



1<sup>st</sup> June 2012  
Steffan Crausaz  
Pharmac  
PO Box 10-254  
Wellington 6143

Dear Steffan,

Re: Comments on Pharmac's OPP Review

I write on behalf of the Breast Cancer Aotearoa Coalition (BCAC) in response to your invitation to comment on Pharmac's Operating Policies and Procedures (OPPs) review. BCAC is an umbrella organisation which represents 32 breast cancer organisations as well as individual members around New Zealand. We appreciate the opportunity to have input into this review.

BCAC's focus in addressing Pharmac's OPPs is principally from the viewpoint of the patients with serious and often life-threatening illness who are in need of access to pharmaceutical treatments in New Zealand. In the treatment of breast cancer, pharmaceutical therapy can have a fundamental impact on the survival and quality of life of individuals. Consequently, the impact of pharmaceutical treatment can also extend to the patients' families and others.

The outcomes of Pharmac's Policies and Procedures have been a focus for BCAC since our inception in 2004 when better and more timely access to medicines for people with breast cancer was identified as one of the objectives of our organisation. Although access to breast cancer treatments may have improved over the past few years, our concerns about; the way in which decisions are made by Pharmac; how these decisions are communicated to interested parties; and overall access to treatments still remain.

BCAC is a member of the OPP Review Group, coordinated by Medicines New Zealand and is fully supportive of the position stated by that group

*Making a difference together*

Mahia kotahi nga rerekētanga

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in their submission and in their meetings with Pharmac. This submission further emphasises the importance to the consumers and others whom BCAC represents of particular aspects of Pharmac's Policies and Procedures.

### **Consumer Input to Pharmac's Policies and Procedures**

Pharmac currently uses 9 Decision Criteria (Section 2.2 of the OPPs dated January 2006) including (a) the health needs of eligible people. BCAC agrees that the health needs of people in New Zealand is an important criterion in decision-making. However, in practice it is difficult to see how Pharmac takes account of or is even aware of these health needs from the perspective of those affected. In this regard BCAC would like to see consumer input to decision-making receiving more prominence. The OPPs should guide Pharmac staff to operate under the principle that consumer input is important and should be taken seriously and given appropriate consideration in carrying out all aspects of their roles. Consumers have often been disappointed at the dismissive way Pharmac staff have responded to their concerns.

Other funding bodies (such as NICE and PBAC) have processes in place which operationalise consumer input into recommendations and decisions. By contrast, Pharmac's processes do not seek consumer input until after recommendations of PTAC have been made or proposals have been substantially negotiated. Pharmac's "Consumer Advisory Committee" has no discernible input into decision making, further indicating that the "needs of eligible people" are not assessed with reference to those affected most by the decision-making.

### **Input of other Stakeholders and Experts**

BCAC supports the suggestion that Pharmac should ensure that there are opportunities within the decision processes that allow for all relevant stakeholders (as well as consumers) to provide advice in the form of written submissions and to appear in front of the clinical committees to share their perspective and expertise. Stakeholder input (including that from consumers) should not be confined to circulating a consultation document for feedback once a decision is virtually final, it should include perspectives being shared at an early stage with the clinical committees involved in interpreting the scientific evidence. The

influence that this input has had on considerations, recommendations and decisions should be recorded and made evident to stakeholders.

There is concern that clinicians working in a specialist field do not necessarily have input into decisions or recommendations made about products used in that field (e.g. Breast Cancer Special Interest Group [BCSIG]). Processes need to be improved so that these specialists are brought in either as members co-opted onto committees or as stakeholders having an opportunity to appear in front of the committee to present their views. The material they submit must be given to the committees and not retained or altered by Pharmac staff. As for consumer input, the influence that this material has had on considerations, recommendations and decisions should be recorded and made evident to stakeholders. This should be included in OPPs because the opportunity for experts to change a proposal once it has already been substantially negotiated is insufficient to allow meaningful input. The inclusion of expert clinical input into Pharmac's processes would increase stakeholder confidence that decisions are soundly evidence-based and have taken health outcomes into account.

### **Communication of recommendations and decisions**

Consumers are often poorly informed about the recommendations and decisions made at various stages of the Pharmac process. Recommendations and decisions should be communicated to stakeholders in a transparent manner and reasons provided.

Even more concerning is the lack of information available when decisions have not been made to progress particular funding proposals. This is because applications can be considered by PTAC only to languish on a list (about which little or no information is available) with no funding decision being made for years. For individual consumers, this does not give the required certainty about treatment decisions, which frequently have to be made with some urgency, to achieve the best health outcome. Given that patients are facing decisions about life-threatening conditions, this is simply unacceptable.

### **Timeframes**

The OPP should specify a time period within which the application process should run and be concluded. This should include timeframes

for various steps in the process. As earlier explained, the associated uncertainty impacts significantly on patients, carers, families and whanau.

### **Reviewing Decision Making**

BCAC believes that Pharmac decision-making should be open to independent review. This is important to enhance confidence in the system and also from the perspective of improving the overall quality of decision-making. The current option of Judicial Review is prohibitively complex, expensive, stressful and often too late for the vast majority of patients.

### **Budget Setting and Forward Planning**

The process by which Pharmac provides input to the pharmaceutical budget setting is still unclear and should be defined in the OPPs. Operating within a fixed budget does not remove the responsibility to provide input into a budget setting process in order to improve the health outcomes achievable from the overall health budget. In particular, BCAC has concerns about the lack of forward planning and preparation that would ensure that appropriate budget is allocated. This is especially the case when horizon scanning foreshadows the availability of new medicines that can dramatically alter treatment outcomes for particular diseases or patient groups.

### **Unapproved Indications and Medicines**

The OPPs need to provide guidance about the approach that Pharmac takes for consideration of products, indications and dosage regimens that are not approved in New Zealand. The funding of unapproved indications or unregistered medicines is an area of substantial risk for patients and prescribers.

We look forward to having further input as the process of Pharmac's OPP review continues.

Kind regards,

Libby Burgess MNZM  
BCAC Chair