Consumers
Health Forum
of Australia

Keep your Cabinet out of our medicines!

Results of a consumer survey on changes to the PBS listing process

April 2011

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Background

Until February 2011, new drugs seeking Government approval were assessed for relative clinical necessity and cost-effectiveness by the Pharmaceutical Benefits Advisory Committee (PBAC), a government-appointed advisory body including clinical and economic experts, as well as consumer expertise.

Drugs that were deemed by PBAC to demonstrate cost-effectiveness and meet a clinical need in the Australian community were recommended to the Minister for Health and Ageing for listing on the Pharmaceutical Benefits Schedule (PBS) – the list of all medicines available to consumers at a Government-subsidised price.

However, in February, citing financial reasons, Cabinet deferred approval of listing for seven new medicines and a vaccine on the PBS, in spite of positive recommendations from the PBAC for their inclusion. These medicines had been evaluated by the PBAC to reflect demonstrated value for money to taxpayers as well as a clinical need for consumers.

Prior to February 2011, only drugs resulting in an anticipated financial impact to Government of $10 million or more per year required approval for listing on the PBS by Cabinet. However, in conjunction with the recent decision to defer listing of medicines, the Government decided, without consultation, that all pharmaceuticals pending approval for the PBS will be required to be reviewed by Cabinet, even after they have been evaluated by the PBAC. This effectively leaves the decision of which medicines will be available to consumers in the hands of politicians.

These decisions were of significant concern to the Consumers Health Forum of Australia (CHF) and many of its two hundred plus members. On 29 March 2011, CHF released a survey seeking the views of consumers, from within CHF networks, about this decision. The survey was also released by research firm UltraFeedback, in order to gain input from a broader range of consumers.

Findings from these surveys have indicated significant concern from health consumers and other members of the public about these decisions. The survey results are explored in more detail below.

Part 1: CHF Survey

Methodology

The survey was distributed electronically to the CHF membership and was advertised broadly via Twitter and on the CHF website. CHF member organisations also distributed it to their membership and networks. The survey was distributed to community groups, support groups and other organisations attached to a community base. CHF connected with a broad base of health consumers proactively involved in different health discussions as well with grassroots consumers – those not currently engaged in the health industry or health consumer or disease groups.

At the time of writing of this report, CHF had received **247 responses** to the survey.

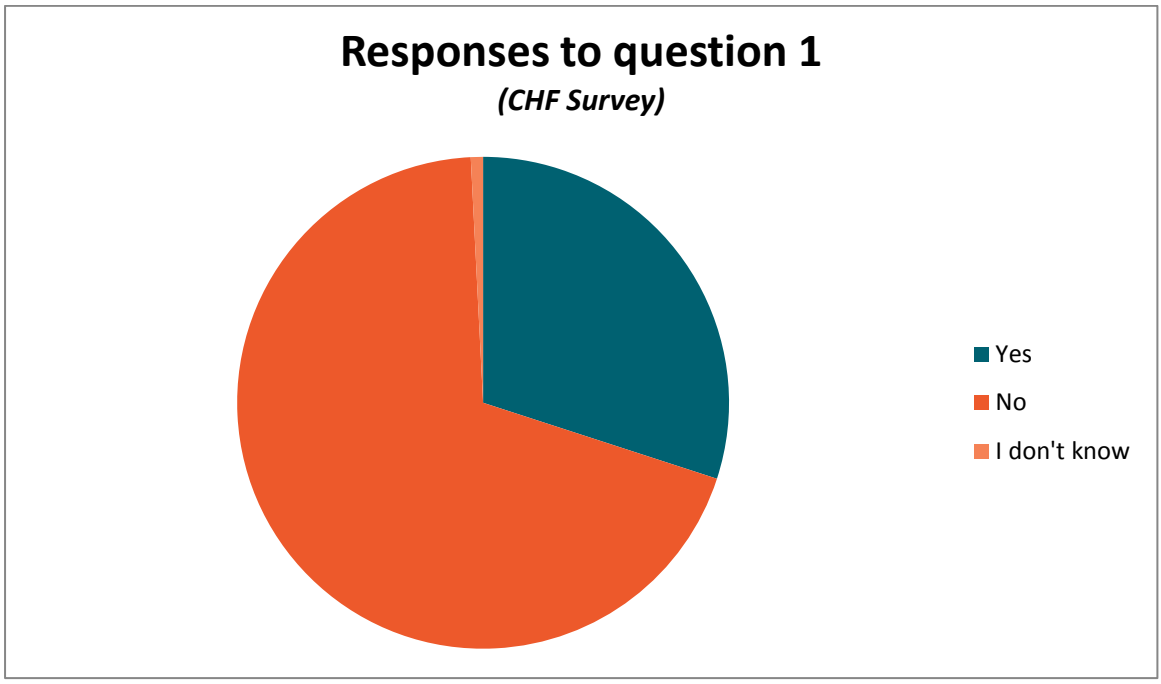
The survey included a brief introduction, designed to give readers a broad overview of both the recent Cabinet decision to defer approval of listing of several new medicines on the PBS, as well as the decision that all new pharmaceuticals pending approval for the PBS will be required to be approved by Cabinet. The introduction also provided a link to CHF's recent media release in which the recent decisions were discussed: https://www.chf.org.au/pdfs/med/med-pbacrelease.pdf3.

Questions were designed to identify consumers' level of knowledge of the recent decisions as well as their views about them. Four open-ended questions were provided to further explore consumer views on the issue and why they thought the issue would (or would not) affect consumers. Consumers were able to skip questions to which they did not wish to respond.

Key Survey Results

The figures and comments below present the results from the CHF survey.

Question 1: Were you aware of the recent Cabinet decision to defer listing of medicines recommended by the PBAC?

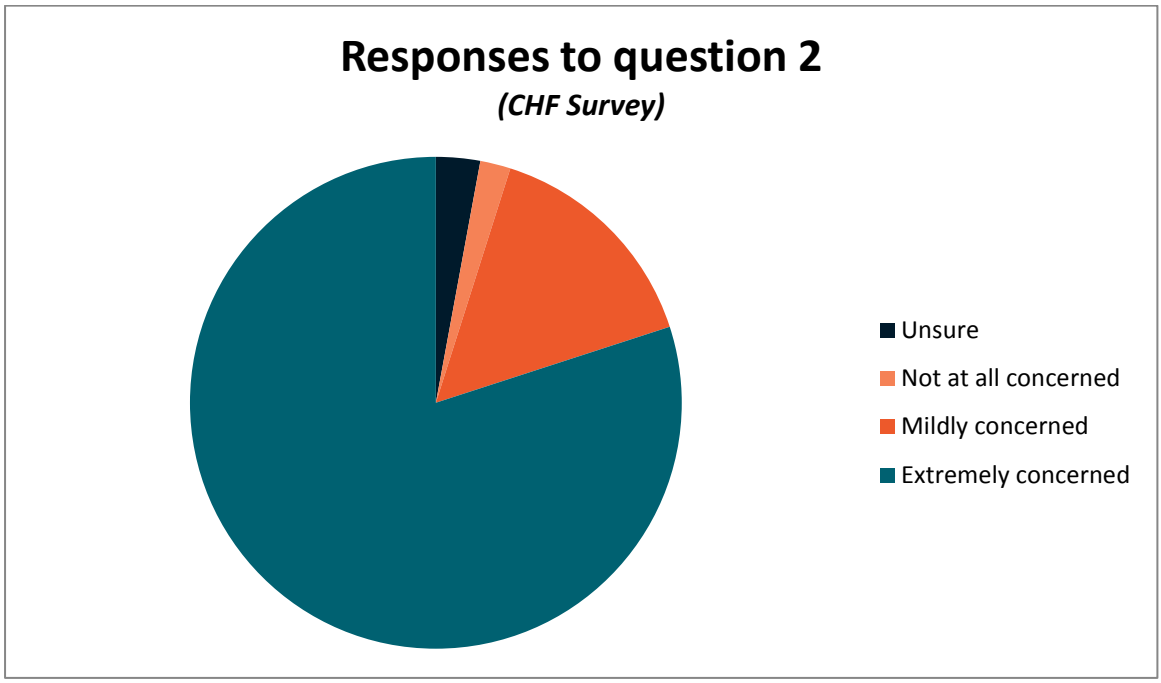


Were you aware of the recent Cabinet decision to defer listing of medicines recommended by the PBAC?		
Answer Options	Response Percent	Response Count
Yes	30.0%	74
No	69.2%	171
I don't know	0.8%	2
answered question		247
skipped question		0

A total of 74 respondents indicated they were aware of the recent Cabinet decision. However, 171 respondents indicated they were not aware of the decision. Only two respondents were unsure about whether or not they knew of the decision.

It could be argued that the high number of respondents who were unaware of this change in procedure indicates a lack of transparency and openness in the Government's decision to change the medicines listing process.

Question 2: How do you feel about this decision?



How do you feel about this decision?		
Answer Options	**Response Percent**	**Response Count**
Unsure	2.9%	7
Not at all concerned	2.0%	5
Mildly concerned	15.1%	37
Extremely Concerned	80.0%	196
	answered question	245
	skipped question	2

Respondents were able to select from four possible answers to the question *'How do you feel about this decision?'* Seven respondents revealed they were *'unsure'* about their feelings and only five respondents indicated they were *'not at all concerned'*. A total of 37 respondents indicated they were *'mildly concerned'* about the changes to PBAC processes. Meaningfully, 196 respondents, or 80 percent of all respondents, revealed that they were *'extremely concerned'* about these decisions.

This result clearly shows that the majority of people (95.1 percent) who responded to this survey are concerned about the decision.

Question 3: Why?

The third question was an open ended question, asking respondents to further explain why they answered the previous question. Of the respondents, 239 people answered the question. Comments from the 233 respondents who were mildly or extremely concerned generally related to concerns about:

- The change of process without consultation
- Cabinet's ability to appropriately make decisions about medications

Delayed or restricted access to necessary medications. Comments included:

I'm not sure what criteria Cabinet will use to assess which ones pass or not, and I think it may also cause delays in getting these drugs to people. At least the PBAC process was reasonably transparent.
The expertise to make these decisions is not at Cabinet level.
It seems the Government is limiting access to medicines that a lot of people will need and may not be able to afford, and changing the goal posts to do it.
I think it should not be a political decision. What are the qualifications of the judge?
We have a process in place to ensure objectivity and consideration of clinical, economic issues etc. Cabinet is a political process only.
I am one of the people who need some of these new drugs, and being on a pension I cannot afford them unless they are on the PBS.
If the Government established a Pharmaceutical Benefits Advisory Committee, it should be prepared to accept the recommendations of the Committee, especially as the Committee already takes cost-effectiveness into account. To do otherwise is politicising the health of the Australian people.
Firstly, members of cabinet lack expertise in regard to medications. Secondly, people's right to health services including medication should not be treated as a political issue. Thirdly, there will always be people who need a certain drug and it should be made affordable by independent authorities.
People need these medications and this decision was made without consultation.
Are politicians experts in prescription medicines???
These are cost effective treatments with negligible (<$10m) cost implications but presumably significant longer term cost implications are involved if they remain unavailable. It's ludicrous to think we cannot afford this, and surely micro management for Cabinet to be approving these.
Who is the expert on the subject - a group with training, knowledge and experience with input from consumers OR Cabinet? I was under the illusion that Cabinet was guided by experts in the field - otherwise why go through the sham of "consultation"?
It is short sighted to think that not including these medicines on the PBS list will actually save money.

How can the government make decisions without consultation? I want to see the information that informed their decision. What does Cabinet know about medicines anyway? This creates a nasty precedent.
While I recognise the responsibility of the Government to manage the public purse on behalf of the nation, Cabinet should not be the final arbiter on which drugs are approved based solely on financial grounds. If the government wishes to set financial performance criteria on the PBS these criteria should be announced beforehand and be open to public scrutiny.
If costs must indeed be curtailed then this decision should be based on the whole of the PBS list not just on those drugs that come up for approval at a particular time. It would be better to work out a system where the PBAC is revamped to have control of a budget. If there are new drugs to be approved then a review of which drugs might be removed from the list should be done by the experts not by the politicians. Exceptions that would mean an overspend in the budget could go to Cabinet along with reasons why savings can't be made elsewhere on the list, together with a cost benefit analysis of the request to go over budget.
PBAC has already determined cost benefit for all Australians. Cabinet should NOT be over-ruling the PBAC decisions based on monetary terms. HEALTH OF AUSTRALIAN CONSUMERS MUST BE FIRST PRIORITY.
We elect our government to make such financial decisions, but we expect them to take expert advice on priorities.
I think it goes against the National Medicines Policy and I am concerned politicians are not qualified to determine patient need. Very few spending initiatives are put under the same scrutiny.
It will lead to long delays, vote buying and political waffle.
That Cabinet cannot see the obvious link between having some initial outlay cost that will reduce in clinician hours over time.
It can affect a significant number of persons with chronic illnesses. Governments are ready to communicate decisions that will benefit their standing but not cases like this.
This decision will prevent medicines evaluated as cost-effective by PBAC from being available to consumers who could benefit from them. It is also a crazy reflection that the political goal of returning the budget to surplus appears more important to the government than the well-being of patients.

Of the seven respondents who indicated they were unsure of their feelings on this decision, four provided a response to this question. Responses were:

I would need to consider each medicine on its merits to decide whether decisions regarding financial impact were more important than the therapeutic.
I do not know which drugs are involved or what it is claimed they can do which would allow me to discuss this with an independent professional.
I don't understand the government's reasons other than cost.

Health costs are escalating and $ must be used wisely and not wastefully. It is difficult to measure the cost benefit of new drugs. If new drugs are costly- more so than existing ones for a similar condition, then what is the benefit? If it will prolong quality of life as well as length of life- especially for the young with families AND it will mean a reduction in treatment costs, then these drugs should be on the PBS. If there is no real gain, then I understand why they can't be afforded.

The five respondents who responded that they were not at all concerned about this decision commented:

Because they will get passed.
Because all policies should be reviewed once in a while regardless of what the money is for. Continual handing out of money without review creates apathy and the PBAC service will suffer as a result.
Because I think the industry recommends many drugs too quickly, when they are not necessarily safe to use and they do need another level of oversight.
I feel this is a good decision with help to stop further short term leakages from the budget.
Compared to other health systems in the world, we have it pretty good.

Question 4: How do you think this change will impact on consumers?

The fourth question in the survey asked respondents how they felt the changes to the PBAC process will impact on consumers. 233 respondents provided an answer to this question.

Generally, answers indicated concern that consumers could be disadvantaged by not having access to up-to-date medications that are affordable. There was also concern indicated by some respondents that there could be a greater delay in items being listed on the PBS as they would have to be assessed by both PBAC and Cabinet.

Comments included:

It may mean delays in getting affordable drugs or that the effective drugs never become affordable.
My husband's medication (he takes up to 60 per day) cost $5 for 5 lots. If it wasn't on the PBS, each lot would cost in excess of $60. That's $300 vs. $5. This medication is a necessity, not a luxury – we couldn't afford it if it was not subsidised.
For an ordinary family it could have devastating effects. It will affect the lower socio economic group. These families do not have the money available to pay for drugs that aren't on the PBS.
Consumers will have to suffer for the sake of political gain.
As I understand it a number of people with a diagnosis of schizophrenia have been involved in a trial of a new antipsychotic which only requires administration on a monthly basis. Because of Cabinet interference these people will not be able to afford continuation of the drug and will require going back to the older form of anti-psychotics. Changing anti-psychotics is always very risky for the person involved.
Most likely fewer medicines will receive approval leading to financial stress on consumers. And if they cannot afford the medicines, possible exacerbation of their illnesses leading to more health costs down the track.
1) Likely to delay implementation of new medication 2) Politicians may not be fully aware of end user consumers' need for such medications 3) Placing a dollar value on human life.
Consumers should have the right to have access to safe and effective drugs to treat their illness, in particular if the drugs can be proven to have positive health benefits, and with reduced side effects and complications.
Introduces inequities in the process, and exposes listing on the PBS to political favouritism (lack of equity and transparency in the processes).
The PBAC supports the listing of these drugs and their decision is now being ignored - the needs of consumers have been completely overlooked.
This will be particularly hard on new patients and will end up costing us more in terms of lives lost and escalating costs of Government if they won't listen to their own advisers.

Some respondents raised concerns about the flow on impact to not-for-profit (NFP) health organisations receiving reduced funding from pharmaceutical companies if their drugs are denied approval on the PBS:

Consumers who are continuing to suffer from disease will not be able to have their symptoms treated with the most up to date medical treatments. Also, services offered to Australian consumers by NFP health organisations are adversely impacted by the reduction of funding from pharmaceutical companies as a result of a drug not being accepted onto PBS.

Because a particular drug has not been accepted, funding that was to come to a NFP Health organisation from a pharmaceutical company to deliver a national disease program will not be received, thereby adversely impacting the Australian consumer who would have benefited from the delivery of the national program.

Fewer than five respondents argued that this change will not impact on consumers, responses included:

It won't (affect consumers) - as it will be reviewed by Government and not private industry it should be fine.

Little impact - the drugs are already not on the PBS.

Question 5: Can you provide any particular examples of the impact of this decision on consumers?

The fifth question in the survey asked respondents to provide particular examples of consequences or impacts of the recent decision on consumers. Of all survey respondents, 177 chose to respond to this question.

One respondent felt that there would be no impact on consumers as a result of this decision:

> Most consumers won't be affected because they will not know that the drugs were not listed.

However, other responses indicated that some consumers are aware of the medications that were approved by the PBAC for listing and were deferred by Cabinet.

Prevenar 13 catch-up

Many consumers reported feeling very concerned about the impact of the deferral of the infant pneumococcal disease vaccine (Prevenar 13 catch-up).

> Immunisation for pneumococcal disease for infants aged 12 to 35 months is essential as it is deadly for children (and adults). All people should have access to this treatment, in the name of good public health practices.

> Disallowing the approval of a vaccine for pneumococcal disease defies logic. Decisions that deny the public access to live saving drugs or vaccines are extremely short-sighted, and will ultimately contribute negatively to the state of public health in Australia.

> Children will be deprived [of] immunisation that could save lives.

> I am concerned particularly for pneumococcal vaccine as a Child Health Nurse.

Invega Sustenna

Some respondents also reported that the decision to defer listing of the new anti-psychotic medication, Invega Sustenna, will disadvantage many consumers. This drug treats schizophrenia and reportedly has many benefits when compared to currently PBS listed medications for this condition, including monthly rather than fortnightly administration, fewer side effects and suitability for injection in the arm rather than the buttocks.

> My two sons have schizophrenia and neither they nor I could afford to pay the full price of a new medication.

> A monthly injection in the deltoid (arm) rather than gluteal (buttocks) injection site [involving a] much thinner less painful needle [and] no need to keep [the drug] chilled [meaning] no cold chain management issues. Very important in rural areas. Minimum weight gain.

Injectable antipsychotic that did not get approved was a monthly injection with less weight gain than currently available fortnightly injection. Especially in rural areas, fewer doses per month would be advantageous.

The Government has promised to increase funding for mental health, yet in this recent decision it has refused to allow a new drug to be listed for the treatment of schizophrenia. As with any drug that treats conditions of the brain, one drug does not suit everyone, and by refusing to allow the availability of a new drug, this Government is depriving those with schizophrenia who have not responded well to existing drugs of an opportunity to achieve good mental health. This action flies in the face of this Government's stated position on mental health.

If the new psych medication is unavailable on PBS, then no consumers will be able to see if it works for them. I know many who experience terrible side effects from existing medications, and others who do not respond to existing meds, or refuse to take any meds.

Targin

Other consumers were particularly concerned about the decision to defer listing for Targin, a medication that treats chronic and disabling pain.

There is a drug called Targin that is supposed to be a good substitute for the more addictive Oxycontin. Why is this being left off the PBS, if it can help with the situation with opioid use that according to other Government bodies is out of control or is being abused?

My niece's life has been ruined by chronic neuropathic pain. She can no longer work as a scientist as the current drugs do not work and have horrible side effects. Politicians should not make clinical decisions.

Targin would be useful in dealing with the side effects of Oxycodine - a pain killer used by Cancer patients.

The effect of the oxycodone/naloxone combination which offers enormous advantages to people with chronic pain, including cancer, MS and post-operative pain.

The oral oxycodone/naloxone prolonged-release tablet (Targin) has clear benefits to patients including some 60% of people with cancer and many thousands who suffer severe, disabling, chronic pain.

Our members are stigmatised for having chronic pain and taking opioid medication. Having the oxycodone/nalozone preparation would have meant that the medication could at least be differentiated from the preferred drugs for diversion to unauthorised use.

The major one is Targin where the drug as a combination of oxycodone and naloxone cleverly avoids the opioid bowel dysfunction seen with other opiod analgesics and reduces significantly the potential for abuse.

Impact of delays

Several respondents also pointed out the danger of delays and deferrals in listing medication on the PBS; for example:

> Delay in listing Azacitidine last year (recommended by PBAC September 2009, listed February 2011) meant some of Leukaemia Foundation's patients died waiting for this new drug while awaiting Cabinet approval for PBS listing

> Deferral of listing Scuptra administration listing for HIV facial wasting treatment has resulted in many being unable to afford to pay for the doctor to administer the treatment

Future listing process

Other consumers were concerned about future impacts of the changes on medications soon to undergo the PBAC process:

> New hepatitis C treatment drugs were due to be put to PBAC very soon. This decision by the Gillard government flies in the face of the government endorsed National Hepatitis C Strategy 2010-2013 and will directly hinder the goal of increasing hepatitis C treatment uptake to prevent a significant and growing burden of end stage liver disease.

> With my knowledge of the autoimmune arthritis conditions it would be devastating if a new arthritis medicine or biologic comes onto the market and is rejected by the government. Each of these medicines has a different effect on different parts of the immune system.

> I am hoping that Growth Hormone will be approved for adults with GH deficiency later this year. Now that this has occurred it makes it all the more unlikely this will happen. This is a depressing outcome for people who have been hoping for this for many years. The cost of GH for adults can range from $8-15,000 per year - not a price someone like myself, on the average Australian income can afford.

> This is just the start. If they can get away with preventing cancer patients from having blood clotting medicines, then it's the beginning of the decline of the PBS.

Question 6: Do you have any other comments?

The final question asked respondents if they wished to make any further comments, 176 respondents chose to do this.

Generally, many respondents were concerned about Cabinet's ability to make decisions about the listing of medications, particularly as the PBAC process is already in place. They also reported concern about Government's decision to place financial concerns ahead of clinical reasoning and consumer needs:

> Cabinet needs to take note of the recommendations made by the expert panel on the PBAC for inclusion on the PBS.

> This is a short-sighted measure which will not only increase physical suffering, and worsen the financial burden on the sick, but will ultimately lead to increased hospitalisations, thereby worsening the financial pressure on the health system.

> If it was a recommendation by PBAC it should be mandatory, it should be taken out of the hands of politicians who are more concerned about finance then health.

> What are experts for if the politicians know everything from climate change to medication? I did not vote for their (non-existent) scientific expertise but for compassionate governance.

> This decision by government to disallow the approval of drugs rigorously assessed as meeting needs in the community is appalling. I hope something is done about this.

> Cabinet do not have clinical and health economics expertise so why are they making these decisions? It is [of] great concern that Cabinet is not making evidence-based decisions and that there is no transparency in this process. Instead they are allowing squeaky wheels [to] determine their decisions. A sign of reactive whim-based decision making not good government or governance.

> The Government has a responsibility to its constituents to provide them with the best, most cost efficient services possible and MUST consider all implications and outcomes of their decisions. Take advice from those people who actually understand these issues.

> I wonder if Cabinet will contain the expertise and unbiased judgement to make these decisions. […] Making so called moral judgements which ignore medical guidelines is a concern when decisions are taken out of the hands of medical experts.

One consumer suggested that if these decisions are to be left to Cabinet then they will need better advice on the impact of their decisions on Australian health consumers:

> There needs to be some kind of 'impact statement' to accompany each approval by Cabinet, since Cabinet members are not experts (including the Health Minister).

Some comments were related to the cost of this change of process:

> The hidden expenses of a Cabinet decision need to be considered.

> It also seems very inefficient use of Cabinet time to be discussing the minutiae of PBS listing.

Some consumers were concerned about the lack of consultation and transparency through which the changes in procedure occurred:

Changes as proposed ought to be advertised in the media, on science programs and [in] doctor's surgeries. Local MPs could do a letter drop asking for community consultations.
If the government wishes to change the process followed by the PBAC, they should do so publicly and in consultation with the community.
There needs to be more transparency about how availability of medications is determined.
In future, there must be full consumer input to Government decisions. Full communications and consumer consultation are the answer. Our Government is doing its best, but we need to communicate exactly what we, the consumers, expect.
Process is not transparent.

Other consumers indicated that they recognised the need to ration some spending on health, but felt it important that this not apply to all new medicines. Instead, review should occur of all PBS medication.

This is a very difficult matter. Health costs have to be contained – but what do you say 'no' to.
Why just reject or defer new medicines? We should have access to the latest, most useful medications.

CHF Survey: Conclusions

The overwhelming majority of those who responded to CHF's survey were concerned about the Government's recent change in procedure which has resulted in all medications now to be considered by Cabinet for approval on the PBS, regardless of the PBAC's recommendation.

Consumers felt there was a lack of transparency and consultation in the decision to change the process for approving medications for the PBS.

Respondents indicated anger and dismay at the decision to defer the listing on the PBS of seven medications and a vaccine. They argued that the Government is putting financial concerns ahead of the needs of health consumers and tax-payers.

There was also a high level of concern about the ability of Cabinet to make informed decisions about the health needs of the Australian community. Many respondents indicated their anger at the Government choosing to ignore the experts on their PBAC committee.

The majority of respondents clearly want the Government to reconsider their decision to defer medications recommended for listing by the PBAC, and restore the previous policy of Cabinet approval only being required for PBS listing of medicines with a projected financial impact of more than $10 million a year.

Part 2: UltraFeedback Survey

Methodology

In order to access a broader spectrum of consumers and gain an insight into their views, CHF asked research company UltraFeedback[1] to distribute the survey more broadly.

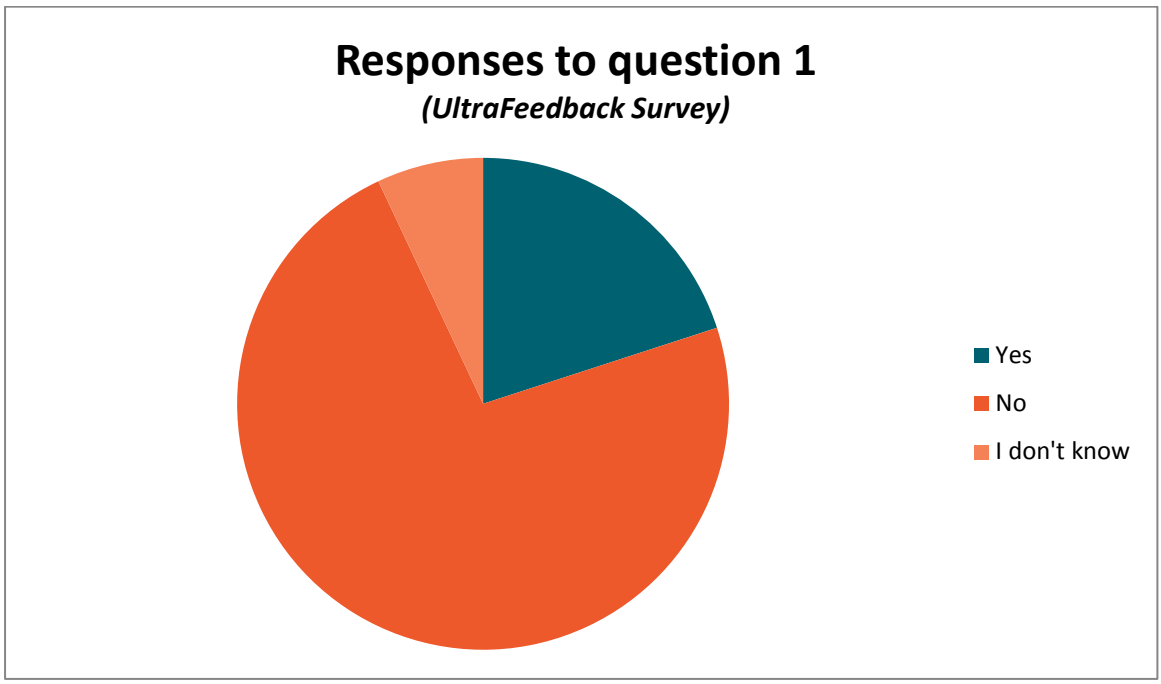
UltraFeedback maintains an internal database containing details of respondents who have participated in past UltraFeedback surveys and have given permission for future contact. An email invitation was sent on 14 April 2011 to individuals aged 18 years and over in the database, directing them to an online survey containing the same questions as CHF's original survey. By 18 April 2011, 340 responses had been received. An analysis of responses was provided to CHF based on these responses.

The sample is not nationally representative, so generalisations should not be made to the Australian population as a whole.

[1] More information on UltraFeedback is available at www.ultrafeedback.com. CHF thanks Tom Holman and Yan Huang from UltraFeedback for their work on the survey analysis.

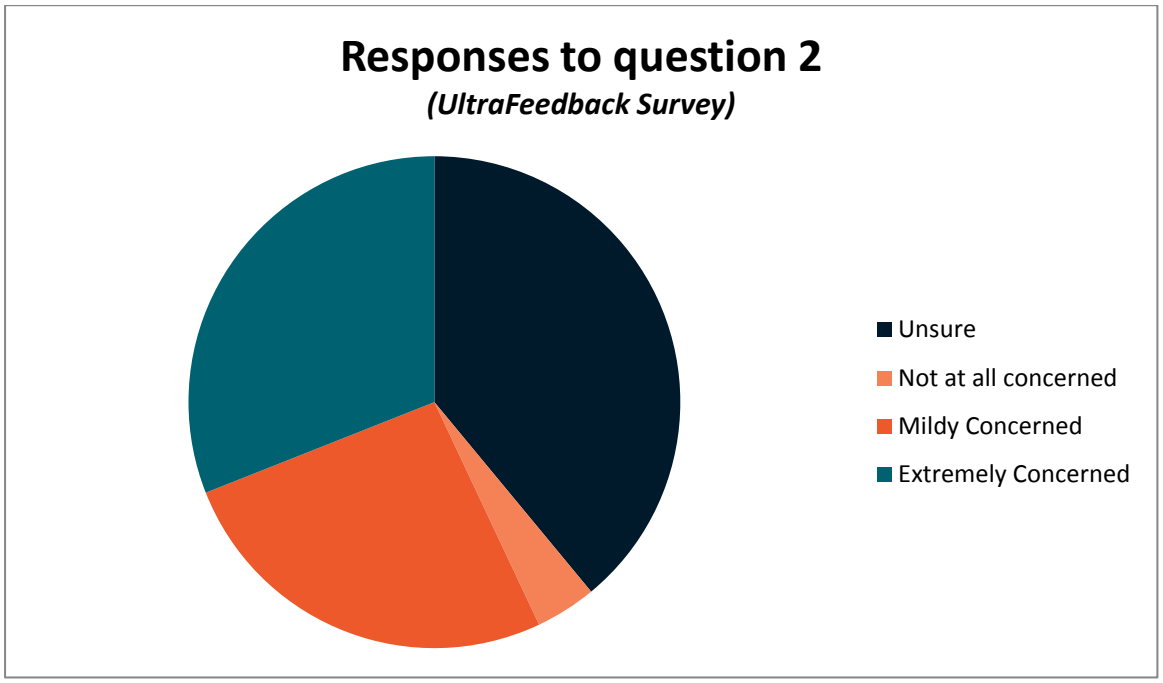
Key Survey Results

Question 1: Were you aware of the recent Cabinet decision to defer listing of medicines recommended by the PBAC?



Overall, 20 percent of respondents indicated that they were aware of the recent Cabinet decision. 73 percent were not aware of the decision, and seven percent did not know if they were aware of the decision.

Question 2: How do you feel about this decision?
Question 3: Why?



Only 4 percent of responses to the UltraFeedback survey reported that they were *'not at all concerned'*.

39 percent of respondents reported that they were '*unsure*' about how they felt about the decision. These respondents were either not aware of, or were uncertain if they were aware of, the Cabinet decision before the survey. 85 percent responded that did not know enough to comment, while another five percent indicated that they did not understand the direct impact of the decision on themselves, their family and/or their community.

Comments included:

I would like to know more about this to make a decision.
I don't know what it means to ME.

26 percent of the respondents reported that they were *'mildly concerned'* about the Cabinet decision. Of these, 27 percent were aware of the decision before the survey, while 71 percent were not. Reasons for feeling *'mildly concerned'* included:

- People need to have access to affordable medicines that matter to them; otherwise their health and life could be in danger (35 percent)
- A health decision should not be made for a financial or political reason (11 percent)
- The government cannot be trusted to make these kind of decisions (8 percent)
- This decision does not affect me personally (8 percent).

Specific comments included:

Probably won't affect myself but could disadvantage many patients who cannot afford medicines.
I am concerned that economic rationalism will trump health care concerns.
I am concerned that decision to allow medications to be released will be held up due to politics and a lack of understanding from those in Cabinet.

31 percent of respondents reported that they were *'extremely concerned'* about the decision. Of these, 35 percent had been aware of the decision before the survey, while 63 percent had not been aware of the decision.

Reasons cited for feeling *'extremely concerned'* included:

- People need to have access to affordable medicines that matter to them; otherwise their health and life could be in danger (48 percent)
- The government cannot be trusted to make this kind of decision (13 percent)
- A health decision should not be made for a financial or political reason (12 percent)
- Health should have a greater focus (8 percent).

Specific comments included:

Delaying making possibly life-saving medications more affordable by putting them on the PBS scheme is ludicrous. The government needs to get their priorities right. Health should be a top priority.
Drugs should be available by clinical need, not political economics.
Cabinet overriding experts in their field is always a concern especially when it can affect user accessibility to valid treatments due to financial considerations.

Question 4: How do you think this change will impact on consumers?
Question 5: Please provide an example of the impact of this decision on consumers?

Responses to this question from respondents to the UltraFeedback survey varied. 27 percent responded that they did not know what the impact would be. Other responses can be themed as follows:

- Higher cost making medication/treatments unaffordable for some (26 percent)
- Lives in danger/reduced health and quality of life (10 percent)
- Reduced availability of medications/reduced choice of treatments (9 percent)
- Have to accept second best options/delay in getting medication or treatments/no medication or treatments at all (8 percent).

Specific responses included:

People will not be able to afford their medicine so their health will worsen, leading to hospitalisations (costing the government more money) or death, or to additional co-existing illnesses.
Patients with cancer and other debilitating illnesses may need a special medication that is not approved, therefore their ability to recover is greatly reduced.
A life-saving cancer drug for example, supplied by a profit driven company, that is not subsidised, may well be out of the financial means of many who need it. Medical breakthroughs should be available to all.
A person may take a medicine currently on the PBS but not take a recommended medicine, thus health is not maintained at an optimal level.

UltraFeedback Survey: Conclusions

While the UltraFeedback respondents did not report the same level of awareness or concern about the recent Cabinet decision as expressed by respondents to CHF's survey, the majority of respondents indicated that they were mildly or extremely concerned by the decision. Respondents to CHF's survey were more aware of the drugs involved and how their deferred listing would impact consumers, but respondents to the UltraFeedback survey expressed similar concerns in more general terms, emphasising access and affordability issues as well as concerns about Cabinet's role in this process.

The high proportion of respondents to the UltraFeedback survey who were not aware of this major change to Government policy indicates that further work is needed to ensure that all Australians are aware of the process for including medicines on the PBS, and changes to this process.

Consumers Health Forum of Australia

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- prevention and early intervention
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach thousands of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.

PO Box 3099, Manuka ACT 2603 ■ Unit 9, 11 National Circuit, Barton ACT 2600
Tel: (02) 6273 5444 Fax: (02) 6273 5888 Email: info@chf.org.au Web: www.chf.org.au
ABN 59 369 286 137