In this chapter we describe why research and evaluation go hand in hand with programme design and implementation and define various types of procedures that NGOs might use for evaluation themselves, or in conjunction with research organizations. Evaluation procedures, including assessment of needs and evaluation of intervention design, process, impact and outcome, are defined, and examples are presented. The ‘precede–proceed’ planning model is described in relation to the design of behavioural change programmes. Surveillance and the importance of cancer registries are also discussed.
Many different types of evaluation can be undertaken at various stages of an intervention. Not all the evaluation procedures described here can be carried out by NGOs, but this chapter provides a basic introduction to what might be done. Its aim is to provide a guide for collaborative work with a range of agencies that could help to fund, facilitate or implement evaluation procedures in conjunction with NGOs. In the context of this chapter, ‘research’ refers to all types of studies that might be undertaken, while ‘evaluation’ is applied to the various parts or components of a research programme. There is considerable variation in the terms used to describe evaluation procedures, and these are defined (largely with respect to short- and long-term perspectives) throughout this chapter.

Why evaluate

Setting goals and objectives is a key part of the planning and design of screening or intervention programmes. Ideally, research and evaluation procedures tell planning teams whether their goals have been achieved, what processes helped or hindered that achievement and how the results can be maintained, reached or improved. Intervention strategies should be designed hand in hand with evaluation procedures to ensure that, at each stage of the process, relevant evaluation is applied to ensure robust evidence to support continuing and further work. The results of multiple stages of evaluation should be examined to ensure that the intervention is continuing to achieve its goals. Long-term measures of research results alone do not allow insight into processes that occur en route.
Communities, as much as funding bodies, and health professionals have to be reassured that public money is being spent on interventions that are effective in achieving the desired objectives and that those objectives are associated with improved health. Interventions must be based on sound evidence, about both exposure to risk and cancer development (e.g. scientific evidence for a relationship between tobacco smoke and lung cancer) and the methods of intervention (e.g. evidence that interventions are effective in reducing exposure to risks), are cost-effective, are not associated with harm or increased risk and can be implemented practically. The results of interventions should be fed back to communities to provide evidence of action and engender support for further work.

Evaluation of complex interventions (e.g. behavioural) to improve health requires qualitative and quantitative evidence. A phased approach to the design and evaluation of interventions has been proposed [1], involving the theoretical basis (preclinical phase), modelling (Phase I), exploratory trial (Phase II), definitive randomized controlled trial (Phase III) and long-term implementation (Phase IV). The details of designing, reporting and interpreting such trials have been described in considerable detail [2] and highlight the complexity of the issues, skills and resources needed for comprehensive evaluation. The ‘gold standard’ design for testing the effectiveness of an intervention is the randomized controlled trial, which involves randomization to allow comparisons of treatments without prejudice from the participants (whether conscious or not) and ‘blinding’, which reduces bias on the part of both participants and researchers after the assignment of participants to a group. Unfortunately, many trials of behavioural interventions cannot achieve randomization, as some participants will not agree to partake in certain interventions, placebos can be difficult to identify (especially in dietary trials), blinding is challenging (e.g. for physical activity interventions), and doses of effective intervention (e.g. amount and duration) cannot always be identified. Many other types of research are, however, appropriate or can be complementary to the randomized controlled trial design. This is an important consideration when examining the transferability of results from a research setting to everyday practice and the context within which an intervention will be implemented.

Local evaluation is as important as national or other large-scale assessments. Local work should mainly address planned and ongoing interventions. It should be designed primarily in relation to local needs, to assess local efforts. In addition, standardized formats of evaluation allow construction of a national picture and adaptation of shared findings for the benefit of the wider community.

Monitoring of changes in health and disease is generally beyond the remit of small community projects [3]. Monitoring alterations in behaviour (e.g. changes in fruit and vegetable consumption) requires adequate, representative samples and, ideally, a control population, in order to exclude effects due to current changes. Results can also be used to provide feedback to the population and to support the need for separate, more robust research.

Types of evaluation
‘Evaluation’ has been defined as the systematic collection of information for the assessment of programmes [4]. Means and issues for assessing the effectiveness of health programmes, such as health communication, have been described in detail by the National Cancer Institute (USA) [5]. The key issues in evaluation are:

- Have the programme objectives been met?
- Were the changes that occurred the result of the programme?
- How well was each stage of programme planning, implementation and assessment handled?

A range of types of evaluation is available to predict the results of a programme, measure its results or help determine why certain results are seen [6]. Many different terms are used, and the nomenclature may vary, but the key evaluation approaches are as follows:

**Needs assessment and evaluation of intervention design**

The initial stage of designing an intervention involves making a needs assessment. This can cover many aspects, including a measure of the disease burden in a population, identifying the needs perceived by the population (e.g. access to opportunities for physical activity, restrictions on local alcohol sales), needs perceived by professionals (e.g. screening facilities and equipment) and information needs (e.g. whether the population already knows about healthy eating and how such messages can be communicated practically). Intervention design is usually evaluated when the goal of the programme is known but the process and routes of achieving the objectives are not yet defined.

Thus, programme design should be evidence-based, combining published intervention strategies with local needs based on an appreciation of cultural and socioeconomic background, and should include evidence that the intervention strategies are appropriate for achieving the declared objectives and identify indicators for later evaluation. At this stage, it is common to use formative research data to design a pilot project, which allows implementation of an intervention and its assessment by process evaluation. If the intervention programme includes health communication, formative research should include pre-testing of materials.
The following methods are appropriate for obtaining the views of the user community on the intended activities:

- self-administered questionnaire (e.g. to obtain individual reactions to proposed work);
- individual interviews (e.g. to ascertain individual responses and beliefs and to discuss issues);
- focus group interviews (e.g. to obtain in-depth information about beliefs and perceptions);
- theatre testing (e.g. to test respondents’ views on audio-visual materials); and
- readability tests (e.g. to assess reading comprehension).

Other qualitative approaches that may be used include structured and unstructured in-depth interviews with individuals and focus groups, observations [7], case histories, analyses of documents and visual material, interviewing and analysis of data from diaries and other sources.

**Process evaluation**

The assessment of process, which can also be described as monitoring, involves understanding and tracking the processes used to implement the intervention programme [4]. It is useful to provide evidence for the progression of the programme, to encourage the participants and to help ensure that the programme is evolving as foreseen. It should be done before impact evaluation. Process evaluation often relies on the collection of qualitative data. Quantitative measures are also used, covering:

- work performed, time schedules and expenditures;
- staff involved (rank, number);
- enquiries and responses;
- frequency of delivery and contact;
- numbers of individuals receiving intervention;
- costs of programme; and
- quality of intervention as perceived by users.

### Example of formative research

**Aim**

To develop targeted skin cancer prevention programmes for children in multi-ethnic Hawaii [6]

**Methods**

Group discussions, interviews with 216 children, 15 parents and 27 recreation staff; quantitative and qualitative analysis.

**Results**

Children were reluctant to dress in a specified manner and did not understand what skin cancer was. Parents and staff were enthusiastic that education and policy support would improve their own and their children’s habits.

**Conclusions**

(for use in developing intervention) Gradual change should be promoted, with environmental support provided and parents and staff being involved.

### Impact evaluation

Impact assessment is evaluation of the short-term effect of an intervention on the objectives. The importance of setting SMART (specific, measurable, achievable, realistic and time bound) programme objectives is crucial to programme development and subsequent evaluation. Most community intervention programmes are designed to change health through intermediate outcomes, e.g., to increase fruit and vegetable consumption by increasing awareness of the message, increasing perceived affordability and increasing access and availability.

### Example of process evaluation

**Aim**

To examine the feasibility of enlisting primary care physicians to implement a dietary intervention.

**Methods**

Group physicians introduced a self-help booklet to promote dietary change at routine appointments. Delivery of the booklet was recorded at the time of the appointment; recipients were contacted 3 months later to ask whether they had received and used the booklet. Discussions and interviews with 216 children, 15 parents and 27 recreation staff. Quantitative and qualitative analysis.

**Results**

96% of participants responded; 90% remembered reading part of the booklet and had been more likely to read it with increasing time spent discussing it.

**Conclusions**

The primary care setting can be used to deliver interventions to change diet. Training a health team and repeating the dietary advice at subsequent visits might increase the success.

### Example of impact evaluation

**Aim**

To assess whether a school-based intervention was effective in reducing risk factors for obesity [14]

**Methods**

The intervention was assessed on the basis of measures of growth (actual height and weight), diet (24-hour recall), physical activity and sedentary behaviour (questionnaire), psychological status (questionnaires on self-perception, dietary restraint, body shape perception), and knowledge and attitudes (focus groups and scoring for groups of children).

**Results**

Changes in vegetable consumption, sedentary behaviour and global self-worth were noted between intervention and control groups and by weight.

**Conclusions**

The programme brought about changes at school level (e.g. improved the environment for changes in behaviour and altered the school ‘ethos’) but had little effect on the children’s behaviour.
**Example of outcome evaluation**

**Effect of community-wide prevention of cardiovascular disease on cancer mortality rates [16]**

**Aim**
To examine the long-term trends in cancer mortality rates after the North Karelia intervention programme.

**Methods**
Age-adjusted mortality calculated for male population, aged 35-64 years in North Karelia during 1989-91. General linear models used for analysis.

**Results**
During the 20-year study period, the cancer mortality rate decreased by 43.5% in North Karelia and by 22.7% in all of Finland.

**Conclusions**
The results support the hypothesis that programmes to reduce the risk for cardiovascular disease can lead to beneficial changes in mortality from cancer, although such changes take longer to manifest.

**Outcome evaluation**

The ‘outcome’ is the total long-term effect on the aim of the programme (actual health behaviour, e.g., long-term maintenance of desired behaviour) of all work within an intervention [15]. Outcome evaluation can also be seen as determining the effect of the intervention on indicators of health and quality of life. Ideally, health behaviour research includes an independent (bio) marker of behaviour in order to demonstrate change rather than reported behaviour. For practical reasons, biomarkers are usually used only for sub-samples, for example, measurements of urinary cotinine to assess smoking behaviour.

One of the limitations of outcome evaluation (and complex interventions in general) is the inability to control for factors associated with the immediate intervention which might influence the results. For example, national campaigns by vested interests or policy implementation on taxation might have a greater influence on behaviour than local action. Other examples include employee strikes, weather conditions, influenza epidemics and transport problems: all have effects for certain periods, which must be considered in evaluations. Information obtained from an outcome evaluation might include changes in:

- morbidity and mortality;
- tumour size;
- exposure to risk factors; and
- rates of recidivism.

Ideally, any intervention should be assessed comprehensively for its effect on changing health (or health behaviour) in both positive and negative directions, and possible side-effects should be considered, as well as the major health outcomes.

**Planning evaluation**

The ‘precede–proceed’ planning model for behavioural change [17] seeks to give individuals the understanding, motivation, skills and active engagement in community affairs necessary to improve their quality of life. The model includes predisposing, enabling and reinforcing factors within communities and the environment.

The model has nine phases, the first of which is social diagnosis of self-determined needs, wants, resources and barriers in target communities, which can be identified through formative research and issues relating to quality of life. Other phases that allow planning of implementation are:

- epidemiological diagnosis;
- behavioural and environmental diagnosis;
- educational and organizational diagnosis; and
- administrative and policy diagnosis.

These early stages of planning should influence the design and implementation of the intervention, which in turn is associated with evaluation procedures, as illustrated in Figure 1.

The elements of an evaluation design proposed by the National Cancer Institute (USA) [5] are as follows:

- clearly defined objectives,
- definition of data to be collected (in relation to the objectives),
- method (design that will allow valid, reliable measurement),
- identification of collection instruments,
- data collection procedures (protocol),
- data processing (how will the data be prepared for analysis) and
- data analysis (statistical techniques).

Evaluation and monitoring (ongoing collection of data) are effective means of obtaining information about the work of health personnel, community involvement in prevention programmes, community knowledge about disease risk and behavioural change. These data can provide support for programmes for changing health behaviour and reducing exposure to risk factors. In a national programme, health outcomes are expressed as morbidity and mortality and can be measured effectively only by surveillance.
surveillance for behavioural change, analysis and feedback. In surveillance, reporting, confirmation, surveillance are detection, registration, with programmes designed particularly for infection, age-standardized cancer registration. Although these actions are activities, measured from indicators of cancer incidence or mortality, adverse reactions (e.g. health or economic) and quality of life [23]. Surveillance must be related to quantitative data on prevalence, methods of diagnosis, stage distribution, treatment patterns and survival [19]. A conceptual framework of public health surveillance [20] and action includes eight core and four support programs work. Research Surveillance planning, and relevant risk factors must be used as feedback for the design of interventions [21]. Mathematical models have been used to quantify the effects of preventive measures [22], which take into account indices of effectiveness, the time course of risk reduction and possible confounding factors. Typically, the measures of success in an intervention programme are cancer incidence or mortality, adverse reactions (e.g. health or economic) and quality of life [23]. Surveillance must be related to policy and programme implementation, with programmes designed in response to the available data. the relevant measures of activity include knowledge about levels of risk, attitudes, intention, behaviour and exposure. Identifying data on the incidence and mortality from particular cancers is crucial in health surveillance planning, and relevant risk factors must be used as feedback for the design of intervention programmes [21]. Mathematical models have been used to quantify the effects of preventive measures [22], which take into account indices of effectiveness, the time course of risk reduction and possible confounding factors. Typically, the measures of success in an intervention programme are cancer incidence or mortality, adverse reactions (e.g. health or economic) and quality of life [23]. Surveillance must be related to policy and programme implementation, with programmes designed in response to the available data.

Key references
