



**Response to the  
Consumers Health Forum of Australia**

**Draft Information Paper:**

**Community Quality Use of Medicines 2008-09 Project**

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## RESPONSE SHEET FOR DRAT INFORMATION PAPER: COMMUNITY QUALITY USE OF MEDICINES 2008-09 PROJECT

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### Question 1:

**Do you, or the members of your organisation, have difficulty in gaining access to medicines?**

N/A

(Note that Health Issues Centre has been an independent, not-for-profit organisation for over 24 years, promoting consumer perspectives in the Australian health system. It is consumer-focussed but not a consumer peak organisation. Its mission is to improve the health outcomes for all Australians, especially those who are disadvantaged. It works with a wide range of consumers, health providers, researchers, governments and other health and community organisations to achieve this. It also undertakes:

- Policy analysis and advocacy from a consumer perspective
- Consumer-focused research
- Dissemination of information

This response to the Information Paper is based on Health Issues Centre work in research, on policy development, practice change and consumer participation.

The questions that cannot be responded to because Health Issues Centre is NOT a consumer peak organisation are indicated by N/A.

### Question 2:

**Do you think that consumers' access to medicines is usually consistent with the principles of QUM (i.e. safe, appropriate and effective use of medicines)?**

Access to medicines will be consistent with the principles of QUM if they are prescribed by a qualified health professional and if the consumer is provided with evidence-based information about the prescription details in a variety of formats and languages.

Health Issues Centre does not believe this happens sufficiently. The written material is often too complex, and more use of videos or DVDs about medications, in appropriate languages (including Plain English) should become routine, to accompany the generally useful advice from pharmacists. There is considerable research to show that consumers are most satisfied when they receive both verbal and either written material or via other media.

If consumers access medicines through supermarket chains, over the counter (without advice from the pharmacist) or on-line – as pointed out in the Information Paper - they access medicines inconsistent with the principles of QUM.

Health Issues Centre believes that consumers would benefit from government policies and regulations to ensure that medicines delivered over the counter or at supermarket chains are accompanied by evidence-based information delivered in a variety of formats and languages.

Health Issues Centre believes that access to medicines on-line is an issue that should be further investigated because of its importance. Consumer's perspectives on accessing medicines on-line should be researched further.

Health Issues Centre suggests that the overall issue of access to medicines consistent with the principles of QUM - as addressed in the Information Paper - should be an integral aspect of the discussions about access to health services. As such this issue should be addressed within the context of the health system reforms currently taking place in the Australian health system. (e.g. National Primary Health Care Strategy, Review of the PBS, National Health and Hospitals Reform Commission).

The National Health and Hospitals Reform Commission argued that:

There is a growing imperative to create and foster a health care system that highly values quality and safety. As a consequence, the concept of paying for performance has gathered momentum in other health systems (see Chapter 13). In Australian general practice, the Practice Incentives Program rewards practices for improvements in areas including information systems, after hours care, teaching, care plans, participation in **National Prescribing Service quality use of medicines**, care of diabetes, asthma, cervical screening or mental health, practice nurses, and rural location.<sup>1</sup>

### **Question 3:**

**How do you think access to medicines could be improved for consumers whose access is currently limited? (E.g. CALD, Indigenous, rural and remote consumers).**

Health Issues Centre believes that the issues of accessibility to medicines for consumers from CALD, indigenous, and rural and remote communities should be also integrated within the overall issues of access to health. There are currently several forums regarding health reform in Australia and they would be appropriate platforms to further pursue the issues concerning QUM for these communities. For example, the National Health and Hospitals Commission report has a section dedicated to the needs of diverse communities which addresses issues of access to health services.<sup>2</sup>

Furthermore, it would be necessary to maintain an ongoing dialogue with consumers, carers and communities to ascertain their priorities and thus adjust health planning and issues concerning QUM to address real community needs.

### **Question 4:**

**How much difficulty do you, or you organisation's members, face in meeting the costs of their medicines?**

N/A

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<sup>1</sup> National Health and Hospitals Reform Commission. 2009. A Healthier Future For All Australians – Interim Report December 2008. Commonwealth of Australia. Canberra. p. 94 and 99

<sup>2</sup> National Health and Hospitals Reform Commission. 2009. A Healthier Future For All Australians – Interim Report December 2008. Commonwealth of Australia. Canberra. Chapters 8 to 11

**Question 5:**

**Are there particular medicines, or types of medicines, that you or your members have cost difficulties with?**

N/A

**Question 6:**

**Please comment on your observations of the availability of CMI.**

In the Information paper, the concept of Consumer Medicine Information (CMI) relates to at least three different sources of information for consumers. These are: information delivered via leaflets, information provided in the bottle or packaging and information delivered by the GP or other health professional.

The Paper refers to the issues of limited availability of and out of date CMIs. Health Issues Centre agrees with CHF that policy recommendations and strategies will need to be in place to keep CMI leaflets up to date in rural areas and widely available in all areas.

The overall discussion about CMI should also be a component of discussions within a national health reform agenda. For example, the National Health and Hospitals Commission addressed the needs for quality health information for consumers affected by chronic conditions.

The lack of high quality health information, and the ability to capture this and share it in a timely and useful format (i.e. content and media), has a particular impact on the treatment of chronic disease. Patients with chronic diseases often are complex and develop conditions that require referrals to a variety of medical and other specialist services. They frequently use multiple medicines and require care over extended periods of time from multiple providers.<sup>3</sup>

The Pharmaceutical Benefits Advisory Committee (PBAC) or other government body should consider for example providing recommendations and guidelines to the providers of these leaflets, the pharmaceutical companies, and to pharmacists (through their professional associations) to audit, update and/or remove their CMI from shelves every two years or according to the recommended timeline for up-dating relevant CMI.

Consumer organisations could also lobby governments for up-to-date, more understandable and better distributed CMI. More studies (such as Vitry et al, quoted in the Paper) will be needed to strengthen the position of consumers in this respect.

*NPS Medicine Name Finder*

Health Issues Centre believes that an on-line tool such as the Medicines Name Finder would be very useful for some consumers, especially those who are computer literate, well educated consumers using PBS medicines. As the tool is not available for non-PBS, over the counter, natural or herbal medicines, the overall benefit is somehow restricted.

However, some disadvantaged consumers, especially those not familiar with computers, older and frail or those with low health literacy, would be unable to benefit from this on-line tool. Given these groups are probably the major users of health services, efforts need to be made to support all consumers by providing information that is user-friendly, accessible and in a variety of formats and languages.

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<sup>3</sup> National Health and Hospitals Reform Commission. 2009. A Healthier Future For All Australians – Interim Report December 2008. Commonwealth of Australia. Canberra. p. 100

## *Prominence of active ingredients and brand name in labels for prescription medicines*

Health Issues Centre agrees with CHF on the need to have clear list of active ingredients on medicine labels for consumers to be informed about the medicines they are taking, and that this information may help consumers to self-manage their health.

With respect to on-line information regarding the 'active ingredients' Health Issues Centre argues that disadvantaged consumers (e.g. older and frail people, people with low literacy, people with intellectual disabilities and some people from CALD and Indigenous backgrounds) who are not necessarily able to self-manage their health may not necessarily benefit from an on-line service.

Disadvantaged consumers affected by chronic illness, with low health literacy levels, old or frail, with intellectual disabilities and from CALD and Indigenous backgrounds need supportive environments, including a health system aware of the way in which social inequalities impact on their capacity to confront challenges in their daily lives.

Consumers and carers need the support of a health system that supports their real needs and works in partnership with them, seek practical ways to satisfy those needs, and provides the information they need in a variety of formats and languages. The employment of staff dedicated to providing advice and educational strategies for individuals and populations with low health literacy needs would go some way towards this. They could be attached to community health services, for example, as well as undertaking outreach work to pharmacies and other community organisations and venues.

### **Question 7: How would you like to see CMI distributed?**

Consultations held by Health Issues Centre with a variety of consumers and carers over the years have showed that that CMI - as any other form of health information - should be distributed both verbally and in written form - by health professionals at point of contact and along the continuum of care. Health Issues Centre would also recommend use of other media including videos and DVDs.

Importantly there is Cochrane evidence to argue that consumer information would be more effective if it is developed in collaboration with consumers.<sup>4</sup>

### **Question 8: How can you or your organisation use the NPS Medicine Name Finder?** N/A

### **Question 9 What approaches would assist you or your organisation with better access to medicines information?**

Health Issues Centre would argue that ongoing dialogue with consumers and carers from a variety of population groups would ensure that the needs of ALL consumers are addressed, especially the needs of disadvantaged population groups. Only disadvantaged people can really provide an understanding of what it is like to live in their unique circumstances and explain what information they require to address their needs.

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<sup>4</sup> Nilsen ES, Myrhaug HT, Johansen M, Oliver S, & Oxman AD. (2006). Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews* (Issue 3. Art. No.: CD004563. DOI: 10.1002/14651858.CD004563.pub2.)

## **Question 10**

**What areas of medicines or health care would you or your members like to see more regulation and/ or transparency in?**

Health Issues Centre welcomes the initiatives referred to in the Paper regarding regulation and transparency, especially the need to strengthen the consumer perspective in Health Technology Assessment (HTA) Reviews as consumers can provide insights on “the important role a new technology will have in someone’s life”. (p.9)

## **Question 11**

**What criteria do you think should be used in working out whether a new medicine should be approved? Why?**

Health Issues Centre agrees with CHF that post-market surveillance should include the perspective of consumers in a systematic way (e.g. as part of doing the surveillance and being surveyed) to ensure their perspective is captured.

Health Issues Centre supports the current PBS structure and agrees with the National Health and Hospitals Reform Commission which said that Australia has a “robust, national approach to decision-making involving the evaluation and funding of pharmaceuticals and medical services”. In particular Australia does this through its “use of cost-effectiveness analysis in reaching decisions about the public funding and listing of pharmaceuticals on the Pharmaceutical Benefits Scheme”.<sup>5</sup>

However, the Commission acknowledges that “these two national processes sit side by side with a patchwork of other processes for evaluation of new technology, medical devices and prostheses”. The Commission suggests that there is need for

an ‘umbrella’ approach to the consistent national evaluation of a broad range of health interventions”. This does not necessarily imply that the identical approach (or how evidence is used and collected) to decision-making on pharmaceuticals has to be rigidly applied to other health interventions. What it does mean is that we need to move towards more common processes. So, for example, a common approach might be applied to evaluating a range of interventions for their effectiveness in managing obesity (such as a new anti-obesity drug and a new gastric banding procedure), rather than evaluating them separately. It might also facilitate evaluation of new interventions that involve close linkage of diagnosis and treatment (such as personalised medicines, responding to the new genomics – especially in the diagnosis and treatment of cancer – and genetic testing and treatment).<sup>6</sup>

Health Issues Centre supports this view, on the basis there is strong consumer participation in its processes.

## **Question 12**

**What kind of post-market surveillance do you think should be done for medicines?**

See response to Question 11.

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<sup>5</sup> National Health and Hospitals Reform Commission. 2009. A Healthier Future For All Australians – Interim Report December 2008. Commonwealth of Australia. Canberra. p. 283

<sup>6</sup> National Health and Hospitals Reform Commission. 2009. A Healthier Future For All Australians – Interim Report December 2008. Commonwealth of Australia. Canberra. p. 284

### **Question 13**

**Which tools do you of your organisation's members find most useful in managing medicines? Can you think of any other strategies that would assist you or your members in managing your medicines?**

N/A

### **Question 14**

**What criteria do you think should be used in working out whether a new medicine should be approved? Why?**

N/A

### **Question 15**

**What barriers or facilitators do you think consumers have to being in a healthcare partnership?**

At a systemic level, Health Issues Centre through its work with the Australian Health Care Reform Alliance (AHCRA), believes that health care partnership would be possible through ongoing consultation with citizens and that consultations should be a crucial component of any decision-making process about setting priorities for health reform. There needs to be a meaningful national dialogue with citizens and consumers to create a common set of values, principles and priorities for the health system of the future

At the individual level, the Paper mentions the needs of rural consumers. In 2008, Health Issues Centre conducted a project funded by the Victorian Government on the needs of rural health consumers.<sup>7</sup> Extensive consultations were undertaken and from the research findings emerged recommendations. These related mainly to the need to address the inequality of access to health services - particularly to overcome the transport and accommodation barriers that limit access to services - and the need to improve service coordination:

At an individual level also, there is strong evidence to support the involvement of consumers, and where appropriate, carers, in decision-making about treatment and care along the continuum of care. Evidence also exists to argue that this involvement should be facilitated by the provision of evidence-based, understandable and accessible information and support. For example, there is Cochrane level evidence that the use of decision aids not only improves consumers' (and where appropriate carers') understanding but in some cases leads to better health outcomes.<sup>8</sup>

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<sup>7</sup> Find full report at <http://www.healthissuescentre.org.au/documents/items/2008/10/233648-upload-00001.pdf>

<sup>8</sup> Nilsen ES, Myrhaug HT, Johansen M, Oliver S, & Oxman AD. (2006). Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews* (Issue 3. Art. No.: CD004563. DOI: 10.1002/14651858.CD004563.pub2.)