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The experience of the European Charter of Patients’ Rights and the project of a European Day of Patients’ Rights

Active Citizenship Network
January 2006

Program
• Presentation of Active Citizenship Network (ACN)
• The experience of the European Charter of Patients’ Rights
• The European Day of Patients’ Rights

Presentation of ACN
• Active Citizenship Network (ACN) is a network of citizens’ organizations working at national level in 30 European countries
• It is a flexible network without formal membership, based on the concrete participation in activities and projects
• About 70 organizations have already participated in our project since December 2001
• Headquarters in Rome and not in Brussels

Presentation of ACN
• The main goal of our network is to promote the participation of citizens’ organizations in Europe:
  – In general policy-making: Representativeness of citizens’ organizations; European Charter of civic participation; etc.
  – In specific public policies such as healthcare.

Charter of Patients’ Rights
• The Charter is a bottom-up initiative.
• It was drafted in 2002 in collaboration between ACN and 12 other citizens’ organizations dealing with health in Europe.
• Not only rights of patients but rather of citizens (including users, family members, vulnerable population and ordinary citizens) with respect to healthcare.

Charter of Patients’ Rights
• Rationale of the project:
  – The same rights are at risk in all EU countries;
  – They are often affirmed in theory but denied in practice;
  – Main reasons: financial constraints; healthcare systems not sufficiently centred on patients; cultural obstacles.
  – Patients’ rights have practically became a European matter (especially increase of patients’ mobility).
Charter of Patients’ Rights

• Content:
  – Definition of 14 rights of citizens to healthcare, based on the fundamental rights established in the Nice Charter
  – Definition of 3 rights of citizens and their organizations to participate in the protection of these rights.

• Aims:
  – To create a European public opinion on patients’ rights
  – To promote a higher degree of protection of rights
  – To promote the participation of citizens’ organizations in healthcare policies

14 Patients’ Rights

1. To preventive measures
2. Of access
3. To information
4. To consent
5. To free choice
6. To privacy and confidentiality
7. To respect of patients’ time
8. To the observance of quality standards
9. To safety
10. To innovation
11. To avoid unnecessary suffering and pain
12. To personalized treatment
13. To complain
14. To compensation

Rights of Active Citizenship

1. To perform general interest activities
   • Concomitant duty of the authorities and all relevant actors to favour such activity for the protection of healthcare rights.
2. To perform advocacy activities
   • Auditing and verification activities in order to measure the effective respect for the rights;
   • Activities to prevent violation of the rights;
   • The right to submit information and proposals and to get a reply;
   • The right to dialogue with public and private health authorities.
3. To participate in policy making
   • The right to participate in the definition, implementation and evaluation of public policies relating to healthcare.

Monitoring of Rights

• ACN and its partners monitored the implementation of the 14 Charter’s rights in the 15 “old” EU MS (2003-04)
• Activities:
  – Definition of a monitoring methodology (including 160 indicators) with the help of health policy experts and statisticians;
  – Carrying out of the monitoring in 3 hospitals / country by national citizens’ organizations (Patients’, consumers’, women’s, welfare organisations, etc.);
  – Analysis of the collected data and drafting of a European working paper on the monitoring results;
  – Presentation of the working paper in the premises of the EP on 28 Feb-1 March 2005.
• The final report on the monitoring results in Oct. 2006.

The European Day

• Project origin / aim:
  – The idea to create a European Day of Patients’ Rights is born in occasion of the Conference in the EP (28 Feb-1 March 2005) as a way to further raise awareness on patients’ rights in Europe, both at the national and the EU level.
• Concrete objectives:
  – To establish a European Day of patients’ rights celebrated on the same date in all EU, Member States and candidate countries (New Europe – NE countries);
  – To extend the monitoring on the Charter’s rights to all NE countries and use the collected data as an instrument to improve the respect of patients’ rights.

The European Day

• Project in 2 steps:
### The European Day

**1/ Conference in the EP**

- **Main objectives:**
  - To launch the European Day project:
    - presenting the commitments of the EU institutions and other healthcare stakeholders;
    - presenting the final report of the monitoring already carried out in 2004 by ACN;
    - decide on the date of the annual European Day.
  - To focus on the application of the European Charter’s rights to cross-border patients.

- **Target**
  - About 150 participants;
  - Representatives of EU institutions, Ministries of health, International organizations, National citizens’ organizations and European networks, Unions of health professionals, Private companies; etc.

- **Chairpersons:**
  - the President of the EP and/or
  - the Minister of Health of the Finnish Presidency.

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**2/ In the NE countries**

- **Main objectives:**
  - to publicize the 14 Charters’ rights as close as possible to European citizens, making these rights concrete;
  - to produce citizens’ data on the respect of patients’ rights in all NE countries;
  - to create partnerships between citizens’ organizations, public institutions and other health care stakeholders in all NE countries, using as a basis the collected data and with the objective to improve the respect of patients’ rights.

- **Main activities:**
  - Celebration of the European Day in hospitals and other health care facilities (2007 + 2008);
  - Celebration of the European Day in an institutional event in every NE country (2007 + 2008);
  - Monitoring of the Charters’ rights in all NE countries (2007-2008);
The European Day 2/ In the NE countries

- European Day in hospitals in 2007 and 2008:
  - All health care facilities in Europe will have the possibility to participate in the European Day;
  - A call for participation will be disseminated in all NE countries in partnership with European regions and European networks of hospitals;
  - The participating hospitals will:
    - distribute materials on the European Charter;
    - organize a symbolic event on one or several patients' rights involving local citizens.

- Institutional events in 2007 and 2008:
  - In every country the partner associations will organize an institutional event on the European Day, with the objective to create partnerships on patients' rights between the different health care stakeholders.
  - Special attention will be dedicated to the media cover of these initiatives.

- The monitoring of patients’ rights implementation:
  - It will be carried out in all NE countries by the partner organizations, using the methodology already tested by ACN in the 15 old EU countries (see slide 10);
  - The activities linked to the monitoring (update of methodology, training of partners, monitoring, reports) will last for 2 years (2007-2008);
  - The monitoring results will be presented on the second annual celebration of the European Day (2008), both at the national and at the EU level.

  - The conclusive event of the whole project will be a conference organized in the European Parliament in occasion of the second celebration of the European Day;
  - It will be an occasion to:
    - present the European report on patients’ rights monitoring;
    - report on all activities carried out at the national level;
    - verify whether the MEPs and other stakeholders have respected the commitments made in 2006.

- Follow-up:
  - The objective is to maintain the annual celebration of the European Day;
  - Therefore, the creation of strong partnerships at the national and the European level with all stakeholders will be one of the main keys for success.

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