

**Recommendation No. R (2000) 5
of the Committee of Ministers to member states
on the development of structures for citizen
and patient participation in the decision-making process
affecting health care**

*(Adopted by the Committee of Ministers
on 24 February 2000
at the 699th meeting of the Ministers' Deputies)*

The Committee of Ministers, under the terms of Article 15.b of the Statute of the Council of Europe,

Considering that the aim of the Council of Europe is to achieve greater unity between its members and that this aim may be pursued, *inter alia*, by the adoption of common action in the public health field;

Bearing in mind Article 11 of the European Social Charter on the right to the protection of health;

Recalling Article 3 of the Convention on Human Rights and Biomedicine requiring the Contracting Parties to provide "equitable access to health care of appropriate quality", and Article 10 on the right of everyone to know any information about his or her health;

Having regard to the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (ETS No. 108) and to the Recommendation No. R (97) 5, as well as to Recommendation No. R (97) 17 on the development and implementation of quality improvement systems in health care;

Bearing in mind the report of the Parliamentary Assembly of the Council of Europe on instruments of citizen participation in representative democracy (Doc. 7781(1977));

Noting the relevance of the World Health Organisation's Health 21 programme for the European region and of its recent policy documents on patients' rights and citizens' participation;

Recalling the Amsterdam Declaration on the Promotion of Patients' Rights in Europe;

Noting that the Ljubljana Charter on Reforming Health Care, endorsed by the WHO, stresses the need for health care systems which focus on people and allow the "citizens' voice and choice to influence the way in which health services are designed and operate";

Further noting the importance of the Ottawa Charter for Health Promotion (1986) and the Jakarta Declaration on Leading Health Promotion into the 21st Century (1997) as statements on the guiding principles for public health;

Recognising that a health care system should be patient-oriented;

Considering that citizens should necessarily participate in decisions regarding their health care;

Recognising the fundamental right of citizens in a free and democratic society to determine the goals and targets of the health care sector;

Recognising the important role that civic and self-help organisations of patients, consumers, insured persons and citizens play in representing "users'" interests in health care and recognising that their primary role is both to provide support and services to and further the interests of their members;

Considering that participation in the decision-making process will lead to public acceptance of health policy goals;

Considering that it is necessary for each member state to help to broaden the public's general knowledge about health problems, promote healthy living, disease prevention and ways of taking responsibility for their own health;

Recognising the fact that empowering citizens revitalises representative democracy, enhances social cohesion, leads to the better functioning of the health care system, and establishes a better balance of interests and a partnership between the various players in the system;

Conscious that patient empowerment and citizen participation can be achieved only if basic patients' rights are implemented and that, in its turn, patient participation is a tool for the full implementation of these rights in daily practice;

Recognising that there are different levels of citizens' empowerment, from the ability to influence the overall administration of the health care system and to participate in the decision-making process, through the ability to further particular interests through organisations of patients or citizens, through representation on boards or executive bodies governing health care establishments, and through direct influence over the provision of health care through the freedom of choice,

Recommends that the governments of member states:

- ensure that citizens' participation should apply to all aspects of health care systems, at national, regional and local levels and should be observed by all health care system operators, including professionals, insurers and the authorities;
- take steps to reflect in their law the guidelines contained in the appendix to this recommendation;
- create legal structures and policies that support the promotion of citizens' participation and patients' rights, if these do not already exist;
- adopt policies that create a supportive environment for the growth, in membership, orientation and tasks, of civic organisations of health care "users", if these do not already exist;
- support the widest possible dissemination of the recommendation and its explanatory memorandum, paying special attention to all individuals and organisations aiming at involvement in decision-making in health care.

Appendix to Recommendation No. R (2000) 5

Guidelines

I. Citizen and patient participation as a democratic process

1. The right of citizens and patients to participate in the decision-making process affecting health care, if they wish to do so, must be viewed as a fundamental and integral part of any democratic society.
2. Governments should develop policies and strategies, which promote patients' rights and citizens' participation in the decision-making in health care, and provide for their dissemination, monitoring and updating.
3. Patient/citizen participation should be an integral part of health care systems and, as such, an indispensable component in current health care reforms.
4. Decision-making should be made more democratic by ensuring:
 - a clear distribution of responsibilities for decision-making in health care;
 - appropriate influence of all interest groups, including civic associations active in health-related matters, and not only of some stakeholders (professionals, insurers, etc.);
 - public access to political debates on such issues;
 - wherever possible, citizens' participation at the problem identification and policy development stages; participation should not be confined to resolving problems and simply choosing between solutions, which have already been drawn up.
5. Public debates should be more widely used to strengthen participatory mechanisms.

II. Information

6. Information on health care and on the mechanisms of the decision-making process should be widely disseminated in order to facilitate participation. It should be easily accessible, timely, easy to understand and relevant.
7. Governments should improve and strengthen their communication and information strategies should be adapted to the population group they address.
8. Regular information campaigns and other methods such as information through telephone hotlines should be used to heighten the public's awareness of patients' rights. Adequate referral systems should be put in place for patients who would like additional information (with regard to their rights and existing enforcement mechanisms).

III. Supportive policies for active participation

9. Governments should create an environment, which is supportive of people's participation and responsibility in decision-making in health care.

This implies:

- instituting or strengthening mechanisms and/or structures for such participation; listening to patients and citizens should become a constant concern for the whole health care system at all administrative levels and in all regional, federal or national branches of health authorities;

- supporting democratic procedures for nominating and selecting citizens' representatives including membership in ethics committees, health boards and advisory bodies or any other structure in charge of taking health-oriented decisions;

- involving citizens and health care users in the management of different structures of the health care system;

- introducing ongoing evaluation of the dynamic participatory processes, in which citizens and patients take part;

- ensuring that all relevant population groups are able to participate on an equal basis;

- eliminating financial, geographical and/or cultural and linguistic restrictions to participation;

- promoting additional assistance to vulnerable groups to facilitate their participation;

- endorsing education and training facilities for citizens in order to develop democratic participation.

10. Governments should adopt policies that create a supportive environment for the growth in membership, orientation and tasks of civic organisations of health care "users" by:

- creating a legal basis for participation of citizens in the management of health care facilities and insurance companies;

- creating favourable conditions, both in the legal and fiscal system, for the founding and operating of such organizations; the health budget, as far as possible, should include allocations to support such organisations;

- creating favourable legal conditions to support financing of such organisations by the industry while avoiding conflicts of interests;

- stimulating co-operation, whenever possible, between organisations, while respecting their diversity. Citizens associations dealing with health matters should work together towards achieving alliance strategies;

- facilitating the provision of services and support by these organisations to as many people as possible;

- granting these organisations a role in providing information to their members and the general public on specific questions and/or general health information;

- allowing such organisations their place among other interest groups in health care (organisations of professionals, insurers, etc.);

- encouraging democratic and ethical debates in these associations;

- developing transparent and open relationships between public authorities and associations.

11. The following complementary measures should be envisaged:

- publishing an annual report on the progress in citizens' participation in the decision-making process affecting health care;

- ensuring that every contract concluded with the public authorities or between key operators in the health care system should include a commitment to develop citizen/patient participation;

- training health professionals in communication and in participation practices;

- developing, in consultation with the NGO's, research programmes on patient/citizen participation in the process of health research and the most effective mechanisms for ensuring participation in the decision-making processes relating to health care.

IV. Participation mechanisms

12. Citizens should participate throughout the legislative process in health care: in the drafting of laws, in their implementation and follow-up, including future modification procedures. This can be achieved through participation in commissions and public debates, whenever appropriate.

13. Citizens/patients should have the possibility of participating in setting priorities in health care.

For this purpose, the various different aspects of priority setting should be clearly explained to ensure responsible and informed participation by citizens. Aims, outcomes and responsibilities attached to these choices must be clearly set out, as well as implications of these choices as regards the allocation of resources, reorganisation of the health system and relations between the different components of the health care system.

14. Patients' viewpoints and expectations should be taken into account when assessing the quality of health care. Patients should have a say in internal evaluation and should also be involved in external evaluation via patients' associations. Contracts with service providers should contain a binding clause to this effect.

15. Patients and their organisations should be granted access to adequate mechanisms for enforcement of their rights in individual cases, which could be complemented by a supervision mechanism by an independent body.

In order to be effective these mechanisms should have a broad range, providing for forms of conciliation and mediation. Formal complaints procedures should be straightforward and easily accessible. Financial barriers to equal access to these mechanisms should be removed, either by making access free of charge or by subsidising people with low incomes who wish to use them.

16. Systematic collection and analysis of patients' complaints should be used to gather information on the quality of health care and as an indication for areas and aspects that need improvement.

