Final Activity Report

Patients' Rights as a Policy Issue in Southeast Europe

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1. According to the proposed timetable, during the fellowship year the following activities have been undertaken:

(a) Collection and analysis of relevant literature, available case studies, reports, legislation, etc.
(b) Questionnaire survey of patients, doctors and other stakeholders and analysis of the answers to the questionnaire (Bitola, Kochani, Glumovo, Shtip, Radovis)
(c) Visit, data collection and interviews with key informants in the SEE countries (Serbia and Montenegro, Croatia, Bulgaria, Romania)
(d) Preparation of draft policy paper and discussions with relevant stakeholders (September workshop)
(e) Presentation of the draft policy papers at Global Patients' Conference, organizaed by the IAPO (International Alliance of Patients' Organizations) held in February 2006 in Barcelona, Spain
(f) Preparation of the Research paper (based on the data collected and results observed) for publication in both English and Macedonian language

Detailed description of each of the activities undertaken:

(a) Collection and analysis of relevant literature

The collection of the relevant resources was targeted at gathering the information related to patients' rights in Southeast Europe. Internet was used as the main resource for document withdrawing, yet some materials were collected during visits of the institutions dealing with this issue. Institutions visited in Macedonia were: Ministry of Health, Health Insurance Fund, Doctors' Chamber of Macedonia, Consumers' Organization of Macedonia, Doctors' Association of Macedonia, Pharmaceutical Chamber of Macedonia, MIA-AIDS (NGO). Additionally, since one of the main objectives of this Project is ***analysis of the patients' rights policies and the level and quality of their implementation*** in different national contexts, contacts have been established with the Institutes of Public Health in Macedonia, Serbia and Montenegro, Bosnia and Herzegovina, Croatia, Albania, Bulgaria and Romania. These contacts induced a joint initiative for a project on Patients' rights in these countries (website: http://www.sharingforaction.med.bg.ac.yu/joint.htm). It was agreed that this initiative has to be further developed in the forthcoming months.

(b) Questionnaire survey and analysis of the results

Part of the research activities are determination of the ***level and quality of implementation of patients' rights***. This included questionnaire survey of Roma patients, as well as with patients from other ethnic groups (using semi-structured interviews as a method, for the purpose of collecting case studies) and interviews with medical professionals and supporting staff.

The sample questionnaire, consisting of about 30 questions was prepared and implemented in June 2005 in the capital city of Skopje, and in several other towns in Macedonia, which include large Roma communities (Bitola, Kochani, Glumovo, Shtip, Radovis). The methodology used was a semi-structured interview, with sampling in the health clinics and in the settlements where Roma population is concentrated.

The most important questions presented in the questionnaire are:

- the level of understanding of their rights as patients
- the level of exercising their rights as patients
- medical coverage (health insurance and access to healthcare)

The total number of interviewed patients was 396. For the purposes of comparison, besides the Roma target group, patients from other ethnic groups have been interviewed.

(c) Preparation of draft policy paper and discussions with relevant stakeholders (September workshop)

The results from the literature review, as well as the conclusions drawn from the health survey undertaken in Roma and mixed communities will be used for drafting the Research Paper and the Policy Study.

The remaining part of this set of activities is the discussion of the draft policy paper with the relevant stakeholders (Ministry of Health, Doctors' Chamber of Macedonia, Doctors' Association, etc), which will be undertaken in a workshop, tentatively scheduled in September 2005. For that purpose, a Policy Brief was prepared that can be found on the website of this project: www.policy.hu/milevska.

(d) Presentation of the draft policy paper at Global Patients' Conference, February 2006, Barcelona, Spain

The draft policy paper "Patients' Rights as a policy issue in Southeast Europe" was presented at the Second Global Patients' Congress, held 22-24 February 2006 in Barcelona, Spain. The Congress was organized by IAPO (International Alliance of Patients' Organizations), a global network organization based in United Kingdom. At the end of the Congress, the participants have adopted a Declaration on Patient-Centered Healthcare. The details of the Congress, as well as the text of the declaration can be found at the following website:
http://www.patientsorganizations.org/showarticle.pl?id=649&n=605

(e) Preparation of the Research publication in English and Macedonian language

As scheduled in the original timetable of this project, the end product of the research is the publication of the results and policy recommendations in a form of a booklet that will be published in both English and Macedonian language. The preparation of the booklet (English editing, translation into Macedonian language, etc.) is in process, and it will most likely be published by September 2006.