Charter for Public Participation in Health

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Com o alto Patrocínio
de Sua Excelência

O Presidente da República

Charter for Public Participation in Health

All people with or without disease - including their representatives - have the right to participate in health decision-making (1) and the Constitution of the Portuguese Republic determines the promotion of participatory democracy[1] and the encouragement of citizens' democratic participation[2], as well as the participatory management of the National Health Service (NHS)[3]. However, people with or without disease and their representatives not only have the right to be involved, but their contribution is relevant and necessary because they have a unique experiential knowledge about the health system, health care and their disease (2-7). In this context, organisations of people with disease, health services users and/or consumers also play a key role in representing and defending the rights and interests of their members (1, 8).

Public participation strengthens the legitimacy, transparency, and accountability of the health system (1, 9, 10). On the other hand, it also responds to the objective of adjusting and aligning health care policy and service delivery, regarding people's unmet needs and priorities, and individual and collective preferences (11-13), thus enhancing the quality of health decision-making processes (2, 14-16). In this way, the participation of people with or without disease and their representatives in decision-making contributes to: (i) the orientation of the health system to the person with or without disease, (ii) the quality, acceptance and effectiveness of health policies and programs, (iii) better health outcomes, (iv) improving and increasing the acceptability of decisions, (v) improving communication between the health system and citizens, (vi) rebalancing the relationship between supply and demand, vii) the recognition of citizens' responsibility and autonomy, viii) the definition of health policies and priorities, ix) favouring involvement in health promotion activities, x) the legitimacy of decisions on complex issues concerning both the cost-effectiveness evaluation of certain interventions and the ethical dilemmas posed by technological innovations (1, 3, 17).

Several organisations[4] have been advocating for the need to ensure public participation in health systems. There are also several examples of initiatives to promote greater and better participation in health decision-making, both at the European Union and Member States level, and also outside Europe[5].

In Portugal, both the National Health Plans (PNS) for 2004-2010 (18) and 2012-2016 (8), and its review and extension to 2020 (19), contemplate the involvement and participation in decisions as a citizens' right, and one of the key strategies to be implemented to maximize health gains. These documents also highlight the responsibility and the key role that organisations of people with disease, health services users and/or consumers have in representing their interests, in their involvement and in promoting literacy, capacity-building and empowerment of their members. However, although there are already some institutionalised initiatives of participation in the health sector in Portugal[6], the World Health Organization (WHO) (20,21) has reiterated that this participation has been selective and insufficient, recommending a more effective involvement of people with or without disease in health decision-making (i.e., earlier and at different moments, and in a more comprehensive and consistent way), including in the scope of government activity.

[1] Article 2 of the Constitution of the Portuguese Republic.
[2] Article 9 (c) of the Constitution of the Portuguese Republic.
[3] Number 4 of Article 64 of the Constitution of the Portuguese Republic.
[4] European Patients' Forum (22,23), International Alliance of Patients' Organizations (12), Active Citizenship Network(24), European Council (1), European Commission (24,25), World Health Organization (26,27), Organisation fot Economic Co-operation and Development (28).
[5] Health Councils – Australia (29), Brazil (30), Spain (31), Canada (29) and United Kingdom (32–34).
Mixed Consulting Boards – Italy (Emilia-Romagna) (35)
Public Consultations – USA (Oregon) and Canada (Ontario) (29)
Regional Health Conferences – France (29).
Assessment of Health Technologies – United Kingdom (National Institute for Health and Care Excellence: citizens council, commissions and work groups, public consultations, etc.) (24,36–39).
Approval of new medicines – European Union (European Medicines Agency: scientific committees, scientific counselling groups, Patients' and Consumers' Working Party, etc.) (40), and USA (Food and Drug Administration: Patient Representative Program) (41).
[6] For example, in the Community Councils of Primary Care Groupings (ACES), Hospital Advisory Councils, the Ethics Commission for Clinical Research (CEIC) and, more recently, the National Health Technology Assessment System (SINATS).

VISION

MORE PARTICIPATION better health

MISSION AND OBJECTIVES

The Charter for Public Participation in Health aims to establish participation of people with or without disease and their representatives in decisions affecting the population health, as well as to encourage health decision-making based on broad public participation.

The Charter also aims to promote and consolidate public participation at the political level and in the various State bodies and institutions in Portugal, by strengthening existing participation processes and creating new participatory spaces and mechanisms.
In this way, the Charter will contribute:

- To promote and to defend the rights of people with or without disease, namely in regard to health protection, information and participation;
- To inform public institutions about the priorities, needs and concerns of people with or without disease and their representatives;
- To make health policies more effective and, consequently, to achieve better health outcomes;
- To promote decision-making transparency and decision-makers accountability;
- To bring the State and civil society closer together, improving the dialogue and regular interaction between them.

PRINCIPLES

Public participation in health should be based on the following principles:

- Recognition of public participation as a right of people with or without disease and their representatives;
- Recognition of people with or without disease and their representatives as partners in decision-making processes;
- Recognition of the importance of the unique knowledge and experience of people with or without disease;
- Autonomy and independence of people with or without disease and their representatives in participatory processes;
- Transparency and public disclosure of participatory processes;
- Creation of the necessary conditions for participation;
- Complementarity and integration between institutions and mechanisms of representative democracy and participatory democracy.

SCOPE

The public participation of people with or without disease and their representatives includes decision-making within the framework of health policy and other related policies, both at the level of the respective Ministry(s) (including integrated services in the direct or indirect administration from the State, advisory bodies and other health related entities), the Portuguese Parliament (and the respective National Councils in the field of health) and also local authorities.

The public participation of people with or without disease and their representatives covers, for example, the following areas:

- The National Health Plan and health programs;
- Management of the National Health Service (including human, material and financial resources) and organisation of health care (primary care units and hospitals);
- State budget for health;
- Health technologies assessment;
- Health quality assessment;
- Standards and guidelines;
- Ethics and health research;
- Rights of people with or without disease and their representatives.

GUIDELINES

Participatory processes in health decision-making must comply with the following guidelines:

A) Representativeness and eligibility

- Involvement of all affected stakeholders, including the most vulnerable;
- Ensuring diversity and parity in participatory processes;
- Establishment of transparent criteria for choosing people and organisations to participate;
- Rotativity of participating people and organisations.

B) Process

- Promotion of truly participatory and democratic processes;
- Formalisation of participatory processes;
- Diversification of forms and opportunities for participation;
- Implementation of mechanisms tailored to specific populations;
- Promotion of autonomy and independence in participatory processes and of people and organisations that participate, avoiding co-optation by the system;
- Continuous monitoring of participatory processes and their results, involving the people and organisations that participate;
- Integration between local, regional and national participatory processes, where they exist.

C) Information and transparency

- Public and timely dissemination of relevant information on health and participatory processes (opportunities, criteria, forms, results, conclusions, etc.) in simple and objective language and in accessible formats;
- Elaboration of an annual report on public participation in health, involving the people and organisations that participate.

D) Conditions for participation

- Provision of the human, material and financial resources necessary for participation;
- Elimination of financial, geographical and/or cultural and linguistic barriers to participation;
- Development of the necessary tools for a widely involvement of people with or without disease and their representatives;
- Encouragement and promotion of actions and programs of institutional support, training and capacity-building regarding public participation, for decision makers, health professionals, people with or without disease and their representatives.

E) Research and cooperation

- Development of research programs on public participation and the most effective mechanisms to ensure participation in health decision-making, involving the people and organisations that participate;
- Enhancing international cooperation in the field of public health participation, through sharing knowledge and tools, including good practices for the participation of people with or without disease and their representatives.

FORMS OF PARTICIPATION

Public participation in health decision-making should include remote and face-to-face mechanisms for participation, both at the initiative of the state institutions and the people and organisations that participate.

Public participation must also be operationalised systematically through different mechanisms, to meet the specificities of all affected stakeholders and to promote broad and diversified participation, through the following:

- Public meetings;
- Public hearings;
- Public consultations;
- Representation in advisory councils, specialised or sectoral committees or working groups on health policy and related policies, at national, regional and local level;
- Community councils, together with the various institutions and services relevant to health policy and related policies;
- Users' committees;
- Municipal Health Councils;
- National Council for Health Participation;
- National Forum for Health Participation;
- Digital platforms for public participation in health.

In addition to the above mechanisms, it should be possible, at any time, to create and experiment new forms of public participation.

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APPENDIX

Eligibility Criteria for the Representation of People with or without Disease in Health Decision-Making in Portugal

The organisations of people with disease, health services users and/or consumers, involved in the activities of the Ministry of Health/National Health Service (NHS), must meet the following criteria:

Legal status

The organisation must be formed under the terms of the general law, have legal status, develop its non-profit activity, be registered in Portugal and be duly recognized, under the terms of the legislation in force.

Mission and goals

The organisation's mission and objectives must be clearly defined in its statutes and demonstrate the organisation's real interest in protecting the rights and interests of people with disease, health services users or consumers, depending on whether they are association of people with disease, health services users or consumers, respectively.

Activities

Activities carried out by the organisation should include activities related to health, which should be documented in the activity reports.

Representation

The organisation must represent and defend the interests and rights of people with disease, health services users and/or consumers (depending on whether it is an association of people with disease, health services users or consumers, respectively) and preferably have a national scope. The organisation shall further demonstrate that it meets at least one of the following criteria:

(I) The majority of voting members of the organisation are:
- people with disease/health services users/consumers,
- their caregivers or legal representatives,
- other people affected,
- or their organisations (in the case of "umbrella" organisations)

with the power to appoint and elect the organisation's governing bodies;

(II) The majority of members of the organisation's governing bodies are
- people with disease/health services users/consumers,
- their caregivers or legal representatives,
- other people affected,
- or their organisations (in the case of "umbrella" organisations);

(III) The organisation has a governance structure to ensure it is oriented to and by people with disease/health services users/consumers, i.e., their needs and points of view significantly guide the strategy, policies and activities of the organisation, allowing for the organisation to represent their needs and views.

Democratic structure

The organisation must have social bodies elected by its members. The organisation must also ensure dialogue and sharing of information in both directions - to and from its members - to ensure their effective participation in decision-making processes.

Responsibility

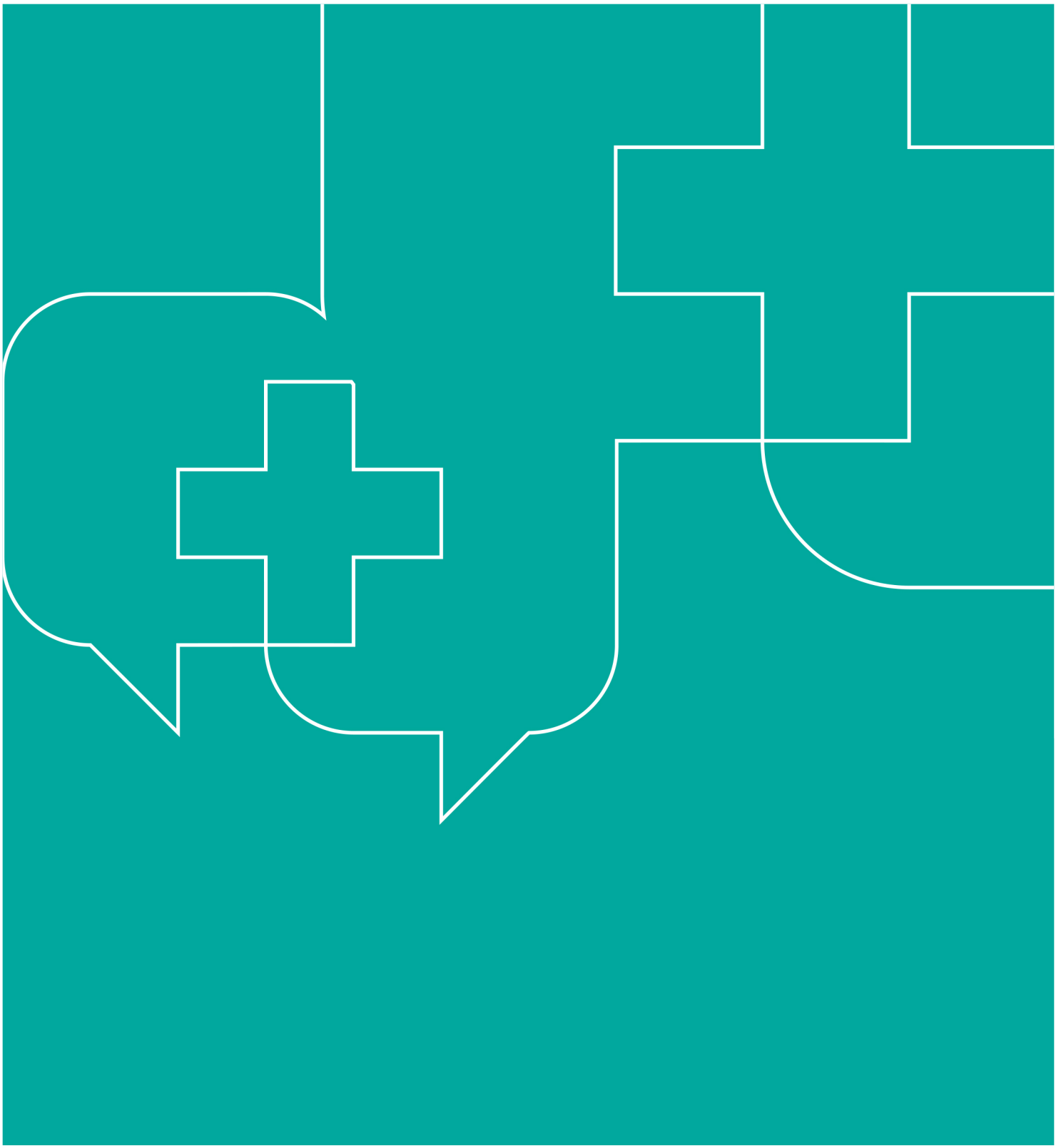
The statements and opinions of the organisation should reflect the views of its members, which should be consulted regularly and appropriately.

Transparency

The organisation shall publish on its website: the organisation's statutes; the management and accounts reports, together with information on the funding sources, both public and private, including the names of donors and their contribution, both in absolute and relative terms; and the activity reports. The organisation shall also follow a code of conduct/policy governing its relationship and independence with respect to funders and other public or private organisations.

SIGNATORIES

The list of entities and personalities who signed the Charter for Public Participation in Health can be consulted at www.participacaosaude.com/carta



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