

## MANIFESTO

### “Empowered patients are a resource ”

#### **Civic Recommendations to improve the empowerment of citizens with chronic and rare diseases and their organizations**

##### **FOREWORD**

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

There is a general concern about the increased costs that shall burden health institutions owing to the pressure exercised by associations of patients with chronic diseases, since their main objective should be increased access to and better reimbursement of innovative and expensive treatments and drugs. However, they play a decisive role in the development of a modern patient-centred health system. Consequently, the empowerment of patient organizations should be considered as an added value, because they become actual partners in the health policy, sharing with the institutions the responsibility of finding the best balance between the interest of patients and the sustainability of the system.

Civic and patients organizations are an indispensable source in the "cultural and social mediation" process between policy makers, health care professionals and patients, in the transparency and the provision of support services to patients and care givers.

This is achieved through the creation of networks and alliances, which allow the identification of common objectives and goals. This includes the development of a global and long-term perspective, which goes beyond the single chronic disease and reflects the general interest of patients.

## **OVERALL RECOMMENDATIONS**

The difficult economic situation Europe is currently living in calls for a recommendation as the necessary premise to the following civic recommendations for the empowerment of citizens with chronic diseases and their organizations. European citizens are in fact asked to participate more and more to the costs of healthcare: those who can pay do it, otherwise the less fortunate go without cure.

Recently, there is an increase in several additional private costs incurred by many patients suffering from chronic diseases, and families are often forced to contribute as well: from the cost for residential/semi residential care, care givers, non reimbursable medication by the National Health Service, “over the counter drugs” (such as dietary supplements, special food, creams and eye drops), energy bills for electro-medical equipment.

How to deal with all this?

- Supporting the Member States in singling out forms of assistance to help families with a member suffering from a chronic disease, starting from low income families with one or more elderly chronic relatives.
- Analyzing at EU level, with the contribution from civic and patient organisations, the phenomenon of unbearably high electricity bills to families with people suffering from chronic diseases and using electro-medical equipment.
- Allowing patients and family members to reconcile their work commitments with the need to take care of their relatives suffering for chronic diseases at home.

Therefore, the Associations mentioned below call for new Members of the European Parliament and all European Institutions to support civic and patient organizations in their activities of Self-management & Education, Participation & Evaluation, Cooperation, Innovation, Information & Communication.

### **SELF MANAGEMENT & EDUCATION:**

Within a supporting healthcare system, patients self manage their own pathologies if correct information on treatment and patients’ rights is supplied to them. A chronic patient, if well supported by “healthcare education programmes”, acquires the correct competences on treatment and crisis management in case of emergencies, relapses and collateral effects.

How can this be guaranteed?

- By providing continuous high quality information and health literacy for people with chronic diseases and their caregivers on all aspects of disease management, to enforce the role and the added value of an “Expert Chronic Patient”<sup>1</sup>;
- By supporting the development of patient and care givers empowerment mechanisms across the EU, with specific focus on Cross-European standards for patient empowerment in clinical healthcare practices;
- By embedding patient empowerment and engagement within the European education frameworks for health care professionals and patients' organizations

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<sup>1</sup> Expert Patient is a person empowered with skills and information to take control of his live, be the key decision-maker and responsible for the management of his long-term condition. He works in Partnership with health professionals.

- Patients must be involved in all elements of healthcare
- Invest in Self-management of chronic disease
- To have access to personal records in order to have information for management of their conditions
- Embedding patients in the co-production of health services they will use

#### **PARTICIPATION & EVALUATION:**

Engage patients collectively and pro-actively through patient organizations in policy decision making (development, implementation and law enforcement), and Health Services evaluation to ensure that all policies and practices reflect patients' real-life needs, preferences and capabilities.

How can this be guaranteed?

- By establishing a Cross-Commission taskforce in the new EU Parliament, in order to facilitate the institutional relationship;
- Adopt a resolution requesting to the Commission to create a EU consultative group for patient and health system users composed of representatives of national associations of patients and users
- By organizing EU Parliamentary hearings (at least once a year) on chronic diseases;
- By embedding representatives of civic and patients organisations in the decision making processes regarding management of the disease policies at EU level;
- By collecting the best practices in terms of involvement by civic and patients organisations both in the programming and in gauging the quality of services.
- Advocate to introduce a systematic participation for healthcare users at national and EU level
- Recognition of participation principle from the EU Parliament at political level

#### **INNOVATION:**

Promote and support public and private research for the development of new therapies for chronic patients and those suffering from rare diseases. Involve civic and patients organizations in faster methods to define new bureaucratic solutions.

How can this be guaranteed?

- By developing a clear framework for chronic patient involvement across the range of health research, through the entire cycle of the innovation chain (starting from Health technology assessment);
- By making the decision and authorisation processes more accessible both at European level through the European Medicine Agency and through the National Medicine Agencies;
- By carrying out a European survey with the contribution of civic and patient associations to define the main obstacles which hinder and discriminate access to pharmaceutical innovation and innovative therapies from one country to another and within parts of the same country;
- By developing new procedures best value for the cost. Simplified bureaucratic procedures: less waiting time for citizens, lower costs for the public administration. By carrying out a research on good practices at European level with the contribution of civic and patients organisation to find solution to define the criteria for access to healthcare allowances and to streamline the procedures enabling chronic patients to use available benefits (i.e. socioeconomic benefits for the recognition of civil disabilities/invalidity, bonuses for electromedical equipment) already included in the current regulations.

## **COOPERATION:**

Foster a collaborative approach among patients and health care professionals.

How can this be guaranteed?

- By promoting initiatives that facilitate meaningful relationship and partnership between patient and health care professionals (doctors, nurses etc.), researchers, health companies etc.
- Reinforcing civic organizations networking at EU level

## **INFORMATION & COMMUNICATION:**

Promote initiatives to empower patient and civic organizations to help patients understand their rights and therefore make informed choices.

How can this be guaranteed?

- By supplying civic information as a necessary support for any research on chronic patients' conditions;
- By supporting a civic assessment on the respect of chronic patients right to avoid unnecessary suffering and pain;
- promoting a EU widespread communication campaign about health and social burden of chronic diseases, in order to stress what for many patients suffering from chronic diseases is not visible in their everyday life;
- By actively informing citizens about their cross-border health care rights. In particular, for chronic patients and those suffering from rare diseases, "the Directive on Patients' Rights in Cross-border Healthcare means empowerment: greater choice of healthcare, more information, easier recognition of prescriptions across-borders"<sup>2</sup>.
- Sustain the monitoring by the civic association of the implementation of the Directive on the cross border care
- Adopt a resolution requesting the Commission to publish a "European Charter of Patients' Rights" to better inform citizens residing in the EU about their health rights



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<sup>2</sup> Tonio Borg, European Commissioner for Health, October 2013.