Developing Evaluation Indicators for Consumer and Community Participation

Margaret Wohlers

Evaluating is an important component of any health care program. Assessing how well and in what areas a program has succeeded helps to establish its value and guide future program development. The National Resource Centre for Consumer Participation is increasingly asked for advice on how to evaluate consumer participation activities, and for examples of performance and outcome indicators. This article draws heavily on the theory of participation, and where possible, demonstrates the theory with practice examples in an effort to encourage progress toward the development of indicators for the evaluation of consumer and community participation activities.

Evaluation is a complex process, as is the process of developing indicators. Indicators provide a measuring stick against which success is gauged. “An indicator is a sign of your program’s anticipated processes and impact. Indicators are used to provide a comparison to assist with decisions about the extent to which your criteria have been met” (Wilson & Wright, p. 21).

Indicators should be included in the evaluation framework to assess process and to ensure baseline data will be available when needed for later impact evaluation. When evaluating consumer participation programs, indicators should not be used to measure subjective things such as the 'likes' and 'dislikes' or "...where the evaluation is focussed on identifying the unknown or unexpected impact of a program, service or project.” (Wilson & Wright, 1993, p. 21) because this type of evaluation is directed not so much at measuring the impact of a program but exploring how or why it has had an impact.

Indicators can be classified into three types: process, performance and outcome indicators. For the purpose of this article, the evaluation process is defined as “evaluating all the processes involved in delivering a service, program or project (Wilson & Wright 1993). In the narrower context of consumer participation, the focus would be on the process of consumer participation, for example, those strategies put in place to address known barriers to participation, organisational capacity to undertake a participation program. Evaluation in this context would focus on the extent to which good practice principles for consumer participation were identified and built into the strategy. The Illawarra Area Health Service report, Consumer Participation Processes: Evaluation, used a measurement tool which looked at five aspects of participation: leadership, organisation, resource mobilisation, management and needs assessment. An additional tool was provided for individuals to assess participation processes.

Much work has already been done in the area of measuring performance in the Australian health system and this includes indicator development processes. In the National Health Performance Committee’s discussion paper, Measuring Performance in the Australian Health System, performance indicators have are identified as encompassing access, efficiency, effectiveness, continuity, acceptability and appropriateness. Similarly, accreditation bodies have made progress in the area of performance measures. The relevance of this work, however, will remain on the
margins of consumer participation until consumer participation indicators are developed with consumer input and incorporated into these broader frameworks.

Evaluating for impact involves “evaluating the short term impact or effects of a service, program or project” whilst evaluating for outcome involves “evaluating the long term effects of a program, say, a few years after it was conducted” (Wilson & Wright, 2000). In the context of consumer participation, impact and outcome indicators would be looking for evidence that the consumer participation activity resulted in change for the better for consumers as users of health services. Outcome indicators for consumer participation could therefore encompass evidence of shared decision-making and collaboration. Evidence of improvements in health outcomes, evidence of an increase in consumer satisfaction, evidence of increased participation of those traditionally marginalised by mainstream health services, evidence of active involvement of consumers at all levels of the development, implementation and evaluation of health strategies.

This article will focus on process indicators but calls for people to start thinking about impact and outcome indicators.

In 1999, the journal, Health Expectations, issued the intent to publish articles concerning evaluating consumer participation (Entwistle 1999, pp. 75-79). Whilst methods review papers did appear in subsequent issues, no articles were published that dealt specifically with the development of evaluation indicators (personal communication, 15 July 2002). As a result, a search of the literature, along with consultations with key people working in the field, was used to identify examples of consumer participation programs evaluation. This research did not however, locate any examples where outcome indicators were part of the evaluation framework.

This research investigated the following questions:

1. Can existing evaluation frameworks be used to evaluate consumer and community participation programs?
2. What is the relationship between evaluation and various types of indicators?
3. Can we use outcome indicators as ‘evidence’ of the benefits of consumer and community participation?
4. What needs to happen to progress the development of indicators for consumer and community participation?

**Evaluation**

“Evaluation involves making decisions about the worth or value of your program, project or service. Therefore you will need to develop criteria to enable you to do this”. (Wilson & Wright 1993, p. 20).

The indicators or criteria used to evaluate consumer participation activities need to be developed to reflect the individual nature of each activity or program. There is no standard set of indicators that can be applied across the board. However, what follows
are some examples of possible process indicators which could be considered for application or modification.

Assessing Present Conditions

The cyclical process of evaluation is the same for consumer participation as it is for most evaluation frameworks. The process starts with an assessment of present conditions, to the development of indicators, strategies for participation and ending with the inevitable question—did we make it? (Department of Health 2000). A process indicator could therefore be present conditions assessed to identify a baseline. Two assessment tools are available to assist with assessing baseline data. These are Consumer and Community Participation Assessment Tool for Hospitals and Primary Care Self Assessment Tool for Community and Consumer Participation. Both tools guide organisations through a series of questions, assisting them in assessing their past and present consumer activities.

Involving Consumers in the Planning Process

Evaluation of consumer participation “… starts at the point that the organisation begins to plan their involvement in supporting participation. It involves making judgements about the worth and appropriateness of your strategies for participation and reaching conclusions that will inform future practice.” (Department of Health 2000, p. 111). Another process indicators could therefore be consumers are involved early in the planning process.

A example of involving consumers early in the planning process occurred when project partners, Lyell McEwin Hospital and the Northern Metropolitan Community Health Service, worked together to explore community needs for acute care services at the Lyell McEwin Emergency Department, and to link community services more closely (Lyell McEwin Health Service 2002).

At the beginning of the project, a Project Advisory Group, which included community representatives, identified goals, objectives and key indicators. The relationship between the project’s goals and objectives and the indicators used to demonstrate their achievement is reflected in the following example:

Goal

To improve the quality of care provided by Lyell McEwin Hospital acute care services through the establishment of links between the Emergency Department, consumers of health services and community based health organisations.

Objective

To identify and respond to community needs (including minority groups) in relation to the Emergency Department at the Lyell McEwin Health Service.

Key Indicator

Evidence of increased participation and contribution by consumers in the planning and development of policy within the Lyell McEwin Emergency Department.
The project’s evaluation identified differences between what staff perceived as priorities compared with the priorities consumers identified. As a result, the project included recommendations for ongoing partnership with the community, and recognition and support for the Emergency Department Consumer Advocacy Group.

In this project, baseline data was gathered which identified differences in how staff and consumers perceived priorities. This data would add value to the evaluation process if used later down the track to measure whether there had been a change in perceptions. In addition, partnership between consumer and service provider was established early in the process and continued throughout the whole process.

**Barriers to Equal Participation**

The complex and variably unequal relationship between consumer and provider should be recognised in the form of a process indicator such as indentifying barriers to equal participation. Similarly Silburn (2001) documents other barriers such as language, culture, illness, lack of interest or understanding of the value of participation. Strategies that help overcome these barriers are also identified by Silburn and referred to as 'appropriateness of the method' of participation chosen. Therefore another process indicator could be identifying strategies for overcoming known barriers.

**Valuing the Experiences of Service Users**

In discussing the evaluation of women’s health services, Wilson and Wright (1993, p. 20) highlight the importance of:

- values and experiences of service users;
- principles or philosophy of the service and staff;
- workers knowledge and understandings;
- agreed views about what is considered good practice, process and desired effects;
- goals of funding bodies; and
- objectives of the particular program.

These same attributes are present in any consumer participation program. It would be valuable to include a process indicator to ensure the values and experiences of service users are acknowledged, for example, identify how experiences of service users are valued.

**Best Practice Principles in Consumer Participation**

An audit of consumer participation activities within South Australia’s Flinders Medical Centre provided insight into the organisational policies and practices that may or may not be in place. Activities were categorised under headings of organisational level, organisation wide and a range of divisional/departmental/project activities.

Following the audit, the Consumer Participation Reference Group went on to advise on the strategic direction, policies and practices Flinders Medical Centre could use to
more actively engage with consumers. The Consumer Participation Policy provides guidance to staff and consumers about their roles and responsibilities, and provides guidelines for best practice consumer participation, rationale for the program, confidentiality of patient information, consumer payment/reimbursement and guidelines for volunteers within the Centre (Johnson 2002).

This example illustrates the need to identify an organisation's commitment to consumer participation and the need for a process indicator such as identify best practice principles as part of the consumer participation strategy.

**Existing Evaluation Frameworks**

Evaluation frameworks exist for all manner of health activities, sectors and disciplines including community health services, acute health services, health promotion initiatives and health policy programs. Evaluation frameworks exist for direct and indirect services, service improvement, from within programs through collaboration, for accreditation and through programs for strategic initiatives. Evaluation ‘preferences’ have moved from first to fourth-generation evaluation. This suggests that community development should move away from an evaluative model based upon empowerment, towards one that considers health and social capital (Guba & Lincoln 1989). In the acute health sector, evidence-based methods dominate as a framework for the evaluating medical interventions, for example, the randomised control trial.

**Philosophical Frameworks and Value Systems**

Just to add to the complexity there are differences in philosophies and/or values which influence processes and commitment within an organisation. The differences in philosophical frameworks in primary care can be seen in Table 1. Process, philosophy and capacity can greatly influence the quality of a project and therefore warrant an indicator which challenges the organisation to acknowledge its ‘thinking’ framework. An indicator is needed to identify the philosophical framework or value system which underpins the organisation.

<table>
<thead>
<tr>
<th>Name of development group</th>
<th>Frameworks used</th>
<th>Elements of the framework which was focussed on</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women’s health group</td>
<td>Women Centred Approach</td>
<td>Demonstration of a women’s centred approach</td>
</tr>
<tr>
<td>Northern Metropolitan Community Health Service</td>
<td>Ottawa Charter for Health Promotion</td>
<td>Strengthen Community Action</td>
</tr>
<tr>
<td>Adelaide Central Community Health Service</td>
<td>Ottawa Charter for Health Promotion</td>
<td>Strengthen Community Action</td>
</tr>
</tbody>
</table>
Statewide Primary Health Care Network | Capacity Building Model | Workforce development
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Noarlunga and Inner Southern Community Health Services | Capacity Building Model | Creating supportive environments
Department of Human Services - Service Agreement | Primary Health Care Approach | Access and Equity for the most disadvantaged
South East Primary Health Care Providers Group | Primary Health Care Approach | Equity of health outcome

(Community Health project Working Group 2002, p. 13).

**Capacity to Undertake a Consumer Participation Program**

Organisations also need to question early in the process what capacity they have to implement consumer participation activities or programs. This creates the need for a process indicator such as identify the organisation's capacity to undertake a consumer participation program.

Wingecarribee Health Service undertook four workshop sessions of two and a half hours duration where 43 managers discussed issues such as:

- the organisation's capacity to undertake effective community participation;
- the values, knowledge and skills that will need to be effective;
- the challenges of involving the community in health decision-making; and
- actions that can be taken to address the challenges.

Capacity assessments were completed and analysed. Whilst caution has been advised regarding the analysis, conclusions were drawn that members of the Wingecarribee Health Service have an understanding of the organisation's commitment to community participation. Suggestions for future action to increase the organisation's capacity to effectively involve the community were also identified (Brown 2001).

**Issues Specific to Consumer Participation**

The politics of consumer participation will also need to inform the development of the evaluation framework. For example, development of partnerships between consumer and provider has been identified as a process to be aspired to. These partnerships can be at a personal level between consumer and provider, or they can be between consumer advocate and a board of health service providers, and can be stressful for all involved. It is strongly argued in the literature of consumer participation that the consumer is the least empowered and care must be taken to adequately facilitate their participation.
“…partnerships require the benefits and the risks of joint ventures to be shared. Though users have some shared concerns with professionals … they also have very different interests which may conflict with the interests of the other ‘partners’. Furthermore, the ‘risks’ they [consumers] take are different from those taken by professionals … Patients have much more to win and much more to lose: the type of health care they receive may be a matter of life or death” (Hogg, p. 171).

Another example of the politics in consumer participation is the popular but frequently criticised method of involving consumers through a ‘survey’ designed to gather feedback from consumers about health services. This method is criticised because it involves one-way communication, and is a ‘one-off’ activity not designed for sustained consumer participation or the development of partnerships.

For some time now there has been a push for the participation strategy to be consumer initiated (Wadsworth 2001, p. 63) and there is accumulating evidence of the importance of consumers to the process with the recently released research report, Consumer Participation in Safety and Quality at Flinders Medical Centre: The Search for a Consumer-Focused Model.

Evidence for Consumer Participation

The publication, The Evidence Supporting Consumer Participation in Health, provides an overview of the growing evidence that consumer participation in decision-making in individual care leads to improvements in health outcomes. For example, quality information is known to facilitate decision-making; active consumer participation leads to more accessible and effective health services; effective consumer participation uses methods that facilitate participation by those traditionally marginalised by mainstream health services. (Consumer Focus Collaboration 2001, p. 2).

This publication provides examples in the acute health sector where participation at the individual level led to improved outcomes, for example, “A study … showed women with breast cancer were less likely to suffer depression and anxiety if treated by a doctor with a more participative consultation approach”. (p. 3) At the organisation level, a study undertaken by Alexander and Hicks (p. 23) “… concluded that developing an understanding of people’s values provides important information to support more equitable and effective decision-making for health services planning”.

These examples illustrate that it is possible to aim for impact and outcome data when evaluating consumer and community activities. It also shows that up until now the only scientific evidence comes from randomised controlled trials. Extra effort is needed to demonstrate the value of consumer and community activities across all sectors, not just the acute sector, if the current swell of support for consumer and community participation is to be sustained.

Although the focus here has been on identifying process indicators, the importance of the other types, performance and outcome indicators which should not be underestimated. Outcome indicators are more difficult to identify and much work is needed, particularly in the primary health care sector. In the meantime, services are encouraged to think about the different types of indicators (process, performance and
outcome), to gather that essential baseline data, and to start including outcome type indicators in their evaluation framework. Otherwise the data will be severely limited when the time comes to assess processes, performance and outcome or impact.

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The National Resource Centre for Consumer Participation in Health is keen to hear from anyone working on or interested in the development of an evaluation framework for consumer and community participation. The Centre is also keen to gather examples where consumer participation activities have been evaluated, particularly where the framework included impact and/or outcome indicators and ‘evidence’ that consumer and community participation can lead to better health outcomes for individuals and increased provider confidence. If you are able to help, please contact Margaret Wohlers at: Email: m.wohlers@latrobe.edu.au or Ph: (03) 9479 3947.

**References**


Community Health Project Working Group 2002, *Performance Indicators in Community Health: Development of a Process*, Department of Human Services & Community Health Services, South Australia


NSW Health 2000, *Indicators to Help with Capacity Building in Health Promotion*, NSW Health Department, Sydney.

