

Victorian Government Department of Human Services Health Promotion Framework Discussion Paper – Response Form

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Question 1: What do you think of the proposed framework as the basis for developing a strategic state level response for each of the seven priorities? I.e. Is it clear and logical? What are the positive aspects from your viewpoint? Any gaps? Suggestions to improve it?

We would like to congratulate the Department on the development of a comprehensive framework for Health Promotion in Victoria, and thank you for the opportunity to provide input on this world-class initiative.

The conclusions drawn from the evidence presented are logical. The framework itself appears to be consistent with the evidence presented.

The consultation process, as demonstrated by the membership of the Advisory Group, as well as the evidence presented do not appear to have sufficiently included the type of activities and organisations that we could broadly name 'community groups' - that is, support networks, community action activities and groups, self-help groups, the voluntary sector or what the Wagner model for Chronic Illness Care helpfully names 'community resources' (Wagner 1998).

We cannot state explicitly how the framework would be changed if community groups were effectively consulted and able to contribute but we would like to highlight the need for this important and oft overlooked (and admittedly sometimes difficult to fully access) perspective be included.

Question 2: How useful might the framework be in helping you/your organisation conceptualise 'big picture thinking' prior to undertaking health promotion planning? Please explain.

The introduction to the framework states that its focus excludes people with 'established disease' or 'controlled chronic disease'. Our organisation believes that firstly, the term 'chronic disease' is being misused in this context, and secondly, the principles of health promotion, and the framework proposed, are extremely relevant to the population who have a chronic disease, most especially when considered with its true meaning.

We would like to highlight an important confusion in terminology - in your writings the term chronic disease is being used to refer to conditions with modifiable risk factors, such that you describe the stages of health and wellbeing as progressing from 'well population' to 'at risk' to 'established disease' to controlled chronic disease'. This is consistent with the etiology of conditions such as heart disease and Type 2 diabetes but excludes long-term or chronic diseases which occur (often much earlier in life) without the presentation of risk factors, such as Type 1 diabetes, rheumatoid arthritis, multiple sclerosis and epilepsy to name but a few. This latter group of conditions and their affected populations have quite a separate nature to those with 'modifiable risk factor chronic diseases' and the rationale presented for excluding those with established disease or controlled chronic disease from a health promotion framework no longer applies when chronic disease is more accurately defined.

Whilst we appreciate that every condition, risk factor or individual circumstance cannot be considered within a 'big picture thinking' framework, we know that the 30,000 Victorians with Type 1 diabetes could benefit greatly in some very specific ways from the application of a health promotion approach to their long-term health and wellbeing, where the current framework for their care – very much a medical model – is proving to be highly ineffective. A number of other conditions and population groups may well benefit in similar ways from a broader application.

People with chronic diseases that do not have modifiable risk factors and often present earlier in life are being shown by emerging research, from our own organisation as well as other groups, to function with high levels of independence from the traditional 'health system'. The Type 1 Diabetes Network recently presented research at the World Diabetes Congress to show that only 22% of Australian adults with Type 1 diabetes have been shown to meet the minimum standards of the traditional model for medical support with their condition, that is, annual consultations with an endocrinologist, a diabetes nurse and a dietitian; the remainder are consulting a more limited range of health professionals less frequently (Gilbert 2006). Our research was consistent with a major study at St Vincent's Hospital in Sydney (Bryant, 2006). Further to these findings, a key indicator for engagement with the necessary self-care is compliance with recommended screening and blood testing activities, and our research went on to show that those who were using more independent models did *not* have significantly lower rates of upkeep with the requirements - thus the influencing factors for people with Type 1 diabetes to maintain self-care activities appear to be independent from their direct and ongoing contact with the medical system (Gilbert et al, 2006). We believe that given this population demonstrating its independence from the traditional medical system, that they must be considered - and even prioritised - within broader health promotion frameworks.

Our organisation would be most interested in using the DHS health promotion framework to plan our work, both internally and collaboratively. We would also be delighted to see other organisations working with people who have chronic conditions without modifiable risk factors engaging in the planning for health promotion which the framework will encourage, if the framework was presented in a way which made it relevant to these groups, as we believe it should be.

Indeed, the potential for a health promotion framework to significantly benefit people functioning independently with their chronic disease we believe to be very high and there would be great benefit in exploration of appropriate health promotion target populations within this forgotten group.

Question 3: How useful might the framework be in developing partnerships between health and non-health sectors in work around the seven priorities? Please explain.

The potential role of 'community groups' has been significantly under-represented in the framework.

Our organisation is an entirely volunteer-run community group which has worked for almost 10 years to provide peer support opportunities for people with Type 1 diabetes, predominantly young adults, through a range of methods such as publications, events, online discussion forums, research and advocacy. Through that time we believe the traditional health sector has predominantly regarded our work as being outside of the health sector whilst those outside the health sector would regard our work as a part of the health system, that is, groups such as ours sit on the boundary.

Community groups such as ours employ techniques from all range of fields including medical education and health promotion to community development, sport, recreation, arts and entertainment to engage a population of people with a health issue. As such, we are an important link between the health sector and the wider community and we believe that we can contribute important learnings from our work to the health promotion field.

Community groups should also be considered in our own right as an important piece of the health promotion puzzle, despite receiving a scant (if any at all) allocation of the health resources – significantly less than health promotion which itself receives only a small portion.

Should the framework be amended to embrace the active participation of community groups, we believe this could be an important link between the health and non-health sectors. In its current form, if a funding or policy making body was to apply your framework to their calls for interest, it would be unlikely to approach community groups.

Indeed, the framework appears to have a focus on relevance to larger DHS-funded agencies and not actively involved the community sector, which is ably represented by groups such as the Chronic Illness Alliance, the Collective of Self-Help Groups, OurCommunity.com and others whose contributions would be valuable.

Question 4: What specific strategies should be included in an overarching systems action plan for the HP priorities (see page 18 of the discussion paper)? (Eg. Evaluation support, improved surveillance systems)

As a general point made earlier in this submission, we believe that the framework should be made relevant to the people of people with chronic diseases with unmodifiable risk factors, and therefore relevant to the organisations and systems which support them, as described earlier.

As such, specific strategies we would suggest to be included are:

- **Identification of 'diseased' target population groups** that fall outside the traditional medical system and should be included in a health promotion strategy
- **Funding research projects into effective strategies for promoting health in people with early-onset / unmodifiable risk factor chronic diseases**, who comprise a sub-group of the 'well population' that is largely invisible to the health system at the crucial time when health promotion would be most effective.
- **Establishment of a health promotion program to promote monitoring for early-stage complications in people with Type 1 diabetes.** The medical system is currently failing miserably at this basic preventative measure. Diabetic complications can be treated/slowed/delayed if and only if they are detected before symptoms present, and annual screening is essential for early detection. The complications of diabetes cause enormous burden to the individual and health system is they progress to the stage where symptoms do present - by this stage they are often untreatable leading to blindness and dialysis.

A large study at St Vincent's Hospital, Sydney showed 53% of patients with Type 1 diabetes had been tested for kidney disease (Bryant, 2006). Our own research showed annual screening ranged between 22% and 60% for the different recommended tests, even within groups who were consulting multidisciplinary medical teams at recommended intervals (Gilbert 2006). Much better strategies are required to promote the need for this basic screening and early detection. We believe health promotion offers the appropriate framework to make an impact in this area, where the medical system has not.

Question 5: After the framework is released in December, how could DHS and VicHealth best support the use of such a framework to inform your current work?

This question calls on us to recap on the two issues we have been raising throughout this paper: the acknowledgement of the link between health promotion and people with chronic disease who are well and independent would be required, and acknowledgement of the contribution that can be made by community groups is also crucial.

Some specific suggestions include:

- Commissioning **research into effective strategies** for health promotion within chronic disease population groups
- Clarifying the **definition of chronic disease** in future publications so that the term is not solely used to refer to conditions with modifiable risk factors
- **A seminar targeting voluntary/community groups** about the health promotion framework and its relevance to them - held at times accessible to volunteers, often out of hours
- **Identification of programs** employing health promotion techniques with people who have chronic disease as described, and **support of their evaluation** to understand effectiveness or otherwise

Question 6: What barriers to utilising the proposed framework do you envisage? How might these be overcome?

Communicating the relevance of health promotion to our work, as has been described above, will be a barrier in the framework's current form that blankly excludes 'chronic disease'.

As an extension of the issue of relevance, the allocation of resources to health promotion in Victoria appear to go to agencies with existing DHS funding such as community health services - opportunities to participate are not often opened to a wider range of groups and organisations. More open allocation of funding, even a small component thereof, would greatly benefit the wider sector's engagement in health promotion.

Our existing partners and colleagues' understanding of the relevance of such a framework to their work may be a significant barrier in some cases. For example, there are a large number of member and volunteer-driven organisations which contribute substantial resources to the health sector but being largely outside of DHS funding streams do not apply such frameworks in the same ways that DHS-funded services may do so – and this creates lost opportunities. This includes national or federated organisations that may have difficulties in applying state-based frameworks and instead apply funds in ad hoc ways – making the framework relevant to such groups would be beneficial.

It would require a shift for our organisation, and other disease-specific community groups, to understand that health promotion may provide a very useful context and framework for our work where previously we either did not have a framework, or applied frameworks from a mix of sectors erring on the side of more medical approaches, but we believe that this is an excellent path to take and will be pursuing it to the best of our ability.

An exciting opportunity exists with the forthcoming conference "Self Help: The Path to Health and Wellbeing" which is being supported by VicHealth and the Type 1 Diabetes Network is pleased to have been invited by the conference organisers to present some workshops - will be able to ensure that such issues as applying health promotion frameworks to community groups are discussed, and look forward to the opportunities that will certainly arise.

13 September 2007