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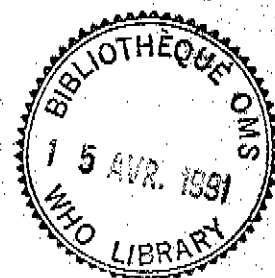
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# COMMUNITY INVOLVEMENT IN HEALTH: INDICATORS

Report on a WHO Study



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EUR/HFA TARGET 26

This document presents the results of a WHO study on the development of indicators for community involvement in health coordinated by Ms Monique van Dormael, Prince Leopold Institute of Tropical Medicine, WHO collaborating centre for primary health care, Antwerp, Belgium. The work is aimed at achieving the following target in the health for all strategy.<sup>a</sup>

## **TARGET 26**

### **A HEALTH CARE SYSTEM BASED ON PRIMARY HEALTH CARE**

*By 1990, all Member States, through effective community representation, should have developed health care systems that are based on primary health care and supported by secondary and tertiary care as outlined at the Alma-Ata Conference.*

### **Index terms**

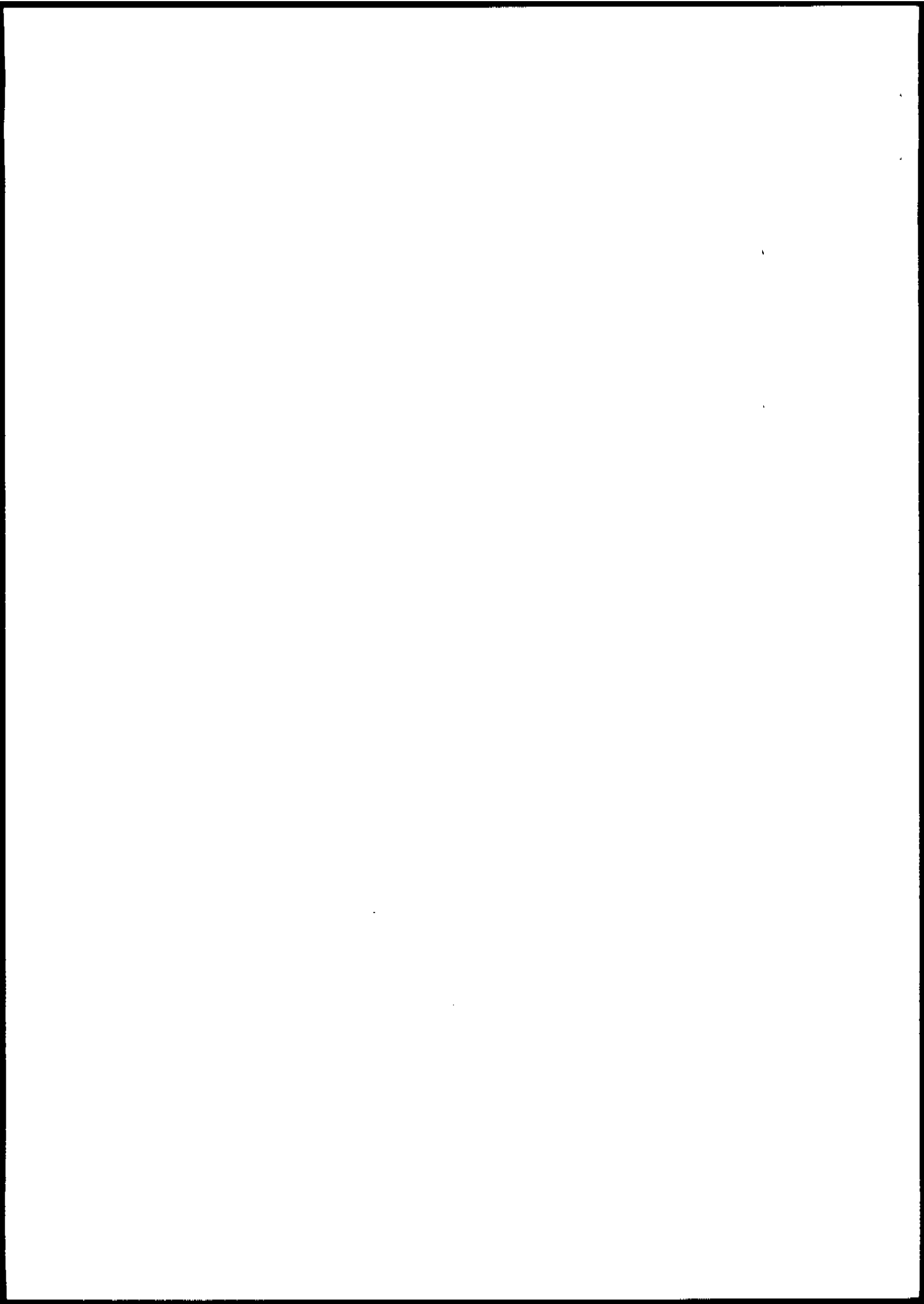
COMMUNITY HEALTH SERVICES  
PRIMARY HEALTH CARE  
CONSUMER PARTICIPATION  
EVALUATION  
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<sup>a</sup> *Targets for health for all.* Copenhagen, WHO Regional Office Europe, 1985 (European Health for All Series, No. 1).

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## The study

### Assessing community involvement in health

Community involvement in health is an important issue, both as a democratic goal in itself and as a potentially useful means of achieving an improvement in health (1).

The Alma-Ata Declaration promoted worldwide official recognition of community participation as an essential element in primary health care (2). The development of the targets for health for all in the European Region relies firmly on community participation as a key element in the attainment of the goal of health for all. Target 26 states that: "By 1990, all Member States, through effective community representation, should have developed health care systems that are based on primary health care and supported by secondary and tertiary care as outlined at the Alma Ata Conference" (3).

More recently, the declaration of the Harare conference on strengthening district health systems based on primary health care (4) ratified the strategic directions for primary health care by focusing on the strengthening of health systems at district level. Once again, community involvement was stressed as a major dimension of district health systems.

The Regional Office for Europe adopted this new approach by formulating the following objective in its 1988-1989 programme: "To promote community involvement in decisions related to the establishment or further development of district health systems".

However, the consensus surrounding community participation does not mask the variety of underlying intentions, approaches and realities (5,6,7).

Community involvement in health is difficult to measure because of an absence of commonly accepted definitions and goals, the complexity of community involvement mechanisms which are difficult to represent unidimensionally, and the important qualitative dimensions involved.

However, a means of assessing community involvement in health is needed for the following reasons:

- the community itself, local authorities health professionals should be enabled to assess community involvement in health in order to improve it;
- national authorities need indicators to enable them to improve conditions at national level for the development of community involvement in health;
- international agencies such as the World Health Organization need to be able to monitor community involvement in health at international level.

Interesting attempts have been made to propose methods of evaluating community participation in specific projects (8,9). Indicators which could be valid at national and cross-national level are difficult to define as they can only be expressed in general terms (10,11).

At present the Regional Office for Europe uses the following indicator for community involvement in health:

Existence of mechanisms for involving lay members of the community in the implementation of national health strategies and in the delivery of health services at regional and local levels, including responsibility for allocation and/or use of funds (12).

Since there is still little research on measuring community involvement in health, the Regional Office for Europe initiated an international study with the general aim of developing indicators for its assessment.

The study was conducted in Belgium, France, the Netherlands, Spain and Yugoslavia by researchers from those countries and was coordinated by the Public Health Research and Training Unit of the Prince Leopold Institute of Tropical Medicine in Antwerp. Two international consultations were held in Antwerp, one in December 1988 to agree on the terms of reference for the study and the other in January 1990 to discuss the results. The first consultation included researchers from Belgium, Finland, France, the Netherlands, Spain, the USSR and Yugoslavia. The second consultation included researchers from Belgium, France, the Netherlands, Spain and Yugoslavia.

#### Objectives and procedure

The objective of this study was to propose an organized list of tracers with a dual function:

- a list of possible indicators to be tested for their validity, from which indicators with cross-national validity could be selected (this list should not yet be seen as part of an information system or as a valid tool for systematic comparative research) (13);
- a tool for those concerned with community involvement in health at local or district level (representatives of communities, professionals, local authorities, researchers, etc.) to use in analysing the present state and evolution of such involvement in their own situations and drawing up strategies to improve it.

The study proceeded as below:

- a review of literature on indicators for community involvement in health;
- development of and agreement on a conceptual model for community involvement in health which defined what was to be measured;
- expansion from this conceptual model to an untested list of tracers designed to assess the various dimensions of community involvement in health;
- the testing of this list for its suitability in assessing community involvement in health at district level in the participating countries through panels of experts, which should be organized:
  - at district level (or close equivalent);
  - to include representatives from the community, the health services, professionals and authorities, academics and researchers;

- for these people to see whether the items on the checklist were intelligible in the local context, adequate to describe the situation, and stimulated new thinking about the improvement of local community involvement in health;
- consideration of reports from the participating countries describing the assessment of the checklist and its results, both generally and in detail;
- assessment of country results and revision of the list.

Conclusions from field trials of the test have been incorporated in the revised list (see list of tracers below). Some may be mentioned here.

- The absence of a clearly defined district level, as usually found in pluralist systems, can create problems. This also appears to be an obstacle in the development of community involvement in health at all. The revised list should, however, be adaptable to both pluralist and planned systems.
- The existence of formal mechanisms, as usually found in planned systems, is important in facilitating community involvement in health, but they are not in themselves the goal. The focus should be on the actual functioning of community involvement in health, which always includes informal as well as formal mechanisms (when the latter exist).
- The way in which the checklist is used could be as important as the list itself. Its use in local settings stimulated discussion and contributed to a working conception of community involvement in health.

#### The questionnaire: list of tracers

##### Introduction

The questionnaire is primarily aimed at those people (the community and its representatives, local authorities and politicians, health professionals) who want to promote and improve community involvement in health at their district or local level and therefore need a tool for assessing it.

It is designed to be flexible and adaptable to specific situations, particularly to local health systems. It may also need to be adapted in the course of translation into the local language.

It should be used to assess not only community involvement in health per se, but also aspects of such involvement in specific issues (mental health, the health of elderly people, immunization, etc.). Community involvement in health should contribute to the achievement of any of the health for all targets as well as being a goal in itself.

##### Community involvement in health: a conceptual framework

The concept used in this document is based on four ideas:

- effective communication and interaction between the community and the other parts of the health system;
- representation of all sections of the community;

- proper information as a basis for sound decision-making;
- decision-making mechanisms which involve the community.

#### *Communication*

Community involvement in health is a partnership between the community and the other parts of the health system (health services, authorities, other related sectors). Individuals and families concerned privately and groups within the community and/or their representatives concerned collectively with health related issues are included in the community.

Health services and professionals providing professional care, the authorities administering health policy and other health-related sectors of social life cooperate with the community. Opportunities for partnership with the health services are available but underused: these should be encouraged.

Partnership involves communication and interaction whereby individuals or the community can express their demands, needs or complaints and discuss issues with the health services or authorities.

Mechanisms for communication can be either formal or informal. To be effective, the relevant partners must be easily identifiable. This is easier in areas where the people and organizations concerned are clearly defined (clear population boundaries, health services specific to the population of a particular district, well identified health authorities).

Communication in this context is a circular process with perpetual feedback, including negotiation. It can be behavioural as well as verbal: dissatisfaction with the health services can be expressed through underuse, and it is up to the authorities to interpret the messages reaching them.

The subjects of communication should be important local health issues related to the organization, environment and resource allocation of the health services. This implies that the decision-making processes should be sufficiently decentralized to allow significant decisions to be discussed at district level.

#### *Representation*

Communities, far from being homogenous groups of people bound by common interests or ties, are usually heterogeneous collections of individuals and groups with widely divergent interests. Community involvement in health therefore means that all those sections of the community having a particular interest in health-related issues can pursue them either directly or through representatives.

Representativeness can be interpreted either in the sense of a representative sample (the sharing of common characteristics by both representatives and those represented) or as the designation (by election or nomination) of the representatives by those represented.

Effective channels of communication must exist between all sections of the community and the representatives if the latter are to speak in the name of the community.

Representation should not be allowed to become a permanent and quasi-professional activity.

*Information as a basis for decision-making*

The information needed by the community if it is to make informed choices should be:

- accurate (reflecting common scientific knowledge, including uncertainties);
- complete (the advantages and disadvantages (including costs) of alternative solutions to a problem);
- intelligible (formulated in unambiguous terms and related to the cultural background of the local population).

Available relevant information should be increased through the inclusion of lay knowledge as well as the results of scientific research. It should emanate from the health authorities and professionals, who must therefore be in a position to provide it. But the community itself should also be involved in defining and searching for the required information, which implies the ability to formulate problems and questions and seek for the relevant information.

*Decision-making mechanisms involving the community*

Proper information is supposed to enable the community to choose, among technically adequate alternative solutions, the one that corresponds best to its value system.

Community involvement in health means that subgroups and/or their representatives should influence decision-making processes as concerns the health system. Although formal mechanisms can be useful in this process, it is the community's own influence which is essential.

This influence can be exerted in various ways (direct participation in decision-making or pressure on decision-makers, public opinion, market mechanisms) and at various stages of the decision-making process (identification of the problem, proposal and choice of solution and method of implementation, evaluation, allocation of resources). It is not, however, expected to lead to solutions that are either ineffective or inconsistent with priorities in the use of available resources. This differentiates community involvement in health (a combination of technical dimensions and individual and community value systems) from pure consumerism (the priority of demand regardless of need). Community involvement in health therefore underlines the responsibility of the health services to provide continuous information on the technical aspects of health issues.

Since communities are heterogeneous, the influence of certain groups is likely to be dominant in decision-taking. Conflicts between different value systems and interests within the community should be dealt with in a way that ensures that the values of the dominated or less well represented subgroups are taken into account in the decision-making process.

### Directions for use

The list of questions in Annex 1 aims at assessing how far community involvement in a given setting (district, municipality, etc.) corresponds to the criteria mentioned above.

The questionnaire should be used at district or local level. Where districts do not exist, the closest equivalent (which will vary from country to country) should be taken.

Since the objective is the assessment and analysis of a given health situation in order to improve the involvement of the local community, the most appropriate method is panel discussion. Participants should include:

- official representatives of the community;
- unofficial representatives (people who are active in social matters or members of voluntary organizations);
- health professionals, either on their own behalf or representing health services;
- representatives of the district or local health authorities.

The panel should be small (8-15 people). Discussion could be facilitated by someone from an external research or development institution, and would probably last for about four hours, depending on local conditions. The aim would be to identify problems in the involvement of the local community in its own health.

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Annex 1

QUESTIONNAIRE

The questionnaire starts with general questions describing the setting and identifying the people and organizations concerned locally in community involvement in health. Subsequent sections deal with each of the dimensions proposed in the conceptual framework.

General characteristics of the health system

1. To what extent is the direction of the country's health system influenced by planning and regulations (a planned national health service type system) or by market mechanisms (pluralist systems)? In the former case, which are the influential authorities? In the latter case, how do health professionals and consumers each influence the system?

2. Is a health district<sup>a</sup> or its equivalent identifiable, i.e. a defined geographical area comprising a population of approximately 50 000-300 000 people with political and administrative authorities responsible for health issues at this level and some coordination between institutions providing care?

If such a district is not administratively definable, is there an informal district?

3. How far is health system planning decentralized, i.e. which decisions can be taken at this level and which have to be taken at regional or national level?

4. In your district, are the people involved in the community's health

- members of the community - what are the criteria for defining the population boundaries;
- local authorities - who are they and with what health policy issues do they deal;
- the health services - which health services and professionals provide what kind of care?

5. Which political representatives or delegates in formal bodies can be considered official community representatives for health system questions in your locality?

6. Which voluntary organizations dealing with health-related issues can be considered to reflect the community's point of view in your locality and what are their demands?

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<sup>a</sup> The Harare Conference on Strengthening District Health Systems based on Primary Health Care declared a health district to be "a more or less self-contained segment of the national health system which comprises a well-defined population living within a clearly defined administrative and geographical area, either rural or urban, and all institutions and sectors whose activities contribute to health".

7. Is there an official declaration of intent at national level that communities should be involved in questions relating to the health system? In what areas and through what mechanisms is community involvement in health officially recognized (health care organization, resource allocation, environmental or ethical issues, etc.)? Since when?

8. Who really wants the community to be involved in its health and why? What attitude do the professionals, the authorities and the community have towards its desirability? Has there been an evolution in recent years?

9. Is there a tradition of community involvement in fields other than health? Has there been an evolution in recent years?

Communication and interaction between the community and the other parts of the health system

10. What means are available to individuals and to the community or its representatives to complain or express satisfaction or dissatisfaction about or express needs or demands related to the health care services or the physical or social environment?

12. Are these means known to the public, and how accessible are they?

13. How far is individual and community opinion implicit and behavioural (e.g. through use or non-use of services)?

14. How far is individual and community opinion explicit and verbal (e.g. through press conferences, the mass media, demonstrations, the courts, the Ombudsman)?

15. To what extent is it considered legitimate for lay people to assess the quality of health care? What tools do they use in making such assessments? Are standards available?

16. Do community representatives exert influence on public opinion in health issues, and if so, what use do they make of the press and other media?

17. Do community representatives participate directly in the organization of the health system in your locality and/or at higher levels?

18. In which fora can community representatives speak in your locality and at regional and/or national level?

19. Are these representatives officially in the majority or minority in these fora, and who are the other participants?

20. What issues are discussed and what positions have been adopted by these community representatives in these fora in recent years?

21. What resources are available to support community involvement in health (financial support for representatives' activities and for communication between them and the community, e.g. meeting-rooms, radio services, press)? Where do these resources come from? Are the amounts important?

Representation

22. What is the social composition of the population in your locality? Can you identify subgroups (socioeconomic groups or categories such as handicapped or elderly people) with specific health needs or specific value systems? What are the inequalities in health in your locality?

23. Do subgroups in your community disagree about health questions? How are such disagreements managed?

24. How do you select official representatives of the community in fora dealing with health matters (election, appointment, by whom, for how long)? How are unofficial representatives who speak for the community on health questions selected (self-selection, appointment, election by an organization)?

25. Are the personal characteristics (social class, age, sex, etc.) of the official and unofficial representatives of your community comparable to those of the community?

26. What is the nature of the relationship between the official representatives of the community and the community? In particular,

- do mechanisms exist for consultation and the exchange of information on health questions between the official representatives and the community in your locality, and are such mechanisms regulated;
- are official representatives accountable to the community, and through what mechanisms;
- is communication between official representatives of the community and the community frequent, through what channels and with what content;
- do official representatives lead or follow public opinion?

27. What is the nature of the relationship between unofficial representatives of the community and the community? In particular,

- are such representatives backed by voluntary organizations, and are they accountable to these organizations;
- do they lead or follow public opinion;
- do mechanisms exist for consultation and the exchange of information on health questions between the unofficial representatives and the community in your locality, and are such mechanisms regulated;
- is communication frequent between the unofficial representatives and the community, through what channels and with what content?

Proper information as a basis for sound decisions

28. Do regulations or legislation concerning the right of the individual and the community to be informed about health-related issues exist

- in relation to individuals' personal health problems
- in relation to health service organization issues at local level

- in relation to environmental problems at local level
- at regional/national level?

29. How much useful technical information are the providers of health care able to provide to individuals about their personal health problems? Do they propose alternative solutions to enable the people concerned to make choices? Are these providers trained to provide such information?

30. How much useful technical information are health care providers and health authorities able to provide to your local community about problems related to the organization of the health service and the environment? Are health care providers and health authorities trained to provide such information?

31. Have any problems occurred in your locality in this connection? If so, who gave the information involved? To what extent was this information accurate (reflecting common scientific knowledge, including any uncertainties), complete (listing all the advantages and disadvantages, including costs, of alternative solutions to the problem) and intelligible (formulated clearly and related to the cultural background of the population)? How useful was this information to the community (e.g. in enabling it to decide on a strategy)?

32. Have there been occasions when an excess of irrelevant information has had a suffocating effect?

33. Do you have examples of occasions when lay knowledge about a problem (gained through experience) has been taken into account in the identification and analysis of a problem in your locality? And when it has not?

34. To what extent are individuals able to look for information about their own health problems?

35. To what extent is the community (or its representatives) able to ask for information, to interpret it, to ask questions and to raise objections?

36. Has your community requested information on health-related issues? To whom, was the request made and what was it about?

#### Decision-making mechanisms involving the community

37. Do official mechanisms exist whereby communities are or can be involved in decisions related to the health system at health service level, local or district level and regional or national level?

38. Do official and unofficial representatives of the community have the right to intervene in health policy decision-making through being informed or consulted, negotiating, participating in decision-making or exercising a veto?

39. Do indirect mechanisms exist whereby the community can influence decisions related to the health system (pressure on public opinion, market mechanisms, etc.)? Are there examples in your locality?

40. Is discussion of controversial health issues usually limited to the authorities and experts, or do official and/or unofficial representatives participate?

41. Are there examples of disagreements or conflicts of interest between the community and health professionals about issues related to the health system in your locality and at national level? How can the community influence the decisions?

42. Are there examples of disagreements or conflicts of interest between subgroups in the community about issues related to the health system in your locality? Are there any subgroups that do not have the rights listed in 37? To what extent and how are the interests of the less influential or less well represented subgroups taken into consideration in the decisions?

43. Can you cite examples of decisions related to the health system both locally and nationally on which the community exerted some influence (allocation of resources, ethical issues, etc.)?

Annex 2

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