not involve unnecessary waste of time and resources. The implementation of this project will hopefully lead to decrease in burden on patients and empower in their actions to achieve a better quality healthy life despite their chronic condition.
Appropriateness:	Yes as it was easy to adopt, learn and transfer the knowledge gained to our members.

OTHER INFORMATIONS

WEBSITE OF ORGANISERS – PROJECT IN AMSTERDAM

Contact person of the Organizing Project of Train the Trainees at Amsterdam - Elena Tsigki email address: elenatsigki@hotmail.com

Best practice N.16

CONTACT DETAILS

Name and Surname	Frank Portelli ; Janet Mifsud; Victoria Dimech; Mario Dimech
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Short description of the organization/public institution

The Caritas Malta Epilepsy Association (CMEA) www.caritasmalta/epilepsy is a 100% voluntary organisation. It was set up in 1996 and now lists almost 300 members. In May 2001, the Association was accepted as a Full Member of the International Bureau for Epilepsy (IBE). It is estimated that there are more than 4,000 persons with epilepsy in the Maltese Islands. The Association aims to promote education and local awareness about epilepsy, especially because of the stigma suffered by people with this condition in society. Our campaign is aimed at improving health care services, and treatment and social acceptance of epilepsy. Raising public and professional awareness and dispelling myths about epilepsy is one of our key objectives through talks on T.V. and radio, lectures at schools and parishes, in-service courses for educators, seminars for police recruits, articles in the local papers, a production of a video/DVD on epilepsy in Maltese and distribution of flyers, patient diaries and patient identity cards as well as teacher's packs and book marks. CMEA works closely in Malta with the Department of Clinical Pharmacology and Therapeutics at the University of Malta and the Maltese Chapter of the International League Against Epilepsy, The Epilepsy Society of Malta which is the professional organization

DESCRIPTION

Title of the BP	
"Living Beyond Epilepsy – A Resource for Educators" : a Teacher's pack on Epilepsy	
Policy Field:	<p>X empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p>X empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.</p> <p>For example: courses in self-management, integration of hospital/community</p>

	services, involvement of chronic patient associations in the organization of services, etc.
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Actors of the Best Practice	<p><input checked="" type="checkbox"/> Public Institution(s)</p> <p>All educators, school principals, teachers, learning support assistants in all state private and church schools, at primary and secondary levels ie all those responsible for the education of children from ages 3 to 16 years in Malta and Gozo</p> <p><input checked="" type="checkbox"/> Civic Organization(s)</p> <p>Caritas Malta Epilepsy Association</p> <p><input type="checkbox"/> Other Subjects involved</p>
Location	All Malta and Gozo
Term	July 2011 and is still ongoing
Objectives	<p>Write a brief description</p> <p>Improving information about epilepsy and addressing stigma towards epilepsy by educators in educational settings is a key step in ensuring an improvement of the quality of life of young persons with epilepsy. The aim of this best practice was to use a teacher's pack to reduce the perceived stigma towards epilepsy by educators, in Malta and Gozo and improve their knowledge of epilepsy</p> <p>"Living Beyond Epilepsy – A Resource for Educators" is an information pack on epilepsy which allows educators to how to learn more about epilepsy and understand better children with epilepsy and their families. It is now available to all school teachers and learning support assistants in all schools in Malta and Gozo. It forms part of the Caritas Malta Epilepsy Association's outreach programme.</p> <p>The Teacher's Pack was launched by the former Minister for Education, Employment and the Family Mrs Dolores Cristina in July 2011. The pack is directed at teaching staff as part of an awareness campaign on epilepsy, a condition which is known to have been encountered in schools. Knowledge on how to deal with such situations could be of great assistance to persons affected as well as to those around them.</p> <p>The pack contains information addressing issues such as explaining epilepsy, seizures in schools, what to do in the case of a seizure, and a checklist on what teachers should know about this condition. Epilepsy can affect anyone, at any age, from any social or racial background, damage health and disrupt every aspect of life, imposing physical, psychological and social burdens on individuals and families. It is estimated that 40% of children with epilepsy have difficulty at school.</p> <p>An estimated 300,000 new cases of epilepsy are diagnosed each year in</p>



	Europe, where more than six million people have this condition, affecting 20 million family members.
Outcomes Impact on participants	<p>Explain what benefits has been identified as a result of this practice (for public institutions, patients and civic organization)</p> <p>Increasing information and addressing stigma towards epilepsy by educators in educational settings is a key step in ensuring an improvement of the quality of life of young persons with epilepsy.</p> <p>The pack has been used as an integral part of a 3 day inservice course for educators. A social stigma of epilepsy instrument was used to assess which contained questions about the individual perception of epilepsy. Participants were asked to check the most appropriate class of answers for each item. The SSE scores ranged from 0 (no stigma) to 100 (maximum stigma) The overall mean scores of the SSE at the beginning of the course were 31.86 while following the course, it was reduced to 27.86. At the beginning of the course, the items which were perceived as beginning the most common difficulties people with epilepsy have in their daily lives are emotions and prejudice, while at the end of the course, these were school and work.</p> <p>This analysis showed that this pack is a very useful tool for tailoring the education of educators working in this field of epilepsy.</p>
Resources	<p>Identify inherent indispensable resources to carrying-out the initiative (human and financial resources, logistic facilities, information, experiences etc.)</p> <ul style="list-style-type: none"> ▪ Preparation of text and photos for leaflets and ensuring information is relevant to the Maltese context ▪ Fund raising and seeking sponsorship for costs involved in the printing of the pack (each pack costs around 3 euros to print and over 3000 have been printed so far) ▪ Liaison with printer to ensure the pack is printed as requested using full colour ▪ Meeting with various Ministers of Education to support printing costs and ensure media distributes information about the packs see http://www.caritasmalta.org/?m=news&id=33 ▪ Distribution of packs to all schools in Malta and Gozo through the Ministry of Education ▪ Reinforcement of the information provided in the packs by means of annual in-service courses of teachers ▪ Liaison with Education Officers in the Ministry of Education to ensure that seminars which use the pack are offered to all schools on a voluntary basis ▪ Promotion on media and websites about the Teacher's Packs

ANALYSIS

Development of the BP	<ul style="list-style-type: none"> ▪ The pack was developed over four months by a subcommittee of the CMEA in 2011. The material had to be written and adapted for the Maltese scenario. Appropriate photos and other material were adapted from various openly available sources and permission was sought to reuse some material from Brainwave (Epilepsy Ireland). The information written in the teacher's pack was then reviewed by
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	<p>a consultant neuropaediatrician to ensure all the information provided was correct.</p> <ul style="list-style-type: none"> ▪ Quotes for printing costs from various printers were sought and the most advantageous offer identified ▪ Printing was challenge since the pack consists of various different leaflets of different sizes, and a A3 sided sheet full of games, together with a folder to put everything in together ▪ Meeting with Minister of Education was then obtained and press launch organised. ▪ Minister agreed to co sponsor printing in order that every single teacher in Malta has a copy. ▪ The pack has been used in various in service courses organised by CMEA in conjunction with Ministry for Education. ▪ In 2013, the new Minister of Education, Mr Evarist Bartolo, has reiterated his intention to continue supporting this best practise. ▪ Meetings have been held with the Director of Strategy at the Ministry of Education, Ms Elizabeth Pisani and as a result the teacher's pack has was redistributed to all schools again in January 2014, together with posters on first aid and what to do if someone has an epileptic seizure.
Did you meet any obstacles?	<p>X Yes:</p> <p>It was important to ensure that the pack remains available to every single teacher and learning support assistant in Malta and Gozo at the beginning of each scholastic year. New teachers graduate and are employed by the various schools on an annual basis.</p> <p>Moreover the momentum for the distribution of these teacher's pack had to be maintained despite a change in government and thus changes in Ministers and state stakeholders. However we managed to maintain the interest and across partylines to ensure that the information is disseminated.</p>
Factors enabling the process	<p>The support of the paediatricians, nurses and care workers in the health care system has certainly assisted our best practice. A3 size posters and bookmarks have now also been printed to complement the teachers packs and also to promote information about the NGO (see enclosed).</p>

EVALUATION

Reproducibility:	Yes – it can easily be used in other countries – among all schools
Innovativeness:	It also led to the printing in 2013 of posters and bookmarks on what to do if someone has an epileptic seizure (see enclosed). It has been possible to print these new materials through a Leonardo EU project CMEA are involved in.
Added value:	Certainly since teachers could take it away with them and read it at leisure. It also empowered educators to understand more about epilepsy and also be more willing to accept and integrate children with epilepsy in the classroom
Appropriateness:	Yes –educators greatly appreciated having information available to them on a personal basis. It also included games which children can use to better

	understand epilepsy.
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Best practice N.17

CONTACT DETAILS

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Short description of the organization/public institution

The St Jeanne Antide Foundation (registered NGO with remunerated professionals and a cadre of around 51 volunteers).

DESCRIPTION

Title of the BP	
LWIEN – community outreach work to identify and provide support to hard-to-reach family caregivers of the mentally ill in their self-empowerment process. (LWIEN in Maltese means colours and hues)	
Policy Field:	<p><input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p><input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<p><input checked="" type="checkbox"/> Public Institution(s) Ministry responsible for health and community care</p> <p><input checked="" type="checkbox"/> Civic Organization(s) The St Jeanne Antide Foundation</p>
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	The Mental Health Association Malta
Location	Malta , South-East
Term	2012 -2014
Objectives	<p>Broad aims: - To reduce isolation amongst family caregivers of mentally ill persons. - To reduce self-stigma. - To prevent burnout and depression of family caregivers and breakdown of supportive family systems. - To stimulate a readiness for advocacy work. Specific objectives - To identify a highly underserved category of citizens - family caregivers of mentally ill persons. - To provide family-focused consultations on issues that have become family stressors. - To facilitate self-empowerment processes. - To highlight the key role that family plays in providing care and support. - To stimulate family caregivers to advocate on behalf of very vulnerable others. - To identify issues of common concern and to transmit these to policy makers. - To work in partnership with other NGOs and public entities active in the fields of health and mental health.</p>
Outcomes Impact on participants	<p>Weekly outreach work in depressed neighborhoods leading to identification of vulnerable families & a number of mis-diagnosed sufferers. - Family Consultations on two weekdays. - 2 radio programs. - 3 Support Groups for family caregivers with a high level of anxiety. - Joint publications with Mental Health Association: Stars shine brightly in the dark, written by family caregivers out in February. - Supportive CBOs. - Case-studies for evidence-based evaluation and training.</p> <p>The passion of Partner NGOs to support a vulnerable sector of society and to advocate is bearing fruit and leading to innovative actions. Vulnerable socially excluded Families: - express surprise that there are professionals who reach out to them in this manner. - overcome mistrust and access services they need or re-engage with them. - view support groups as a self-care space & encourage their children to similarly connect. - express gratitude for support to understand treatment regimen side-effects & how they can be counteracted, and mapping out a cognitive behavior therapy plan whose outcomes benefits the whole family. - are poignantly emotional seeing their family breakdown being prevented, especially where mis-diagnosis, resistance to treatment, lack of a diagnosis, & lack of support threaten family relations. - shed stress and anxiety when a mis-diagnosis identified by the team is confirmed & changes in medication result in recovery. - Families: "A dream of a service"</p>
Resources	<p>An experienced Psychiatric Nurse. A Community Social Worker. Collaborative work with Mental Health Association for media promotion and support work. Joint development of publications for family caregivers. Community outreach workers. Welcoming premises for support work with families. Start-up funding from the Ministry of Health since initiative complements government policy to provide community-based services for sufferers. practitioners provide free consultations over the phone.</p>

ANALYSIS

<p>Development of the BP</p>	<p>Two stated principles of the St Jeanne Antide Foundation are to identify un-served or under-served categories of vulnerable citizens and to avoid duplicating services that already exist. Through its community outreach work, the Foundation came in touch with a significant number of overwhelmed informal carers struggling to cope with their caring responsibilities without any support from mainstream health service provision. Carers who self-administered a questionnaire to determine their level of anxiety showed maximum level. A highly competent psychiatric nurse was engaged to provide family consultations. The Ministry responsible for health and community care was contacted to provide start-up funding for this innovative initiative. The Ministry agreed immediately. The Foundation stepped up its collaborative work with the Mental Health Association. 3 support groups were started. Radio programs were aired from August to December.</p>
<p>Did you meet any obstacles?</p>	<p>1. Lack of funding due to the economic meltdown. 2. There is always a primary informal carer who absorbs all the caring responsibility when other family members shirk sharing the responsibility, standing comfortably back. 3. Self-stigma amongst relatives of mentally ill; stigma nationally is still rife. 4. Poor and vulnerable families cannot afford to pay for a private consultation – as carers - with a psychiatrist. 5. The fact that family caregivers have as yet not formed lobby groups as has been done in other sectors. 6. The health and mental health system is yet to extend its support mechanism to family caregivers who shoulder the main burden of day-to-day care of a family member</p>
<p>Factors enabling the process</p>	<p>. 1. Outreach work has proved to be a crucial tool in the identification of many suffering families who have no means of accessing the kind of support they desperately need. 2. The fact that hardly any public health service exists that targets family caregivers of the mentally ill. 3. The readiness of family caregivers to write/speak out to combat stigma. 4. The readiness of Foundation professionals to knock on doors in depressed neighborhoods to reach out to families, even during weekends.</p>

EVALUATION

<p>Reproducibility:</p>	<p>Any organisation can replicate or adapt the model as long as personnel are ready to carry out outreach work in neighbourhoods with a concentration of social problems and to work in partnership with other organisations at both community & other levels</p>
<p>Innovativeness:</p>	<p>No such service existed where overstressed vulnerable caregivers could sit down as a family with a professional to collectively thrash out their concerns. EUFAMI will edit the English version of the book for relatives by relatives being published.</p>
<p>Added value:</p>	<p>Both organisations are helping a community-based group to survey the incidence of mental illness so as to identify needs for community-based</p>

	support. Other localities will become interested. -Passion for reaching out to most hard-to-reach families.
Appropriateness:	Giving a voice to a very vulnerable and unrecognized significant

OTHER INFORMATIONS

It is hoped that the LWIEN initiative becomes a centre of excellence on working with families of mentally ill persons. A small house close to the Foundation's premises is being refurbished by a group of prisoners. The work is slowly creating an awareness

Best practice N.18

CONTACT DETAILS

Name and Surname	Moerdijk, Yvette
Organization	Fibromyalgie en Samenleving (F.E.S), de Nationale Vereniging voor Fibromyalgie-patiënten
Country	The Netherlands
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Phone number	0031624240622

Short description of the organization/public institution

The F.E.S. was founded in 1986 in the northern part of The Netherlands. The main reason for this was the lack of awareness for fibromyalgia. In a reasonably short period of time the association started to grow and is becoming one of the largest specific patient associations of The Netherlands. The aim of the founders, to create an association where fibromyalgia patients could tell their story and learn from each other, has succeeded. Now-a-days the organization spends time and money on; fellow-sufferer contacts , information and guidance and promotion of awareness.

DESCRIPTION

Title of the BP : Passport to suited work

It is developed by the Dutch Fibromyalgia Association F.E.S. together with a team of the University of Utrecht under supervision of Prof. Dr. Rinie Geenen, faculty of Clinical & health psychology and the speciality psycho social aspects of Rheumatic diseases. It is a “passport” in which patients (in this case fibromyalgia) can prepare themselves to the get to the labour market again in a way they can stay at work with their condition.

Policy Field:

empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients’ organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.

empowerment of patients’ organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.
For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice

Public Institution(s)
F.E.S. and University of Utrecht

Location	The Netherlands/Utrecht
Term	We developed a passport for people who are looking for a suitable job
Objectives	It is a “passport” in which patients (in this case fibromyalgia) can prepare themselves to get to the labour market again in a way they can stay at work with their condition.
Outcomes Impact on participants	To help Fibromyalgia and similar patients to get a suitable job.
Resources	Research for what is suitable for patients.

ANALYSIS

Development of the BP	We did not analyse yet but the first results were positive. The patients are very enthusiastic about working with the passport.
Did you meet any obstacles?	<input checked="" type="checkbox"/> No

Best practice N.19

CONTACT DETAILS

Name and Surname	Raican Dan Stoian
Organization	Antiparkinson Association
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Short description of the organization/public institution

The Antiparkinson Association, the only one in Romania who fight for rights of 72000 ill people of Parkinson disease. The association was affiliated with the international bodies, becoming a member with full rights of the European Parkinson's Disease, Parkinson's disease Foundation in the USA, Michael J. Fox – USA, Parkinson association of the Rockies, World Parkinson Congress (WPC), being invited and taking part in international congresses. In 2009 for the book and project " Life with Parkinson Disease" win the Special prize Carol Davila , and for the project secure stoc win Mention in Civic society Gala. For the national Campaign initiate with Patronage of the Pharmacologists from Romania the Capital newspaper give OSKAR PRIZE. In 17 .05. 2010 won the prize: the most active Association of patients from Romania offer by the chief of all medicine in Romania

In 2011 in the People for People Gala was given the prize for remarkable contribution to Mr. Raican Dan the creator and president of antiparkinson association with Parkinson disease since 2000.

DESCRIPTION

Title of the BP	
Hand to hand	
Policy Field:	<input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.
	<input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice	<p>x Public Institution(s) Health Ministry.</p> <p>x Civic Organization(s) Antiparkinson Association .</p> <p>x Other Subjects involved Red Cross</p>
Did you directly experience the BP above mentioned?	x Yes
Location	Deva Region Hunedoara Romania
Term	10/02/2011 – 22/12/2011
Objectives	<p>The principles at the basis of granting social services are:</p> <p>a). Respecting the individuality of each person; b). Respecting the freedom of choosing the social service depending on the social need; c). Ensuring the access to social services in equal terms through eliminating privileges and all forms of discrimination; d). Ensuring quality, accessible, flexible services adapted to the social needs; e). Ensuring the rights and safety of the beneficiaries, at the same time protecting both the community's and others' interests; f). Ensuring access to information regarding fundamental rights, legal measures of protection, as well as the possibility to contest the decision granting some social services; g) Respecting the privacy of the person; h). Respecting confidentiality; i). Developing the partnership between the parties involved in the process of granting the social services and the beneficiaries.</p>
Outcomes Impact on participants	<p>The initiative to make newspaper for Parkinson patients was a better idea because they have access of news on the research in this field.</p> <p>With this project the Parkinson patients have the possibility to integrate themselves in the civil society. The most important impact is for the population who understood the disease and could help people.</p>
Resources	The project involved a PR service and over 30 volunteer. The financial problem is resolved with private fund most of them manufactories like mineral water, cake.

ANALYSIS

Development of the BP	The project has an internet page of association who contain a forum very easy to access. Since a lot of patients are old, the communication are made with postal letters and round table or conferences in big city near their home.
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<p>Did you meet any obstacles?</p>	<p>Yes:</p> <p>The first and most important obstacles is the isolation of ill people. They not cooperated from the beginning but I found two powerful alliance: Red Cross and Church who engaged home visits and discussion. In same time volunteers of the Association learn to take care of Parkinson patients. With help of doctor and the spiritual we go in front and the obstacles was beaten and stay behind</p>
<p>Factors enabling the process</p>	<p>The date from the book who I edited help people to understand and monitor the ill. At the same time the patients found the right and what it is necessary make to have</p>

EVALUATION

<p>Reproducibility:</p>	<p>Yes The project is reproducible of any patients association. With human help you can make similar action and the idea to have centers to help social and psychological problems the ill person is an important point of medicine without barriers.</p>
<p>Innovativeness:</p>	<p>Antiparkinson Association have tree important events where take part in generally old people affect by Parkinson and young people who singing or dancing for them. This celebration is The European Right day celebration with International Parkinson day in 11 April (the day of born of discover the ill James Parkinson) The annual congress of Parkinson disease and the Christmas's event.</p>
<p>Added value:</p>	<p>Using BP the project add value and have the honor of civil society</p>
<p>Appropriateness:</p>	<p>The management of the project help Parkinson ill to not feel discriminated and to integrate in society. They put together medical doctor and patients.</p>

Best practice N.20

CONTACT DETAILS

Name and Surname	Manuel Serrano
Organization	Education Health and Society Foundation
Country	Spain
Email	manuel.serrano@globalalliancesms.org
Phone number	34650061175

Short description of the organization/public institution

Education Health and Society Foundation is a non-profit national Foundation, from Spain. It led the Expert Patient Program from 2009 to 2013 at the Murcia Region, reaching 6000 patients with obesity/type 2 Diabetes and since 2012 is involved on the EUWISE 7th Framework European Project, with other six institutions from five European countries.

DESCRIPTION

Title of the BP	
EUGENIE intervention	
Policy Field:	<p>X <u>empowerment of individual patients</u>: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p>X <u>empowerment of patients' organisations</u> by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.</p> <p>For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<p>X Public Institution(s)</p> <p>University of Southampton (UK). Coordinator</p> <p>University of Navarre (Spain)</p> <p>University of World Economy (Bulgary)</p>
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	University of Oslo (Norway) University of Nijmegen (Netherlands) University of Crete (Greece) X Civic Organization(s) Education Health and Society Foundation (Spain) Other Subjects involved
Location	United Kingdom: Southampton Spain: Navarre, Murcia Norway: Oslo Greece: Crete Bulgaria: Sophia
Term	January 2012-December 2016
Objectives	The intervention is focused on the role that social networks play in chronic illness management and aims to enhance access to resources and to improve support for health and well-being.
Outcomes Impact on participants	2013-2014) Spread and detailed outcomes. Newsletter I and II 2014) Publications: http://eu-wise.com/new-eu-wise-publication/ Social support systems as determinants of self-management and quality of life of people with diabetes across Europe: study protocol for an observational study, by Jan Koetsenruijter, Jan van Lieshout, Ivo Vassilev, Mari Carmen Portillo, Manuel Serrano, Ingrid Knutsen, Poli Roukova, Christos Lionis, Elka Todorova, Christina Foss, Anne Rogers and Michel Wensing. Health and Quality of Life Outcomes 2014, 12:29 doi:10.1186/1477-7525-12-2

ANALYSIS

Development of the BP	Brief description of the main activities (Who, How, main steps) http://eu-wise.com/work-packages/
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EVALUATION

Reproducibility:	Yes. This is the purpose of the EUGENIE online intervention
Innovativeness:	Yes. This is the first transnational project on social networks and chronic diseases across Europe
Added value:	Yes. No other previous experiences

Best practice N.21

CONTACT DETAILS

Organization	Spanish Family and Community Medicine Society
Country	Spain
Email	papps@semfyc.es - semfyc@semfyc.es
Phone number	(+34) 93 317 03 33

Short description of the organization/public institution

The semFYC is the federation of the 17 societies of Family and Community Medicine that exist in Spain and brings together more than 19,500 family physicians. The organization is articulated in delegation, sections, committees, working groups and programs.

DESCRIPTION

Title of the BP	
Preventive Activities and Health Promotion Programme	
Policy Field:	<input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.
	<input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) . <input type="checkbox"/> Civic Organization(s) <input checked="" type="checkbox"/> Other Subjects involved
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	Spanish Family and Community Medicine Society
Location	The capital city of each Spanish region
Objectives	1.- To promote quality in primary health care provision through the integration of health promotion with its usual functions 2.- To identify the difficulties of integrating health promotion in primary healthcare centres with the needs of such centres (staff and infrastructures) 3.- To generate evidence based recommendations for public health and health promotion. 4.- To promote training and research in health promotion.
Outcomes Impact on participants	This program is one of the biggest health promotion programmes currently being carried out in Spain. Due to its complex structure (which involves the Spanish primary health centres network in strategies in health promotion), the programme encompasses a wide array of professionals from fields of medicine and social sciences.
Resources	Coordinated by the Spanish family and community medicine society (SemFYC). Each partner has their own funders

ANALYSIS

Development of the BP	The programme aims to promote notions of health promotion at the local level through primary health care. Through specific sub-programs, each health centre is responsible for applying and evaluating the models. The findings from all the various outcomes are centralised for conclusions. 4 subprograms: Mental health for adults and young people (2), general health promotion, and disease prevention for children and adults.
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EVALUATION

Reproducibility:	The programme is currently running in all regions across the country.
Innovativeness:	Operating at a local level in every region of the country, the programme searches for evidence of effective health promotion with regard to individuals in the target groups; community integration of the centers; management and organization of the centers.

OTHER INFORMATIONS

<http://www.semfyec.es/es/> - <http://www.papps.org/>

Best practice N.22

CONTACT DETAILS

Name and Surname	Celia Marín
Organization	Acción Psoriasis (Spanish Psoriasis and Psoriatic Arthritis Patients Association)
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Email	cmarin@acciopsoriasi.org
Phone number	0034608964996

Short description of the organization/public institution

Acción Psoriasis is a Spanish non-profit association, made up of psoriasis and psoriatic arthritis patients and their relatives to provide information and support patients and improve their quality of life. Our main objectives are:

Providing information and support to psoriasis and psoriatic arthritis patients

Public opinion awareness by increasing knowledge of psoriasis.

Provide the patients point of view to health care providers and society

Collaborate with other associations with psoriasis and psoriatic arthritis as well as international partnerships IFPA, EUROPSO and IAPO.

Support the social integration of patients, fighting ignorance, prejudice and discrimination. Improving the quality of life of patients in dermatological, social and psychological aspects. Maintaining contacts with organizations and associations dedicated to the study of this disease inside and outside our country.

Support research and encourage studies on the incidence, causes, evolution, treatment, and consequences of the disease. We focus our work in several areas: training and patient information, health care providers and society in general; spreading and publishing psoriasis materials; representation in national and international forums; support and collaboration in healthcare and scientific research; association and personalized patient support.

DESCRIPTION

Title of the BP Accion@ : Online educational platform for patients with psoriasis and psoriatic arthritis

Policy Field:

empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.

empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create

	<p>partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.</p> <p>For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>
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Actors of the Best Practice	<p>√ Public Institution(s) Spanish Academy of Dermatology and Venereology</p> <p>√ Civic Organization(s) Acción Psoriasis</p> <p>√ Other Subjects involved It is planned to involve other public institutions such as the Spanish Society of Rheumatology, the Official College of Physicians, Nurses and Pharmacists and other private institutions that support the project.</p>
Location	Internet so its sphere of action is global, it operates worldwide.
Term	Start in May 2014 It has no end date because this action will develop wherever there is need to educate the psoriasis patients
Objectives	<p>MAIN</p> <p>1. Creating an expert psoriasis and psoriatic arthritis patients network</p> <p>SECONDARY</p> <p>1. Testing the level of knowledge about the disease at baseline.</p> <p>2. Generating an e-learning platform for psoriasis and psoriatic arthritis patients and their relatives.</p> <p>3. Checking the level of benefit for each subject of the training.</p>
Outcomes Impact on participants	<p>1. For patients: The psoriasis and psoriatic arthritis patient who becomes aware and takes an active role with the pathology learns and educates, improves the health outcomes and adherence. And also help other patients by providing information and support.</p> <p>2. For health care providers: The expert and informed patient manage the disease in a better way, has a better health-care, take better the treatment and makes easier the communication and relationship with the health care provider saving time and efforts.</p> <p>3. For public institutions: The expert patient saves money by public health system that does not waste resources and to optimize the management of their disease using less medication and fewer visits to health care providers that are covered by the information through the online platform.</p> <p>4. For civic organization: Psoriasis Action aims to improve the lives of patients with psoriasis and psoriatic arthritis. This activity improves quality of life of these patients working in different areas: directly with the patient and family and secondly to improve the patient's condition in the health system and society in general. The online educational platform is within the Psoriasis Action website so the patient and family can easily find other resources of the association offered on this website.</p>
Resources	The online training course of expert patients in psoriasis and psoriatic

	<p>arthritis has been devised by the patient organization Action Psoriasis. It has been especially involved the Communication Department, composed of 4 people that has guided and reviewed the course content. The association has trained a person responsible in patients contact and management of online activity. It has been also tested the course with different patients profiles. The project has been developed by company specialist in developing projects in the health area who has created the online platform and project communication plan. It has been necessary financial resources provided by the association and by various sponsors who contribute to the support of Acción Psoriasis activities.</p>
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ANALYSIS

Development of the BP	<p>The patient performs this activity and may:</p> <p>Knowing what it is and how the disease works.</p> <p>Learn what these tests or checks to be held.</p> <p>Report on what is the best treatment for each patient and what is its purpose.</p> <p>Clarify doubts about basic issues of the day a day of the disease.</p> <p>Accion@ has 3 phases: 1. Initial evaluation 2.Training the patient and family 3. Evaluate effectiveness and usefulness. The patient and / or their relatives make this course, patients become experts in psoriasis and psoriatic arthritis and receive a certificate of expert patient. The patient can do the course at any time, and is always available online from anywhere in the world.</p>
Factors enabling the process	<p>Two principal factors:</p> <ol style="list-style-type: none"> 1. The patient's need to better understand their disease, treatment options available, the tools to live better with this chronic disease. 2. Innovation, there is no training for psoriasis patients online

EVALUATION

Reproducibility:	Yes, we can reproduce this activity in different languages and also in different diseases
Innovativeness:	Yes, there is no online courses for psoriasis patients
Added value:	The association develops numerous and awareness activities training for patients, health and society in general but the online course complements patient education and aims to create a network of experts that integrate patients in the volunteer association network. In addition, through the online platform we provides access to patient education that cannot be physically moved to our training meetings in different cities or countries.
Appropriateness:	Yes, because we have an ongoing evaluation of the data provides the online platform: number of participants, course status, customer online patient, resolving doubts and we know if we are meeting the needs of the patient or if this demand more information in certain areas.

OTHER INFORMATIONS

This activity is newly created and startup and is the result of many months of work and planning. We believe it can deliver excellent results and offers a new and necessary service to the psoriasis and psoriatic arthritis patient.

Best practice N.23

CONTACT DETAILS

Name and Surname	Sara Rubinelli
Organization	Swiss Paraplegic Research
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Short description of the organization/public institution

Swiss Paraplegic Research is the research institute of the Swiss Paraplegic Group, a unique network of services for people with spinal cord injury (SCI), from primary care to long-life support. The Swiss Paraplegic Group aims to provide holistic rehabilitation and to reintegrate people affected by SCI into family, working and social life. The mission of Swiss Paraplegic Research is to achieve a long-term and sustained improvement in the function capability, social integration, equality of opportunity, health, self-determination and the quality of life of people with SCI through clinical and interdisciplinary research. To this end, Swiss Paraplegic Research has established a national and international research network for integrated rehabilitation research.

DESCRIPTION

Title of the BP

Health literacy and self-management through online communication. The website www.paraforum.ch as a case in point.

Policy Field:

empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.

empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.
For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice	<input checked="" type="checkbox"/> Public Institution(s) Swiss Paraplegic Research, Swiss Paraplegic Foundation, Swiss Paraplegic Association, Swiss Paraplegic Center <input type="checkbox"/> Civic Organization(s) <input type="checkbox"/> Other Subjects involved
Location	Nottwil, Switzerland
Term	September 2011 - ongoing
Objectives	<p>Health organizations are increasingly present online through websites that provide health information to consumers. In producing these websites, health organizations invest significant resources: health information is created by groups of experts in the field as a resource for the community. These websites are important educational endeavours. They foster the growth of health literacy that is at the core of self-management of health conditions. Thanks to the advancement of the Web 2.0, the websites that support interactivity can be used by health organizations and health professionals to identify needs and gaps in the resources people have at disposal to self-manage their health conditions. In order to do this, however, it is fundamental to enhance collaborative attitudes of users and clear processes and standards for managing content, and creating and translating knowledge.</p> <p>The objective of this presentation is to illustrate the challenges of building an online community of patients/consumers that proactively contributes to the exchange of information and experiences online. Overall, it aims to identify best practices to enhance health literacy and self-management through online communication.</p> <p>This issue will be addressed by illustrating the development of the online community of the website <i>paraforum</i> (www.paraforum.ch), a consumer oriented website in the field of SCI developed by Swiss Paraplegic Research on behalf of Swiss Paraplegic Foundation and launched in December 2013.</p>
Outcomes Impact on participants	<p>The main benefits of analysing the development and use of the website <i>paraforum</i> are:</p> <ol style="list-style-type: none"> 1) A focused understanding of the relationship between health literacy and self-management and of the knowledge and skills that people with SCI need in their empowerment process; 2) The role that computer-based communication can have in enhancing health literacy and self-management, with a focus on what the Web 2.0 enables users to do; 3) The challenges linked to the development and establishment of an active community of users (in this case individuals with SCI and

	<p>their families) who share knowledge and experiences in interaction with the health professionals;</p> <p>4) The role that online communities of patients and consumers can have in creating through participatory design knowledge that can be used to inspire the design of innovative educational programs in specific health settings.</p>
Resources	The project PARAFORUM has been funded by Swiss Paraplegic Research and Swiss Paraplegic Foundation. The team of the project is led by Sara Rubinelli and is composed of 3 project scientists, 2 PhD students and 2 technologists expert in online systems for health communication.

ANALYSIS

Development of the BP	<p>The main steps of this best practice are:</p> <ol style="list-style-type: none"> 1) Conceptual design of the website <i>paraforum</i> (through qualitative participatory research with key stakeholders in the field of SCI) (between September 2011 and June 2012) 2) Development of the website <i>paraforum</i> (from July 2012 to December 2013) 3) Implementation of <i>paraforum</i> and formative evaluation with the first community of users (from December 2013 and ongoing)
Did you meet any obstacles?	<p><input checked="" type="checkbox"/> Yes:</p> <p>The project <i>paraforum</i> encountered difficulties in all its phases. Main difficulties include: 1) difficulties due lack of time ad resource of health professional in working with the <i>paraforum</i> team; 2) difficulties in developing a social network that – differently from <i>Facebook</i> – focuses only on SCI; 3) difficulties in engaging a community to become active on the website.</p> <p>The means used to overcome these difficulties are: 1) To build a partnership with health professionals by assisting them in developing content to be put online. A team of communication experts assisted the health professionals in creating their contributions to be published on <i>paraforum</i>. 2) To avoid a top-down approach and to work together with the SCI community to understand how to enhance the technological quality of <i>paraforum</i> and of the services it offers (user-based design). 3) To carve out a useful niche of users by choosing the scope of the community, in terms of the breadth of topics to cover, the activities to support and the purpose of the community. To make strategic choices by addressing its compatibility and integration with other communities. To leverage early participants to attract later ones, and setting expectations about the future evolution of the community. To reach a critical mass of users to enable multi-level communication.</p>
Factors enabling the	The SCI community has a lot of know-how. It is the ideal community to share knowledge and experiences and, thus, to foster the growth of health

process	literacy and self-management skills among its members. Also, it is a community that makes use of technologies, and is keen to explore the potential of the internet as a channel for communication at different levels.
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EVALUATION

Reproducibility:	The website <i>paraforum</i> can be reproduced and implemented in other fields, with a specific focus on chronic health conditions where the empowerment of patients in self-management is of key importance.
Innovativeness:	The website <i>paraforum</i> is unique in the exploitation of web 2.0 services in the field of health. Thus, in addition to a traditional Forum, it implement a section called <i>My Diary</i> (where people can self-track their health states), a section called <i>My Ideas</i> (focused on enhancing collaboration of users in brainstorming potentially innovative ideas) and a section called the <i>Research Corner</i> aimed at fostering participatory research between researchers and consumers.
Added value:	The project <i>paraforum</i> is of key importance to understand how to program and deliver educational interventions to enhance self-management through online communication. A main added value of this project is the fact of working together with a real community and not in a fictional experimental setting.
Appropriateness:	Yes. The various needs of the stakeholders have been taken into consideration and addressed.

OTHER INFORMATIONS

There is a main paper on the project *paraforum*, published in the peer-reviewed journal "Patient Education and Counseling", namely:

Rubinelli S, Collm A, Glässer A, Diesner F, Kinast J, Stucki G, Brach M. (2013). Designing interactivity on consumer health websites: PARAFORUM for spinal cord injury. *Patient Educ Couns* 93(3):459-63

This publication is open access and can thus be downloaded for free.

Best practice N.24

CONTACT DETAILS

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Country	United Kingdom
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Phone number	T: (+44) 020 8709 9700 - F: (+44) 020 8880 6608

Short description of the organization/public institution

Bromley-by-Bow is one of the most deprived areas in the UK, with multiple social problems. At the same time, there are great reserves of energy and ability in the local community. The Bromley by Bow Centre is a community organisation which runs a variety of projects in an integrated way -linking health with education and enterprise, for example, or environment with training and family support - to serve as a focus for that energy and ability and so to help regenerate the area.

Its Community Care project, for example, thrives on bringing together different groups such as older and disabled people in a wider policy context that increasingly promotes separate provision. In the organizations efforts to build trust, relationality and interdependence among members of a deprived community, distinctions between care-givers and -receivers are blurred, with those needing care also providing it and vice versa. The Centre also appreciates the potential need of particularly its more vulnerable users to be passive.

DESCRIPTION

Title of the BP	
Bromley by Bow Centre	
Policy Field:	<p><input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.</p> <p><input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.</p> <p>For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.</p>

Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) <input checked="" type="checkbox"/> Civic Organization(s) Bromley by Bow Centre
Location	Bromley-by-Bow - deprived district in East London
Term	01/01/1984 – on going
Objectives	Health promotion, social entrepreneurship, active citizenship, integrated working and community regeneration, the Centre's approach is essentially experimental, holistic and relational
Outcomes Impact on participants	The centre has been successful at achieving a level of community regeneration, health promotion and wellbeing, particularly through inter-generational and inter-ethnic activities

ANALYSIS

Development of the BP	A number of activities are run around core themes of art, creativity and reflection. There a wide range of activities organised for all ages and older people are encouraged to get involved. Frequently these opportunities arise in relation to food and this naturally leads on to health promotion events on nutrition. Such work goes beyond providing information and is grounded in inclusion and relationships. Other examples of how arts is related towards health promotion include the diabetes fair. A wide range of educational programmes are also run.
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EVALUATION

Reproducibility:	No apparent direct transference, however the model is seen as a flagship of innovative community work by the current Government. There is significant discussion within the projects evaluation literature of potential transferability
Innovativeness:	Model seen as a flagship of inter-generational and multi-ethnic team-working aimed at community regeneration.

OTHER INFORMATIONS

<http://www.bbbsc.org.uk/>

Best practice N.25

CONTACT DETAILS

Name and Surname	Jane Clayton-Jones
Organization	Rutland Citizens Advice Bureau, Oakham, Rutland LE15 6AL
Country	United Kingdom
Email	jcj@rutlandcab.org.uk
Phone number	01572 757420

Short description of the organization/public institution

Healthwatch was established in England in April 2013 by the UK Government. It is a patient champion in health and social care, operating on two levels: firstly at a national level through Healthwatch England and secondly working at a local level through Healthwatch. Healthwatch Rutland (HWR) is an independent organization, but funded by central government via local government. HWR provides public access from the Citizens Advice Bureau (CAB) in the High Street of the county town of Oakham. CAB collaborates with HWR to provide an “Information and Signposting service” alongside its other advice services. A separate office base at Voluntary Action Rutland provides a base for a part time Manager and a full time administrator. Much of the work of HWR is carried out by Task Groups, consisting of local volunteers, which are overseen and supported by the Manager and the Administrator, who report to a Chair and Board of Trustees. The Task Groups work on a range of health and social care issues of concern to the local population and bring them to the attention of the appropriate health and social care providers so that they are aware and can respond to the experiences of patients from Rutland.

DESCRIPTION

Title of the BP	
Health watch: a new patient champion in health and social care	
Policy Field:	X <u>empowerment of individual patients</u> : information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients’ organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.
	X <u>empowerment of patients’ organisations</u> by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) X Civic Organization(s) Healthwatch <input type="checkbox"/> Other Subjects involved
Location	Rutland, England
Term	April 2013 - March 2015
Objectives	To improve the quality, and shape the delivery, of health and social care so that it better meets the needs of patients in Rutland.
Outcomes Impact on participants	<p>Explain what benefits has been identified as a result of this practice (for public institutions, patients and civic organization)</p> <p>Services change and improvement reflects input by patients and public, facilitated by Healthwatch</p> <p>Local Healthwatch is trusted by people who use health and social care services and by the public.</p> <p>Local Healthwatch is seen as a credible and effective organisation by partners in local authorities, the National Health Service, other statutory bodies and the voluntary and community sectors (VCS).</p> <p>Services change and improve to meet needs identified.</p> <p>Local people are enabled easily to access information about the standard of provision of local care services.</p> <p>Consumer and community views are evident in commissioning decisions and direction of services.</p> <p>Specific services developed to respond to gaps and inequalities identified through community engagement.</p> <p>The quality of care improves overall and issues of dignity and respect are prioritised in response to highlighting and evidence from local Healthwatch.</p> <p>Local Healthwatch is fully embedded in the community, is recognised as a key element in the voluntary and community sector infrastructure and is trusted by and engaged with a diverse range of people.</p> <p>Healthwatch and other agencies/bodies have supported each other in developing an integrated and inclusive approach to citizen engagement across all services.</p>
Resources	<p>Identify inherent indispensable resources to carrying-out the initiative (human and financial resources, logistic facilities, information, experiences etc.)</p> <p>In order to act as patient champion financial resources are required to:</p> <ol style="list-style-type: none"> 1. Employ staff to run HWR, to set up information services and recruit and manage volunteers, to identify the needs of patients and inspect health and social care premises 2. Rent, set up and run an office 3. Liaise with other organizations, e.g. Healthwatch England, CAB, local healthcare commissioners (Clinical Commissioning Groups).

ANALYSIS

Development of the BP	4. HWR was established by government reform and funding to act as an independent body to champion patients' health and social care
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	<p>needs. This involves liaising with other local Healthwatch to share good practice and to report issues of concern to Healthwatch England. In order to improve health and social care provided to patients in Rutland, three main activities have been identified by HWR:</p> <ol style="list-style-type: none"> 5. Listening to the concerns of patients 6. Signposting (directing) patients to sources of information and support 7. Influencing the commissioners and providers of health and social care
Did you meet any obstacles?	<p>X Yes:</p> <p>There are operational obstacles in terms of funding, as central government has passed the money to local government for distribution to local Healthwatch such as HWR at a time when local governments face severe financial pressure. Perhaps inevitably, in spite of long negotiations, HWR has not received the full financial allocation from central government. To ensure that the functioning of HWR is not adversely affected, consideration is being given to how to raise funds from other sources.</p>
Factors enabling the process	<p>In England there is widespread support among patients and commissioners and providers of health care for the concept of patient-centred care and responsiveness to patients' needs.</p>

EVALUATION

Reproducibility:	Yes, Healthwatch is an approach that could easily be replicated in other situations and places. It is a national network in the UK.
Innovativeness:	Healthwatch Rutland, like other local Healthwatch, is set up as independent organizations to operate fully independently of local and national government. They have the power to enter the premises of health and social care providers and report their findings.
Added value:	Healthwatch are expected to shape the provision of health and social care from the perspective of patients and carers.
Appropriateness:	A comprehensive picture can be drawn to influence appropriate commissioning to meet the need.

Best practice N.26

CONTACT DETAILS

Name and Surname	Dee O'Sullivan
Organization	Myhealthapps.net / PatientView
Country	United Kingdom
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Phone number	+32 495 893925 (Belgium)

Short description of the organization/public institution

Myhealthapps.net is a free portal of only health and wellbeing apps that have been recommended and reviewed by patient and consumer groups. It is an initiative of PatientView, a UK-based data, research and publishing consultancy that works with 120,000 patient groups worldwide to canvass and reflect the views of patients on their healthcare.

DESCRIPTION

Title of the BP	
Patient-Recommended Apps to Support Better Self-Care	
Policy Field:	<input checked="" type="checkbox"/> empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.
	<input type="checkbox"/> empowerment of patients' organisations by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making. For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice	<input type="checkbox"/> Public Institution(s) <input checked="" type="checkbox"/> Civic Organization(s) Over 500 patient and consumer organisations have contributed reviews of the apps – for full list please go to http://myhealthapps.net/reviewers
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	<p>X Other Subjects involved</p> <p>The website was developed with the support (commercial and non-commercial) of the European Health Forum Gastein, GSK, Janssen, NHS England's Health Apps Library, Novo Nordisk, O2 Telefonica and the Vodafone Foundation. It also received strong encouragement from the European Commission's DG Connect.</p>
Location	Global (the site features apps from around the world).
Term	Official launch: 14 November 2013 (ongoing)
Objectives	Myhealthapps.net was launched in November 2013 as a free web portal to empower patients, health-aware consumers and the general public to support better self-care and management of their own and their families' health conditions by finding trusted health and wellbeing apps.
Outcomes Impact on participants	<p>myhealthapps.net cuts through the estimated 100,000 'health' apps on the market to only feature those that have been recommended and reviewed by patient and consumer groups. The site now features 350 apps (with new apps added each month), covering 150 health specialties and 50 languages.</p> <p>It also has a unique 'heart' rating system developed from the results of a 2013 study carried out by PatientView of 250 patient, disability and consumer groups from 16 countries around the world into what people want from their health apps. Their five key attributes were:</p> <ol style="list-style-type: none"> 1. Give people more control over their condition, or keep them healthy 2. Be easy to use 3. Be able to be used regularly 4. Allow networking with other people like them, or with people who understand them 5. Be trustworthy. <p>Visitors to the site can be sure that the apps featured have been tried and trusted by other people with the same health conditions</p>
Resources	We are working with our existing partners and seeking new partners to develop and increase awareness of the site and provide useful related information (eg regulatory updates, surveys, white papers, reports etc). The core team (5 – content, editorial, database and general management and patient engagement) is based in the UK with 1 person in Brussels managing day-to-day operations.

ANALYSIS

Development of the BP	During 2013 PatientView worked with Minervation Ltd, a UK evidence-based healthcare consultancy and web design agency that has been building award-winning websites for charities, companies and the NHS for over a decade, to create a simple, accessible web portal where patients, their families and carers and the health-aware consumer could find apps that have been tried and trusted by people like them. The site is organised into 11 main health categories each containing detailed sub-categories so visitors can quickly find the health specialty they're looking for, plus useful related apps for their particular condition (eg specialist diets, exercise, sports etc). Our partners also gave welcome input and the launch event in
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	Brussels on 14 November 2013 was designed to allow all stakeholders (patients, healthcare professionals, policy-makers, health researchers, pharma/medtech/mobile industry representatives, app developers etc) to come and try out the site and provide feedback on its usefulness and user-friendliness.
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EVALUATION

Reproducibility:	There are other app sites out there but none that we know of that only feature patient -recommended apps.
Innovativeness:	myhealthapps.net in itself is not innovative but the site is an entirely novel concept, whose intention is to enable health apps go mainstream, increase.
Added value:	As all the apps featured have been submitted by patient or consumer groups this has greatly increased their relevance to other people with the same health conditions. For example, a cystic fibrosis sufferer has very different nutritional needs (high-fat diet) to the standard recommended healthy diet by public health authorities. We show related apps that have been recommended as particularly useful for a particular health condition.
Appropriateness:	We believe myhealthapps.net is a useful tool to help patients and consumers find health and wellbeing apps that they can trust.

Best practice N.27

CONTACT DETAILS

Name and Surname	Ivone Machado Coutinho
Organization	Diabetic Association of São Miguel and Sta Maria Islands
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Phone number	+351962821247

Short description of the organization/public institution

Social and community integration of diabetics and the protection of their rights;
 The protection of diabetic patients in a situation of manifest and recognized economic shortage;
 The Association, in its capital-related development experience will encourage and promote education, prevention and scientific research in the scope of diabetes.

DESCRIPTION

Organization of a network of associations of chronic pain

Policy Field:

Surveys of Chronic Pain to patients and their families

Lectures, Conferences

Partnerships

Group Therapies

X **empowerment of individual patients**: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.

X **empowerment of patients' organisations** by the creation of national or Eu. networks, which transfer to them competences and tools, help them create partnerships, identify common objectives, etc., so as to have an effective impact on the health policy-making.
 For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organization of services, etc.

Actors of the Best Practice

X **Civic Organization(s)**

4 Associations:

Diabetic Association of São Miguel and Sta Maria Islands

Senior Association

Azorean Association of Children with Disabilities

Machado Joseph Association

	X Other Subjects involved Regional Pain Control Program , Regional Health Department Azores
Location	Ponta Delgada, S. Miguel, Açores
Term	After the network associations has been established
Objectives	Identify people with pain, their limitations, forwarding treatment Flag and identify risk factors for pain Present measures and strategies (with or without drugs) to pain control Present measures for improvement of quality of life for the patient with pain “Teach” how to live with pain Show that the treatment of pain is a human right
Outcomes Impact on participants	Epidemiologic studies Pain Treatment Live Quality Improvement Improvement acceptance of illness condition
Resources	Health Professionals participation in different areas Civic organizations Flyers Financial resources

ANALYSIS

Development of the BP	Health Professionals that usually deals and have training with pain and relationship with specialists from each of the areas involved Community activities Screening programs
Did you meet any obstacles?	X Yes: Means used to overcome or remove the obstacles: find not people coping with chronic disease
Factors enabling the process	Commemorative days of each associations and related institutions

Best practice N.28

CONTACT DETAILS

Name and Surname	Birgit Beger
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Short description of the organization/public institution

The Standing Committee of European Doctors (CPME) represents national medical associations across Europe. We are committed to contributing the medical profession's point of view to EU and European policy-making through pro-active cooperation on a wide range of health and healthcare related issues.

We believe the best possible quality of health and access to healthcare should be a reality for everyone. To achieve this, CPME promotes the highest level of medical training and practice, the safe mobility of physicians and patients, lawful and supportive working conditions for physicians and the provision of evidence-based, ethical and equitable healthcare services. We offer support to those working towards these objectives whenever needed.

We see the patient-doctor relationship as fundamental in achieving these objectives and are committed to ensuring its trust and confidentiality are protected while the relationship evolves with healthcare systems. Patient safety and quality of care are central to our policies.

We strongly advocate a 'health in all policies' approach to encourage cross-sectoral awareness for and action on the determinants of health, to prevent disease and promote good health across society.

CPME's policies are shaped through the expertise provided by our membership of national medical associations, representing physicians across all medical specialties all over Europe and creating a dialogue between the national and European dimensions of health and healthcare.

DESCRIPTION

Title of the BP

International surveys on health literacy of functional decline and frailty related to ageing

Policy Field:

X empowerment of individual patients: information, support and capacity-building of individual patients with chronic diseases and chronic pain, as well as their relatives, who usually play an essential role in helping them to deal with their conditions, including their social, psychological, and other impacts. This includes partnerships between patients' organisations and other stakeholders, i.e. health professionals, public institutions, media, healthcare industry, etc.

X empowerment of patients' organisations by the creation of national or EU level networks, which transfer competences and tools to patients' organisations, help to create partnerships, identify common objectives, etc., so as to have an effective impact on health policy-making.

For example: courses in self-management, integration of hospital/community services, involvement of chronic patient associations in the organisation of services, etc.

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Actors of the Best Practice	<p>X Public Institution(s)</p> <p>The following international organisations, public institutions, civic organisations participated: CPME, the European Patients’ Forum, the Council of European Dentists, the Romanian College of Physicians, the Latvian Medical Association, the Israel Medical Association, Teaching University Hospital ‘Bagdasar Arseni’, Bucharest, St. Luca Chronic Disease Hospital, Riga Stradinš University, the University of Maastricht University, the Bone and Joint Decade.</p> <p>List of personal contributors (in alphabetical order): Dr Gunta Ancane, Latvian Medical Association Michelle Glekin, Israeli Medical Association Prof Dr Tomasz Kostka, Medical University Lodz Prof Dr Gelu Onose, Chair CPME WG Healthy ageing – coordinating editor Dr Konstanty Radziwill, CPME Immediate Past President Olga Rostowska, President of the European Medical Students’ Association Dr Itzhak Siev-Ner, Israeli Medical Association Prof Kristine Sorensen, Maastricht University, Consortium partner of HLS-EU Prof. Dr. Tiberiu Spiricu, Romanian statistics expert Dr Jacques van der Vliet, CPME expert EIPAHA Dr Anthony Woolf, the Bone and Joint Decade Association</p> <p>CPME Secretariat: Anamaria Corca, CPME EU Policy Advisor Henry Kizito, CPME Maastricht University Intern Daria Zygmunt, CPME EU Policy Intern</p>
Location	<p>It is an ongoing initiative aimed to assess the health literacy of doctors and patients concerning prevention of frailty and functional decline related to ageing. Two international surveys will be launched between April and June 2014 in the following countries: Romania, Israel, Latvia, Belgium and the UK. Other countries might follow.</p> <p>The objective is to gather data and evidence concerning barriers to health literacy of functional decline and frailty related to ageing.</p>
Term	April 2014 – October 2014
Objectives	<p>The main objective of the surveys is to assess the levels of health literacy on frailty and functional decline related to ageing and gather data and evidence concerning barriers to health literacy on these matters.</p> <p>The two surveys are aimed at doctors and 60+ older adult patients. The survey for doctors aims to assess the awareness of doctors on functional performance (/capacity) as well as decline and frailty related to ageing and their possibilities to prevent/ delay the onset of these issues and/or mitigate</p>

	<p>their consequences.</p> <p>The survey for patients also aims to assess the awareness, opinion and attitude of the population aged over 60 regarding healthy and active ageing. The surveys build on the conceptual framework of the European Health Literacy Project (HLS-EU).</p>
<p>Outcomes Impact on participants</p>	<p>This is an ongoing initiative and the impact and outcomes will be assessed towards the end of the initiative, by October 2014.</p>
<p>Resources</p>	<p>The initiative is the result of voluntary work in partnership. Main resources were human resources and time.</p>

ANALYSIS

<p>Development of the BP</p>	<p>This initiative is part of the European Innovation Partnership on Active and Healthy Ageing (EIPAHA). It represents a commitment to contribute to 'Prevention of frailty and functional decline', as specified in the A3 Action Plan on this topic (Action Plan, 2012 p. 40). This commitment appears on the A3 Action Plan on Prevention of frailty and functional decline and it refers to 'a health literacy programme and educational programmes for patients and caregivers'. A first step for the development of the programme refers to a report on findings concerning the level of health literacy of functional decline and frailty related to age.</p> <p>The initiative will result in an assessment of the views, needs, benefits and barriers related to health literacy of functional decline and frailty. The findings and the recommendations will constitute a unique tool to inform policies and decision-making at various levels.</p> <p><i>Structure of the survey</i></p> <p>The survey consists of a general section and five specific sections as follows:</p> <ul style="list-style-type: none"> A. <i>General personal information on the respondent</i> B. <i>Specific sections:</i> <ul style="list-style-type: none"> I. <i>Awareness and understanding of the concepts of functional decline and frailty related to age</i> II. <i>Access information on functional decline and frailty related to age</i> III. <i>Understand information on functional decline and frailty related to age</i> IV. <i>Appraise the information on functional decline and frailty related to age</i> V. <i>Apply the information on functional decline and frailty related to age</i> <p>The methodology of the surveys includes specifications on:</p> <ul style="list-style-type: none"> - Translation, collection of data and data analysis
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	<ul style="list-style-type: none"> - Sampling - Ethical considerations
Did you meet any obstacles?	<input type="checkbox"/> No <input checked="" type="checkbox"/> Yes: The initiative is a result of voluntary work in partnership. Obstacles referred to human resources and financing. These were overcome when the coalition widened and the initiative received more support.
Factors enabling the process	During the development of the survey partners interacted on a regular basis. As more trust emerged between different partners, the initiative also developed at a faster pace.

EVALUATION

Reproducibility:	Yes. The coordinator of the initiative would have to assess the most effective ways to advance the initiative and communicate very clearly to the different partners.
Innovativeness:	Yes. The two surveys are the first of their kind to be launched at EU and international level. Furthermore, they take a patient-centric approach and the findings will inform policy-making at EU and national levels, especially with regard to prevention of frailty and functional decline, as newly emerging, non-disease specific approaches of prevention.
Added value:	Yes, collaborative work was fruitful and the views of different partners strengthened the overall process to develop a strong initiative.
Appropriateness:	The work relied very much on a collaborative approach and it enabled an appropriate management of the process.

OTHER INFORMATION – please see below

Conceptual framework and methodology

The conceptual framework of the questionnaires was derived from the conceptual model and definition developed by the HLS-EU, where HL is defined as "linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course."⁵ Hence, this survey focuses on the ability of doctors and patients to find, understand, judge and use information to make decisions concerning the prevention of functional (/capacity) decline and frailty, related to ageing. Functional (/capacity) decline and frailty can be defined as outlined below and further, in the Annex below.

Definition(s) of awareness: "Knowledge or perception of a situation or fact" or "Concern about and well-informed interest in a particular situation or development"⁶. "Knowledge that something exists, or understanding of a situation or subject at the present time based on information or experience"⁷. Customized definition for health/ medical awareness: "having knowledge/ notion or conscious understanding of an event or medical subject" (J. v. d. Vliet)

Definition of frailty: *Frailty** is a "state of increased ("secondary"⁸) vulnerability"⁸ in older adults, "with multiple system impairments" and consequent decline "in physiological reserves", and functional "capacity"⁹ (but, admissible, dialectically balanced⁸, by "resilience", regarding the "ability to cope with everyday or acute stressors"⁹ – see adding and comments below and further). It "carries an increased risk for poor health outcomes including falls, incident disability, hospitalization, and mortality."⁹

Introductory outlining of functionality – performance and capacity: An individual's **functional performance**, including with its age-related decline/ impairment, mainly refers to "somatic"/ "neuro--myo--arthro--kinetic" items, basically of **ADLs/ IADLs** type – but also with necessary underpinning cognitive connections – **whereas** his/her **functional capacity** (also including with its age-related decline/ impairment) is considered to be described – quantitatively, too – by the aerobic power¹¹. So, as above emphasized, these terms address two very closely inter-conditioned, but not identical, bio-functional categories/ states. Defining **functional decline**, including – especially, according to our focus: in older adults – there is also important to be pointed out the difference between the theoretical capability/ declared by the elderly "in standard functional disability assessments" and their "actual performance in daily life (enacted)" "tenses"¹². This is mainly due to the fact that "some people may compensate for underlying functional decrements by adapting to a modified daily routine (e.g., the use of assistive devices) in order to maintain the same level of performance in real life (enacted)" and/or with "social support", within "internal", respectively, "external" "compensatory strategies"⁹. On the other hand, it is to be noted that different pathological/ para-physiological disabling statuses and/or "various demographic factors/ variables" may also "influence" on self-reported activity restriction/ functional limitations at older ages" (e.g.: "higher for people with several types of limitations, especially orientation and physical controlling for such limitations", "increased with age beyond 70", "higher for men than women below 70", "higher in institutions than in households")¹³. Regarding the **functional performance and its related to ageing decline**, for instance, the Functional Independence Measure (FIM) instrument can measure them both – see further.

*term with quite large/ growing recognition in the literature, although not yet unanimously

accepted

**with intricate – in "self-perpetuating"/ vicious circle – para-physiological/ clinical occurrences, usually matching an "aggregate" "in a hierarchical order" into "syndromal presentation" (notion outlined as "a group of signs and symptoms that occur together and characterize a particular abnormality")⁹

***hence possibly being preventable and even reversible, especially in its early stages; therefore, it is likely rather (only) a "precursor of disability"¹⁰

"The conceptual model integrates three health relevant areas (health care, disease prevention, health promotion) and four information processing stages (access, understand, appraise, apply) related to health relevant decision-making and tasks."¹⁴ Awareness is a 5th area next to the health relevant areas. The 4 main domains (general knowledge, healthcare, disease prevention, health promotion) are assessed through 4 stages of HL related "information processing stages" (access, understand, appraise, apply).

These join in an evaluation paradigm based on a 4 points scale, ranging from "very easy" to "very difficult" as well as 'don't know'. Figure 1 below depicts the main parts of this model.

The conceptual model for the questionnaires within the survey(s) was operationalized to cover five domains/sections:

- Awareness on the subject matter
- Ability to access information concerning functional decline and frailty related to ageing
- Ability to understand information concerning functional decline and frailty related to ageing
- Ability to appraise information concerning functional decline and frailty related to ageing
- Ability to apply information concerning functional decline and frailty related to ageing

For each of these five domains two sets of questions were developed which related to doctors and 60+ older adult patients, respectively. The questions were developed by an expert panel from various disciplines such as gerontology, HL, Physical & Rehabilitation Medicine, Occupational medicine, General Practice etc. Specific attention was given to ensure plain and simple wording – despite approaching a quite new and complex field – in the development of questions. The questionnaires for 60+ older adult patients will be translated from English (originally elaborated) into **four languages (Romanian, Latvian, French, Hebrew)** by the use of translation-back-translation and uploaded into the electronic questionnaire platform, using Survey Monkey.

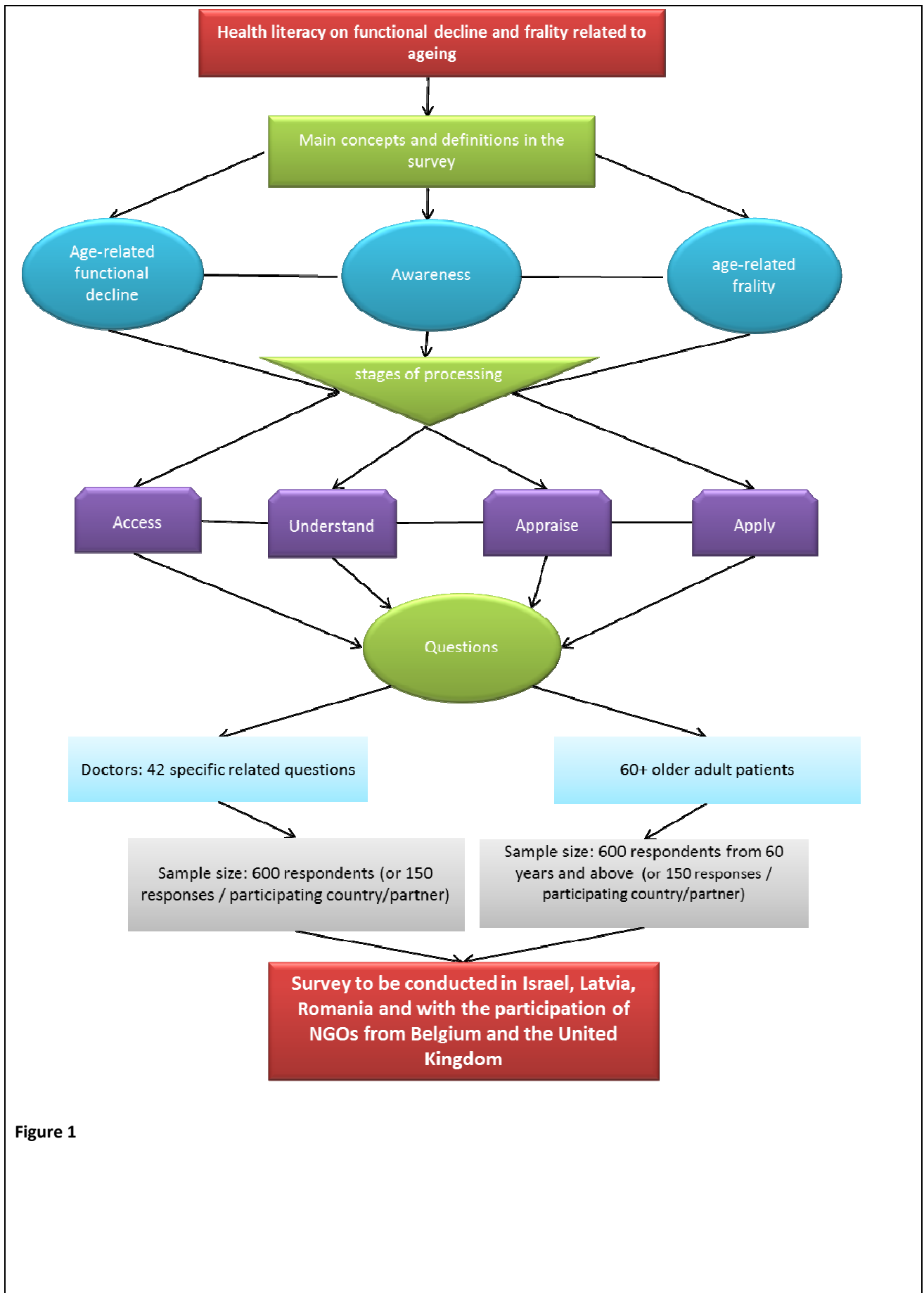


Figure 1

Construction of indices regarding HL on functional decline and frailty related to ageing

The conceptual model is sustained by several indices. In each case, a dimension within the conceptual model is matched by a stage of processing and each index represents this conceptualization.

Following the literature on measuring scales for health surveys, the two surveys include several correlations in order to ensure construct validity as well as criterion validity to a high degree.

The types of answer options enable statistical analysis in the sense that both surveys may include, too, for calculations, models such as: ordinal integrated (instead of numerical) – median (inter-quartile) frequency of correct answers, dispersion instead of variance, Somer’s delta instead of Pearson correlation coefficient – or binary (frequency of yes answers) and also, possibly, refinements based on weights of items within the questionnaires^{15,16}. Following the survey analysis methodology in healthcare, provided by Ian McDowell, the construct of these two surveys reflected on construct validity and reliability making sure appropriate correlations, are in place¹⁷.

Structure of the questionnaire for doctors <i>The questionnaire for doctors consists of 42 questions</i>	Structure of the questionnaire for 60+ older adult patients <i>The questionnaire for 60+ older adult patients consists of 46 questions</i>
Each questionnaire consists of a general and five specific sections:	
<ul style="list-style-type: none"> • General personal information on the respondent; 	
<ul style="list-style-type: none"> • Awareness and understanding of the concepts of functional decline and frailty related to ageing 	
<ul style="list-style-type: none"> • Access information on functional decline and frailty related to ageing 	
<ul style="list-style-type: none"> • Understand information on functional decline and frailty related to ageing 	
<ul style="list-style-type: none"> • Appraise the information on functional decline and frailty related to ageing 	
<ul style="list-style-type: none"> • Apply the information on functional decline and frailty related to ageing 	

Sampling

It is estimated that a sample of 150 respondents from each participating country will satisfy the statistical requirements of sampling.

A sample size of 600 (from the participating countries and NGOs) will ensure normally the identification of a 7% (or more) significant difference between two proportions, when one of them is 25% or less. (The signification level is supposed 0.05, the power 0.8.).

- For the survey for doctors, the participating countries and NGOs will recruit each 150 doctors. Additionally, the survey will be launched online increasing the number of respondents.
- For the survey for patients, the participating countries and NGOs will recruit each 150 patients. Additionally, the European Patient Forum may support to ensure a wider recruitment.

- Data will be stored in two ways:
 - o For the online questionnaire, it will automatically be stored within Survey Monkey.
 - o For the printed questionnaires, it will be sent back by each participating country and collected within the CPME Secretariat.

Data analysis

Once the data is collected both from Survey Monkey and via the 4 member states participating, the analysis will be performed by the participating organisations together with the support of a statistician. The survey respondents may be extended to other European countries.

The surveys are available on the CPME website as well as the European Commission website. Please see the links below:

CPME
Survey for doctors: http://www.cpme.eu/survey/health-literacy-of-frailty-and-functional-decline/
Survey for patients: http://www.cpme.eu/survey/health-literacy-of-functional-decline-and-frailty-related-to-ageing-pilot-questionnaire-for-patients/
Methodology http://www.cpme.eu/survey/health-literacy-survey-on-functional-decline-and-frailty-introduction-and-methodological-background/
European Commission
http://ec.europa.eu/health/ageing/portal/index_en.htm http://ec.europa.eu/health/ageing/portal/news/index_en.htm

Ethics

All respondents are informed about the aim of the survey and how the results will be used and disseminated and asked for informed consent when filling out the questionnaires.

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