

## CLINICAL STUDY

## Stakeholder approach in strengthening the patients' rights in the Slovak Republic

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### Abstract

**Objectives:** The described project aimed to promote patients' rights in the Slovak Republic that are stipulated by law but in practice not observed fully.

**Background:** The project was based on a bi-lateral agreement between the Netherlands and the Slovak Republic in the framework of European Union pre-accession program and implemented in the period from January 2002 to June 2003.

**Methods:** Successful Dutch models of patients' rights promotion were used. They were applied under Slovak conditions and focused on the areas in the greatest need of attention, such as information campaigning and public awareness of patients' rights issues. The initiation of a cooperation of various stakeholders active in healthcare and national patients' right forums was among the most positive aspects of the project.

**Results:** The information campaign was constructed in order to educate citizens about their entitlements and rights within healthcare. Healthcare professionals were trained on respecting the rights of their clients. Pilots were started in several hospitals and in Healthy City projects, and patients' rights modules were made available at educational centers and various private and health organizations. Some of the cooperating healthcare professionals expressed their fear that the public might misuse the gained advocacy skills. This idea has originated from the current situation in Slovak healthcare, where inadequate financing, education, and management is a barrier in the physician's ability to serve the patient's best interest.

**Conclusions:** The implemented project started wide public discussion on patients' rights and stimulated a cooperation of a large number of stakeholders in the promotion of patients' rights (*Tab. 2, Ref. 13*).

Full Text (Free, PDF) [www.bmj.sk](http://www.bmj.sk).

**Key words:** patients' rights, Slovak Republic, public awareness, stakeholder approach.

The Slovak Republic (SR) was established in 1993 as one of two successors of former Czechoslovakia. Slovak Republic observes the rights of its citizens by declaring them in the constitutional laws and is bound by international and national legislation to create mechanisms for the protection and promotion of these rights, and to support citizens and citizen groups in the active exercise of their rights. The same applies for the area of healthcare. Healthcare, although being fundamentally a moral enterprise, must be built on sound business principles – clients and providers must know their rights and responsibilities (1, 2).

The Constitution of the Slovak Republic guarantees the right to health care to every citizen. A detailed proclamation of patients' rights is anchored in several acts of the Slovak legislation.

Civic activities promoting patients' rights in the Slovak Republic started a decade ago. Compared to the situation in some European Union countries, patients' groups and civic organiza-

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**Institution where the work was done:** The project described in the article was implemented within a program Matra financed by the Government of the Kingdom of Netherlands. The project lasted 18 months and it was implemented by a Dutch organization Interaction in Health in cooperation with Slovak experts. The project coordination office was located at the Ministry of Health of the Slovak Republic.

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tions in SR are considerably less active and effective in patients' rights promotion than health professionals, their organizations, and official institutions.

A work group of medical and legal experts, in cooperation with the Ministry of Health of SR prepared the Charter of Patients' Rights in the Slovak Republic. Prior to the Charter, a public awareness survey was conducted in 1999 showing an unsatisfactory general knowledge of rights and responsibilities in health care. The Government of the Slovak Republic adopted the Charter in April 2001 (3).

To have a charter as a well-defined summary of all patients' rights was the first step for enhancing the situation. Afterwards the Ministry of Health of SR decided to order an analysis and improvement of the situation in practice, by means of approaching the Dutch Government for expertise. The project 'Promotion of Patients' Rights in Slovakia' was implemented as a result of this international cooperation in the framework of bi-lateral cooperation for the European Union accession. This article describes the project implementation, outcomes and results.

### Methodology

The main approaches used in the project were methods of stakeholder involvement, consensus development, professional and continuous education, and media-based enhancement of public awareness. The project activities were driven by the vision of a continuous legacy for the Slovak Republic after the completion of the project. The emphasis was therefore put on the formation of partnerships, learning by doing, and team building in a broader sense of the term. Project consultants were aware of the political dimension of the result seen within a broader scope of healthcare reform. Important elements were to sustain patients' group involvement and development, but also to put patients' rights firmly on the agenda of the Ministry of Health by establishing a patients' rights unit and with health insurance funds and regional government.

The Strategic Committee (SC) was established at the very beginning of the project. The committee was composed of representatives of 30 stakeholder institutions. The bulk of their work was to evaluate the progress of the project every trimester. Members had a major say in outlining and designing the National Program of Patients' Rights (NPPR), important project output. A wide range of organizations was represented to ensure that the Program would cover most of society – from the patients' self-help groups through health insurance companies to municipal and state health authorities. Members of the Strategic Committee developed their own Action Plans to be included in the Program. Action plans were seen as a primary tool to initiate and sustain the activities in the area of patients' rights promotion of individual organizations during and after the project. Once the Action Plans were developed and publicly discussed, the Program became a lively document proving useful for navigation through various activities and indicating targets for subsequent actions. The Program was publicly discussed at the platform of the second session of the National Forum on Patients' Rights.

A questionnaire survey was deployed to assess the success of the project by evaluating the public's understanding of patients' rights issues during the initial and final phases of the project with a time difference of one year. A questionnaire based on 11 questions was distributed by survey interviewers (Master of Public Health students of Trnava University) to 200 respondents in 4 cities. The results were analyzed using simple descriptive statistical methods. No random sampling was performed.

Four locations were selected to evaluate the impact of activities developed by the project team: Bratislava (the capital of Slovak Republic), Trnava (West Slovakia), Banská Bystrica (Central Slovakia) and Levoča (East Slovakia). Target audiences included hospitals, local elected governments, schools, and state healthcare agencies.

Pilot projects were deployed to test the methodology and to sensitize the public. Public lectures were organized in Bratislava (the capital of Slovak Republic) in cooperation with the City Hall. Several seminars on patients' rights were organized for employees of the Public Healthcare Institute of SR and national headquarters of 36 regional and district institutions. National and local media were contacted in the initial part of the project and provided a continuous coverage on the project activities, overall progress and results. A close cooperation with local civic organizations supported by the Healthy Cities Program (4) was initiated in Trnava (western Slovakia). 3 roundtables on the priorities and development in the area of patients' rights promotion were held there. The project experts participated twice in the annual Trnava Health Days, a town festival dedicated to health promotion. A public lecture was organized in cooperation with an educational centre of the Community of Catholic Church. Public Health Institute of Trnava hosted a seminar on patients' rights advocacy, and on the role of the health promotion officers. Local newspapers, radio and television covered all project activities organized in the city.

A close cooperation with the regional Public Health Institute and the Economic Faculty of University of Matej Bel was established in Banská Bystrica (central Slovakia). One-day seminars on patients' rights for the students and a comprehensive training for the employees of the Advisory Centres of all Public Health Institutes in Slovakia were organized. Advisory Centres are in each of the 36 regional and district Public Healthcare Institutes all over the country. Their objective is to provide counseling on health risk factors to the citizens. They are financed from the state budget. Local media cooperated closely and reported on all pilot activities.

An active group of hospital managers was formed to improve the way patients are informed about services provided by the hospital in Levoča (Eastern Slovakia). The second hospital in Humenné joined the project due to efficient local media coverage. Both of them focused on restructuring their information strategy, developed a general information brochure for admitted patients and information manuals on individual hospital wards. Both hospitals also revised the patients' satisfaction questionnaire and its evaluation procedure.

The educational part of the project started with the design and development of a set of training modules. Each module con-

sisted of an outline of the session, PowerPoint presentation and a list of examples and cases. These were used during the entire project period for training seminars and workshops. The final version of the modules was distributed on CDs and as a booklet (both in English and Slovak languages) to all of the project stakeholders. The project provided training events for inspector physicians from the General Health Insurance Company, for employees of the Public Health Institutes, and for representatives of patients and consumers. The training of trainers was held as well, with a vision of sustained training activities. All selected trainees are in positions capable to act as intermediaries between the public and healthcare system and able to promote patients' rights in their work.

Three groups nominated by the beneficiary (the Ministry of Health of the SR) visited relevant Dutch institutions. One group was oriented to patients' and consumers' organizations. The second group was from the Ministry of Health, regional health departments, district hospitals and public health institutes. The third group was from the General Health Insurance Company. The aim of these study tours was to familiarize the participants with patients' rights management in the Dutch society. Visitors had the opportunity to establish personal contacts with their Dutch counterparts, to discuss their experiences and to obtain materials relevant to their interests.

Inspector physicians from the General Health Insurance Company were chosen because of their role as the regulators of the quality of healthcare. Employees of the Advisory Centers of the Public Health Institutes provide counseling on health risks to citizens. By means of the training they enhanced their counseling skills on how to exercise the patients' rights in healthcare. Patients' self-help groups and consumer organizations activists gained knowledge and skills for further use in their advocacy activities. Trainers were selected based on criteria of their abilities to disseminate the gained knowledge through their professional work.

Two national conferences, the National Forums, established space facilitating the exchanging of ideas, experiences, and good examples of patients' rights promotion between Dutch and Slovak participants. A strategic document, 'The National Program of Patients' Rights' was developed to help sustain the patients' rights promotion in the country. The document was outlined by the project, and all of the project stakeholders contributed with

their action plans and their suggestions. The Program was submitted to the Minister of Health of SR at the end of the project. An administrative body 'Patients' Rights Unit' was established at the Ministry of Health of the Slovak Republic to ensure the continued success of the project, and to facilitate the implementation of developed strategies.

A continuous information campaign was carried out during the entire project. The Charter of Patients' Rights in the Slovak Republic was published in form of a brochure and broadly distributed to the stakeholders. A number of other media related activities took place. Effective cooperation with local and national media was established and all of the project activities were presented to the public.

The 'Promotion of Patients' Rights in Slovakia' project was implemented within the pre-accession program MATRA, financed by the Government of the Netherlands as a support for the Ministry of Health of the Slovak Republic in soft acquisition of EU practices. The project was carried out for over 18 months. The implementing institution was 'Interaction in Health' from the Netherlands, a consulting group working for governments, NGO's and bi lateral organizations in health, operating through a group consisting of both Dutch and Slovak experts.

## Results

The initial survey designed to estimate the public awareness showed that less than 60 % of the population is aware that the rights of patients are covered by the legislation and more than 80 % of respondents think these rights are not observed. In response to the practical implementation of particular rights, such as the right to information, informed consent, choice of physician or health care facility, refusal of treatment or participation in medical research, a very low number of respondents were familiar with their rights (50–60 %). An identical survey was conducted at the end of the project duration (time difference of one year) to assess the project's impact. This survey showed that the public awareness on the issue had increased in several areas (Tab. 1).

The communication campaign was based on local and national media as well as supported by web site. To summarize the overall media coverage of project activities there were 10 articles published in the national newspapers and 20 in local newspapers, 2 national and 6 local television news broadcasts cov-

**Tab. 1. Differences of the results of the initial and follow up surveys (time difference of one year).**

Initial Survey	Follow up Survey
more respondents knew their right to refuse health care	fewer respondents expressed the opinion patients' rights are not observed in the SR
more respondents knew their right to receive health care only after a properly informed consent	more respondents reported they were properly informed and instructed while receiving health care
more respondents mentioned compliance with treatment regime to be the most important patient's responsibility	

**Tab. 2. List of educational modules developed within the project.**

Module	Module Title
1	Patients' Rights in the SR and selected European Countries
2	Human Rights and Patients' Rights
3	Choice of a Healthcare Provider
4	Information for Patients
5	Communication
6	Acceptation and Consent
7	Health Care Strategies
8	Quality of health Care
9	Professional ethics
10	Patients' Rights and Specific Patients' Groups
11	Advocacy
12	Stakeholders' Involvement, Complaint Procedure
13	National Program on Patients' Rights
14	Project Management

**Tab. 3. Numbers of training participants from stakeholder organizations.**

Name of organization	Number of employees participating in trainings organized by the project
General Health Insurance Company	45
Public Health Institutes	35
Patients' and consumers' organization	30
Various	20
<b>Total</b>	<b>130</b>

ered the project events, 4 national and 6 local radio broadcasts informed about the activities.

Educational and training activities were among the priorities of the project. A set of 14 educational modules was developed and used in 4 educational activities (Tab. 2).

The trainings had an audience of 130 professionals and activists within the duration of the project (Tab. 3).

The Unit of Patients' Rights Promotion was established at the Ministry of Health of SR in the final phase of the project as an administrative support to the promotion of the rights. Later it was transferred to the new Health Care Surveillance Authority. The role envisaged for the Unit was to carry out the activities initiated within the project and to oversee the implementation of the National Program of Patients' Rights. By the time of publication of this article the unit served as a public information center on the structure and scope of healthcare services rather than as an active patients' rights-promoting institution.

National Program of Patients' Rights (NPPR) is a strategic document developed for sustaining the project activities, and for general strategy of cooperation of healthcare providers and consumers, civic and governmental organizations and other institutions. The goal of the NPPR is to support the civic society in understanding and practicing their rights in relationship with healthcare delivery.

Today, 4 years after the project completion, we can say the situation in patients' rights awareness in the Slovak Republic has improved. Media coverage on project activities together with the presentation of healthcare reform steps has made the rights of patient well-known. The patients' organizations involved in project implementation are active in patients' rights promotion activities, many of them also at the international level. Public Health Institutes and hospitals involved in the project continue with their patients' rights promotion activities.

However, the National Program of Patients' Rights was not implemented after it had been submitted to the Ministry of Health at the end of the project. The reason for this was the lack of political will and the change of the Health Minister shortly after the project finalization.

The Health Care Surveillance Authority (HCSA), established in 2004, oversees the quality of healthcare delivery, and operates The Unit of Patients' Rights Promotion transferred here from the Ministry of Health. HCSA also investigates reported cases of medical errors and negligence, or other types of reported breeches of patients' rights.

In June 2006 the Declaration of the Health Sector was signed between the Association of Health Insurance Companies Slovakia ([www.zzp-sr.sk](http://www.zzp-sr.sk)), Association for Patients' Rights Protection ([www.aopp.sk](http://www.aopp.sk)), Association of Slovak Hospitals ([www.ans.szm.sk](http://www.ans.szm.sk)), Association of Private Physicians of Slovakia ([www.aslsr.sk](http://www.aslsr.sk)), Slovak Chamber of Other Health Care Employers ([www.skizpalt.sk](http://www.skizpalt.sk)), Slovak Chamber of Physicians ([www.lekom.sk](http://www.lekom.sk)), Slovak Medical Association ([www.sls.sk-eu.com](http://www.sls.sk-eu.com)), Slovak Medical Union of Specialists ([www.slus.sk](http://www.slus.sk)). The declaration represents joint effort of the parties to give expert opinion on the official health policy actions in the Slovak Republic. Several patients' organizations are active in representation of patient's voice and lobbying for the best interest of healthcare consumers, namely the nongovernmental organization Association for Patients' Rights Protection and National Council of People with Disabilities ([www.nrozp.sk](http://www.nrozp.sk)).

## Discussion

During the past fifteen years, an increasing number of European, mainly post-communist countries, have adopted laws protecting the patients' rights (5). The need of new legislation reflected the societal changes that affected all areas of life in these countries in the past 15 years, healthcare including. Character of patient-doctor relationship started to change in these countries after the fall of totalitarian regime, as it is changing also in other developed countries for several decades now. The former paternalistic relationship is transforming into a communicative model, a partnership, where the physician informs the patient and gives possible alternatives and the informed patient actively protects his health and in the state of illness decides on the treatment options. This is an ideal model and in all the countries there are still many obstacles and barriers to achieve it. Very often, especially in the post-communist countries, all rights of patients are stated in legislation – that is right to redress, right to access to



medical care and autonomy rights – but usually they are not observed in practice thoroughly (6, 7).

Slovak Republic followed the similar path since its establishment as an independent state in 1989, adopted new healthcare legislation (1994, significantly amended in 2004), and specified rights of patients (3).

The major question the project tried to answer is how to bring the promotion of patients' rights to life as a contribution to the civil society.

According to the Constitution of the Slovak Republic and other national legislation, the state provides its citizens with the patients' rights as stipulated in international standards. Under international human rights law the governments are responsible to respect, protect and fulfill rights, including the obligation to promote the right in question (8).

WHO experts evaluated the state of the legislation on patients' rights in Europe, with a few years time difference (9, 10). This review demonstrates the Slovak Republic concerns with patients' rights for a much shorter time when compared with other European Union countries, and the scope of the rights declared in Slovak legislation is smaller (10). E.g., when compared with several other European countries, a Slovak citizen has a right to look into his or her health documentation and take notes on the spot. However, he or she was not entitled to make a copy of it in the time of project implementation. Only the patient himself may look into his documentation, nobody else, not even a close relative or a legal representative. Some rights are stated by the legislation but it is almost impossible to exercise them in practice. For example, everyone is entitled to choose a general practitioner and a healthcare facility, but the criteria for selecting the provider are not available. There is no concern for cultural diversities in the Slovak healthcare delivery regulation so far, even though there are at least two large minorities living in the country, the Hungarians and the Roma (11, 12).

The ongoing healthcare reform plans the development of standards of health care. An institute for monitoring and control of healthcare delivery was established. Nevertheless, the reform focuses on healthcare financing mechanisms and their better efficiency. There is no strategy for the empowerment of patients, effective patients' rights implementation, education on patients' rights for the public and professionals, etc. The results of the presented project can become an effective tool for the Ministry of Health of the SR in empowering the client in use of health care services. Much will also depend on the institutional development and broadness of analysis and perspective of the existing patient organizations in Slovakia. There is about 200 active patients' organizations in the Slovak Republic currently, several are nation-wide with regional branches, others are local. Often there is a competition between individual institutions, mainly to get to the restricted national and international resources. Instead of the competition, a joint cooperation leading to mutual benefit should be exercised.

Apart from implementing the project activities on national level, the project team also participated on the preparation of the European Charter of Patients Rights. The development of the

Charter was initiated by the Italian civic organization Cittadinanzattiva – Active Citizenship Network and work group consisting of public health professionals and activists from several European countries. The Charter was presented at the assembly of the European Parliament and it is a recommended standard for all EU member and pre-accession states (13). The amendment of healthcare legislation in 2004 incorporated the European Charter in the Health Care Act. The described project laid the basis for efficient patients' rights promotion and enforcement in the Slovak Republic.

## Conclusion

The implemented project sparked a public discussion on patients' rights, stimulated a cooperation of a large number of stakeholders in the promotion of patients' rights and set up a structure for sustainability of the project results. Summarizing the project outcomes, a number of recommendations were made. It is recommended to improve the knowledge of healthcare employees in the area of patients' rights and medical ethics, to improve the public knowledge in this area, and to introduce mechanisms and structures for effective exercising of these rights. The overall recommendation is to strengthen the position of citizens in control of health-care at all levels. This stakeholders' approach, with its entire balance may prove to be a good tool to start up. But it does ask for an investment from both the citizens' (patients') movement and the providers, especially regional government and health insurance could find allies here in making the health sector more need-oriented and transparent. Establishing the Unit for Patients' Rights Promotion at the Ministry of Health was a significant success, however, the unit should be granted more power to mobilize stakeholders in order to empower them in exercising the patients' rights in practice.

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Received September 10, 2007.

Accepted September 20, 2007.