

TOOLKIT ON SOCIAL PARTICIPATION





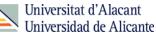
REGIONAL OFFICE FOR Europe

TOOLKIT ON SOCIAL PARTICIPATION

Methods and techniques for ensuring the social participation of Roma populations and other social groups in the design, implementation, monitoring and evaluation of policies and programmes to improve their health

By: Francisco Francés Daniel La Parra María Asunción Martínez Román Gaby Ortiz-Barreda Erica Briones-Vozmediano





Abstract

The toolkit on social participation was developed to help various stakeholders to promote social participation in the design, implementation, monitoring and evaluation of strategies, programmes and/or activities to improve the health of the population. This document is intended for use by policy-makers, project coordinators, professionals and nongovernmental organizations involved in promoting social participation of the general population, including Roma and other social groups (with the understanding that social participation processes must explicitly include Roma, but not exclusively). The toolkit comprises a detailed list of methods and techniques (tools) for promoting social participation throughout the policy process, providing examples and case studies mainly based on experiences of promoting social participation of Roma populations in Europe.

Keywords

SOCIAL PARTICIPATION CONSUMER PARTICIPATION - methods DELIVERY OF HEALTH CARE - organization and administration ROMA

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Abbreviations

PSL1local health programmesPSPparticipatory strategic planningRomani CRISSRoma Centre for Social Intervention and StudiesSRAPAddiction Prevention within Roma and Sinti communitiesSWOTstrengths, weaknesses, opportunities, threats (analysis)UNDPUnited Nations Development ProgrammeUNFPAUnited Nations Population FundUNICEFUnited Nations Children's Fund	CLAS ¹ DAW EU GRAS HSUO IOM LCC MDG NGO NHS OHCHR OSF PAR	Local Health Administration Communities United Nations Division for the Advancement of Women European Union Gender Responsive Assessment Scale Health service users' ombudsman/-woman International Organization for Migration Leicestershire County Council Millennium Development Goal nongovernmental organization National Health Service Office of the High Commissioner for Human Rights Open Society Foundations participatory action research
OHCHROffice of the High Commissioner for Human RightsOSFOpen Society FoundationsPARparticipatory action researchPSL1local health programmesPSPparticipatory strategic planningRomani CRISSRoma Centre for Social Intervention and StudiesSRAPAddiction Prevention within Roma and Sinti communitiesSWOTstrengths, weaknesses, opportunities, threats (analysis)UNDPUnited Nations Development ProgrammeUNFPAUnited Nations Population Fund		8
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UNDPUnited Nations Development ProgrammeUNFPAUnited Nations Population Fund	SRAP	Addiction Prevention within Roma and Sinti communities
UNFPA United Nations Population Fund	SWOT	strengths, weaknesses, opportunities, threats (analysis)
1	UNDP	United Nations Development Programme
UNICEF United Nations Children's Fund	UNFPA	United Nations Population Fund
	UNICEF	United Nations Children's Fund

1 Spanish acronym

Foreword

One of the most serious weaknesses of many health strategies, programmes and activities is that these are planned, designed, implemented, monitored and evaluated in a top-down manner, without considering the equally important bottom-up approach. This means that it is the experts who identify the problems and formulate interventions, while the problems and solutions as perceived by those at particular risk rarely constitute the base for action. What needs to be changed is then defined primarily in political and professional terms, without those targeted having the possibility to influence and control various determinants of health. For example, because of power imbalances and the low (if any) representation of disadvantaged social groups in decision-making bodies, these people can seldom make their voices heard. As a result, health interventions and services designed in a top-down manner will not necessarily correspond to the health needs of groups at risk.

Health policies and activities are most meaningful when target communities and groups are involved in all aspects of policy and programme development, implementation and evaluation. Promoting the social participation of people in policy development is also coherent with democratic principles. Creating resilient communities in which people are empowered and given the opportunity to express their needs and interests in the development of policy is one of the priority actions of the European policy framework for health and well-being (Health 2020), formally endorsed at the 62nd session of the WHO Regional Committee for Europe held in Malta in September 2012, which comprised health ministers and senior officials from the 53 countries of the WHO European Region.

Creating space for social participation for all social groups – including those most disadvantaged, such as Roma – is crucial, but not easy. This toolkit, which has been developed by the Interuniversity Institute of Social Development and Peace, University of Alicante (WHO Collaborating Centre on Social Inclusion and Health) and published by the WHO Regional Office for Europe, presents numerous methods and techniques that can help government authorities, institutions, organizations and individuals to create such spaces.

Dr Piroska Östlin

Programme Manager, Vulnerability and Health WHO Regional Office for Europe

1. INTRODUCTION

Background

The first draft of the document that became this toolkit was sent for review to the participants of the initial meeting on Roma health by the Roma Civil Society Group on the Right to Health (January 2012), seeking case studies and experiences involving Roma populations. The document was also presented at the meeting on improving Roma health policies (held on 28–29 November 2013 in Budapest, Hungary and hosted by Semmelweis University's Faculty of Health Sciences), within the framework of the European Cooperation in Science and Technology action IS1103 "Adapting European health systems to diversity" project, coordinated by David Ingleby. A more developed version of the toolkit was presented at the meeting "Integrating migrant and ethnic minority users' perspectives in health care governance: strategies, measurement and impact" (held on 8–9 May 2014 in Lisbon, Portugal) dealing with migrant and ethnic minority inclusion/exclusion in health participatory fora and also organized in the context of the Cooperation in Science and Technology action (Adapting European health systems to diversity).

Why this toolkit?

This toolkit was developed to help people to promote social participation in the design, implementation, monitoring and evaluation of strategies, programmes and/or activities to improve the health of the population. It introduces a set of tools that could be applied throughout all the stages of the policy process.

The toolkit builds upon the concepts and principles of the WHO's Commission on Social Determinants of Health (1):

The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities – the unfair and avoidable differences in health status seen within and between countries.

Promoting social participation is important for a more equal distribution of power. In this context, social participation is considered both as a means for and as a goal of health equity policies. In that sense, health equity could not be achieved without the active participation of the concerned population. The tools described in this toolkit could be applied to promote social participation for the effective integration of equity into health strategies, programmes and activities.

This toolkit has been developed in the context of a training course on reorienting strategies, programmes and activities related to the Millennium Development Goals (MDGs) 4 and 5 for greater health equity, with an explicit (but not exclusive) focus on the Roma population. The course was organized and facilitated in 2012 and 2013 by the

WHO Regional Office for Europe in collaboration with the University of Alicante's Interuniversity Institute for Social Development and Peace (which is also the WHO Collaborating Centre on Social Inclusion and Health) and the Spanish Ministry of Health, Social Services and Equality, with the involvement of four pilot countries: Bulgaria, Montenegro, Serbia and the former Yugoslav Republic of Macedonia. It was organized in the framework of an interagency coordination initiative entitled "Scaling up action towards MDGs 4 and 5 in the context of the Decade of Roma Inclusion and in support of National Roma Integration Strategies". This initiative was facilitated by WHO, involving the United Nations Population Fund (UNFPA), the Office of the High Commissioner for Human Rights (OHCHR), the United Nations Development Programme (UNDP), the United Nations Children's Fund (UNICEF) and the International Organization for Migration (IOM).

The toolkit provides examples and case studies mainly based on experiences of promoting social participation of the Roma population in Europe. It is understood that social participation processes must explicitly include Roma, but not exclusively. This document is intended for use by policy-makers, project coordinators, professionals and nongovernmental organizations (NGOs) involved in promoting social participation of the general population, including Roma and other social groups.

The Roma are a heterogeneous and diverse social group. For instance, gender norms could vary from one country to another, but also within a country. For this reason, the toolkit could not provide detailed instructions about how to promote social participation for specific social groups within a population. In fact, it was considered that social participation could not be promoted according to a set of fixed instructions, as the processes must be always adapted to times, places and people.

Who can use the toolkit?

The toolkit has been developed particularly for decision-makers and professionals in the health sector, as well as those working in sectors that impact the health of the population.

Roma NGOs could also find this toolkit useful for at least two purposes: first, to advocate the promotion of social participation throughout the health policy process; and second, to promote social participation in their own health projects.

The toolkit could be also used for academic purposes, as a reference guide on how to promote social participation in the health sector (and other sectors that impact the health of the population).

Toolkit description

The toolkit is divided into three parts, following this introduction, with further reading and additional information provided at the end.

- » Chapter 2 provides a short introduction to the concept of social participation and its dimensions.
- » Chapter 3 is a detailed list of methods and techniques (tools) for promoting social participation throughout the policy process, divided into different stages (diagnosis, planning, implementation, monitoring and evaluation).
- » Chapter 4 provides an evaluation of the components of participation processes.

How to use the toolkit

This toolkit provides a set of tools to promote social participation. The range of tools shows the extent of the strategies that could be applied, organized according to the different stages of the policy process (diagnosis, planning, implementation, monitoring and evaluation). The list of tools is neither exhaustive nor prescriptive; rather, it provides options and could be useful as a first introduction to promoting social participation. Every policy process will require its own techniques to be selected and tailored, according to the social reality (time, people, place and culture, among others), political will, and other factors, such as resource availability and the expectations of citizens.

For every tool, there are three distinct sections.

- » A "description and objectives" section explains the main characteristics of the technique.
- » A "method" section provides a short introduction on how to apply the technique, plus a link to a more detailed description of how to apply it (and consulting the further reading provided throughout and at the end of the toolkit is recommended).
- » A "case study" section describes a real experience of applying the tool, and within this there are various subsections, including: a background description, a list of the objectives, a description of the development of the process, details of the results and evaluation of the experience, relevant sources, and suggestions for further reading.

Reference

1. Social determinants of health. Report by the Secretariat. Geneva: World Health Organization; 2012 (http://www.who.int/social_determinants/B_132_14-en. pdf?ua=1, accessed 28 January 2016).

2. INTRODUCING THE CONCEPT OF SOCIAL PARTICIPATION

What is the operational definition of social participation?

To participate is to take part in something, but also to play an active part, in this context influencing the public decisions that affect the community. When considered from this active point of view, participation entails the collective definition of what the community understands the common good ought to be. Through this conceptual vision of participation, women and men as subjects no longer play a passive role in planning processes and public management; instead, they take on a central role as social agents with their own significance, as members of social networks, as collectives or individual stakeholders, with a whole host of possibilities to take part in the public decisions affecting them.

Based on the classic definitions provided in the relevant literature, WHO also emphasizes this idea, understanding participating as *(1)*:

[A] process by which people are enabled to become actively involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change.

In 1978, focusing specifically on the sphere of health, the International Conference on Primary Health Care declared that participation in health is (2):

[T]he process by which individuals and families assume responsibility for their own health and welfare and for those of the community, and develop the capacity to contribute to their personal and community development. They come to know their own situation better and are motivated to solve their common problems. This enables them to become agents of their own development instead of passive beneficiaries.

Box 2.1 proposes a further definition of participation in health and Box 2.2 outlines some of the reasons why Roma involvement in health policy-making is important.

Box 2.1 Proposed operational definition of participation in health

An operational definition of participation in health could be: the processes of collective reflection through which the population is enabled to construct significant information in the area of health, and to deliberate on the basis of this in order to make decisions through participatory mechanisms, in collaboration with the institutions responsible for them and involving them both in the planning and subsequent implementation of these decisions.

Box 2.2 Why is Roma participation important?

Listed below are some points that highlight why Roma participation in health policies is important.

- » Previously absent or excluded collectives and subjects both women and men can be included in controlling the allocation of resources and services.
- » The self-awareness and health knowledge of the Roma population can be increased through collective reflection.
- » A transversal approach to community development can be implemented through the emergence of comprehensive requests from the population, not only linked with (although related to) the health dimension.
- » Resources and synergic satisfiers can be identified by men and women from the population.
- » Greater involvement and commitment from the population can be generated in terms of reaching decisions, as the result of an interactive context identified by the population and felt to be their own, rather than solutions imposed from outside their culture.
- » The efficiency and effectiveness of institutional action can be improved, by allowing for planning based on demand, not supply.
- » New channels of communication between different institutional or administrative levels and the Roma population can be generated or consolidated.
- » The social visibility of community-based Roma organizations can be increased.

Levels and degrees of social participation

Participation is not so much a question of nature (that is, whether there is or there is not participation in the area of health), but rather of degrees (namely, contexts with greater or lesser participatory potential).

Anyone using this toolkit should spend a few minutes thinking about the context in which they carry out their activity in relation to the existing scenario for participation. The decision to implement one participation model rather than another in relation to the Roma community largely defines how these women and men are viewed and the nature of participation in public action. Fig. 2.1 outlines various models for fostering Roma participation in health.

Dimensions of social participation

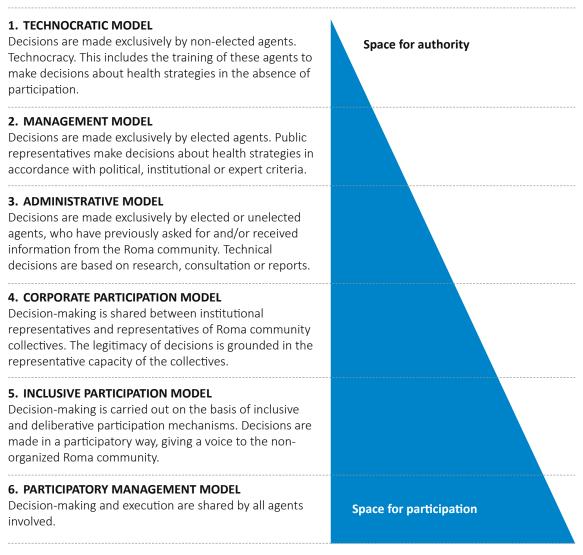
Participation is a multidimensional concept. Archon Fung systematized the three principal dimensions of any context or process of participation, as shown in Box 2.3.

Box 2.3 Dimensions to assess the scope of participatory processes

- » *Inclusiveness* is the degree of openness to participation of people who are not formally organized.
- » *Intensity* deals with the extent to which participants interact, exchange information and influence decision-making in participation processes.
- » *Influence* encompasses the orientation of participation processes in relation to government or institution actions.

Source: Fung (3).

Fig. 2.1 Models to foster Roma participation in health



Source: based on Tannenbaum & Schmidt (4).

The role of social participation as an effective strategy to reduce social inequities in health and promote social inclusion justify the need to design participatory mechanisms capable of progressing as far as possible with the Roma people within the three dimensions outlined in Box 2.3. In other words, the processes should be as inclusive as possible (permitting the participation of any Roma person who so wishes), develop the greatest possible intensity (enabling participants to carry out all the actions encompassed by the process) and have the capacity to influence public policy (recognizing the links between the decisions reached and institutional action). These dimensions could be evaluated through the instruments presented in Chapter 3 of this toolkit.

Main barriers to Roma participation

The barriers that prevent Roma women and men from participating in decisions about health policies that affect them could stem from various sources and stakeholders. Participatory barriers can be identified in the way that institutions understand their relationship with the Roma community. Others are grounded in the internal characteristics of the collectives and organizations in which the formal participation of Roma people is crystallized. Finally, participatory barriers in the Roma community itself can also be identified. The main barriers to participation are summarized in Fig. 2.2.

These barriers must be taken into account in each context in which the aim is to activate participatory mechanisms to enable the Roma population to take part in the design, planning or implementation of health programmes. Some barriers can be solved, others minimized, and some – although they cannot be eliminated – could be borne in mind when analysing the situation prior to launching participatory processes.

Enablers of social participation

In a great majority of experiences relating to participation in health, the promoter of participatory processes is the institutional or administrative agent at the various levels involved. Without support and institutional commitment, it makes no sense to initiate a participatory process aimed precisely at generating programmes which, in many cases, must be developed by an institution. That is why the first step in a process relating to Roma participation in health should be the explicit commitment of the Government. Box 2.4 outlines the governmental responsibilities relating to Roma participation in health.

The objective is to create a participatory space for collective deliberation. Deliberation is a far cry from the idea of merely pooling interests; it requires stakeholders to reach a knowledge-based consensus on the contributing factors relating to existing problems,

Fig. 2.2 Main barriers to Roma participation

Institutions, technical staff and professionals

- » Racism
- » Paternalism
- » Gender discrimination
- » Technocratic and managerialist management styles
- » Ignorance of demand and needs
- » Questioning of the efficiency of participatory processes
- » Image of the Roma population as abusive users of the health care system
- » Lack of references for participatory initiatives

Roma or organizations and institutions

- » Difficulty representing internal hetero geneity (age, gender, level of education, occupational situation, geographical area)
- » Deficient management capacity and control of bureaucracy
- » Pessimistic view of involving the social base
- » Limited information of government actions

Social base

- » Lack of information
- » Lack of training
- » Irregular administrative status
- » Language and communication issues
- » Mistrust of institutions
- » Lack of participation channels for the non-organized Roma population

and this knowledge is achieved through communicative interaction between the social stakeholders affected by the problem.

Box 2.4 Government responsibilities in initiatives aimed at facilitating Roma participation in health

The government should:

- » guarantee political conditions and technical structures, with sufficient resources to achieve the social and economic sustainability of the initiative and its adaptability to different contexts;
- » promote and facilitate training for all stakeholders who intervene and take part in the development of the new participation initiative;
- » seek and establish new spaces for meeting and debate (in addition to the existing ones), striving to ensure they are not perceived by the Roma population as external or excessively institutionalized;
- » generate a legal or normative framework that will allow for the direct democratic participation of the Roma population in health spheres that are open to participation, co-responsibility and decision-making, including establishing new structures for formal behaviour that are designed for this purpose.

Source: based on Ruiz-Gimenez (5).

Characteristics of a participatory space which fosters collective deliberation include:

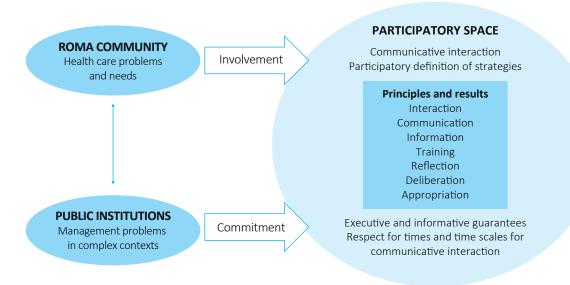
- » horizontal communication, allowing for all stakeholders to contribute information;
- » deployment of resources for training and the appropriation of knowledge related to the relevant health issues, by the stakeholders involved, particularly those who will benefit from the intervention;
- » sufficient time and time scales to allow for debate and consensus regarding the form Roma participation should take;
- reaching decisions or agreements through consensus, not majority/minority interplay;
- » political, technical and community representation within the deliberative space in order to guarantee that contributions made in the participatory process are based on consensus between all health policy stakeholders.

Fig. 2.3 depicts the structure of such a participatory space for involving Roma in health matters.

Participatory process scheme

Outlining the basic scheme for a participatory process is not an easy task. Participatory initiatives in the field of health can encompass very different areas of work and, furthermore, one of the features of any participatory process is the flexibility of its methodology and design, which adds complication.

Fig. 2.3 Structure of the participatory space for involving the Roma population in health



Prior to the promotion of a participatory health initiative, at an institutional, technical or professional level, it is necessary to establish a strategy through which the Roma community will be contacted and their participation requested. The final decision regarding which strategy to adopt for this purpose will largely determine the nature of the stakeholders that will be involved in the participatory space and, therefore, the manner in which the relationship between the Roma community and public administration will be articulated. There are basically three options, which are not mutually exclusive by any means (see Fig. 2.4).

In order to provide an overview of the stages of a participatory process, a scheme can be outlined to indicate the various actions involved in the development of such a process to involve women and men from the Roma population in health strategies (see Fig. 2.5).

Fig. 2.4 Fieldwork approach strategies for Roma participation in health strategies

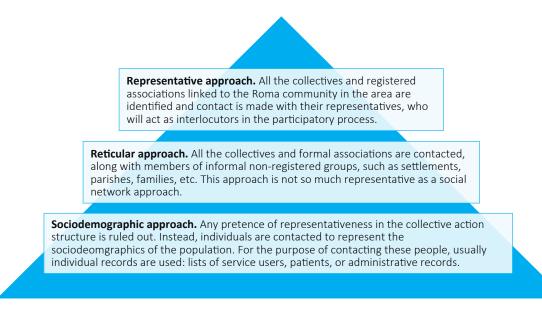


Fig. 2.5 Steps involved in establishing Roma participation in health matters

Stage 1. Identification of needs and objectives, and compilation of basic information

The aim of this first stage is to involve all stakeholders and to establish the objectives to be achieved through the process. Unlike other approaches to intervention, the initial objectives are not fixed by the promoting agents, but rather it is the Roma community itself which must establish the needs or problems requiring the greatest attention and prioritize where action is needed. The administration, on the other hand, in this initial stage, establishes the limits of participatory action (the extent to which it can influence or determine) and sets out the conditions governing collective deliberation.

Running parallel to this task, secondary data or contextual information should be gathered to determine the characteristics of the community in the area (demographic and economic data, urban planning, social structure, etc.).



Stage 2. Applying methods and participatory techniques, and establishing strategic decisions to be followed

This is the stage at which the participatory process is more open, since it is a period for collective reflection. The entire range of methodological tools required should be deployed at this point, to carry out a full participatory diagnosis of the situation. The ultimate aim of this stage is critical analysis of the conditioning factors influencing the matter at hand, and identifying alternatives for improvement, which will define the basic lines along which potential strategies could be implemented. Among the different alternatives, those that are strategic to the community will be prioritized by means of participation.

Stage 3. Implementing the strategies

This stage entails the programming and implementation of action or intervention strategies. This implementation is carried out with the support of participatory methods and techniques, which must generate an increasingly greater involvement and empowerment of the Roma community in the area being tackled by the strategy. The ultimate aim is to create stable platforms that invigorate the community, which are also capable of evaluating the process and generating feedback on the projects.



Stage 4. Evaluating, and redefining needs

Following implementation, once again collective reflection becomes important in evaluating the actions carried out. Therefore, the original problem can be re-appraised and approached differently, allowing a new spiral of analysis to be initiated, whereby the subject matter tackled or other issues that are identified as important over the course of the process can in turn open up a new cycle of reflection—action—reflection.

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3. PARTICIPATORY METHODS AND TECHNIQUES

This chapter is divided into several sections in order to study the different participatory methods and techniques that could be applied when setting up institutional integration programmes in the field of health (and related fields).

Each section includes a description of the tool and its objectives, the basic steps for implementation and a real example of its use. The sections are structured according to the different stages of the complete intervention cycle:

- » diagnosis
- » planning
- » implementation
- » monitoring
- » evaluation.

This makes it easier for all the tools to be used in a coordinated way when developing programmes, or independently for one specific stage. Each tool could be used to promote different participation dimensions and components. The tool description begins with a box detailing the impacts of each technique or method in terms of (a) participation criteria, (b) components of participation and (c) participation dimensions (see the matrix of criteria in Table 3.1).

- (a) Participation criteria to be used when evaluating participation are also outlined (Table 3.1).
- (b) Components of participation are discussed in further detail in Chapter 4. For every participatory component a list of dimensions is given, in order to evaluate the participation (see Table 3.1).
- (c) Participation dimensions are described in detail in section 2.3. They refer to *inclusiveness/participant selection methods* (the degree of openness to participation of people who are not formally organized); *intensity/modes of communication and decisions* (the extent to which participants interact, exchange information and influence decision-making in participation processes); and *influence/authority and power* (the orientation of participation processes in relation to government or institution actions.

These three elements can be useful to select properly one or another technique for participatory evaluation. The selection of a technique must be in line with the dimensions and components that have been identified for improvement, to ensure successful evaluation.

In line with the matrix of criteria to evaluate social participation, a table has been designed (Table 3.2) to summarize all the tools presented in this toolkit and to show their relationship with the dimensions of social participation and the evaluation criteria.

Participation dimension	Components to evaluate participation	Criteria	Description
Participant selection methods/inclusiveness	Inclusiveness	Type of participants	Participants include politicians, experts, professionals, NGOs, members of the general public
Participant selection methods/inclusiveness		Effective inclusion	Strategies are employed to include social groups that are commonly excluded (by gender, social class, educational level, occupation) A point to remember: "explicit, but not exclusive targeting" (i.e. the Roma population must be included, alongside other social groups)
Modes of communication and decisions/intensity	Education	Learning	Participants should gain knowledge in the process
Modes of communication and decisions/intensity		Understanding	Participants should understand the objectives, actions, limits and scope of the process
Modes of communication and decisions/intensity	Information	Information management	Consideration must be given to how and when information flows within the process, both vertically (between levels) and horizontally (across sectors and/or stakeholders)
Modes of communication and decisions/intensity		Account-giving	Accountability is key: various modes and spaces should be used to inform participants and the general population about the process and results
Modes of communication and decisions/intensity	Discussion	Time for discussion	Time and space should be allowed for discussion
Modes of communication and decisions/intensity		Types of agreements	Participants should be encouraged to reach a consensus/absolute majority, with the criteria for reaching an agreement established among the participants in advance
Modes of communication and decisions/intensity		Conflict resolution	A system should be used to resolve conflicts (i.e. intervention by external agents, along with internal mechanisms)
Modes of communication and decisions/intensity	Decision	Decision criteria	Various criteria are used to guide the decision-making process (equity, equality, efficiency, sustainability, empowerment)
Modes of communication and decisions/intensity		Transparency	How decisions are made should be transparent
Modes of communication and decisions/intensity		Degree of participation	Participants should be involved in producing and receiving information, making decisions, deciding criteria, reaching agreements, developing ideas, and managing results

Table 3.1 Matrix of criteria to evaluate participation

Table 3.1 contd

Participation dimension	Components to evaluate participation	Criteria	Description
Authority and power/ influence	Institutional development	Responsibility	It is important to decide who is responsible for the participation process
Authority and power/ influence		Norms	Legislative development should be provided to support participation. Consideration should be given to the kinds of institutions used to promote participation, as well as the legal status of those institutions
Modes of communication and decisions/intensity Authority and power/ influence		Sustainability	It should be decided whether the participation process could continue without official support
Modes of communication and decisions/intensity Authority and power/ influence		Control	Responsibility should be allocated for inspecting and controlling the agreements
Participant selection methods/inclusiveness Modes of communication and decisions/intensity Authority and power/ influence		Funding	Budget should be agreed and allocated for the participation process
Participant selection methods/inclusiveness Modes of communication and decisions/intensity Authority and power/ influence		Logistics	Certain resources are required (human, technological, spaces) to promote participation
Authority and power/ influence	Link with policy and political action	Political will	Political will is required to promote participation and to transform agreements into action
Authority and power/ influence		Intersectorality	In order to apply the results, an intersectorality commitment will be needed
Authority and power/ influence		Timing	Time should be allowed between an agreements and its implementation
Authority and power/ influence		Budgeting	The type and amount of resources should be established to transform agreements into political action
Authority and power/ influence		Legal	Legal support will be required for the agreements
Authority and power/ influence		Commitment	A degree of formal commitment is needed to transform the agreement into political action

Notes. Mechanisms of participation vary along three important dimensions (according to Fung (1)): (a) who participates? (participant selection methods); (b) how do participants communicate with one another and make decisions together? (modes of communication and decision); and (c) how are discussions linked with policy or public action? (authority and power). *Sources:* Fung (1); adapted from Francés García (2).

Account-giving rogistics Buipun∃ Control VilidenietsuS Norms Responsibility participation Degree of Participation criteria Transparency Decision criteria Conflict resolution agreements Types of Time for discussion յութուցքնուն Information **B**nibnetsnebnU ฏ กากรู มี Effective inclusion Type of participants political action Link with policy and Components to evaluate participation tnemqoleveb lenothutter Decision Discussion Information Education lnclusiveness bower Authority and Participation dimension decision bne notication and fo seboM Participant selection Participant selection Participatory techniques and methods Health mediator programmes Health participatory council Participatory photography Co-management services Participatory monitoring Participatory budgeting Participatory diagnosis Situational flow-gram Participatory survey Deliberative survey IMPLEMENTATION Future workshops Friendly hospital SWOT analysis MONITORING **EVALUATION** (PhotoVoice) Citizens' jury Focus group DIAGNOSIS PLANNING HSUO PAR PSP

Table 3.2 Summary of tools for participation evaluation

Participatory evaluation

Diagnosis Participatory diagnosis

Participation criteria	Type of participants; effective inclusion; learning; understanding; time for discussion; types of agreements; conflict resolution; degree of participation
Components to evaluate participation	Inclusiveness; education; information; discussion
Participation dimension	Participant selection methods; modes of communication and decisions

Description and objectives

Participatory diagnosis involves compiling and systematizing information by consulting the population affected by a specific area of social action, in this case public health.

It entails identifying and understanding problems and needs within a given context, their causes and evolution over time, as well as conditioning and risk factors and their foreseeable trends. Consequently, problems and needs are classified in order of importance, with a view to establishing priorities and intervention strategies, so that their feasibility can be determined in advance, considering both the resources available and the social agents and forces involved.

Method

Participatory diagnosis is not so much a technique as a method, or a strategic collective approach to studying reality. It is based on the premise that, in order to resolve a problem, all stakeholders must be involved and have a voice in the process.

Diagnosis begins with the negotiation of objectives to be achieved through the participatory process. At least three agents should be present in such negotiations: community representatives or delegates, technical staff responsible for the area of health involved in the diagnosis, and political or institutional representatives. Each of these stakeholders establishes the potential objectives of the diagnosis within their own sphere (for example, ascertaining the main health problems among the population, establishing new channels for social and health mediation, improving a certain service, and so on). On the basis of these demands, which constitute part of the larger picture, a consensus must be reached among all the stakeholders to define the priority elements for collective reflection.

Once the objectives or demands have been jointly defined, the situation can be analysed. Normally, this begins with an initial process of self-analysis. Stakeholders express how they perceive and explain the problem and provide an analysis of their situation, in order to uncover any contradictions, limitations and also potential areas requiring further work in the future. During this stage, which involves working with each stakeholder separately, the technical staff responsible for the diagnosis should use information-building techniques applied in groups: group interviews, discussion groups, focus groups, nominal groups, socio-grams, flow-grams, and so on. All these techniques help to position the discourse of each of the stakeholders involved. Some of these methodological tools are described in detail in later subsections of this chapter. Having completed this stage of self-analysis, group discussion can then be promoted among the different stakeholders, so that the problem can be approached from a different angle, through synthesis and feedback provided by the researcher. This process of reconsideration feeds into the task of objectification, entailing a description of the problem, an explanation, and possible action strategies. At this stage, group dynamics are generally used in the form of workshops or assemblies, with a dual purpose. First, what is known (in participatory methodologies) as feedback is used; in other words, validating in the minds of the protagonists themselves the information constructed during the initial stage of reflection. Second, inter-stakeholder group dynamics can summarize the information generated in the diagnosis to establish, through collective reflection, the key strategic elements required to transform the starting-point reality in line with the goals that have been set (Fig. 3.1). It is recommended to create groups comprising only women, only men and a mix of the two.

In accordance with these parameters, the output of the diagnosis has two aspects to consider: on the one hand, a description of the collective analysis of the current reality; and, on the other hand, strategies to determine which projects or actions should be undertaken in the future, based on the generation of joint action plans. In other words, a vast network of stakeholders is recommended, to ensure that the intervention applied uses as many synergies as possible. Case study 3.1 describes a study of stakeholder perspectives using participatory diagnosis in Romania.

Fig. 3.1 Methodological diagram for participatory diagnosis



Intra-stakeholder analysis Inter-stakeholder analysis Agreed diagnosis and strategies

Further reading on the tool method

Community-based participatory research: assessing the evidence. Evidence report/ Technology assessment number 99. Rockville (MD): Agency for Healthcare Research and Quality; 2004 (http://archive.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf, accessed 5 December 2014).

Case study 3.1 Romania. Roma health: perspective of stakeholders involved in the health system (doctors, health mediators and patients)

Background

In 2008 the Romanian Government issued a decree to decentralize mediation in health care. This decree was implemented in accordance with a planning process devised solely by the administration, without consulting society or the municipalities with regard to implementing the process. In light of complaints from the mediators regarding the imbalances created, the Roma Centre for Social Intervention and Studies (Romani CRISS) – a charity organization that defends the rights of the Roma population in Romania – carried out a participatory diagnosis *(1)*.

Case study 3.1 contd

Objectives

The aims of the study were to:

- » register the perceptions of the Roma population in relation to health problems and access to health care services;
- » incorporate into one forum the opinions of the main stakeholders involved in the health system (doctors, health mediators and patients).

Development of the process

Various information gathering techniques were used in the participatory diagnosis. In total, 17 interviews were conducted with health mediators, building a body of information about the living conditions of Roma communities and the past experiences of health mediators. In addition, 400 questionnaires were carried out, assessing different issues, including family planning, hygiene, vaccination and illness. Various focus groups were set up with Roma users of the health system, with a view to ascertaining and discussing the main health care problems and needs as perceived by the Roma population (2).

Results and evaluation of the experience

The diagnosis collectively highlighted the importance of issues such as: discrimination caused by lack of administrative accreditation among Roma users; segregation in maternity areas; ethnic discrimination in terms of the order in which patients are attended by health services; use of offensive language by professionals; the need for continuing professional training among health mediators; problems related to job security for health care professionals; and the need to bring about pressure on the health ministry to broaden the scope and reach of the diagnosis.

The process for the participatory diagnosis remained in place until 2011, diversifying the information gathering techniques and expanding the scope of the study.

References

- Wamsiedel M, Jitariu C, Barbu S, Cnab T. Sănătate și comunitatea romă. Analiză asupra situației din România [Health and the Roma community. Analysis of the situation in Romania]. Madrid: Romani Centrul Romilor pentru Intervenție Socială și Studii (CRISS); 2009 (http://www.romanicriss.org/Sanatatea%20si%20comunitatea%20roma%20-%20 analiza%20a%20situatiei%20din%20Romania.pdf, accessed 2 June 2015).
- Wamsiedel M, Vincze E, Ionescu I. Roma health: perspective of the actors involved in the health system – doctors, health mediators and patients. Bucharest: Romani CRISS; 2012 (http://www.romanicriss.org/PDF/raport%20final%20osi%20health%20_engleza.pdf, accessed 5 December 2014).

Further example of similar techniques or methods

Welschhoff A. Community participation and primary health care in India (dissertation). Munich: Ludwig Maximilian University of Munich; 2007 (http://edoc.ub.uni-muenchen. de/6954/1/Welschhoff_Anja.pdf, accessed 5 December 2014).

Participation criteria	Type of participants; effective inclusion
Components to evaluate participation	Education; information
Participation dimension	Participant selection methods

Participatory survey

Description and objectives

The participatory survey follows the research logic of any conventional survey, but with one specific feature: it is the members of the population that determine the contents and questions to be asked by the questionnaire, based on the logic that the issues covered in the survey should be considered important by the population in order to analyse and understand the health problem being diagnosed.

The survey makes it possible to achieve dual objectives. First, as with any survey, it obtains significant information from the subjects with regard to the target area of health. Second, it allows for a certain degree of self-knowledge and initial collective reflection, since it is the population members themselves that must deliberate on the contents to be tackled in the questionnaire, thereby developing a certain capacity to analyse and prioritize the problems affecting them.

It is also a very useful resource for carrying out social and health research or interventions in cases of limited resources, both economic and human, since the sample itself is used for these purposes.

Method

The participatory survey begins with the design of the diagnosis questionnaire. In the framework of group dynamics or workshops, the different stakeholders reflect upon and discuss which contents should be included in the questionnaire, as well as the possible response categories which should be present in each question and the appropriate language to use, eventually drawing up the final questionnaire.

Having devised the questionnaire, fieldwork begins with a chain dynamic. The team of professionals or researchers gives out the questionnaires to the women and men who took part in devising them and these subjects then take the survey. They are also given additional copies so they can in turn administer the survey to other subjects, and so on, until the broadest possible sample size is achieved. The sample is generally non-representative in statistical terms and therefore does not allow for extrapolations or inferences. However, this is not the aim of the technique. In fact, the aim is to ensure that information is gathered from as large a proportion of the population as possible and, more importantly, to create networks of subjects or stakeholders throughout the fieldwork process, who could potentially participate in any action agreed upon and carried out subsequent to the diagnosis. The networks could consider the importance of gender criteria in their composition. Furthermore, steady growth can be expected in the degree of involvement among the population, as they start to take an active part in diagnosing their problems. This will consequently minimize any resistance or reactivity that could be sparked by a study conducted by agents beyond the community.

Once fieldwork is complete, the questionnaires are recorded and formatted by the technical team. These results are disseminated and explained through workshops to the women and men who participated in the design of the survey. However, it would be a good idea to integrate new people into the group, alongside the agents that participated in the fieldwork, particularly those that collaborated in the interviews.

The information is analysed and discussed in a participatory way by the affected population group with the help and assistance of the technical team, in order to achieve a diagnosis by consensus, based on the data gathered (Fig. 3.2). Case study 3.2 describes a participatory survey undertaken in Detroit.

Fig. 3.2 Methodological diagram for the participatory survey



Further reading on the tool method

Participatory polling in divided societies and in peacebuilding contexts. Nicosia: Center for Sustainable Peace and Democratic Development (SeeD); 2013 (http://www.seedsofpeace.eu/research/participatory-polling/reports/item/80-participatory-polling-in-divided-societies-and-in-peacebuilding-contexts, accessed 5 December 2014).

Case study 3.2 Detroit (MI) (United States of America). Participatory communitybased survey for a community health intervention

Background

In 1996, owing to the poor health results of women and children in East Detroit, the East Side Village Health Worker launched a project to design, implement and evaluate a health intervention in order to deal with the factors associated with this population group (1). The project also aimed to identify institutional, organizational and community resources associated with the health of the population targeted by future interventions, with contributions from members of the community themselves as regards both protective and risk factors. To achieve this, the method decided upon was a participatory survey.

Objectives

The objectives of the survey were to:

- » evaluate the concerns of the community as regards health and the resources required to guide the intervention;
- » compile reference data to evaluate the effects of the intervention on change at community level;
- » increase the participation of the community in designing coping strategies to improve the health of women and children.

Development of the process

First, the Village Health Worker contacted community organizations located on Detroit's East Side with a history of effective collaboration at community level. These organizations worked with the university community and the Department of Health through regular meetings across several months in order to define the population targeted by the study, the content of the questionnaire and the most suitable procedures for its application.

Fieldwork was initiated by nine interviewers from among the community, which was gradually increased to 23 interviewers, who compiled a total of 700 completed questionnaires.

Once the fieldwork was completed, a discussion was held over a period of several months on the results and implications of the survey, involving mediators, members of the community, representatives from the Department of Health and other organizations, with a view to planning the intervention.

Case study 3.2 contd

Results and evaluation of the experience

The participatory survey provided information about the dimensions of public health that were prioritized by the community. Since the participants themselves designed the questionnaire and collected the information, new ways of understanding the relationship between the community and health problems were developed. For this purpose, the involvement and technical support received from the Department of Health and academic institutions were key. Furthermore, this research enabled new channels of communication to be set up between the local administration and the community.

Reference

1. Schulz AJ, Parker EA, Israel BA, Becker AB, Maciak BJ, Hollis R. Conducting a participatory community-based survey for a community health intervention on Detroit's east side. J Public Health Manag Pract. 1998;4:10–24.

Further examples of similar techniques or methods

- Nussbaum RĤ, Hoober PP, Grossman CM, Nussbaum FD. Community-based participatory health survey of Hanford, WA, downwinders: a model for citizen empowerment. Soc Nat Resour. 2004;17(6):547–559.
- REF conducts a monitoring visit to Bulgaria [website]. Budapest: Roma Education Fund (REF); 2014 (http://www.romaeducationfund.hu/news/ref/news-and-events/ref-conducts-monitoring-visit-bulgaria?page=1, accessed 5 December 2014).

Welschhoff A. Community participation and primary health care in India (dissertation). Munich: Ludwig Maximilian University of Munich; 2007 (http://edoc.ub.uni-muenchen. de/6954/1/Welschhoff_Anja.pdf, accessed 5 December 2014).

Deliberative survey

Participation criteria	Type of participants; effective inclusion; learning; understanding; information
Components to evaluate participation	Inclusiveness; education; information; discussion
Participation dimension	Participant selection methods; modes of communication and decisions

Description and objectives

Deliberative polling was conceived in 1988 by Professor James Fishkin of Stanford University, Massachusetts (3). It is essentially applied to a sample of the population involved in a problem to allow them to reflect and deliberate, with the help of experts, in relation to key decisions which should be taken in order to implement a strategy.

The difference between a deliberative survey and more traditional surveys is the mediation of a deliberative forum between two moments in the collection of data. Comparison between the results obtained in the surveys prior to and after the deliberative process make it possible to evaluate the impact that greater information and the possibility for reflection have on shaping people's opinions and attitudes towards the issue at hand.

Method

From a methodological perspective, the application of this technique implies an extensive information gathering process articulated around three moments or sequential stages.

- 1. The survey is conducted on a representative sample of the target population. The subject matter of the questionnaire is approached taking into account the beliefs, knowledge and attitudes of the population towards the problem or issue raised. As well as answering the survey itself, at this stage, all the interviewees are invited to take part in a deliberative forum. Those who agree are given detailed information prior to the forum about the issues that will be addressed at the event. All social groups must be represented (women and men, across all age groups, ethnic groups, and social classes).
- 2. A deliberative forum is held, with two dynamics. On the one hand, various experts, political leaders, representatives of collectives and so on express their different viewpoints regarding the subject of the survey. Here, the participants can ask the agents any questions they might have. In parallel, participants develop collective dynamics in relation to the subject matter by participating in small discussion groups and subsequently sharing their findings. The intention of this forum is to incorporate deliberation into the decisions to be reached. Greater reflective participation gives rise to higher quality results and also re-appraises the role of the community in public decision-making. Furthermore, the forum is able to overcome the limitations of traditional surveys as instruments that aim to reflect the real opinions of citizens but are often based on insufficient information to establish reasoned criteria for decision-making.
- 3. Once the deliberative forum has concluded, the initial survey is once again administered (re-survey) to the participants in the forum, comparing the results with those of the survey carried out prior to the deliberative process. This survey usually also contemplates new questions related to the evaluation of the forum and the participatory experience.

In some deliberative surveys, the process is completed with a further (re-)survey for control purposes, conducted a few months after the forum, to observe whether the opinions and preferences remain the same as they were following the deliberation stage or whether, to the contrary, they have changed (Fig. 3.3). Case study 3.3 describes a deliberative survey carried out among the Roma population in Bulgaria.

Fig. 3.3 Methodological diagram for the deliberative survey



Further reading on the tool method

What is deliberative polling? [website]. Stanford (CA): Stanford University Center for Deliberative Democracy; 2014 (http://cdd.stanford.edu/polls/, accessed 5 December 2014).

Case study 3.3 Bulgaria. National deliberative poll: policies aimed at Roma in Bulgaria

Background

In 2007 the Bulgarian Government stated that although the Roma population receive social welfare assistance, their situation is not improving. Many are living in extreme poverty, isolated in ghettos, lacking a decent education, and with little chance of finding work. To analyse the situation and possible strategies, the Government launched a deliberative poll, organized by the Centre for Liberal Strategies, Bulgarian National Television, Alpha Research Polling Agency and the Open Society Institute (Sofia) (1).

Objectives

The objectives of the survey were to:

- » ascertain opinions about possible changes in public policies aimed at the Roma population;
- » revitalize democratic support for public policies.

Development of the process

The process began with an initial survey on a sample of 1344 Bulgarians, with questions about issues related to housing, crime and education. Of those surveyed, 255 were selected for a deliberative forum. These people received information, including proposals by political parties, government and NGOs. The forum was held in Sofia. Over two days, a debate was held with experts and politicians, and they worked in small groups with the assistance of moderators trained for this purpose. Six hours of debating was broadcast on national television.

Once the deliberative process was concluded, the participants completed the questionnaire again, and these results were compared with those of the initial survey.

Results and evaluation of the experience

The results of the post-forum survey revealed major changes in opinion in relation to the integration process of the Roma population. Following deliberation, for example, the percentage of people who thought Roma people should live in separate neighbourhoods decreased from 43% to 21%. Support for maintaining separate schools for the Roma population also decreased from 46% to 24%.

In fact, the interpretation of the results indicated that the majority of Bulgarian citizens are willing to support measures to integrate the Roma people into society, despite the hostile language used by nationalist politicians to describe the Roma situation.

Reference

1. National deliberative poll policies toward the Roma in Bulgaria. Stanford (CA): Stanford University Center for Deliberative Democracy; 2007 (http://cdd.stanford.edu/docs/2007/bulgaria-roma-2007.pdf, accessed 5 December 2014).

Further examples of similar techniques or methods

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Participatory photography (PhotoVoice method)

Participation criteria	Type of participants; effective inclusion; learning; degree of participation
Components to evaluate participation	Inclusiveness; education; information
Participation dimension	Participant selection methods

Description and objectives

PhotoVoice, also known as participatory photography, is a method that uses images (normally photographs, but also videos, drawings or maps) created by members of a community to activate or catalyse discourse and participatory action around a common problem.

In the diagnosis stage, the use of participatory photography helps to increase the visibility of the contexts, problems or lifestyles of minority or marginalized social groups. With the assistance of facilitators, these communities use cameras to define, communicate and improve their situation or influence public policies.

Method

There are multiple strategies and methodological approaches to these visual techniques, depending on the objectives of the process to be developed, but they all share common elements: they are all based on the premise of the catalysing capacity of visual images as a point of reference for diagnosis and reflection about the problems of the community and their relationships with their surroundings.

The first stage involves selecting or calling for reporters within the population, who will act as "community photographers". These reporters can be individuals or small groups whose members carry out some kind of common activity. The reporters must represent sociodemographic or socioeconomic sections of the community, in accordance with certain criteria, such as gender, age, economic activity, earnings, and state of health.

Then, training sessions are held with a view to familiarizing reporters with the use of cameras and the objectives of gathering information. The objectives or subject areas to be recorded must be debated in a participatory way, and they can be general in nature (reflecting lifestyles, the places where social activity takes place, health conditions, and so on in the photographs) or specific (recording problematic situations, specific needs, spaces of conflict, and so on). In these training sessions, information is provided about how to obtain the informed consent of the population captured in the photographs, which will be used purely for research purposes.

Having trained the community photographers and distributed the cameras, fieldwork begins, giving them enough time to capture images. Once the fieldwork is complete, the cameras are handed back to the technical or research teams, who develop the images.

Once the photographs have been developed, it is time for debate and discussion on the basis of the material generated. This normally takes place in groups, and can be structured by means of workshops. Different strategies can be applied to this stage, but one operational recommendation would be to divide the process into a number of smaller steps: first, the reporters are asked to choose from each series a small number of images they consider to be particularly significant; using these images as a basis, the group debate commences, not only with the reporters but with the community as a whole. For each image, participants are then asked to express what they see happening in the photographed scene, what it represents in their daily lives, what problems it reflects, and what can be done in relation to these problems. In order to triangulate the information, these steps should also be carried out with stakeholders or sections of the population from outside the Roma community, to establish different visions of the problems at hand. On the basis of these cross-reflections, different lines of action or strategies might also need to be established to deal with the problems arising in reality.

Having developed the participatory analysis of the information, a plan must be established to design a method whereby the results can be shared with public leaders, professionals, technical staff, or populations outside the community. The aim of this dissemination stage is to increase the visibility of problems surrounding the subject areas tackled in the diagnosis (Fig. 3.4). Case study 3.4 describes the application of the PhotoVoice method among Roma in Hungary.

Fig. 3.4 Methodological diagram for PhotoVoice



Further reading on the tool method

Kansas University Work Group for Community Health and Development. Community tool box. Chapter 3. Assessing community needs and resources. Section 20. Implementing PhotoVoice in your community [website]. Lawrence (KS): University of Kansas; 2014 (http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/conduct-focus-groups/main, accessed 5 December 2014).

Case study 3.4 Sajószentpéter (Hungary). Across the bridge: using the PhotoVoice method to study environment and health in a Hungarian Roma community

Background

Sajószentpéter is a town in the north-east of Hungary with high levels of unemployment, as its most important industry, a glass factory, closed down in the 1990s. Within the context of this crisis, the Roma community – which accounts for approximately 20% of the town's population – has been particularly vulnerable.

In 2007 the Sajó Association proposed a diagnosis project in a predominantly Roma neighbourhood on the other side of the bridge that leads off the main town square. Although it is part of the municipality, this neighbourhood has received much less investment for the construction of public infrastructures than the neighbourhoods on the other side of the river.

Case study 3.4 contd

Objectives

The objectives of this research were to:

- » evaluate concerns in relation to the environment and health in a predominantly Roma neighbourhood;
- » increase the visibility of the needs and concerns of the Roma population among a wider audience.

Development of the process

The technical team, led by anthropologist Krista Harper, associate professor at the University of Massachussets Amherst, proposed two major subject areas to be recorded: the environment and health (1). The participating photographers introduced a third subject: individuality as a stereotype in interventions with the Roma population.

The fieldwork and the capturing of images were carried out by the community photographers. Using the images generated, the participatory discussion was based on the concerns of the community, as well as the elements that created a sense of pride among the subjects.

Results and evaluation of the experience

PhotoVoice proved to be a good tool for communication, within the Roma community and also to enable communication with the rest of the town's (non-Roma) inhabitants. It raised awareness about various concerns, including access to basic public infrastructures (such as running water in homes, sewerage, safe, waste disposal, energy) and other issues, such as play areas and the low quality of housing. Aspects that contributed to the community's sense of pride also emerged, such as their attachment to their surroundings or existing informal networks, which play a fundamental role in the prevention of racism and social exclusion.

Reference

 Harper K. Across the bridge: using PhotoVoice to investigate environment and health in a Hungarian Romani (Gypsy) community. Maynooth: European Association of Social Anthropologists; 2010 (http://works.bepress.com/krista_harper/15/, accessed 5 December 2014).

Further examples of similar techniques or methods

National Resource Centre for Ethnic Minority Health. Voices from the north. Exploratory needs assessment of Gypsy/Traveller communities in the north of Scotland. Edinburgh: Health Scotland; 2007 (http://www.healthscotland.com/uploads/documents/7855-VoicesFromTheNorth.pdf, accessed 5 December 2014).

University College Dublin. All-Ireland traveller health study. Dublin: An Roinn Sláinte Department of Health (Ireland); 2010 (http://health.gov.ie/blog/publications/all-irelandtraveller-health-study/, accessed 5 December 2014).

Wang CC. Photovoice: a participatory action research strategy applied to women's health. J Women's Health 1999;8(2):185–192.

Focus group

Participation criteria	Type of participants; effective inclusion; learning; degree of participation
Components to evaluate participation	Inclusiveness; education; information
Participation dimension	Participant selection methods

Description and objectives

The focus group is a group dynamic in which a group of (between four and 12) people discuss a policy or social intervention that affects them. The main objective of a focus group is to obtain information from the participants about their opinions, perceptions, attitudes, experiences and even their expectations regarding the subject matter discussed. It can be defined as a combination between a focus interview and a discussion group, and as a resource it is able to build a picture quickly from information gathered.

Focus groups are used very frequently in institutional action for the initial exploration of problems, in order to generate creative ideas, as well as to analyse the impact of public decisions.

Method

The preparatory stage for a focus group is determined by the objective pursued by the organizers. There are two basic options. If the aim is to expand on and develop the information available about the subject matter at hand, internally homogeneous groups should be designed. Homogeneity can respond to sociodemographic criteria (age, sex, income, and so on) or position within the structure of the area studied (professionals, public representatives, organizations, civil society, and so on). However, if the aim is to compare and contrast differing opinions and ideas, it is advisable to design groups capable of presenting internal heterogeneity, either on the basis of the sociodemographic status of the subjects or of position in the structure of the conceptual sphere being tackled by the group dynamic.

Within the participatory logic, the choice of a subject or purpose of the focus groups should be decided collectively among representatives of the stakeholders involved in the problem. This search for consensus at the start will help to reveal the different interests of the stakeholders present in the diagnosis of the reality being analysed. Furthermore, it will help to duly document the scripts used by moderators in focus group sessions.

When selecting the group participants, as well as taking account of the aforementioned internal composition criteria, a set of requirements should be met in order to maximize the construction of information in the group dynamic: the moderator should not know the participants previously; the participants should not know one another; and the venue chosen to hold the focus group sessions should be a space that is familiar to the participants, where they feel comfortable and safe.

Focus groups usually last between one and two hours, but on occasion it could be necessary to divide them into several sessions, depending on the scope of the debate. At the start, the moderator should ensure that the participants introduce themselves. The discussion begins with broad, simple questions, on which a consensus is relatively easy to reach, and from there moves into more specific, detailed questions. During the debate, the moderator may use materials (boards, flip charts, specific project examples, and so on) to illustrate the ideas expressed, although the participants themselves should, where possible, be responsible for taking notes. The debate concludes by summarizing the contributions and ascertaining whether the summary is correct, or if any content has been omitted. Contributions are collected by the focus group leaders and sorted into categories by means of a subject-specific transversal analysis. With the resulting documentation, participants can be called back, but this time into a joint session, to compare the information, initiate a broader discussion, and identify the main driving principles; that is, the contributions on which there is sufficient consensus to generate social action (Fig. 3.5). Case study 3.5 describes how focus groups were used to help prevent addiction in Sinti and Roma communities across Europe.

Fig. 3.5 Methodological diagram for the focus group



Further reading on the tool method

Kansas University Work Group for Community Health and Development. Community tool box. Chapter 3. Assessing community needs and resources. Section 20. Implementing PhotoVoice in your community [website]. Lawrence (KS): University of Kansas; 2014 (http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/photovoice/main, accessed 5 December 2014).

Case study 3.5 Project SRAP: Addiction Prevention within Roma and Sinti communities

Background

This project was launched in 2010, led by the city of Bologna together with 11 organizations (town councils, NGOs and universities) from various countries in Europe.

An initial diagnosis carried out by the city of Bologna explained the deficient living conditions of young Roma people, the difficulties they encounter in accessing health care services and their erroneous perception of health and drugs. These elements led to poor health and increased the vulnerability of this segment of the population. The SRAP project was therefore launched, funded by the European Union (EU). The beneficiaries of the project are young Roma and Sinti aged 15 to 24 years, along with social services and health care services working in the area of drug addiction prevention and, more generally, municipalities which have a significant population of young Roma and Sinti (1).

Objectives

The main objectives of the project were to:

- » reduce the damage caused by the use and/or abuse of drugs and prevent their consumption among young European Roma and Sinti;
- » facilitate access to social and health care services in these areas for young Roma and Sinti;
- » design a participatory intervention model relating to this problem, valid in all contexts and European territories.

Development of the process

With a view to increasing knowledge about the problem of drug addiction among young Roma, a series of focus groups were carried out involving the Roma population and professionals specializing in the prevention of drug dependency. To triangulate the information produced in the focus groups, young Roma people were also surveyed and field trips were organized.

Case study 3.5 contd

Results and evaluation of the experience

The results of the focus groups were discussed in each of the countries involved in the project, with participation extended to local organizations and other stakeholders interested in the problem.

Thanks to the focus groups, the level of knowledge held by Roma youth in relation to the consumption of drugs has increased. Similarly, knowledge about different strategies for the prevention of drug abuse has also increased, and the average age at which Roma youth tend to begin to take drugs is now later than it was previously.

Reference

 Marcu O, Marani P.Understanding drug addiction in Roma communities. Bologna: Addiction Prevention within Roma and Sinti communities (SRAP); 2012 (http:// srap-project.eu/files/2012/06/SRAP-Action-research-final-report-Long.pdf, accessed 5 December 2014).

Further examples of similar techniques or methods

- Krumova T, Ilianova M. The health status of Romani women in Bulgaria. Veliko Tarnovo: Centre for Interethnic Dialogue and Tolerance "Amalipe"; 2008 (http://amalipe.com/files/ publications/Health%20report_AMALIPE.pdf, accessed 5 December 2014).
- Petek D, Rotar PD, Svab I, Lolic D. Attitudes of Roma toward smoking: qualitative study in Slovenia. Croatian Med J. 2006;47(2):344–347.
- Smoliska-Poffley S, Ingmire S. Roma mental health advocacy project. Evaluation report. London: Roma Support Group; 2012 (http://romasupportgroup.org.uk/wp/wp-content/ uploads/2011/08/Roma-Mental-Health-Advocacy-Project-Evaluation-Report.pdf, accessed 5 December 2014).

Participation criteria	Type of participants; effective inclusion; learning; degree of participation	
Components to evaluate participation	Inclusiveness; education; information	
Participation dimension	Participant selection methods	

Situational flow-gram

Description and objectives

The flow-gram is a technique used in the situational strategic planning approach developed by the late Carlos Matus, former economist at Harvard University, Massachusetts (4). The aim of the flow-gram is to compile valid information for the diagnosis of problems through the collective construction of a matrix. Collective work carried out on this matrix sheds light on the cause-and-effect relationships between the different elements that surround the issue being discussed and the stakeholders involved, with a view to establishing so-called critical nodes, and the main components which could be used to tackle the problem.

The aim of this technique is to link the problems defined by individuals (both women and men) from among the population with the different stakeholders responsible for dealing with them, determining the resolution capacity of each stakeholder in relation to each problem. Another purpose of this strategic technique is to prioritize the main critical nodes which hamper the process, in order to trace causal chains that link problems to the stakeholders responsible for them.

Method

The methods that can be used to approach flow-grams are diverse. Different analytical axes can be situated in the coordinates of the matrix, but here the most productive strategy for the diagnosis of problems in relation to health is described.

Before applying flow-grams, the different stakeholders involved in the problem at hand must be established. In the first stage, members or representatives of each of the stakeholder groups will develop flow-grams separately and then subsequently pool them with the other participating stakeholders.

The technique is based on the definition provided by participants of the main problems in the proposed area for study, which are transcribed onto cards. Problems can be articulated by the participants within the dynamic itself or can lead on from elements registered using other diagnosis techniques, such as those presented in this toolkit.

Once the main problems have been determined, the coordinator then presents the analysis matrix using a graphic medium. The rows (three) of the matrix will discriminate between the problems, according to whether or not they fall within the participants' sphere of influence (that is, whether they depend on the participants, or whether they do not, whether they can be resolved with the collaboration of other stakeholders, or whether they are completely outside the participants' control). The columns (usually between three and five) of the matrix will distinguish between the problems in different thematic areas, so they can be integrated into a thematic logic (for example, discrimination, prevention, information, assistance, and so on). This gives rise to a matrix which represents the level of the stakeholder's influence in terms of generating change (vertical axis) and the area with which the identified problems are associated.

Once the analysis matrix has been presented, the problems articulated by the participants can be positioned in the different quadrants. The ideal situation in this respect is for the positioning of the cards to be discussed one by one until they are all placed on the matrix. This would situate the problems in relation to the participants' capacity for influence and the spheres of action.

The next task in the group dynamic is to work collectively on the relationships between problems, which, in this case, will be cause-and-effect relationships. One problem can be the total or partial cause of another or others identified, so that causal chains can be established between the items proposed by the participants. For each problem, the number of arrows registered entering (causes) and exiting (effects) each box are counted. Those with a high number of exiting arrows will constitute causal elements, whereas those with lots of entering arrows can be identified as consequences. The problems which simultaneously accumulate a high number of arrows entering and exiting represent the critical nodes to be resolved in terms of the subject matter at hand (Fig. 3.6).

Case study 3.6 describes the use of situational flow-grams in local-level strategic health care planning in Venezuela.

The relationship analysis concludes here but at another stage it would be possible to: (a) propose strategies relating to the factors being analysed; (b) formulate proposals to make effective the influence that exists over the nodes described (according to the matrix); and (c) examine possible actions that will make any unattainable elements controllable, in the mid or short term, or at least place them within the sphere of influence.

Fig. 3.6 Methodological diagram for the flow-gram



Further reading on the tool method

Socas J, Saavedra LM, Hernández G. La técnica del flujograma: apuntes desde la práctica. Experto en Nuevas Metodologías de las Ciencias Sociales [Flowchart technique: practice notes. Expert in New Methodologies of Social Sciences]. Madrid: International Observatory of Citizenship and Sustainable Environment (CIMAS); 2003 (http://www.redcimas.org/wordpress/wp-content/uploads/2014/02/m_La-tecnicadel-flujograma.pdf, accessed 5 December 2014).

Case study 3.6 Venezuela. Communicative approach to situational strategic planning at the local level: health and equity in Venezuela

Background

This case study corresponds to research conducted in Venezuela with regard to equity in health. In Venezuela, the emergence of communal councils and their involvement in the health planning process revealed the importance of using tools that would facilitate the participation of the different stakeholders involved.

To do this, a pilot scheme was conducted in the State of Aragua in 2007, using workshops involving key selected stakeholders and applying the flow-gram approach, among other techniques *(1)*.

Objectives

The research objectives were to:

- » assess the communicative aspects of health information;
- » identify and represent the health needs of the population;
- » apply situational strategic planning at the local level of health care, incorporating the dimension of equity.

Development of the process

The research team used parishes as the unit of analysis, with a view to encouraging reflection that was more in keeping with existing social networks. A total of 38 parishes took part in the research. In the five parishes with the greatest needs, the participatory analysis of key stakeholders (residents of the parish, communal councils, health councils, education team, health team, and so on) was established, with a view to the development of the plan.

Case study 3.6 contd

The first step was to identify the main health problems, relating them to the articles of the Venezuelan constitution which were not being fulfilled.

These problems provided the foundation for constructing flow-grams in participatory workshops. All the problems were situated according to their level of impact, with participants identifying them as centres of action, or highlighting the existence of political opportunities for action related to them. The critical nodes were then established through the Matus assessment matrix (2) and the stakeholders who controlled the variables of each critical node were identified.

Results and evaluation of the experience

The application of the situational flow-grams required the discussion and explanation of different aspects of reality from different viewpoints, which was achieved by looking in greater depth at the communicative dimension of the participatory approach used by this tool. Finally, the participants identified critical nodes such as: insufficient organization and community participation in health promotion actions; lack of articulation of actions within the different levels of health care; and lack of qualified human resources at some levels of care.

References

- 1. Heredia H, Harman E, Lopéz N, Useche J. Approaches to determine priorities and to analyze problems of health with a look from the equity: experience in the local level in Venezuela. Cienc Saude Colectiva 2011;16(3):1887–1898.
- 2. Matus C. El método PES: Planeamiento Estratégico Situacional [SSP method: situational strategic planning]. Mexico City: Fondo de Cultura Económica; 1996.

Further example of similar techniques or methods

Participación social en salud. Reflexiones y herramientas para la acción social en Chile [Social participation in health. Reflections and tools for social action in Chile]. Santiago: Ministry of Health of Chile; 2009 (http://www.redcimas.org/wordpress/wp-content/uploads/2012/08/m_MINSAL_MANUALdeSALUD.pdf, accessed 5 December 2014).

Strengths, weaknesses, opportunities and threats (SWOT) analysis

Participation criteria	Type of participants; effective inclusion; learning; degree of participation	
Components to evaluate participation	Inclusiveness; education; information	
Participation dimension	Participant selection methods	

Description and objectives

The SWOT method is a technique which essentially tackles the prospective capacity of social diagnosis; in other words, looking at operational strategies for the future based on an analysis of the present situation. The SWOT method involves organizing the information generated through a group dynamic into a dual-entry table, which situates this information in accordance with limitations (weaknesses and threats) and potential capacity (strengths and opportunities) provided by a social stakeholder or a certain situation.

Through the application of this technique, information is obtained about the positive and negative aspects of a specific context, both for the present and the future.

- » Strengths (S) are all the positive aspects which should be maintained or reinforced. These are the capacities or success factors of the stakeholder. From strengths, maintenance strategies can be developed.
- » Weaknesses (W) are the current requirements that imply negative aspects in need of modification. This refers to the stakeholder's limitations or internal self-critique. From weaknesses, correction strategies can be established.
- » Opportunities (O) are all the capacities or potential resources which should be harnessed and which are present in the stakeholder's surroundings. From opportunities, strategies for harnessing them can be identified.
- » Threats (T) include everything that entails potential risks and which must be prevented, but which do not depend on the action of the stakeholder; rather, they are external elements, originating from the environment. From threats, strategies to tackle them can be developed.

The identification of diagnostic factors corresponding to each conceptual space proposed by the SWOT analysis on the one hand, and the design of strategies linked to the items identified on the other, results in an analytical table (Table 3.3), which is useful for planning.

Table 3.3 SWOT analysis

	Dependent on the stakeholder	Dependent on the environment
Negative aspects	WEAKNESSES (used to design <i>correction strategies</i>)	THREATS (used to design <i>tackling strategies</i>)
Positive aspects	STRENGTHS (used to design <i>maintenance strategies</i>)	OPPORTUNITIES (used to design <i>harnessing strategies</i>)

Method

In a SWOT analysis approached in a participatory way, both the gathering of information and the analysis of the results obtained through this technique revolve around participant expression.

Initially, the technique should be applied separately for the different stakeholders involved in the situation being assessed (civil society, organizations, professionals, public representatives and so on). The objective of this first stage is to establish homogeneous diagnoses according to the problems and interests of the different stakeholders.

With the participants gathered together, the matrix is constructed using a graphic medium (a sheet of paper or card, or a board, for example), visible to everyone. To simplify proceedings, the process can start by highlighting positive and negative issues in the social reality of the stakeholder or social group, in relation to the situation studied, and then subsequently the items can be placed in their respective quadrants, seeking debate and consensus for each of them.

When the items drawn from the diagnosis have been placed in the different spaces on the matrix, if there are a very large number of items, they must be prioritized in order to discuss action strategies in relation to the most important ones, establishing for this purpose the necessary transformative actions. In a subsequent stage, the SWOT analyses drawn up by the different stakeholders should be shared with a view to reaching agreements about strategies that encompass as broad a set of actions as possible. Fig. 3.7 presents a simple depiction of this methodology, and Case study 3.7 describes the use of SWOT analysis to help reduce health inequalities among the Roma population in Spain.

Fig. 3.7 Methodological diagram for SWOT analyses



Further reading on the tool method

Kansas University Work Group for Community Health and Development. Community tool box. Chapter 3. Assessing community needs and resources. Section 20.

Implementing PhotoVoice in your community [website]. Lawrence (KS): University of Kansas; 2014 (http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/swot-analysis/main, accessed 5 December 2014).

Case study 3.7 Spain. Health and the Roma community. Spanish Ministry of Health: SWOT analysis

Background

In 2004 the Ministry of Health and Consumption and the Roma Secretariat Foundation reached an agreement to endeavour to reduce health inequality in the Spanish Roma community. The first step was to conduct an investigation into the social and health situation of the Spanish Roma population in order to determine its main needs (1).

Among other diagnosis tools, the technical team conducted a qualitative study based on a SWOT analysis.

Objectives

The main objectives of the agreement were to:

- » carry out an operational and consensual diagnosis which would provide key strategies and intervention factors with the Roma population from within standardized health services;
- » contribute to the promotion of active policies within the country's autonomous regions in order to improve equality of opportunities for the Roma people in relation to the use of community goods and services.

Development of the process

Given the scant information available to develop a diagnosis of situation regarding the Roma population and health in Spain, the Ministry of Health and Consumption and the Roma Secretariat Foundation set up a working group composed of social and health care professionals experienced in working with the Roma population, in order to carry out an initial diagnosis.

Based on the information obtained from the initial diagnosis, a national seminar was launched entitled "Equity in Health and the Roma Community", held by the Ministry of Health and Consumption. Academic and administrative organizations took part in the seminar, along with Roma collectives. The results of this debate took the form of a SWOT analysis, with a view to developing a specific policy to ensure equity in health for the Roma population.

Case study 3.7 contd

Results and evaluation of the experience

The participatory debate between stakeholders concluded with the establishment of lines of analysis and planning in the SWOT quadrants, which were then crystallized into a final diagnosis report. On the basis of the diagnosis conclusions, a series of relevant strategic actions were carried out, such as the first National Health Survey on the Roma population, in 2006, with a view to resolving the health care deficiencies and needs of the Roma population.

Reference

1. Fundación Secretariado Gitano, Spanish Directorate-General for Public Health, Spanish Ministry of Health and Consumer Affairs. Health and the Roma community. Analysis of action proposals. Madrid: Ministry of Health and Consumer Affairs; 2005 (http://www.msc.es/profesionales/saludPublica/prevPromocion/promocion/desigualdadSalud/docs/Health_and_the_Roma_Community.pdf, accessed 5 December 2014).

Further examples of similar techniques or methods

- Cicea C, Busu C, Armeanu E. The SWOT analysis of the Romanian health care system and the key elements for resources allocation. MRP 2011;3(3):32–41.
- National strategic framework for Roma. Athens: Hellenic Republic Ministry of Labour and Social Security; 2011 (http://ec.europa.eu/justice/discrimination/files/roma_greece_strategy_en.pdf, accessed 5 December 2014).

Planning Participatory budgeting

Participation criteria	Type of participants; effective inclusion; learning; understanding; information management; account-giving; time for discussion; types of agreements; conflict resolution; decision criteria; transparency; degree of participation; responsibility; norms; sustainability; control; funding; logistics
Components to evaluate participation	Inclusiveness; education; information; discussion; decision; institutional development; link with policy and political action
Participation dimension	Participant selection methods; modes of communication and decisions; authority and power

Description and objectives

Participatory budgeting is a participation, decision-making and management instrument for the prioritization of public spending in a specific area.

The main objective of participatory budgeting is the direct participation of individuals (both women and men) who belong to a community, with a view to establishing their main daily needs and including them in the annual public budgeting process, prioritizing the most important areas and monitoring the commitments made.

Among other things, it can: improve transparency in institutional management; increase the co-responsibility of the population in the management of resources and reporting in relation to institutional development; improve communication between a community and various institutions; and identify agreed solutions to the community's problems. Participatory budgeting is also compatible with gender-responsive budgeting.

Method

Participatory budgeting can be implemented using a variety of different methodological options, although a series of common stages are identifiable in most experiences.

Initially, it must be decided at administrative or institutional level which public resources should be made available to community debate on budget planning. These resources normally relate to public spending decisions in relation to investments or scheduling.

Having agreed which resources will be involved in the participatory process, the next stage is to raise awareness and inform the community, inviting them to participate in budgetary decisions relating to these resources. Although the main aim of this stage is to encourage participation, it is also usually supported by various training events, whereby technical staff explain the relevant structure and budgetary conditions relating to the resources on which the population will deliberate.

Running parallel to this informative process and with the aid of the technical team, a group of representatives from the community usually draws up the regulations governing the different stages of participatory budgeting: who can participate, how they can participate, how decisions will be made, and so on.

During the next stage, the participatory action of the population acquires even greater importance. Citizens' meetings are initiated, in which individuals or groups draw up public spending collectives which they consider urgent in the area under discussion. The different proposals are then opened up for collective deliberation across several sessions, setting the scene for the prioritization process. Prioritization involves establishing a list of proposals or demands from the community, in order of importance and urgency.

In consultation with the technical staff members of the administration, the proposals are shaped with a view to ensuring they are financially and technically viable. The viable proposals are then included in the institution's budgetary programme, allocating the resources required and establishing time frames for each of them.

Finally, the community chooses a set of representatives or delegates who, together with the institution, will be in charge of supervising and controlling the effective implementation of citizen demands. Fig. 3.8 shows clearly the basics of the methodology for participatory budgeting, and Case study 3.8 describes the participatory budgeting process employed in the Chilean West Metropolitan health service.

Fig. 3.8 Methodological diagram for participatory budgeting

Establishment of resources open to debate	Information and training in planning	Defining proposals and prioritization	Inclusion in the budget and monitoring of agreements
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Further reading on the tool method

Participatory budgeting in the UK – a toolkit. Second edition, January 2010. Manchester: Church Action on Poverty PB Unit; 2010 (http://www.pbpartners.org.uk/participatory-budgeting-toolkit-2010/, accessed 5 December 2014).

Case study 3.8 Chile. Participatory budgeting experiment in the West Metropolitan health service

Background

During the 1990s the Chilean Government initiated a process to decentralize services to regional entities, with a view to transforming styles of organization and management. These processes included the reform of health services. As part of this policy, at the end of 2007 the West Metropolitan Department of Health, together with the Department of Participation made the decision to develop a participatory budgeting process for health care in the commune of Melipilla, which had about 150 000 inhabitants (1).

Objectives

The objectives of the process were to:

- » carry out a training and operational pilot scheme, aimed at increasing the role played by the community in deliberations regarding the allocation of health resources, in a participatory way;
- » train the stakeholders involved in the area of public health and health policy;
- » identify health problems, establishing priorities and proposals for solutions;
- » improve satisfaction among health service users.

Development of the process

The first stage of participatory budgeting for health was to set up a technical-political committee to launch the initiative and prepare the administration for participatory inclusion in spending decisions.

A regional meeting was then held, open to participation by all citizen organizations in the area, with a view to informing and collectively debating the main health problems in the community. This meeting resulted in a list of 46 health problems deemed to be important by women and men from the community. After a series of further meetings, this number was reduced to 26 problems.

Results and evaluation of the experience

The participants from the community indicated a lack of health care establishments, along with a lack of specialized services (hindering referrals to hospitals for more complex treatment), and the increasing isolation of individuals in winter conditions as being the main priority problems. In addition, the participatory budgeting process also helped to create new relationship networks between technical staff from different areas, since some of the citizens' proposals demanded interdepartmental coordination, thereby generating greater comprehensiveness in terms of health care intervention with the population.

Reference

1. Ministry of Health of Chile. Participación social en salud. Reflexiones y herramientas para la acción social en Chile [Social participation in health. Reflections and tools for social action in Chile]. Santiago: Ministry of Health of Chile; 2009 (http://www.redcimas. org/wordpress/wp-content/uploads/2012/08/m_MINSAL_MANUALdeSALUD.pdf, accessed 5 December 2014).

Case study 3.8 contd

Further examples of similar techniques or methods

Participatory budgeting. Rio Grande do Sul: Porto Alegre Municipal Council on Health; 2014 (http://www2.portoalegre.rs.gov.br/op/, accessed 5 December 2014).

The people's budget. How participatory budgeting works. Manchester: Church Action on Poverty; 2015 (http://www.thepeoplesbudget.org.uk/what/howpbworks/, accessed 16 June 2015).

Your community, your health, your voice in Southampton. Thornhill: PB Network; 2014 (http:// pbnetwork.org.uk/your-community-your-health-your-voice/, accessed

Citizens' jury

Participation criteria	Type of participants; learning; understanding; information management; time for discussion; types of agreements; conflict resolution; decision criteria; transparency; responsibility; control; funding; logistics	
Components to evaluate participation	Education; information; discussion ; decision; link with policy and political action	
Participation dimension	Participant selection methods; modes of communication and decisions	

Description and objectives

The citizens' jury is a method developed by Professor James Fishkin of Stanford University. It is a consultative mechanism for citizen participation, based on the collective deliberation of a group of subjects selected randomly, to help with the making of certain public decisions.

For this purpose, a small group of people is chosen to discuss an issue over the course of a few days. Citizens' juries are inspired by the juries typically used in law courts. The difference between the two is based on two aspects: discussions are led by neutral mediators, and the jury simply issues a series of recommendations about the matters at hand, which makes them consultative, not binding.

In general, citizens' juries are deliberative bodies which draft political reports, helping to improve and facilitate the traditional process of decision-making. On occasion, the findings of citizens' juries are incorporated into reports about the issue at hand.

Method

The group of citizens that make up the jury (usually between 10 and 20 people) are chosen at random, or in accordance with sociodemographic criteria.

Once the subjects have been selected and informed of the internal logic of the citizens' jury, they are required to confirm that they agree to take part.

Before the jury is convened, the institution involved in the process, together with technical representatives from the administration draw up reports regarding the status of

the situation and the different options for the future. Similarly, technical impact reports should also be drawn up about the potential results of the jury's decisions. All this information is sent to the members of the jury before they meet, so they are as informed as possible regarding the nature of the issue and the potential implications of various alternatives.

A citizens' jury meeting normally lasts between two and four days. At the start, the moderator should introduce him/herself; this individual is responsible for informing the members of the jury how the process is to be carried out, the agenda and the format of the final ruling.

During the working sessions, the members of the jury are trained and given detailed information by the public administration's technical representatives or experts in the matter being discussed. It is important that that this information is diverse and can serve as the basis for sound judgement and decision-making on the part of the jury members. Relevant social organizations, political parties, companies and other collectives also put forward their demands to the citizens' jury, representing voices that contribute elements to the overall judgement, during the deliberation stage of the process.

Usually, various matters are put to the citizens' jury for its consideration, and the members work by combining sessions in small groups with plenary sessions in order to evaluate the decisions to be made.

The final ruling can be reached by means of an individual questionnaire, answered by each member of the jury, or by joint agreement. Fig. 3.9 provides a clear overview of the methodology for a citizens' jury, and Case study 3.9 describes the citizens' jury set up to help Leicestershire's ethnic minority population.

Fig. 3.9 Methodological diagram for a citizen's jury

Specification of
the decisions to be
reached by the jury
and jury designSelection of
participant and
convening processCollective debate
with experts and
stakeholders involvedFind
on c

Findings and report on decisions reached

Further reading on the tool method

Citizens jury handbook. Saint Paul (MN): Jefferson Center; 2004 (http://www.epfound. ge/files/citizens_jury_handbook.pdf, accessed 5 December 2014).

Case study 3.9 Leicestershire (United Kingdom). Leicestershire's ethnic minority citizens' jury

Background

In 2005 Leicestershire County Council (LCC) launched an investigation into the needs of the population's ethnic minorities. Based on prior experience with citizens' juries in the area (in relation to rural services, young people and disabled people), it was felt that a citizens' jury would be ideal for planning public action related to the integration of ethnic minorities (1).

Case study 3.9 contd

Objectives

The main objectives of the citizens' jury were to:

- » identify the main obstacles blocking the expansion of participation among ethnic minorities as fully fledged citizens;
- » give service providers the opportunity to gain a better understanding of the growing needs of resident ethnic minorities;
- » provide public service users with an effective space to raise demands and evaluate the various public services available.

Development of the process

The process took place over a series of stages, based on the LCC's prior experience in the organization of citizens' juries. Having carried out various collective dynamics, the main issues chosen for deliberation in the citizens' jury were: understanding ethnic diversity in Leicestershire; information and advice in relation to public services; and access to key public services by ethnic minorities.

The jury comprised 18 people. Before the deliberation process was initiated, a training day was held to create the right climate for cooperation and to inform the jurors of the objectives of the process and how it works. The deliberation process then took place over two days. Public and private stakeholders involved in the issue spoke at each of the themed sessions. Following the interventions on each subject matter, the jury asked questions, raised queries or voiced doubts, helping them with the decision-making process. In this way, debate and deliberation were brought together, giving rise to a final output in the form of a report and recommendations for an action plan.

Results and evaluation of the experience

One of the jury's main findings was that public entities were still too far-removed to be able to understand the public service needs of ethnic minorities. It was also concluded that both the solutions identified by the jury and those activated by the public entities themselves should be monitored to ensure fair access to health care and public services for the population, regardless of their background.

Reference

1. Leicestershire County Council. Leicestershire's black minority ethnic citizens' jury. A final report on the process and the outcomes. London: ECOTEC; 2006 (http://www.leicestershiretogether.org/bmecj_agreed_final_report_march_2006.pdf, accessed 5 December 2014).

Further examples of similar techniques or methods

Buckinghamshire Citizen's Jury. Learning and outcomes report. Dementia services. Aylesbury: Buckinghamshire County Council; 2011 (https:// democracy.buckscc.gov.uk/Published/C00000710/M00004795/AI00019093/ BuckinghamshireCitizensJuryLearningReportFinal6102011.pdf, accessed 5 December 2014).

Citizens' jury on health priorities 2010 – report by ACT Health Council. Canberra: Australian Capital Territory (ACT) Health Council; 2010.

Participation criteria	Type of participants; effective inclusion; learning; understanding; information management; time for discussion; types of agreements; conflict resolution	
Components to evaluate participation	Inclusiveness; education; information; discussion; decision	
Participation dimension	Participant selection methods; modes of communication and decisions	

Future workshop/Scenario workshop

Description and objectives

Future workshops or scenario workshops are very similar techniques. They both involve participants proposing descriptions of possible future scenarios, based on reflections related to the dynamic of events that occur, changes in relations between stakeholders, and any decisions stakeholders make over time. In the development of this technique, participants identify desirable futures and tackle proposals for change, so that the problem they are dealing with can evolve as desired.

Such workshops are usually used to analyse possible alternatives with regard to past or present situations that are viewed as negative. The basis for such analysis is often complex problems, situations where there is a high probability of change, or contexts in which the foreseeable future is deemed to be undesirable.

Method

In the initial preparation stage, a subject matter must be chosen for the workshop, and all the social agents involved in the problem are invited to participate in the workshop. Before the workshop takes place, secondary or contextual data should be compiled (economic, legal, cultural, administrative, and so on) to help document any reflections and discussion generated.

Once the workshop is under way, the first stage is to establish the main problems surrounding the issue for debate. Based on their personal experiences, the participants highlight the problematic aspects they perceive, using cards or similar formats. Depending on the number of participants, the formulation of problems can be carried out individually or in small groups.

Having mapped out the problems, the next stage is to tap into the creativity of the participants, with a view to establishing the potential capacities of the different stakeholders involved to resolve the problems identified, taking into account the real or potential resources available, and possible implications of any decisions that might be made. To do this, the degree of power or capacity to initiate change of each of these stakeholders must be specified, along with any present and future conflicts that might be generated between these social agents.

Having defined (a) the problems and (b) the structure of forces, the possible future or futures can be considered, starting with the definition of the scenario that most of the stakeholders feel is desirable, and then comparing it with the scenario that seems to be

likely or probable. If the two do not coincide, alternative scenarios must be designed. It is a good idea to work with opposing conceptual axes, describing situations that are desirable and those that are to be avoided, tracing out for each of these opposing scenarios the trajectories or routes to achieve them (for desired ones) or to neutralize them (for the ones to be avoided).

The result of a scenario workshop is usually crystallized in one or several maps or graphics, accompanied by a narrative description. These maps should reflect possible events and changes in relationships that will occur between the stakeholders involved. Furthermore, in relation to planning, future maps should incorporate trajectory indicators. These indicators act as an alarm or signal, if the future of the subject matter at hand is heading towards one scenario or another, with a view to adjusting interventions where required. Fig. 3.10 defines the methodology for the future workshop, and Case study 3.10 describes the use of scenarios to improve strategic collaboration in the United Kingdom's NHS.

Fig. 3.10 Methodological diagram for the future workshop

Choice of subject matter for debate, documentation and invitation to participate	Analysis of problems and capacity for change	Establishment of desirable and/or probable futures	Creation of scenarios and strategies to achieve them
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Further reading on the tool method

Valqui Vidal RV. Chapter 6. The future workshop. In: Valqui Vidal RV. Creative and participative problem solving – the art and the science. Lyngby: Technical University of Denmark; 2006:1–21 (http://www2.imm.dtu.dk/~rvvv/ CPPS/6Chapter6Thefutureworkshop.pdf, accessed 5 December 2014).

Case study 3.10 United Kingdom, National Health Service (NHS) North West. Using scenarios to explore opportunities for strategic collaboration between the social community sectors and the NHS

Background

In 2007 NHS North West embarked on a strategic planning process to design its health care policy. A prior diagnosis of the situation had identified a series of key changes within the context of health care, such as the progressive reduction of resources or the inability of traditional methods to care properly for an increasingly heterogeneous population with a growing presence of minorities. In order to tackle these challenges, questionnaires were designed using a bottom-up model; in other words, in which the population and social agents involved in the matter played a predominant role (1).

Objectives

The main objectives of the process were to:

- » generate a collective sense of the strategic dimension of health care planning;
- » develop different perspectives about short- and medium-term strategic orientation;
- » identify in advance any possible negative consequences of strategic plans at an early stage, with a view to adjusting priorities and programmes as necessary.

Case study 3.10 contd

Development of the process

The construction of scenarios took a total of 12 months. During the first three months of this process, data were collected about the characteristics participants considered to be desirable and wanted included in health care by the year 2020. For this purpose, over 100 interviews were conducted with NHS staff, doctors, local civil servants and representatives of citizens' organizations.

In stage two, five scenario-building workshops were held, each involving between 40 and 70 participants, who discussed 24 key questions compiled from the interviews held in the previous stage. Furthermore, to construct each scenario, strategic points were discussed, such as: which key characteristics define the scenario; how inequalities in health will be affected; which main roles will be transformed; who is responsible for making decisions; what impact the scenario will have on costs and resources; and so on.

Using the information gathered at the workshops, over the following six months, the scenarios were drawn up, detailed and tested in different contexts of health care.

Results and evaluation of the experience

The work carried out in the scenario workshops gave rise to an operational guide to health care which has laid the foundations for future work on the strategies defined.

Reference

 Duggan M, Pashley S. Using scenarios to explore opportunities for strategic collaboration between the social community sectors and the NHS in the north west. Report from a joint NHS/social sector workshop held 23–24 February 2009. Manchester: NHS North West; 2009 (http://www.vsnw.org.uk/files/Publications/Social_sector_Workshop.doc, accessed 16 June 2015).

Further examples of similar techniques or methods

Our shared future. Wetherby: Commission on Integration and Cohesion (Crown Copyright); 2007 (http://resources.cohesioninstitute.org.uk/Publications/Documents/Document/ DownloadDocumentsFile.aspx?recordId=18&file=PDFversion, accessed 5 December 2014).

South Somerset Together Partnership. Shaping south Somerset: a strategy for sustainable communities 2008–2026. Wincanton: South Somerset District Council; 2008 (http://www.southsomerset.gov.uk/media/15625/South_Somerset_Community_Strategy.pdf, accessed 5 December 2014).

Participation criteria	Type of participants; effective inclusion; learning; understanding; information management; account-giving; time for discussion; types of agreements; conflict resolution; transparency; degree of participation; responsibility; norms; sustainability; control
Components to evaluate participation	Inclusiveness; education; information; discussion ; decision; link with policy and political action
Participation dimension	Participant selection methods; modes of communication and decisions; authority and power

Participatory action research (PAR)

Description and objectives

PAR is a method that combines research, planning and socio-community intervention. Essentially, it aims to compile the demands of stakeholders involved in a process of

social action, with a view to transforming existing realities and helping the community to appropriate organizational resources (networks, proposals, actions) and knowledge (tools for analysis and self-diagnosis).

Its main aim is to construct, by means of participatory analysis, institutional programmes which involve citizens in both the design and subsequent development of such actions.

Method

PAR integrates different techniques and methodologies. Although a general guide to different stages and moments within PAR can be established, it is often not presented sequentially or in stages, but rather overlaps. It can begin with a moment of initial reflection for social programmes, or alternatively with reflections on socio-community interventions to redirect future action.

Stage 1: negotiation of demand and preliminary study

The aim of this first stage is to involve all stakeholders and to establish the objectives of the process. In contrast to other research approaches, the initial objectives are not fixed by the research team or the promoters of the initiative, but rather the community itself must establish which issues or problems require greater attention or priority action. In parallel to this task, a preliminary and provisional study must be conducted of the area and the population targeted by the study, with a view to contextualizing the community situation through secondary data (data on demographics, economics, urban planning, social structure, and so on).

Once this exploration has been carried out, structured feedback must be given to stakeholders in a systematized way, as occurs at all stages of this research. By means of successive approximations, this systematic feedback is a way of gradually obtaining a list of issues to be studied that are considered to be significant by the people involved (particularly the community).

Stage 2: self-diagnosis

The main objective of this diagnosis – developed by the stakeholders themselves with the assistance of the research team – is the critical analysis of problems considered to be a priority by the community subjects. Here, many of the techniques described in this toolkit, in relation with the diagnosis stage, can be brought into action. Self-diagnosis normally concludes with workshops or assemblies, whereby the research is summarized and, through collective reflection, future projects or actions are proposed.

Stage 3: programming and implementation of projects

This last stage entails programming and implementing an action plan. The work carried out during the research stage, and specifically the information obtained through workshops and reports, can be channelled through integral self-directed programming. Such programming develops a series of specific tasks to be carried out based on the timeline, planned budget and action groups that have materialized throughout the research process and which must act as driving forces behind the activities to be carried out. It is self-directed because it aims to structure and achieve cooperation among different groups in a series of actions, as citizen-centred and driven as possible, so that new forms of design and management can emerge with the aim of achieving permanence over time. Finally, it is also integral because it ties generator issues in with integral issues to be developed; it is not just the sum of problems which have emerged over the course of the process.

The ultimate objective is to create stable platforms that will invigorate the community, capable of executing, evaluating and giving feedback on the projects devised and launched.

Following the moment of collective reflection which evaluates transformative actions, the problem and starting situation can be re-appraised, leading to a new spiral wherein the issue tackled or other issues identified as being important over the course of the process open up a new cycle of reflection–action–reflection. Fig. 3.11 depicts the PAR methodology, and Case study 3.11 details the use of PAR to assess the health needs of the Roma population in Scotland (often referred to as the Gypsy/Traveller population in the United Kingdom context).

Fig. 3.11 Methodological diagram for PAR



Further reading on the tool method

Chevalier JM, Buckles DJ. Handbook for participatory action research, planning and evaluation. Ottawa: SAS2 Dialogue Inc.; 2013 (http://www.sas2.net/sites/default/files/ sites/all/files/manager/Toolkit_En_March7_2013-S.pdf, accessed 5 December 2014).

Case study 3.11 Scotland (United Kingdom). Voices from the north: exploratory needs assessment of Gypsy/Traveller communities in the north of Scotland

Background

Various studies conducted between 1990 and 2004 have demonstrated that the United Kingdom's Roma population suffers from very poor health, even in comparison with other underprivileged communities. The main problems identified include the lack of continuity in health care, deficient preventive health care, and the intolerant attitudes of health care staff. In this context, in 2005 Scotland's National Resource Centre for Ethnic Minority Health launched a pilot study using participatory methods to ascertain the health care needs of the Highlands' Gypsy/Traveller population (1).

Objectives

The main objectives of this project were to:

- » explore methodologies to engage Gypsy/Traveller communities in a health needs assessment;
- » carry out a pilot participatory health needs assessment.

Case study 3.11 contd

Development of the process

PAR was carried out for a period of nine months, to allow for sufficient time to develop bonds of trust and participation with the Gypsy/Traveller community, and also to involve Traveller communities with a seasonal (not permanent) presence in the territory. Together with community leaders, a series of workshops and events were held over several months, with a view to establishing the main health care needs of the Gypsy/Traveller community. The data generated led to a report for the NHS, and were also converted into information for use by the community itself and the social health care services.

Results and evaluation of the experience

The main key factors to improve their health identified by the Gypsy/Traveller population were: environmental factors related to basic sewerage services; protection against discrimination and prejudices in health care; the need for access to information about nutritional guidelines; and the need for information and help in preventing drug addiction.

This experience highlighted the importance of putting action at the heart of the process. The research findings were used to advise the NHS on its design of programmes, as well as the Community Health Exchange, local services and community organizations. The research conducted also highlighted the need to involve the Gypsy/Traveller community, which played a fundamental role in guiding the methodology and drawing up recommendations.

Reference

 National Resource Centre for Ethnic Minority Health. Voices from the north. Exploratory needs assessment of gypsy/traveller communities in the north of Scotland. Edinburgh: Health Scotland; 2007 (http://www.healthscotland.com/uploads/documents/7855-VoicesFromTheNorth.pdf, accessed 5 December 2014).

Further examples of similar techniques or methods

- Horton MM. The health and site needs of the transient gypsies and travellers of Leeds [website]. Leeds: Gypsy Roma Traveller Leeds; 2004 (http://www.grtleeds.co.uk/Health/transientStudy.html, accessed 5 December 2014).
- Improving engagement with the Roma community. Research report. London: Roma Support Group; 2009 (http://www.romasupportgroup.org.uk/documents/Roma%20Support%20 Group%20Research%20Report.pdf, accessed 5 December 2014).

Participation criteria	Type of participants; effective inclusion; learning; understanding; information management; time for discussion; types of agreements; Conflict resolution; decision criteria; transparency; degree of participation; responsibility; norms; sustainability; control; funding; logistics.	
Components to evaluate participation	Inclusiveness; education; information; discussion; decision; institutional development; link with policy and political action	
Participation dimension	Participant selection methods; modes of communication and decisions; authority and power	

Participatory strategic planning (PSP)

Description and objectives

PSP is a planning and management tool which aims to guide the endeavours of a community towards a desired future. Based on the principles of population participation

and consensus among stakeholders, viable community development projects are programmed in detail. Its principles are, therefore: participation as a method of organization and collective learning; monitoring of changes; the collective evaluation of achievements; seeking to create large spaces for synergies; and social articulation.

PSP is also integral in nature, as (at least in theory) it aims to encompass the multiple dimensions of the social, cultural, political, economic and ecological reality surrounding a problem.

Method

The participatory planning process essentially depends on the specific characteristics of the social context in which it is promoted and the issues tackled. However, a core methodological schema can be outlined.

All planning starts with a vision of how a community wants its future to be. The first step in PSP is to establish the community vision; in other words, the mental picture the population envisages for its future in the mid to long term. This vision, which constitutes the driving idea, will act as a backdrop to the entire process. It must be shared with as broad a cross-section of stakeholders as possible, so it is a good idea to implement some of the participatory techniques previously outlined in this toolkit, such as the future or scenario workshops. With the vision established, which in itself is usually general and relatively abstract, it must then be turned into a mission, which will be much more specific. The mission is the general objective pursued in the medium term (normally no longer than five years), and it must be achieved through the completion of strategic actions over the course of the planning process, allowing for the expected result to emerge.

The next stage involves establishing the current strategic positioning in the community situation. With the assistance of diagnostic tools, the present problem must be correctly described, and the stakeholders and social forces involved must be identified, along with the resources available and the existing or possible organizational models.

Having established guidelines to understand the present and glimpse the desired future, the next stage is to activate all actions pertaining to the strategic planning. This involves drawing up an action plan. First, this involves structuring the community mission into dimensions or specific objectives, and the participants and social agents must design actions to achieve each of these. Similarly, there must be a collective negotiation of the timeline (which links actions with time frames), and a feasibility analysis of each action (administrative, economic, organizational, and so on). A secondary objective of this negotiation or consensus agreement is to find synergies between the participants and the driving agents of the plan, to make the most of the resources present in the community and within institutions, with a view to achieving the objectives set.

Once the plan is in motion, the monitoring process begins. Actions must be monitored in a participatory way in order to verify achievements effectively and to allow for mutual account-giving between the stakeholders involved. Furthermore, the aim of this monitoring is also to spark debate around the possible introduction of adjustments or modifications to the plan on the basis of social or other change that might occur over time.

At the end of the process – but also running simultaneously to its implementation – participatory evaluation is carried out. Both the purpose and the execution of this evaluation should be participatory; in other words, the lessons learned should be useful not only for planning agents but also for the population involved in its operation as a community. Fig. 3.12 presents the methodology for PSP, and Case study 3.12 describes the use of PSP to empower minority communities in Albania.

Fig. 3.12 Methodological diagram for PSP



Further reading on the tool method

Bath P. Participatory strategic planning. A how-to guide for nonprofits. Aligning visions. Truckee (CA): Aligning Visions LLC; 2013 (http://www.aligningvisions.com/19.html, accessed 5 December 2014).

Case study 3.12 Albania. Empowering the vulnerable minority communities of Albania

Background

This project – launched in 2008 – is part of the UNDP. It emerged essentially from the deficient living conditions detected among ethnic minorities living in Albania, particularly the Roma and Egyptian populations. In this context, the programme known as "Empowering Vulnerable Local Communities of Albania" was launched, which focused on the local level, supporting Roma and Egyptian communities, as well as the central level, supporting the Ministry of Labour Social Affairs and equal opportunities in implementing and monitoring the National Roma Strategy (1).

Objectives

The main objectives of this programme were to:

- » increase and strengthen confidence, capacity and dignity;
- » reduce the social exclusion of vulnerable ethnic minorities in Albania, especially the Roma and Egyptian populations.

Development of the process

The project coordinated the activities of agencies working with vulnerable minorities and provided direct assistance to the poorest and most marginalized Roma communities at the local level (villages and quarters) in three regions of Albania: Tirana, Elbasan and Fier. The project activities directly assisted the communities by promoting participatory planning. Participatory development planning approaches supported the participation of vulnerable communities in local decision-making through the identification of priorities, the preparation of community development plans and the implementation of community development projects in partnership with local governments.

Case study 3.12 contd

Results and evaluation of the experience

The following common elements, among others, were identified in the PSP processes.

- » Specific actions are needed, aiming to provide specific training to medical and nursing staff working with ethnic minorities.
- » Regular consultation meetings should be held with Roma NGOs, with a view to working on priorities for this population segment in the period 2013–2017.
- » Awareness needs to be raised through meetings with Roma community members regarding how to approach respective local authorities when addressing issues related to urban waste, water supply and sewerage services.

The programme is also working in partnership with the Albanian Government and civil society to implement the National Roma Strategy in Albania.

Reference

1. Empowering vulnerable local communities – UN joint programme [website]. Tirana: United Nations Development Programme Albania; 2010 (http://www.undp.org.al/index. php?page=projects/project&id=201, accessed 5 December 2014).

Further examples of similar techniques or methods

- Review of EU framework national Roma integration strategies (NRIS). Open Society Foundations review of NRIS submitted by Bulgaria, the Czech Republic, Hungary, Romania and Slovakia. New York (NY): Open Society Foundations; 2012 (http://www. opensocietyfoundations.org/sites/default/files/roma-integration-strategies-20120221.pdf, accessed 5 December 2014).
- Youth participation in neighborhood planning for community health. Final report. Participatory planning with young people in the Brightmoor and Rosedale Park neighborhoods of Detroit. Detroit (MI): University of Michigan; 2010 (http://ssw.umich.edu/public/currentprojects/youthandcommunity/neighborhoodPlanningReport.pdf, accessed 5 December 2014).

Implementation *Co-management of health services*

Participation criteria	Type of participants; effective inclusion; learning; understanding; information management; account-giving; types of agreements; conflict resolution; transparency; responsibility; norms; sustainability; control; funding; logistics	
Components to evaluate participation	Inclusiveness; education; information; decision; institutional development; link with policy and political action	
Participation dimension	Modes of communication and decisions; authority and power	

Description and objectives

The co-management of health services is a specific way of structuring participatory spaces linked to the idea of community governance. Co-management involves the community and the different groups it comprises participating and cooperating under equal conditions with institutions in the management of public health services. This participatory resource seeks to increase the creativity, commitment and co-responsibility of community stakeholders in designing and monitoring health programmes.

Ideally, the co-management of health services should be the product of a PSP process. We have seen that participatory planning tools develop a series of areas for action. Within this sphere, co-management is often one of the working areas resulting from a participatory planning process, while also providing a coherent indicator of participatory management. The ultimate objective is to generate stable platforms and/or partnerships for collaboration on health care between a country's administration and civil society.

Method

A series of stages or steps is necessary for devising a model for participatory co-management.

The first step could be referred to as the preparatory stage. Here, the institutional level, together with social organizations, must evaluate the need to set up a co-management mechanism and whether it is technically and financially viable. It will be necessary (if it has not already been carried out in a prior planning process) to map out the social agents involved in or affected by the issue at hand and to contact them in order to set up preliminary meetings to specifically define the needs to be met and the services that will be co-managed. It is useful to apply participatory techniques for diagnosis or planning, such as those described in this toolkit.

The second stage involves negotiating the responsibilities of different stakeholders, defining the legal form of the co-management agreement and drafting rules of operation. This requires special technical assistance to ensure that the results of the participatory debate among the different stakeholders can be feasibly translated to a valid legal framework within the relevant legal context. Through various meetings and workshops, self-regulations must be developed to manage the chosen health services. To devise these self-regulations, each of the headings or points must be the subject of debate and collective deliberation, so that the final regulations fully reflect the achievements reached. Specifically, the rules of operation should detail the procedures followed, considering the competences of each stakeholder, the resources available to implement these competences, how to mediate potential conflicts, and the protocols for following up on actions.

The third stage entails implementing the co-management model. Processes are launched whereby the different stakeholders involved develop co-management protocols and continually reflect on the results generated, allowing for the re-introduction of new styles and agreed actions. To achieve this, regular meetings should take place with the community to evaluate the results and lessons learned during the process, modifying where necessary the conditions of co-management. Fig. 3.13 presents the methodology for the co-management of health services, and Case study 3.13 describes how community participation and co-management have been used by citizens' organizations in Peru.

Fig. 3.13 Methodological diagram for the co-management of health services

Preparation: participatory diagnosis of needs and management model	Negotiation drawing up self-regulations	Implementation development of management protocols	Regular monitoring
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Further reading on the tool method

Society of Hospital Medicine. A guide to building a co-management program. Philadelphia (PA): Hospital Medicine Organization; 2005 (http://www. hospitalmedicine.org/Web/Practice_Management/Co-Management/program_ building_guide.aspx, accessed 5 December 2014).

Case study 3.13 Peru. Local Health Administration Communities (CLAS)

Background

CLAS are citizens' organizations, promoted by Peru's Ministry of Health, which are made up of representatives of society. In 1993 the Peruvian Government launched the Shared Administration and CLAS Programme. The aim of this programme was to respond to the difficult situation Peru was facing following years of violent conflict and hyperinflation, which came to a head in the late 1980s and early 1990s. In this context, CLAS were developed with a new funding and management model for primary health care, with community participation as a key component of co-management (1, 2).

Objectives

The main objective of the CLAS is to improve the coverage and quality of primary health care services by means of community co-management.

Development of the process

The purpose and practicality of CLAS revolves around monitoring the management of primary health care services and helping to implement them, with a view to ensuring their quality. A formal contract signed by each CLAS and the Regional Department of Health in each area specifies the responsibilities pertaining to local health plans (PSL²). To this end, CLAS design, implement and evaluate the PSL on the basis of community consensus, detailing activities and annual health care targets. They also recruit and evaluate the staff working in health care facilities, and procure the goods and services required to run the PSL.

Every month, the CLAS present to the Department of Health reports justifying their spending and detailing their PSL progress, on the basis of which the Government authorizes the transfer of resources for the next month. Furthermore, every year, the accounts are reviewed and audited, and a report is submitted on the activities carried out. The Government provides funding, as well as advice for health care, legal issues, taxation and community participation, to members of the CLAS.

Results and evaluation of the experience

The implementation of the local health management model based on CLAS entailed the reorganization of health care administration. The model operates in the country's 24 regional departments. Currently, close to 3000 members of the community participate in the comanagement of health through CLAS, but it is estimated that over 6000 have participated since the start of the programme. The Peruvian Government has gradually expanded this health care funding and management model through CLAS and has even provided the opportunity to directly manage the resources assigned to over 1200 health facilities in the country.

References

- 1. Orientaciones para una conformación más participativa de las CLAS y su vínculo a los gobiernos locales, en un marco de Enfoque Basado en Derechos [Guidelines for a more participatory conformation of CLAS and its link to local governments, in the context of a rights-based approach]. Lima: CARE Peru; 2007 (http://www.bvcooperacion.pe/biblioteca/bitstream/123456789/2441/1/BVCI0001748.pdf, accessed 5 December 2014).
- 2. Díaz RM. CLAS: Una experiencia para descentralizar servicios de salud [CLAS: an experience to decentralize health services]. Semanario Gestión Médica 2001;6(226):18–19.

² Spanish acronym.

Case study 3.13 contd

Further examples of similar techniques or methods

Ford R, Angermeier I. Creating a learning health care organization for participatory management: a case analysis. J Health Organ Manag. 2008;22(3):269–293.

Mbengue CSA, Tingbe-Azalou A, Omyale P. Health zones, co-management, and decentralization in Benin (Technical Report No. 52). Bethesda (MD): Partnerships for Health Reform Project, ABT Associates Inc.; 2000 (http://pdf.usaid.gov/pdf_docs/ Pnacm262.pdf, accessed 5 December 2014).

Friendly hospital

Participation criteria	Type of participants; effective inclusion; control; funding; logistics
Components to evaluate participation	Inclusiveness; education; link with policy and political action
Participation dimension	Modes of communication and decisions

Description and objectives

The friendly hospital is a model of intervention in hospitals aimed at minority groups (ethnic minorities, migrants, groups that are discriminated against, and so on). The main objective is to ensure the suitability of communication and health care protocols to encourage these groups to cooperate in the area of health care and, thereby, improve the state of their own health.

In these processes, the participation of the target community is fundamental, so that hospitals can correctly assess their needs and tailor their communication accordingly. The cooperation of community-based social organizations in implementing the model allows a receptive vision of hospitals to be generated by these minority population groups, who will also act as advisors and bridge the communication gap between hospitals and subjects.

Method

The development of friendly hospital models normally begins with an internal evaluation of the health care institutions that drive the process, to determine the main problems faced when treating and communicating with target population groups. During this preliminary stage, it is also useful to gather secondary data to contextualize the population in sociodemographic terms and establish the most commonly found clinical profiles.

Having determined internal needs, different social organizations linked to the target community and individual subjects belonging to these communities (health care service users, patients, carers, and so on) are invited to take part in the project. Through the application of participatory diagnostic techniques, the aim of this stage is to assess the main health care needs of the population and the problems they express in their everyday dealings with health care staff. The diagnostic process should establish at least the following issues:

- » the main health risks in the community
- » priority health care areas that require intervention
- » early action protocols
- » prevention measures
- » elements of cultural diversity related to health
- » requirements regarding the communicative competence of health care staff.

During the diagnostic process, a coordination and monitoring group is usually set up, consisting of community organization representatives, health care policy leaders and medical professionals. This group acts as a regular communication channel between hospital institutions and the community. With the results of the diagnosis, various preparatory actions are carried out, alongside training and the design of communication strategies tailored towards the target population.

The next stage is to implement the model, which is usually carried out internally within the different health care departments of the hospital institution, or through the creation of intercultural mediation services. In the latter case, the service can depend on the hospital itself or can be implemented by establishing partnerships with community organizations linked to the target population. Fig. 3.14 details the methodology for the patient-friendly hospital, and Case study 3.14 describes the process followed to introduce migrant-friendly health centres in Catalonia.

Fig. 3.14 Methodological diagram for the patient-friendly hospital



Further reading on the tool method

European Commission. The migrant-friendly hospitals project – in a nutshell. Vienna: Ludwig Boltzmann Institute for the Sociology of Health and Medicine (WHO Collaborating Centre for Hospitals and Health Promotion); 2005 (http://www.mfh-eu. net/public/home.htm, accessed 5 December 2014).

Case study 3.14 Catalonia (Spain). Evolution towards migrant-friendly health centres

Background

This is a collaborative project launched in June 2003 with the participation of the health care association entitled Asociación Salud y Familia and the public health care system in Catalonia. The Asociación Salud y Familia is an NGO which designs and promotes models to improve the accessibility and use of health services, targeting vulnerable groups, such as migrants in socially and culturally disadvantaged positions *(1)*.

Five hospitals and 18 primary health care centres took part in the project, mostly in areas with a strong presence of ethnic minorities and migrants, with both legal and illegal status.

Case study 3.14 contd

Objectives

The main objectives of the project were to:

- » improve general conditions for the provision of health care to the migrant population;
- » increase the availability of culturally adapted services;
- » improve communication by breaking down language and cultural barriers between health care staff and migrants;
- » increase the appropriate use of services and the level of satisfaction among patients from the migrant population.

Development of the process

Certain sequences of events were followed for the development of this project in different hospitals and health care centres.

The first task was to assess the internal needs of the centres with regard to the intercultural adaptation of health care services and protocols. Then, coordination groups were set up, comprising health care centre professionals and community organizations, with a view to sharing knowledge, experience and behavioural guidelines in order to improve the quality of care provided to the migrant population. Finally, intercultural mediation units were set up to advise hospital institutions and guide the migrant population in meeting their health care needs. The profile of these intercultural mediation units has been raised, making them more visible in health care centres and in areas with significant foreign populations.

Results and evaluation of the experience

The health care centres taking part in this project actively use around 30 mediators from community organizations, which cover areas with a strong presence of migrants from Latin America, North Africa, Pakistan, Romania and China, and give direct support to 100 000 migrant patients. The project is working towards the intercultural adaptation of information and health education materials. It has also begun to review procedures that generate intercultural conflict, and some of the participating centres plan to incorporate ethnic minorities into their new staff recruitment plans.

Reference

1. Immigration and health area [website]. Barcelona: Asociación Salud y Familia; 2013 (http://www.saludyfamilia.es/en/immigration-health/from-compatriot-to-compatriot, accessed 5 December 2014).

Further examples of similar techniques or methods

Baby-friendly hospital initiative [website]. Geneva: World Health Organization; 2009 (http://www.who.int/nutrition/topics/bfhi/en/, accessed 5 December 2014).

Mendez E. Evolution towards migrant friendly health centers. Paper presented at the 16th International Conference on Health Promoting Hospitals and Health Services, Berlin, 14–16 May 2008. Barcelona: Asociación Salud y Familia; 2008 (http://www.ausl.re.it/ HPH/FRONTEND/Home/DocumentViewer.aspx?document_id=238, accessed 5 December 2014).

Participation criteria	Type of participants; effective inclusion; control; funding; logistics
Components to evaluate participation	Inclusiveness; education; information; decision; institutional development
Participation dimension	Modes of communication and decisions

Health mediator programmes

Description and objectives

Health mediator programmes offer an intervention resource aiming to facilitate communication and dialogue between minority groups and public authorities, with a view to improving or tailoring health for these groups. This tool refers to a job profile with a series of specific skills, rather than a community process.

The important participatory element in this case is the prominent role of agents linked to the community as mediators. From this position, perceptions, opinions and behaviours of the minority population can be considered when implementing health services. Consequently, the mediator acts as a bridge between the minorities and the social and health services.

Method

The first step when creating health mediator programmes is for the health authorities to detect problems in their interaction with minorities or specific populations.

Having identified the places and areas in which there are real or potential conflicts in health (in terms of reproductive health, preventive health care, primary health care, and so on), the next stage focuses on designing a training plan for community health care mediators.

In practice, these training plans can be very different in format. Some cases incorporate training into official education programmes and others design specific training activities outside the traditional academic sphere. Some training receives public funding, while other programmes are funded privately or by foundations. The content of training sessions is usually focused towards medical issues, specifically concentrating on concepts and protocols applied to different areas of health care provision in which special mediation needs have been detected. The training also often introduces content aimed at providing mediators with communicative skills, with a view to designing adequate formats or strategies for communication with the community. Training pathways, which normally aim to be comprehensive in their approach, bring a range of different social agents on board as teachers/trainers: these include researchers, medical and nursing staff, experts in ethnical issues and minority populations, representatives of the public health system, and also citizens' organizations linked to the minority populations being targeted by the mediation work.

Specifically, the main functions of a health mediator are to:

- » advise minorities about how to obtain the administrative documentation they need to access health care cover;
- » raise awareness about the importance of preventive health and the need to visit health care services to resolve health problems;
- » direct people towards the appropriate health services in each case;
- » act as a translator for medical professionals in order to overcome language barriers;
- advise local health authorities to launch campaigns or informative activities aiming to reach minority communities;
- » develop health education programmes with communities;
- » provide legal assistance to people who have suffered discrimination of any kind within the heath context.

Following training, the programmes are then implemented. At this point, two recommendations should be established, which will largely determine the success of these programmes. First, by including a significant number of members from the minority communities in the team of mediators, it is easier to achieve greater community involvement in resolving the issues at hand. Second, if health mediator programmes are implemented in conjunction with other programmes that aim to reduce poverty or discrimination, the outcomes tend to be much more successful. Fig. 3.15 shows the methodology for health mediator programmes, and Case study 3.15 describes how the position of Roma Health Mediator was introduced into the health care system in Romania.

Fig. 3.15 Methodological diagram for health mediator programmes



Further reading on the tool method

Mediating Romani health. Policy and program opportunities. New York (NY): Open Society Institute; 2005 (http://www.opensocietyfoundations.org/sites/default/files/roma_health_mediators.pdf, accessed 5 December 2014).

Case study 3.15 Romania. Roma Health Mediation Programme

Background

Romania was the first country in eastern Europe to launch a health mediation programme aimed at the Roma population. In 2005 a study conducted by the National Agency for Roma in collaboration with the World Bank established that about a million Roma people were living in compact communities in Romania. This minority presented by far the worst health results of the country's population.

In this context, in August 2002 the Ministry of Family and Health passed a decree that made Roma Health Mediator an official profession within the Romanian public health system (1, 2).

The main objectives of the Roma Health Mediation Programme were to:

- » improve the access of Roma communities to preventive and health care services;
- » offer employment to Roma women, within their community;
- » fight discrimination by emphasizing social participation;
- » increase the knowledge of Roma communities in the field of health promotion, focusing particularly on child and family health, highlighting the importance of education;
- » foster active cooperation and involvement of the community in implementing national policies and programmes in the field of health care.

Development of the process

The programme started in October 2002 and had two main components: first, training health mediators through a partnership between the Ministry of Health and Romani CRISS (an NGO that is partially owned by the Roma population), and second, developing the activities of the health mediators. According to a ministerial decree, all mediators must be trained and certified by Romani CRISS.

Case study 3.15 contd

Results and evaluation of the experience

One of the keys to the success of this social intervention is that the first step – the basic training – was developed by Roma specialists; hence, the Roma population was involved from the very start of the programme.

The main activities carried out by the mediators were: facilitating communication between patients and medical staff; advising on bureaucratic processes with the Roma population in order to ensure their medical assistance; and carrying out community work with the population in order to encourage prevention in health care and to improve access to the health care system.

In 2008 about 700 health mediators took part in the programme, and the resources allocated to it have increased tenfold since the start.

References

- Roma health mediation in Romania: case study. Copenhagen: WHO Regional Office for Europe; 2013 (Roma Health Case Study Series No. 1) (http://www.euro.who.int/en/ publications/abstracts/roma-health-mediation-in-romania, accessed 19 June 2015).
- 2. Gheorghiu V, Dumitra G, Domiloiu AM. Involving the Roma health mediators in the national program for immunization in the Roma communities in Romania. Presentation poster for ECDC consultation meeting "Inform, protect, immunize: engaging underserved populations" in Dublin, Ireland, 4–6 September 2012. Solna: European Centre for Disease Prevention and Control; 2012 (http://ecdc.europa.eu/en/press/events/Documents/ Romania-Involving-Roma-Health-Mediator-into-national-program-immunization-Roma. pdf, accessed 19 June 2015).

Further examples of similar techniques or methods

- Roma health mediators: successes and challenges. New York (NY): Open Society Foundations; 2011 (http://www.opensocietyfoundations.org/sites/default/files/roma-health-mediators-20111022.pdf, accessed 5 December 2014).
- Training of Roma health mediators in reproductive health. Bucharest: JSI Research & Training Institute Inc.; 2005 (http://romania.jsi.com/Docs/rfhi_rhm_training_rh.pdf, accessed 5 December 2014).

Monitoring Participatory monitoring

Participation criteria	Type of participants; effective inclusion; learning; understanding; information management; account-giving; degree of participation; responsibility; sustainability; control; logistics
Components to evaluate participation	Inclusiveness; education; information; discussion
Participation dimension	Participant selection methods; modes of communication and decisions

Description and objectives

Participatory monitoring involves critically monitoring programmes or plans through the active involvement of the community. This process represents a continuation of participatory diagnosis and planning, although it can also be used even if previous stages have not been constructed or carried out in a participatory way. The fundamental objective of this method is to verify the programmes set in motion and to adapt them according to the results, based on the reflections of the stakeholders involved.

Method

The first task in participatory monitoring is to involve all the stakeholders or social agents who were involved in the planning stages and are present in the implementation of the projects. The participatory spaces created for monitoring can be formal or informal, but it is advisable to set up a body that is recognized for this purpose by both the community and the institutions involved. In many cases, this body is set up as a monitoring committee, the first meetings of which usually focus on training the members. The aim of this introductory process is for the stakeholders involved to gain the knowledge and skills they need in relation to the legal, technical and budgetary factors of the health policies being monitored.

Having activated mutual cooperation and established the necessary competences required, the next step is to define the elements of the project(s) to be monitored. These can be activities, services, products, and so on. By defining these elements operationally, different instruments or devices can be designed to record information.

This marks the start of data gathering, which aims to systematically compile the experiences of the community alongside the projects and, above all, to record the changes taking place as a result of the actions developed. Furthermore, during this stage, participatory methods should also be used to design indicators capable of registering the progress of the actions initiated. This task can be carried out using a wide range of techniques: workshops, public forums, local meetings, health facility surveys, community visits, social budget audits, and so on.

Regardless of the technique used, the content recorded should focus mainly on the community's assessment of the services or actions carried out, and the suitability and allocation of technical and human resources, highlighting in both cases the achievements made and the difficulties encountered. This information can be gathered at a specific point of the process, although it is advisable to gather information periodically throughout, in order to register any changes over time.

Once the information has been systematized, it is time for collective reflection and debate, aiming to assess effective changes in the community's quality of life that are linked to the implementation of the project. It is advisable to draw up a report based on this data analyses to present to the authorities responsible for the different projects, together with a participatory action plan to resolve any problems identified.

Given that monitoring is periodic in nature, once these tasks are completed, a new round of information gathering and analysis should be initiated to assess changes in relation to the most recent monitoring cycle. Fig. 3.16 presents the methodology for participatory monitoring, and Case study 3.16 describes the results of a meeting report from a gathering of practitioners discussing community monitoring for accountability in health.

Fig. 3.16 Methodological diagram for participatory monitoring



Further reading on the tool method

Barreto Dillon L. Participatory monitoring and evaluation [website]. Basel: Sustainable Sanitation and Water Management Toolbox (Seecon International); 2013 (http://www.sswm.info/category/planning-process-tools/ensuring-sustainability/tools-ensure-sustainability/ensure-sustain-0, accessed 11 June 2015).

Case study 3.16 Open Society Foundations (OSF). Practitioners convening on community monitoring for accountability in health: participant experiences in community monitoring

Background

This example is not a specific experience, but rather reflects the main components of a report conducted within the framework of the meeting on community monitoring in health, which took place in Johannesburg, South Africa, in July 2011. The report was drawn up by the Accountability and Monitoring in Health Initiative of the OSF's Public Health Program, in collaboration with an advisory group of experienced practitioners. The findings of the report are based on the analysis of semi-structured questionnaires completed by 21 organizations in Africa, the Americas and Asia (1).

Objectives

The main objective of the report was to reflect different experiences, approaches and methodologies used in the implementation of participatory monitoring in relation to health initiatives.

Development of the process

The most frequent objective when setting up a participatory monitoring initiative in health was – in the opinion of the organizations involved – to improve public health services and enhance communication between public administration and the community.

When defining the participatory monitoring processes, the authorities collaborated on the one hand in training and on the other by providing the documentation required by the organizations responsible for monitoring, as well as legal and technical assistance in collective reflections.

A wide variety of data gathering and analysis techniques were used: score cards, for users of health services to rate the quality of these services; interviews with community leaders and participants; analysis of health intervention records; focus groups; analysis of communicative media; and so on.

Results and evaluation of the experience

Monitoring processes improved the response capacity of the authorities, owing to citizen vigilance, while also increasing mutual trust through the experience of working together. The more negative aspects of the process included a significant percentage of responses that alluded to the excessive amount of time spent monitoring, and the difficulty encountered in involving the most marginalized populations in the process.

Case study 3.16 contd

Reference

 Practitioners convening on community monitoring for accountability in health: participant experiences in community monitoring. New York (NY): Open Society Foundations; 2011 (http://health.accel-it.lt/assets/110718%20Johanesburg/Synthensis%20of%20 Practitioner%20Experiences%20in%20community%20monitoring.pdf, accessed 5 December 2014).

Further examples of similar techniques or methods

- Goverment of Croatia Office for National Minorities. Summary report on the workshop on participative monitoring & evaluation of the national programme for Roma, Zagreb & Čakovec, 11–12 February 2005. Strasbourg: Council of Europe Roma and Travellers Division Migration and Roma Department; 2005 (http://www.coe.int/t/dg3/ romatravellers/archive/stabilitypact/activities/croatia/participativemonitoring05_en.asp, accessed 5 December 2014).
- Kropiwnicki ZDS, Deans F. Mapping the terrain: exploring participatory monitoring and evaluation of Roma programming in an enlarged European Union. Oxford: International NGO Training and Research Centre; 2006 (Occasional Paper Series No. 47) (http:// www.intrac.org/data/files/resources/405/OPS-47-Mapping-the-Terrain.pdf, accessed 5 December 2014).

Participatory health councils

Participation criteria	Type of participants; effective inclusion; learning; understanding; information management; account-giving; time for discussion; types of agreements; conflict resolution; decision criteria; transparency; degree of participation; responsibility; norms; sustainability; control; funding; logistics
Components to evaluate participation	Inclusiveness; education; information; discussion; decision; link with policy and political action
Participation dimension	Participant selection methods; modes of communication and decisions; authority and power

Description and objectives

Participatory health councils are citizen participation bodies that advise health authorities on management-related aspects: informing, proposing, promoting, consulting, evaluating and decision-making. These councils usually comprise members of citizens' organizations, volunteer groups, groups of users or patients, technical staff members of the administration and political leaders, although there are often channels set up to encourage the participation of individual members of the public.

The functions performed by such participatory councils include: drafting reports about the health needs of the population for decision-making; monitoring health care services from an executive perspective; setting up local strategic partnerships; implementing publicity or health information campaigns; and organizing community events related to public health.

Method

In order to set up a participatory health council, various issues must first be addressed.

The first element to be taken into consideration is representation, in terms of the internal composition of the council. Criteria must be established to integrate different dimensions of civil society into the participatory health council, along with groups that have traditionally been excluded from accessing health services. Opting for a corporate criterion (only representatives of formal organizations; the most common approach) can be exclusive. It is important to remember that councils do not replace the citizen movement; rather, one of their key functions is to promote it. As well as including citizens' organizations working in the health field, multiple alternatives exist to open up participation to non-organized segments of the population (that is, the general public). Forums, assemblies and other participatory mechanisms can be set up, offering structures that allow citizens to participate regularly at all levels. In addition to citizens' organizations and the aforementioned non-organized civil society, the council must also include representatives of health services and centres, alongside the institutional authorities responsible for health policy.

The second issue to be tackled is how to design internal participatory procedures to allow the council to debate and make decisions. Here, working dynamics should be created that allow for cooperation and consensus in decision-making, rather than implementing decision-making models based on majorities. Decision-making based on consensus is desirable because the actions of the council must focus on dealing with priority health needs, regardless of whether they pertain to the majority or not.

A third aspect to consider when designing participatory health councils is the issue of training. In many cases, people who represent the most underprivileged sectors of the population (ethnic minorities and marginalized groups, especially women) have a lower level of education than other participants in the councils, which often leads to an imbalance in the participants' technical knowledge and how they deal with information. It is therefore important to run training programmes for all participants in order to allow a horizontal debate to develop under equal conditions.

A fourth element is the council's degree of influence in public decisions; in other words, its executive capacity. If the participants can only be informed or consulted by the authorities with regard to health policies, without any capacity to make binding decisions, experience indicates that these bodies tend to lose effectiveness over time. In contrast, if the participatory decisions made by councils are binding, the involvement of individuals from civil society usually increases significantly.

One final issue to take into consideration is sustainability. Given that, by nature, participatory councils are linked to public action, they should be integrated into the legal or organic framework of the institution responsible for the area in question, so that their existence does not depend solely on political will, but rather is the result of permanent institutional commitment. Fig. 3.17 details the methodology for participatory health councils, and Case study 3.17 describes the designing of a citizen participation model as part of the strategic health plan in the Castilla-La Mancha region of Spain.

Fig. 3.17 Methodological diagram for participatory health councils



Further reading on the tool method

Coelho VSP. Brazil's health councils: the challenge of building participatory political institutions. IDS Bull. 2004;35(2):33–39 (http://r4d.dfid.gov.uk/PDF/Outputs/CentreOnCitizenship/1052734356-coelho.2004-brazil.pdf, accessed 5 December 2014).

Case study 3.17 Castilla-La Mancha (Spain). Designing a citizen participation model to launch a participatory health council

Background

In 2001 the regional government of Castilla-La Mancha developed a strategic health plan to put citizens and users at the heart of the health system. To do this, it designed a system of health councils with progressive territorial and thematic decentralization: Castilla-La Mancha Health Council, Castilla-La Mancha Health Service Administration Council, Healthcare Area Councils and Basic Healthcare Area Councils (1).

Objectives

The main objectives of the plan were to:

- » improve the channels of citizen participation, increasing their effective participation and their decision-making capacity in the public health system;
- » implement channels of communication between health services, health service users, social and professional organizations to encourage and invigorate citizen participation.

Development of the process

To design the plan in a participatory way, two major participatory meetings were set up with citizens to discuss the health system, along with five focus groups involving health professionals and representatives of social organizations. The result of all discussions was that a new regional health model was launched, adding three participatory bodies to the existing structure of participation.

- 1. The Participatory Health Area Forum allows for direct participation in each area of health. It is further divided into a Plenary Assembly and a Forum Council. Citizens attend the Plenary Assembly, bringing with them general interest proposals of a budgetary nature. The Forum Council then debates and coordinates all these proposals.
- 2. The second new body is the Participation and Administration Council, which prioritizes the citizens' proposals that emerge from the aforementioned Participatory Health Area Forum. It is made up of members of the forum, along with those in charge of management, and various institutional representatives. The proposals are then incorporated into the region's annual budget bill.
- 3. Finally, the third new element is the Regional Virtual Health Forum, which is the main channel for individual participation, using a webpage to compile proposals and suggestions, referring them to the Plenary Assembly of the corresponding Participatory Health Area Forum.

Results and evaluation of the experience

The programme was launched with a pilot scheme in the small town of Puertollano, enabling citizens to present health proposals (78 proposed the first year), prioritize the actions and investments of local health services and monitor the decisions made.

Case study 3.17 contd

Reference

 Bleda JMG, Santos AG, Carretero CF. Diseño de un modelo de participación ciudadana en salud en la Comunidad de Castilla-La Mancha e implementación del mismo en el Área de Salud de Puertollano (2005–2008) [Design of a citizen participation in health in the community of Castilla-La Mancha and implementation of it in the health care area of Puertollano (2005–2008)]. Revista de Administración Sanitaria 2008; Siglo XXI 6(4):699–714.

Further examples of similar techniques or methods

- A stronger local voice: a framework for creating a stronger local voice in the development of health and social services. A document for information and comment. London: United Kingdom Department of Health; 2006 (http://webarchive.nationalarchives.gov. uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@ dh/@en/documents/digitalasset/dh_4137041.pdf, accessed 5 December 2014).
- O Conselho Municipal de Saúde [The Municipal Health Council] [website]. Rio Grande do Sul: Porto Alegre Municipal Council on Health; 2014 (http://www2.portoalegre.rs.gov.br/ cms/, accessed 5 December 2014).

Health service users' ombudsman/-woman (HSUO)

Participation criteria	Type of participants; information management; transparency; responsibility; norms; control; funding; logistics
Components to evaluate participation	Inclusiveness; information; link with policy and political action
Participation dimension	Modes of communication and decisions; authority and power

Description and objectives

Patient ombudsmen/-women are not strictly speaking a participatory method, but rather figures who mediate and allow for participatory monitoring elements to be introduced into health services.

HSUOs, present in many EU countries, are 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 in public health services.

Method

To design the profile of an HSUO, which incorporates participatory functions, a series of conditions must be met. First, a decision must be reached regarding which social or institutional agents are held accountable to this figure. Although this individual is usually situated within a public department, the HSUO must be an independent authority. Therefore, the reports of her/his activity must be submitted, both to institutions and the community. This requirement for independence also includes the need for technical, administrative and financial facilities to carry out this function.

Having met these stipulations of operation, the tasks most frequently carried out by the HSUO include:

- » dealing with complaints, claims and suggestions presented by health service users;
- » formulating suggestions to improve user services;
- » ensuring the effective development of citizen participation mechanisms in the health system;
- » mediating between health system users and the authorities in the event of conflict;
- » informing users on the range of health services available and the administrative procedures linked to them;
- » advising minority groups to guarantee their health care and that they use the health services available;
- » reporting discriminatory action by institutions or health care staff.

In order to guarantee community participation in the development of HSUO activity, this figure often oversees a series of participatory initiatives.

One such action is to regularly visit citizens' organizations that represent or work with minority groups, or those who have difficulty exercising their health care rights. In extreme or particularly complex situations, the HSUO can represent these groups as part of her/his health care mediation work.

Another common participatory initiative is the organization of community meetings or consultations, in order to guarantee that marginalized populations can assess the health services they use.

Finally, in some situations, the HSUO develops platforms or consultation councils, which represent the main segments of the population, to consult with health care staff and the authorities within these HSUO collaborative bodies. Fig. 3.18 shows the methodology for the HSUO, and Case study 3.18 describes the role of the Ombudsman for Minorities in providing local advisory and support services for minority populations in Finland.

Fig. 3.18 Methodological diagram for the HSUO



Further reading on the tool method

Health advocacy framework. Strengthening health advocacy in Queensland. Brisbane (QLD): Health Consumers Queensland; 2011 (http://www.health.qld.gov.au/hcq/publications/hcq_framework_may11.pdf, accessed 5 December 2014).

Case study 3.18 Finland. Ombudsman for Minorities of Finland: local-level advisory and support services for ethnic minorities, migrants, Sami and Roma people

Background

In 2006 Finland introduced the Governmental Migratory Policy Programme. One of the measures approved through this plan was the active support of services to defend victims of discrimination or racism. Another measure was based on the idea of delegating to the areas responsible for basic population services (including health) the task of creating good practices at both local and state levels to reduce racism and discrimination. These good practices included the role of Ombudsman for Minorities, which carried out a study demonstrating the need to create local advisory services to defend against discrimination for ethnic minorities, particularly the Roma community (1, 2).

Objectives

The main objectives of the Ombudsman for Minorities in this project were to:

- » collaborate with the municipalities;
- » offer advice on situations in which discrimination is identified in core public and private services.

Development of the process

As part of the project coordinated by the Ombudsman for Minorities, three participatory meetings were held, focusing particularly on issues relating to the Roma community. Each of these meetings focused on one particular issue, respectively: tools to recognize discrimination; problems relating to accommodation and housing; and cooperation between Roma organizations with advice on the matter of discrimination. Based on the information gathered at these meetings, a plan was conceived to define the contents and working methodology of future local advisory services designed to defending against discrimination of ethnic minorities.

Results and evaluation of the experience

The participatory meetings helped, among other things, to create a foundation for developing advisory services to defend against ethnic discrimination at local and regional levels. Furthermore, various areas were identified for specific attention: creating collaboration networks by contacting members of the Roma community; acquiring detailed knowledge of settlements; generating stable spaces for dialogue between the different social agents involved; developing local action protocols against discriminatory behaviour; creating online advisory and reporting mechanisms; scheduling planning processes in accordance with equity principles; and implementing training programmes to prevent discrimination (aimed at professionals in the core services sectors).

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- 2. Regional development of anti-discrimination advisory services. Experiences from the implementation of advisory services and results on the identification and tackling of discrimination. Helsinki: Ombudsman for Minorities; 2011 (http://yhdenvertaisuus-fi-bin. directo.fi/@Bin/f084f7c013319f025a1f3cf1a4cecc81/1358879193/application/pdf/200534/ Alueellinen%20neuvonta_englanti.pdf, accessed 5 December 2014).

Further example of similar techniques or methods

Roma rights. Discrimination, paths of redress and how the law can improve the situation of Roma. Stockholm: Swedish Equality Ombudsman; 2011 (http://www.do.se/Documents/ sprak/english/Roma%20rights.pdf, accessed 5 December 2014).

Participation criteria	Type of participants; effective inclusion; learning; understanding; information management; account-giving; time for discussion; types of agreements; conflict resolution; decision criteria; transparency; degree of participation; responsibility; norms; sustainability; control; funding; logistics
Components to evaluate participation	Inclusiveness; education; information; discussion; decision; institutional development; link with policy and political action
Participation dimension	Participant selection methods; modes of communication and decisions; authority and power

Evaluation Participatory evaluation

Description and objectives

Participatory evaluation is a method for evaluating activities, programmes and policies which entails the active involvement of all stakeholders involved in the process of designing and implementing an action. The participatory logic of this method responds to its particular utility in cases in which the implementation process has presented difficulties, or when there are doubts about the real impact of the project on the beneficiary population. The main principles that govern participatory evaluation are described here.

- » Participation is the driving force in this task. All stakeholders, especially representatives of the community, must participate in all stages of the evaluation process, from making the decision to evaluate in the first place to the final use of the evaluation findings.
- » Negotiation means that the participants must agree on the aspects of the project to be emphasized by the evaluation process, along with how it should be carried out, based on a horizontal structure of relations and a guarantee that all perspectives will be reflected.
- » Learning means that evaluation must help to strengthen the community and facilitate horizontal development. Not only are the achievements of the project to be evaluated, but also the social assets generated by the design and implementation process.
- » Flexibility is the final principle. Participatory evaluation is a dynamic method that must constantly adapt to the needs and capacities of the participants. As such, the evaluation process can take place at the end of the project, but it should also be set in motion during the implementation stage, to allow the project to be refocused if necessary.

Method

A series of common steps or stages exist in participatory evaluation processes.

The first step is to decide who will participate in the evaluation of the project or programme. The broader the spectrum of stakeholders involved, the greater the degree of collective reflection achieved. In a participatory approach, the evaluation process must involve at least: political or institutional representatives; technical staff representing the

administration; professionals who have carried out tasks during or relating to the project; and community social organizations.

The second stage entails designing the evaluation plan. By means of collaborative work, the evaluation team must decide on the priority aspects for evaluation. Three key elements must be defined at this point: the main objectives or results to be evaluated, the indicators chosen to ascertain the real situation relating to these objectives and, finally, how the information required to evaluate progress will be gathered. It is important to remember two key elements about participatory evaluation. First, objectives do not refer solely to the final results of the project, but also to the evaluation of the process; in other words, how community articulation and its relations with the other stakeholders have varied over the course of the project. Second, the indicators must be valid and recognized as being useful by all stakeholders, not just by those promoting the process.

The third stage focuses on gathering and analysing the information required to conduct the evaluation, in accordance with the indicators chosen. Owing to the nature of the information to be gathered, it is not always quantitative or easily to compare. Many evaluation objectives focus on intangible but nonetheless relevant elements of the process. Therefore, the gathering of objective data should be combined with the application of participatory production and information techniques, such as those outlined earlier for the diagnosis stage (focus groups, participatory surveys, flow-grams, SWOT analysis, visualization techniques, and so on).

Finally, with all the available information, the last stage of the evaluation process focuses on collective discussion to draw conclusions and produce reports. Here, the evaluation team must achieve a consensus regarding the results generated by the analysis of indicators and, on the basis of the conclusions reached, draw up an action plan either to redirect the project (for evaluations included during the implementation process) or to be taken into account when designing future projects. Fig. 3.19 outlines the methodology for participatory evaluation, and Case study 3.19 details the inclusion of participatory evaluation in the final report of the European project "Health and the Roma community, analysis of the situation in Europe".

Fig. 3.19 Methodological diagram for participatory evaluation



Further reading on the tool method

Zukoski A, Luluquisen M. Participatory evaluation. What is it? Why do it? What are the challenges? Community-based public health policy and practice. Partnership for the public's health. Washington (DC): The California Endowment; 2002 (http://depts. washington.edu/ccph/pdf_files/Evaluation.pdf, accessed 5 December 2014).

Case study 3.19 Europe. Final evaluation report for the project "Health and the Roma community, analysis of the situation in Europe"

Background

The final external evaluation report for the project "Health and the Roma community, analysis of the situation in Europe" is funded by the EU as part of the European public health programme and coordinated by La Fundación Secretariado Gitano, a Spanish charity organization. The external evaluation was carried out by Dinamia, an external consultancy firm (1).

The direct beneficiaries of the project were the Roma population living in Europe, particularly in the seven participating European countries (Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia and Spain), each with a significant Roma population.

Objectives

The main objective of this evaluation was to analyse the achievements of the project, combining conventional evaluation methods with participatory evaluation.

Development of the process

During the evaluation of the project, a conventional strategy was applied which combined quantitative and qualitative data analysis, as well as the information produced throughout the project, measuring efficacy, pertinence, efficiency, impact, participation and coordination.

In order to triangulate the information, participatory evaluation processes were also introduced. A meeting was held with community organizations from the countries participating in the project. At this meeting, in order to develop the contents of the participatory evaluation, various group dynamics were organized using surveys for evaluation and SWOT analysis. The aim was to encourage the stakeholders to evaluate the achievements of the project, as well as the satisfaction of the agents involved in the process and the utility of the conclusions or recommendations that emerged.

Results and evaluation of the experience

The participants in the evaluation assessed the use of methods that were not overly sophisticated and complex to gather pertinent information in the evaluation, which provided a useful evaluation of the participatory methods. The reflections presented at the participatory meetings, chiefly in the form of feedback and proposals, were used by the evaluators as a basis for drawing up the final evaluation report.

Reference

 Evaluation final report "Health and the Roma community, analysis of the situation in Europe". Madrid: Dinamia consultoría social; 2009 (http://www.gitanos.org/upload/02/77/ External_evaluation_report.pdf, accessed 5 December 2014).

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4. EVALUATING SOCIAL PARTICIPATION

This chapter could be used as a quick-start guide to evaluate different components of social participation.

Evaluating the level of social participation

As this toolkit describes, different levels of social participation exist. The selected model of social participation determines how the Roma community is defined, along with the purpose and level of social participation.

The considerations defined in Table 4.1 should be taken into account in understanding the scope of the participation model being applied.

•	Table 4.1	Participa	tion of t	the Ro	ma popu	lation in	health	care: l	evels	of pa	rticipat	tion

	Technocratic model Management model	Administrative model Corporate participation model	Inclusive participation model Participatory management model
Definition of the Roma community	Users or customers	Population living in the area	Heterogeneous groups of marginalized populations (sex, age)
Group/individuals representing the Roma community	Most influential users	Associations and NGOs with formal representative status	Individual subjects and social networks
Participation of the Roma community as a means of:	 » expanding the scope of health care policy » increasing resources » supporting infrastructures 	 improving the efficiency and management of health services 	 » increasing the effectiveness of services » improving accountability and transparency » increasing the legitimacy of decisions
Depth of participation	Information	Consultation	Participatory decision-making
Scope of participation	Service provision	Provision of services and management in certain areas	Health care policy, planning and provision of services at all levels
Method and direction of participation	As users Top-down	As representatives of collectives Top-down	As subjects within the community Top-down and bottom-up

Source: based on Murthy & Klugman (1).

Evaluating inclusiveness

The dimension of inclusiveness refers to the people eligible for the participatory processes and how they become participants. This answers the question of who participates. For instance, gender parity is a basic criteria to assess the degree of inclusiveness. The scale depicted in Table 4.2 could be useful to evaluate inclusiveness in participatory processes.

Less inclusive	Elected representatives	This is a restrictive normative configuration for the selection of participants. Only the elected representatives of citizens are allowed to participate; in other words, political leaders.
	Government experts	These are politicians and government experts (government technicians at different levels of government, researchers, and analysts contracted for their knowledge).
	Formal collectives and associations	Formal collectives and organizations with a presence and the legal capacity to act within the community are also authorized to take part. The process would not be confined purely to the sphere of government but would be opened up to the population through the representative logic of associations representing different segments of the population. These associations, which would make up a selective process of participation, would represent the interests of the community and would act as an interlocutor between the community and institutions in the development of demands and interests in the area of health.
	Broad public sphere	Individual participants from among the general public do not need to play an active role, but rather are generally consulted for information gathering, without necessarily having to be involved actively in the process. Nevertheless, it is clear that the launch of the participatory process provides structural incentives which make the participatory event more attractive to people who would otherwise not normally participate.
	People selected randomly	Randomly selected individuals are authorized to participate, for example through opinion panels, surveys or citizens' juries.
More	Self-selected people	This group reflects the greatest scope for inclusiveness, since anyone with institutionally recognized capacity and legitimacy may take part in the various activities involved in the participatory process. The aim here is to not achieve a representative capacity of the participants, with regard to the population as a whole (a logic often obeyed by random selection), but rather to ensure that a subset of the Roma population becomes involved in the resolution of health-related problems and issues.

Table 4.2 Inclusiveness evaluation scale

Evaluating intensity

A second dimension that is useful for describing the different participatory experiences is that of intensity, which describes how participants interact, exchange information and make decisions, bringing to the forefront the functional and educational capacity of these processes in the appropriation of knowledge by the subjects carrying out participatory actions. This dimension responds to the basic question of how people (both women and men) participate. Table 4.3 depicts a scale that can be used to evaluate the intensity dimension in participatory experiences.

Lov inten	ater	Listening as a spectator	As spectators, people are only enabled to listen to what happens. This level corresponds to a passive conception of participation in which subjects participate as spectators, generally with a view to receiving information about policies or specific projects which are implemented by other stakeholders.
		Expressing preferences	At this level of intensity, people can express opinions and preferences. Participating subjects not only listen to what others say, but are also empowered to establish two-way communication, expressing their opinions and interests in relation to the health issues put forward for debate, albeit without the effective capacity to articulate them within the logic proposed by the participatory space.
		Developing preferences and deliberating	Here, participants have the recognized capacity to develop preferences and interests, thereby opening up a flow of communication which becomes deliberative in nature, insofar as it allows for an interactive process which is (to a certain extent) horizontal, facilitating the mutual exploration of interests and the transformation of preferences through shared debate.
Grea		Negotiating and voting	As participants at this level of intensity, women and men are empowered to vote and make decisions. Occasionally, negotiation and voting are not necessarily linked to a prior process of common deliberation, but could result from a simple mechanism of majority agreements regarding the examination of interests not subject to communicative action. Hence, this scale is not strictly linear.
		Acquiring technical knowledge	As the intensity of subject participation increases, a series of problems and technical factors begin to emerge which – at a less ambitious level – are dealt with internally by the institution involved. However, when participation is more ambitious in scope, these technical issues enter the public domain and must be dealt with publicly. It is precisely the understanding of these kinds of contributing factors – which often condition the technical, legal or jurisdictional feasibility of popular initiatives – that endows these kinds of processes (and the participants) with greater educational capacity. This in turn leads to greater appropriation of knowledge, as all the possibilities can be considered as a whole and, therefore, be situated at the end of the proposed scale (greater intensity).

Table 4.3 Intensity evaluation scale

Evaluating influence

The dimension of influence focuses on the orientation of participatory processes in relation to government action. To put it another way, it measures the effective and real capacity for impact (ultimately the authority) of the participatory process, with regard to the information generated through it. This dimension responds to the question of what participation is for and, within this dimension – as with the previous ones – a gradual arc of responsibilities can be identified. Table 4.4 presents the scale to be used to evaluate influence in a participatory process.

Evaluating gender equality

Social participation can be gender blind if gender is not addressed in the participation process. The key questions listed in Table 4.5, adapted from the WHO Gender Responsive Assessment Scale (GRAS), could be applied when analysing a participation process.

Table 4.4 Influence evaluation scale

	ess ience	Persuasion	Participants have no expectations of influencing institutional policy relating to the participatory process they are joining. The influence of the subject at this level is minimal, with persuasion, argumentation or seduction being the only resources available to influence the decisions others will make.
		Public information	This refers to the capacity of the participants and the processes themselves to – at least – generate information for the Roma population; hence, their influence is not restricted to the internal sphere of processes but rather transcends them, and the aim is to socialize information through dissemination strategies (campaigns, reports, the media, etc.), through which health policy is also influenced.
		Consultation	Through consultation mechanisms, a channel is set up, which – although the authority of political leaders remains intact – recognizes the utility of receiving opinions or advice from participants and from the Roma population in general.
		Decision	Coinciding with the classic scales of participation, participatory mechanisms exist in which participants exert sufficient influence to make binding decisions relating to the implementation or specification of health-related policies or programmes. At this level, empowerment of participants is key, in so far as the deliberative process not only leads to a consensus or agreement regarding the common good, but in addition, such consensus is shaped into executive decisions based on the existence of an institutional commitment to implement them.
		Co-management	This refers to the creation of mechanisms that allow participants and institutions to jointly manage the way in which political policies resulting from the participation process in health are managed, and, further, to establish suitable monitoring structures to assess them.
Grea influe		Co-government	This is the most ambitious level of influence, rooted in the creation of participatory processes that establish a horizontal and symmetrical relationship between the participating individuals and government, moulded into co-government formulas for public action.

The United Nations Division for the Advancement of Women (DAW), in collaboration with the Inter-Parliamentary Union and the Economic Commission for Africa organized an expert group meeting on "Equal participation of women and men in decision-making processes, with particular emphasis on political participation and leadership" (Addis Ababa, Ethiopia, 24–27 October 2005). The resulting document (2) focused on participation in political processes in Africa and addressed recommendations to government actors, political parties, electoral management bodies, international actors and civil society. However, some of the recommendations are also valid for participation processes related to health policies and the health system in other geographical areas. Box 4.1 provides a summary of the (adapted) proposed recommendations to be considered when promoting participation relating to health policies and the health system.

Is the participation process	Characteristics to be considered (one or more may apply)					
	Whether or not the participation process:					
gender-unequal?	 » perpetuates gender inequalities by reinforcing unbalanced norms, roles and relations; » privileges men over women (or vice versa); » often leads to one sex enjoying more opportunities to participate than the other; 					
gender-blind?	 » ignores gender norms, roles and relations; » very often reinforces gender-based discrimination; » ignores differences in opportunities and resource allocation for women and men; » is often based on principles of being fair by treating everyone the same; 					
gender-sensitive? gender-specific?	 considers gender norms, roles and relations; does not address inequality generated by unequal norms, roles or relations; indicates gender awareness, although often no remedial action is developed; 					
	 acknowledges different norms and roles for women and men and how these influence the participation process; takes account of the specific needs of both women and men; intentionally targets and benefits a specific group of women or men; makes it easier for women and men to fulfil their gender roles; 					
gender-transformative?	 acknowledges different norms and roles for women and men and that these influence the participation process; takes account of the specific needs of both women and men; addresses the causes of gender-based differences in participation; includes ways to transform gender norms, roles and relations; includes strategies to foster equal power relationships between women and men. 					
gender-sensitive? gender-specific?	 » privileges men over women (or vice versa); » often leads to one sex enjoying more opportunities to participate than the other; » ignores gender norms, roles and relations; » very often reinforces gender-based discrimination; » ignores differences in opportunities and resource allocation for women and men; » is often based on principles of being fair by treating everyone the same; » considers gender norms, roles and relations; » does not address inequality generated by unequal norms, roles or relations; » indicates gender awareness, although often no remedial action is developed; » acknowledges different norms and roles for women and men; » intentionally targets and benefits a specific group of women or m » makes it easier for women and men to fulfil their gender roles; » takes account of the specific needs of both women and men and these influence the participation process; » takes account of the specific needs of both women and men; » intentionally targets and benefits a specific group of women or m » makes it easier for women and men to fulfil their gender roles; » takes account of the specific needs of both women and men and these influence the participation process; » takes account of the specific needs of both women and men and these influence the participation process; » takes account of the specific needs of both women and men and these influence the participation process; » takes account of the specific needs of both women and men and these influence the participation process; » takes account of the specific needs of both women and men and these influence the participation process; » takes account of the specific needs of both women and men; » addresses the causes of gender-based differences in participation; » includes ways to transform gender norms, roles and relations; » includ					

Table 4.5 Gender equality evaluation questions

Note. The GRAS is a gender analysis tool for assessing policies and programmes based on five criteria, which could be useful to go beyond other gender-sensitivity programmes in order to take action to change gender norms, roles and relations that might affect women.

Source: adapted from WHO (3).

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Box 4.1 Adapted recommendations for increasing the number of women in decision-making

- » Gender parity should be sought in all decision-making bodies.
- » Special measures should be put in place to guarantee women enter decision-making positions.
- » Resources should be provided for training for women on how to use information and communication technologies as a tool; in particular, to overcome the digital divide between men and women in the use of new technologies and to provide women with equal access to information.
- » Clear rules should be adopted for representative selection.
- » Statistical data should be provided on the participation process, disaggregated by sex.
- » Gender-sensitive language should be used, and negative portrayals of women avoided.
- » Research should be facilitated on the conditions under which women's participation and representation is increased and enhanced.
- » Reporting on progress in increasing women's participation and accountability for gender bias should be ensured, particularly with respect to women in decision-making.
- » Women should receive sufficient administrative support, guidance and adequate financial resources to overcome participation barriers, and gender bias should be removed from the allocation of participation resources.
- » Women should be encouraged to seek greater involvement in decision-making processes at all levels and to exert a significant influence on decision-making processes and policy outcomes.

Source: adapted from DAW (2).

5. ONLINE HANDBOOKS ON PARTICIPATORY METHODS

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