

# **Brief Guideline** to Social Participation



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# **PRESENTATION**

Based on the **Guía de Participación Social sobre los Determinantes Sociales de la Salud**<sup>1</sup>, developed with the support of the NCD Alliance by Juan Arturo Sabines Torres and coordinated by Juan Núñez Guadarrama, this **Brief Guideline** offers a set of recommendations for the development of social participation strategies that civil society organizations, as well as individuals interested in contributing to the prevention and care of non-communicable diseases, can undertake. It also provides directives on the essential actions the public sector should take to support these initiatives, ultimately leading to more efficient use of resources to preserve and improve the population's conditions and quality of life.

<sup>&</sup>lt;sup>1</sup>. Guide to Social Participation on the Social Determinants of Health.

# INTRODUCTION

Health is fundamental for the full development of an individual. It is the responsibility of the State to provide services and facilities that can be accessed in the event of any health issue, as well as to implement preventive measures and disseminate information to promote self-care among individuals, families, and communities. Through these efforts, people can become more aware of early signs of health problems, maintain a proper and healthy diet, exercise regularly, and avoid consuming substances that impair mental functions. These practices will lead to early responses to adverse conditions and increase the likelihood of achieving a more satisfying and fulfilling life.

However, health encompasses not only matters related to the body and mind but also integrates elements stemming from social, cultural, and environmental factors, ultimately requiring an appropriate balance between mind and body. Additionally, a series of elements influence health from two key areas: social determinants and commercial determinants, as we will explore in this guideline. These elements are closely linked to Non-Communicable Diseases (NCDs), a group of conditions that have garnered significant attention due to their impact on population health in recent decades.

First, the characteristics of these diseases are outlined, followed by a review of relevant aspects of the Determinants of Health. This serves as the foundation to highlight the importance of social participation in the population's lives, particularly in health. Emphasis is placed on the conditions and characteristics that enable the impact of social involvement on the well-being and quality of life of communities and on what organizations and population groups should demand from the public sector to open the necessary pathways and support collaboration with civil society.

The text concludes with a Decalogue for Social Participation in Health, which reaffirms and synthesizes the content outlined in this Brief Guide. This effort and the provided action strategies will serve as a foundation for moving closer to fostering more active involvement of individuals and organizations in promoting personal and community health.



# **CONTENT**

Presentation	р3
Introduction	p 4
1. Non-communicable diseases (NCDs)	p 8
2. Determinants of Health	p 11
3. Social Participation	p 23
4. Social Participation in Health	p 31
5. Recommendations for Social Participation in Health	p 46
6. Social Participation in Health Policy Formulation	p 50
7. Conditions and Factors Affecting Social Participation in Health	p 61



# 1. NON-COMMUNICABLE DISEASES (NCDS)

These conditions have health consequences and are not caused by contagion from other people who suffer from them or are carriers of a virus or infection. Given their chronic nature, these diseases necessitate long-term management and care.

Among noncommunicable diseases (NCDs), cancers, cardiovascular diseases, diabetes, and chronic pulmonary diseases stand out. These conditions have become a significant challenge to global health in the 21st century, with an estimated 36 million deaths annually worldwide from these diseases, with slightly less than half of those deaths occurring among individuals aged 30 to 70. A staggering 86% of these premature deaths occur in low- and lower-middle-income countries, underscoring the urgent need for effective prevention strategies and improved healthcare access in these regions.

Each case has a significant impact on family groups and communities, especially among the poorest and most vulnerable, who are exposed to a higher proportion of risk factors, such as smoking, harmful alcohol consumption, physical inactivity, and ingestion of toxic or unhealthy products. These two last factors have been linked to significant health concerns, including high blood pressure, elevated blood glucose or lipids, and the development of obesity.

Vulnerable and socially disadvantaged populations often face illness and premature death due to their heightened exposure to these risk factors, compounded by limited access to healthcare services and difficulties in accessing them. For all these reasons, as outlined in the Agenda for Sustainable Development (UN, 2018), it is essential to "reduce by one-third premature mortality from non-communicable diseases through prevention and treatment, and to promote mental health and well-being." To achieve this, countries are urged to implement policies related to tobacco consumption, harmful use of alcohol, unhealthy diets, physical inactivity, and clinical care for cardiovascular diseases, diabetes, and cancer. The outcomes achieved through implementing these policies are amplified when coordinated with others sharing the same objectives. For instance, campaigns promoting physical activity while simultaneously ensuring low-salt food options can significantly reduce the risk of developing cardiovascular diseases.

#### **DEMOGRAPHIC AND EPIDEMIOLOGICAL TRANSITION**

Significant progress has been made in population health, including reducing infant mortality. This progress can be attributed to enhanced control of infectious diseases, improved childcare and nurturing practices during early childhood, and other factors. Additionally, urbanization processes and migration from rural areas with limited access to healthcare services to regions with better conditions have contributed to this progress. Consequently, the population's average life expectancy has increased, resulting in a growing segment of older adults. However, this demographic shift comes with a heightened risk of non-communicable diseases (NCDs), which are known to lead to disability and mortality.

Consequently, life expectancy has increased, surpassing 60 years in most countries. The global population has also grown exponentially, exceeding 8 billion by the end of 2022, more than three times the mid-20th-century population. This marks a substantial increase compared to the estimated 2.5 billion people in 1950. Projections indicate that the global population will reach 9.7 billion by 2050.



BRIEF GUIDELINE TO SOCIAL PARTICIPATION

#### **RISK FACTORS**

These elements are associated with certain behaviors, situations, or disorders, and when positively modified, they can help prevent their development.

These may include behaviors such as smoking, excessive salt intake, insufficient physical activity, or metabolic risks, such as those related to high blood pressure. It is also crucial to consider environmental factors, as air pollution is responsible for 6.7 million deaths worldwide each year, with 5.7 million of these deaths linked to NCDs, including strokes, ischemic heart disease, and lung cancer.

Some of these factors not only represent a risk but are also considered within the framework of NCDs, such as addictions to tobacco, alcohol, or other legal and illicit substances, as well as obesity. Obesity, in particular, is responsible for 5 million deaths per year worldwide.

Preventing risk factors associated with NCDs has become the central objective of public health policies. In addition to a curative approach targeting specific diseases, these policies must integrate a more comprehensive strategy to promote population well-being and address social and commercial determinants. Achieving these goals requires the active engagement of the population through social participation in collaboration with authorities, regulators, and local governments.

This entails recognizing and supporting civil society organizations, individuals living with NCDs and their caregivers, and communities at all levels, from local to global. It is essential to avoid paternalistic approaches that merely distribute benefits without allowing the population to demand transparency and accountability. This approach empowers individuals to articulate their needs, expectations, and priorities, becoming active partners in defining and shaping their health.

## 2. DETERMINANTS OF HEALTH

These refer to situations, elements, or services that influence the health of individuals and communities, in addition to biological or genetic factors and the risks to which they may be exposed. They are generally less subject to individual capacity for modification. However, some can be altered through the collective efforts of groups that propose or support public policies or changes in social norms.

Two main areas of determinants are recognized: Social and Commercial.

#### SOCIAL DETERMINANTS OF HEALTH

According to the World Health Organization (WHO), social determinants of health are "the circumstances in which people are born, grow, work, live, and age, including the broader set of forces and systems that influence daily life conditions." Some of these conditions depend on factors beyond individuals' capacity to address them, such as access to services and medications to alleviate or resolve health issues. These factors underscore inequity, power, income, and resource distribution within and between rural and urban areas. Additionally, social determinants of health are influenced by norms of inclusion or exclusion prevalent in different cultural groups, affected by factors such as ethnicity, educational or socioeconomic level, gender, age group, or other drivers of discrimination. These determinants are critical in shaping health outcomes and disparities across populations.

This understanding is based on the available capabilities to understand and seek solutions for the population's health problems and the possibility of directing research outcomes or creating, regulating, and maintaining public policies. Achieving these goals necessitates the presence of trained personnel, adequate equipment and resources, and effective communication strategies to enhance public awareness. These efforts are crucial in encouraging individuals to utilize available services and access vital information for early health problem detection, as illustrated in Chart 1.

Collective factors stem from the environment in which the population operates and conditions that enable healthy development. These include the infrastructure of sanitary and educational services, job availability, access to healthy nutrition, an adequate supply of potable water, and suitable spaces for physical exercise and recreation.

Finally, there are individual elements, some of which each person can exert influence, such as the development of hygiene habits, dietary practices, leisure activities, and the ability to address problems and collaborate effectively in the face of risks within their family and community.

Chart 2 provides a detailed explanation of these determinants, introducing genetic elements or those arising from natural disasters. Only preventive or coping measures can be planned for these factors.

These two charts show the necessary interrelationship among the various social determinants. These determinants collaborate on health, either benefiting or harming it.



#### **INEQUALITY AND INEQUITY IN HEALTH**

The unequal distribution of power, income, goods, and services impacts the immediate living conditions of the population and hinders the ability of the most disadvantaged individuals to maintain their health. Furthermore, it influences a country's social health gradient, exacerbating health inequalities.

Unemployment, particularly long-term, job insecurity, work overload, poor conditions in facilities and housing, and excessive domestic and caregiving responsibilities negatively impact people's health. Conversely, living in environments with abundant green spaces and strong community support networks reduces premature deaths and significantly improves health.

#### SOCIAL DETERMINANTS OF HEALTH:

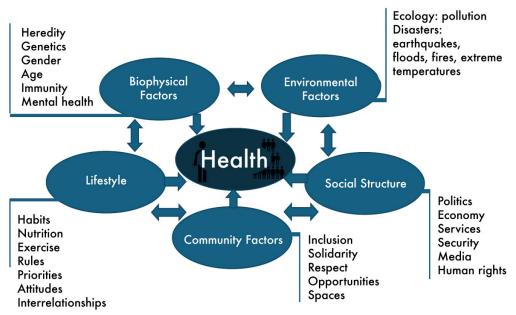


Chart 1. Source: C. Millé (2029) Presentation on Social Determinants.

In light of these Social Determinants, the community and each of its members can influence their context through various actions, such as those proposed below.

#### **ACTIONS ON SOCIAL DETERMINANTS**

The WHO established the Commission on Social Determinants of Health in 2005 to address these determinants' global challenges. This Commission reviews the evidence generated, promotes social debate, and recommends policies to improve the health of the most vulnerable populations. While primarily aimed at creating public policies, the Commission's recommendations should also be widely known among the general population and social organizations. This heightened awareness is pivotal for fostering advocacy and supporting the formulation of these policies. Among these recommendations, two stand out as particularly applicable to community groups.

TABLE 1. IMPROVE LIVING CONDITIONS

PUBLIC POLICIES	SUGGESTED ACTIONS FOR THE COMMUNITY
a) Focus particularly on early childhood development, strengthening existing programs and expanding those aimed at socio-emotional and linguistic-cognitive development.	To understand and apply evidence-based parenting strategies that positively affect early childhood development.
b) Enhance urban management and planning while simultaneously focusing on investing in rural development and combating exclusion. Exclusion generates poverty by depriving farmers of their land and displacing populations from their places of origin.	To support both national and foreign migrants forced to relocate due to lack of sustenance or violence and exclusion.
c) Ensure that health equity is considered in economic and social policies addressing climate change and other environmental degradation processes.	Understand what is needed and possible in your environment to address climate change.

d) To establish full employment, labor equity, and decent work as fundamental objectives of social and economic policies while improving working conditions to reduce workers' exposure to risks, stress, and behaviors detrimental to their health.	To ensure the establishment of risk reduction strategies and the promotion of health within the community, as well as the proper implementation of regulations related to the workplace.
e) Establish social protection policies that enable the entire population to enjoy a sufficient income and lead a healthy life.	Urge authorities to create and maintain recreational, leisure, and sports facilities that are accessible to everyone.
f) Establish primary healthcare systems within the health sector that provide universal healthcare coverage.	Understanding the rights of users of heal- thcare facilities and promoting universal access to care.

TABLE 2. COMBAT THE INEQUITABLE DISTRIBUTION OF POWER, MONEY, AND RESOURCES

PUBLIC POLICIES	SUGGESTED ACTIONS FOR THE COMMUNITY
a) To hold the highest governmental authorities accountable for acting in favor of health and health equity, ensuring that all policies coherently contribute to this objective.	Review the relevance and implementation of policies promoting health and equity, providing recommendations or suggestions as needed.
b) Integrate social determinants into the normative and programmatic functions of the health sector and strengthen the stewardship role of health ministries so that the government adopts an approach focused on these determinants.	It is essential to consider the challenges of acting individually on determinants and promote the organization of community groups that collaborate with public entities to address those deemed
c) Strengthen public funding to address the social determinants of health, increasing international funds to promote health equity by an action framework focused on these determinants.	To become acquainted with and establish connections with national and international funds that can support community groups' work in promoting strategies to address social determinants.

d) Strengthen the role of the State in the provision of essential health services (such as those related to water and sanitation) and in the regulation of goods and services with significant health implications, such as tobacco, alcohol, and food.	To ensure the proper enforcement of regulations concerning services and products that harm health.
e) Combat sexist biases in social structures, laws, and their implementation within organizations and interventions, as well as how a country's economic performance is measured.	To collaborate in the reduction of sexist, ethnic, or age-related prejudices within the culture and norms of the community.
f) Reaffirm the commitment to promote sexual and reproductive health and related rights from the perspective of universality.	Provide support and promote universal access to and utilization of healthcare services.
g) Empower all groups within society through a fair representation system in decision-making processes regarding society's functioning, particularly in decisions that may impact health equity. This involves establishing and maintaining a framework for social participation in policy formulation.	Contribute to making social participation in health a reality by responding to the health sector's calls and collaborating in decision-making regarding health equity.
h) Promote respect for political and social rights that impact health equity, facilitating the organization and action of civil society.	Monitor the implementation of political and social rights regarding health equity, identifying and reporting any deviations.

#### COMMERCIAL DETERMINANTS OF HEALTH

These determinants, which encompass negative and positive impacts on health, refer to the intricate systems, practices, and pathways through which commercial actors (businesses, corporations, industries) influence health. On the positive side, they are often recognized as sources of employment and revenue for public structures through taxation, thereby supporting countries' economic development. However, this dual role presents a complex challenge, complicating the implementation of measures to regulate or control their influence.

A wide diversity of generators of these determinants often employs non-obvious strategies through other companies, making them challenging to detect and address. On occasion, governments and intergovernmental organizations support them or at least do not obstruct their work or try to reduce their independence and constrain or limit the health damage they cause.

These commercial determinants can develop at high levels (within the political and economic systems), promoting the consumption of products that harm health or restricting access to essential health services and supplies for individuals who lack the financial means to obtain them.

They can significantly influence societal norms by being supported by media outlets representing corporations and businesses' interests. The most influential of these entities can sway political decisions and regulations, making it more difficult to approve policies that could protect public health.

The chart 3 illustrates how commercial determinants can impact health, from the production and marketing of harmful products to the influence on societal norms and political decisions.

#### **KEY PRACTICES IN THE COMMERCIAL SECTOR**

These practices are categorized into seven mutually reinforcing areas: political, scientific, marketing, supply chain and waste management, labor and employment, financial, and reputational management. The latter is placed at the center because if the commercial actor enhances legitimacy and credibility, it fosters the development of the other six.

Financial

Scientific

Reputation management employment

Supply chain

Political

Scientific

Reputation Marketing

Chart 2. Seven key practices of the commercial sector

**Political Practices:** They ensure preferential treatment or prevent, shape, circumvent, or undermine public policies in ways that favor corporate interests.

**Scientific Practices:** These practices aim to alter products and/or ensure favorable outcomes for the industry by exerting influence over the research process, the production of evidence, its dissemination, and its use. This is often achieved through funding studies that may contain biases or by discrediting evidence free from conflicts of interest.

Marketing Practices: These aim to increase the demand and consumption of unhealthy products, often altering physical environments (such as bars or the number of sales outlets) and information landscapes. They also target specific geographic areas and population subgroups based on ethnicity or vulnerability, shaping new cultures and norms to drive consumption.

**Supply Chain and Waste Practices:** The creation, distribution, retail, and waste management of products or services negatively impact global public health.

**Labor and Employment Practices:** Weakening of labor market regulations through adverse conditions impact on the health of low-income workers, particularly in low- and middle-income countries.

**Financial Practices:** These include tax avoidance and evasion, mergers and acquisitions (aimed at reducing competition or eliminating superior or healthier products), price fixing, promotion of indebtedness, accounting and stock market fraud, and financial flows. These can reduce state revenues, with implications for health and well-being.

**Reputation Management Practices:** Aimed at shaping legitimacy and credibility while enhancing the corporate brand image. These practices encompass social responsibility initiatives and environmental, social, and governance (ESG) measures, ostensibly committed to adhering to ethical standards and avoiding harm. However, they often fail to generate tangible benefits for society.

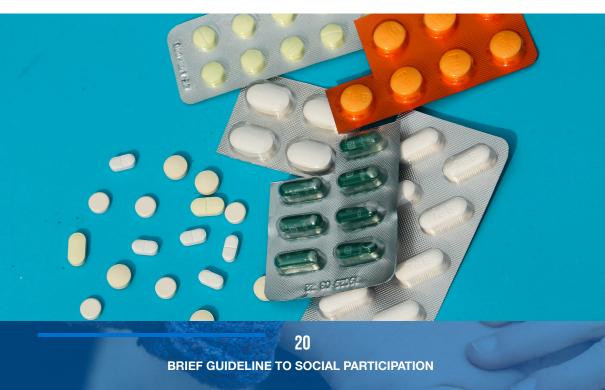
Most evidence of substantial damages pertains to transnational corporations, as they can exert greater power and influence and are less likely to be held accountable in low—and middle-income countries. These corporations can collaborate, obstructing bills and reforms aimed at consumer or worker protection and enacting tax and antitrust legislation.

The costs associated with the damage caused by production, consumption, and waste, as well as the expenses related to the treatment of NCDs, are linked to the social harms of alcoholic beverages, gambling, oil spill cleanups, and the disposal of plastic waste. States, families, and affected individuals bear these costs. This situation reduces allocations for housing, healthcare, welfare, and

#### **IMPACT ON COMMERCIAL DETERMINANTS OF HEALTH**

Community groups can influence through their participation to bring about changes in five key areas:

- 1. Highlight the extent of damage to health and equity caused by commercial actors.
- 2. Expose the role of commercial actors in causing harm and raise awareness about harmful commercial practices.
- **3.** Advocate for governments to implement policies that encourage businesses to contribute positively to the health and well-being of people and the planet.
- **4.** Reframe policy debates and counter industry narratives and interference.
- **5.** Influence governance structures to enhance transparency in commercial actors' involvement in political processes, eliminate undue influence on science, and amplify the voices of those adversely affected.



#### CORPORATE CAPTURE OF PUBLIC HEALTH

It is the process by which political decisions are influenced to serve private, particular interests at the expense of public interest. As a result, unjust regulations are enacted, or necessary regulations are omitted, even when they are essential for protecting the common good. Thus, the deliberate actions of private actors influence political decisions, favoring a small group of individuals or organizations by increasing their economic benefits to maximize returns for their shareholders.

There are four modalities of corporate capture of public policies that complement and reinforce each other:

- **1.** Material or Corrosive Influence: This pertains to illegal activities, such as accepting bribes or political party donations in exchange for making legislative changes.
- 2. Intellectual Influence: Within the scientific and academic spheres, this involves directing research programs, distorting scientific findings, and controlling the training of professionals.
- **3.** Social Influence: In the realm of information and communication, this includes creating a positive image of corporations, diverting attention from their products' harmful effects, or promoting opinions against specific regulations.
- **4.** Cultural Influence: occurs through continuous, intense, and covert interactions between private sector representatives and regulators. These regulators are exposed to corporate ideas and proposals, often at the expense of those from the public and experts, making them more inclined to align with industry interests and their approach to problem-solving.

#### CONFLICT OF INTEREST

A conflict of interest refers to a set of conditions and circumstances that may unduly influence professional judgment regarding a primary interest (such as the well-being and treatment of a patient or population, or the validity of research) in favor of a secondary interest (such as financial gain, the pursuit of recognition, prestige, professional advancement, or personal promotion).

It may be attributed to political, academic, religious, or personal pressures, although it is most frequently economic.

An example is the interaction between physicians and the pharmaceutical industry, which can influence prescribing practices and professional behavior. These relationships can take various forms: gifts, sponsorship of cultural and scientific activities, continuing education through seminars, roundtable discussions, conferences—all funded by the pharmaceutical industry—as well as the transfer of stocks or financial securities, funding for academic chairs or professional associations, consultancies, or the ghostwriting of supposedly scientific articles by third parties. There are approximately 81,000 pharmaceutical industry representatives in the United States, each of whom visits between five and ten physicians daily.

The WHO Framework Convention on Tobacco Control, which came into force in 2005, establishes the mandate to protect tobacco policies from the commercial interests of the tobacco industry or those working to promote them. The Parties to this Convention committed to adopting governance practices to regulate the interaction of public officials with industry representatives, thereby ensuring transparency and ethical conduct.



#### 3. SOCIAL PARTICIPATION

Society has always been involved in actions related to its well-being and that of its families and communities. Participation implies the involvement or mobilization of individuals, families, groups, social and community organizations, private institutions, and other sectors in the social, cultural, health, economic, or political processes that affect them.

Civil society's organized action is crucial for progress in the fight against NCDs, similar to the advances achieved in tobacco control. Thus, non-profit public health organizations, grassroots groups, journalists, and academics are significant in mobilizing and advocating for health-related actions.

Social participation involves community mobilization stemming from identified needs within a specific context. These needs compel or motivate those affected to organize themselves to address or respond to these needs without such actions being dictated by an authority. An example is the self-managed interventions that arise in the face of natural disasters, such as earthquakes, hurricanes, floods, or wildfires.

It may also involve groups and organizations representing a specific territory's population, such as committees, associations, or local and regional organizations.



Chart 3. Types of community participation

#### **PARTICIPATION CAN BE CLASSIFIED AS FOLLOWS:**

**Social Participation** encompasses the private and group environments where individuals interact independently with other organizations or institutions without needing a fixed or predetermined structure.

Community Engagement aims to improve living conditions and standards within a specific context through self-management or initiative proposals.

**Citizen Participation** is characterized by a higher degree of organization and integration of individuals who come together to engage in matters of the public sphere that affect them.

**Political Participation** is where civil society directs its efforts toward defining or attempting to modify public or common interests.

#### CHARACTERISTICS OF SOCIAL PARTICIPATION IN HEALTH

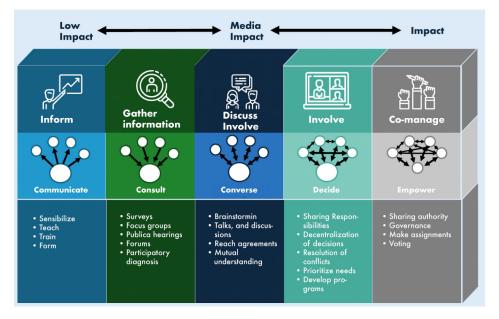
It encompasses various forms arising from the specificities of each community, organization, or group that promotes it. It evolves in response to the inevitable changes in the population's health status, the services provided, and the prevailing social and commercial determinants.

Therefore, the actions undertaken also vary, ranging from information, consultation, and dialogue with health authorities to support campaigns, surveys, and media outreach to the analysis and public questioning of projects and decision-making alternatives presented by health organizations, citizen meetings, assemblies, and other initiatives.

Consequently, actions can be divided into two major processes: consultation and engagement. In the former, including citizens leads to better-informed decisions by health authorities as they validate or prioritize the options. In the latter, participation begins with defining the problem to be addressed, encompassing the reconciliation of interests, negotiation, and establishing longer-term commitments. These processes stem from a broader call to action and involve more representative sectors of the population with greater autonomy, yielding outcomes beyond defining priorities.

The relevance of applying these two processes depends on the objective for which they are employed. For instance, the consultation process will be most useful when a public hearing is held. In contrast, engagement processes will be more suitable for responding to disasters or events where the population has generated response mechanisms, covering the organization of actions.

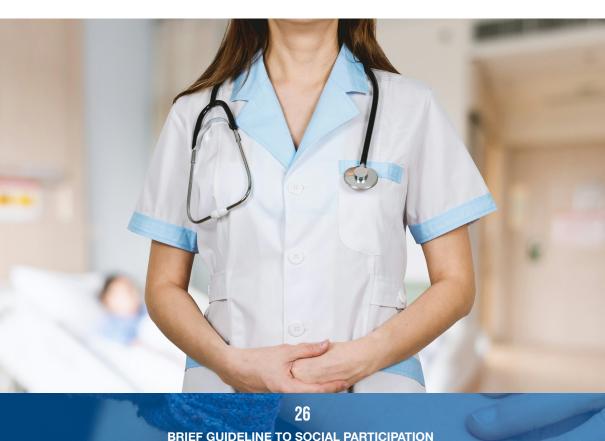
Chart 4. Relationship between goals, impact, and level of participation.



#### REQUIREMENTS FOR ENABLING SOCIAL PARTICIPATION IN HEALTH

The role of governments is to remain open and receptive, willing to listen to what citizens wish to communicate to improve public policy and the management of public affairs. It is essential to create an environment where individuals feel empowered to express their opinions, reinforcing the maintenance and enrichment of their health and well-being. However, this involvement will only be possible if effective mechanisms are institutionalized, recognizing the value of participation in enhancing the quality of policies and their acceptance by the population. Governance is strengthened by systematically incorporating the community's voice into policy formulation and decision-making processes.

In this regard, Social Participation is understood as a legitimate right of citizens rather than a concession granted by institutions. To facilitate this process, a legal framework and democratic mechanisms are required to promote and widely disseminate the necessary conditions for organized communities to make their voices and proposals heard at all levels of government.



# STRENGTHENING THE RELATIONSHIP BETWEEN THE POPULATION AND THE PUBLIC SECTOR

While the following actions primarily fall under the public sector's responsibility, the population needs to be aware of them, monitor their implementation, and reinforce their outcomes from their perspective. These actions involve issuing broad and diverse calls that include various social actors with cultural relevance and adaptation to local dynamics. The proposed measures are as follows:

- Reduce technical jargon by using clear and understandable language, explicitly stating agreements and commitments, and always adhering to what has been agreed upon.
- Conduct binding processes that enable the community to participate in decision-making.
- Employ working methods that foster all participants' opinions, inclusion, and active engagement.
- To assess the progress of intervention processes in a participatory and ongoing manner.
- Permanently share the findings and lessons learned.
- Analyze the impact of participatory processes on decision-making regarding health-related policies, identifying the factors that facilitate and hinder them.
- Reflect on the cultural barriers that may hinder the adoption of a comprehensive health approach due to limited information, prejudices, gender stereotypes, and beliefs about addressing health issues.



# TYPES OF INVOLVEMENTS BETWEEN THE POPULATION AND THE DEFINITION OF PUBLIC POLICIES

Participation can take on four different types, depending on the level of commitment from the participants and the options provided to them:

**Instrumental**, which is not linked to decision-making but instead responds to the interests of the convener.

Clientelistic, in which the convener retains the power to decide.

**Deliberative**, where opinions are exchanged in the pursuit of agreements.

**Propositive** grants the population the most significant critical and creative capacity to propose solutions to a given situation.

#### **CIVIL SOCIETY ORGANIZATIONS (CSOs)**

These organizations emerge from groups of citizens who act in the interest of the common good without being affiliated with a political party or a government entity and without seeking economic benefits.

The Inter-American Development Bank includes within this concept a wide range of organizations: associations, academic and non-profit institutions, professional and corporate social responsibility groups, non-governmental organizations, labor unions, foundations, religious institutions, youth groups, indigenous groups, Afro-descendant organizations, as well as formal and informal community organizations with philanthropic, ethical, cultural, ethnic, spiritual, and scientific perspectives. These entities can engage in one or several activities, such as advocacy, research, microcredit management, or education; they can operate at the local, national, and international levels.

CSOs are formed by individuals who come together voluntarily and operate outside the governmental structure. Although they may receive funding from the State or private foundations, this does not mean they must align with or base their actions on any political stance or support commercial interests.

They strive to collaborate through various modes of action to resolve or mitigate the intensity of the issues or situations they aim to address within their communities.

They are called CSOs (Civil Society Organizations) rather than Non-Governmental Organizations (NGOs) to emphasize their active role in contributing to society rather than simply indicating that they operate independently of the government. These CSOs include regional and national advocacy groups, service providers, and community-based self-managed and autonomous associations.

Among their functions are generating knowledge, promoting priority issues, monitoring public services, contributing proposals and guidance on policies to support vulnerable populations, and demanding accountability from state entities. These are organizations that play a significant role in society, as they:

- Identify or provide solutions to address the needs of the population.
- Support the State, particularly in countries with budgetary constraints, to ensure social welfare.
- Participate in implementing strategies that contribute to social development and rights defense.

#### Their main characteristics are:

- An organizational structure without the need for a specific legal formulation.
- Separation from the State and public administration, although they may receive financial support from the government under specific contracts.
- Non-profit nature, as the profits and capital generated from their operations are reinvested and allocated to fulfill their mission without being distributed among their members.
- Autonomy and control over their actions.

#### **COMMUNITY ORGANIZATIONS**

They possess characteristics that sometimes do not meet the stipulations for Civil Society Organizations (CSOs), which is why they are considered a separate category from them. They encompass various types, depending on the interests that drive their actions:

- Faith-based organizations.
- Identity-based organizations.
- Local organizations.
- Health-related, such as patient groups or support groups for addressing a specific issue or illness.

They do not require sophisticated structures or networks to collect and maintain resources, yet they play a significant role in initiating collective action and influencing a community's well-being.



#### 4. SOCIAL PARTICIPATION IN HEALTH

The involvement of individuals and groups in society has existed since its inception, manifesting in acts of solidarity among its members and in the care of the most vulnerable. Some organizations originated within churches, such as the Ladies of Charity, which began their activities in the early 17th century. However, it was not until the 20th century that their structure evolved, leading to the autonomy they are known for today. For instance, in 1940, the movement to combat poverty and the initiatives that emerged in the United Kingdom encouraged population participation to develop local actions to promote welfare. These efforts remain a significant component of healthcare today.

In the 1960s, many community participation projects were established in various countries, achieving diverse objectives, but they did not significantly expand low-cost services. During that decade, all federal programs in the United States incorporated citizen participation laws. In Colombia, Health Committees were established, composed of neighborhood representatives from specific communities, which later evolved into Local Health Councils.

During those years, the Union of Soviet Socialist Republics saw the emergence of Social Councils that engaged the population in addressing health-related issues. In the People's Republic of China, Patriotic Health Campaigns were developed, involving the public in responding to various health challenges.

A few years later, in the 1970s, the need for collaboration between governmental institutions and the population was recognized. Starting in 1978, with the **Declaration of Alma-Ata,** community participation became a key strategy to achieve the goal of "Health for All by the Year 2000." This initiative aimed to extend health services to the entire population, particularly high-risk groups and those with limited access to such services.

This strategy, promoted by the WHO-PAHO and supported by the United Nations International Children's Emergency Fund (UNICEF), led to various initiatives in different parts of the world, demonstrating ways to embrace social participation. These international organizations continued to emphasize the importance of social participation in health through the Ottawa Charter, issued and signed by the governments that participated in 1986. The charter highlights Health Promotion as a viable alternative that includes community support through strengthening social participation. During those years, One Health Promotion was established in communities through the Healthy Municipalities Movement, which later evolved into the Healthy Cities initiative in Europe.

The achievement of these approaches made it possible for the Pan American Health Organization (PAHO) to approve a Resolution in 1988 to develop health infrastructure based on the adoption of Local Health Systems. These systems represent defined territorial areas where sectoral, extra-sectoral, and local resources are combined, interacting with the population to promote and provide healthcare through primary care. Within these systems, actions aimed at stimulating and strengthening social participation processes gained particular importance as a foundation for health.

Since the early 1990s, "social participation" has begun to encompass a series of actions considering the involvement of organized communities and society.

Evidence suggests that to develop local health programs, it is essential to decentralize decision-making, thereby altering the power structure so that not only are functions delegated, but dependence on central health structures is also avoided. In this way, the locality can determine its priorities, contributing to defining actions and allocating resources and funding. Indeed, the success of social health programs or projects does not stem solely from sound design, a sufficient budget, or trained human resources. It also requires the motivation and commitment of the beneficiaries, who actively participate in their well-being.

#### TYPES OF SOCIAL PARTICIPATION IN HEALTH

Social participation can manifest through various actions, such as:

**Collaboration** occurs when users are called upon to provide support through their labor or other resources without having any influence over the direction or management of the process. In this scenario, specific population segments may replace lower-skilled officials in executing specific tasks.

**Co-management:** When organized communities participate in decision-making, they promote the decentralization and democratization of power and the mechanisms to access it. Obstacles to its implementation have been observed, primarily due to the resistance of health services to distribute power, which remains concentrated in the hands of medical professionals.

**Self-management** is a form of participation that is more independent of institutional will. It can emerge when transitioning from a guided process to autonomy or due to demands by marginalized social groups seeking self-determination.

**Negotiation:** This concept arises when it is assumed that the state and its institutions are responsible for providing quality services to society as a whole, while society, in turn, must focus on self-care and promoting healthy habits. In this context, participation is limited to consensus-building and oversight of the actions of sectoral bodies. This may require social groups, vigilant of their rights, to mobilize and defend them when compromised.



#### **FORMS OF PARTICIPATION**

**Attendance:** The population responds spontaneously and positively to actions that the coordinators of health-related projects invite them to participate in. By doing so, they contribute to the community's epidemiological profile, providing direct insight into health issues and their frequency of occurrence. This information is essential for effective planning.

**Permanent:** Neighborhood associations coordinators, health promoters, community leaders, teachers, and family members are identified and analyzed to determine whether the project presented to them is significant. They participate in assessing the health situation and living conditions.

**Organic:** The community embraces the project, sharing its objectives and contributing knowledge and resources to achieve the goals. If necessary, participants are invited to workshops to strengthen their leadership, organizational, technological, or other relevant skills.

To these forms of participation, certain attitudes or stances that participants may adopt can be added:

Passive: when individuals merely comply with the requests made by administrative or managerial areas without their opinions or proposals being considered.

**Informative:** When individuals respond to the data they are asked about without having access to the use of that information.

**Consultative:** When they provide their viewpoints, the experts define health priorities and potential solutions.

**Negotiating:** When incentives are distributed in exchange for specific tasks without continuity in participation or the opportunity to make decisions.

**Interactive:** When they participate in formulating, implementing, and evaluating the project through interdisciplinary methodologies encompassing multiple perspectives and utilizing systematic processes and structured learning.

#### **ADVANTAGES OF SOCIAL PARTICIPATION IN HEALTH**

The individual and collective commitment to responsibility for health issues, which constitutes Social Participation, offers numerous advantages and benefits. Among the most notable are the following:

#### Enhancing Social Oversight in Decision-Making by:

- Promoting more effective primary healthcare.
- Empowering individuals to take control and participate in decisions that impact their lives.
- Influencing public health planning.

#### Promoting the Quality of Healthcare Services:

- Improvement in the quality, access, and adaptability of healthcare services.
- More effective primary healthcare.
- Greater commitment and sense of responsibility toward the healthcare system.

## Behavior Change and Health Promotion:

- Encouraging the modification of habits and other collective behaviors and fostering the development of healthier lifestyles.
- Proactively addressing health threats by planning timely and effective responses.

### Reduction in Health Expenditure:

- Improved guidance, optimal utilization of health spending, and more efficient resource management.
- Appropriate prioritization of community needs and expectations, avoiding unnecessary expenses.

#### Community Control and Decision-Making:

- Development of more democratic leadership, promoting open and collaborative communication.
- Relationships based on trust and mutual respect between community members and healthcare personnel.
- Community influence in health planning and decision-making processes.

## Improvement in Relations Between Healthcare Staff and the Community:

- Professionalize collaboration among social organizations to advocate for their interests.
- Strengthening relationships and social support, benefiting and/or empowering marginalized sectors.

# Promoting Development in Marginalized Sectors:

- Inclusion of all community members, fostering equity and justice in access to healthcare.
- Empowerment of marginalized communities, enhancing their resilience.

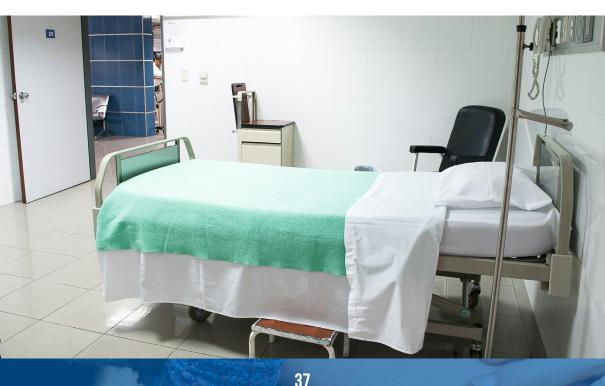


### **MECHANISMS OF SOCIAL PARTICIPATION IN HEALTH**

At its highest level, social participation in health enhances the degrees of delegation and control. This is demonstrated through public scrutiny of projects and decision-making alternatives proposed by health organizations facilitated by mechanisms such as referendums, citizen meetings, or assemblies.

It is crucial that community participation processes, including negotiation processes and the establishment of commitments, are initiated from the earliest stages of problem definition.

It is necessary to examine participatory mechanisms and processes, taking into account the effects that different design options produce. No mechanism is perfect for all communities; instead, it must align with their organizational structures, priorities, and capacity to commit.



**BRIEF GUIDELINE TO SOCIAL PARTICIPATION** 

### INVOLVEMENT OF INDIVIDUALS WITH LIVED EXPERIENCE

Community participation is not only important but integral to the success of our healthcare initiatives. Its perspectives and experiences are crucial in accelerating progress and making global policy discussions more efficient and productive.

Lived experience is a form of specialized knowledge and applying it can enhance health. It refers to experiences that foster a deeper understanding and access to insights about what it means to suffer from an illness, as opposed to those who have only heard about it or studied it theoretically.

Listening to those with lived experience in care is about adopting a person-centered approach and understanding the full spectrum of health: physical, mental, emotional, and cultural. It's about respecting the rights and responsibilities in the patient-caregiver relationship, it means respecting the rights and responsibilities both parties have, and ensuring that clinical decisions are shared. Recognizing how an individual experiences an ailment enables the joint creation and improvement of policies, programs, and services.

Thus, experience-based living encompasses two complementary fields: individuals who are experts in their lives and peer experts. Both possess knowledge and developskills through their identity and personal perspective.

The WHO Independent High-Level Commission on Non-Communicable Diseases (2017) highlighted the importance of meaningful participation by individuals with lived experience. This recommendation reaffirms the support governments should provide to promote and encourage civil society's involvement in preventing and controlling NCDs and promoting mental health. It emphasizes the need to create opportunities for those affected by these diseases, their caregivers, and communities to have accessible avenues for participating in decisions regarding laws, policies, healthcare services, and other matters related to such NCDs.

By implementing the strategies outlined in this Recommendation, it is possible to establish programs and services that are appropriate, equitable, and tailored to the context, thereby enhancing their relevance and acceptance among the target population. Furthermore, investments in health will become more effective and sustainable, leading to increased efficiency and more significant benefits.

The concept of care needs is thus redefined, extending beyond mere attention (caring for) to encompass the social capacity to contribute to well-being (care of, care with). Social connections are gradually being forged to foster mutual care through, for example, the association of patients, caregivers, professionals, social activists, decision-makers, and citizens. This can give rise to instances of dialogue, such as a community conversation, which can take place at a neighbor's kitchen table, a neighborhood meeting in the municipal auditorium, or begin to take shape through a digital social network, ultimately bringing together a large number of people in a forum or discussion panel.



#### **COMMUNITY CONVERSATION**

A community conversation is a small group discussion involving local or virtual community members. It is designed to understand their concerns and proposals regarding a shared issue that affects them. The aim is to seek solutions and foster constructive, empowering dialogue among individuals with lived experiences related to a NCD.

These discussions can shape an agenda and a proposal for political advocacy that addresses the most relevant issues and demands concrete measures from decision-makers. Additionally, they can contribute to forming support and solidarity networks among participants, fostering solutions that alleviate the emotional and economic burden and time commitment associated with managing an NCD.

It can be prepared or supplemented through virtual consultations, allowing those who cannot leave their homes or travel easily to participate. At the same time, the involvement of individuals living with NCDs as active participants, along with broader access to tools that empower and amplify their skills and knowledge to take on leadership roles and engage in the response to these diseases, helps to reduce the stigma and discrimination with which they are often marginalized.

As an example of potential actions of this nature, the following can be highlighted:

- Surveys were conducted with a sample of individuals living with NCDs to understand their shared challenges while exploring potential solutions from within the community, supported by healthcare services.
  - Development of an agenda grounded in the perspectives of individuals living with NCDs, promoted through traditional or digital community media, to influence public policies.
  - Promoting public discourse to address misconceptions and explain everyday situations surrounding people living with NCDs, aiming to eliminate stigma and discrimination.
  - Expanding the participant base to include individuals with NCDs, youth, merchants, religious communities, and local leaders committed to offering support. This initiative aims to help identify and dismantle barriers to positive change and uncover innovative ideas.

#### **CONDITIONS FOR SOCIAL PARTICIPATION IN HEALTH**

As previously discussed, we understand community participation in health as involving communities in decision-making and the planning, design, coordination, and implementation of services using collaborative and empowering methods. To achieve outcomes that benefit the population, it is essential to establish trust and respect relationships among community members and between them and health teams. This enhances their motivation to influence social and commercial determinants and reduce health inequalities affecting everyone.

### STRATEGIES EMPLOYED BY CIVIL SOCIETY TO ACHIEVE CHANGE

The following actions represent methods of forming a united front among individuals or groups to alter situations or policies that do not support their interests.

Building Coalitions: These alliances, provided they achieve strength and unity, can attain a high level of representativeness and be regarded as partners by health authorities. As such, they can raise awareness among other community members about shared issues and persuade decision-makers to take action.

Advocacy and Campaigns: To demand and promote evidence-based policies, targeting specific corporations, industries, or government agencies and modifying or updating their actions in response to changing conditions.

Arguments for Divestment: The goal is to encourage the withdrawal of funds from industries that harm public health, such as tobacco, fossil fuels, and firearms, through persuasive messaging aimed at investors. This strategy highlights the financial risks associated with these sectors while promoting socially responsible investments.

Strategic litigation: undertaken against commercial actors that harm health and the environment, seeks compensation for victims, reimbursement to governments for remediation costs, the promotion of adequate regulations, and the shaping of public opinion.



#### **EMPOWERMENT**

This concept refers to the ability of an individual or group to perceive and act autonomously regarding a situation or issue that concerns them. It is rooted in collective contributions to the construction of knowledge and experience. Some factors associated with empowerment, crucial for improving community health, include a sense of belonging as a community member, mutual trust, and an understanding of local perspectives, culture, and social structure.

Empowerment aims to enable individuals to participate in or influence decisions that affect them.

Empowerment is about more than participation; it's about making well-informed decisions. As individuals, it's up to us to understand our health and that of our family and community and to use that understanding to make the best decisions for our well-being.

- It strengthens the community as a group of individuals who are self-assured in their ability to manage and influence the health of their members collectively.
- It is present in an **organization, group, or institution** with technical expertise and applies it to foster trust and respect within and among the population. This enables the utilization of their resources and capabilities to influence health-related decisions.

To promote or strengthen the empowerment of individuals who can engage in health participation, they must have opportunities and resources to develop their knowledge, skills, commitments, structures, and leadership capabilities. This will enable them to protect and improve health effectively, allowing them to pursue their specific goals and implement practices, approaches, and structures that support and enhance responses to NCDs.

## **SKILLS FOR SOCIAL PARTICIPATION**

These competencies are contingent upon the context in which such participation occurs and are essential for fostering constructive commitments between governments and the population. They may encompass technical, recognition, and communication skills.

**Technical competencies** encompass not only the technical knowledge of the subject matter but also the generation and utilization of such knowledge. They are essential for making informed decisions on participating, doing so appropriately, and engaging with authorities under the best conditions of equality.

Technical topics must be connected to people's daily lives to generate interest in their development. This includes support to overcome practical barriers to participation, such as access to the Internet, affordable transportation, or suitable meeting spaces.

Individuals with lived experience in NCDs and areas such as community leadership and media use possess valuable expertise.

Recognition competencies contribute to the engagement of communities and civil society in social participation. These comprise their involvement in planning and developing policies that benefit individuals' goals and expectations.

They are related to assertiveness regarding their needs and opinions, critical awareness of what happens in their environment, and understanding the importance of public accountability.

Enhancing **communication skills** improves the quality of interaction with other stakeholders, particularly governmental entities, and is crucial for engaging effectively in social participation processes. These skills are closely tied to well-constructed arguments and the appropriate justification of proposals and actions.

These competencies enable individuals to speak and be understood by an audience. They also allow them to listen to others' opinions, draw conclusions, take on responsibilities, and adapt communication to different audiences, which can facilitate the creation of coalitions. Civil society can achieve a better relationship with the media through these competencies, enabling them to communicate their positions and proposals more effectively and influence public opinion more significantly.

These three competencies are strengthened through practice in the establishment of participatory spaces.

Table 3. Examples of Competencies in Social Participation

Examples of cross-cutting aspects	Technical competencies	Recognition competencies	Communication competencies
Use of language: Participation processes depend on the ability to communicate effectively.	Understanding/ speaking techni- cal language to interact effecti- vely and partici- pate in delibera- tions.	Being prepared to speak assertively in front of an au- dience and with various stakehol- ders.	Address the audience using language that is comprehensible to all participants in the collaborative space.
Importance of Experience: sharing personal testimonies alongside technical and scientific contributions	Support and strengthen te- chnical opinions with the knowle- dge gained from lived experience	Acknowledge the indispensable resource provided by individuals with lived experience.	Craft messa- ges that honor the knowledge gained from lived experiences.
Learning by doing: Participa- tory spaces offer the opportunity to develop skills for engagement.	Participation in forums and deba- tes enhances the technical com- petencies of the participants	Participating in forums and debates enhances the recognition that engagement is a valuable resource for the community.	Opening channels of participation provide opportunities to enhance communication skills.

#### **COMMUNITY INTEGRATED CARE**

This initiative aims to enhance the quality of life for individuals, families, and communities by improving health and social care service delivery through partnerships among stakeholders and intersectoral, interdisciplinary collaborations. It involves a development process in which those traditionally perceived as patients or recipients of care feel like equal partners.

#### Some of its characteristics include:

- Individuals recognize their environments and focus on promoting health and well-being while addressing social exclusion and isolation.
- There is a focus on accountability and the fulfillment of responsibility by governmental structures toward an entire territorially defined population rather than limiting attention to individual problems and cases.
- Local individuals and communities are engaged and empowered, recognizing their central role in the health response.
- Social bonds among individuals are activated and strengthened, enhancing social cohesion and positively impacting health.
- It supports people's priorities and goals, leveraging individual and community strengths and resources.
- It adopts a dynamic approach characterized by non-hierarchical processes, with shared leadership between highly committed and participatory communities, responsive healthcare teams, and decision-makers who recognize them as key stakeholders.

# 5. RECOMMENDATIONS FOR SOCIAL PARTICIPATION IN HEALTH

Given that one objective of social participation in the health field is to influence the development of health policies, the following recommendations are provided to guide the achievement of this goal. These recommendations can be implemented through measures taken by both the governmental sphere and civil society, including organizations and individuals committed to improving health standards and addressing NCDs.

#### I. GENERAL PRINCIPLES OF GOOD PRACTICE IN SOCIAL PARTICIPATION

1. The main actors of social participation, such as communities, community organizations, or interest groups, collaborate with public administrations in planning, developing, implementing, and evaluating actions related to community health and well-being. To make this possible, these civil society sectors must demonstrate their commitment and find openness, trust, and respect from the authorities.

Existing community networks, as well as those that may be formed by groups interested in participation, are required to contribute with their knowledge, skills, and experiences, facilitating the exchange of information among themselves and with health authorities.

In this horizontal exchange relationship, both parties must establish and communicate:

- · Their objectives,
- The areas and types of decisions in which they will collaborate and
- The support that members of civil society are willing to provide and that health authorities are prepared to accept, offering training if required.

2. Trust, commitment, leadership, and capabilities are developed through a process that requires time, resource planning, and concrete and practical working methods that satisfy both parties.

To achieve this, civil society members must articulate their expectations and available time, outline their priorities, and follow up on each individual's actions and adherence to the proposed goals.

**3.** Local community members committed to participating should receive the agreed-upon support while maintaining the planned actions within the established timeframe.

The formation of networks among individuals and community organizations contributes to the sustainability of initiatives and integrates them into structures and systems that enable their monitoring, tracking, and evaluation.

- **4.** While collaborating with health authorities on agreed-upon tasks, community members also represent and serve as spokespersons for broader community networks. As such, they convey their perspectives and sentiments in decision-making processes and those of the other individuals they represent.
- 5. To ensure the lasting impact of this social participation in health, the achievements must be widely communicated, utilizing local media outlets or community groups' websites. Additionally, public events held in community spaces will acknowledge the significance of this collaboration for community health and well-being.



# II. COOPERATION AND PARTNERSHIPS TO ADDRESS LOCAL NEEDS, RESOURCES, AND PRIORITIES

Local organizations, deeply embedded in the social fabric of their communities, possess the most comprehensive understanding of the prevailing health and wellness conditions, as well as the existing inequalities and challenges. Their collaboration with health authorities, through establishing partnerships with clear objectives and achievable goals, is essential for improving the quality of life in these communities.

These partnerships must possess specific characteristics:

- Be grounded in the needs and priorities perceived by the community members.
- Consider the resources and strengths available to the community, particularly those of the individuals actively participating.
- Collaboratively address the risks and root causes that impact health indicators, prioritizing initial actions toward those that highlight greater vulnerability within any population group.
- Permanently enhance the knowledge of those involved, ensuring all collaborators engage in a participatory research process rooted in their community. This process should not be limited to data collection but should address the identified problems or situations.
- Integrate urban and rural regeneration and development into actions to address social or economic disadvantages.
- Maintain attention to ensure that collaboration strategies guarantee that community members and government institution representatives participate equally in the design, prevention, and control of diseases, promoting health and well-being.

## III. CONTRIBUTE TO THE IDENTIFICATION OF LOCAL NEEDS AND PRIORITIES.

Community organizations have firsthand knowledge of the diversity of the context in which they operate, as well as the needs and priorities of their communities. Therefore, it is of great importance that:

- Act as a bridge and establish effective connections with institutions, identifying the types of communication that would most effectively encourage others to participate.
- Train others to collaborate, provide information, and offer support within the same community or neighboring ones.
- Identify community health leaders or representatives, reach out to groups in situations of greater vulnerability, and encourage their participation.
- Demonstrate an interest in organizing among themselves and other community members to take action on health issues.
- Be willing to receive advice, training, and support to enhance their skills and further strengthen collaborative efforts with community health authorities while gaining the recognition they deserve for their contributions.

## IV. INTEGRATE COMMUNITY PARTICIPATION INTO HEALTH AND WELLNESS INITIATIVES FROM A LOCAL PERSPECTIVE

To ensure that community participation is effectively integrated into health actions, the organizations and individuals from civil society involved must remain vigilant in ensuring that health authorities provide them with:

- Conditions and processes that facilitate their participation.
- Inclusion of clauses in grant guidelines and service provider contract documentation that consider the involvement of local communities.
- Guarantees that public healthcare service management agreements incorporate collaboration with local communities as part of their objectives.
- Integration of community engagement principles into the activities of local administrations.
- Provisions in planning resources, including human, economic, and material, to ensure sufficient support for developing community engagement initiatives.
- Methods for monitoring, evaluating, and providing feedback on the involvement of local communities and community organizations.
- Demonstrations that the learning derived from community engagement is reflected in health and well-being initiatives, promoting their assessment and considering the outcomes to agree on subsequent actions.

All these points, once agreed upon, will be monitored by organizations and community groups, ensuring that it becomes possible to:

- Conduct a strategic analysis with government health authorities to understand the sociodemographic situation of the communities.
- Facilitate greater engagement and commitment from individuals to collaborate.
- Identify community resources: skills, knowledge, networks, relationships, and available facilities.
- Ensure local actions comply with public entities' regulatory and statutory obligations.
- Address the needs and priorities of the community and consider changes that occur over time.
- Pay special attention to situations of inequality based on gender, ethnicity, migration status, place of birth, cultural group, age, socioeconomic and educational level, identity, sexual orientation, and functional diversity.

## V. ENCOURAGE A MORE SIGNIFICANT NUMBER OF PEOPLE TO PARTICIPATE AND COMMIT

The local community and community organizations, in collaboration with local authorities, should work towards:

- Identify barriers to participation, particularly among vulnerable groups ornewly established communities.
- Develop communication strategies that address the needs of vulnerable or isolated groups, individuals with low educational attainment, those facing learning challenges, or others with limited language proficiency or digital literacy.
- Provide information (verbal, written, or audiovisual) in clear, concise language and the various languages spoken by community members.
- Utilize all available means within the community, such as telephone, email, traditional mail, social media, community bulletin boards, or home visits.
- Incorporate inclusive, participatory processes from an intercultural perspective to engage with individuals from diverse cultural groups.
- Adapt the scheduling of communication activities or events to the timings and accessibility that best suit the needs of the expected attendees.
- Provide services such as playrooms, daycare centers, or home assistance to ensure support for children or dependent individuals whose caregivers are collaborating and participating.
- Monitor that the irregular administrative status of individuals or groups in vulnerable or isolated situations does not hinder their participation.

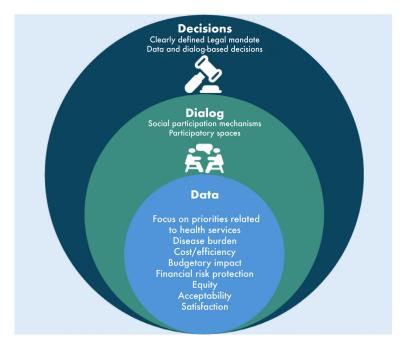


# 6. SOCIAL PARTICIPATION IN HEALTH POLICY FORMULATION

Social participation is crucial in formulating policies and decision-making processes. In some cases, it represents the only counterbalance to the pressure exerted by powerful economic interests, such as those of the non-nutritious food, tobacco, alcohol, and sugary beverage industries.

For CSOs to effectively influence public policies that protect health, it is recommended that they use the 3D method, which has been shown to achieve better outcomes. This method encompasses three key areas: Data, Dialogue, and Decisions.

Chart 5. 3D Method



The smallest space corresponds to **data**, which refers to the information that must be generated and analyzed to make decisions. This may involve obtaining scientific data based on research, reports, or surveys of the same population or similar population groups. Still, it also includes information derived from direct contact with problems and from interviews or discussion groups within the community. Citizen participation is a key element in contributing to and supporting innovative solutions. Data collection and open access to structured information represent the best practices that enable citizens to identify opportunities and new challenges in advancing the fight against NCDs.

The following space is dedicated to **dialogue**, where participants and authorities review the information gathered and examine it from various perspectives and angles. This process may aim to open a topic for discussion, establish specific agreements based on mutually defined procedures for their implementation, or organize open assemblies or town hall meetings. Community members consult and create proposals, sharing or defining health-related actions for the common good.

The final component, **decision-making**, refers to integrating data and the analysis applied to it into actions and policies. Regarding social participation in health, the decisions that emerge from this process enable the improvement of health problem resolution, which is always influenced by many factors stemming from the biopsychosocial and ecological elements of the health-disease process. Additionally, citizens must exercise their individual and collective democratic rights, taking on an active, autonomous, and responsible role in health-related issues and healthcare services.



#### SPECIFIC OBJECTIVES OF SOCIAL PARTICIPATION IN HEALTH

Below are some objectives that civil society groups may aim for when participating in the health sector.

Analyzing their health issues: the community identifies its own cultural and social risk factors related to health and illness, which foster both individual and collective autonomy. By sharing these factors with healthcare staff, these professionals gain a deeper understanding of how the community lives and what their main concerns are, enabling the identification of priority needs.

Strengthening their role as active participants in their health care: individuals decide when they require professional assistance for their health and how they will follow the recommendations provided, thereby enhancing the effectiveness of the healthcare system's actions and promoting the rational use of resources.

Strengthening the multisectoral approach and coordination of services with a community health focus: When faced with various health issues, the community coordinates care and resource use, collaborating to link the health sector with other social services. This enhances resource utilization efficiency and personal relevance by addressing one's problems.

Participate in the planning and evaluation of service operations: Through social participation in health, indicators of change are identified in, for example, health disparities, access to services, quality of life, and the degree of satisfaction of the population's needs about the services provided. These indicators would be complex for health authorities to ascertain on their own.

**Expressing opinions, demands, and recommendations:** Through participation in forums, discussions, citizen suggestion boxes, or within the collaborative frameworks established by the participation plan, individuals can highlight situations and issues that have the potential to shape or correct government actions in public health, including the social and commercial determinants of health.

**Demanding accountability in public health policies:** Civil society monitors authorities' actions as a right of citizenship to oversee the State's activities and request transparency in public actions.

**Participation in advisory bodies:** Civil society representatives are integrated into consultation spaces, such as councils or committees, where public health policies are debated. This formalizes their involvement as non-governmental actors in public affairs.

Advocating for legislative and policy actions: Community organizations or groups drive initiatives to promote reforms or new legal frameworks that establish guidelines for designing and implementing public health policies. Building alliances with health authorities: This contributes to better addressing current and future challenges, optimizing the management and use of available resources, and anticipating needs in the face of a disruptive event.

**Building alliances with health authorities:** This contributes to better addressing current and future challenges, optimizing the management and use of available resources, and anticipating needs in the face of a disruptive event.

#### CHARACTERISTICS OF COMMUNITY PARTICIPATION IN HEALTH

The participatory community process exhibits the following characteristics:

- Active: The population participates in all phases of diagnosis, planning, execution, monitoring, and evaluation through effective and democratic participatory processes.
- Aware: The community is aware of existing problems and transforms them into needs to be addressed.
- Accountable: Participants commit and decide according to their rights and responsibilities.
- Deliberate and voluntary: Interventions are carried out willingly and planned, ensuring that community groups maintain their autonomy and undertake tasks with commitment and responsibility.
- Organized: The population has its organization, independent of healthcare services, integrating activities with objectives aimed at community development.
- Sustained: It addresses health issues, and the process is maintained over time rather than representing a response to temporary or situational pressures.

#### SOCIAL PARTICIPATION: A PERSONAL PROCESS

Participation begins as an individual process, where persons recognize their competencies and potential to engage with a group that shares characteristics or goals with which they identify.

Participation can only be individual, but it always involves a relationship with the healthcare system, not exclusively in medical care but also in promoting and adopting healthy lifestyles, disease prevention, and attention to health's social and commercial determinants.

Every participatory process aims to transform a situation or problem and requires taking stances and making decisions to achieve change. Consequently, specific personal attributes, such as those outlined below, are necessary for individual participation.

**Personal Awareness:** The Individual develop a sense of self, an understanding of their rights, and a recognition of their belonging to a group or community.

**Decision-Making:** They take positions independently, with autonomy and freedom, and decide to propose ideas or take action.

Fundamental Right: The right to express oneself freely and to act, contributing to society, is acknowledged.



#### **VOLUNTEERING**

One of the most common forms of individual participation is volunteering in social or public organizations aimed at contributing to society by addressing inequities or conditions of inequality. Thus, volunteering expresses solidarity and commitment to existing needs and collective goals. It involves an individual's affiliation with various organizations that tackle diverse issues and situations but rely on voluntary participation to address social needs, problems, and interests to improve collective life. Such affiliation requires a commitment to carrying out the tasks one freely takes responsibility for, which vary depending on the context and type of volunteering.

**Social Volunteering:** Assists individuals in situations of vulnerability, deprivation, or lack of rights or opportunities.

**Development Cooperation Volunteering:** promotes socioeconomic advancement or community development to combat poverty and improve living conditions for a community or social sector, whether within one's own country or in another where such support is needed.

**Environmental Volunteering:** This initiative aims to reduce human activity's negative ecological impact while highlighting the value of existing natural heritage, animal and plant species, ecosystems, and natural resources. It involves actions

focused on protecting and restoring flora and fauna, conserving and improving water quality in lakes, rivers, and seas, and preserving mountains. Additionally, it includes efforts in environmental education and awareness-raising.

**Cultural Volunteering:** Promotes and advocates for access to artistic expressions and the cultural integration of all individuals in collaboration with museums, libraries, and spaces dedicated to art and cultural expression. It also supports the celebration of traditional or newly created community festive events.

**Sports Volunteering:** Encourages civic and social cohesion through physical fitness and sports, fostering participation in popular and amateur sports that contribute to social coexistence and inclusion.

**Educational Volunteering:** Supports work in classrooms, workshops, and other facilities, promoting complementary extracurricular activities for the education of children and young people. This helps to address social, personal, or economic inequalities.

**Social and Health Volunteering:** Combines efforts to promote health, prevent diseases, and provide healthcare, rehabilitation, and social support to vulnerable groups. This may include participation in health campaigns, for example.

**Recreation and Leisure Volunteering:** Involves engaging in non-formal educational activities that promote personal growth, group development, and community building. It encourages the development of skills, competencies, and attitudes that foster solidarity and inclusion.

**Community Volunteering:** This type involves collaborating with civic, neighborhood, collective, and citizen participation movements aimed at community development and cohesion.

**Civil Protection Volunteering:** supports emergency management, disaster prevention, and response to natural catastrophes by providing immediate assistance, such as distributing food, clothing, personal hygiene items, and other essential supplies.

#### DIGITAL ACTIVISM OR CYBERACTIVISM IN HEALTH

When advocating for person-centered health services, individual participation leverages the Internet and social media, powerful tools for rapid and effective communication. Cyberactivism, which involves embracing or individually supporting initiatives to drive social or political change within specific times and contexts, is possible through these platforms.

Traditionally, activism has taken place on the streets, through protests and demonstrations in public spaces or in front of institutional or corporate buildings. Without abandoning these in-person forms of engagement, technology has become predominant in recent years. The same arguments and causes are now presented, shared, and disseminated through computers and cell phones, allowing real-time interaction with members of small or large groups. These digital tools update commitments or extend invitations to in-person activities. This way, public protests, rallies, or public awareness campaigns are promoted or remembered, often with minimal costs and without extensive paperwork.

Digital activism enables individuals to connect, exchange information, participate in collective decision-making, and influence others at a great distance. At the same time, it opens channels for being proactive rather than just passive recipients, giving a voice, educating, and mobilizing society.

Cyberactivism employs tools such as:

**SMS:** It was one of the earliest means of disseminating calls to action. However, it has now been replaced by other platforms that allow for the integration of numerous additional functions within a single device.

**Email:** This is also a medium in decline, yet it is still used to coordinate social demonstrations.

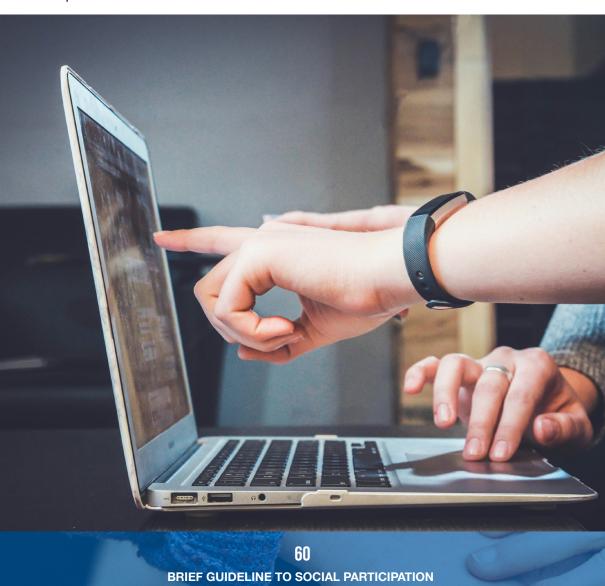
**Social Media:** These are the most significant platforms due to the vast number of users who engage with them daily, such as Facebook, X (formerly Twitter), TikTok, Instagram, and YouTube.

**Signature Collection:** These initiatives aim to garner public support for addressing undesirable societal issues. Examples include platforms like Amnesty International or Change.org.

Mass Surveys: These serve as a sounding board to promote ideas or proposals with widespread backing, such as Appgree, Cityzn, YoVeoVeo, or Maple.

**Videos:** These are highly effective due to their potential for virality and the powerful impact they can convey through platforms like YouTube or others.

**Podcast:** Audio or video files that are broadcasted over the internet. Anyone can download or stream them online, and they play a significant role in disseminating political and social ideas.



# 7. CONDITIONS AND FACTORS AFFECTING SOCIAL PARTICIPATION IN HEALTH

Social Participation in Health is undeniably fundamental to developing effective policies and programs. For it to thrive, it is essential to consider the conditions that either facilitate or hinder its progress.

#### **ELEMENTS HINDERING SOCIAL PARTICIPATION IN HEALTH**

The obstacles that may arise concerning the development of social participation stem from various spheres, where many factors come into play. Among these, the following are particularly noteworthy:

#### **POLITICAL SPHERE**

- The erosion of public systems and the advancement of privatization processes empower and favor the interests of specific groups without giving sufficient weight to strategies for health promotion and community participation.
- The dominance of large institutions often distorts intersectoral collaboration and coordination, exacerbating centralization and hierarchical structures within institutional frameworks, as well as prioritizing top-down programs that leave little room for community-driven initiatives.
- The reduction of community participation to merely serve as a source of information on health or healthcare services rather than involving communities in decision-making processes or negotiating matters that concern them.

#### TECHNICAL-PROFESSIONAL FIELD

- The Dominance of the Biomedical Model: This model prevails and restricts the development of other elements stemming from psychological and social factors, such as analyzing the impact of social and commercial determinants.
- Work Overload in Healthcare Teams: Excessive workloads, the overcrowding of healthcare services, and the rigidity of organizational models.
- Inadequate Training of Healthcare Teams: Insufficient education in community coordination, health education, and health promotion.

### **SOCIAL SPHERE**

- Within most healthcare services and community settings, there is insufficient knowledge on effectively integrating social participation.
- Expertise is fragmented according to the specialties of each team member's training, hindering decision-making within healthcare teams and in collaboration with community members.
- Responses tend to focus more on individual demands rather than social needs. This trend is also observed within the organization and functioning of social movements, where issues of representativeness arise, leading to disengagement among members.
- There is an inevitable disillusionment regarding the usefulness and effectiveness of health councils or committees, discouraging active participation.

#### **ELEMENTS THAT FOSTER SOCIAL PARTICIPATION IN HEALTH**

Successful participation experiences, such as those detailed below, demonstrate greater effectiveness when a wide range of perspectives are included and marginalized or vulnerable populations are integrated.

#### **BEST PRACTICES IN HEALTH POLICY**

- A National Health Plan: Establishing a national health plan that outlines clear objectives and allocates resources to promote community involvement in health initiatives.
- Legal Framework for Participation: Implementing a legal framework enables direct participation in healthcare services, clearly delegates responsibilities, and empowers decision-making through formally constituted bodies.
- Decentralization of Healthcare Services: Decentralizing healthcare services to allow for local planning and adaptation to specific needs, ensuring ongoing coordination among health teams, administrators, and community members.
- Promoting Citizen Participation Awareness: Strengthening awareness
  of the value of citizen participation at the highest political levels, within
  the professional sphere, and across society.

#### **BEST PRACTICES IN HEALTH SERVICES**

- Ensure that healthcare providers are trained to understand the importance of a positive attitude toward integrating social participation. This facilitates the establishment of shared goals, coherent organization, and the implementation of a comprehensive model with specific community outreach programs.
- Encouraging the development of joint action programs between public and private organizations at national, regional, and local levels.
- Recognizing and accepting the population's needs and priorities entails
  acquiring and practicing new knowledge and skills, which can lead to a
  change in communication with the population.
- The involvement of administrative areas to establish political and technical structures with sufficient resources, enabling the achievement of social and economic sustainability of the health system, adapting it to the shared commitment.
- The promotion and training of all actors within the same community who
  participate in developing the citizen participation model, creating new
  spaces for dialogue and debate.
- The development of studies to understand the opinions and attitudes of citizens and professionals, and the application of such knowledge in health services.

 Strengthening structures and spaces for community participation in health promotion, such as councils, settings for individual, group, and community health education, improvement of service quality, involvement in community health, mutual aid groups, and voluntary organizations working in health.

#### **BEST PRACTICES IN THE COMMUNITY**

- Community organizations promote social movements demonstrating leadership, mutual support systems, and individual benefits for participants.
   These elements are key to achieving favorable outcomes.
- Community representatives reflect specific social and demographic characteristics and exhibit a genuine interest and dedication to public affairs.
   They act as messengers of community interests while maintaining flexibility and respect for the opinions of all group members.
- The population demands and is provided with ongoing information and communication channels with support services. This enables its members to acquire the necessary training to enhance the effectiveness and efficiency of their participation and shared responsibility.

#### PERCEPTION OF SOCIAL PARTICIPATION IN HEALTH

One of the most significant factors in effective participation lies in stakeholders' perceptions, including community members and decision-makers. It is essential to recognize and share an understanding of Social Participation as a form of community empowerment within an institutional framework that facilitates collective experience.

Thus, there is a shift from a utilitarian conception, in which the community maintains a passive role as a recipient of information and services or as a demander of healthcare, to becoming an active participant in health decision-making on issues affect it empowering themselves to identify and achieve the desired outcomes.

This allows decision-makers and community members to internalize that social participation is a mechanism for incorporating the population into health decision-making processes while institutional services align with the community's interests and priorities.



#### SOCIAL PARTICIPATION IN HEALTH AS AN INSTITUTIONAL MECHANISM

Within health services, decision-makers tend to continue programs that the population was already involved in, and that had been previously developed, such as health fairs or local committees. However, to establish social participation as a central element, it is necessary to foster more horizontal relationships with the community, committing to creating new channels of communication and joint action.

To achieve this, it is essential to move away from a paternalistic perspective and instead transform community members into partners as active agents who collaborate in promoting health and implementing measures that facilitate the control of NCDs and other disorders.

## SOCIAL PARTICIPATION IN HEALTH AS AN EMBODIMENT OF COLLECTIVE EXPERIENCE

Upon becoming aware of their role as participatory agents, health service users identify participation by recognizing their involvement in various activities, such as mental health groups, health workshops, and mutual aid collaboration.

Community groups can serve as agents of change capable of elevating population health levels, provided they receive support and backing from health teams and authorities. This support should include opportunities to demonstrate their commitment, respect for their opinions and experiences, and recognition of their contributions.

#### **DECALOGUE OF SOCIAL PARTICIPATION IN HEALTH**

- 1. Information: The community must have access to up-to-date and easily accessible data on health topics and services.
- **2. Education:** Education should empower individuals to make informed decisions about their well-being using readily available resources.
- **3. Access:** Everyone must have equitable access to the health services they require, regardless of socioeconomic status.
- **4. Inclusion:** All voices must be heard in decision-making processes regarding community health.
- **5. Empowerment:** Pathways should be established to enable all individuals to influence the health policies and practices that affect them.
- **6. Collaboration:** All sectors of society should feel responsible for cooperating to improve community health.
- 7. Accountability: Individuals and communities must be responsible for their health.
- **8. Respect:** Cultural diversity and individual differences should be considered relevant in all health initiatives.
- **9. Transparency:** Health-related decision-making processes must be open to public scrutiny.
- **10. Sustainability:** From their initial design, all health initiatives must assess their economic and technical feasibility and consider future needs.



