



Review of funding arrangements for chemotherapy services Submission by Cancer Voices Australia

Overview

Cancer Voices Australia (CVA) is the independent, volunteer voice of people affected by cancer – since 2000. We appreciate the opportunity to make a submission to this review.

CVA understands that the aim of the review is *“to maximise the benefits consumers receive from chemotherapy infusions by ensuring efficient and effective clinical processes and appropriate funding arrangements for the preparation and supply of chemotherapy medicine infusions”*.

(DOHA Discussion Paper & Call for Submissions, June 2013, p 3)

CVA welcomes the Government’s wish to clarify the present complex and opaque system of funding across all the models of service delivery. CVA hopes the review will recommend a national set of guidelines for standards of care against which all chemotherapy service providers can be measured, and perhaps accredited. Such reassurance of clinical quality would be of great benefit to Australian cancer patients and their medical advisers.

Why is this issue important to CVA and people affected by cancer (consumers)?

Cancer kills more Australians than any other disease and a great many of the 100,000 diagnosed each year are offered chemotherapy as an integral part of their treatment – along with surgery, radiation oncology and endocrine therapies. Proportionately more people are now offered chemotherapy, and quite a large percentage receives it via the private health system in both separate cancer clinics and in hospitals. Cancer Voices is hopeful that with the full advent of targeted, personalised medicine, the need for broad scope chemotherapy will be reduced, but recognises that this may be some years ahead.

CVA welcomes the assurance that the review will fully consider the funding of clinical pharmacist services delivered as part of a cancer patient’s chemotherapy treatment, the various business models in the private and public health sectors and their impact on best practice provision of chemotherapy services for cancer patients.

What do consumers want?

As cancer patients, consumers want access to best practice, safe, affordable services for their treatment, whether public or private, in conveniently located /accessible facilities – and when they need it.

As taxpayers who fund much of chemotherapy treatment, consumers seek efficient and effective cancer services, again whether public or private.

The recent expansion of chemotherapy services in rural and regional cancer centres has been warmly welcomed by consumers. Chemotherapy should be delivered safely and to a uniformly high quality standard whether in the public or private system, large, medium or small facility. Information, prevention and management of treatment related side-effects are an important component of the chemotherapy delivery service for consumers.

CVA in its submissions and statements has consistently called for a review or audit to look at the present complex and obscure system of the funding of clinical pharmacist services. We would like to see the establishment of standards of service, access and cost as a major review recommendation. It is very important to cancer patients that treatment services remain of high standard and accessibility. Needless to say, it is also important that the supply of these is not threatened by providers of those services.

We regard it as particularly important that transparency be introduced to the funding arrangements for chemotherapy services, especially those subsidies covered by the Community Pharmacy Agreements which are paid to pharmacists who dispense chemotherapy infusions.

In its submission to the recent *Senate Inquiry into the supply of chemotherapy drugs such as Docetaxel*, CVA called for a review like this and publicly welcomed the Minister's announcement on 4 May. We are especially pleased by her response and commitment to ensure there is appropriate consultation with relevant stakeholders, and that this now includes consumers – the end beneficiaries of cancer treatment. Cancer Voices is working closely with the Consumers Health Forum of Australia, the national voice for Australian health consumers, which is undertaking structured consumer consultation for the review.

Terms of Reference (ToR)

Generally, CVA believes the ToR will elicit much needed, and to date, hard to ascertain data and information upon which effective and transparent decision making can be made from now on. We recognise that it has been difficult for DOHA to document clearly and exactly how the present funding arrangements operate at the service provision level.

It has also been difficult for consumer groups like ours to identify consumer experiences, due to the fact that most patients undergoing chemotherapy are not aware of what roles which health professionals, including pharmacists, are expected to play in their course of their treatment. Our anecdotal investigations have largely shown that patients are not aware of being directly assisted by pharmacists at either private cancer clinics, or private or public hospitals. We include, as an Appendix, a fuller report from a recent cancer patient who responded to our invitation to comment on the listed roles which follow.

Cancer Voices has been able to extract a list of the roles of pharmacists which various authoritative organisations had advised the Senate Inquiry was their understanding of those roles. We imagine then, not being privy to the arrangements agreed between Government and the Pharmacy Guild via the Fifth Community Pharmacy Agreement (5PCA) that these are the services for which pharmacists are being subsidised.

Roles of pharmacists in chemotherapy services

Reading submissions to the Senate inquiry, it appears that there are large variations in the definition of the standards of clinical pharmacy services associated with the provision of chemotherapy. We flag concern about the use of the term "community pharmacists" which while apparently used to mean those pharmacists working in clinics and hospitals, means to the actual community, local retail pharmacists. Nonetheless, we submit this list with a view to its possible use for assessing which of these services are provided, and which are subsidised, by present funding within the 5PCA, and the Government's recent "top-up" of an extra \$60 per infusion to 31 December 2013.

The **Clinical Oncology Society of Australia (COSA) Guidelines** for the Safe Prescribing, Dispensing and Administration of Cancer Chemotherapy

(https://www.cosa.org.au/media/1093/cosa_guidelines_safeprescribingchemo2008.pdf)

state that the pharmacist is responsible for:

- clinical verification of the drug order
- accurate dispensing of chemotherapy
- appropriate preparation of treatment
- taking a medication history at the patient's initial and subsequent cycles and
- documenting previous and current adverse reactions

With regards to patient information, the Guidelines note that the role of the doctor, nurse and pharmacist in providing this information may vary across institutions. They also note that where the pharmacist is involved directly, delivering appropriate and comprehensive information to a patient is time- consuming and should be taken into account in the costing of pharmacy services.

The **Pharmacy Guild of Australia's** submission to the Senate Inquiry mentions a number of other roles for the pharmacist:

- assessing whether additional pathology tests are required prior to the patient commencing treatment
- collecting and assessing current and past patient clinical, drug and family history necessary to design a pharmacotherapeutic plan
- attending chemotherapy drug/chart write up to consult with treating specialists to discuss treatment
- participating in a multidisciplinary team meetings to establish therapeutic goals in collaboration with patient

The **Australian Private Hospitals Association submission** adds that the pharmacist

- visits all patients in the clinic for assessment of physical signs of drug-related effects
- provides to new patients 'a Patient Care Kit, Cancer Council Kit and information from EVIQ
- monitors compliance with medications, diet, sleeping, nausea, constipation, effect of treatment on lifestyle, medication interactions, liaises with family members

The Integrated Clinical Oncology Network (**ICON**_ submission adds that oncology pharmacists "play a critical role in facilitating special access programs"- also important to cancer patients needing newer drugs.

Discussion

Several submissions to the Senate Inquiry asserted that specialised pharmacist clinical services associated with the provision of chemotherapy should be recognised with explicit funding. The broadening of the role of oncology clinical pharmacists may be welcome and may increase the quality and the safety of chemotherapy services. However, we wonder to what extent these expanded pharmacy services, for example the involvement of clinical pharmacists in multidisciplinary oncology teams, do happen in current practice. We also question whether any of these services have been brought forward by some stakeholders to be able to claim higher pharmacy fees from the government without guarantee that these services are or will be implemented in daily practice. To our knowledge, there is currently no quality program implemented across private and public services that could provide evidence to support claims like these.

We believe that the **overall quality of chemotherapy services** is within the scope of the current review, under the ToR 3 which specifically refers to "securing efficient and effective provision of chemotherapy services". As consumers and taxpayers, we are concerned by both the quality of chemotherapy services across all settings whatever the funding source, and the appropriateness of the fees for providers of those services. We are concerned that the quality of pharmacy services associated with chemotherapy may vary considerably between institutions and may impact on the safety and well-being of patients. The lack of clarity on the scope and quality of pharmacy services associated with the provision of those services means that in some cases, some pharmacy clinical services may be funded but not provided, and in other cases they may be delivered but not adequately funded.

Recommendations

We would welcome the development of national **standards of care** that are not only endorsed by the professional organisations but also by the service providers themselves, as a condition for receiving funding for the provision of chemotherapy services. Consumers should be involved in the development of these standards.

Quality programs and standards should be developed so that consumers can be assured of the ongoing quality of the services they receive whatever the location, public or private, inpatient or outpatient, metropolitan or rural/remote. The results of audits performed during quality assessment should be made publicly available. We suggest that the development of standards may be done in liaison with the

Australian Commission on Quality and Safety in Health Care which is currently working on the development on clinical care standards.

Questions for consumers

Issues that have impacted on access to or the quality of chemotherapy infusion medicines

Cancer Voices has made inquiries, in the short space of time available, with a number of its members about their experiences. We report that they are not aware of the roles mentioned above except the preparation and dispensing of chemotherapy to the care units. One said she was aware that their medical oncologist had consulted with pharmacists when a problem arose with the mix of drugs associated with chemo treatment. Most told us that during treatment their oncology nurses were their main source of information about their “chemo cocktail” and for assistance with side effects and support when needed. CVA is aware that many cancer clinics, even medium sized ones, contract out all pharmacy supply services to a third party, which would account for some of these “nil” reports.

Please see the consumer report attached as Appendix for a fuller response to this subject.

Comments on points raised by Discussion Paper

Consumers seek reassurance that their chemo treatment, regardless of setting (public, private, metro, regional or rural) is of the highest quality and safety. Once data has been collected in answer to these ToR, CVA recommends they be used to create an agreed set of guidelines for all settings.

Before their treatment begins, cancer patients should be provided with full financial information as to its cost; this would comply with requirements for *informed financial consent*. Many are surprised and distressed about the costs they find they are incurring, especially those not covered by their private health insurance, or government subsidies of drugs via the PBS. Even multiple co-payments incurred through a course of chemotherapy can mount to a considerable out of pocket expense.

Rural & regional chemotherapy provision

CVA expects cancer patients who are treated in rural and regional settings to have the same degree of access and assurance of quality treatment as their city cousins. This seems possible due to the relative ease of delivering drugs in good time to rural and regional centres, with adequate notice. We note the discussion paper (p8) suggests that while pharmacists / clinics are not charged for cancelled infusions, “a patient co-payment will be applied”. This seems unreasonable. Although outside the ToR of this inquiry, it would be worthwhile exploring ways, if practicable, for blood tests to be done a day or so in advance of planned chemotherapy treatment, to reduce the incidence of wastage from cancelled infusions.

Quality of infusion preparations

CVA support the Department’s proposal that quality standards be linked to funding arrangements to ensure that consumers receive quality services.

CVA is interested to see the answers to the Discussion Paper’s questions about guidelines and standards and how they may be “enforced” (p9). We recommend that meeting these standards must be mandatory in order to receive the subsidies attached to the service, as is usual practice.

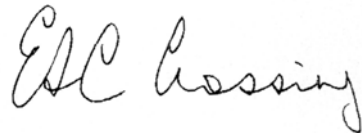
“Other matters”

This section addresses the streamlining and improving of processes “to ensure the efficient use of taxpayer money to fund services” (p10). CVA fully supports this proposal, in the interests of developing a system which is transparent, fair, efficient and cost effective.

Cancer Voices Australia again thanks the Chemotherapy Review Team of the Department of Health & Ageing for this opportunity to provide the broad and independent consumer view.

We are encouraged to think that the Government is keen to address the complex problems which have developed around the funding of chemotherapy services in Australia, and that it wishes to maximise the benefits consumers receive from this important and difficult part of their cancer treatment.

CVA welcomes publication of this submission.



Sally Crossing AM
Cancer Voices Australia Executive Committee

21 July 2013

Cancer Voices Australia is the independent, 100% 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. The CVA network across Australia shares objectives and works together on national issues identified as important by their members, with consumers working to help others affected by cancer.

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



APPENDIX

Response from a cancer patient to our questions regarding the roles of pharmacists listed on pages 2-3 above.

“During my experience as a private cancer patient receiving chemotherapy treatment, I did not ever meet with or have telephone contact with any private pharmacist at all.

From the top down:

Part 1

There was no clinical verification of the drug order, accurate dispensing of chemotherapy, taking of medical history of patient's initial and subsequent cycles and documentation of previous, and current adverse reactions. My drug charts show the drug dose only, no current BSA, no recommended accumulative lifetime dose and accumulative dosage given. My patient records show no education and no health assessments. The chemo was single checked by one RN. This would be standard for most/all the private clinics that run cancer treatments.

The issue is the 'culture' of private doctors, once again. Pharmacists, like nurses and allied health services, are seen and not heard in many/all private hospitals. There is a post graduate qualification for pharmacist delivering chemotherapy. I know the public pharmacists do it. I seriously doubt the private ones do. Higher qualifications mean increased wages.

Part 2

There were no pathology tests done pre chemotherapy treatment, and only one simple test pre each subsequent cycle.

There was no family history, plan, or multidisciplinary team approach at any time during my treatment. This was despite my asking repeatedly for assistance during and after chemo, due to severe ill health and prolonged recovery period.

Part 3

I at no time received a Patient Care Kit, or information from EVIQ. (EVIQ is EXCELLENT quality patient information). There was no documented (or verbal) health assessment before, during or after chemo. There was never any discussion of compliance with medications (I stopped tamoxifen after a month due to severe side effects, the oncologist just rubbished me verbally), there was no discussion of diet (despite losing 15% of my body weight), sleeping or nausea (my numerous phone calls to the private oncologist during chemo complaining about severe nausea were not returned, and anti-nausea drugs had to be obtained from the GP).

My treatment was, and still is, standard for many private cancer treatments.

The involvement of pharmacists in cancer or any other acute treatment occurs only in large public hospitals and large private hospitals that run like public hospitals (like Cabrini). Pharmacists having a 'hands on' role are a new development, called clinical pharmacology (I think). In public hospitals, each speciality area has their own pharmacist, who actually comes around wards, checks drug charts daily, brings meds to the patient and talks to them and liaises with doctors regarding meds. These pharmacists are extremely useful. I have not seen this happen in the private, where the culture and infrastructure is such, that the doctor is the one and only person who makes all the decisions about the patient's entire treatment regime. Their work is not interfered with, supervised or checked by other health staff.”

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