Framework for assessing the impact of new health initiatives and policies on consumers

Will this harm anyone?

What are the risks?

Will those in need understand the message?

Is it sustainable?

How will we know if it has worked?

What if we do nothing?

National Health Priority Action Council
Consumer Network
2005

Framework for assessing the impact of new health initiatives and policies on consumers

What is this framework trying to do?

The framework is designed to assist individuals and committees involved in consultative and decision-making processes in analysing policies, grant applications and initiatives presented to them for consideration. It has a particular focus on access and disadvantage, setting out a series of steps which can be followed to assess the degree to which a proposal has been designed with the needs of disadvantaged groups and individuals in mind.

The framework provides a useful tool for identifying gaps in the development of programs where the needs of disadvantaged groups might not have received due consideration. It is not designed to measure or evaluate the success of a program in its application.

Who is it for?

The framework has been designed for use by consumer representatives on the National Health Priority Action Council (NHPAC) and its expert advisory groups, but is equally applicable for use by other committee members.

Why do we need it?

Consumer and community representatives play several key roles in planning and decision-making processes:

- They bring the perspective of the users of the health system to the decision-making process.
- They can serve as a reminder of the needs and desires of individuals and communities.
- They may have a personal experience of the issues, illnesses or conditions being discussed and can offer a unique perspective as a result.
- They may come from a consumer or community organisation and can bring the views of a wider range of people to the decision-making process.
- They are not working in the health system and are therefore able to provide a unique 'patient' or 'community' friendly perspective.

Acting as a consumer representative can be quite a difficult task. It is impossible for the consumer to represent the views of all people who might be affected by an initiative or policy.

So how can the role of the consumer representative be made more effective? Firstly, it is useful to think about the range of perspectives that the consumer representative can bring:

Your perspective as an individual	The perspectives of the group of people (consumer / community organisation) that you are associated with	The perspectives of the entire population of people potentially affected
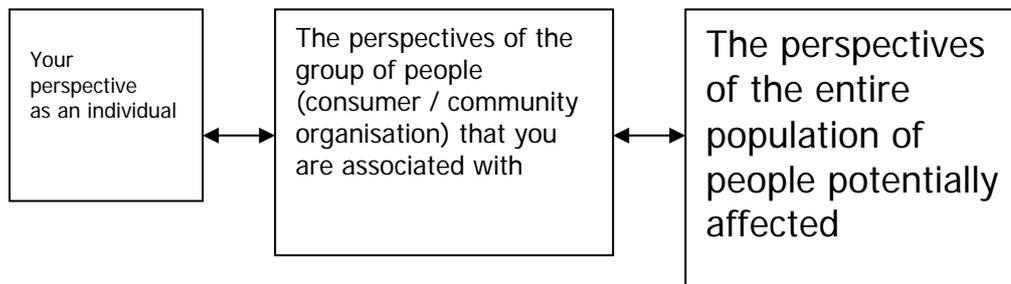
Obviously, their perspective as an individual and the perspective of the group of people they associate with are important. But health committees and consultative bodies are attempting to improve the health outcomes of all people. Only a very small minority of people currently using the health system are linked to consumer organisations. Some groups are particularly under-represented in these organisations (for example: people who do not have English as their first language, people from low socio-economic backgrounds, people with mental illnesses, people from rural areas, Indigenous Australians, young people, people with problems associated with alcohol and other drugs). Yet these people are, in many ways, the most likely people to be at some distance from health promotion initiatives and health services and therefore perhaps, in the greatest need.

People from these groups experience significant barriers that can prevent them from accessing health services and health promotion messages and programs.

There is another way to think about consumer or community representation. Perhaps the most effective role for a consumer or community representative is to make sure that the process, policy or initiative has taken the broadest range of views and perspectives into account. This shifts the role of representative from 'teller of the story of the consumer experience' to 'ensure that the real perspectives of the people in greatest need have been taken fully into account'.

Taking account of the diversity of the Australian community:

The Australian community is very diverse. It comprises people from a wide range of ethnic backgrounds, cultures and educational backgrounds. Consumer representatives have a responsibility to ensure that the processes and decisions they participate in have taken into account the broadest possible range of needs. This is a daunting task. They are better equipped for this task if they have a clear understanding of the diversity of the community, of the range of needs that different groups have and of the barriers that prevent people from accessing the services and programs that they develop.

Try to think about what people will need in order to participate in the initiative under consideration. They might, for instance, need to be able to read and write in English, to have access to a telephone, to have money to pay for fares to get to where the initiative is located, to have access to free childcare, to have a high self-esteem, to belong to a particular cultural group or to be assertive. Then try to determine whether the group of people - being targeted has these things or whether there are barriers that will prevent them from benefiting from the initiative or policy.

How to use this framework:

This framework is a guide for consumer representatives and other committee members in taking on board the needs of the community.

Try to focus only on a finite area of the work you are involved in – one policy, one program or initiative. This will make it easier to identify particular issues and problems.

Read through the materials that you have been provided with that explain the program, policy or initiative.

The checklist is set out under six key headings:

1. Defining the problem
2. Deciding on the approach
3. Target group – winners and losers
4. Safety, privacy, consent and human rights
5. Learning, flexibility, participative processes
6. Accountability, sustainability, risk assessment and evaluation.

Under each heading is a set of core questions. These are designed to help you to critically assess the policy, program or initiative that you are working on.

The *Checklist with Prompts* provides you with some explanation of what each question is trying to discover. You are also provided with a blank checklist – this is your workbook. Read through the questions one section at a time.

Have a look at what the prompts say for each question then write some short dot points next to the question in your workbook. Skip some questions if the answers are not immediately obvious – you can always come back to them later. Your observations might become clearer as you get further into the checklist. Don't be afraid to move around the checklist from section to section or to start in the section that you have the clearest thought about. This will get you moving.

Remember that the workbook is yours – you don't need to show it to anyone. You don't have to be neat, just jot down what you are thinking. You can always do a messy one first and then write a more orderly one when you have finished working through the questions. If you don't like using words, use drawings or diagrams to express what you think. Remember, it's a tool to help you organise your thoughts, not a test!

Feedback:

This is a new area for us and we want to learn as much as we can from you so that we can improve this framework. Please feel free to let us know how you found it and how we can improve it.

Checklist with prompts:

Defining the problem	
1. What problem are we trying to solve by this initiative/policy?	This seems obvious but sometimes the problem is not clearly stated. It is impossible to evaluate impact if we don't know what we are trying to change. The problem might not be a health condition, but a health system problem that is preventing people from becoming more healthy. Even if the initiative is moving ahead at a pace, it is useful to ask this apparently naive question, as it provides a chance to see if everyone is working towards the same end.
2. What evidence is there that this is a significant problem?	Evidence is often lacking. Here we are trying to see why this problem was chosen over other problems. Was it the easiest to solve? Is there some political pressure? Is there consumer/community pressure? Have the other problems been declared 'too hard'? Is evidence defined broadly – are the voices and experiences of consumers being taken into account?
3. What would happen if we did not do this and decided to use these resources elsewhere?	This is seldom asked but is an important thing to consider. Is there enough happening already for this problem or this group? Are we doing this because we have some spare funds available? Who is driving this initiative – politicians, the Health Department, the community? Who has a role in deciding whether the initiative goes ahead? Would the funds be better applied elsewhere? Will it actually make things worse for some people?
Deciding on the approach	
4. What evidence is there that this approach will have a positive impact?	Choosing the most appropriate approach is vital to the success of the initiative or policy. Is the approach clear? Is there a range of different approaches? Have the approaches worked anywhere else? Are there significant differences between the group that the approach worked on and the group we are considering? What level of confidence can we have that the approach will actually work for the group we have identified? Were any other approaches proposed?
5. Have any alternative approaches been considered?	The proposed approach may not be the best way to have an impact on this problem. What alternative approaches have been considered? Who is pushing this particular approach? Do they have a vested interest?
6. Is there any information available about the cost-effectiveness of the model being chosen?	As well as looking at the effectiveness of an approach, we need to have some idea about whether the approach is cost-effective. We have a role here as citizens ensuring that public money is well spent. If an approach is not cost-effective, we could recommend that the money be spent on another priority. Will this initiative just shift the cost elsewhere? To the community? Will this have a negative impact?

7.	What else is already being done to solve this problem?	Often initiatives are proposed without reference to what is already happening to address the problem or issue. Government departments tend to work in 'silos' and communication between sections is often poor. There are many different initiatives that target people with, or at-risk for, chronic illnesses and sometimes little co-ordination between them. At the very least, the proposers of an initiative or policy should know what else is happening in this area and how their policy or initiative will work to complement other efforts. Duplication needs to be minimised. This can only be done if we have had the chance to 'map' what is already happening. Other consumer representatives or consumer and community organisations are a good source of information about initiatives in other areas.
Target group – winners and losers		
8.	Who is the primary target group or the group most likely to be affected?	Is this clearly set out? If the target group is 'all people with diabetes' or 'people at risk of heart disease' then it is reasonable to ask for some more focus. Which people in particular? Why them? Are there secondary targets (carers, family members)? Getting some clarity here makes it easier to measure success or impact.
9.	Who is likely to benefit from this and who will lose?	It is sometimes easy to see who will benefit but it is equally important to think about the losers. Will the policy or initiative further disadvantage anyone? Are there unintended victims? Remember that bringing about change in one area can cause unexpected changes in other areas.
10.	What will people need to have in order to participate in or benefit from this initiative?	What will people need in order to participate or benefit from this: English literacy, health literacy, access to a telephone or internet-connected computer, money, a home, transport, energy, high self-esteem, advanced social skills, assertiveness, spare time, a supportive social network, carers? What if there are people who have not got these things? What are the barriers to participation or access or benefit? How can the design be changed to minimise these?
11.	Is the primary target group already advantaged and likely to access what it needs without this initiative?	White, English-speaking, educated, middle class, health literate people often have the skills and resources they need to get what they need from the health system. Yet they are sometimes the most direct beneficiaries of new initiatives. Sometimes this is not intentional; it is just that there has not been adequate attention paid to the barriers that prevent anyone else from benefiting. Sometimes it is just that the designers of the initiative come from this group and they have assumed that everyone is just like them. It can be a real challenge to move beyond this advantaged group, but the whole purpose of health initiatives is to address this imbalance.

12.	Who is not represented in the design of this initiative or program and how can their perspectives be sought?	Are there groups of people who will be directly affected by this initiative or policy whose voices have not been heard in some way in the planning/design process? How can their voices or perspectives be included? Can we slow the process down and set aside some time for input from harder to reach groups?
13.	Will people with chronic illnesses be disadvantaged?	Even though we design initiatives disease by disease, life is usually more complex than this. People, communities and families have a range of illnesses and risks all at once. The individual disease approach that we take does not usually reflect the complexity of people's lives. Will people who already have one or more chronic illness be disadvantaged by this initiative or policy? Will their illness or the limits it places on them act as a barrier to participation? How can this be overcome?
14.	Can the messages be understood by the people who most need to access them?	Who has developed the messages and the information that is associated with this initiative? Has the target group had any say? There is ample evidence in the peer education and health promotion literature to support the involvement of communities in the design of their own health messages, services and initiatives. Have these principles been followed or is someone telling you that they 'know the needs of the target population already'? Do they?
15.	Is the method for delivering these messages the best way to reach this target group?	Even if the messages and the information are right for the target group, the delivery method may not be effective. How has the delivery method been chosen? How do we know it will work? Have alternatives been considered? Who was asked?

Safety, privacy, consent, human rights

16.	Is the initiative or policy likely to cause harm to anyone?	Has there been a risk-assessment to determine any harm that might come from the initiative? Is it safe? Will there be people who are further disadvantaged by the initiative?
17.	How have the impacts of this initiative/policy on the rights of participants and others been considered?	Is this initiative or policy likely to cause harm or disadvantage? How are individual and community rights to be protected? What happens to participants when the initiative finishes? Will they be worse off?
18.	How are issues of privacy and consent dealt with?	How do people become involved? Is it voluntary? Is there informed consent? What confidence do we have that the participants really understand what they are participating in and any consequences their participation might have? How is their privacy protected? Who has access to the information that is collected?

Learning, flexibility, participative processes	
19. Is there a process in place for feedback, reflection, ongoing learning and flexibility of approach?	Situations and contexts change over time. Is there scope for reflection and change in the initiative? Is there some way to determine barriers, mistakes or problems early in the life of the initiative and to make changes in the approach to take account of these? Are there set points for reflection throughout the implementation of the initiative?
20. Is there a process in place for consumer and community participation?	Having a consumer representative on the development group for the initiative is one level of participation but does the initiative itself have consumer and community participation in its implementation and evaluation?
Sustainability, accountability, risk assessment & evaluation	
21. Is this initiative likely to be sustainable or able to be integrated into the health system?	There have been many one-off health initiatives over the years and some of them have produced a positive benefit for people involved in them, but how many have resulted in system change that has been widespread and beneficial? Have a look around the decision-making table – are people from the health system represented? Are they thinking about how this initiative can be embedded into the system so that it can have longer-term benefit? Is this initiative working alongside the mainstream health system without any clear links?
22. How will we know if it has worked?	We often get to the end of an initiative and realise that we cannot tell whether it really made any difference or not. How will impact be measured? Will the process of implementation be evaluated in some way? Is there some internal system for evaluation, reflection, learning and change? What if it is going wrong half way through? How will we know? Is there a mechanism for remaining flexible, for modifying the approach as we go along? Is there any independent evaluation?
23. How is it accountable to communities? To taxpayers?	How do we know that this is the best way to spend the money? How can people interact with the initiative? Is there a steering committee? Is it clear how decisions will be made? What is in place to make sure that the processes are transparent?
24. Have any potential risks and threats been identified?	One of the most important aspects of good planning and design is risk assessment. Has anyone thought about the things that might threaten the success of the initiative? Is there a plan to deal with these risks? Risk to individuals participating in or otherwise affected by the proposal must also be considered.

Summary

There is a section at the end of the table to write some summary observations. In this section, read over what you have written on the checklist and try to summarise your observations and concerns. This can act as a prompt for you in the next committee or group meeting.

Checklist

Defining the problem	
1. What problem are we trying to solve by this initiative/policy?	
2. What evidence is there that this is a significant problem?	
3. What would happen if we did not do this and decided to use these resources elsewhere?	
Deciding on the approach	
4. What evidence is there that this approach will have a positive impact?	
5. Have any alternative approaches been considered?	
6. Is there any information available about the cost-effectiveness of the model being chosen?	
7. What else is already being done to solve this problem?	
Target group – winners and losers	
8. Who is the primary target group or the group most likely to be affected?	
9. Who is likely to benefit from this and who will lose?	
10. What will people need to have in order to participate in or benefit from this initiative?	
11. Is the primary target group already advantaged and likely to access what it needs without this initiative?	

12.	Who is not represented in the design of this initiative or program?	
13.	Will people with chronic illnesses be disadvantaged?	
14.	Can the messages be understood by the people who most need to access them?	
15.	Is the method for delivering these messages the best way to reach this target group?	

Safety, privacy, consent, human rights

16.	Is the initiative or policy likely to cause harm to anyone?	
17.	Is the method for delivering these messages the best way to reach this target group?	
18.	How have the impacts of this initiative/policy on the rights of participants and others been considered?	
19.	How are issues of privacy and consent dealt with?	

Learning, flexibility, participative processes

20.	Is there a process in place for feedback, reflection, ongoing learning and flexibility of approach?	
21.	Is there a process in place for consumer and community participation?	

Sustainability, accountability, risk assessment & evaluation

22.	Is this initiative likely to be sustainable or able to be integrated into the health system?	
23.	How will we know if it has worked?	
24.	How is it accountable to communities? To taxpayers?	
25.	Have any potential risks and threats been identified?	

Summary:

Defining the problem	
Deciding on the approach	
Target group – winners and losers	
Privacy, consent, human rights	
Sustainability, accountability, risk assessment & evaluation	