

GUIDE FOR MIGRANTS TO PARTICIPATE

in health organisations and policies



The “Informa em Ação” project was developed to enable more effective access for people of diverse backgrounds and migrants by gathering and compiling information of relevance. Translation in various languages was developed through mediation focussing on perception of concepts by people from different origins and National Health Service professionals, side-by-side, engaged in a process that envisioned building and sharing understanding through the lens of different cultural frameworks, by using cultural mediation and dialogic tools.

The formal partner of this project is GAT - Grupo de Ativistas em Tratamentos, and non-formal partners include ACeS Lisboa Central (Central Lisbon Health Units cluster) and GABIP Almirante Reis (promoted by Lisbon Municipality, Aga Khan Foundation Portugal and Arroios Borough). Translations were carried out by partners and community groups, who actively participated in the development process for this production in the following languages: Bengali, English, French, Mandarin, Nepali, and Portuguese.

A WHY PARTICIPATE?

Exercising citizenship can also involve active participation in defining, monitoring and evaluating health policies.

It is important for people to contribute with their experience to improve health policies and how they are implemented. Each culture may have specific needs that should be suitably met by health services. For example, medicine dosages available in Europe are usually much higher than those approved for Japan - perhaps people of Japanese descent wish to petition the body that regulates medicines to make it mandatory to produce smaller dosages (both for Japanese and people with similar physiologies and/or for children). Some medicines interact with some herbal teas - maybe people simply wish to report an undesirable effect from a medicine they suspect to have been caused by interaction with a beverage they are used to drinking. Or maybe people have another unmet need in their culture regarding health care services that should be addressed by a proper body.



PROMOTER:



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These contributions can be more specific or more general:

- how can people's specific characteristics (sensory, motor, physical, linguistic, cultural etc.) be dealt with?
- how can responses best be adapted to people rather than forcing them to adapt to services' different operating traditions?
- how can access and patient service be guaranteed within the National Health Service (“*Serviço Nacional de Saúde - SNS*”)?
- how can the dissemination of information about health policy evaluation be guaranteed?
- how can health be implemented in all policies?

...And so on.

SHORT GLOSSARY FOR PORTUGAL:

- ACES: a group of health centres with a common management;
- Decreto-Lei (DL): a law issued by the cabinet/government;
- Lei: a law issued by Parliament.

B GUIDING PRINCIPLES

In Article 64, the Constitution of the Portuguese Republic establishes that “everyone has the right to the protection of health and the duty to defend and promote health” and that “management of the national health service shall be decentralised and participatory” - this statement is reiterated in Principle 20 of the Fundamental Law on Health (“*Lei de Bases da Saúde - LBS*”).

IMPORTANT: Fundamental Law on Health - Law no. 95/2019.

Law no. 108/2019 approved the Charter for Public Participation in Health (“*Carta para a Participação Pública em Saúde*”) and how it should be disseminated, implemented and evaluated. This law is still awaiting specific regulations for it to be implemented. It was passed following a community-based process that began four years beforehand.



C OPPORTUNITIES FOR PARTICIPATION

1. REQUESTS FOR INFORMATION, SUGGESTIONS, PRAISE AND COMPLAINTS

Participation on an individual basis or via associations includes “simple” acts such as requesting information, making suggestions, praising services or staff members or submitting complaints.

Compliments and complaints may be submitted in person by writing in the Complaints Book (“*Livro de Reclamações*”) - Yellow book at public services - or using the online form available on the website of the Health Regulation Authority (“*Entidade Reguladora da Saúde - ERS*”) [www.ers.pt].

As well as the ERS, the following national bodies can also be contacted:

- the Office of Legal Affairs and Citizens of the Regional Health Administration, at regional level;
- the Office of Citizens for Groups of Health Centres (ACES) for primary health care;
- the Office of Citizens for Hospitals regarding hospital care.

IMPORTANT:

You can request administrative and environmental information relating to public management from the competent authorities under the Law on Access to Administrative Documents (“*Lei de Acesso aos Documentos Administrativos*”), Law no. 26/2016. If your request is not answered or if this law is breached, a complaint can be lodged with the Access to Administrative Documents Commission (“*Comissão de Acesso aos Documentos Administrativos*”), an independent body that operates at the Portuguese Parliament.



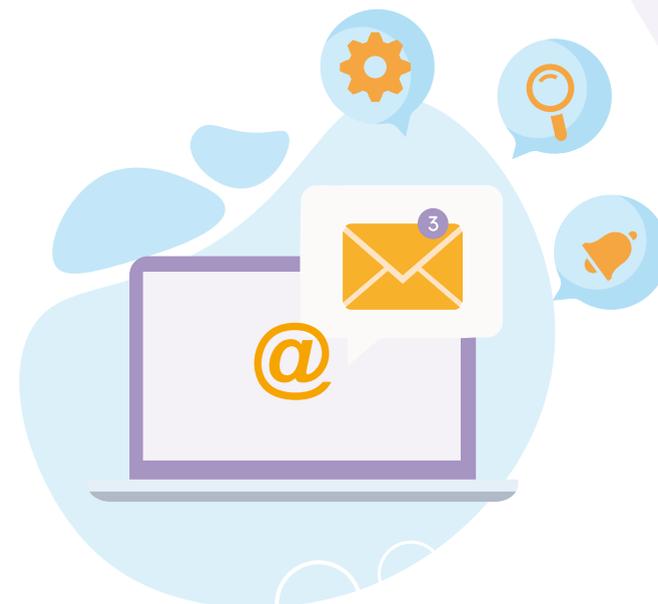
2. PUBLIC CONSULTATIONS

The central and local administrations regularly provide a range of regulations, guidelines and other instruments for public consultation. During the consultation or public hearing period, any person or organisation may study the document and send a contribution. All contributions are valid, from proposed amendments to comments that support a certain orientation.

Some examples of these documents include:

- the National Health Plan and sector-based priority programmes;
- Regional Health Plans;
- Local Health Plans;
- Charters, strategies, plans and other municipal instruments regarding health.

Participation is usually done in writing and by email, and conditions should be guaranteed to include the greatest number of people possible and should take into account different individual needs.



3. PUBLIC HEARINGS BY PARLIAMENTARY COMMITTEES AND GROUPS

The Portuguese Parliament (*Assembleia da República*) is the Portuguese Republic's body that has the power to make laws and, in some cases, delegate that ability to the government (although for some matters included in the organisation of services overseen by the government, it is only the government that can create laws and regulations). To streamline its work, the Parliament is organised into committees and thematic working groups.

Committees may be temporary (when there is a timeline and/or specific objectives) or standing committees. Standing committees are set up after every election and last for the whole duration of that Parliament; a health committee has been always been included. Working groups have more specific themes and may be closed before the end of the legislature provided that their missions have been completed.

As well as these internal organisation structures at the Parliament, there are also parliamentary groups for each party that has elected two or more representatives.

Committees, working groups and parliamentary groups may organise public hearings. They generally invite specific bodies and people to be heard on a certain topic, and hearings are open to participation by any association. However, it is rare for people to participate as individuals.

For more information, see the Parliament's website -
[www.parlamento.pt]



4. PARTICIPATION IN HEARINGS BY WORKING GROUPS FOR A SPECIFIC TASK

There are specific formal participation spaces connected to working groups set up for a specific task, generally set up by representatives of people who use health services. When the task has been completed, the working group is wound down.

Some examples of working groups of this type are:

- The advisory board for the National Health Plan ("*Plano Nacional de Saúde - PNS*") 2021-2030;
- The Independent Technical Group to evaluate Access Management Systems for Healthcare in the National Health Service.



5. ADVISORY BOARDS FOR NATIONAL BODIES

5.1 THE NATIONAL HEALTH BOARD (“CONSELHO NACIONAL DE SAÚDE – CNS”)

The current Fundamental Law on Health establishes that “the National Health Board is an independent participatory body that plays an advisory role to the government in establishing health policy and represents stakeholders in the operation of the health system”.

The functioning of the CNS is defined in Decree-Law (“Decreto Lei”) no. 49/2016. It comprises 30 members, of which 6 (20%) are “representatives of users, elected by the Portuguese Parliament by an absolute majority of MPs in full exercise of their office, including patients’ associations”.

Currently, all the people representing users on the CNS are there on behalf of associations that represent people with illnesses.

On its own initiative or whenever requested by the government or the Parliament, the CNS is responsible for “considering and issuing opinions and recommendations on matters regarding themes related to health policy”, including the National Health Plan and research and innovation in different areas of health. It is also responsible, among other duties, for encouraging analysis and public debate on health policy.

The CNS may request that any public or private body provide elements indispensable to pursuing its mission, and these bodies shall provide all the support requested from them, within the scope of their competences and responsibilities.



5.2 NATIONAL BOARD FOR PROBLEMS RELATED TO DRUGS, DRUG ADDICTION AND HARMFUL ALCOHOL CONSUMPTION

Set up by Decree-Law (“Decreto-Lei”) no. 1/2003 - amended by Decree-Law (“Decreto-Lei”) no. 40/2010), this national board “is the advisory body to the prime minister and the government on policy related to drugs, drugs addictions and the harmful consumption of alcohol, and is responsible for pronouncing itself on defining and executing the main instruments in the programmes for these matters, as well as on any matters submitted to it by the prime minister or by the members of the government responsible for coordinating policy regarding drugs, drug addictions and the harmful consumption of alcohol”.

Participation in this board is only through of one of the organisations that form it and its composition is fixed.

5.3 ADVISORY BOARDS FOR THE BODIES OF THE CENTRAL ADMINISTRATION

Several bodies of the central administration have advisory boards. These boards provide contributions for them to better perform the duties that are assigned to them, since the information held by their managing boards and technical staff, as users of health services, do not have the entire variety of experiences possible. An advisory board that includes representatives of associations representing people with and without illnesses, consumers and users of healthcare in general will collect more complete information and can make more effective contributions.

Examples of bodies that have advisory boards:

- the National Medication and Health Product Authority (“*Autoridade Nacional do Medicamento e Produtos de Saúde, I. P.- INFARMED*”), and
- the Health Regulatory Body.

All national sectoral bodies that work in the health field should have advisory boards.

6. COMMUNITY BOARDS FOR GROUPS OF HEALTH CENTRES (ACES)

In 1971, the public health service was reorganised. It was only in the 1999 reform that a body was set up to formalise citizens' participation in health centres - the advisory board - which was retained in the 2003 reform. Decree-Law ("Decreto Lei") no. 28/2008 replaced the advisory board for health centres with the community board for Groups of Health Centres ("Agrupamento de Centros de Saúde - ACES") and set the composition of the board in the same (or quite similar) way for the entire country.

Among other more or less direct representatives of citizens, each community board also includes a representative of users of the ACES in question.

The person who chairs the community board, which is always indicated by the municipal councils of the area where the ACES operates, is also on the executive board of the ACES.

The community board should meet at least once every six months.

7. ADVISORY BOARDS FOR HOSPITALS AND LOCAL HEALTH UNITS

Advisory boards are part of the organisation framework of hospitals in the SNS - Decree-Law ("Decreto Lei") no. 18/2017, provided that they are public business bodies; in other words, privately-managed public hospitals (public-private partnership hospitals) are excluded.

Advisory boards include a "representative of users, appointed by the relevant association or equivalent representation structure".

As happens with the community boards at ACES, advisory boards for hospitals should meet at least once every six months.

8. ETHICS COMMITTEES FOR HEALTH

Decree-Law ("Decreto-Lei") no. 80/2018 "establishes the principles and rules that apply to the composition, formation, competences and functioning of Ethics Committees that operate within health institutions in the public, private and social sectors, as well as at higher education institutions that carry out clinical research and biomedical research centres that carry out clinical research".

Committees comprise 5 to 11 members (always an odd number) and at least one must be recruited from the community. Whenever deemed necessary, depending on the matters to be addressed, committees may request support from other experts, who may be members of the community.

9. OTHER FORMS OF FORMAL PARTICIPATION

All people may participate in other ways, such as using citizens' legislative initiatives (a right laid down in Article 167 of the Constitution and regulated by Law no. 17/2003 in its current wording), petitions to local bodies, reports to the state prosecutor, civil legal proceedings, etc.

Law no. 44/2005 provides the framework for associations that defend health users that enjoy special rights.

With the transfer of some competences from the central administration to municipalities, we may see an increase in participation in local policy through candidatures (and, if elected, the exercise of mandates) by groups of independent citizen voters whose manifestos focus specifically on matters related to public policy for health.



Voting in general, local and presidential elections is a valuable contribution to participation in a range of areas, including public health in Portugal!

Some immigrants who have a valid residency document in Portugal may vote. Political rights are not the same for all nationalities. Find out about the different conditions for each type of election and country of origin. For non-Portuguese people, registration on the electoral roll is not automatic.

**More information is available at the
Voters' Portal (Portal do Eleitor)**

[www.portaldoeleitor.pt]



10. INDIRECT PARTICIPATION

Participation may occur through associations with other main areas of work - whether by implementing measures to promote health literacy among young people, for example, or by encouraging the use of inclusive, accessible language (in interpersonal communication and information materials).

Another more recent form of participation with an impact on health policy is the promotion of education for cybersecurity, since there are more and more health apps, more medical devices connected to the internet and more registers of personal data (including health data) to be protected, and there are new phenomena that have an impact on health, particularly social and mental health (cyberbullying, doxxing, exposure of sexual intimacy on the internet and other digital crimes).

Activism and associations have a direct and indirect impact on defining health policy. Activism is implemented through movements that defend the rights of people who use drugs, sex workers, people who are victims of crime or migrant people and refugees.

DEFINITIONS:

Cyberbullying: is a type of violence perpetrated against someone via the internet or other related technologies. It means intimidating or attacking a person in the virtual space.

Doxxing: This fundamentally involves obtaining a person's private data and making it public on the web. It is often joined by harassment.





To get information in Portuguese about health care for migrants within the National Health Service “**SERVIÇO NACIONAL DE SAÚDE (SNS)**” visit the following websites:

www.sns.gov.pt | www.dgs.pt | www.acss.min-saude.pt | www.ers.pt