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Submission to the Senate Inquiry re supply of chemotherapy drugs such as Docetaxel

Cancer Voices Australia is pleased to provide a contribution to the Senate's Inquiry into this issue.

Cancer Voices Australia is the independent, volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the patient perspective is heard. Cancer Voices has led the cancer consumer movement in Australia since 2000. Cancer Voices organisations across Australia share the same objectives and work together on national issues identified by their members, with consumers working to help others affected by cancer.

Introduction

Cancer Voices Australia (CVA) made a public statement on 27 November 2012 in response to advice that a special interest campaign, was seeking extra subsidies from Government to support private services, including dispensing services, to cancer patients receiving chemotherapy. It was claimed that price reductions for the major cancer chemotherapy drug Docetaxel, now off patent and due to be reduced on 1 December 2012, would cause private clinics and hospitals to reduce their services to cancer patients, forcing them to onto the public system with consequent pressure on both State and Commonwealth governments. We are particularly concerned about this as around 60% of cancer treatment is undertaken in the private sector, and many move between the two systems. We also note that this issue does not only apply to Docetaxel, but to a range of cancer drugs, the commonly prescribed Docetaxel being seen as a test case in the broader argument.

We find the logic of a connection between reduced costs to Government by paying market prices for Pharmaceutical Benefits Scheme (PBS) approved cancer drugs, and threats to reduce or withdraw services to cancer patients, quite baffling. Threats like these may point to bigger questions about the level of standards of cancer care offered by some providers of private cancer services.

We note that Price Disclosure, one of the reforms to the PBS process, aimed to bring the subsidies paid to pharmacists in line with the price those pharmacists paid for the drugs – with a substantial saving to Government. As the recent Grattan Institute Report *"Australia's bad drug deal; high pharmaceutical prices"* (Stephen Duckett, March 2013) says that the price discrepancies which have developed suggest that the current system is in urgent need of review. We support its recommendation that "The pricing agreement between the Government and drug companies expires in the middle of next year. Now is the time to make changes that will end Australia's bad drug deal".

CVA continues to support the government's position and its efforts to resolve the problem in the short term. We hope this Inquiry will recommend a longer term solution be developed wherein negotiations are transparent and include the health consumer view.

With reference to the Inquiry's Terms of Reference:

(a) **the supply of chemotherapy drugs such as Docetaxel, particularly in relation to**

(i) *patient access to treatment*

We understand that last November's threats have not materialised. We object to the tactic whereby patients' access to treatment is used as a bargaining tool. We are advised that no pharmacist can refuse to dispense PBS subsidised drugs to a cancer patient, where these have been prescribed by the treating clinician, or charge above the fixed co-payment rates.

We are concerned that at least one of those operators quoted by the press in November 2012 was the recipient of federal regional cancer centre incentive funding. The Cancer Voices movement throughout Australia has been very appreciative of the Government's extra financial support to increase access to cancer treatment for patients. We are surprised that a private centre is asking for more subsidies to provide services which must have been part of their business case to government for such funding. Perhaps that funding could be better used to increase cancer services at public hospitals where this kind of practice is not an issue.

The PBS continues to pay for chemotherapy costs, including Docetaxel and its generic forms, as it always has – the patient pays a co-payment of \$35.40 or \$5.80 for each new script.

Cancer Voices has recently been involved in the issue whereby some hospitals have charged patients multiple co-payments. For example, it has been reported that some NSW hospitals, public and private had been charging multiple co-payments over the same course of chemotherapy, instead of once only. Following our expressions of concern, this situation was addressed by a NSW Government Directive, effective 1 January 2013. Cancer patients in Victorian public hospitals are not charged co-payments at all as they are treated as inpatients, rather than as outpatients as in NSW hospitals.

To understand further whether patients are being disadvantaged re access to treatment, Cancer Voices NSW has asked its members, via current newsletters and its website, to report any instances of either (i) co-payments sought more than once per drug script, (ii) higher charges than the standard co-payments and (iii) *withdrawal of offered cancer services by private clinics / hospitals*. We will collate any information received over the next few months, recognising that only a fairly small proportion of our members are undergoing chemotherapy at one time. Cancer Voices has also alerted the Cancer Council NSW to these matters in order to broaden the reach.

(ii) *costs to pharmacists and suppliers*

Pharmacists and suppliers are made aware, through Price Disclosure Agreements, of any pricing changes to drug subsidies on the PBS, and well in advance. We understand that private hospitals, like community pharmacies, buy their drugs at discounted prices from wholesalers, but are often reimbursed by the PBS at higher rates. The Price Disclosure reforms threaten to reduce those 'windfall' profits, making available the difference for more drugs to be subsidised via the PBS.

In effect they have been charging the government more than the market price, which is what Price Disclosure was designed to avoid.

As a patient advocacy organisation, we are not privy to private sector cost structures, but as taxpayers, we do have concerns when public money is used to subsidise private businesses. We, and the general community, seek transparency and evidence that the benefits outweigh the cost, or is at least good value for society.

(iii) *costs to the private and public hospital systems*

This situation does not appear to arise in the public system. We understand the problem arises in only a few private hospitals supplied by "community pharmacists". Government has asked that details of difficulty being experienced by those few, who are seeking, for example, an extra \$100 per infusion, should be provided as a basis for discussion under the terms of the Fifth Community Pharmacy Agreement.

(b) any long-term sustainable funding models for the supply of chemotherapy drugs, including Docetaxel

We support the PBS as the appropriate long-term funding model for the supply of chemotherapy and other drugs to cancer patients.

We are aware that further subsidies are paid to pharmacists to dispense cancer drugs, to recognise the relative complexity of dispensing them. Funding for this should be part of the Fifth Community Pharmacy Agreement, under which pharmacists are subsidised to dispense drugs on the Pharmaceutical Benefits Schedule (PBS) and provide consumers with information about their use. Taxpayers fund this to the sum of \$15.6 billion, currently over a five year period to 2016. There are no stakeholders, other than the Pharmacy Guild and the Government, involved in negotiations about the content of these Agreements. CVA supports the inclusion in negotiations of our peak national organisation, Consumers' Health Forum of Australia (CHF), to represent the end beneficiaries of this huge subsidy. We also support CHF's call for greater transparency regarding this expenditure of public funds.

(c) any related matters

- (i) Following our comment above, CVA seeks an open review of the Fifth Community Pharmacy Agreement, which includes health consumer representation, to establish exactly what it pays pharmacists to do on behalf of the taxpayer.
- (ii) We support the Grattan Report's Overview recommendation "The pricing agreement between the Government and drug companies expires in the middle of next year. Now is the time to make changes that will end Australia's bad drug deal".
- (iii) We flag the potential need for an inquiry into the standard of clinical practice and treatment in private hospitals and clinics treating cancer patients. While the hospitals themselves must be accredited regarding expected safety and quality standards, the clinical services provided to patients are not. CVA has received concerns about this aspect from members and is looking into raising the problem with Government. If some private clinics and hospitals are threatening to reduce their services and the standard of those services is not formally guaranteed, we are concerned that private patients may not be getting best practice treatment and care.

Conclusion

Cancer Voices Australia recommends that the government brings together all genuine parties to **seek a workable, accountable and transparent solution**, creating a clean slate regarding subsidies to the pharmacy and pharmaceutical industries. Negotiations to achieve this should include the health consumer voice. Price Disclosure, which we strongly support, has disclosed an odd system which needs to be regularised in the public interest.

We are happy for this submission to be placed on the public record and to answer further questions if invited.

Yours sincerely



Sally Crossing AM
CVA Executive Committee

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Cancer Voices Australia is the independent, volunteer voice of people affected by cancer since 2000.

