

**Involving patient organizations in health policy decision-making**

# **The conquest of spaces for public participation in the field of health in Portugal**

**8<sup>th</sup> September 2022**



# MORE PARTICIPATION better health: about us



Seguro | <https://www.participacaosaude.com/historia>

**MAIS PARTICIPAÇÃO**  
melhor saúde

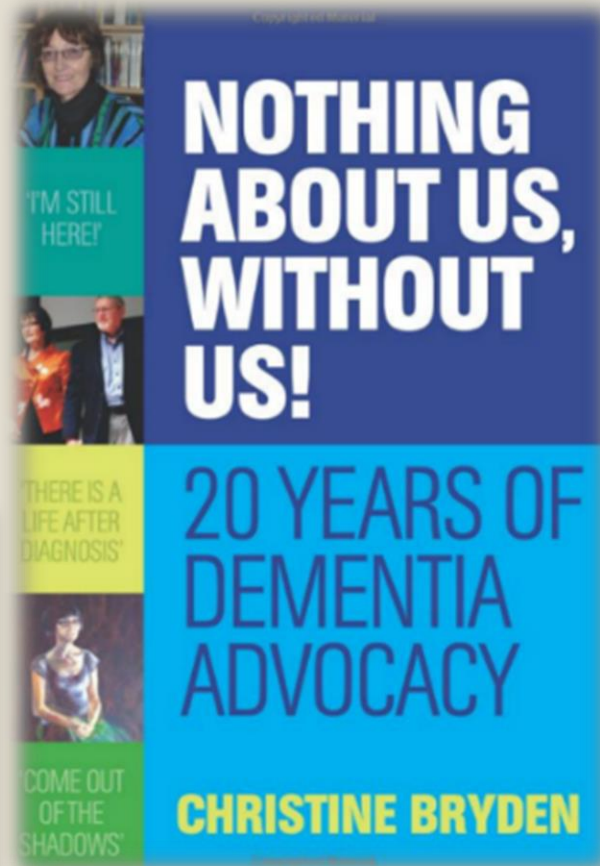
Início CAPACITAR+ CARTA Sobre o MPms Contacto

**A NOSSA HISTÓRIA**

**MAIS PARTICIPAÇÃO melhor saúde** é um projeto colaborativo de investigação-ação promovido pelo GAT - Grupo de Ativistas em Tratamentos, em colaboração com outros atores na área da saúde e da participação cidadã. O projeto tem como objetivo promover a participação e a capacitação de representantes das pessoas com ou sem doença, no âmbito dos processos de tomada de decisão em saúde, a nível político e



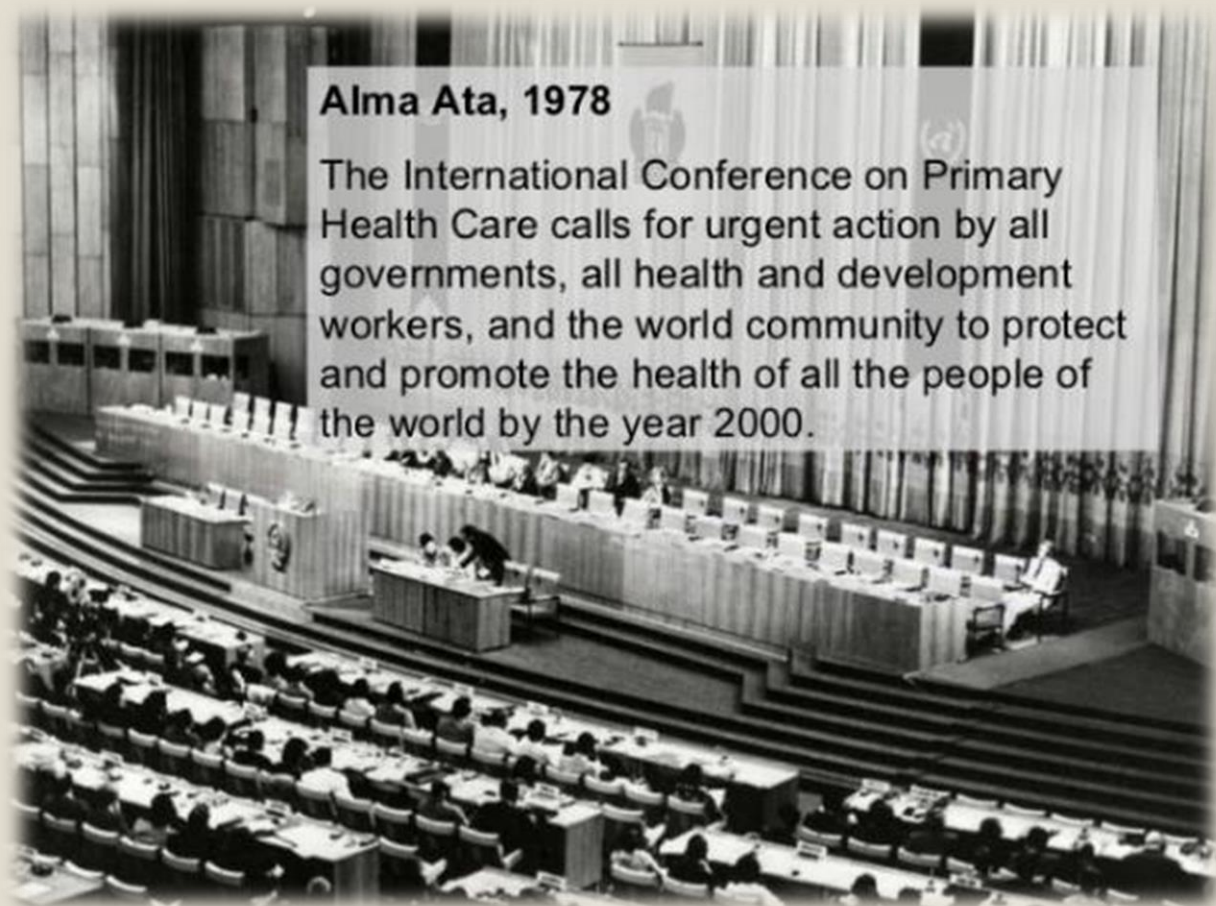
# Nothing about us without us Since 1980's



# Alma-Ata (1978)

“The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.”

[www.who.int/publications/almaata\\_declaration\\_en.pdf](http://www.who.int/publications/almaata_declaration_en.pdf)



# Constitution of the Portuguese Republic, 1976



Article 64

Health

4. The national health service has decentralized and participative management

<https://www.parlamento.pt/sites/EN/Parliament/Documents/Constitution7th.pdf>

# *previous* **Health Basic Law – Law n.º 48/90** *[revoked]*

Base 2

Health Policy

1 – Health policy has national scope, following these guidelines: (...)

g) It promotes the participation of individuals and of the organized community in the definition of health policy and planning, and in the control of services' operation;



# Law on associations for the defense of healthcare users – Law n.º 44/2005

## Article 5 – Rights (...)

- a) Participate in legislative processes relating to health policy, as well as in other public consultation and hearing processes to be carried out in the course of decision-making likely to affect the rights and interests of health users;
- b) Statute of social partner in matters concerning health policy, translated into the appointment of representatives for consultation and participation bodies that work with entities that have competence in the field of health; (...)
- g) Participate in the elaboration and monitoring of national health strategies, plans and programs;



# Ethics committees for health – Decree-Law n.º 80/2018

## Article 6 – Composition

4 - According to the object of each institution, the appointments of members to the ethics committee must respect the following multidisciplinary composition:  
(...)

b) At least 2 elements external to the institution in which the ethics committee is integrated, with 1 of these members recruited from the community, in order to guarantee the cultural and moral values of the community.

# Health Basic Law – Law n.º 95/2019, of 4-sep

Base 5

Participation



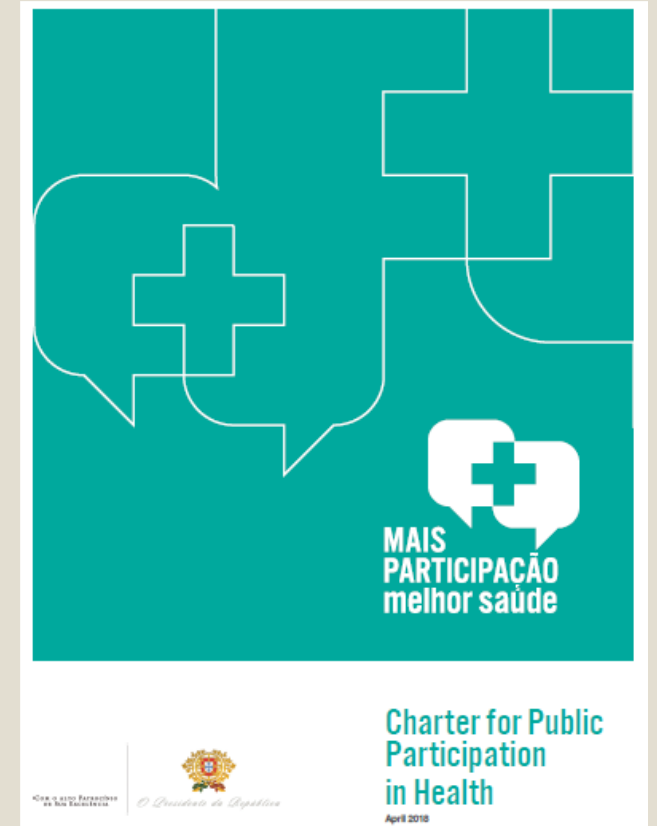
1 - The State shall promote the participation of individuals in the definition, monitoring and evaluation of health policy, promoting health literacy.

2 - The participation referred to in the preceding paragraph may occur on an individual basis or through entities created for this purpose.

# Charter for Public Participation in Health

- Approved as a law in Portugal (*Law 108/2019, 9<sup>th</sup> September*)
- Signed by more than 100 organizations
- Principles, goals, priorities, forms of participation, guidelines

[www.participacaosaude.com/charter-public-participation-health](http://www.participacaosaude.com/charter-public-participation-health)



# Charter for Public Participation in Health

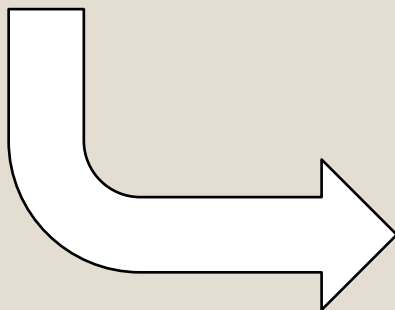


## Petition

Delivered in the Portuguese Parliament (PP) **29/03/2018**

Discussion by political parties represented in the PP

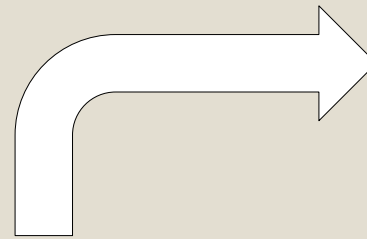
**09/02/2019**



## 2 Legislative initiatives

And 1 was approved: Approves the Charter for Public Participation in Health and the terms of its dissemination, implementation and evaluation

**19/07/2019**



**Law 108/2019, 9<sup>th</sup> September** – Charter for Public Participation in Health



# Spaces for public participation (I)

- National Health Council (DL n.º 49/2016)
- National Council for Mental Health (DL n.º 35/99)
- National Council for Drug Problems, Drug Addiction and the Harmful Use of Alcohol (DL n.º 1/2003)
- Health Regulatory Authority: Advisory Council (DL n.º 126/2014)

# Spaces for public participation (II)

- INFARMED – Medicines Regulatory Authority: Advisory Council (DL n.º 46/2012), Health Technology Assessment Committee (Deliberação n.º 662/2016) and INCLUIR Project
- NHS units
  - Primary Care Units: Community Council (was DL n.º 28/2008 , revoked by DL n.º 52/2022\*)
  - Hospitals: Advisory Council (was DL n.º 233/2005, revoked by DL n.º 52/2022\*)
  - Healthcare Users' Committees and other associations for the defense of healthcare users (Law n.º 44/2005)
  - Citizens' Office in Hospitals (Disp. n.º 26/86, «Users' ...»), revoked by Desp. 8958/2013)
  - Citizens' Office in Clusters of Primary Healthcare Centers (DL n.º 28/2008)



# Spaces for public participation (III)

- *Ad-hoc* initiative, such as:
  - Commission for the Revision of the Health Basic Law);
  - Independent Technical Group to evaluate Access-to-Care Management Systems in the National Health Service;
  - Monitoring Group on the implementation of measures from the national Recovery and Resilience Plan (mainly regarding digital transition in healthcare and new services for healthcare users).

# What have we learned?

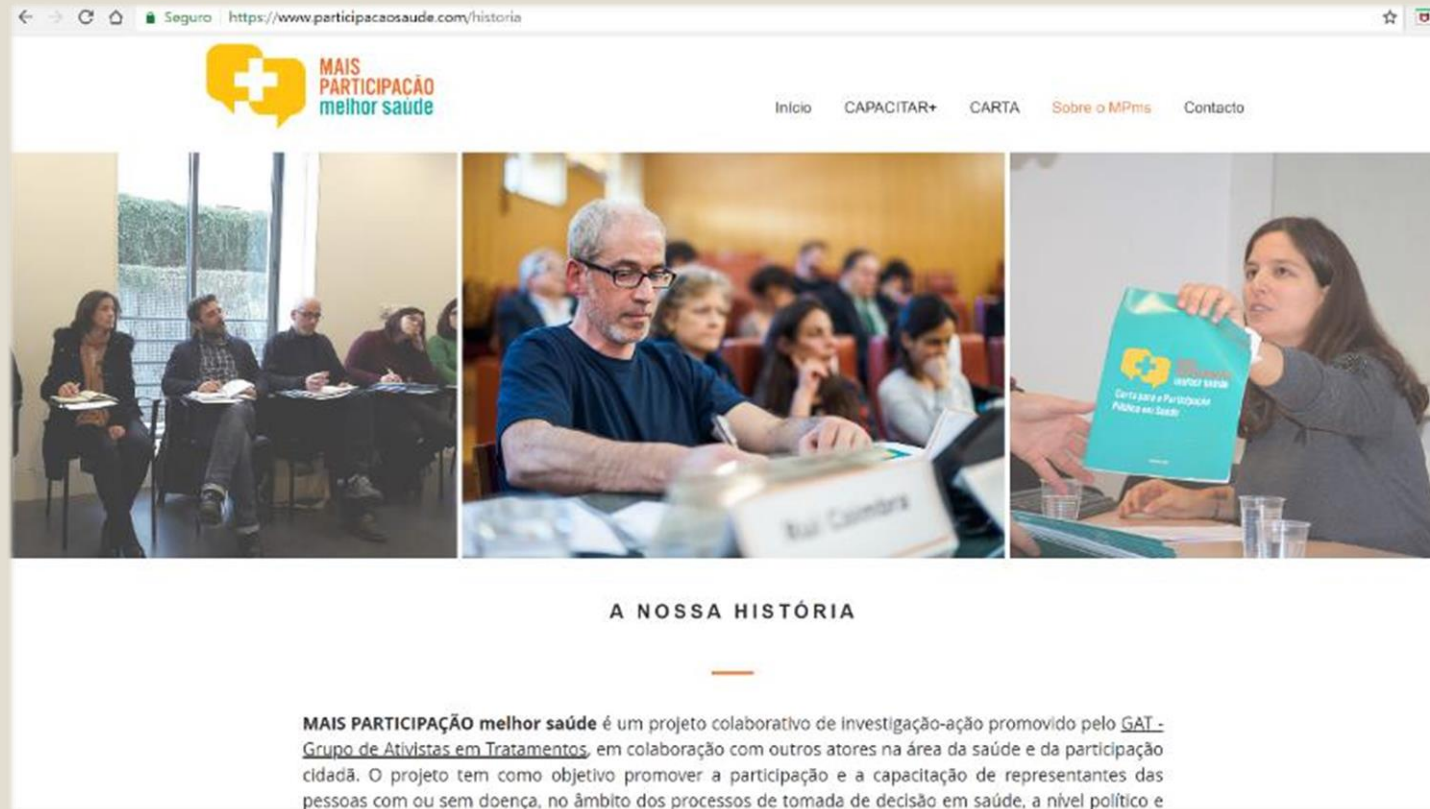
- A participatory and bottom-up participatory approach to decision-making is feasible and builds trust amongst stakeholders
- Success influencers
  - Legitimacy, representativeness and autonomy
  - Partnership
  - Resources
  - Feedback/communication
  - Impact of involvement must be visible
  - Involvement from the beginning
  - Transparency and public information

# Challenges

- Promotion of health literacy and participation of migrant citizens and other marginalized or underserved populations – there are linguistic, cultural, and social obstacles...



# MORE PARTICIPATION better health



The screenshot shows the website's header with the logo 'MAIS PARTICIPAÇÃO melhor saúde' and a navigation menu with links: 'Início', 'CAPACITAR+', 'CARTA', 'Sobre o MPms', and 'Contacto'. Below the menu are three photographs: a group of people sitting at tables in a meeting room, a man in a blue shirt writing in a notebook, and a woman holding a blue folder with the project logo and text 'Carta para a Participação Pública em Saúde'.

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Thank you!  
[maisparticipacao@gmail.com](mailto:maisparticipacao@gmail.com)  
[geral@gatportugal.org](mailto:geral@gatportugal.org)

