



participation

# Participation as a driver of health equity







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## ABSTRACT

Social participation is about population involvement in decisions that affect their health. The promotion of this social innovation as a general rule of governance in all policies would be a key driver of health equity. In general, responsibility for organization of participatory processes falls to the public administration, but participatory processes can also be initiatives of companies, social entities or nongovernmental organizations, enabling numerous entry points and opportunities to promote more participatory social processes even in contexts in which there is no participatory tradition. Specifically, the health community can promote a greater level of social participation through the whole policy process, from diagnosis to evaluation, from health provider-level to health system-level, and when working on intersectoral strategies, programmes and activities. This paper ends with a proposal for evaluation purposes that identifies six basic components to be measured: (i) inclusion; (ii) deliberation; (iii) information flow; (iv) decision-making; (v) institutional political will; and (vi) community capacity.

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## Executive summary

Social participation is described in this paper as population involvement in decisions that affect their health. Participation therefore implies involvement and influence in the decisions affecting health status and health-care services, implementation of decisions, evaluation and monitoring and, most importantly, defining the problem.

As health can be determined by a myriad of social processes, participation in health implies the promotion of social participation as a general rule of governance in all policies. It signals a collective reflection by individuals or groups, deliberation and making decisions in collaboration with the institutions responsible, including involvement in planning and subsequent implementation of decisions.


The promotion of social participation is a key driver of health equity because it supports governance mechanisms that provide opportunities for greater health equality: raising awareness and recognition of the rights of groups with the highest level of health disadvantage; transforming so-called vulnerable groups into agents and protagonists of the policies and programmes that affect them; producing new collective knowledge that challenges dominant narratives; promoting coherence, responsiveness, transparency and the rule of law; facilitating the implementation and evaluation of strategies, programmes and activities; and promoting population consciousness of the private sector strategies used to promote products and choices that are detrimental to health.

Reduced levels of social participation in the decision-making process limits opportunities to detect the specific needs of social groups, biases political decisions in favour of the most advantaged social groups, dismisses population knowledge about their own needs, excludes the groups with the highest level of health disadvantage in decisions affecting their health, bases decisions in available knowledge (not developing specific knowledge adapted to the topic under discussion and the concerned social groups), does not coordinate the visions and actions of the different actors (affecting the coherence, effectiveness and efficiency of interventions), and implies fewer mechanisms of public control and accountability, eliciting a higher potential risk of corruption.

Flawed participation, defined as presenting a process as participatory when it is characterized by low inclusiveness, poor deliberation or intensity and no influence (for more detail, see the evaluation section in “Participation as a key driver of health equity”), has great potential to produce negative consequences such as health inequity and inefficiency.

Social participation can be considered an innovative social practice that could be applied at all governance levels and in a variety of sectors. In general, responsibility for organization of participatory processes falls to the public administration, but participatory processes can also be initiatives of other social actors, such as companies, social entities or nongovernmental organizations, enabling numerous entry points and opportunities to promote more participatory social processes even in contexts in which there is no participatory tradition. This is especially relevant in the current institutional context of the WHO European Region, where degrees of development of democratic processes are very diverse in terms of civil liberties protection, levels of political participation, pluralism, balances on the exercise of government authority, free press and other basic democratic indicators.

The health community is in a strategic institutional position to promote a greater level of social participation through the whole policy process, from diagnosis to evaluation, from health provider-



level to health system-level, and when working in intersectoral strategies, programmes and activities. All kind of institutions – public institutions in sectors other than health, private companies (through, for instance, their corporate social responsibility programmes) and third sector organizations – can also promote greater levels of health equity through social participation.

An agenda to promote social participation would include: adopting a participatory institutional culture; including the whole population in the different stages of the policy process (diagnosis, planning, implementation, and monitoring and evaluation); establishing partnerships with other sectors (supported by joint commissioning, data-sharing and joint delivery); and developing an evaluation culture of participation. Participation processes therefore need to be arranged by the organizations that promote them, with the initial objective of establishing a space for communication and decision-making that permits reflection on how to define and approach problems. Decisions taken are then implemented, with involvement of actors who participated in the prior discussions; participation therefore also means inclusion in planning, implementation, supervision and evaluation.

To evaluate social participation, at least three key questions should be answered.

- Who participates (inclusivity)?
- How do they participate (intensity)?
- How are discussions and decisions linked with policy or public action (influence)?

Classical consultation processes are usually very limited in terms of intensity and influence.

This paper presents a proposal to operationalize participation measurement for evaluation purposes that identifies six basic components to be measured: (i) inclusion (measuring the heterogeneity of the involved, selected or recruited population and the conditions in which they take part in a participatory process); (ii) deliberation (measuring the effects of the communication interaction on the participants); (iii) information flow (measuring the flow of health information in a participatory process during the phase of generation of proposals and ideas, and once results have been generated); (iv) decision-making (evaluating the circumstances that surround decision-making on behalf of the participants); (v) institutional commitment (measuring the degree of institutional political will, and generating the required conditions for carrying out the results of the participatory process); and (vi) community capacity (measuring community power in relation to control over the participatory process, and capacity of the community to own the assets generated by the participatory process).



# Social participation in health

Social participation in health refers to the population's involvement in decisions that affect their health status.<sup>1</sup>

The Alma-Ata Declaration acknowledged the “maximum community and individual self-reliance and **participation** in the planning, organization, operation and control of primary health care” as a prerequisite for health protection and promotion (2). Participation therefore implies involvement and influence in (3):

- decisions affecting health status and health-care services
- implementation of decisions
- evaluation and monitoring
- most importantly, defining the problem (4).

It is not so much a question of whether participation occurs, but rather the degree of participation (namely, which contexts have greater or lesser potential for participation). Three of the main dimensions used to assess the scope of participatory processes (5) are shown in Table 1.

**Table 1. Participation dimensions for assessment of participatory processes**

Dimension	Key question	Description
Inclusivity	Who participates?	The degree of openness to participation of people who are not formally organized
Intensity	How do they participate?	The extent to which participants interact, exchange information and influence decision-making in participation processes
Influence	How are discussions and decisions linked with policy or public action?	The orientation of participation processes in relation to government or institutional actions

Source: adapted by the authors from Fung (5).

Francés et al. (6) have provided a comprehensive definition of social participation in health. They describe it as:

*the processes of collective reflection that enable the population [individuals or groups] to construct significant information in the area of health, and to deliberate on it in order to make decisions through participatory mechanisms, in collaboration with the institutions responsible and including involvement in both the planning and subsequent implementation of these decisions.*

<sup>1</sup> “Social” in social participation refers to institutionalized and noninstitutionalized forms of participation. Institutionalized forms of participation are those conducted through institutional channels and mechanisms, whereas noninstitutionalized participation is that carried out by other means (Ganuza & Francés (1)).

Three key components can be identified in this definition.

1. These are collective processes that need to be organized. In general, responsibility for organization of participatory processes corresponds to the organizations that promote them. In the area of health, this refers primarily to the public administration, but participatory processes can also be initiatives of other social actors, such as social entities or nongovernmental organizations.
2. The initial objective is to establish a space for communication and decision-making that permits reflection on how to define and approach problems.
3. The decisions taken are implemented with the participation of the actors that participated in the prior discussion, meaning that participation also means inclusion in planning, implementation, supervision and evaluation.

## Participation as a key driver of health equity

Social participation is an essential part of the WHO definition of health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (7), given that it provides:

- more meaning or purpose in life as a result of becoming an agent of one’s own destiny and making decisions affecting health status and its wider determinants;
- better social relationships and community connectedness, thanks to the incorporation of spaces for social interaction that promote participatory processes;
- a feeling of control over one’s life and living conditions, because they are consequences of one’s own decisions; and
- opportunities to do things one enjoys, because the ability to do these things will depend on the decisions made.

Participation therefore is intrinsically related to health as a holistic and positive concept. Without social participation, it is impossible to achieve true health, especially in the areas of mental and social health cited in the WHO definition above. Social participation promotes a shared definition of well-being and supports the subjective identification of individuals with this definition. If social participation processes are inclusive – meaning that all of the population are entitled and have the skills to participate – social participation can be understood as a key driver of health equity.

On the other hand, it can be argued that social participation has an instrumental value related to health equity. The promotion of social participatory systems can be an efficient formula for reducing inequities in health. One of the principal mechanisms that produces the relationship between social participation and greater health equity is the central role of social participation in governance (8).

### Participatory components

Governance relates to how governments and other social organizations interact, how they relate to citizens, and how decisions are made in a complex world. Governance requires: spaces for discussion with citizens in which to reflect on the nature of problems; spaces for decision-making with organized interaction with citizens, civil society groups, governments and other actors to establish plans of action; organization of such actions involving all stakeholders; and their involvement in evaluation (9) (Table 2).

**Table 2. Governance for health equity: participatory components of governance and their impact on health equity**

Participatory components	Dimensions	Health equity impacts
Spaces for discussion	Communication-related	Raising visibility Recognition of rights
	Reflexive	Prioritization of people with greater needs
	Pedagogical	Health literacy
Decision-making	Coherence	Strategic vision that includes the objective of health equity

Table 2 contd

Participatory components	Dimensions	Health equity impacts
Decision-making (contd)	Responsiveness	Towards those in situations of greater need
	Transparency	Greater knowledge of the social determinants of health
	Rule of law	Reduction of discriminatory practices and abuse of power
Implementation	Coordinated action	Efficiency and effectiveness
	Identification	Reduction in symbolic violence
Evaluation	Impact assessment	Determine the impact of actions on health equity and reorient towards equity
	Return of the results	Health literacy and validation of results

### *Spaces for discussion*

The configuration of participatory institutional and noninstitutional spaces for discussion offers opportunities for promoting health equity.

#### *Communication-related opportunities for health equity*

The configuration of a participatory space requires that all affected stakeholders, including those in disadvantaged situations due to social conditions (groups with lower socioeconomic capacity, invisible and subordinate groups, and minorities, for instance), are contacted and their participation facilitated. The creation of a participatory space (through specific communication and mobilization strategies for groups that are disadvantaged in terms of health) supposes raising awareness and recognition of the rights of groups with the highest level of health disadvantage.

#### *Reflexive opportunities for health equity*

Opening a space for participation provides a reflexive (or deliberative) opportunity through interaction, communication, information production, training, reflection, deliberation and appropriation, defining problems and the agenda of priorities based on the needs of those who participate in the process, and not only on technocratic or administrative criteria. This requires, therefore, a change in the collective framing of the problem and priority-setting to take account of the most disadvantaged groups, who go from being considered mere beneficiaries of interventions to agents and protagonists of the policies and programmes that affect them.

#### *Pedagogical opportunities for health equity*

Opening a space for communication and discussion on health issues generates a space for learning that encourages health literacy (10), through which individuals gain control over individual behaviours that promote health. Health literacy can be understood as a bidirectional process, as health professionals, scientists, civil servants and others can gain knowledge about the wider determinants of health inequities through participants' narratives (11).

## **Decision-making**

Establishing a more or less formalized system for interaction with citizens, civil society groups, governments and other stakeholders allows for an approach to address problems that generate inequality in health.

### *Coherence*

Participatory processes can serve to align the objectives of different actors in the struggle against health inequity to achieve a more consensus-based strategic vision.

### *Responsiveness*

As a result of negotiation, deliberation and opening spaces for consensus (or conflict), responsiveness is developed on behalf of all intervening stakeholders in general, and governments in particular, enabling institutions to better serve all stakeholders, including those most in need.

### *Transparency*

Interaction requires the development of a transparent system of exchange. It should guarantee that information is available, accessible and comprehensible. Participants' narratives and the available information create new knowledge about the social determinants of health.

### *Rule of law*

There is a tendency to formalize the decision-making process to favour the rule of law (because of a restriction in the informal exercise of power) to reduce possible mechanisms of abuse of power and discrimination.

## **Implementation**

The participation of everyone with a stake in decisions in applying strategies, programmes and activities permits the following to occur.

### *Coordinated action*

This involves stakeholders involved in the participatory process working in synergy, improving effectiveness and the efficiency of interventions.

### *Identification of the population with policies*

It is possible to achieve greater acceptance of policies in which the population feels ownership due to participation in their development and implementation. When policy implementation takes place from a technocratic model in which elites make decisions based on technical and professional criteria, there is a tendency to generate greater symbolic violence (12) with groups that do not share the cultural codes of the socially dominant groups because of their positions in the social structure.

## **Evaluation**

Evaluation favours the following issues.

### *Determining the impact of health policies*

Impact evaluation links decisions made with possible effects on the population, which increases information about how decisions increase or reduce health inequalities. This serves to reorient action towards health equity.

### *Return of results*

The return of results is a two-way process. On the one hand, it permits the population to make use of the knowledge and information provided (which, in reality, is their own), and on the other, it is helpful in validating the information obtained in the participatory process (results validation).

To summarize, social participatory processes play a promotional role in prioritizing action on health equity and its determinants in driving forward intersectoral work (in areas such as the economy, environment, education, employment and poverty).

## **Social participation and the commercial determinants of health**

Opening the 8th Global Conference on Health Promotion in Helsinki, Finland on 10 June 2013, Dr Margaret Chan, WHO Director-General, said, “It is not just Big Tobacco anymore. Public health must also contend with Big Food, Big Soda, and Big Alcohol”.

The commercial determinants of health reflect mainly the commercialization of unhealthy commodities and corporate practices harmful to health. They have been defined as the “strategies and approaches used by the private sector to promote products and choices that are detrimental to health” (13).

The decision-making process in private companies does not usually reflect social participatory principles, with decisions generally taken by a small number of actors (executives, managers, owners and investors) in their best interests. A transformation in the decision-making process to promote greater inclusiveness, giving a wider spectrum of social actors a more decisive role and influence in the decision-making process, cannot be expected. There is therefore little room for greater social participation in big companies, even if there are some important exceptions to this rule (see, for instance, the case of the Mondragon Corporation (14)).

The adoption of social participatory processes by certain institutions or social groups can shape the commercial determinants of health. Some examples are shown in Box 1.

### **Box 1. Adoption of social participatory processes by institutions and groups**

#### **The San Francisco Tobacco-free project**

The community action model adopted by the San Francisco Department of Public Health in the United States of America brings together community individuals and organizations with public institutions to design and implement campaigns. As a result of the participatory process, the city has developed innovative solutions to reducing the effects of the tobacco epidemic. Measures include a new ordinance to cap the number of tobacco-retailer licences in each jurisdiction, smoke-free building spaces, rejection of funding from tobacco companies and their subsidiaries, increasing knowledge among participants about tobacco companies’ strategies, voluntary removal of tobacco advertising by merchants, and smoking-free homes (15).

**Box 1 contd**

**Participatory action research to support healthy eating**

The Nutrition Friendly Schools and Communities initiative actively engages the school community to prevent overweight in students. The initiative promoted changes in school meal planning and food services to ensure they adhere to recommendations for fat, saturated fat, sodium and cholesterol for breakfast, lunch and snacks (16).

**The Icelandic model for young alcohol consumption**

The Drug-free Iceland programme included a variety of measures to reduce drugs consumption (alcohol, tobacco, hashish and other substances). One of the guiding principles was the active participation of all stakeholders across sectors and levels; a promotional campaign, for instance, was prepared and implemented with direct participation of teenagers. The strategy was successful in securing reductions in young people who reported being drunk, smoking and having tried hashish over a 10-year period (17,18).

## Role of the professional health community in promoting social participation and health equity

The introduction of participatory processes promoted by the health community is critical for health equity at three levels: health-professional level; health-facility level; and health-system and health-policy level. The following is a list of recommendations for promoting social participation and health equity, taking into account the three different levels.

### Health-professional level

Health providers can promote social participation in the activities they design (medical encounters, working with communities and so on). Activities they can consider include:

- promoting “collaboration and communication with local communities” to strengthen relationships of trust and respect (19);
- engaging in programme coordination with organizations that work directly with less advantaged social groups so that organizations gain knowledge of available health services and support provided by health-care workers; organizations can also contribute to the design, implementation and evaluation of the programme;
- sharing effective practices, programmes and experiences with other health professionals to promote participation;
- engaging in joint programming and policy development work with those in the public, private and civil society sectors with a stake in health determinants (7);
- supporting community organization and action on health determinants through dedicated community development and competent health staff and programmes (7);
- recognizing that people know their own life experiences best and that it is only possible to act to the benefit of the population when their knowledge has been taken into account; their know-how is key to identifying needs and problems and exploring possible solutions; and
- being honest about participatory objectives.

In relation to the last point on the list, if the objective of a participatory process is to obtain (diagnostic) information, it is not appropriate to make the population believe they will influence the decisions taken. Participatory processes often are merely attempts to legitimize a policy and comply with a legal obligation through a consultation. In such cases, health professionals who participate in the project should make explicit the objectives of the participatory process. This can be summarized with the formula  $S=(E-R)$ , where satisfaction (S) is determined by the relationship between expectations (E) and results (R).

### Health-facility level

The following activities are especially important at this level:

- promoting the creation of formal spaces for social participation (commissions to evaluate the quality of health-care services, for instance);



- creating governance roles for representatives of local populations or standing advisory bodies involving civil society; and
- applying participatory diagnosis techniques for compiling and systematizing information.

Participatory diagnosis techniques are useful in determining the health needs of a given area or population group. Various techniques can be used to create participatory diagnosis: deliberative surveys (20), participatory community-based surveys (21), PhotoVoice methods (22) (Example 1 (23)), focus groups (24), situational flow-grams (25) and SWOT (strengths, weaknesses, opportunities and threats) analyses (26), among others. Participatory diagnosis techniques can be applied directly by health facilities or in coordination with other institutions.

#### **Example 1. PhotoVoice**

In 2007, the Sajó Association in Sajószentpéter, Hungary, proposed a diagnosis project in a predominantly Roma neighbourhood. The technical team, led by anthropologist Krista Harper, associate professor at the University of Massachusetts Amherst, proposed two major subject areas to be addressed: the environment and health. The fieldwork and capturing of images were carried out by community photographers. The participating photographers introduced a third subject: individuality as a stereotype in interventions with the Roma population (23).

Planning services by involving the intended beneficiary population is also important. Participatory planning techniques can include prioritization of public spending using participatory budgeting tools (27) (Example 2 (28)), consultative mechanisms such as citizen juries (29), scenario or future workshops to identify desirable futures and tackle proposals for change, participatory action research that combines research (30), planning and community intervention (31), or participatory strategic planning (32).

#### **Example 2. Participatory budgeting**

The participatory budgeting project “Your Health, Your Community, Your Vote” in Southampton, United Kingdom, aimed to empower local groups to bid for money and manage health-related projects. The evaluation of the process highlighted the following results (28):

Resident voting was successful, and almost everyone seemed clear on the role they played in the process. Other, less measurable outcomes were also health related – everyone found the process a positive and uplifting experience. It also helped to raise awareness of the services available to residents, and residents were made aware that they were very welcome to take up volunteering opportunities with the projects on offer.

Community organizations can be incorporated within programme implementation, strategies and activities related to health through techniques such as co-management of health services (33), friendly hospitals (34) and health mediation programmes (35) (Example 3 (36)).

#### **Example 3. Health mediation**

The Roma health mediation programme in Romania started in October 2002 through a partnership between the Ministry of Health and Romani CRISS (a nongovernmental organization that is partially owned by the Roma population). The Roma population was involved from the start of the programme, and the mediators were trained by Roma specialists. The main activities carried out by the mediators were: facilitating communication between patients and medical staff; advising on bureaucratic processes with the Roma population to ensure they could access medical assistance; and carrying out community work with the population to encourage prevention in health care and improve access to the health-care system (36).

The programmes, strategies and activities developed by the health facility are monitored and evaluated by the population and other stakeholders using techniques like participatory monitoring (37),

participatory health councils (38), health service users' ombudspersons (39) (Example 4 (40,41)) and participatory evaluation (42).

#### Example 4. Ombudspersons

The Ombudsman for Minorities of Finland provides local-level advisory and support services for ethnic minorities, migrants, and Sami and Roma people. The Ombudsman, a figure dedicated to supervising and ensuring that the rights and interests of health service users are defended and promoted vis-à-vis actions, errors, malpractice or omissions, carried out a study demonstrating the need to create local advisory services to defend ethnic minorities, particularly the Roma community, against discrimination. Three participatory meetings were held to define the contents and working methodology of future local advisory services. The meetings focused on tools to recognize discrimination, problems of accommodation and housing, and cooperation between Roma organizations, with advice on the matter of discrimination (40,41).

## Health-system and health-policy level

The following activities are especially important at this level:

- adopting a participatory institutional culture: the culture of the institution is based on democratic principles, so social participation is promoted in the whole decision-making process;
- establishing partnerships with other sectors: partnerships are maintained, enhanced and supported by joint commissioning, data-sharing and joint delivery, and their design and assessment are carried out through participatory social processes;
- including all the population in the different stages of the health-policy process (diagnosis, planning, implementation, monitoring and evaluation): universal health coverage could be a prerequisite for this; citizenship can be considered an abstract concept, but when it manifests in the form of specific formal rights and entitlements (like access to health care for all inhabitants, not only nationals), it can promote a sense of belonging that is essential in terms of motivating people to take part in participatory processes; and
- external evaluation of participatory processes: participatory social processes are assessed and evaluated by independent observers in terms of inclusiveness, intensity and influence; additionally, social inequities in participatory processes (based on gender, social class, ethnic group, age group, religion, sexual orientation or others) should be reported.

Recommended participatory processes at the three levels are summarized in Table 3.

**Table 3. Working for social participation and health equity: recommendations for acting on health inequalities**

Level	Ways to take action
Health-professional	Promoting collaboration and communication with local communities
	Engaging in programme coordination with organizations that work directly with less advantaged social groups
	Networking: sharing of participatory experiences
	Engaging in joint programming and policy development work
	Supporting community organizations and action on health determinants
	Acknowledging lay knowledge
	Being honest about participation aims

**Table 3 contd**

Level	Ways to take action
Health-facility	Creating formal spaces for social participation
	Creating governance roles for representatives of local populations or standing advisory bodies involving civil society
	Participatory diagnosis
	Participatory planning
	Participatory implementation
	Participatory monitoring and evaluation
Health-system and health-policy	Adopting a participatory institutional culture
	Establishing partnership with other sectors
	Universal health coverage as a mechanism of inclusive citizenship
	External evaluation of participatory processes

The health community can promote social participation by ensuring:

- all health strategies, programmes and activities use methods and techniques for promoting social participation;
- social participation is promoted throughout all the policy process at all stages: diagnosis, planning, implementation, monitoring and evaluation (7);
- social participation is promoted from health-provider to health-system level; and
- the health community engages in participatory processes with other sectors to promote health equity and social participation in all policies.

Box 2 focuses on social participation as a mechanism for combating discrimination.

#### **Box 2. Social participation as a mechanism for combating discrimination**

Legal texts such as the United Kingdom Equality Act (2010) usually distinguish between two principal forms of discrimination: direct and indirect. Direct discrimination occurs when one person or group of people is treated differently (less fairly) than another person or group because of age, disability, gender reassignment, marriage or civil partnership, pregnancy and maternity, race, ethnicity, religion or belief, sex, sexual orientation or other social characteristics. Indirect discrimination occurs when there is a rule, regulation or procedure (also a practice or a policy) that may appear neutral because it applies to everyone in the same way, but that negatively affects some people (or groups) but not others.

Direct discrimination refers to the social forms of interaction that are less structured than those observed within institutions. There are no formalized rules, regulations, procedures, practices or policies, only guidelines for interaction among individuals that are more spontaneous. Because participatory processes have the potential to involve multiple social actors in a coordinated way, they can favour the transmission of a critical vision of the social stratification system and its legitimizing mechanisms (ways of thinking that are, for instance, sexist, classist, homophobic, racist, ageist or intolerant of religion). In this sense, the recognition of certain groups' right to participate (for example, ethnic minority women) can serve to question unequal gender relations and systems of ethnic domination, in addition to their interaction. Participatory processes can therefore play a preventive role in combatting discrimination.

In the case of indirect discrimination, it is necessary to identify the rules, regulations, procedures, practices and policies causing discrimination. In this sense, when an institution decides to organize its course of action based on participatory processes, it creates an important window of opportunity for identifying discriminatory mechanisms. This window opens when groups who suffer the negative effects of institutional action are given a voice. It gives them visibility and, through the possibility to intervening in the decision-making process, can reorient institutional action to avoid and prevent discriminatory practices.

## How is participation currently being measured?

Efforts to measure participation frequently focus on two types of strategies: comparing indicators related to institutional practices in different countries; and opinion studies on social participation.

Comparison of institutional practice indicators is based on evaluation of participatory guarantees and conditions present in the institutional practices of geographic areas, regions and states. The intention is to achieve a comparative vision of participation in public action in different locations. Measurement criteria usually come from the field of institutional analysis and, more specifically, from evaluation of areas such as participation guarantees provided by legislation, participation promotion policies, and governance-related concepts such as responsiveness and accountability. In broader terms, criteria for health evaluation may also be related to democratic elements such as respect for civil liberties, independence of the media, celebration of free and fair elections or the strength of civil society organizations (43). Generally, these macro-level indicators are combined and integrated into synthetic indices, such as social participation indices, civic engagement indices and citizen participation indices.

Opinion studies on social participation are related to the analysis of survey results. Measurement of social participation is based on the aggregate consideration of a set of predispositions and behaviours that people living in a certain location possess, related to concepts like civic involvement, social capital or sociopolitical activity. The premise of measurement lies in the characteristics of these concepts, such as networks of interaction, belonging to organizations and the nexus among them, public participation in social media activity, and the existence of a group of shared norms and values. This permits the emergence of collective action. Collective action is the framework in which a community begins to identify the collective good and interact to achieve it. The consideration of the individual as a unit of measurement or classification is used in the area of health in many of the reference documents used by WHO, such as the framework for classification of participation proposed by the International Classification of Functioning, Disability and Health (44). This framework proposes typologies of participation based on the engagement of individuals in the community and in public life.

Both strategies have disadvantages. In the first, the indices behave almost as a constant for western liberal democracies, because the indicators refer to the minimum guarantees for democratic functioning. Scores frequently are quite high with little distance between countries or regions, which tends to minimize existing differences. This style of measuring participation also reflects a single participatory dimension (the institutional or instrumental-organic dimension), leaving out other dimensions that are more related to community capacity, such as empowerment, the prominence of civil society in policy design, or the resolution of inequalities and inequities.

The abundant use of indicators that are standardized and formalized reflects a measurement of participation that is guided by the vision of those promoting participation, focused on concepts that are in many cases linked to institutional modernization (transparency, governance, information exchange and support between different administrative levels, accountability and existence of consultative bodies). This gives greater attention to measurement of institutional outputs in terms of supply and guarantees than to the evaluation of participation made by citizens. There is frequently no special attention paid to measurement of how these outputs are managed or administered (45). This solution has therefore been determined in different areas to be insufficient, inexact and difficult to measure, even in this limited scope (46).

On the other hand, there are also limitations when opinion surveys are used to measure the nature of participation. Besides being based on instruments using indirect measurement (based on responses to surveys and not on actual behaviour, which can introduce biases), they share the disadvantage of being unable to capture indicators of true measurement of participatory processes in a region. This is reflected in the conceptual dimensions of the proposals developed by Fung (5), Burton (47), Rowe & Frewer (48) or Lestrelin et al. (49), which are discussed below.

## How participation could better be measured

### *Measurement criteria*

Any attempt to measure social reality requires answers to two basic questions: what to measure, and related to whom or what? It is important here to differentiate (for methodology purposes) between the unit of analysis (at macro level, this tends to be a territory or country, and at micro level, individuals) and the unit of measurement (which normally refers to one of the aspects that make up the unit of analysis). It could be, for example, that a region has a highly advanced policy related to participation in territorial organization, but no such policy in the area of health, or vice versa. Measuring the state of participation in the whole region could therefore give an inaccurate image of the level of community participation. In reality, it is not territories, but rather processes, policies, programmes or experiences, that are measured. Seen in this way, territories can be considered ecological frameworks for participatory practices in terms of measuring participation.

When the unit of analysis of participation is the individual instead of the territory, aggregating the results of individual responses can produce a distorted picture of the way participatory practices function. It could be, for example, that people have a high level of participation in the area of education, but are more passive in the area of health, or vice versa. In this case, using individuals as the unit of measurement for participation would be insufficient. A more coherent approach would be to design indicators using units of measurement of processes, programmes and policies, which permits a certain level of comparability and greater validity, instead of using territories or individuals, which present the considerable limitations demonstrated above. These are the two most frequent limitations presented in the description of common practices for measuring participation based on institutional practices or individual opinion surveys (see above).

It is important to achieve a certain level of consensus related to what constitutes a participatory process, which is a question under constant debate (50): what type of activities can be included, whether institutional or non-institutional (51), the dimensions to include in measurement, and their interactions (52). A participatory process can be defined along these lines as: a process of interaction among people or social actors in places designed to carry out this interaction in an organized – though not closed – way, with the aim of collectively developing activities to transform their social reality.

The strategy to measure these processes provides a double advantage: it integrates the top-down vision (that of institutions) with the bottom-up vision (the vision of the people who participate) to evaluate the objective conditions of participation, taking into account the importance of community input while recognizing that without institutional support, these participatory processes are limited in reaching their full potential (53).

The following section aims to attempt to set out how to operationally identify participation in processes, programmes or policies.

## First step. Measuring the degree of participation: what is the reach of participation?

The first key question in the design of any participatory process is related to the actual reach the process will have in terms of institutional action. One of the most frequent concerns related to participatory experiences relates to what its aim and reach will be.

Different realities can function under the idea of participation in the process that are based on the relative power of the institutions and the citizenry. Table 4 illustrates this issue.

Measuring the level of participation can occur along a continuous axis; at one extreme is absolute control of the process by institutions, and at the other, the control of the whole population. Based on this idea, authors have generated operational proposals for measuring the level of participation. Some of these formulas are shown in Fig. 1.

**Table 4. Different conceptions of a participatory process for carrying out a programme for prevention of pregnancy in adolescence**

Concept	Control
The community is articulated internally through a group of mechanisms and bodies for the solicitation, design, planning and implementation of the programme with the support of the institutions	Population control
The social actors affected and the responsible departments co-manage collaboratively implementation of the actions decided upon during the participatory process	
The social actors affected or the members of the community are recognized or entrusted with deciding upon priorities and content of the prevention programme; the responsible institutions implement the programme according to what was decided in the participatory process	
The social actors affected by the topic or the community members are consulted so they can provide suggestions, ideas or initiatives for developing the programme, which is designed and implemented by the responsible institutions	
The institutions responsible inform social actors of the community affected by the problem (such as educational centres, women's associations, young people's organizations, health professionals and experts) and the community in general about the programme actions	
The institutions responsible plan and implement the preventive activities without inquiring about the opinion of the community	

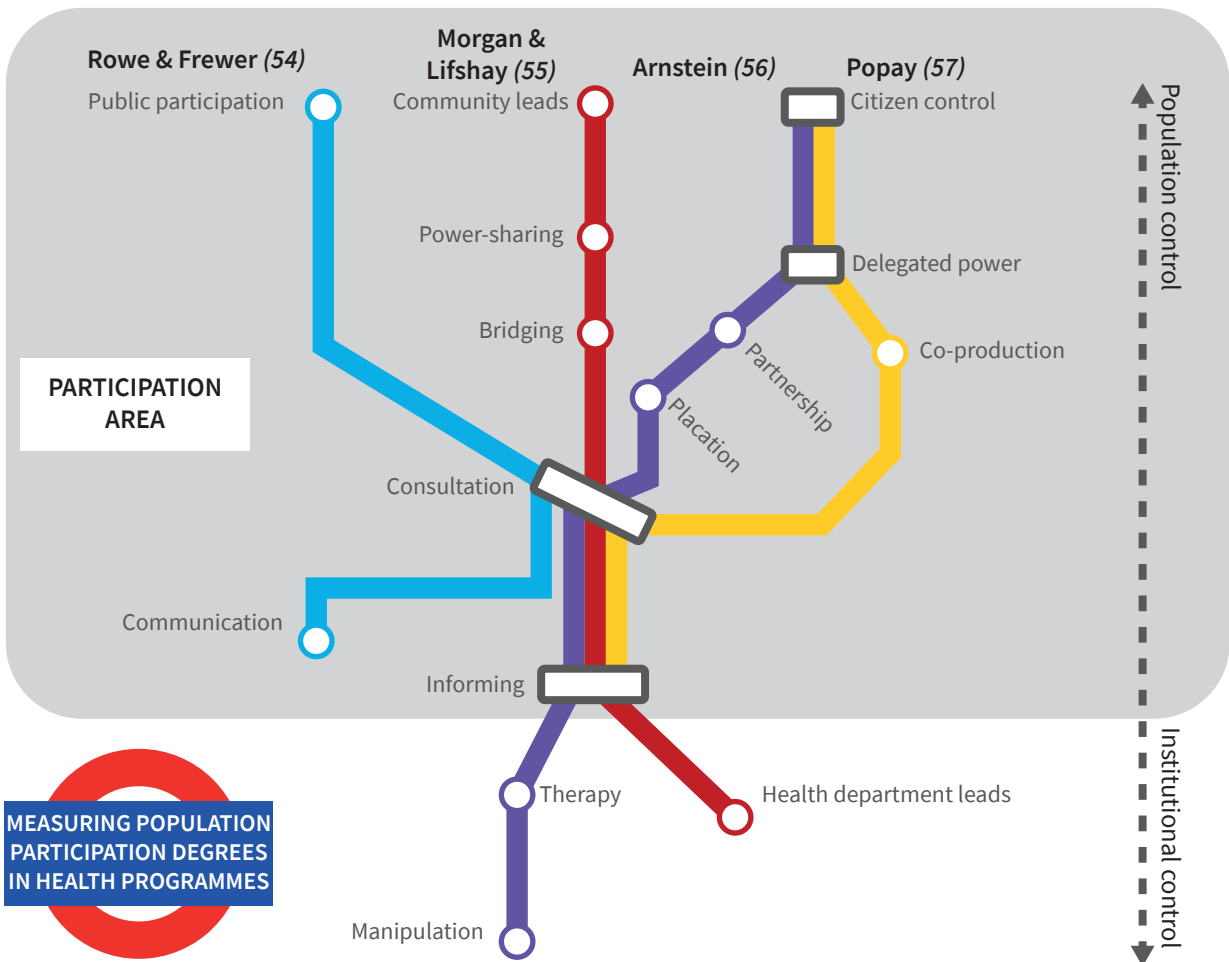
Fig. 1 constitutes a graphic tool designed to permit measurement of the depth of participation achieved for each reality, process, programme or policy related to health. In the absence of being situated in the highest “stations” of the participatory path, it provides a roadmap for efforts to increase the level of participation. While it is not necessary to clarify or detail the concepts shown in Fig. 1 here (they are used frequently, and readers are referred to the figure references (54–57) for further information), it nevertheless is important to comment on some analyses derived from it.

First, not all forms of interaction among institutions and citizens qualify as participatory processes. At the lowest levels (see the high institutional control section in Fig. 1), when it is highly institutionalized and when information shared in the area of health is highly limited or biased, participatory processes do not exist in practical terms.

Secondly, although the areas of focus of the degrees of participation differ among the authors, they share a series of common “stations” that serve as participatory steps for all of the scales. Consensus

exists that providing information constitutes a prerequisite for any participatory process, but is not enough to classify the process as participative. Even though it supposes a limited conception of participation, information provides a receptive or passive role for participants and a minimum distribution of power. It constitutes a first step in the necessary interaction for more profound participatory action.

**Fig. 1. Levels of participation possible in institutional policies, programmes or processes**



There is also agreement that the Consultation “station” is the second step in the participatory process. Consultation does not necessarily involve redistribution of power, so the results of consultation with participants tend not to be binding. It nevertheless constitutes an effort to incorporate certain participatory premises, such as interaction, collective evaluation of needs and opinions, and the incorporation (at least in an advisory way) of citizens’ preferences in the design of public action.

Informing, communication and consultation are low-level areas for evaluating possible degrees of participation. Reaching higher-level areas is subject mostly to the specific objective of the participatory process, the available resources, political will and the articulation capacity of the community in terms of collective action.

## Second step. Measuring participation criteria: what type of participation?

Whatever the degree of participation achieved or foreseen for a given process, a second step in any measurement strategy is determining what type of participation is desired. This leads to consideration of the architecture of participatory processes based on the three fundamental dimensions mentioned in Table 1: inclusivity, intensity and influence.

Interesting efforts have been made in recent decades to operationalize these three dimensions, which provide conceptual elements for their measurement. Table 5 presents some of the most important strategies in this sense.

According to these strategies, inclusivity is defined by conceptual elements, such as the ways in which people become part of a participatory process and the evaluation of the degree of agreement between participant composition and the real structure of the community. Intensity looks at determining the ways in which participant action is produced, under which conditions this interaction is produced, and how collective action is constructed based on the participatory relationships established in the process. Finally, the dimension of influence seeks to identify how collective decisions are made in a participatory process, what is the effective power of the community in the process and the results achieved, and how institutions articulate these results with public action in the area of health.

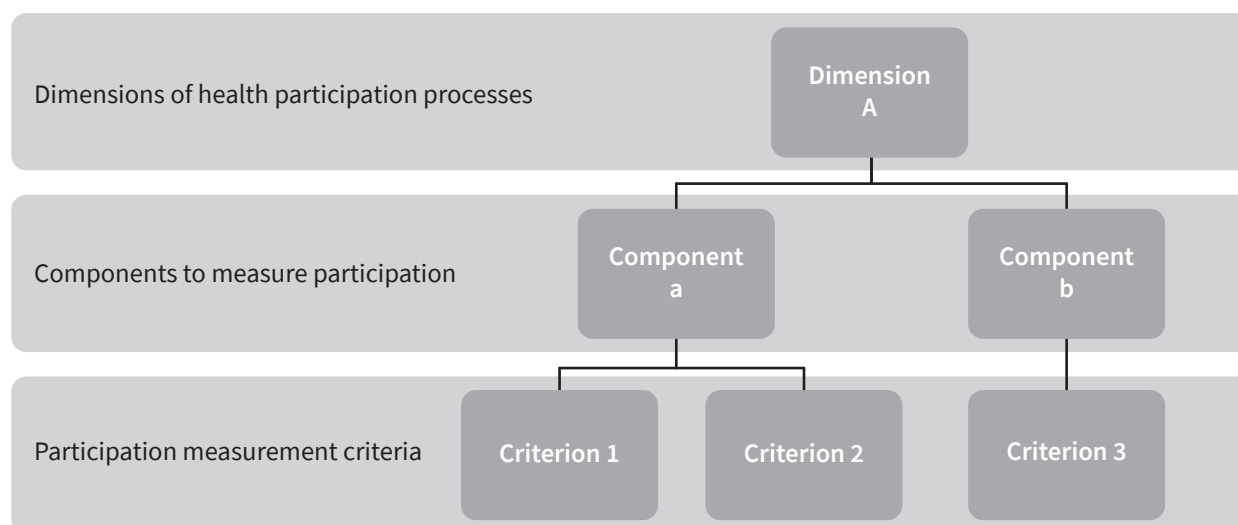
**Table 5. Dimensions, conceptual criteria and components for the measurement of participation**

		Dimensions		
		Inclusivity	Intensity	Influence
Conceptual elements of the referenced authors	Rowe & Frewer (48)	Representativeness	Independence, early implication, transparency, resources, task definition, cost–benefit effectiveness	Influence Decision structure
	Fung (5)	Modes for selection of participants	Communication and decision modes	Authority and power
	Burton (47)	Modes of choice and selection	Participatory relationships	Levels of areas of decision
	Lestrelin et al. (49)	Presence	Voice	Understanding
Components to measure participation		Inclusion	Deliberation	Information flow Decision-making Institutional commitment Community capacity

Measurement is introduced as a part of the process of operationalization that begins with the most theoretical and abstract concepts and in which the hope is to identify criteria that permit measurement of the reality of the programme or participatory process in question. Fig. 2 summarizes this operationalization process.

Having identified the three basic dimensions, it becomes necessary to find those components of measurement that can best respond to the conceptual elements described.



**Fig. 2. Operationalization scheme for measurement of participatory processes in the area of health**

This question results in the formulation of a series of axes or components that when put together are capable of registering the considerable variety of situations that may occur and which define the structure and character of a participatory process. The proposal presented here incorporates six operational components of measurement that respond to the three dimensions of inclusivity, intensity and influence. In some cases, the components are linked to a single dimension and in others, as is seen in Table 5, they possess the synergistic capacity to serve as factors that simultaneously measure aspects of more than one dimension.

The six components of participation measurement are as follows.

1. **Inclusion** (linked to the dimension of inclusivity): this looks to operational criteria to measure the heterogeneity of the involved, selected or recruited population (58) and the conditions in which they take part in a participatory process. At high levels, all actors involved in a programme or health policy (such as civic health organizations, patients, health-service users, sectors of affected populations, professionals and experts) take part in the process, and possess the capacity to intervene and find adequate channels for involvement.
2. **Deliberation** (linked to the dimension of intensity): deliberation should incorporate criteria for measurement of the effects of the communication interaction on the participants. Deliberation conditions are affected by aspects such as time and available information to reach consensus on diagnosis of the health issue area. The effects of deliberation should register to what point interaction has generated collective identification with the proposals for action.
3. **Information flow** (linked to the dimensions of intensity and influence): registration measures the flow of health information in a participatory process at two times: during the phase of generation of proposals and ideas, and once decisions have been taken about action or when results have been generated. It is necessary in both phases to measure whether information flows in an equitable and horizontal way among the principal actors (horizontal information flows) and also whether information flows among the different institutional levels responsible for the health issue (vertical information flows). It would also be relevant when analysing information flows to examine whose knowledge is valued, as unequal value assigned to different knowledge (including lay and expert knowledge) could underpin forms of inequity.
4. **Decision-making** (linked to the dimensions of intensity and influence): measurement criteria evaluate the circumstances that surround decision-making on behalf of the participants. These

criteria should pay special attention to the existence (or non-existence) of consensus-based mechanisms for decision-making, the degree of knowledge about the nature and reach of the decisions, and the evaluation of the contextual conditions in which they are made.

5. **Institutional commitment** (linked to the dimensions of intensity and influence): this looks to criteria that should be capable of measuring the degree of efficiency and institutional implication, generating the required conditions for carrying out the results or the decisions of the participatory process with the necessary guarantees.
6. **Community capacity** (linked to the dimension of influence): this integrates criteria to measure community power in relation to two fundamental questions: the first is the capacity to influence the rules of the participatory process to achieve real control over the actions carried out, and the second is linked to the measurement of the community's capacity to own the assets generated by the participatory process.

On this point, it is necessary to distinguish between measurement and assessment or evaluation. Measurement involves assigning a metric according to a reality with respect to the desired information (in this case, participatory processes in the area of health). This is an independent (or at least prior) step to evaluation. Evaluation involves comparing the measurement obtained with a standard measure in the context of which the measurement is carried out, and arriving at a judgement based on this comparison. The measurement allows the degree of participation in the process with respect to a proposed metric to be determined, but it is necessary to contextualize the measurement in terms of what occurs in other participatory processes in similar areas. It is this contextualization that allows the evaluation of participation.

Fig. 3 summarizes this operational proposal to measure participation, in which each component contains six measurable criteria (measurement is therefore carried out using 30 criteria). Measurement can achieve a minimum of zero points (achieves none of the five criteria of the component) and a maximum of five (achieves all of the criteria) for each component.

The result of this measurement exercise is two-fold. The first option is offered in unidimensional terms and permits evaluation of a participatory process, programme or policy based on a range extending from zero (not at all participatory) to 30 points (highly participatory). The second, and very interesting, option is the measurement of the six components that represent the space of the participatory process.

The decision about meeting each criterion can be made in different ways, the choice of which is open to facilitate adaptation to each context in which to capture the participatory reality. Evaluation of each criterion can therefore be dichotomized (meets this criterion/does not meet this criterion) or evaluated by degree. There is also a choice between internal measurement by participating agents or external measurement by independent people.

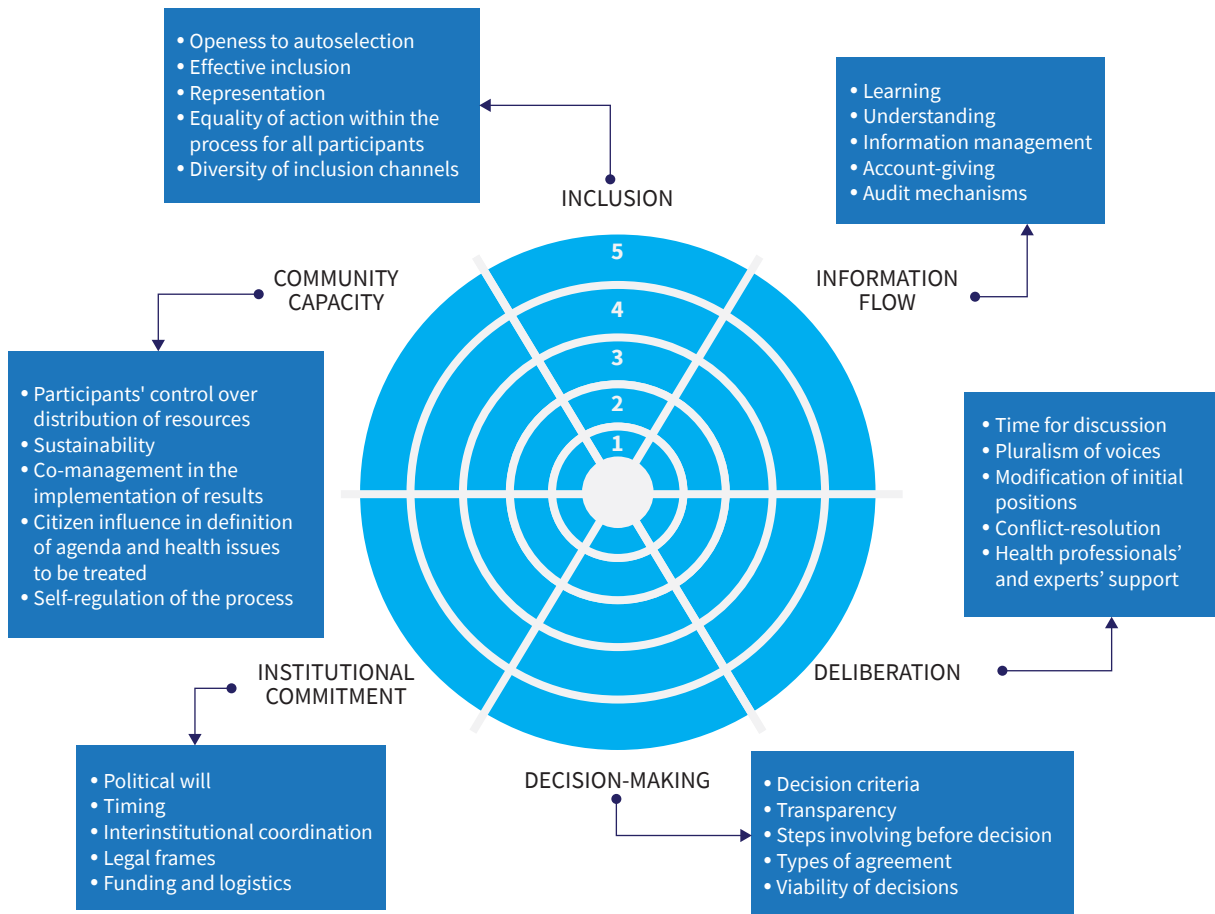
The measurement can also be designed by assigning the same weight to all criteria, or the criteria can be considered to take a determined aspect into account. What is proposed is a generic tool that can be adapted to the participatory reality of each context or programme.

## Unintended consequences of (flawed) social participation: the importance of evaluating participation

Participation could generally be perceived as an efficient mechanism for bringing about greater health equity and other social benefits, but participatory social processes might also produce negative

consequences because of the way they are designed and applied. Understanding of how operations of power affect participation dynamics is a key issue. It is therefore critical to evaluate social participatory processes in terms of components such as inclusion, deliberation, information flow, decision-making, institutional commitment and community capacity. Examples are shown in Box 3.

**Fig. 3. Components and criteria for measuring participatory processes**



**Box 3. Examples**

**The Danish Guetto Strategy**

A strategy aimed at increasing local community participation and volunteering created self-exclusion and exclusionary dynamics in the neighbourhood. The municipality promoted what it perceived as innovative activities, but the residents had neither the cultural capital to fit with the expected innovation nor the power to determine actions taken, as only activities politically assessed as “new” and “innovative” were funded (59).

**Safe drinking-water provision in Bangladesh**

An experiment conducted in Bangladesh compared a top-down intervention and two interventions that delegate decision-making, giving the treated communities the authority to determine outcomes. In one delegated intervention, the community organized itself to make decisions, but the design of the second one sought to limit elite control by requiring the community to make all decisions in a public meeting, which was subject to inclusion criteria requirements. The three interventions increased safe drinking-water provision, but the more inclusive approach increased access by 67% more than the other approaches. This success is explained by the higher diversity of the group of people included in decision-making relative to the other two groups, and produced results in bargaining that limit the influence of elites (60).

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The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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