CHAPTER 11

PARTICIPATION AND HEALTH PROGRAMMES

Community participation in health—one of the central tenets of the World Health Organisation's 'Health-for-All' strategy—provides a mechanism for people to participate in activities that have the potential to impact positively on their wellbeing. For those engaged in humanitarian action, however, this can be an alien and poorly understood concept. The urgency to respond and meet immediate needs on the ground tends to overshadow the complex and interacting needs, demands and expectations of affected communities. As a result, minimal effort is made to investigate the value of community participation, leading to a top-down, supply-driven approach, in which the delivery of medicines and the dispatch of expatriate doctors are seen as key priorities.

That conflicts and natural disasters impact significantly on health and health systems has been well documented. Health needs increase as access to medical services becomes more difficult.

Working with members of the affected population and with existing health systems, traditional or 'modern', can enhance the integration of health interventions into the health strategies of affected populations, thereby improving their relevance, effectiveness, sustainability and impact.

11.1 ASSESSMENT

The way that health needs are assessed, taking into account the different needs of each zone and population group, will determine whether the activity is successful. In most crises, however, participatory assessment is challenged by the pressure to respond quickly. Hence, interventions are not always grounded in an initial appraisal of needs, particularly as perceived by affected populations.

The first step is to decide exactly what information is needed and where to obtain it. A review of written materials, including medical records, attendance registers, reports and minutes of meetings, is crucial. Determining how health needs are identified, though, does not only mean collecting new information, facts and statistics, but also making good use of existing knowledge.

> Following an NGO assessment, a remote 40-bed hospital in northern Afghanistan was rehabilitated and supplied with material and human resources. However, a continuous trend of under use—only one or two patients were brought in each week—called into question the relevance of the assessment. While the assessment emphasised NGO expertise ('providing a hospital service'), it gave insufficient attention to local health needs, constraints, capacities, practices and resources.

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Different levels of analysis are also required.

11.1.1 UNDERSTANDING LOCAL HEALTH BELIEFS AND PRACTICES

One of the most common weaknesses of health assessments in the humanitarian sector is the tendency to construct a purely epidemiological picture of the situation. Certainly, the epidemiological assessment is fundamental, but it often masks social and cultural specificities pertaining to the affected population. Throughout the assessment process, you can ask yourself: Am I paying sufficient attention to the social and cultural dynamics that affect health?

These specificities can include: the rate of attendance at health centres and the population's perception of them ('I only go when all else has failed, because those who go always die'); the use of traditional health practitioner networks and the employment of practices inspired by religious beliefs (traditional healers and plant medicines, for instance); the population's trust in the health practices that you are promoting (degree of acceptance by local leaders and their reaction); and the affected population's perception of the damage caused to the health infrastructure by the crisis.

> In Afghanistan, the pharmacy is one of the most popular shops in the bazaar, present in any village, and often run by a person with no medical training. The population regularly consumes drugs (particular via injection) that are often bought without a medical prescription.
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> In a remote area, under-serviced in regard to the health infrastructure, an NGO set up a clinic with a medical doctor, specifically trained in administering drugs. Some population members, nevertheless, refused to attend the clinic. As one woman explained: 'They don't even have a real doctor there. They only give little white pills, and not the coloured ones, and they refuse to give injections'.

To help understand these issues, it can be very useful to establish a **community profile.** Focus groups can be organised to address the following questions.

- How is the society organised? What is the composition of the affected population (in terms of gender, age and ethnic group)?
- How is the population distributed geographically in the area?
- What health services and practices exist, both traditional (related to religion and witchcraft, for instance) and 'Western'?
- What is the distribution of health centres and practitioners, both traditional (including the house of the Traditional Birth Attendant (TBA)), and 'Western' (such as the vaccination centre)?

- Are social structures, networks or key individuals active in the health sector (health committees, networks of community health workers, nurses)? What is their position in the population?

Tools available to tackle these questions include **mapping** (showing the distribution of health structures, for example), and a **stakeholder analysis** (see below).

Observation techniques provide an opportunity to examine the way that a health infrastructure or mobile team functions. Informal discussions can also be held on site, such as in clinic waiting rooms, or in the home of the TBA. If such sites are selected, it is important to ensure that you hold discussions in a variety of places, to avoid bias in relation to the collected information (the population attending the clinics may constitute a minority, for instance).

Incorporating the characteristics of specific groups can enrich the community profile. They include:

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- the views of certain religions in regard to blood transfusions;
- the values of certain population groups in relation to birth control; and
- the perceptions of certain illnesses and diseases (for example, the marginalisation of patients with HIV/AIDS, and the association of disease with curses or divine punishment).

Specific **focus groups** can be organised around these issues.

You should exercise care in regard to the composition of the focus group. Individuals, particularly those affected by a disease or health problem, should feel comfortable in speaking.

It is useful to put together a compendium of local diseases, vectors, therapeutic plants, and health practitioners. This is what you should refer to when discussing health issues with members of the affected

population. It is important to ensure that there are no misunderstandings. Furthermore, people are more likely to extend their trust to those who they feel understand their concerns or are at least making an effort to do so.

Finally, health professionals tend to see specialised medical knowledge as essential to planning and decision-making. It will be very important, therefore, to understand the nature of interactions between health staff and members of the affected population.

11.1.2 UNDERSTANDING WHO IS WHO

In many situations, humanitarian actors are a substitute for local health systems, either because of circumstances, or because they have failed to acknowledge these systems in their assessment. This not only compromises the sustainability of health interventions, but it can also undermine local health capacity in the long term. It is important, therefore, to work with existing health structures throughout the project process.

> Under the Taliban regime, in **Afghanistan**, the degree of involvement by the MoH remained minimal. Most health assessments were conducted outside of state institutions, with relief aid constituting the primary tool of NGO engagement.

Doctors, teachers, nurses, social workers, traditional healers, MoH personnel, and community health workers are in regular, if not daily, contact with the affected population. Their relationships with the population, their practices, and their perceptions of local health patterns, not to mention their technical and psychological *savoir-faire*, are important sources of knowledge. Working with them can help you to ground your intervention in local networks and to increase the relevance of your intervention to the population.

But this does not mean that all health professionals know perfectly the environment that they are working in. They are sometimes unaware of certain realities on the ground and do not appreciate the existence of informal support networks and alternative practices. Involving these professionals, therefore, should not exclude direct consultation with the affected population.

Carrying out a **stakeholder analysis** (using a **Venn diagram,** for example) can help you to identify who you should be working with. In particular, the relationships and power dynamics between various health practitioners and the affected population, as defined by participants (particularly non-health professionals), can be most informative.

Local health professionals are often respected and influential members of the community. Their involvement in a programme can strengthen its legitimacy. They can act as an intermediary between your organisation and the population, especially when the project involves addressing certain beliefs and customs.

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11.1.3 ESTABLISHING THE EPIDEMIOLOGICAL PICTURE

To construct an epidemiological picture of the area, data gathering on morbidity and mortality patterns can be carried out through MoH institutions. **Working in collaboration with local administrations is crucial,** but, in conflict situations, the legitimacy and authority of the state may be contested by national and international actors, and even by affected populations.

The epidemiological picture can be validated and enriched using participatory methods; the objective is to understand the prevalence of disease and disease vectors by zone and population group. Focus groups involving different population groups and interviews with local health professionals (see section 11.1.2.) can be useful.

Several techniques are available, such as the collective elaboration of **calendars,** to identify the seasonality of certain diseases and their association with vectors (like mosquitoes and flies) and natural phenomena (such as floods and droughts), and **incidence mapping,** showing the vulnerability of specific zones and population groups.

11.1.4 IDENTIFYING SPECIFIC NEEDS

Developing an accurate understanding of a community's needs, resources, social structure, values and coping strategies is critical to identifying key issues related to health beliefs, health-seeking behaviours and the practices of health providers.

At this stage, a collective exercise to pinpoint and prioritise needs and demands can occur. Specific groups identified in the stakeholder analysis can be invited to attend. Participatory analysis of needs—such as via the elaboration of a **problem tree**—can be a strong basis for participatory programme design.

> In south Sudan, the ongoing war and the lack of local health counterparts encouraged the international community to develop health projects. An NGO thus engaged directly with members of the population, conducted a participatory assessment that combined semi-structured interviews, focus groups, and discussions with key informants. Men and women in all parts of the region were asked about their health priorities. River blindness (or onchocerciasis) was flagged as a key concern. In partnership with the agency coordinating the Southern Sudan Onchocerciasis Control Programme, the NGO developed a project to educate local village-level health workers and to train volunteers.

11.2 DESIGN

11.2.1 DEFINING THE OBJECTIVE OF THE PROGRAMME

The main health problems identified in the assessment phase (causes and implications) can be ranked using **problem and solution trees.** This exercise often reveals different priorities to those perceived by humanitarian aid organisations.

An immediate effect of a crisis is the disruption of health systems, including disease prevention and control programmes. As a result, interventions place emphasis on disease monitoring and the control of large-scale epidemics, which tends to increase the focus on vertical programmes and the demand for curative care. Health systems operating in conflict contexts should ensure that not only are basic curative health services maintained, but also that preventive and public health services are developed. Such services can be efficiently implemented with the participation of local health networks (such as community health workers), and do not necessarily require expensive external inputs, thereby favouring programme ownership by the population and sustainability.

> In Tigray, Ethiopia, the possibility of establishing a community health system during the conflict in the mid-1980s was explored. A preventive approach was the priority, alongside improving the quality of the health service. Specific health programmes, involving farmers and the region's youth, were designed. They included a health education component and annual malaria campaigns and drainage programmes to dry swamps.

When consulting people on their health needs, it is common for the population to focus on highly medical solutions ('we need a clinic' or 'we need a surgeon', for instance), to the detriment of primary healthcare and preventive interventions that may be more appropriate. It can be important to resist such pressures, and to recognise the difference between needs and demands (see chapter 3).

11.2.2 TARGETING

Experience of the allocation of resources, not on the basis of health needs, but on the basis of ethnic and political priorities, demands caution when it comes to targeting. For example, the establishment of health services to serve populations that have been forced to relocate to camps may attract the attention of neighbouring populations that lack these services and legitimise relocation strategies. Refugee camps may also have better access to health facilities than host populations.

Before a strategy is agreed upon, it is important to explain clearly why certain groups or geographical areas are in most need of assistance, in order to minimise social friction and to increase transparency.

> In the mid-1980s, refugee camps in Honduras were offering prime medical care to Salvadorians, at a time when the local population was experiencing considerable difficulty in accessing health services. In agreement with the UNHCR and local authorities, the NGO responsible for healthcare decided to open a part-time outpatients department for members of the local population and to train Honduran health staff in administering essential drugs and carrying out minor surgery.

11.2.3 WHO SHOULD BE INVOLVED?

In the stakeholder analysis, the advantages of employing local health professionals has been developed. Nevertheless, the issue of the **balance of power** must be considered carefully. When members of the affected population participate alongside health professionals and project managers, those with the greatest professional standing are likely to have a greater impact on the process. Participation should not narrowly consolidate medical power, at the expense of achieving broad-based local involvement. In some settings, there can be political and/or socio-cultural barriers to expanding community participation initiatives, which will require prudent analysis at the design stage, so that community participation does not constitute mere 'lip-service'.

In the 1990s in Cambodia, many so-called community health projects failed to acknowledge the nature of the communist regime and its impact on social relations, and the fact that traditional systems of social organisation did not entail strong ties beyond those established within the nuclear family. Both factors explain, in part, why villagers were suspicious of community participation.

11.3 IMPLEMENTATION

11.3.1 WORKING WITH LOCAL STRUCTURES

At this operational stage, much can be achieved, and changes to implementation strategies can increase opportunities for learning.

Participation can translate into the establishment of suitable formal organisation (like a committee or board), which should be developed with significant community input, and which should have positive links with local MoH structures.

In some situations, you can work in partnership with existing health entities that have a strong foundation within the local population. But be careful, experience shows that some structures can be more bureaucratic than participatory and established at the behest of governments and international agencies.

In Afghanistan today, a few NGOs have successfully engaged communities in decision-making by interacting and involving traditional leadership bodies. In the eastern province, community *shuras* have been instrumental in: selecting TBAs and women eligible for a proposed auxiliary midwife training course; providing accommodation for health providers; and choosing clinic sites and providing land for them.

In many humanitarian crises, Community Health Workers (CHW) and TBAs have reportedly played a crucial role in delivering services in very difficult circumstances, often where no alternatives were available. Their potential role should be acknowledged and supported, even though volunteers can only provide a partial answer to existing health problems.

> During the Gujarat earthquake in India, humanitarian agencies worked with and employed members of the local population in a mental healthcare programme. Since expatriates could only assume a limited role in view of cultural, linguistic and social barriers, sharing skills with health volunteers was found to be the most effective way of providing care.

11.3.2 INVOLVING THE AFFECTED POPULATION: WHO HAS THE CAPACITY?

A key issue in ensuring the participation of affected populations in the implementation of health programmes is to make sure that they have the capacity to participate. The challenge is to identify who has and who does not have this capacity.

The time involved in participation also needs to be taken into account. In many instances, despite the emphasis on promoting the health of women and children, women, due to their heavy workload, can be virtually absent from local health committees.

After acute crises, for example, depressed, anxious or extremely upset people are not able to participate effectively. Individuals may no longer be able to process information or to make realistic decisions. Part of the health intervention, therefore, may involve setting up support groups in which people can talk about their problems and how to address them.

Conversely, groups that, initially, you might think could not be involved, may have the capacity to contribute strongly to a programme.

In Afghanistan, an NGO has trained community volunteers in treating bed nets (something that has to be done every year)—in return for a small commission. In fact, since sponging livestock and domestic animals with insecticide has proved cheaper and more effective than the standard technique of house spraying, full responsibility for malaria prevention is gradually being handed to local communities. Children are being taught how to spot breeding sites. The village health worker is then called on to organise drainage or treatment with larvicides.

Children can be involved in disease prevention and public health initiatives, notably by conveying information to other children and their families. UNICEF has worked for many years in the high altitude valleys of Pakistan, areas that have a high incidence of goitre. Given that schoolchildren are among the few literate or semi-literate members of the community, it was decided to involve them in communicating a message about iodine salt distribution, as part of a healthcare programme. A popular local story was adapted for the purpose and printed, thereby also serving as elementary reading material. Schoolchildren were able to spread the message among local families.[17]

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In East Timor, under the former Indonesian health system, which was characterised by a top-down approach, community participation was less of a priority. After the regime fell in 1999–2000, the implementation of health committees met with little success. An evaluation showed that the establishment of these health committees was nothing other than a quick-fix strategy to shift responsibility to communities.

11.3.3 SUSTAINABILITY

In a context of war and political instability, the financing of health systems usually decreases as a result of a decline in the capacity of the state. Given the conditions in countries affected by conflict, inputs, such as drugs, are provided free-of-charge during emergencies. If and when

[17] UNICEF experience in Pakistan,'News from UNICEF'. Number 114, 1983. pp12-14

the situation improves and moves into a development phase, drugs are usually provided on a cost-recovery basis, a participatory and complex process that requires experience, public information and transparency.

This is why establishing strategies to ensure the sustainability of the intervention (notably when it involves creating or supporting health structures), such as setting up **cost-recovery systems** and **integrating interventions into state structures** (MoH), and **training local health personnel**, are key elements of implementation. Putting these systems in place via a participatory process can ensure that these strategies are locally appropriate and feasible.

> In the municipalities of Luanda, Angola, the public health system suffered as a result of low morale and the poor salaries paid to staff. Consequently, personnel often engaged in rent-seeking behaviour. The NGO in charge of medical care thus designed a new system, whereby the population would make a financial contribution towards the cost of drugs. The revenue was used to provide bonuses to health workers.

Be careful when setting-up cost-recovery systems to ensure that they do not become a source of discrimination. It is important to clarify whether the contributions are in line with what the affected population is able to give. In some cases, it may be necessary to recognise that the centre simply cannot be self-sustaining.

> In the Kasaï region, a remote part of Eastern DRC, NGOs attempted to introduce a healthcare centre that would be sustainable for future use, which was why the programme included a cost-recovery system. However, at the end of the programme, it was found that the healthcare centre was not sustainable, primarily because the population was so isolated and had no access to cash. The centre thus had to depend on the aid organisation.

11.4 MONITORING

In most emergencies, the monitoring of health needs focuses substantially on quantitative targets (such as coverage in regard to measles vaccinations, the number of new cases diagnosed, and admission and discharge rates), with participation often limited to the collection of health data.

> During the 1995 floods in Bangladesh, trained health volunteers responsible for monitoring diarrhoeal diseases, particularly cholera, were actively involved in house-to-house case detection.

While there is regular consultation between health providers and members of the affected population, it is less frequent than one might expect. To ensure that lessons are learned and to solicit the views of members of the population, participatory methods that go beyond simple data collection and the use of checklists should be employed. In addition to supportive supervision and regular follow-up, focus groups and semi-structured interviews can generate additional information on people's needs and their changing priorities.

11.5 EVALUATION

When assessing the effects of emergency health programmes, changes in populations, individuals or health environment are considered. Interviews with a sample drawn from among the affected population are usually a mandatory part of the evaluation of humanitarian assistance.

Whether an external or internal evaluation, the process of consulting members of the affected population and health services is often based on a top-down approach. Consequently, the perceptions of experts and health managers and members of the affected populations, in regard to performance, can diverge significantly. To garner the community's views

on the positive and negative impacts of health programmes requires myriad skills and experience. A combination of interviews with individual households and focus groups can be very productive, although it may be necessary to ensure the **confidentiality** of some individual interviewees.

A complementary means of identifying the key issues is to request that health providers, health committees and volunteers involved in the programme carry out part of the evaluation to ensure that those being assessed feel included and valued. The importance of using evaluation results to strengthen humanitarian programmes and to make them more effective has been recognised for some time, but the evidence suggests that they are rarely shared with communities.

All too often, only health staff report on the evaluation results. Affected populations usually have little influence over them and how they are reported. In addition, many written evaluation reports are not intended for, and hence not designed to be understood by, anyone who does not work for the MoH, an NGO or a funding agency.

While some appropriate mechanisms, such as meetings and discussions, are needed to ensure proper feedback, it is essential that the presentation does not merely become an exercise in adding up numbers, and that the affected population understands the meaning of the results and can influence the outcome.

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