NATIONAL COUNCIL OF WOMEN OF NEW ZEALAND
TE KAUNIHERA WAHINE O AOTEAROA

30 August 2013 S13.10

Pharmac- Decision Criteria Consultation
Submission by National Council of Women New Zealand

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 47 organisations affiliated at national level and a further 41 organisations affiliated at branch level. It has 22 branches throughout the country attended by representatives of these organisations, as well as individual members. NCWNZ's function is to represent and promote the interests of New Zealand women through research, discussion and action. This submission has been prepared by the NCWNZ Health Standing Committee after consultation with the membership of NCWNZ.

The majority of comments that came through from National Council of Women branches and individual member submitters were supportive of the work that Pharmac does, and stated that the current criteria should stay as it is. Several branches submitted that there should be more flexibility in the criteria:

"There needs to be enough flexibility in the system so that individual cases can be considered as a one size fits all approach will always leave some people with great need left out. The wider cost scene should be considered i.e. family, ability to earn, treatment alternatives, quality of life. Pharmaceuticals should be considered in the overall package of care, not as a single solution."

Specific comments that were received in relation to each criterion:

1. No change to the criteria that focuses on health needs of all New Zealanders. (Majority of submitters).

2. This criterion caused the most debate and response amongst our members. A mixture of responses were received. Some members felt strongly that the focus should be on need, rather than on ethnic groupings. Other members submitted that there does need to be a focus on the health needs of population groupings- in particular our Maori and Pacific populations are mentioned with priority.

3. Pharmac should be more pro-active in considering the funding of newer medications which have been shown to be more effective than existing medication. While they may be more expensive, their use could save the country money in the long run if these medications allow people to work, or to stay active in the community rather than remaining on benefits and /or requiring hospitalisation.

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4. The criteria used to determine clinical benefits are open to debate. e.g. the decision regarding the provision of herceptin. Clinical benefits should be based on international, current, proven, evidence- based clinical trials

5. The criteria for cost effectiveness is important to the funding of pharmaceuticals. Although pharmaceutical supplies are separate services from other publicly funded health and disability support services, both are important to patient care. We would rather see the words "rather than" replaced by words such as "as well as". We would not support any reduction in funding for either area.

6. Budgetary impact on changes to the schedule should not be the only criteria. Health effectiveness and efficiency must be considered with such changes to both Pharmac's and the government's budget, for example recent changes to diabetes testing equipment.

7. The direct cost to health service users must remain a criteria. However if treatment is improving the lives of people with significant outcomes, it is important that Pharmac is open to consider case by case outcomes and the patient's socio-economic circumstances.

8. The government of the day need to be well informed before setting their funding criteria which they notify to Pharmac. It needs to be based on well researched policy, current health statistics, community needs and with some allowance made for bio-socio-economic trends and changing demographics, such as increases in dementia (and lack of hospital wards). Funding may be necessary for development of devices such as 'watches' that track people with dementia inclined to wander aimlessly away.

9. Majority agree with this criteria. One submitter felt that criterion 9 needed more clarification.

Criteria 8 and 9 are both too open ended. For example in criterion 8 what does "or elsewhere" cover. Criterion 9 allows Pharmac to prioritise as it sees fit rather than what may be in the best interests of individuals or the country.

A few general comments were received about the importance of PHARMAC being free of political interference.

Comments received about new criteria and issues raised from reviewing the current criteria:

Not many suggestions for new criteria were received. There were many comments received about the need to continously consult with communities about treatment needs.

"Dissatisfaction is publicly expressed mainly when patients could be treated with available medicines are not provided with the medicines because they are very expensive; still regarded as experimental; or are not considered to be cost effective under Pharmac's criteria."

Cases need to be carefully looked at on an individual basis, taking into consideration emerging diseases, illnesses with new research providing cures, plus increased costs. Any new criteria should consider impact of quality of family life and consideration of economic effects on small communities.

This section covers a question we asked our members about funding priorities:

The majority of our members/branches stated that the focus should be on improving the quality of life of people, and on doing the greatest good for the greatest number of people. Most comments talked about equality of access to medications/treatments for all. A few comments were made about the possibility of means testing- that those who can afford it should pay a little. A few comments felt that the needs of young people should be prioritised. Other submitters felt strongly that age should not be a factor, and that the prognosis of the condition, and quality of life are the most important thing.

"However we do acknowledge that with the aging baby boomers PHARMAC costs will skyrocket, but we want to avoid people being denied the quality of care they need. Secondly, we think it is important to consider quality of life as having different outcomes if it is applied to age and older people. People in the newly retired age group are quite distinct from the frail elderly in their 90s and the different ages and stages in between. When talking about older people, this term can be misleading as it can mean a span or period of 30-40 years. It is suggested that social assessments of individuals and/or groups carried out prior to a funding decision may assist with the information required for making a robust decision. Funding availability should not be the criteria of most importance, although important."

"We do not believe that it is acceptable to relegate a section of the community to the 'not worthy of treatment' basket."

There were a few comments that there should be an emphasis on prevention vs. intervention.

Health issues specific to Women that were raised in relation to this review:

"It was thought that mammogram screening for woman should be extended to 80 years. We look forward to innovation being produced for the treatment of breast cancer. We commend the government on the cervical cancer treatment and also other cancers experienced by people. We endorse the continuation of patches for nicotine addiction and preventative programmes for diabetes/ stroke, heart disorders."

Concern was voiced about the impact of the time lag for breast cancer drugs plus the limited availability of herceptin to all breast cancer patients – the added emotional cost to families of sending women overseas for treatment needs to factored into decisions .There needs to be flexibility in the decision making on a case by case basis. (A number of submissions commented on Herceptin).

Various issues around access to an affordable range of contraception were raised in a few submissions- (Abortion Law Reform Association gave a particular submission that is attached as Appendix 1).

Comments about the negative impact of equipment changes for type 1 diabetics came up throughout many of the submissions we received.

Positive comments were received about the availability of the free cervical cancer vaccine.

Comments on funding new emerging conditions and specific case examples.

For comments in this section our members were asked to consider the specific case of child with a new genetic condition that requires up to $500,000 in drug funding each year. Most submitters commented that they recognise Phramac has a limited funding pool. Some felt that other government funding needs to be found for these particular cases. Most submitters agreed that Pharmac needs more funding generally- especially with new and emerging cases, and our ageing population. Several submitters support the idea of the QALY of the family being tested, rather than just the QALY of the individual in making funding decisions. There was general concern that if PHARMAC funded expensive, high needs cases that this would take away funding from population groups.

2 case examples received:

“Our family had a car accident when my son was two years old breaking bones in his face. He was in Middlemore Hospital For nearly two months.When he was eight it was decided he needed an operation which could not be done in Auckland so he would have to go to Adelaide, Australia.

My marriage had broken down and I had no way of getting him to Adelaide. I approached ACC who said it was the hospitals problem that they couldn’t operate and the hospital said it should be paid by ACC.

One day a man from the Kiwanis organisation came to see me. He had talked to my doctor telling him that their project for the year was “ Walk With A Child”. My doctor sent him round to me.Fund raising was started and we went to Adelaide and had a very successful operation. On our return ACC decided they would cover the costs after all.

Because the public had donated the funds we were required to hold a public meeting to reimburse those who wanted to. Not one person did so a trust fund was set up to allow any other child in Tauranga to benefit. Organisations will assist if they can.”

“There is a North Island family where the father has MS and trying to hold down a full time job with support his wife and children. Their two children (aged 10 & 11) both have Type 1 diabetes. This required the family to save up for some years to buy equipment to manage their diabetes. Despite support from medical professionals and specialists, efforts to acquire funding for this equipment and the resources required was very limited. Family members, a community organization and the father’s employer contributed to the purchase of the devices. After many years of struggle last year PHARMAC fortunately has provided considerable help to this family. They and the wider family are grateful for this assistance.

However, one of these two diabetic children has celiac disease, which also requires separate food preparation and extra spending on gluten free foods, which mainly falls to their mother to carry out. Food purchase and preparation as well as carrying the responsibility of what

nearly amounts to full time nurse for the rest of the family, means the mother is severely restricted in her ability to earn because of additional parental responsibilities and tasks. She is fortunate to have family close by to help with this."

It is not suggested that such family cases are fully funded by the government via Pharmac, but it is suggested that there is a mechanism by which families can have their social and health context needs assessed and a certain portion of what falls under PHARMAC's budget criteria is funded if all other criteria is met. Local Communities may need to set up a Trust Account whereby the Trust can apply for financial assistance from Pharmac towards costs for emerging and ongoing case treatments or those that apply to PHARMAC.

There was a lot of discussion about the needs of people with new and emerging conditions- one submitter wrote about NPPA:

'The Named Patient Pharmaceutical Assessment (NPPA) provides a mechanism for individual patients to apply for funding for medicines not listed in the pharmaceutical schedule (either at all or for the named patient's clinical circumstances). There are three pathways to NPPA funding:

- Unusual clinical circumstances
- Urgent Assessment
- Hospital pharmaceuticals in the community

This relates to our thoughts that there needs to be more awareness of the avenues individuals have if/when they have specific and possibly more unusual requirements.

Additional comments received:

"One member pointed out that the money supply was not a finite one, e.g. "taxpayer dollars" as the only source. Given the political will, the publicly owned Reserve Bank could be directed to create the funding necessary to provide treatment for both common conditions and very rare ones, just as it created the money to back the banks during the credit crisis in 2008. If millions can be created for commercial banks, then surely Jethro Morrow deserves to be helped too."

"There was also some discussion on the danger our visionary Pharmac system is in from the Trans Pacific Partnership Agreementthat New Zealand is about to sign – a treaty fashioned by and for the profits of multinationals, including the huge drug companies."

"I do wonder about the 'usefulness' of people taking up to 16 tablets a day, as so many seem to. Are they all absolutely necessary and do they counteract each other at times?"

"It is interesting to note that the first of the discussion criteria reads "The health needs of ALL eligible people with in New Zealand." It was felt that this implies that everyone is to be treated equally. With our comparatively small population that is clearly not possible."

"One person commented that the Government's priorities for health funding are at threat each time there is a change of Government. This could be due to change of priorities,

pressure from Pharmac or from funding agreements. Any of these can cause fragmentation of supply and stress to those being funded or looking for finding."

"Pharmac has a role to play in educating the public."

Appendix 1

Abortion Law Reform Association of New Zealand Submission on contraception

ALRANZ places great emphasis on people being able to control their fertility and it is important to have a wide range of affordable contraceptive methods for both male and female. Not only will this help couples decide the number and spacing of their children but it will also help to prevent unplanned pregnancies and reduce the number of abortions. The social and economic costs associated with unplanned pregnancies are considerable.

There has been a decline in the number of abortions from 18,511 in 2003 to 14,745, in 2012 and a significant decrease in the general abortion rate per 1,000 women aged 15-44 from 20.8 in 2003 to 16.1 in 2012.

The reasons for this decline are likely to be complex and there is no New Zealand research elucidating the relative importance of different factors. One of the factors considered important by certifying consultants, general practitioners and family planning doctors and nurses is the availability of long acting reversible contraceptives (LARCs) namely intra-uterine devices (IUDs) and implants. This is also supported by overseas research and by the adoption of a government policy in October 2012 making LARCs available to women on a benefit or dependent children of beneficiaries aged 16-19 years.

If LARCs are already making a difference to the abortion rate then increasing access to LARCs is a strategy worth expanding, especially as there are additional health benefits for women using these methods.

The Multiload Cu375 intrauterine device has been subsidised for many years, however the Mirena IUS (intrauterine system) is not subsidised for contraception but only for heavy menstrual bleeding problems. Mirena is an excellent method for women of all ages and ALRANZ supports making both the Multiload Cu375 and Mirena fully funded.

At $320 plus the cost of the doctor's consultation Mirena is unaffordable for many women who would benefit greatly from this method. Examples are young women, with heavy periods affecting days off work and school attendance, who do not meet the strict criteria for the Mirena subsidy and women in poor economic circumstances unsuited to other methods of contraception.

Funding for the two-rod, five-yearly implant Jadelle was introduced in October 2010 and this has proved to be a popular choice. Implanon is a one-rod, three-yearly implant which is not subsidised and costs $270 plus consultation fees. However a significant advantage of Implanon is that it is easier to train nurses and doctors to insert and remove Implanon. ALRANZ supports making this device fully funded in addition to Jadelle.

Māori women and Polynesian women have a higher rate of abortion than European women and the cost of contraception is likely to be one of the factors behind this statistic.
In conclusion ALRANZ strongly recommends that, in addition to the LARCs already funded, the Mirena IUS and Implanon implant be fully funded for all women.

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