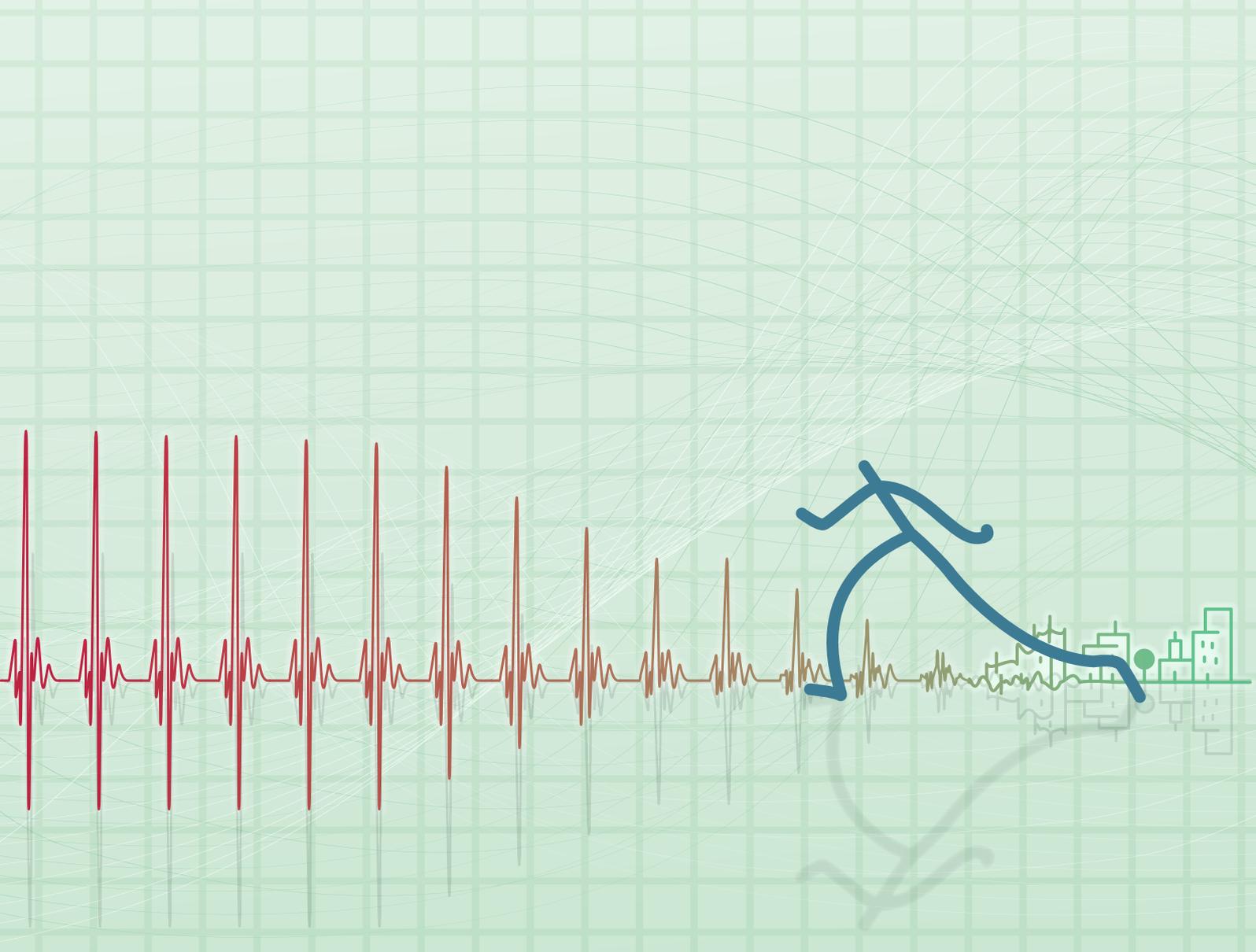




BEST PRACTICES OF CIVIC PARTICIPATION IN HEALTH

EUROPEAN AWARD



“Best practices of Civic Participation in Health” European Award

The aim of this action has been identifying and **awarding a prize for the 3 best practices** of involving citizens and patients organizations in health policy.

Active Citizenship has decided to dedicate this award to the **European Year of Voluntary Activities Promoting Active Citizenship**, designated by EU for the 2011.

A best practice of civic participation in health is a successful initiative that has been implemented regarding the participation of citizens' organizations in health policies on the basis of the 3 rights of active citizenship as declared in **European Charter of Patients' Rights**.

The collection of the best practices has took place on ACN web site between the 20 of January and the 20 of February 2011.

A special jury of experts¹ evaluated the content of the 33 best practices collected, on the basis of the suitability to the established four criteria (Reproducibility; Innovativeness; Added Value; Appropriateness).

Three Prizes money of euro 3,000 for the first placed BP, euro 2,000 for the second one and euro 1,000 for the third one will be awarded to the three best practices during the conference.

The winners

1st Classified:

BP. n. 14 “Chance for life”. Organization: Association of Women with Cancer and Adherents. Bulgaria

2nd Classified:

BP. n. 33 “Play-therapy and pain in children”. Organization: Unità Operativa di Pediatria Pession. Oncologia ed Ematologia Pediatrica. Policlinico S. Orsola Malpigli. Italy

3rd Classified:

BP. n. 30 “Patient Involvement in Health Technology Assessment (HTA) and clinical guidelines”. Organization: Pelvic Pain Support Network. United Kingdom

All the best practice collected and the criteria are available on ACN website:
www.activecitizenship.net

¹ A special thanks to: **Mary Baker**, European Federation of Neurological Associations (EFNA); **Nicola Bedlington**, European Patients' Forum (EPF); **Birgit Beger**, Standing Committee of European Doctors (CPME); **John Chave**, Pharmaceutical Group of the European Union (PGEU); **Pim De Graaf**, European Forum for Primary Care (EFPC); **Paul De Raeve**, European Federation of Nurses Associations (EFN); **Pascal Garel**, European Hospital and Healthcare Federation (HOPE); **Francesca Moccia**, Tribunal for Patients' Rights – Cittadinanzattiva; **Cira Solimene** (UILDM).

Best Practices of Civic Participation in Health - Number 1

[Best Practices List](#)

Your contact details

Name and Surname: Dudu Cosmina

Organization: Romanian Multiple Sclerosis Society

Email: cosmina.dudu@smromania.ro

Phone Number: +40725544833

Country: Romania

Description

Title of the BP: Seminar: "Multiple Sclerosis and Rare Diseases - examples of good practice"

1. Actors of the Best Practice

Civic Organization(s): Romanian Multiple Sclerosis Society and Romanian National Alliance for Rare Diseases

Public Institution(s): Ministry of Health and National Authority for People with Disabilities

Other Subjects involved: National Union of Organizations of People Affected by HIV / AIDS,
(max 250 char) Civic Organization

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Bucharest / South

Country: Romania

4. Duration

Starting date: 27th May 2010

Ending date: 29th May 2010

4. Object

- Objectives:**
(max 1000 char) Romanian Multiple Sclerosis Society initiated in partnership with the Romanian National Alliance for Rare Diseases, a seminar dialogue between young people affected by these diseases and central public authorities competent to solve the problems they have. Young people with multiple sclerosis and rare diseases dialogue with central government authorities to debate problems that they face. Young people with multiple sclerosis and rare diseases with central authorities to identify viable solutions to the problems presented by these young people. Young people with MS and rare diseases with central authorities worked together and prepare a strategy to resolve the problems presented.
- Resources:**
(max 500 char) Financing through the Youth in Action Programme and 25% Romanian Multiple Sclerosis Society contribution.
- Outcomes:**
(max 500 char) - 37 young people affected by MS, and rare diseases in all regions of Romania, participated at the seminar - 8 participants were present from the central authorities (Ministry of Health and the National Authority for Persons with Disabilities); - 5 participants from the National Union of Organizations of Persons Affected by HIV/AIDS; - It was made a lobbying and advocacy strategy by the young participants and representatives of the authorities. Objectives for the seminar were achieved successfully!
-

Analysis

- Policy Field** Youth Participation in Health
- Type of Best Practice** Dialogue
- Development of the BP**
(max 1000 char) To accomplish the seminar we had to make a progressive information for the authorities about this initiative. We have completed two training courses for young patients so that they could learn to relate to the authorities. We also covered two round tables that were held for the young patients in order for them to have the opportunity to meet the government.
- Obstacles found**
(max 1000 char) It was difficult to convince the authorities to have a positive answer to our proposal and we could see that from the small level of participation at the two roundtables that we organised.
- Means used to overcome or remove the obstacles**
(max 500 char) The authorities were continuously informed about the events by receiving official letters and reports about the youth health issue and their initiative to overcome these problems that they are facing.
- Factors that facilitated the process**
(max 500 char) Factors that have facilitated the process were: involvement of the media during the entire process; The partnership with the National Alliance for Rare Diseases has been a powerful voice to convince the authorities. In Romania, the private public partnership is in development process and we encouraged this partnership in our relationship with central authorities.

**Impact on the participants
(max 1000 char)**

At the end of the seminar, after it was determined the final form of the strategy, five young patients were responsible and accountable for the strategy step by step. The young participants were involved in local and regional organizations in lobbying and advocacy campaigns organized. One of the young participants had taken steps for setting up an civic organization for patients in her home town. Central government authorities who were present at the seminar, still participate with us at the public projects such as: information and awareness about MS and other diseases, improving the quality of life through quality services and employment.

Evaluation

- 1. Reproducibility
(max 250 char)** Young patients went at home, in all regions and got involved in their home town. They have initiated dialogue with local authorities and they go to other young patients to tell them how to get involved. The initiative may take place at EU level.
 - 2. Innovativeness
(max 250 char)** Dialogue with the authorities did not end with the seminar. Young participants can apply directly to the authorities and now they are along the same road. Innovation was that the patients had taken the first step in the difficult situation they are.
 - 3. Added value
(max 250 char)** From this experience all together learned that many parts united, solve problems more easily and as an important step for best solutions is the dialogue!
 - 4. Appropriateness
(max 250 char)** Through this dialogue, patients know their rights better and authorities know their problems now about failure patients rights and inaccess at health care services.
-

Other information: www.smromania.ro
[http://www.msyouth.ro/en/tineri_in_actiune/proiecte-in-derulare/action_5.1__training_for_social_involvement_/](http://www.msyouth.ro/en/tineri_in_actiune/proiecte-in-derulare/action_5.1__training_for_social_involvement/)

Best Practices of Civic Participation in Health - Number 2

[Best Practices List](#)

Your contact details

Name and Surname: Ludmila Mincheva

Organization: Index Foundation

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Phone Number: +35924806801

Country: Bulgaria

Description

Title of the BP: Ombudsmann in Health

1. Actors of the Best Practice

Civic Organization(s): Index FOundation and NGOs in Yambol city

Public Institution(s): municipality of Yambol,

Other Subjects involved: journalists, media, cable TV channels
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Yambol

Country: Bulgaria

4. Duration

Starting date: 1.1.2003

Ending date: 31.12.2004

4. Object

Objectives: (max 1000 char) Provide general and legal advice to the local population on issues related to health rights and healthcare

Resources: (max 500 char) The practice was initiated with a small grant from a donor.

Outcomes: (max 500 char) Over 1000 people were directly consulted in the office of the Ombudsmann. An estimated 5000 were consulted via a TV channel ed through a special session two times a week on one of the local cable TV channels.

Analysis

Policy Field Consulting the citizens of their rights in the health care system

Type of Best Practice Health Ombudsmann in one municipality

Development of the BP (max 1000 char) Following promotional events and meetings in the community a local legal expert was elected to act as Ombudsmann. The municipality provided office space and facilities. Index Foundation provided methodological guidance and covered the communication costs.

Obstacles found (max 1000 char) Initially the Ombudsmann was not popular enough and people (especially minorities had some fear to approach her)

Means used to overcome or remove the obstacles (max 500 char) PR campaign, involvement of the local journalists, training of the media reporters on patient rights,

Factors that facilitated the process (max 500 char) The interest of the local public, the support of all stakeholders - physicians, municipal staff, local NGOs, media

Impact on the participants (max 1000 char) This was the first Ombudsmann in health care ever in Bulgaria. The general public was able to get acquainted with their rights through experienced legal professional. For the first time the question of patient rights was raised. Some 150 people were able to resolve an administrative problem related to the health care system.

Evaluation

1. Reproducibility (max 250 char) The model is easy to replicate and not costly.

2. Innovativeness (max 250 char) This was the first Ombudsmann in healthcare in Bulgaria. After the official expiry of the project the Municipal Council voted to continue this practice and the municipality provided funds for the salary of the Ombudsmann.

3. Added value (max 250 char) All stakeholders were involved. A large coverage was obtained through the media

4 Appropriateness The practice was and remains to be very appropriate even today. Still

(max 250 char) a great portion of the population is at lost when an issue related to health rights occurs.

Other information:

Best Practices of Civic Participation in Health - Number 3

[Best Practices List](#)

Your contact details

Name and Surname: Raican Dan

Organization: Antiparkinson Asociation

Email: robotul2003@yahoo.com

Phone Number: 0040745231153

Country: Romania

Description

Title of the BP: Magic T Shirt

1. Actors of the Best Practice

Civic Organization(s): Antiparkinson Asociation

Public Institution(s):

Other Subjects involved: Church Baptist from Deva
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Deva/Hunedoara

Country: Romania

4. Duration

Starting date: 20.03.2011

Ending date: 20.04.2011

4. Object

- Objectives:** (max 1000 char) Organize a competition of painting how we see the respect of patient right on T shirt After T shirt is painting children wherit in the scool home town church.The best send to make a exposition in the European Parliament
- Resources:** (max 500 char) 20 T shirt ; 15 botol of special colur for t shirt ,20 brush,20 children
- Outcomes:** (max 500 char) To sensibilize the authority to put the helth of the person on the first plice To make peopel more carfully for her helth
-

Analysis

- Policy Field** Health
- Type of Best Practice** Parteneriship
- Development of the BP** (max 1000 char) The members of Antiparkinson Asociation partcipe of cultural show give by the children from School Samuel in the baptist cherchThe children help peopel with Parkinson to celebrate the inaternational Parkinson Day , The Cristmas or wester singing on instruments or with the voice painting , arange cristams tree.
- Obstacles found** (max 1000 char) It is a difrence how is perception the right of ill children adulth person ill person Now talent of painting Distroy T shirt becose the not have experience
- Means used to overcome or remove the obstacles** (max 500 char) Make exercise on ather pice of shirt and make the picture on the page and after that on T shirt competition Existing the specialis person who teach the paint and explain the object of competition
- Factors that facilitated the process** (max 500 char) It make posibil donation from the curch to asociationThe Antiparkinson asociation asure the material and the painth to make posibil competition
- Impact on the participants** (max 1000 char) Make beter capacity of non verbal comunication improvements.Stronger relation bethen organization Sensibilisy the peopel and authority.The resulth it see imadiathly but on the long-therms the benefits is stronger becose education is give more oportunity
-

Evaluation

- 1. Reproducibility** (max 250 char) It is posibil to transfer and implement in ather place but the impact is stronger how it is the original idee
- 2. Innovativeness** (max 250 char) The competition is wery new and give a great impact on peopel Resolth is see imadiatly
- 3. Added value** (max 250 char) The competition produice a great impact compare with resoulth obtain list year where is organize a similar competition but on normal paper

4. Appropriateness (max 250 char) The practice is efficient and give more oportunity to educate children

Other information: Picture on the competition is put on the public site
<http://danrobotul.sunphoto.ro/> with ather action of Antiparkinson
Asocia

Best Practices of Civic Participation in Health - Number 4

[Best Practices List](#)

Your contact details

Name and Surname: Nora Macelli

Organization: St Jeanne Antide Foundation

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Country: Malta

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)

1. Actors of the Best Practice

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

Public Institution(s): Ministry responsible for health and community care

Other Subjects involved: The Mental Health Association Malta (registered voluntary organisation made up of relatives of mentally ill persons with caring responsibilities) affiliated to EUFAMI. Some members are professionals in the health, mental health, & social work fields.
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: South-East

Country: Malta

4. Duration

Starting date: 2012

Ending date: 2014

4. Object

Objectives:
(max 1000 char)

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.

Resources:
(max 500 char)

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.

Outcomes:
(max 500 char)

- Weekly outreach work in depressed neighbourhoods leading to identification of vulnerable families & a number of mis-diagnosed sufferers. - Family Consultations on two weekdays. - 2 radio programmes. - 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.

Analysis

Policy Field Mental Health

Type of Best Practice

Partnership with another civil society organisation – the Mental Health Association Malta - with start-up funding from the Ministry responsible for health and community care. Community outreach used as a tool to identify vulnerable families at risk of br

Development of the BP
(max 1000 char)

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 programmes were aired from August to December.

**Obstacles found
(max 1000 char)**

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.

**Means used
to overcome or
remove the obstacles
(max 500 char)**

1. The Ministry responsible for health accepted the justifications presented to it and provided start-up funding for the initiative. 2. Whole family consultations enables a frank discussion of the family dynamic and the key role of each member. 3. Combating stigma and self-stigma through radio programmes and publications through which family caregivers share their experience. 4. Provision of whole-family consultations. 5. Partnership with the Mental Health Association Malta.

**Factors that facilitated
the process
(max 500 char)**

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 neighbourhoods to reach out to families, even during weekends.

**Impact on the
participants
(max 1000 char)**

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 behaviour 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"

Evaluation

**1. Reproducibility
(max 250 char)**

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

2. Innovativeness

No such service existed where overstressed vulnerable caregivers could sit down as a family with a professional to collectively thrash

(max 250 char) out their concerns. EUFAMI will edit the English version of the book for relatives by relatives being published.

3. Added value (max 250 char) -Both organisations are helping a community-based group to survey the incidence of mental illness so as to identify needs for community-based support. Other localities will become interested. -Passion for reaching out to most hard-to-reach families.

4. Appropriateness (max 250 char) - Giving a voice to a very vulnerable and unrecognised significant segment of society. - Enabling family caregivers of the mentally ill to become well-informed, more skilled and ultimately more ready to support othe carers themselves.

Other information: 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 Practices of Civic Participation in Health - Number 5

[Best Practices List](#)

Your contact details

Name and Surname: Joana Nogueira

Organization: Associação Par - Respostas Sociais

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Phone Number: 21 093 53 49

Country: Portugal

Description

Title of the BP: Clown Doctors

1. Actors of the Best Practice

Civic Organization(s): Operation Red Nose

Public Institution(s): Directorate General of Health - Ministry of Health

Other Subjects involved: They work in multiple hospitals in the country
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Lisboa

Country: Portugal

4. Duration

Starting date: 04/06/2002

Ending date: 00/00/0000

4. Object

Objectives: (max 1000 char)	Bring joy to hospitalized children, their families and health professionals, through art and image of Dr. Clown, a regular and a team of professionals with specific training. Promoting good humor as an antidote to stress along the general public through workshops, lectures and publications.
Resources: (max 500 char)	Human Resources: A team (8 staff) to ensure the logistics, administrative management of the Private Institution of Social Solidarity, and are employed 20 animators trained to perform the animations and events. Funding is provided by various companies and individuals through donations, through various fundraising campaigns, with various partners, associates, who contribute monetarily or through transfer of resources and space.
Outcomes: (max 500 char)	In addition to the animations, training and workshops, awareness campaigns that take place in hospitals and schools also collaborate and assist other associations. In 2009 visited 34,000 children in 713 visits to 11 hospitals where they work.

Analysis

Policy Field	Pediatric Health
Type of Best Practice	Collaboration
Development of the BP (max 1000 char)	Hospitals are with protocols that allow the animations to happen, there is no direct funding. The work raises awareness and promotes the involvement of users in the process and discussion of their diagnoses and treatments of choice, training for self-expression, in promoting a healthy relationship between user-medical personnel, dispelling fears and constraints, helping to understand processes. Training and teaching professionals themselves communicate more effectively with their patients.
Obstacles found (max 1000 char)	Issues of funding, which is all from private sources. Space and acceptance granted by some professionals, who consider only a joke and who resist the communication together.
Means used to overcome or remove the obstacles (max 500 char)	Regularity and seriousness with which play their animations and visits, which contribute to the growing respect and acceptance for their work in the institutions involved. Sharing of practical strategies for communication and approach to facilitate the achievement of medical work.
Factors that facilitated the process (max 500 char)	Companies who contribute financially on a regular basis, famous people joining the cause and help the growth in activity.
Impact on the participants (max 1000 char)	In the patients, and the ability to communicate, contribute, understand their rights, participate, engage with the medical staff. In the medical staff, teaching strategies, communication, awareness about the different rights and acceptance by the patient's experience in a hospital environment, the acceptance of their health conditions.

Evaluation

- 1. Reproducibility (max 250 char)** Animations can be located anywhere, where there is medical treatment provided to children.
- 2. Innovativeness (max 250 char)** Promotes the acceptance in public health, citizens and volunteers who can participate together.
- 3. Added value (max 250 char)** Operation Red Nose helps in raising awareness of some diseases, resource requirements, the need to improve the spaces and experiences in health, for the participation and collaboration between professionals and patients.
- 4. Appropriateness (max 250 char)** Promotes children and young people to establish good relationships with health professionals, with respect for their own rights and active participation.
-

Other information: <http://www.narizvermelho.pt>

Best Practices of Civic Participation in Health - Number 6

[Best Practices List](#)

Your contact details

Name and Surname: Katja Rupp

Organization: DGVP

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Country: Germany

Description

Title of the BP: Koalition gegen den Schmerz

1. Actors of the Best Practice

Civic Organization(s): Deutsche Gesellschaft für Palliativmedizin, Deutsche Schmerzliga (e.V.), Deutsche Gesellschaft für Schmerztherapie e.V. (DGS), Interdisziplinäre Gesellschaft für orthopädische und unfallchirurgische Schmerztherapie e.V. (IGOST), Berufsverband der Schmerz

Public Institution(s): Committee on Health of the German Bundestag

Other Subjects involved: chief editor of Vincentz Network (a newsletter on political health issues), the media
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Berlin

Country: Germany

4. Duration

Starting date: March 2009

Ending date: December 2010

4. Object

Objectives:
(max 1000 char)

The main object is to improve the medical provision of patients suffering from severe pain. Since 2008 there are contracts between health insurance companies and pharmaceutical companies. They result in automatic exchanges of drugs with changing contracts. Opioids that are subject to the narcotic-regulation (BtMVV) also have to be exchanged which leads to growing pain and severe side effects especially for those patients strongly suffering from pain. The coalition wants these opioids to be abolished from the automatic exchange by having the law changed.

Resources:
(max 500 char)

Preliminary meetings at Frankfurt + Berlin to work on the statements and demands. Experience of the organizations involved/ their representatives in the field of patients' needs/current health issues is vital. Breakfast round table with members of the Committee of Health of the German Bundestag in Berlin moderated by the chief editor of Gelber Dienst. Subsequently: press conference at the Federal Press Conference Center in Berlin. Costs were covered by a sponsor (approx. 10.000 EUR)

Outcomes:
(max 500 char)

the issues was discussed in the Committee of Health. Unfortunately it did not make it into the final draft of the new drug law that came into effect in December 2010 although many members of the Committee of Health wanted to support it. As an important outcome there was a wide discussion in media and the German public on the discount system of prescription drugs in general and especially the exchange of opioids.

Analysis

Policy Field Health

Type of Best Practice DIALOGUE

Development of the BP
(max 1000 char)

After the internal meetings preparing arguments the members of the Committee of health were invited to a breakfast where the discussion/ talks took place. It was a form of round table. Information was presented and handed out to them. A report was presented to the press at the Federal press center, press releases were launched, interviews given by the representatives of the initiative. As the initiative was not successful, a petition was addressed on the Petitions Committee with the aim to have the new drug law revised.

Obstacles found
(max 1000 char)

Although the politicians seemed to agree with the initiative they finally did not make any objections to the law and did not strongly recommend having it revised. They seemed to pay lip service, however did not act.

**Means used
to overcome or
remove the obstacles**
(max 500 char)

The initiative provides more arguments and finally addressed a petition on the Petitions Committee with the aim to have the new drug law revised.

Factors that facilitated the process (max 500 char)

Having found a sponsor to cover costs for the round table was a big help, otherwise the initiative wouldn't have been able to carry it through. The moderator of the round table is a big networking person and knows many politicians well.

Impact on the participants (max 1000 char)

The civic organizations involved got to know each other –and their arguments- much better. Networking has increased. Several small cooperation ideas have been called into live. Contact to the members of the Health Committee has improved which is a big help for all organizations involved as far as lobbying is concerned.

Evaluation

1. Reproducibility (max 250 char)

The kind of activity (round table, meeting) etc can be transferred to any problem in any country. It is necessary to identify the main target group (e.g. politicians in the Health Committee) and present the arguments

2. Innovativeness (max 250 char)

So far the various interest groups/ civic organization presented their arguments on their own. Joining and cooperating was a new approach. Also more politicians were addressed personally at the same time (usually 1-to-1 talks)

3. Added value (max 250 char)

By cooperating they got more interest and attention. Also, the joined effort resulted in less costs for the individual civic organization and a broader approach (more personal contacts could be used, more attention by the media)

4. Appropriateness (max 250 char)

Joined efforts result in less costs, efficient time management for those involved (less meetings, discussion on the topic), presentation of objective arguments which are not too specific but show the general need of the patients.

Other information: none

Best Practices of Civic Participation in Health - Number 7

[Best Practices List](#)

Your contact details

Name and Surname: Verkaar, Eric

Organization: Zorgbelang Gelderland

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Country: Netherlands

Description

Title of the BP: Housing needs specific client groups

1. Actors of the Best Practice

Civic Organization(s): Zorgbelang Gelderland

Public Institution(s): Vivare

Other Subjects involved: About 30 people (clients, patients) with different health problems, disabilities etc.
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Arnhem

Country: the Netherlands

4. Duration

Starting date: August 1, 2010

Ending date: December 31, 2010

4. Object

- Objectives:**
(max 1000 char) Vivare, a public housing company, wanted to assess the housing and living needs of specific groups of patients, clients, or people with disabilities. This housing corporation noticed that more and more of their renters are part of specific groups with specific needs. This is due to a long process of exramuralisation of institutions for people with all kind of health problems. More and more people with health problems are no longer living in these institutions, but rent houses or rooms from public housing corporations. For Vivare the question was whether their housing accommodations do meet the needs of these people, now and in the next 20 years.
- Resources:**
(max 500 char) - 350 hours of advice from Zorgbelang Gelderland, paid for by Vivare - about 30 people from specific groups (people with mental and physical disabilities). They volunteered their personal expertise. - Access to demographic databases
- Outcomes:**
(max 500 char) - Scenario's for over the next 20 years of housing and living needs for 3 major groups (mental health problems, physical disabilities and mental disabilities in 6 communities. - These scenarios give estimations in volume (how many people) and in quality (what do these people want).
-

Analysis

- Policy Field** Housing and health
- Type of Best Practice** Partnership
- Development of the BP**
(max 1000 char) Within half a year, these scenario's were developed, in collaboration with the housing corporation and people from different groups with different kind of health problems.
- Obstacles found**
(max 1000 char) Finding volunteers is sometimes difficult
- Means used to overcome or remove the obstacles**
(max 500 char) Finding people through our network of volunteers
- Factors that facilitated the process**
(max 500 char) - The housing corporation had a real need and searched for real participation of people with health problems -The housing corporation was willing to pay for support.
- Impact on the participants**
(max 1000 char) -Participants (volunteers) were very happy to learn that a housing corporation wants to respect their needs and wishes. The housing corporation was very impressed by the expertise from these volunteers.
-

Evaluation

- 1. Reproducibility**
(max 250 char) This kind of project can be reproduced all over Europe. There are housing corporations and people with specific needs, everywhere.

- 2. Innovativeness (max 250 char)** This is one of the first experiments where a housing corporation bases its planning of building on wishes of specific groups of people with health problems.
- 3. Added value (max 250 char)** This project has a large impact on the living situation of the groups with health problems in the 6 communities, over the next 20 years.
- 4. Appropriateness (max 250 char)** This project is very efficient: it prevents relocations in housing situations after having build of rebuilt houses, which (without this project) do not meet the needs of specific groups of people who are going to live in these houses the next 20 years
-
-
-

Other information:

Best Practices of Civic Participation in Health - Number 8

[Best Practices List](#)

Your contact details

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Organization: Zorgbelang Gelderland

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Phone Number: +31263842822

Country: The Netherlands

Description

Title of the BP: Hospital Mystery Patients

1. Actors of the Best Practice

Civic Organization(s): Zorgbelang Gelderland

Public Institution(s): Slingeland Ziekenhuis Doetinchem

Other Subjects involved: Patients of 24 ambulatory clinics of the the Slingeland Ziekenhuis in
(max 250 char) Doetinchem

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Doetinchem

Country: the Netherlands

4. Duration

Starting date: May 1, 2010

Ending date: December 18, 2010

4. Object

- Objectives:** (max 1000 char) The Slingeland Hospital wished to improve the quality of care on their 24 ambulatory clinics, from the perspective of patients and not from the perspective of the doctors, nurses and management.
- Resources:** (max 500 char) - About 250 hours of support / advice - about 40 patients from the hospital: at least one mystery patient per ambulatory clinic
- Outcomes:** (max 500 char) - 24 reports from the mystery patients, one for every ambulatory clinic each. - 5 'Mirror group' reviews by patients already carried out, 10 more of these group sessions are planned. - Presentation (in competition) doctors, staff and management about what they learned by the reviews of patients.
-

Analysis

- Policy Field** Health, Hospital care
- Type of Best Practice** Partnership
- Development of the BP** (max 1000 char) - The 24 mystery patient reviews were successfully carried out. Although at the start it was difficult to find Mystery Patients. - From the 24 planned 'Mirror group reviews' 5, were successfully carried out at first. Now these group reviews are successful, another 10 reviews are planned. The other 9 ambulatory clinics still hesitate to perform such a patient audit.
- Obstacles found** (max 1000 char) - Difficulty to find Mystery patients - Difficulty to convince doctors, staff and management to participate in 'mirror group reviews' by patients.
- Means used to overcome or remove the obstacles** (max 500 char) - For finding more mystery patients, direct contact with patients in the hospital was necessary. Originally the MP's were sought by advertisements. - The ambulatory clinics which hesitate to 'undergo' a 'mirror group review' are now convinced by members of staff from the other more forthcoming ambulatory clinics.
- Factors that facilitated the process** (max 500 char) - The willingness of the management of the hospital to let patients participate in the process of quality improvement - the willingness of the management of the hospital to pay for support and advice - The element of competition
- Impact on the participants** (max 1000 char) - 15 of the 24 ambulatory clinics are actively engaged in letting patients participate in their process of improving quality of care. These people (doctors, staff, management) are highly motivated now in improving their care. Patients are also quite thrilled to be able to influence their quality of care.
-

Evaluation

- 1. Reproducibility** (max 250 char) This project can be reproduced in any hospital
- 2. Innovativeness** (max 250 char) This kind of patient participation in improving quality of hospital care, is rare.

3. Added value The effectiveness of improving quality of care, by standards of what patients want, if hughe.
(max 250 char)

4. Appropriateness This is a relatively simple project, which is easy to carry out, with al large effective outcome.
(max 250 char)

Other information:

Best Practices of Civic Participation in Health - Number 9

[Best Practices List](#)

Your contact details

Name and Surname: Antoinette Zahra

Organization: Malta Health Network

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Phone Number: 0035679230568

Country: Malta

Description

Title of the BP: Meals-on-Wheels Service in Gozo

1. Actors of the Best Practice

Civic Organization(s): The Friends of the Sick & Elderly in Gozo (FSEG)

Public Institution(s): The Ministry for Gozo

Other Subjects involved: The Department Care for the Elderly (Gozo) Restaurant & Caterer in
(max 250 char) the premises owned by MAS Volunteer clerk accountable to MAS A
van provided by FSEG Driver employed by FSEG

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Gozo

Country: Malta

4. Duration

Starting date: 01/12/1999

Ending date: N/A

4. Object

- Objectives:**
(max 1000 char) To ensure adequate nutrition in vulnerable persons, especially the housebound, the elderly, the bedridden and those with poor mobility or other special needs.
- Resources:**
(max 500 char) Funds are provided from the Ministry for Gozo: food is provided by a caterer under contract and paid for at subsidised rate by clients on receipt of meals; the meals are wholesome 3 course menu with two alternating fortnightly menus; the meals are delivered by FSEG driver in the donated FSEG van; the system is monitored by the department for the care for the elderly, the MAS and the FSEG in a committee to ensure good quality of service.
- Outcomes:**
(max 500 char) Successful outcome evidenced by the ever increasing satisfied clientele.
-

Analysis

- Policy Field** Health - Nutrition
- Type of Best Practice** Better nutrition for housebound patients
- Development of the BP**
(max 1000 char) The idea was mooted in 1999 by the FSEG in collaboration with a newly erected MAS Sheltered Residence for the Older, incorporating a new restaurant. The suggestion was accepted by the Ministry for Gozo and a partnership of the three entities was established by contract. The FSEG donated a new van expressly for delivery of meals in Gozo prepared in the MAS restaurant, bound by contract to a specific tariff, with the Ministry funding the running costs of the vehicle and providing the necessary food containers of suitable material for insulating heat. The delivery of meals is done daily - 365 days a year. The project had a slow start but has been running steadily now for 11 years with increasing success. The number of meals delivered is on the rise. There have been very few complaints and none in the past few years; so, there is general satisfaction among the users. At this rate, the Meal-on Wheels in Gozo promises to continue indefinitely.
- Obstacles found**
(max 1000 char) In the initial years, some elderly people thought that these relatively cheap meals would be like the wartime 'Victory Kitchens', but their fears were quickly neutralised by excellent food quality and preparation.
- Means used to overcome or remove the obstacles**
(max 500 char) There were some menu suggestions to suit individual likes & dislikes, but these were met head on and the clients' wishes were met reasonably well.
- Factors that facilitated the process**
(max 500 char) Factors included the good will, determination for the venture to work well, the perseverance of the actors, careful monitoring of the system and a common sense approach without rigid attitudes in regard to the clients' personal wishes.
- Impact on the participants**
(max 1000 char) General satisfaction combined with a positive will to give even better service.

Evaluation

- 1. Reproducibility
(max 250 char)** The meals-on-wheels project on the above lines should be easily reproducible in a small community with genuine charitable organisations and a cooperative governmental entity.
- 2. Innovativeness
(max 250 char)** The Meals-on-wheels idea itself is not new, but the co-operative approach in our venture is exemplary.
- 3. Added value
(max 250 char)** Added value is the end result of better nourishment and health, together with kindly regular social surveillance, for the vulnerable elderly or weak persons, especially those living alone and would not bother to cook.
- 4. Appropriateness
(max 250 char)** In spite of it having been operative in the island of Malta for many years, the meals-on-wheels service never existed in the island of Gozo until this co-operative effort was made.

Other information:

Best Practices of Civic Participation in Health - Number 10

[Best Practices List](#)

Your contact details

Name and Surname: Antoinette Zahra

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Phone Number: 0035679230568

Country: Malta

Description

Title of the BP: Including one's consent to donate his/her organs for transplants following death in the new Maltese Identity Cards

1. Actors of the Best Practice

Civic Organization(s): Eventually, The Police Dept (Comm: of Police)

Public Institution(s): The Transplant Support Group (Malta)

Other Subjects involved: M. Fsadni & Associates(who caried a National Survey on the subject on behalf of the Group.
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization:

Public Institution:

3. Location

City / Region: Hamrun

Country: Malta

4. Duration

Starting date: September 2010

Ending date: December 2010

4. Object

- Objectives:**
(max 1000 char) To have the consent of onets wish to donate his/her organs following death, for transplants, included in the new Maltese Identity Cards which will be renewed and updated shortly.
- Resources:**
(max 500 char) Report primarily referred to the Electoral Commissioner then to the Minister of Information and finally, to the Commissioner of Police the Department of which will have charge of the ID Cards renewal
- Outcomes:**
(max 500 char) A, successful outcome is widenced by the support received from both sided of Malta's Parliament and endorsed, supported and recommended by H.E. The President of the Malta during a recent National Conference organized by the Group.
-

Analysis

- Policy Field** Health
- Type of Best Practice** The idea to have one's consent to donate his/her organs for transplants, after death,
- Development of the BP**
(max 1000 char) In september of last year, this practice was approved and enacted in Italy. Although the issuing of a Donor Card is, in it self, a means of identifying a person as a prospective organ donor, this Card is not backed by a Law. Since the Iderty Card is a legal document, one's wish so expressed in this document, will have alegal binding. And, also, will provide a statistical background to our Group. The Italian experience prompted our Group Committee to pursue the matter by drawing a report which was initially directed to the Electoral Commissioner who directed us to the Hon. Minister of Information who advised us to refer our request to the Commissioner of Police as the Police Dept. will be responsible for the renewal of the Identity Cards. The general feeling is that the matter was being favourably considered and, will eventually, be approved. Govenrment and Opposition members of Parliament have openly expressed that they wil back this request and even the President of the Malta
- Obstacles found**
(max 1000 char) Fortunately, no obstacles were encountered. On the contrary, our request was met by widespread approval, all sided expressing their willingness to cooperate.
- Means used to overcome or remove the obstacles**
(max 500 char) Even the E.U is now recormending that all States promote and endorse the same policy
- Factors that facilitated the process**
(max 500 char) The process included the goodwill and collaboration of all parties that were contacted and consulted on the project. In fact, there is a general feeling of satisfaction in seeing that one's decision to donate organs after death is now receiving a final and legal endorsement.
- Impact on the participants**
(max 1000 char) With such an endorsement on Identity Cards one's consent will have a legal backing and will ensure that no organs for transplants will be lost.
-

Evaluation

- 1. Reproducibility
(max 250 char)** The project will, in the immediate term, ensure that one's organ donation consent will be honoured and not hindered by the next-of-kin.
- 2. Innovativeness
(max 250 char)** The project is innovative ' We have suggestd this matter years ago although it is now being so aggressively persued.
- 3. Added value
(max 250 char)** The end result will legally endorse one's consent and will put the issue of organ donation on a more sound footing .
- 4. Appropriateness
(max 250 char)** In spite of years of issuing Donor Cards to registered donors, this had not a legal backing. With such an endorsement on Identity Cards one's consent will have a legal backing and will ensure that no organs for transplants will be lost.

Other information:

Best Practices of Civic Participation in Health - Number 11

[Best Practices List](#)

Your contact details

Name and Surname: Jim Reilly
Organization: Patient Focus
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Country: Ireland

Description

Title of the BP: National Standards for Safer Better Healthcare

1. Actors of the Best Practice

Civic Organization(s): Patient Focus
Public Institution(s): Health Information and Quality Authority
Other Subjects involved: Health Services Executive, Dept of Health, Health/Social Care
(max 250 char) Regulatory Forum, Independent Hospitals, Forum of Post Grad
Training Bodies, Mental Health Commission, Irish Assoc of Directors
of Nursing, Clinical Indemnity Scheme, Other Advocacy Groups

2. Who initiated the Best Practice?

Civic Organization:
Public Institution: si

3. Location

City / Region: National
Country: Republic of Ireland

4. Duration

Starting date: April 2009

Ending date: April 2011

4. Object

Objectives: To develop National Standards for the quality and safety of healthcare services in Ireland
(max 1000 char)

Resources: An advisory group that was representative of all stakeholders in the Irish Healthcare system was convened. The group met on numerous occasions. A literature review was also done by the Public body. A poll was carried out of members of the public seeking their opinion on what were the important areas to be covered. The final draft was then put out to public consultation.
(max 500 char)

Outcomes: The outcome of the public consultation has been collated and a final meeting of the advisory group will be held on 8th March. Following that the standards will go to the board of the authority for approval. If approved they then go to the Minister for Health for approval and hopefully the standards will be effective from late 2011 or early 2012.
(max 500 char)

Analysis

Policy Field Health

Type of Best Practice Collaboration

Development of the BP
(max 1000 char)

The development of the standards has been facilitated by the involvement of all stakeholders and especially beneficial has been the involvement of Patient Focus and other patient advocates. The Authority has a policy of involving service users in all of their activities and our national coordinator is actually a Board Member. They have conducted many service reviews and developed a range of standards and all have involved the convening of a review or advisory group with a service user involvement. As a reputable patient advocacy group dealing in particular with damaged patients we are regularly asked to be members of such review or advisory groups. The advisory group met in regular well attended meetings. Draft documents were circulated to all for comment. The meetings were always full of open and frank discussion given the diverse background of the participants but it was generally always possible to get a consensus opinion.

Obstacles found
(max 1000 char)

As stated above the fact that some people were coming with diverse views on some issues e.g. patient advocates and hospital consultants presented some obstacles. Other obstacles were the fact that sometimes the time allowed for the meeting proved to be too short.

Means used to overcome or remove the obstacles
(max 500 char)

The chair of the Advisory Group Dr. Jon Billings done an admirable job on ensuring that any obstacles encountered were overcome as soon as possible. The ability to provide feedback by email following meetings also got around the issue of some issues not being fully discussed at meetings.

Factors that facilitated the process
(max 500 char)

A good chairperson, a reasonably convenient meeting location and excellent secretarial support to the group.

Impact on the participants
(max 1000 char)

The long term benefits probably will not be fully realised until the standards become operational. However a significant benefit has been the development of constructive dialogue and a breaking down of barriers between patient groups and the healthcare system. It has also facilitated networking and development of other links outside of the project.

Evaluation

- 1. Reproducibility**
(max 250 char) I think the process is one that could easily be replicated in other settings and particularly in countries of a size similar to Ireland.
 - 2. Innovativeness**
(max 250 char) In Ireland the concept of service user involvement is only recently developing and the production of a set of standards that can be applied to all healthcare provision is unique in our country and will hopefully lead to safer and better healthcare.
 - 3. Added value**
(max 250 char) The added value is that the development of the standards was open to all stakeholders and therefore the involvement of all will give the final version added value.
 - 4. Appropriateness**
(max 250 char) Unfortunately in Ireland in recent years we have had too many adverse patient safety events. The development of the standards we hope will reduce the risk of such incidents in the future.
-

Other information:

Best Practices of Civic Participation in Health - Number 12

[Best Practices List](#)

Your contact details

Name and Surname: Antoinette Zahra

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Phone Number: 0035679230568

Country: Malta

Description

Title of the BP: A Maltese NGO implementing ISO 9001

1. Actors of the Best Practice

Civic Organization(s): Richmond Foundation

Public Institution(s):

Other Subjects involved:
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: St. Venera

Country: Malta

4. Duration

Starting date: January 2008

Ending date: December 2010

4. Object

Objectives: (max 1000 char)	The effective implementation of ISO 9001:2008 within all the units of Richmond Foundation (NGO). ISO 9001 is a global quality management standard. ISO 9001 is a systemic proof that the Foundation is committed to promote mental health, prevent mental illness and provide quality services to persons with mental health problems or those who are at risk of experiencing such problems. It locates the service user at the centre; the feedback of service users is paramount in delivering the service.
Resources: (max 500 char)	The operations manager of the foundation was managing the project under the guidance of the Chief Executive Officer. The coordinators of each unit collaborated with the operations manager and the internal and external auditors who carried out extensive audits throughout the process.
Outcomes: (max 500 char)	An ISOed NGO which is very much concerned on quality service, with service users (customers) at the centre of the process.

Analysis

Policy Field	Health
Type of Best Practice	A Maltese NGO implementing ISO 9001
Development of the BP (max 1000 char)	Introducing the ISO 9001 system at Richmond Foundation has been a laborious process that took almost three years, since January 2008. ISO is not just a matter of paper work and lip service. It is 'do what you preach and give evidence / show what you do. Certainly, Richmond Foundation has been doing what it has been preaching, however, the evidence was not in place. Much, even more than statutorily required, was being done, yet evidence was not systematically recorded. The whole exercise indeed required a paradigm shift... a radical change in mentality.
Obstacles found (max 1000 char)	Limited human and financial resources. The Foundation could not afford the assistance of private consultants but managed to find experienced people and other help and opportunities along the way. IT WAS DOUBLY DIFFICULT AS THE FOUNDATION COULD NOT LOOK AT THE EXPERIENCES OF OTHER NGOS (trying to adopt this system) as the Foundation was the first one in doing so. Resistance to change is natural especially when the proposed change was perceived as challenging and it puts everyone 'accountable' to his/her actions. Organisation's cultural change - The whole exercise indeed required a paradigm shift... a radical shift in mentality.
Means used to overcome or remove the obstacles (max 500 char)	It is not enough in acquiring such certification: one needs to maintain it. To ensure quality of services and strict adherence to ISO 9001 requirements, there are two internal auditors who periodically visit the units of the foundation and carry out an extensive internal audit. External audits by the Malta Standard Authority (MSA) will be carried out bi-annually.
Factors that facilitated	The management believed in the strategy and did all what was possible to convince everyone within the organisation that such change was crucial and necessary. An external consultant who

(max 500 char) mainly sponsored by Malta Enterprise and Social Policy students on placements assisted the operations manager. The implementation and effective use of a digital recording and filing system made available documents more accessible and streamlined.

**Impact on the participants
(max 1000 char)**

An important issue of ISO is the feedback system which has to be put in place. Stakeholders may either pass positive or negative feedback, compliments suggestions or even complaints. The latter are adequately addresses to make sure that the foundation honours agreements with its stakeholders, being service users, professionals or suppliers etc. This exercise would have been futile if it did not help the foundation to put the service user at the centre of the system. Service users are also given systematic opportunities to give us feedback and rate satisfaction about our services.

Evaluation

**1. Reproducibility
(max 250 char)**

ISO 9001 is a quality standard that is generally adopted by private businesses in manufacture and services. It is about quality management systems and it can definitely be adopted anyhow, anywhere in any organisation, even low budget ones.

**2. Innovativeness
(max 250 char)**

It is the first NGO in Malta, in the field of health and social care, that adopted this standard. This standard is hardly adopted in NGOs as normally even large businesses struggle to adopt this system.

**3. Added value
(max 250 char)**

With ISO 9001 in place, Richmond foundation is in better position to mainstream issues of mental health especially in the private sector. This prestigious ISO label counterbalances the prevailing stigma around mental health services.

**4. Appropriateness
(max 250 char)**

Quality management system is very important, especially in organisation where 'consumers' are likely to be vulnerable. It is an integrated system of 'checks and balances' that ensures an evidence-based quality service.

Other information:

Best Practices of Civic Participation in Health - Number 13

[Best Practices List](#)

Your contact details

Name and Surname: Stella Playbell

Organization: Committee for the Protection of the Rights of People with Mental Handicap

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Phone Number: 00357 22871335

Country: Cyprus

Description

Title of the BP: Liaison service for early childhood intervention

1. Actors of the Best Practice

Civic Organization(s): Committee for the Protection of the Rights of People with Mental Handicap

Public Institution(s): Ministry of Labour and Social Insurance

Other Subjects involved: Ministry of Health, Ministry of Education, Parents Organization, Local Authorities
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution: si

3. Location

City / Region: Main office in Nicosia, there are also 2 branches at municipalities in Limassol and Larnaca

Country: Cyprus

4. Duration

Starting date: 2003

Ending date: Contracts of Liaisons end Sept 2011 but is expected to be renewed

4. Object

Objectives:
(max 1000 char) 2) to provide consultation to parents how to manage with any needs arising from the above and to exercise any right to promote the welfare of their children 3) to make the liaison and facilitate the provision of any intervention services / therapies to children from professionals 4) to establish a registry that will be utilized at the age of starting school. It should be noted that early intervention comprises services that work on physical, speech, cognitive development and self care skills

Resources:
(max 500 char) At the moment recourse for this program are 4 liaison officers with psychological and sociological academic background. These officers are currently facilitating around 300 families all over the country. There are offices at Nicosia and in two municipalities at Limassol and Larnaca. Details about the service can be found at www.cpmental.com.cy under the section Inspection of policy, "Intervention"

Outcomes:
(max 500 char) Minimise the risk for developmental disability. This is beneficial both for the children and their families but also for the state as these children in future will be less dependent upon public allowances and state support

Analysis

Policy Field	Health and Welfare
Type of Best Practice	Collaboration
Development of the BP (max 1000 char)	In Cyprus early intervention services are offered to some extent at the relevant Departments of the ministries of Health, Labour and Social Insurance and Education and Culture, as well as via a number of volunteer programs. Additional services can be found in the private sector. However there are a lot of drawbacks in the coordination of these services and lack of an over all assessment of needs required. In 2001 by order of the Cyprus Cabinet, a Liaison service was established under the supervision of the Committee for the Protection of the Rights of People with a Mental Handicap
Obstacles found (max 1000 char)	The relevant Committee spent many years to persuade the government to establish this service. The service is still running as a pilot project as the 4 liaison officers can not meet all needs and are employed on a temporary basis. Obstacles were found in the establishment of a network with relevant therapists and paediatricians as well as with welfare officers. Finally effort was made to make this service tailored to the model of community basis
Means used to overcome or remove the obstacles (max 500 char)	A lot of effort has been made from the Committee to deal with bureaucratic procedures to renew the contracts of Liaisons since were on a yearly basis. Also effort was made to give publicity to the service and strengthen the cooperation and collaboration with various agencies
Factors that facilitated	Interpersonal contacts of Liaisons with all relevant agents facilitated the process. Also local authorities and in particular the municipality of Nicosia and Kato Pafos provide valuable assistance in the

(max 500 char) of Aradippou and Kato Polemidia provide valuable assistance in the promotion of this service for the districts of Larnaca / Famagusta and Limassol / Paphos respectively

**Impact on the participants
(max 1000 char)**

The impact of the families as clients to this service has been assessed in 2009 and main findings are the following: Parents valued home visits Parents valued early and effective access to contact offices of liaison Parents were enabled to make right decisions regarding the progress of their children and handle their feelings Parents were empowered in terms of securing appropriate benefits and services and overall information about advocating for their children's rights in health and welfare

Evaluation

**1. Reproducibility
(max 250 char)**

There is evidence for an ongoing need for this project. Demand for these services have increased as a result of increased migration from EU or other countries. The project must be repeated at various geographic areas especially in the country side.

**2. Innovativeness
(max 250 char)**

It is a unique initiative for Cyprus with a remarkable outcome Added value: The collaboration of the Committee as an advocate for disabled children with state and volunteer resources has a synergetic effect and enhances the overall aim

**3. Added value
(max 250 char)**

The collaboration of the Committee as an advocate for disabled children with the state and volunteer resources has a synergetic effect and enhances the overall aim

**4. Appropriateness
(max 250 char)**

This service, if it will applied on a national level, meets all the requirements regarding availability, proximity, affordability, interdisciplinary

Other information:

Best Practices of Civic Participation in Health - Number 14

[Best Practices List](#)

Your contact details

Name and Surname: Yana Georgieva

Organization: Association of Women with Cancer and Adherents

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Phone Number: 00359 52 616937 for Bulgarian, and 0031 24 8480864 for English

Country: Bulgaria

Description

Title of the BP: Chance for life

1. Actors of the Best Practice

Civic Organization(s): Association of Women with Cancer and Adherents;Bulgarian Cancer Association;Confederation for Health Protection

Public Institution(s): 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;

Other Subjects involved:
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Varna

Country: Bulgaria

4. Duration

Starting date: July 2007

Ending date: May 2010

4. Object

Objectives:
(max 1000 char) 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

Resources:
(max 500 char) 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.

Outcomes:
(max 500 char) 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

Analysis

Policy Field Health

Type of Best Practice Dialogue

Development of the BP
(max 1000 char) 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!

**Obstacles found
(max 1000 char)**

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 can not 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.

**Means used
to overcome or
remove the obstacles
(max 500 char)**

The long period of silence and no solution often leads to despair. However, we didn't hesitate to continuously turn to, in various forms, all individuals and institutions working in the field and seek a solution. This was a test which we knew could be solved successfully with patience, faith, good will and hard work. We felt we stood for thousands of people, not just those being sick but the whole society and it gave us extra strength and courage. As for the financial issue, it was all upon us.

**Factors that facilitated
the process
(max 500 char)**

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.

**Impact on the
participants
(max 1000 char)**

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.

Evaluation

**1. Reproducibility
(max 250 char)**

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.

2. Innovativeness
(max 250 char)

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 life saving problem, was found.

3. Added value
(max 250 char)

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.

4. Appropriateness
(max 250 char)

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.

Other information: <http://varna.bgcancer.org/english/chanceforlife.html>

Your contact details

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Country: Finland

Description

Title of the BP: Experience-Based (EB) Education Initiative

1. Actors of the Best Practice

Civic Organization(s): 25 Civic Organisations, stakeholders of various disease and handicap groups

Public Institution(s): The Ministry of Education, the Finnish National Board of Education, 24 Teaching Units (TU) of the social and health care sector

Other Subjects involved: 250 Experience-Based (EB) educators from the participating organizations
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: 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.

Country: Finland

4. Duration

Starting date: 1.3.2008

Ending date: 31.12.2011

4. Object

Objectives:
(max 1000 char) 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.

Resources:
(max 500 char) 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.

Outcomes:
(max 500 char) 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.

Analysis

Policy Field health

Type of Best Practice Collaboration

Development of the BP
(max 1000 char) 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.

**Obstacles found
(max 1000 char)**

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.

**Means used
to overcome or
remove the obstacles
(max 500 char)**

Key actors have been teachers who have seen the potential of the initiative and actively promoted the use of EB educators in their own units. After the initiative has become established in one TU, it has been easy to use it as an example in other TU's. And if the TU has not had an initial interest in the initiative, the matter has been taken up later. It is important also that the initiative will not remain dependent on one interested teacher but spreads within the TU.

**Factors that facilitated
the process
(max 500 char)**

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.

**Impact on the
participants
(max 1000 char)**

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.

Evaluation

**1. Reproducibility
(max 250 char)**

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.

**2. Innovativeness
(max 250 char)**

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.

**3. Added value
(max 250 char)**

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 room in their curricula for EB knowledge.

**4. Appropriateness
(max 250 char)**

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.

Other information: -

Best Practices of Civic Participation in Health - Number 16

[Best Practices List](#)

Your contact details

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Country: Greece

Description

Title of the BP: Red Button

1. Actors of the Best Practice

Civic Organization(s): Life Line

Public Institution(s):

Other Subjects involved:
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Attica

Country: Greece

4. Duration

Starting date: 2006

Ending date: 2011

4. Object

- Objectives:**
(max 1000 char) To provide to elderly people leaving alone and with mobility problems access to health care and emergency care with the press of a button in their house 24/7
- Resources:**
(max 500 char) Volunteer assistance of medical personnel and privately founded by individuals and corporate donors
- Outcomes:**
(max 500 char) Hundreds of elderly people have been assisted by this service and have access to health care and emergency cases have been medically assisted for the past 4 years that the project has been running. Access to the service of the red button have every elderly person after applying for it.
-

Analysis

- Policy Field** Health care of elderly
- Type of Best Practice** civil society action
- Development of the BP**
(max 1000 char) Started in 2006 as an initiative of the NGO Life Line.
- Obstacles found**
(max 1000 char) Funding of the project was precarious but the acceptance of the action from society attracted the interest of the corporate sector. Now though funds are being secured they are still not enough to provide the red button to all people requesting it
- Means used to overcome or remove the obstacles**
(max 500 char) Publicity and advertisement to gain more funds and secure the participation of more people in need.
- Factors that facilitated the process**
(max 500 char) The participation of medical personnel in a volunteer bases and the motivation of relatives and neighbours of the elderly using the red button
- Impact on the participants**
(max 1000 char) More elderly people now have access to regular health care and assistance.
-

Evaluation

- 1. Reproducibility**
(max 250 char) So far Life Line is the only organization that provides telecommunication to the elderly with the press of a button. However a lot of municipalities have been inspired and have created unites of "doctor at home".
- 2. Innovativeness**
(max 250 char) As mentioned above technology use of telecommunication with the elderly has been the innovative method that has not yet been adopted by any other organization of medical unit
- 3. Added value**
(max 250 char) Protection of the level of access to health care for people of old age and with mobility problems has been the main concern of the action

4. Appropriateness The action has been serving its main scope for 4 years and is only getting better and wider in population coverage
(max 250 char)

Other information:

Best Practices of Civic Participation in Health - Number 17

[Best Practices List](#)

Your contact details

Name and Surname: Fco Carceles

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Country: spain

Description

Title of the BP: difusion y formacion en derechos y deberes servicios de salud

1. Actors of the Best Practice

Civic Organization(s): SEAUS

Public Institution(s): UOC

Other Subjects involved: colaboracion con universidades publicas UOC
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: cataluña

Country: Spain

4. Duration

Starting date: Octubre 2010

Ending date: continua

4. Object

Objectives: difusión de toda normativa legal existente en el ámbito nacional y europeo, así como formación en temas relacionados con el ámbito de la salud y con los derechos y deberes
(max 1000 char)

iniciativa del presidente de la sociedad y de la vicepresidenta, junto a la búsqueda de profesores y personal

Resources: experto en la temática a tratar en el master, con un programa que incluye ver
(max 500 char) pag.[http://sociedadseaus.blogspot.com/http://www.seaus.net/http://www.uoc.edu/masters/esp/web/ciencias_salud/Gestio/master/atencion_usuario_servicios_sanitarios/](http://sociedadseaus.blogspot.com/http://www.seaus.net/http://www.uoc.edu/masters/esp/web/ciencias_salud/Gestio/master/atencion_usuario_servicios_sanitarios/http://www.uoc.edu/masters/esp/web/ciencias_salud/Gestio/master/atencion_usuario_servicios_sanitarios/)

Outcomes: se han matriculado en el mismo un total de 15 alumnos en la primera edición de máster, ya se realizó una primera experiencia de formación en temas de derechos y deberes en el área sanitaria de Ibiza y Formentera para médicos de familia en formación periodo MIR y asignatura optativa en Univ de Lleida recordar que en el año 2011 se realizó el congreso nacional número 16 así como 9 simposios realizados y jornadas autonómicas realizadas, todo realizado por los socios y miembros de la junta
(max 500 char)

Analysis

Policy Field difusión normativa y leyes existentes en relación a los derechos y deberes de los pacientes

Type of Best Practice difusión y adquisición de conocimientos derechos y deberes a través de formación reglada on line

Development of the BP interrelación iniciativa asociación cívica profesionales de la salud junto a universidad pública con acceso libre a la formación para todos
(max 1000 char)

Obstacles found Se definió un programa con las asignaturas que debía contener así como la impartición de los mismos por parte de una serie de expertos en el tema
(max 1000 char)

Means used to overcome or remove the obstacles Conseguir que un tema como la difusión de los derechos y deberes pudiese formar parte de una formación reglada y abierta tanto para los profesionales de la salud como para los ciudadanos en general y la difusión del mismo para contar con un número mínimo de participantes que posibiliten que se pueda llevar a cabo.
(max 500 char)

Factors that facilitated the process La trayectoria de la SEAUS y su credibilidad junto a la trayectoria de su presidente actual.
(max 500 char)

Impact on the participants A largo no podemos evaluarlos pues la experiencia del master es de un escaso año, pero si contamos con la realizada en la universidad de Lleida, dependiente de la universidad central de Barcelona donde se impartía la signatura de atención al paciente al igual que la experiencia de formación de los médicos en el área de Ibiza que ha creado masa crítica y conocedora de algo muy reciente en nuestra cultura los primeros servicios de atención al paciente son del año 1984, a nivel de INSALUD.
(max 1000 char)

Evaluation

- 1. Reproducibility**
(max 250 char) es reproducible, existen universidades y organizaciones en todos los países miembros
- 2. Innovativeness**
(max 250 char) difusión y da rango necesario de conocimiento en materia sanitaria de los derechos y deberes.
- 3. Added value**
(max 250 char) amplifica las actuaciones llevadas a cabo por los diferentes servicios de atención al paciente.
- 4. Appropriateness**
(max 250 char) La atención al paciente como valor añadido de la asistencia sanitaria, paciente informado, paciente con capacidad de autonomía.

Other information:

http://sociedadseaus.blogspot.com/http://www.seaus.net/http://www.uoc.edu/masters/esp/web/ciencias_salud/Gestio/master/atencion_usuario_servicios_sanitarios/
http://www.uoc.edu/masters/esp/web/ciencias_salud/Gestio/master/atencion_usuario_servicios_sanitar

Best Practices of Civic Participation in Health - Number 18 (and 19)

[Best Practices List](#)

Your contact details

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Country: Netherlands

Description

Title of the BP: Regional Expert Teams

1. Actors of the Best Practice

Civic Organization(s): A general patiënt organisation (= Zorgbelang) and consumerorganisations (i.e. organisations of specific diseases, such as breast cancer, lung cancer, reumatism etc)

Public Institution(s): (Menzis), Providers of health care (hospitals)

Other Subjects involved:
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Groningen

Country: the Netherlands

4. Duration

Starting date: Januari 201

Ending date: December 2011

4. Object

Objectives:
(max 1000 char) Introducing the perspective and wishes of the patient in guidelines used by professionals, and in the information on paper and online (website) which is given to patients about their disease. And introducing the perspective of the patient in the policy of Health Insurance Company en the policy of providers of Health Care

Resources:
(max 500 char) Financed by Health Insurance Company and providers of healthcare
Most important resource: the experiences of patients with the care for their disease in the hospitals with wich we collaborate

Outcomes:
(max 500 char) Better quality of healthcare in terms of the perspective of the patient.
The three factions (Helath Insurance company, providers of health care and patients/patientorganisations) consider each other as equivalent partners

Analysis

Policy Field Health

Type of Best Practice Dialoge

Development of the BP
(max 1000 char) In all hospitals (5) in the region the method is used.

Obstacles found
(max 1000 char) In the beginning it was difficult to see each other as real partners in the proces, as equivalent. Now an obastacle lays in the shortage of commitment of some managers in the hospitals and also in the pressure on the doctors and specialized nurses who also have to do such projects (even when they really want to do it !!)

Means used to overcome or remove the obstacles
(max 500 char) For the first obstacle working together was the remedium to overcome. Looking for committed managers in the hospitals as allies was another. And: we have the Health Insurance Company as strong ally.

Factors that facilitated the process
(max 500 char) - A good and committed manager who can take decisions of the department of the hospital with which there is a collaboration - The fact that the Health Care Insurance Company has a very great interest in this collaboration to know what are the wishes of the patiens for their treatment and care - The fact that the Heath Care Insurance Company has an influence on the defrayment of the project - The fact that the patients unions has already good patient criteria for good treatment and care

Impact on the participants
(max 1000 char) The participants see how important it is to have a dialogue and trialogue about the quality of the quality of treatmant and care with using the experiences of patients in their departments.

Evaluation

1. Reproducibility The method can be used in other regions as well as in other fields of healthcare for example primary health care, mental health care,

(max 250 char) home care and nursing care. Zorgbelang Groningen is currently describing the method so it can be used by others.

2. Innovativeness (max 250 char) The dialogue between Health Insurance Company, Health Care Provider and Patients is innovative.

3. Added value (max 250 char) The perspective of the patient is introduced in policy making and in guidelines for professionals

4. Appropriateness (max 250 char) The method can be used in other regions as well as in other fields of healthcare for example psychiatric care, home care and nursing care.

Other information:

Your contact details

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Phone Number: +31263842822

Country: Netherlands

Description

Title of the BP: Star guide for local health policy

1. Actors of the Best Practice

Civic Organization(s): Foar Elkoar and Zorgbelang Fryslân

Public Institution(s): Local communities in Fryslân

Other Subjects involved:
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Fryslân

Country: the Netherlands

4. Duration

Starting date: januari 1 2007

Ending date: december 10, 2008

4. Object

Objectives: (max 1000 char)	Goal was to stimulate local government to help their constituents find the way to the help they need. New law 'Wet Maatschappelijke Ondersteuning' was in progress since January 1st 2007, making it a local government issue to provide that information and guidance. Sterrengids aimed at making public how good the information and guidance suited the wishes of the people it was ment for, by using a ranking with one to five stars.
Resources: (max 500 char)	Foar Elkoar received funding from the national government and paid for the realisation of the Sterrengids.
Outcomes: (max 500 char)	Local government wanted to learn about the wishes of people as provided by Zorgbelang Fryslan beforehand, so that they could make their way of providing information and guidance as good as possible before the testteam came. Results were made visible on www.sterrengids.org

Analysis

Policy Field	Community care
Type of Best Practice	Partnership
Development of the BP (max 1000 char)	Province of Fryslan was done in 2008. Next province was Noord Holland
Obstacles found (max 1000 char)	after the first rating in 2008, funding was a problem for making it sustainable. Local government did not want to pay for it
Means used to overcome or remove the obstacles (max 500 char)	we are still talking to local government to get them to pay for a bi-annual rating. We think that if more provinces are in the rating people will look at the site and ask their local council why there are no stars in their area. ___
Factors that facilitated the process (max 500 char)	___the public funding of Foar Elkoar was sufficient and the partnership between Foar Elkoar and Zorgbelang Fryslân was good
Impact on the participants (max 1000 char)	People are still very proud to have cooperated in het project. The way local government gives information and guidance has been influenced for the better

Evaluation

- 1. Reproducibility**
(max 250 char) The method is documented very clearly, so it can easily be reproduced
- 2. Innovativeness**
(max 250 char) had not been done before in this manner and still excites interest
- 3. Added value**
(max 250 char) The quality of local policy on community care is increasing because of the comparative judgment by civilians.
- 4. Appropriateness** This method can be used all over the world in stimulating the quality

(max 250 char) of ocal policy.

Other information:

Best Practices of Civic Participation in Health - Number 21

[Best Practices List](#)

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Country: Netherlands

Description

Title of the BP: Eigenwijs spel

1. Actors of the Best Practice

Civic Organization(s): Zorbelang Gelderland

Public Institution(s):

Other Subjects involved: 6 Charity Funds:. Identity games (profesional game developing company)
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Netherlands

Country: the Netherlands

4. Duration

Starting date: Januari 1 2010

Ending date: December 31, 2010

4. Object

Objectives: To develop a board game for people with mental health problems, to discuss these with their relatives, friends etc.
(max 1000 char)

Resources: Funding by 6 charity funds. About 100 volunteers (patients, professionals) who developed and tested this game.
(max 500 char)

Outcomes: A highly successful game (within 2 months more than 500 copies sold)
(max 500 char)

Analysis

Policy Field Mental Health care

Type of Best Practice Dialogue

Development of the BP In 2010 about 1200 volunteers have thought out and tested this game in several sessions. The volunteers were mostly patients and some professionals.
(max 1000 char)

Obstacles found It takes a lot of time to develop a game and specific skills are required
(max 1000 char)

Means used to overcome or remove the obstacles Extra efforts (in time) were needed and cooperation with a professional developing company were sought.
(max 500 char)

Factors that facilitated the process The availability of the funds
(max 500 char)

Impact on the participants This game is a very important asset for people with mental problems, to discuss these with their relatives, friends etc.
(max 1000 char)

Evaluation

1. Reproducibility This game can be 'translated' all over the world.
(max 250 char)

2. Innovativeness I have never seen a game like this before. Even the developing of a game for participation of people with an illness, is new.
(max 250 char)

3. Added value It's a therapeutic instrument for both patients (self help) and professionals.
(max 250 char)

4. Appropriateness The game is a very effective and appropriate instrument for participation of patients with mental problems.
(max 250 char)

Other information: look for www.eigenwijsspel.nl and phone for an example of the game

Best Practices of Civic Participation in Health - Number 22

[Best Practices List](#)

Your contact details

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Description

Title of the BP: Activities against unauthorized Medical Devices

1. Actors of the Best Practice

Civic Organization(s): OMBUDSPOT

Public Institution(s): Ministry of Health

Other Subjects involved: Slovak Trade Inspection (SOI), Public Health Authority (UVZ), State Drug Control Authority (SUKL), Slovak Chamber of Doctors (SLK), Healthcare Supervision Authority (UDZS), Office for Normalization and Metrology (UNMS). All of them are public bodies.
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Kosice, Banska Bystrica, Poprad

Country: Slovakia

4. Duration

Starting date: 9.2.2010

Ending date: 14.2.2011

4. Object

Objectives:
(max 1000 char)

The main objective of this practice is to point to the unfair practice on the market of medical devices sold mainly through the distance and doorstep selling method. A lot of such devices are not at all medical devices and have no proven effects on ones health. They are mainly sold to the elderly people without proper access to the information giving them hope to improve their health. These devices are overpriced and bring no positives for their users. The problem arises, when consumer wants to withdraw from the contract and none of the health related authorities has the power to charge such case.

Resources:
(max 500 char)

There is mainly our junior lawyer engaged (Ms Danova) in the procedure of communicating with institutions and suggesting solutions and further steps. Luckily all the involved institutions are communicating with us and supporting our strives for change in legislation. The practice and all its activities are financed from the resources of the project of Institutionalisation of out of court solution funded from EEA/Norway grants.

Outcomes:
(max 500 char)

This has started as a common consumer complaint. But after first few attempts to solve it with public authorities we found out it requires deeper attention and more detailed work. The practice is still not finished, because we need to bring in legislative amendment that would prohibit the sale of unregistered medical devices and set the exact rules for public institutions responsible for handling problematic cases. All of the involved institutions are ready to support our amendment.

Analysis

Policy Field Medical Devices

Type of Best Practice Collaboration

Development of the BP
(max 1000 char)

Our consumer has bought a detoxication device, because during promotional presentation it was presented like universal device for healing almost all kinds of health related issues. After a week of using this our consumer was recommended by the doctor not to use this device. The consumer tried to withdraw from the contract, but the seller never accepted it. Our next steps led to a never ending communication with public institutions in order to prove the illegality of such device sold as medical device. Our initiatives triggered the communication of Metrology Office (UNMS) with Ministry of Health in the specific area of medical devices and the need for legislative amendment. We are remaining active in the case and we have prepared very concrete proposals for amendments. This proposal was presented to all involved institutions and most of them promised to support our proposal. We hope it won't take too long before this proposal will get into Slovak Parliament.

Obstacles found
(max 1000 char)

The most noticeable obstacle in solving this issue was bureaucracy of our authorities along with lack of legislative measures that would give powers to respective authority in solving this particular issue. The institutions will never solve an issue if it is not explicitly stated.

Means used to overcome or remove the obstacles (max 500 char) In order to prevent from such problems we have prepared a legislative amendment that if adopted can help consumers to avoid misleading selling of so called medical devices and will give powers to particular authority to deal with unfair traders.

Factors that facilitated the process (max 500 char) Most important facilitation of the process is the fact, that Metrology Authority (UNMS) started a communication with Ministry of Health. Their strives have led to our legislative amendment and their support can help us to push the amendment through.

Impact on the participants (max 1000 char) Our organization can possibly achieve another very important milestone in its existence, because as a result of our work many people will be protected from unfair traders selling medical devices that are not medical devices and provide misleading information. This will save the consumers significant amounts of money, but more important than that it will protect their health from unauthorized treatment and possible damages. The simple fact, that someone has bought a device that doesn't work often causes heart and blood pressure problems and negative impact on mental health. The positive impact on the involved institutions will be in clarified structure of competences in the area of medical devices.

Evaluation

- 1. Reproducibility (max 250 char)** Medical devices are being sold across Europe in all its states. Too many unfair traders have sold too many unauthorized medical devices that not only bring zero effect on humans' health, but also can causes damages. Our proposal on regulation of this
- 2. Innovativeness (max 250 char)** Innovativeness of our practice comes along with the development on the market and technological development. Issues like this didn't arise in the past, since no such devices have been produced. Every new development has impact on all parties and it n
- 3. Added value (max 250 char)** Dialogue and cooperation of several institutions has the potential to bring the most effective solution of problematic situation. The more involved subjects, the higher attention it will attract from the respective places and the sooner we can expect
- 4. Appropriateness (max 250 char)** During the entire case we have thought of many possible scenarios, but after several unsuccessful attempts to solve this issue with the trader or public authorities we decide it would be most appropriate to evolve our activities further on and try to

Other information:

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Country: Croatia

Description

Title of the BP: World congress on medical law - Development of the protection of the patients' rights

1. Actors of the Best Practice

Civic Organization(s): Croatian Association for Patients' Rights

Public Institution(s): University of Zagreb, Faculty of Law

Other Subjects involved: World Association for Medical Law, Ministry of Health of Croatian Republic, Croatian Touristic Board
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Split and Zagreb

Country: Croatia

4. Duration

Starting date: August 2000

Ending date: August 2010

4. Object

Objectives:
(max 1000 char)

The patients' rights protection was very poor in Croatia as there was a lack of the legislation on patients' rights and not efficient courts as heritage of the communistic regime. That resulted with lack of the efficient ways to sue whenever the patients' rights were violated. All together resulted with no experts' interest in health law and that field was "tabula rasa" for almost all the experts and citizens. Interested in protection of the patients' rights in Croatia, we concluded that we could not expect to have good and efficient legal frame on patients' rights in Croatia without any interest of the law experts, but other experts too. Without experts on the field of health law we cannot expect significant recognition and consecutive protection of the patients' rights. The goal - to involve as possible experts to show their interest in health law, became focus of our interests with aim to create preconditions for development of an efficient way of protection of the patients' rights.

Resources:
(max 500 char)

Experts in various fields established the CAPR, but the members are mainly patients. We have more than six hundred members and four branches. We have 14 volunteers, administrative worker and executive body called Presidency. We have the President who is surgeon and was the cancer patient with strong motivation to help with all the experience she has in different fields. Financial resources: EU, Ministry of Health, Touristic board, National Found for CS, Ministry of Foreign Affairs, WHO,...

Outcomes:
(max 500 char)

4 years no institution, experts' association or individuals showed interest in health law, congresses and conferences we tried to involve them to participate (and so to start the work on systemic development of that field of law). So, we decided to bring to them the world congress and to bring it into "their home". We passed all the way to the bid by our own, but then we find partners in organization-Faculty of Law. The 18th World Congress on Medical Law was held in Zagreb, 8-12 August 2010.

Analysis

Policy Field Health care policy

Type of Best Practice partnership

Development of the BP
(max 1000 char)

We started "ab ovo" regarding the patients' rights in Croatia. We had to prepare the public and politicians that we need the legislation on patients' rights, and we had to prepare experts to participate in a filed of health law. We did it by providing more than 60 projects on promotion of the patients' rights and we promoted health law in our reports on our participation on conferences and congresses all over the world on health law, bioethics and medical law. The interest for health law was growing. In the end, we develop the partnership with University of Zagreb, Faculty of Law to organize the 18th World Congress on Medical Law together. That was the trigger for development of the health law as separate discipline with separate curricula on some faculties in Croatia and we are proud that the health law has multidisciplinary approach in Croatia, what could be seen from the development of the common curricula and lessons for both, medicine and law students in the same time.

**Obstacles found
(max 1000 char)**

We found many obstacles on our way: Patients' rights were taboo before the CAPR was established, paternalistic attitudes are very strong in all the Croatian society and even more in the health care system and medicine itself. Croatia didn't have any legislation on patients' rights. No law experts were specialized in health law and patients had no one to ask for help as lawyers were not interested in such field, as patients' suits could not bring them money in a system with no recognition of the patients rights, no legislation and no experts in the field. In the end, it was not common that some NGO use initiative in development considering scientific issues as health law it is. That fact caused obstacles made by experts themselves for so many years.

**Means used
to overcome or
remove the obstacles
(max 500 char)**

We started by campaign providing public tribunes, promotional materials as flyers, posters, bulletin "Patient", producing TV talk-in show, giving advises to the patients. Then we started initiative and push hard to the politicians and the Croatia has the Act on Patients Rights Protection from 2004. We provide 15 presentations on patients' rights for health care workers. We gave almost finished materials to the FL and that was a very demanding task, as we had no "big scientific name" among us.

**Factors that facilitated
the process
(max 500 char)**

We are sure that the main factor that facilitated all the process was the fact that the Croatia is in front of the door of the European Union.

**Impact on the
participants
(max 1000 char)**

We can use our Croatian patients' as participants of the project as resolving their problems were the main motive for the project. Every day they were calling and asking for help. More then 11000 calls we received in 11 years and their every-day pushing and asking for help was their main impact to our project. But, participant of the project were also our members who were active in all the activities to reach the goal. They were organizing tribunes and other public events, distributing promotional materials and promoting patients' rights in their surrounding all over the Croatia.

Evaluation

**1. Reproducibility
(max 250 char)**

We think that our experience could be reproducible in other countries with lack of the legislation and health law knowledge as all the NGOs on patients' rights have many experts as members and consultants.

**2. Innovativeness
(max 250 char)**

We never heard that one NGO was organizer of the experts' world congress and it is possible with hard and dedicated work. It is very innovative approach to the development of the protection of the patients' rights in some society.

**3. Added value
(max 250 char)**

The fact is that the NGOs alone could not interfere on the politics without the cooperation with experts but when that experts are not existing at all, then our "forcing" the experts to start to deal with the issue brings real added values to both.

**4. Appropriateness
(max 250 char)**

Our strategy was persistence and it was very appropriate to the resistance of the experts and politicians. After we did so much to bring the world congress in Croatia experts could not refuse it. So, we approach our goal and it was appropriate.

Other information: www.pravapacijenata.hr/eng

Best Practices of Civic Participation in Health - Number 24

[Best Practices List](#)

Your contact details

Name and Surname: Diliana Dilkova

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Country: Bulgaria

Description

Title of the BP: Initiative for vaccine prophylaxis among vulnerable groups

1. Actors of the Best Practice

Civic Organization(s): National Network of the Health Mediators, Ethnic Minorities Health Problems Foundation, Bulgarian Association for Family Plannig, Open Society Institute, National Association of the General Practitioners in Bulgaria, National Association of the Municipali

Public Institution(s): Ministry of Health, Ministry of Labor and Social Policy

Other Subjects involved: GlaxoSmithKlein Bulgaria (pharmaceutics company)
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution: si

3. Location

City / Region: All 28 districts of the Bulgaria

Country: Bulgaria

4. Duration

Starting date: March 2010

Ending date: November 2010

4. Object

- In 2010 large scale measles epidemic affected mostly Roma communities in the country because of the low vaccination coverage of Roma population (28-30% compared to 95% planned coverage). This extreme situation required undertaking of unprecedented measures and cooperation of all actors in the healthcare field. A coalition of organizations came together with the following objectives: – Improving the vaccination coverage among Roma with the vaccines from the official Immunization calendar of Bulgaria. - Improving the collaboration between health mediators and medical specialists from out hospital health care and with the regional structures of the Ministry of Health. - Popularization and multiplication of “good practices” with regard to the health mediators’ profession, rising the public and institution’s awareness for the benefits from keeping and developing the health mediator’s model.
- Objectives:**
(max 1000 char)
- Resources:**
(max 500 char)
- Outcomes:**
(max 500 char)
- 80 Health mediators (HM) - more than 700 General Practitioners - Lecturers (epidemiologists, pediatricians and other medical specialists) for the organized trainings - Experts experienced in working with minorities in the country - Financial resources for carrying out of trainings, press conferences, round tables, media coverage of the initiative, extra vaccines for the vaccinations.
 - Each HM worked with approximately 300 Roma in order to convince them to get vaccinated during the organized immunization campaign. - Working teams including representatives of the Regional structures of the Ministry of Health, General Practitioners, Pediatricians and HMs were established in many districts of the country. -Good practices of these teams were presented at training organized for municipal representatives and HMs at the end of the campaign. All objectives were reached.
-

Analysis

- Policy Field** Health
- Type of Best Practice** Collaboration, Partnership
- Development of the BP**
(max 1000 char)
- After the outbreak of measles epidemic in the country the Ministry of Health decided to undertake urgent measures. The company that produces the vaccine – GlaxoSmithKlein joined the initiative and provided the vaccines needed for the extraordinary immunizations; the company organized a number of events. Press-conference took place at the start of the initiative and another one - for reporting the achieved results. Round table was carried out in the Parliament. Training for HMs and General Practitioners took place aiming to facilitate the establishment of working teams that were going to work on the field. In 9 towns meetings for General Practitioners and HMs from the 28 districts took place. Epidemiologists and pediatricians presented detailed information concerning the vaccines, approaches for convincing the people to vaccinate, etc. At a meeting between state institutions, municipal mayors and HMs the cooperation between institutions and HMs in the districts was presented.

**Obstacles found
(max 1000 char)**

The obstacles found were mainly due to cultural specifics of the affected population. The vaccination campaign was an attempt to overcome the obstacles that lead to the result that large number of Roma are not vaccinated or have not all of the needed vaccinations. These obstacles are due to several reasons – financial (there are many Roma that are not health insured), cultural (the health is not a value), problematic access to healthcare (remote areas, people living in ghettos), other (some people are afraid that the vaccination is dangerous, that it harms the children or even causes sterility).

**Means used
to overcome or
remove the obstacles
(max 500 char)**

The role of the HMs was crucial for overcoming the stated above obstacles - organizing the vaccinations among the Roma population required the participation of HMs in the working out of schedules for vaccination; they visited the families that haven't vaccinated their children and talked to them in order to convince them that vaccination is important for their children's health; when needed health mediators accompanied the families to the places where the vaccinations were made.

**Factors that facilitated
the process
(max 500 char)**

The good collaboration between state and local institutions and HMs facilitated the process as well as their common understanding of the problems and of the ways for solving them. This good communication was due mainly to the number of joint meetings and discussions between the multidisciplinary teams.

**Impact on the
participants
(max 1000 char)**

The public institutions representatives that participated in the initiative succeeded to take a closer look at the problems of the vulnerable minorities and to realize all the factors that have impact on the health condition of these communities – complex of social, health, infrastructural and educational problems. The collaboration between institutions and specialists improved in all the places. The HMs gained a lot of new knowledge grace to the organized meetings-trainings (types of vaccines, how they work, benefits from vaccination, impact, etc.). The position of the HMs in the established working teams was strengthened and the interest towards the HM's profession increased on behalf of the municipal representatives.

Evaluation

**1. Reproducibility
(max 250 char)**

The initiative was successful and could be implemented in other places – it could become a model for dealing with emergency situations concerning groups in disadvantaged position (crisis, epidemics).

**2. Innovativeness
(max 250 char)**

This practice is unique for Bulgaria – for the first time the efforts of all stakeholders joined – state institutions, local authorities, NGO sector and business sector worked together for solving of the problem.

**3. Added value
(max 250 char)**

The success of this practice was impossible without the collaboration between all these parties. This model seems to be appropriate for initiatives outside the health sector also and could be developed in the future.

**4. Appropriateness
(max 250 char)**

This practice showed to be one of the most appropriate practices in the recent years - the target group (the Roma population) had its representatives - Health mediators - who ensured that all the activities will be consistent and effective.

Your contact details

Name and Surname: Neda Milevska-Kostova

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Phone Number: + 389 2 3065 837

Country: Macedonia, The Former Yugoslav Republic Of

Description

Title of the BP: Steering Committee for Advancement of Healthcare

1. Actors of the Best Practice

Civic Organization(s): Over 30 CSOs active in field of healthcare and professional associations

Public Institution(s): Ministry of Health and other public institutions

Other Subjects involved: Individuals, other public institutions (Health Insurance Fund, (max 250 char) Ombudsman, etc.)

2. Who initiated the Best Practice?

Civic Organization:

Public Institution: si

3. Location

City / Region: Skopje

Country: Macedonia

4. Duration

Starting date: July 2009

Ending date: March 2010

4. Object

Objectives: (max 1000 char)	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.
Resources: (max 500 char)	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.
Outcomes: (max 500 char)	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.

Analysis

Policy Field	healthcare
Type of Best Practice	cooperation for exchange of policy ideas
Development of the BP (max 1000 char)	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.
Obstacles found (max 1000 char)	After the completion of the process, seeking of funding for the implementation of proposed ideas was seen as a challenge.
Means used to overcome or remove the obstacles (max 500 char)	Still in progress.
Factors that facilitated the process (max 500 char)	Overwhelming interest by all involved stakeholders to participate in the process.
Impact on the participants (max 1000 char)	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.

Evaluation

- 1. Reproducibility**
(max 250 char) Highly reproducible.
- 2. Innovativeness**
(max 250 char) This kind of process has never been initiated in Macedonia before, in any other sector.

**3. Added value
(max 250 char)**

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.

**4. Appropriateness
(max 250 char)**

Highly appropriate.

Other information:

Your contact details

Name and Surname: Jean Mossman

Organization: European Federation of Neurological Associations

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Country: UK

Description

Title of the BP: Health Technology Assessment Patient Academy

1. Actors of the Best Practice

Civic Organization(s): European Federation of Neurological Associations

Public Institution(s): London School of Economics and Political Science

Other Subjects involved: A number of keynote speakers are involved in delivering the patient academy from the EMA, European Commission, Spanish Patients Association, NICE and Lf. Participants have come from patient groups across Europe from a range of therapeutic areas.
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution: si

3. Location

City / Region: Course is delivered in London but for groups from across Europe

Country: the United Kingdom

4. Duration

Starting date: Sept 2009

Ending date: ongoing in 2011

4. Object

Objectives:
(max 1000 char)

The objective of the Patient Academy is to increase the capacity of patient groups to contribute effectively to HTA processes. HTA is the systematic evaluation of the clinical effectiveness and/or cost-effectiveness of the health, social and ethical impact of a health technology on the lives of patients and the health care system. Very bluntly put - it is the process that is used to decide which new medicines and other medical technologies will be made available and to whom. Currently, HTA is used explicitly as a decision tool in more than 17 European countries. Patient groups are able to contribute to the process in a number of countries but unless they know how the process operates (what data influences decisions) and how they can provide evidence, their contribution may not be effective. The patient Academy aims at ensuring that patient groups have the necessary knowledge and skills to represent the needs of their constituents in the HTA process.

Resources:
(max 500 char)

Resources include obtaining funding for participants' travel, accommodation and meals plus the costs of the LSE in delivering the course. Sponsorship is obtained from at least 16 pharma companies. Resources also include the donation of time from the keynote speakers, including an after dinner speaker for the course dinner.

Outcomes:
(max 500 char)

The impact can be assessed by: participants have praised the course as truly outstanding in terms of education and providing skills essential to engage with policy-makers; by the ongoing requests from groups wishing to participate in the next course; by feedback from groups now able to engage successfully with HTA bodies; by the international awareness and recognition this initiative has attained, particularly by EU-bodies (such as the European Commission and the EMA) and national HTA bodies.

Analysis

Policy Field Health

Type of Best Practice Collaboration

Development of the BP
(max 1000 char)

The idea behind this initiative originated in discussions that the course organisers (Dr Kanavos - LSE and Dr Baker and Jean Mossman- EFNA) had in 2007 and 2008. It followed from the publication of a toolkit for patient groups on how to contribute to an HTA (now translated into Italian, Spanish, Swedish, Polish and Mandarin and currently being revised for use in Brazil). The rising importance of HTA in decision-making and the need of patient groups to understand how this works and how they can become effectively engaged, led to the original course design. A course outline to suit patient groups needs was produced in late 2008. EFNA fundraised to ensure the first course could take place in September 2009 and recruited the first 30 course participants from neurology and oncology. LSE faculty, Dr Mary Baker and Jean Mossman from EFNA and international decision-makers and faculty delivered the first 3-day course in June. The course has since opened to groups from all therapeutic areas.

**Obstacles found
(max 1000 char)**

We have faced and addressed a number of challenges: first, many of our participants are patients themselves, thus it is important to be aware of accessibility issues and that long days of workshops may be difficult for individuals with certain conditions. Second, the level at which the course is pitched needs to be adapted to reflect the audience's lack of prior knowledge on the subject; and, third, while the discussions in our sessions benefit from the geographically-diverse audience, it is important speakers are aware that not all participants are native-English speakers and to ensure the discussion is not too centred on one single country.

**Means used
to overcome or
remove the obstacles
(max 500 char)**

Removing the obstacles has been a matter of learning from past experiences: this means, for example, ensuring that the workshop programme has frequent breaks and is interactive rather than didactic, that the facilities are accessible to wheelchair users and that speakers discuss a variety of European-wide experiences, rather than focussing on one country.

**Factors that facilitated
the process
(max 500 char)**

HTA is not high on the agenda for many patient groups so it has been necessary to make it cost-neutral for participants. This has involved intensive fund-raising (from a number of companies to protect speakers such as Thomas Longren and Mike Rawlins).the meeting is held in a prestigious institution and all participants get a certificate from the LSE to show they have successfully completed the course. Making it easy to participate (no complicated registration forms) is essential.

**Impact on the
participants
(max 1000 char)**

The course gives the participants the knoweldge, confidence and skills to participate in HTA processes (or similar reimbursemet processes) in their own country. In addition it gives them a basic understanding of health economics and quality of life measures. In addition it allows participants to form new relationships with colleagues in other therapeutic areas from their own country and more widley and to exchange knowledge and skills with them. Participants talk about 'being able to speak a new language, that of decision makers' and teaches them that health economists are important partners in decision making about access to innovative therapies.

Evaluation

**1. Reproducibility
(max 250 char)**

The view of a reviewer about the course: Is easily transferable as a complete programme to other organisations/ settings with little or no adaptation required.

**2. Innovativeness
(max 250 char)**

This initiative is unique:it fulfils a significant unmet need. Robust and tailor-made for patient groups, the programme is completely novel.

**3. Added value
(max 250 char)**

The course provides skills that they cannot gain from any other course. It equips them to argue effectively on the needs of patients and to present patient evidence in a systematic, reliable manner. The only cost to participants is time.

**4. Appropriateness
(max 250 char)**

The course is tailor made for patient groups and Jean Mossman (who has contributed to several HTAs) works closely with the LSE to ensure that the course delivers that patient groups need to take part effectively in HTA processes.

Other information:

We want to make this a lasting initiative that brings together patient groups and a variety of stakeholders together with academia in order to continue to provide the training. As part of this we are setting up a Patient Academy, which will be steered by



Best Practices of Civic Participation in Health - Number 27

[Best Practices List](#)

Your contact details

Name and Surname: Neda Milevska-Kostova

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Phone Number: + 389 2 3065 837

Country: Macedonia

Description

Title of the BP: European Antibiotic Awareness Day

1. Actors of the Best Practice

Civic Organization(s): CRPRC Studiorum

Public Institution(s): Ministry of Health, Medical Faculty, Institute of Public Health

Other Subjects involved: ECDC (indirect involvement)
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Skopje

Country: Macedonia

4. Duration

Starting date: Nov 18, 2008

Ending date: Nov 18, 2010

4. Object

Objectives: (max 1000 char)	European Antibiotic Awareness Day (EAAD) is an initiative of the European Centre for Disease Prevention and Control (ECDC), in which all EU member states and candidate countries participate. This initiative was launched in 2008, with the celebration of EAAD on November 18, with various events that are directed at the prevention of antibiotic resistance, reduced antibiotic dispensing and consumption, and so on. In Macedonia, the involvement of our country was initiated by NGO CRPRC Studiorum, in the attempt to actively and effectively assist the public sector in issues of public health importance.
Resources: (max 500 char)	CRPRC Studiorum, Medical Faculty, Institute of Public Health and the Ministry of Health have all joined their physical, material and human resources to enable outreach to all stakeholders throughout the country.
Outcomes: (max 500 char)	In the first year, we sent out informative materials to all primary healthcare physicians (brochures, information sheets for doctors, flyers for patients, posters, etc), in the second year we managed to inform the public through wide-spread activities, press conference, and informative programs broadcasted on national media. In the third year, the target were hospital doctors, which were reached in a scientific conference, with many useful presentations and plenty of useful materials.

Analysis

Policy Field	healthcare
Type of Best Practice	information and awareness raising
Development of the BP (max 1000 char)	The original initiative of ECDC was started in Macedonia by CRPRC Studiorum, when the Ministry of Health and other public actors have gladly joined, understanding the added value that such joint activities will have in providing the necessary outreach.
Obstacles found (max 1000 char)	N/A
Means used to overcome or remove the obstacles (max 500 char)	N/A
Factors that facilitated the process (max 500 char)	Enthusiasm of the civil society organization and of the professionals working at the Medical Faculty and the Public Health Institute, supported by the political will of the Ministry of Health.
Impact on the participants (max 1000 char)	Over the three years that the event has been held so far, over 4,000 people have been reached. We will continue to organize these events, as the impact is great, by the feedback received from the targeted audience.

Evaluation

- 1. Reproducibility**
(max 250 char) Highly reproducible.
- 2. Innovativeness**
(max 250 char) Standard approach was used.
- 3. Added value**
(max 250 char) Provided better outreach to the target audience than if each actor would acted on its own.
- 4. Appropriateness**
(max 250 char) Highly appropriate.

Other information:

Your contact details

Name and Surname: Maie Egipt

Organization: Estonian Cancer Society

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Phone Number: +372 6311730

Country: Estonia

Description

Title of the BP: Program and campaign „Early detected breast cancer is treatable“ (consisting of 3 parts: breast cancer screenings „Give yourself confidence!“, campaign against breast cancer in jeans „Don't be late!“ and breast health day „Don't be late!“)

1. Actors of the Best Practice

Civic Organization(s): Estonian Cancer Screening Foundation, Estonian Cancer Society (informing)

Public Institution(s): Estonian Health Insurance Fund, Estonian National Institute for Health Development

Other Subjects involved: Estonian Ministry of Social Affairs, medical advisor dr Tiiu Tigane
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: all over Estonia

Country: Estonia

4. Duration

Starting date: 2002 (pilot project started 1996)

Ending date: ever continuing program

4. Object

Objectives:
(max 1000 char) Whereas the most spread type of cancer in Estonia is breast cancer (ca 600 women detected each year), the program aimed at detecting it in as early stage as possible to avoid early deaths and enhance life quality of patients. Hence the main objectives of the early detection campaign: 1. in long perspective - a growing number of survivals of breast cancer patients within five years; 2. increase the number of women taking the screening test among those invited to the screening by 70 percent in 2011; 3. cutting the number of deaths in breast cancer cases and get the detection of breast cancer in early stage up to 75 percent of all cancer detections. Invitations are sent to women aged 50-62 by Estonian Health Insurance Fund every second year according to national cancer strategy (passed in 2002). The screenings are free of charge for those participating, paid by Health Insurance.

Resources:
(max 500 char) Estonian Health Insurance Fund stands for sending out invitations to screenings, Estonian Cancer Society spreads information and enhances awareness of women about the necessity to detect cancer in early stage, Estonian Cancer Screening Foundation carries out the screenings and informs of detected ailments. Two major informative campaigns are held in May and October: a press conference attended by representatives of media, posters in bus shelters and flyers in most popular womens' magazine.

Outcomes:
(max 500 char) 74 percent of 24 389 women invited to the screening participated in 2010, about 6 breast cancer cases were detected out of 1000 screenings, about 4 percent are re-invited to specify the diagnosis. 52 000 women aged 50-62 will be called to the screening in 2011, every year the number of screenings has increased. The awareness of Estonian women about the need to detect breast cancer early has increased.

Analysis

Policy Field health, prevention

Type of Best Practice Collaboration

Development of the BP
(max 1000 char)): The pilot project of early detection of breast cancer started in Estonia in 1996, the first all-Estonian project to detect breast cancer in early stage for health insured women aged 50-62 was initiated in cooperation with Estonian Health Insurance Fund for the years 2002-2006. Health Insurance Fund posts an invitation to women aged 50-62 every second year, where the contact number and address of screening services are marked. The results are posted by the service provider. If necessary, women are invited to an additional appointment. Number of screenings in 2002 was 14 908, in 2003 – 17 547, in 2004 – 18 500, in 2005 – 20 101, in 2006 – 22 635, in 2008 – 30 053, in 2009 – 30 528.

At the beginning only 47% of women invited really participated in the

(max 1000 char) screening, in 2003-2004 the problem was too few participants – in rural areas about 50%, in Tallinn about 30% (in Finland and Sweden the numbers were 89% and 81%). According to Estonian Cancer Register only 39.3% of all breast cancer cases were detected in early stage, while 70% of breast cancer cases detected in screenings of 2002-2003 were in early stage - those women have much more perspective to get well. Some women living in rural areas found it expensive to attend the screenings (due to expenses on transport).

Means used to overcome or remove the obstacles (max 500 char) In order to solve the problem, Estonian Cancer Society initiated all-Estonian campaigns "Don't be late!" in cooperation with media and local governments, where women were informed of the necessity of the screenings and invited to participate. Mammography bus was brought to circle in rural areas and make the necessary screenings.

Factors that facilitated the process (max 500 char) Since 2002 cooperation with media to organise campaigns "Don't be late!" with different design every year, cosmetics producer Avon has joined the prevention campaign - together lots of events have been organised as donation walks and outdoor concerts in the center of the capital where beloved doctors and the medical advisor of Cancer Society perform. Last year two events were added: „Fighting against cancer in jeans“ in cooperation with internet portal femme.ee and Breast Health Day in October.

Impact on the participants (max 1000 char) In connection with the prevention campaign, the number of calls to information phone of Cancer Society has increased, the internet site has been visited more often and the advisor of Cancer Society has been asked more questions. The number of participants in screening has increased to 69% of those invited in 2007-2009. Awareness of Estonian women has increased on necessity of early detection of breast cancer.

Evaluation

- 1. Reproducibility (max 250 char)** If the screenings become part of national cancer strategy, the reproducibility is guaranteed each year, which should be supported by an informative campaign organised in a different form each year to guarantee the increasing awareness among people.
- 2. Innovativeness (max 250 char)** New mammography bus started going around in Estonia (see <http://www.cancer.ee/?setlang=eng>) where digital screenings are made for women living in rural areas. Special fund was founded to buy a DR mammography system which helps to get better quality.
- 3. Added value (max 250 char)** Informative campaigns awareness has increased among all women, not only those invited to screenings. A national round table of specialists gathered in 2010 to start a screening register.
- 4. Appropriateness (max 250 char)** International conference for gynecologists and general practitioners was organised in April 2010 on cancer screening. Research among participating women proved: information on screenings is expected from GPs a.o health practitioners, media.

Other information: Thank you and nice cooperation possibilities in the future!

Best Practices of Civic Participation in Health - Number 29

[Best Practices List](#)

Your contact details

Name and Surname: Lindsey Dyer & Judy Birch

Organization: Mersey Care NHS Trust & Pelvic Pain Support Network

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Phone Number: 01202 603447

Country: UK

Description

Title of the BP: A Human Rights based approach to involving mental health service users and carers

1. Actors of the Best Practice

Civic Organization(s): Mersey Care NHS Trust

Public Institution(s):

Other Subjects involved:
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization:

Public Institution: si

3. Location

City / Region: Liverpool, Merseyside

Country: the United Kingdom

4. Duration

Starting date: April 2001

Ending date: No end date , continuous

4. Object

Objectives: (max 1000 char)	<p>Mersey Care NHS Trust provides specialist mental health and learning disability services. It was the first NHS organisation to take a human rights based approach to involving service users and carers. A clear strategic objective, from its formation in April 2001, has been that service users and carers have the right to be involved, not only in decisions about care and treatment, but involved as equal citizens in all the decisions which affect their lives- everything the Trust does. The Trust takes an innovative approach to involvement which is based on human rights values of fairness, respect, equality, dignity and autonomy (the FREDAs principles) and seeks to engage a wide range of service users and carers in real and important decisions.</p>
Resources: (max 500 char)	<p>1. Board level leadership – Director Service Users and Carers who works with and through a network of Trust staff. Cost @ £200,000 pa 2. Payments to Service Users and Carers – who are valued and respected and offered payment for their time (£12 an hour plus travel) Cost@ £100,000 pa From a Trust income of £200m + p.a.</p>
Outcomes: (max 500 char)	<p>About 250 service users and carers are involved at any time and reflect the diverse population served by the Trust. The involvement of service users and carers is independently evaluated by service users – the SURE (Service User Research and Evaluation) Group. The 2011 SURE evaluation found: Service Users and Carers • 78% of service users and 79% of carers said involvement had a positive impact on their mental health recovery and well being • 80% said they felt valued • 69% said they had gained in confidence • 68% said they had meaningful things to do • 53% said they had learned new skills • 41% said that the money was useful • 25% said that it helped in getting a job • 61% of service users said they felt more involved in their care and treatment than they did 3 years ago when the last SURE evaluation took place. Service users and carers also enjoyed meeting new people and being with people “who understood.” Carers also enjoyed getting a break from their caring role. Managers and Clinicians • 96% said involving service users and carers had made a positive difference to them as a person • 74% said involving service users and carers had positively changed their practice • 68% said involving service users and carers had positively changed their attitudes Mersey Care NHS Trust SURE found strong evidence that involvement of service users and carers impacts positively on the culture of the organisation which has become a better, more person focused organisation as a result</p>

Analysis

Policy Field	Health
Type of Best Practice	<p>Dialogue, collaboration and partnershipThe strong partnership with service users/carers in Mersey Care NHS Trust is led from the top (Trust Board) who have invested in Board level leadership (Director) to ensure this partnership of equals is not confined</p> <p>Any service user/carer can join the involvement scheme; receive</p>

(max 1000 char) information every month about new involvement opportunities; get involved as much or as little as they wish. Their first priority was recruitment of staff. To be involved in decisions about who comes into their homes and lives when vulnerable. They wanted staff with empathy and understanding as well as technical skills as doctors and nurses. Over 80 service users/carers are trained, supported and take part as equals in the recruitment of all Trust staff – over 2,750 appointments to date. Other service users/carers are involved in decision making at the Board and Senior Management Teams; in setting objectives and evaluating performance of the Chief Executive, Executive Team and Psychiatrists; in financial decisions; in development of new services (eg appointing architects, designing buildings, setting quality standards); investigating complaints and serious incidents and much, much more!

**Obstacles found
(max 1000 char)**

- Staff resistance to changing traditional power relationship between staff and service users/carers
- Implementing change across a complex organisation with services previously managed by 7 different organisations with different cultures
- Ensuring service users/carers are not out of pocket and get their expenses on the day

**Means used
to overcome or
remove the obstacles
(max 500 char)**

Board level leadership means involving service users/carers is not negotiable and the Trust has invested in skilled leadership to show how it can be done. The Chief Executive, Medical Director and senior staff have modelled new ways of working with service users/carers. Time has been spent with unions/staff groups explaining the rationale, the benefits, addressing concerns. Finance Director put new petty cash system in place.

**Factors that facilitated
the process
(max 500 char)**

Service users/carers are the best advocates and, because they have a good experience of being involved and treated with respect, they encourage other service users/carers to get involved. The Trust's involvement scheme is independently evaluated by service users (SURE) every 3 years and this enables service users/carers to make their views known and the Trust to continually learn from them and improve the involvement scheme. SURE evaluations show there are great outcomes

**Impact on the
participants
(max 1000 char)**

96% of Managers and Clinicians say involving service users and carers makes a positive difference to them as a person. Changing Attitudes e.g. "Lets you see past the illness to the person"; "Less likely to view a service user "simply" as a patient." Changing Practice e.g. "It has resulted in me thinking about what additional information I can provide for hospital inpatients during their stay." 94% of service users/carers say getting involved makes a positive difference to them. E.g. "It has helped me regain my sense of purpose in life and a lot of my dignity following my breakdown"; "I have new life skills. It has improved my communication skills and my confidence within myself and so enabled me to work full time."; "Involvement with Mersey Care has given me a sense of purpose, greater confidence and most importantly, the opportunity to mix with others and feel valued and respected as an equal." (All quotations from 2011 SURE evaluation)

Evaluation

The Mersey Care approach to involving service users and carers is recognised as good practice. The Trust hosts visits from and offers advice to a wide range of other mental health NHS Trusts and independent sector organisations. A number, including Coventry and

Warwickshire NHS Trust and Dorset Healthcare NHS Foundation Trust, have begun to replicate the approach. The human rights based approach to involvement in Mersey Care was identified by the Equality and Human Rights Commission (Human Rights Inquiry, Equality and Human Rights Commission, 2009) as an exemplary example of how a human rights based approach can and should be applied in public services.

**2. Innovativeness
(max 250 char)**

Mersey Care has taken an innovative approach based firmly on human rights values of fairness, respect, equality, dignity and autonomy. This approach has engaged hundreds of service users and carers in a wide range of important and innovative decision making and delivered great outcomes for service users and carers, managers and clinicians and the Trust. Mersey Care's innovative approach to involvement was recognised by the Equality and Human Rights Commission (2009) as an outstanding case study of a human rights based approach in public services.

**3. Added value
(max 250 char)**

In Mersey Care, service users and carers have the right to be involved in all the decisions which affect their lives. This is an important end in itself in promoting human rights values of fairness, respect, equality, dignity and autonomy and in promoting citizenship for people with mental health problems and learning disabilities who are among the most vulnerable and stigmatised members of society. The added value comes from the hugely positive effect a human rights based approach to involvement has on the: * Mental health and well being of service users and carers * Attitudes and practices of managers and clinicians * Culture of the whole organisation

**4. Appropriateness
(max 250 char)**

The Department of Health has a longstanding policy of promoting patient involvement. People with mental health problems and learning disabilities are among some of the most vulnerable people in our society and most at risk of not having their voices heard. Health organisations, like Mersey Care, who work with vulnerable people have a responsibility to show the way and enable them to make their views known and involve them in all the decisions which affect their lives. Human rights are a cornerstone of the NHS Constitution so it is more than appropriate that an NHS Trust, like Mersey Care, takes an explicit human rights based approach to involvement

Other information:

Mersey Care believes there is a lot of transferable experience from its approach to involvement to other health organisations and would be very happy to share this example of good practice in a European setting

Best Practices of Civic Participation in Health - Number 30

[Best Practices List](#)

Your contact details

Name and Surname: Judy Birch

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Country: UK

Description

Title of the BP: Patient Involvement in Health Technology Assessment (HTA) and clinical guidelines

1. Actors of the Best Practice

Civic Organization(s):

Public Institution(s): National Institute for Health and Clinical Excellence (NICE) and Scottish Medicines Consortium (SMC)

Other Subjects involved: Many patient organizations, patients and carers
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization:

Public Institution: si

3. Location

City / Region: London and Glasgow

Country: the United Kingdom

4. Duration

Starting date: 2002

Ending date: Ongoing

4. Object

- Objectives:** (max 1000 char) To involve patient experts in the HTA process. At NICE this includes at the scoping stage, in written submissions and representation in person at meetings and on appraisal and guideline committees. The SMC supports patient organizations in making written submissions.
- Resources:** (max 500 char) Staff time, volunteer time, reimbursement for travel expenses for patient experts/representatives/carers and honoraria.
- Outcomes:** (max 500 char) A more balanced approach to evaluating the benefits of a technology alongside the clinical and economic evidence presented. Increased knowledge of the impact of a disease on the patient from the personal view of the patient.
-

Analysis

- Policy Field** Health
- Type of Best Practice** This involves dialogue and collaboration between health professionals, health economists, policy makers and patients. HTA is one of the few areas in healthcare where all of these areas of interest come together. As a result of the dialogue and participat
- Development of the BP** (max 1000 char) The ethos around involving patient experts and the rationale for doing so in all aspects of the institution's activities, needs to be embedded within the institution through representation at board level. It requires the majority of staff to be supportive and in a large organization it requires several members of staff to ensure that what should happen , does happen.
- Obstacles found** (max 1000 char) Staff objections to investing in patient involvement/not understanding the value of such input. Time pressure and conflicts with budgetary issues. Lack of support, confidence, knowledge or experience amongst patients to contribute effectively to complex meetings.
- Means used to overcome or remove the obstacles** (max 500 char) There needs to be training of staff and other committee members to persuade them of the value of involving patient experts. A convincing case can be put to argue the societal cost of not involving patients. Ensure that there is support at board level for patient involvement. Induction/training sessions for patients in how they can contribute effectively to the process. A budget needs to be allocated to ensure that patients and representatives are reimbursed for expenses.
- Factors that facilitated the process** (max 500 char) Clear published processes for patient involvement. Support from key members of the organization and members of the Board and an independent facilitator if necessary. The existence of the Health and Social Care Act and the NHS Constitution (England) that require patients and service users to be consulted and involved in decisions that affect them.
- Impact on the participants** (max 1000 char) Staff members appreciate and understand the reasons for involving patient experts. The board has the support of staff. Patients feel that their needs are being considered and that their input is valued.
-

Evaluation

1. Reproducibility
(max 250 char)

Countries may vary in whether they involve patients in HTA and also in how they involve them. The above approach can be adapted to any organization or institution in any field of health. The rationale for introducing such an approach needs to be presented from the point of view of Patient's Rights.

2. Innovativeness
(max 250 char)

Some countries have a long established tradition of involving patients in such initiatives even before the existence of HTA. For some countries this idea may be very new and challenging. The educational process and the cultural change surrounding involving patient experts in HTA and clinical guidelines can be seen as innovative

3. Added value
(max 250 char)

The attendance of patient experts at meetings is a powerful vehicle for input and change. It provides a more balanced view in addition to the clinical and economic data. Patient evidence can identify limitations in the published research literature: in particular the failure to capture the true concerns of individual patients related to HRQL over and above measurements using standardised instruments

4. Appropriateness
(max 250 char)

This is a way of managing resources, evidence and taking account of the experience and needs of patients or subgroups of patients to reach a decision about the recommendation of a diagnostic, device or medication or a consensus using guidance or a guideline.

Other information: N/A

Your contact details

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Country: Estonia

Description

Title of the BP: Better and more equal access to dental care for Estonian patients

1. Actors of the Best Practice

Civic Organization(s): EPAA, Estonian Dental Association

Public Institution(s): Estonian Ministry of Social Affairs, Estonian Health Insurance Fund, Chancellor of Justice

Other Subjects involved: Patient defence organisation Radix, Tallinn Dental Clinic, social commission of the Estonian Parliament (Riigikogu)
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Tallinn

Country: Estonia

4. Duration

Starting date: January 2006

Ending date: January 2008

4. Object

Objectives:
(max 1000 char)

Whereas dental care in Estonia was for a long time supported by the Health Insurance Fund only by 150 EEK a year for treatment and by 2000 EEK per 3 years for dentures (and only for those aged over 63), lots of patients were suffering from dental pain and could not even afford to extract a tooth, far from affording a treatment. At the same time patients with psychiatric diseases take medicaments which impair teeth and need dentures earlier than at the age of 63. EPAA found that old-age pensioners and disability pensioners were not treated equally. The situation was in contradiction with Estonian Constitution § 28, European Social Charter § 11,13 and Patients' Rights Charter.

Resources:
(max 500 char)

In 2005, EPAA carried out a questionnaire among patients of clinics and those visiting EPAA offices about their possibilities to afford dental care. Despite the fact that 70% of those questioned were working, 74% of them had to delay dental care due to economic situation (could not afford it). Several disability pensioners had not visited dentist for years as they had no money left and it was not possible to treat a tooth for 150 EEK, thus having potential inflammation lesions.

Outcomes:
(max 500 char)

EPAA made a suggestion to Social Ministry, the Riigikogu and the Insurance Fund to make amendments in legislation to compensate people with psychiatric diseases and special needs equally with old-age pensioners in dental care. EPAA also made a suggestion to increase the amount of compensation from 150 EEK to 1000 EEK per year. Estonian Dental Association added a suggestion that denture compensations should also be covered in a bigger amount whereas the cost of materials rises every year.

Analysis

Policy Field dental care

Type of Best Practice dialogue

Development of the BP
(max 1000 char)

First of all, EPAA took contact with the Dental Association (January 2006) and made a suggestion to compose a joint letter (forwarded in March). As for equal access to dental care, EPAA approached the Chancellor of Justice in June 2006 who on his part pointed out the discord in legislations to Ministry of Social Affairs (May 2006). EPAA and the stomatologists forwarded their suggestions to increase the amount of compensations in June 2006. The problem was also presented to the media in cooperation with Chancellor of Justice (September 2006), and to Riigikogu (March 2006). A round table gathered in the Ministry of Social Affairs in October 2006 where it was agreed that denture compensation will be also paid to disabled pensioners and will be increased from 2000 to 3000 EEK and the treatment compensation will be increased from 150 to 300 EEK.

Obstacles found
(max 1000 char)

The Dental Association was not very eager to cooperate, it took time to activate them, but once EPAA won their trust, they were dedicated. The first answer from the Ministry of Social Affairs said it is not possible to increase compensation for people with psychiatric diseases only as there are more people with special needs and a

profound analysis is needed to decide on additional compensation of dental care. Negotiations and analysis started in this point on specifying those people who needed increased compensation.

**Means used
to overcome or
remove the obstacles
(max 500 char)**

Estonian Dental Association was approached several times to send a joint letter to the Ministry of Social Affairs and the Health Insurance Fund. Chancellor of Justice was included in the process to acknowledge the need for amendments in legislation. Other patient organisations were asked for opinion. Information was shared between dentists and the ministry officials on the price lift in dental materials. Media was informed of the problems followed by articles exerting pressure of public opinion.

**Factors that facilitated
the process
(max 500 char)**

1. By autumn 2006, all parts came to a common understanding of a need for change – everybody agreed that different kinds of pensioners should be treated equally and the compensations are too low compared to patients' incomes. 2. Compromising on the amount of compensation in mutual understanding, avoiding confrontation.

**Impact on the
participants
(max 1000 char)**

An amendment in the Health Insurance Act by the end of 2007 which took effect in January 2008 according to which old-age pensioners and disabled pensioners are treated equally since spring 2008, the amount of compensations increased to 300 EEK for treatment and up to 3000 EEK for dentures since January 2008. Closer relationship of cooperation started with stomatologists, Insurance Fund and Social Ministry officials ending up in several round tables in EPAA where different Estonian patient organisations have participated to discuss problems in dental care and possible developments to solve them.

Evaluation

**1. Reproducibility
(max 250 char)**

In a country with a large number of organisations it is possible to start the negotiations at the initiative of roof organisations and find the right officials from the public sector to communicate on a specific problem, finding the right key persons

**2. Innovativeness
(max 250 char)**

This was the first endeavor together with a special doctors' organisation to improve the situation of patients – a step towards cooperation instead of confrontation also in relations with the Ministry of Social Affairs and the Health Insurance Fund.

**3. Added value
(max 250 char)**

Although EPAA started from a suggestion to improve the situation of people with psychiatric diseases, we ended up in getting an amendment in favor of all disabled pensioners. Without EPAA's initiative such amendments would not have been made.

**4. Appropriateness
(max 250 char)**

These negotiations helped to improve the trust of public institutions, which has enabled better contact in solving problems in upcoming years.

Other information:

EPAA followed closely the process, making enquiries to the ministry in critical moments about the progress.

Your contact details

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Country: Italy

Description

Title of the BP: Salute Partecipata –Citizens' Voice

1. Actors of the Best Practice

Civic Organization(s):

Public Institution(s): USL4 Prato health service

Other Subjects involved: Activecitizens Italy and 71 others citizens organizations in Prato
(max 250 char) area-Tuscany

2. Who initiated the Best Practice?

Civic Organization:

Public Institution: si

3. Location

City / Region: Prato/Tuscany

Country: Italy

4. Duration

Starting date: February 23rd 2010

Ending date: December 31st 2010

4. Object

Objectives: (max 1000 char)	<p>In 2010, the Health Service Unit USL4 Prato promote the active participation of citizens in government of health objective. Negotiating annual budget is a tool for the definition of health objectives. These objectives aim to maintain a balance between the needs of public health, essential and appropriate levels of care and sustainability of the system. USL4's strategy reaffirms the need to direct activities towards the health needs of the citizen in order to acquire a role of service according with a vision of "health sector and social rights", designed to implement a welfare system that is sustainable and challenger for the next three years. This project wants to perform these objectives: To define 10-15 budget goals, resulting from the comparison between the representatives of citizens and doctors and nurses. To implement strategies for involvement and citizens' participation. To establish a direct relationship between citizens and active traders in disbursement of benefits.</p>
Resources: (max 500 char)	<p>3800 eu (doctors and nurses)Team building teacher. Action Research-AR is designed to identify problems in clinical practice. Meetings are realized with Metaplan technique. Method: - using cards in different shape and color with different meaning;- each participant receives the same number of cards - each card expresses a single thought (sentence of 7 words, as much as possible self-explanatory) - the cards are collected, discussed and grouped by defining homogeneous areas with the participants.</p>
Outcomes: (max 500 char)	<p>Nine team work developed 56 objectives for budget negotiation. Department's Directors accepted 38 objectives in their budget documents. 58% objectives are realized in 2010. 7% objectives are not realized, 35% objectives are not realized yet, but they'll be realized during 2011.</p>

Analysis

Policy Field	Health
Type of Best Practice	Partnership
Development of the BP (max 1000 char)	<p>Patient organizations link: preliminary telephone contact, which explains the contents and modalities of the meeting, -sending e-mail close to the event;-publication of the timetable and the rationale of the event on USL website. We invited 127 citizens' organizations in Prato area, 72 of them joined the project. All of health department joined to meeting. 42 doctors and nurses met 89 citizens (72 organization). We defined roles and discussion rules in two preliminary meeting. 11 organization and 6 doctors took part in these preliminary meetings. Rules:1 to explain meetings' objectives 2 to introduce participants 3 to explain the method of working 4 participants write problems on coloured cards 5 team leader links problems in different areas 6 brain storming and discussion about hypothetical solutions 7 participants sum up solutions 8 participants turn proposals into budget objectives 9 participants rank objectives.</p>
Obstacles found (max 1000 char)	<p>An obstacle was the complicated communication between the different parts involved in the project.</p>

**Means used
to overcome or
remove the obstacles
(max 500 char)**

Action Research is designed to identify problems in health organization and to propose solutions. It provides for the integration of the views of the participants in the compilation of results and subsequent verification. It found fit to positively influence clinical practice and organization. The instruments used in AR are the meetings for discussion and teamwork. For the realization of meetings was used Metaplan technique, method of displaying the contributions of the participants.

**Factors that facilitated
the process
(max 500 char)**

Transparence: The resulting processed is the first meeting of the subsequent results available for all stakeholders through the link "The health planning is done with the citizens, " the page Internet business. This multi-mode communications and activities to promote and document all phases of the project. Method of sharing: We defined roles and discussion rules in two preliminary meeting. 11 organizations and 6 doctors took part in these preliminary meetings.

**Impact on the
participants
(max 1000 char)**

Participants became able to plan organizations' evolution: February 23rd:Participants know budget's technique:Presentation of the initiative, identification of areas of interest and raising expectations, identification of representatives of the people to define the rules of debate. Participants know the objectives and develop rules and procedures for the discussion. 19:20 March: Participants identify health needs, turning them into targets health. Participants establish a rank for the objectives. Summing up, participants gained organization skills and knowledge of working procedure. They gained an empowerment about their citizens rights

Evaluation

- 1. Reproducibility
(max 250 char)** For reproducing this practise is important the skill of organizing groups. It's also important that Directors believe and support this activity.
 - 2. Innovativeness
(max 250 char)** This project began a new kind of collabouration, not only clinical, but also organizational, based on transparence and involmnet of citizens.
 - 3. Added value
(max 250 char)** Service organization realized in relation to patients' needs. The alliance with citiziens supports skill of doing innovation.
 - 4. Appropriateness
(max 250 char)** Not direct effect on appropriateness, but guidance towards patiens' needs.
-

Other information:

Your contact details

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Country: Italy

Description

Title of the BP: playtherapy and pain in children

1. Actors of the Best Practice

Civic Organization(s): AGEOP (parents association of paediatric oncological and
haematological patiens) Onlus

Public Institution(s): Oncologia ed Ematologia Pediatrica "Lalla Seràgnoli"

Other Subjects involved:
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization:

Public Institution: si

3. Location

City / Region: Bologna. Emilia Romagna

Country: Italy

4. Duration

Starting date: gennaio 2000

Ending date: febbraio 2011

4. Object

- The emotional support to the oncological patient and to his family has an important role within the oncological guidelines. In paediatric experience, the painful perception together with painful manoeuvres, both from the child and from the participating adults, feels the effects of the psychological interventions directed to sustain and encourage. Above all the anxiety connected with the expectation of the manoeuvre, seems to find in the different psychotherapeutic settings, a useful placement that allows the communication of feelings such as fear, rage and anguish. This research project was born to evaluate the painful experience of the patient, of his parents and of the operators through the Faces Pain Scale, during painful manoeuvres effected without anaesthesia, in relation to Play therapy, as ideal psychological support during the evolutive age. The components of the experimental group are supported by a psychologist, before the manoeuvre, through an individual session of Play therapy: after the manoeuvre patients and adults are invited to undergo a test. The strokes obtained by the experimental group, in the scale, were compared to those obtained by the control group, patients undergoing the same manoeuvres, without having been supported with the Play therapy. Also the operators that effected the manoeuvre, the assisting parent. The psychological intervention has made the painful manoeuvre less dramatic and the evaluation has shown significant differences in the pain perception between the two specimens of patients.
- Objectives:**
(max 1000 char)
- for this project we need the collaboration between: a psychologist who leads the play setting, a psychiatrist who can offer some time for the parents, a volunteer ables to play with the patients who decide not to attend the playtherapy, but in any case need a controlled setting, waiting for the painful procedures.
- Resources:**
(max 500 char)
- after the manoeuvre patients and adults are invited to undergo a test. The strokes obtained by the experimental group, in the scale, were compared to those obtained by the control group, patients undergoing the same manoeuvres, without having been supported with the Play therapy. Also the operators that effected the manoeuvre, the assisting parent. The psychological intervention has made the manoeuvre less dramatic and the evaluation has shown significant differences in the pain perception.
- Outcomes:**
(max 500 char)

Analysis

- Policy Field** health
- Type of Best Practice** partnership
- Development of the BP**
(max 1000 char)
- public Institution and civic organization are in the same hospital, sharing some spaces and times, during the daily hospital life of patients and parents. We decided to offer the little patients some occasions to reduce and control pain in a different but continuing way. children can use two different way to face pain and fear. the civic organization offered a financial resource to engage a pscyologist dedicated to play therapy, working inside the

<p>Obstacles found (max 1000 char)</p>	<p>psychological staff. a group of selected volunteers, dedicated to the free play settings, selected and supervised by the psychiatrist of the hospital, are formed to hold the psychological needs of the patients, without any therapeutical approach.</p> <p>we met some different difficulties: first of all the cultural idea from collueges and families, that pain is only a phisical problem and that children with cancer have only somatic symptoms. the other obstacles were related to the collaboration-competition between public and private institutions. another consideration is about the difficulty to collect clinical datas conforing our hypothesis.</p>
<p>Means used to overcome or remove the obstacles (max 500 char)</p>	<p>the psychiatrist played the role of mediator between the differet positions: the somatic/psychological aspects; the medical/psychological staff; ethical/clinical aims.we organized psychological training for all the staff and for volunteers, about the psychological aspects of pain. we promoted the psychological support for children and adolescents waiting for procedures, in according with the parents civic association. we organized the collect of datas demonstrating the good practice.</p>
<p>Factors that facilitated the process (max 500 char)</p>	<p>the communication about the psychological aspects of pain during the public meetings, the supporting groups for parents, during the first 10 years of our activity, realized the assumption to introduce the collaboration: physician-psychologist, public-civic, staff-family, ables to reduce the obstacles in working with suffering people</p>
<p>Impact on the participants (max 1000 char)</p>	<p>The play therapy gave the children the possibility to the facts and to the concrete objects to find "the words in order to say": "I have pain", "I have fear of the illness", "I have fear to be alone ", " I need of you". The children followed with the play-therapy had the opportunity to find expressions for their pain which, wit less anxiety and worry, was perceived smaller. Parents, always very worried that the pain suffered by their child is not sufficiently evaluated, generally act as anxiety amplifiers, that is they tend to describe their child's pain as the "maximum pain". In this case, helped in containing their child's pain, through play-therapy for the child and conversations for them, they managed to minimize the effect of "resonance box" that their own anxiety induces to the painful perception of their child. Similar benefits have been observed in the operators that have effected the painful manoeuvre; whenever they can carry out these painful manoeuvres on less anxious children, they face this experience with more relaxation, being even able to experiment it as a further occasion of comprehension and vicinity with the children.</p>

Evaluation

- 1. Reproducibility**
(max 250 char)

this practice is now improving in other different hospital units of the Paediatric Department, thanks to the large numbers of psychologists in training attending our paediatric oncological unit, drawn from our integrated training programm
- 2. Innovativeness**
(max 250 char)

The results of project underline the importance of educational and support interventions for oncological patients undergoing procedures, with special attention to the use of psychotherapy for patients and their parents, as an important step to the self government of the family in front of emotional pain.
- 3. Added value**
(max 250 char)

the collaboration between public institution and civic organization shows the possibility to organize the work in hospital as like the "good family" does for her children. the attention to the pain is inside

a bigger project forward the care.

**4. Appropriateness
(max 250 char)**

this long experience in the "containing of pain, controlled by the civic organization, the regional quality system, the patients and their parents, offer us the possibility to value our total daily work, and to change every possible human carelessness

Other information:

Best Practices of Civic Participation in Health - Number 34

[Best Practices List](#)

Your contact details

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Country: Poland

Description

Title of the BP: Introduction of the National Mental Health Protection Programme

1. Actors of the Best Practice

Civic Organization(s): Institute for Patient's Rights; Union of Associations of Families & Carers of Mentally Ill Persons "POLFAMILIA";

Public Institution(s): Ministry of Health; Parliamentary Health Committees;

Other Subjects involved: The Institute of Psychiatry & Neurology; The Polish Psychiatric Association
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Warsaw, Toruń

Country: Poland

4. Duration

Starting date: 2007

Ending date: 2011

4. Object

Objectives: To protect the rights of mentally ill persons ; to ensure standards of psychiatric care in local environment
(max 1000 char)

Resources: No information
(max 500 char)

Outcomes: The Parliament enacted the National Mental Health Protection Programme in form of a law and executive acts.
(max 500 char)

Analysis

Policy Field Mental Health

Type of Best Practice Influencing public health policy

Development of the BP
(max 1000 char)

The BP was undertaken in broad collaboration and partnership of many stakeholders of the HC system. The programme which formed outlines for building a system of mental health protection based on environmental psychiatry and rehabilitation had been worked out by a group of experts years ago but could not gain political momentum, until the Institute for Patient's Rights and the Union "Polfamilia" launched a public awareness campaign under a slogan – "Mental health our common interest". A debate with participation of politicians – MPs, government officials and experts on psychiatry took place, the need to introduce the National MH Programme was one of key subjects. Numerous media took part in the campaign, making the problem of mental diseases and the situation of people with mental disorders "issue of the day" on the occasion of the World Mental Health Day. The Institute of Patient's Rights together with the "Polfamilia" participated also in the public consultations of the European Mental health Strategy, providing the European Commission working on the issue with their position paper. Since 2007 the Institute actively supported "Polfamilia" and the Polish Psychiatric Association in their efforts to persuade decision makers and politicians to adopt the law introducing the National MH Programme. The Parliament finally voted the law in 2010 and adopted the executive regulations in January 2011.

Obstacles found
(max 1000 char)

Difficult and lengthy legislative process; lack of political will;

**Means used
to overcome or
remove the obstacles**
(max 500 char)

Public awareness campaign + Advocacy; providing information; personal contacts with decision makers;

**Factors that facilitated
the process**
(max 500 char)

Collaboration of many key state holders in the area of health care, psychiatry & mental health - patients & their families organisations, doctors, decision makers, politicians, experts, media.

Impact on the participants
(max 1000 char)

The National Mental Health Protection Programme will have great impact on Polish patients; it will improve the comfort of their life thanks to the creation of a modern system of environmental psychiatry - effective tools of support to people suffering of mental disorders.

Evaluation

- 1. Reproducibility**
(max 250 char) The system created by the National Programme may serve as an example and GP to other specific medical areas.
 - 2. Innovativeness**
(max 250 char) The system introduced recently is innovative and based on rules adopted by majority of well developed countries.
 - 3. Added value**
(max 250 char) The added value of the system promoted by the National Programme consists in improvement of the quality of life of families and carers of mentally ill people.
 - 4. Appropriateness**
(max 250 char) It is appropriate to have effective support to people with mental disorders.
-

Other information: no

Your contact details

Name and Surname: Staša Barbič

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Phone Number: 0038640340318

Country: Slovenia

Description

Title of the BP: O2 belongs to you

1. Actors of the Best Practice

Civic Organization(s): No excuse - Brez izgovora

Public Institution(s): Ministry of health, European Commission with HELP, Ministry of education and sport – office of youth, municipalities

Other Subjects involved: Slovenian institution for Health (NGO), Student organizations,
(max 250 char) Slovenian coalition for tobacco control

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: They have to main locations, but activities are in different regions

Country: Slovenia

4. Duration

Starting date: 2007

Ending date: 2011

4. Object

Objectives:
(max 1000 char)

The project "O2 belongs to you" is a youth developed and youth-led project, which aims at raising awareness among young people about the effects of active and passive smoking as well as about the immoral methods of the tobacco industry. Besides the prevention in primary school and the cure at faculties, we want to spread awareness mainly among secondary school students. Since the project is aimed at young people from the age of 12 to 25, we have appropriately adjusted our contents to the different age groups – primary school students and their parents, secondary school and university students. Our aim is to raise awareness about the harmful effects of active and passive smoking among young people (from 12 – 25) in the chosen areas in Slovenia • directly (through workshops in schools, faculties and with booths) and • indirectly (through researches and media appearances).

Resources:
(max 500 char)

There are 2 project leaders and 50 activists working on the project. Financial resources come from local and national tenders.

Outcomes:
(max 500 char)

In 2010 6822 young people were informed - all together, 36057 young people were informed.

Analysis

Policy Field	Health
Type of Best Practice	Collaboration
Development of the BP (max 1000 char)	In cooperation with the partners No excuse organized: - promotional stands - public discussions - motivational weekends - trainings - workshops on elementary schools and high schools - press conferences - courses on tobacco conspiracy. workshops
Obstacles found (max 1000 char)	Public didn't have interest in the topic and didn't find it important.
Means used to overcome or remove the obstacles (max 500 char)	By getting support from Ministries and local authority, they got more recognition from the public.
Factors that facilitated the process (max 500 char)	Financial support, recognition from the public, support from other subjects - student organizations, schools etc.
Impact on the participants (max 1000 char)	They approach 1,500 young people (mainly secondary school students) through the research called Indirect Tobacco Advertising in the Media and to inform them about the immoral tools of the tobacco industry and the conspiracy towards young people. In 2010 6822 young people were informed - all together, 36057 young people were informed.

Evaluation

- 1. Reproducibility** (max 250 char) The project is long-term and its goal is to affect 100.000 young people in ten years, in all Slovenian regions.
- 2. Innovativeness** (max 250 char) The are lead by the fact that the goal in a particular age group can only be achieved by using an understandable and interesting approach. That is why they use the peer-to-peer education method.
- 3. Added value** (max 250 char) Project does not only influence young people, but also wider public - by raising awareness about the effects of active and passive smoking as well as about the immoral methods of the tobacco industry.
- 4. Appropriateness** (max 250 char) Smoking is a big issue in Europe and majority of people start to smoke before the age 18. That is why this project is important - to influence (future) smokers in their early age.
-

Other information:

Your contact details

Name and Surname: Tanya Tisheva

Organization: Alzheimer compassion NGO

Email: compassion.alz@abv.bg

Phone Number: 003592 963 53 57

Country: Bulgaria

Description

Title of the BP: Alzheimer Compassion

1. Actors of the Best Practice

Civic Organization(s):

Public Institution(s): Alzheimer Compassion

Other Subjects involved: Alzheimer Bulgaria
(max 250 char)

2. Who initiated the Best Practice?

Civic Organization: si

Public Institution:

3. Location

City / Region: Nation-wide

Country: Bulgaria

4. Duration

Starting date: 2009

Ending date: on going

4. Object

Objectives: (max 1000 char)	Public awareness raising about the social implications of Alzheimer disease ; adoption of specific policies and measures ; development of a National plan for prevention of the disease ; development of a programme for adequate services ; termination of discriminative practices with respect of sick persons ; promotion of treatment for sowing down the developmnet of the disease ; reimbursement policies ; dialogue with the national institutions ; facebook page ; lobbying.
Resources: (max 500 char)	human resources provided on voluntary basis; mobilization of all stakeholders; promotion of the dialogue with the public institutions. PR campaign implemented
Outcomes: (max 500 char)	Sensitization of the Health Minister; adoption of a decision for free hospital treatment of the disease in Bg;submission of Declaration to the EU delegates – 16 of all BG delegates signed a declaration recognizing the social implications of the disease; AS a result of the signing of the declaration by 485 MEPs a legislative procedure started to recognize the disease as a socially one and the development of a Directive to this end.So Alz. has been recognized as a socially disease in the whole EU.

Analysis

Policy Field	Health
Type of Best Practice	Dialogue, Collaboration, Partnership
Development of the BP (max 1000 char)	In 2009 a pilot project was initiatedfor socials ervices of people affected by Alzheimer. The project was initially financed by the Ministry of Labour and Social Policy in Bulgaria. For 5 months over 300 families received social, psychological and legal consulting as well as referral of sick people. Two reception centres were opened in Sofia and Varna. A lobbying campaign was then organized to recognize the social implications of the disease. The purpose was to adopt a National Plan for prevention and specific policies; anti-discrimination and promotion of treatment with specific medication. A dialogue with the public institutions was initiated and the trade unions were mobilized.
Obstacles found (max 1000 char)	No response whatever from the Ministry of Health. Means used to overcome or remove the obstacles WE keep on submitting the same letter to the Ministry of Health to which we never received a response!!!
Means used to overcome or remove the obstacles (max 500 char)	Collaboration with other NGOs, big support from affected people and their families. Support from Open Society Support from Balkan Trust for Civil Society
Factors that facilitated the process (max 500 char)	Collaboration with other NGOs, big support from affected people and their families. Support from Open Society Support from Balkan Trust for Civil Society
Impact on the participants	Free hospital treatment Public awareness raised All stakeholders mobilized EU Directive

(max 1000 char)

Evaluation

- 1. Reproducibility**
(max 250 char) the practice can be reproduced for any disease
 - 2. Innovativeness**
(max 250 char) first effort nation wide for this disease
 - 3. Added value**
(max 250 char) Public awareness raised; national dialogue initiated; all stakehodlers mobilized
 - 4. Appropriateness**
(max 250 char) Highly appropriate, no other initiative of this scope and range
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Other information: www.alzheimerbulgaria.org

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