Consumer and Community Input into the
Review of Funding Arrangements for Chemotherapy Services:

Final Report

September 2013
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Executive Summary

The Consumers Health Forum of Australia (CHF) has undertaken a program of community consultations to provide input into the review of chemotherapy funding arrangements through August 2013. This project is part of a broader review of funding arrangements for chemotherapy services that is being undertaken by the Department of Health and Ageing (DoHA).

CHF drew on a range of consultation mechanisms, including an online survey, face-to-face consultations, teleconsultations, written submissions, and one-on-one interviews with consumers. These consultations were targeted to consumers who had accessed chemotherapy services, and voting members of CHF who represent the views of consumers around Australia.

As outlined in the overview of consultation findings, these consultations found that consumers receiving chemotherapy treatment identified safety, quality and access as key issues that should be taken into consideration when determining the funding and delivery arrangements for chemotherapy services.

Consumers told CHF that they did not view the existing global funding arrangements for chemotherapy, provided through the Fifth Community Pharmacy Agreement (5CPA), as meeting acceptable standards of transparency and accountability. They reported that this arrangement did not represent good value for public investment. Consumers also told CHF that they want a chemotherapy funding arrangement that is transparent, equitable and good value for money. They want arrangements to explicitly outline which services were being purchased through these agreements, and believed that only the cost of medicines should be funded through the Pharmaceutical Benefits Scheme (PBS).

Consumers also recognised that other funding arrangements, including the arrangements between States, Territories and the Commonwealth, and the interaction of arrangements between the public and private health systems, impacted on the experiences of, and outcomes for, consumers undergoing chemotherapy treatment and also required improvement.

Participants in CHF’s consultations shared their experiences in accessing chemotherapy services, highlighting the significant out-of-pocket costs, challenges in accessing services and concerns they had about how safety and quality was built into current funding arrangements.

Recommendations contained in the report are outlined below.
List of Recommendations

**Recommendation 1:** that the PBS subsidy for chemotherapy drugs reflect the market price of the medicine.

**Recommendation 2:** that the PBS subsidies should not be used to cross-subsidise other aspects of the provision of chemotherapy drugs.

**Recommendation 3:** that the principles identified by consumers through this consultation process be used to inform any future funding arrangements for the provision of chemotherapy drugs and services.

**Recommendation 4:** that consumers are involved in the development of all future funding arrangements for the provision of chemotherapy to ensure that funding arrangements enhance patient-centred care.

**Recommendation 5:** that the Government, in consultation with consumers and other stakeholders, explore alternative funding models to determine which one would best meet the needs of the community.

**Recommendation 6:** that when Government, in consultation with consumers and other stakeholders, explore alternative funding models, the issues and options raised within this consultation process are considered.

**Recommendation 7:** that international best practice models for chemotherapy funding are reviewed and used to inform future funding arrangements.

**Recommendation 8:** that the Commonwealth Government seeks agreement from State and Territory Governments that no co-payments will be charged for the provision of chemotherapy in public hospitals.

**Recommendation 9:** that the Government obtain data on the provision of chemotherapy in the private sector, including the number of patients treated, the location of treatment, and the associated out-of-pocket costs.

**Recommendation 10:** that the Government commission research for out-of-pocket costs for consumers undergoing chemotherapy, recognising the particular issues facing rural, regional and remote consumers.

**Recommendation 11:** that any future funding agreement recognises rural, regional and remote consumers’ entitlement to equal access.

**Recommendation 12:** that an economic analysis is undertaken to assess the cost of the specific services involved in the provision of chemotherapy services and drugs, including an analysis of the cost-effectiveness of different models of chemotherapy provision.

**Recommendation 13:** that future funding agreements for chemotherapy contain dispute resolution provisions to resolve disagreements over funding levels without impacting on consumers.
Recommendation 14: that future pharmacy agreements prohibit providers and provider groups from threatening consumers with loss of access to chemotherapy services.

Recommendation 15: that the Government take steps to ensure the supply of chemotherapy drugs.

Recommendation 16: should the delivery of chemotherapy drugs require additional funding, it should be pursued separate to the PBS subsidy, and be based on a transparent costing process.

Recommendation 17: that national clinical standards for the provision of chemotherapy be developed, drawing on the input of consumers and other stakeholders.

Recommendation 18: that future funding arrangements link funding to the adherence to safety and quality standards.

Recommendation 19: that research on the issues surrounding the provision of chemotherapy in Australia is given priority, including where chemotherapy is provided, co-payment arrangements, models of treatment (including the role of pharmacists and third-party compounders), cost effectiveness, quality and safety and consumer experiences. The findings of any research in these areas should be used inform future funding arrangements for chemotherapy.
Introduction

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 has been funded by the Department of Health and Ageing to consult with consumers and consumer organisations on the Review of Funding Arrangements for Chemotherapy Services. The broader Review is investigating and reporting on:

a. Current arrangements for funding of chemotherapy services;
b. How those arrangements have changed over time;
c. How chemotherapy services are provided, including in relation to:
   i. Different hospital and community settings
   ii. Different business models
   iii. Use of third party compounders
   iv. Integration of hospital, pharmacy and oncology services;
d. The involvement of public and private hospitals in providing chemotherapy services, including:
   i. the extent to which each sector provides services
   ii. differences by state
   iii. how that service mix has changed over time
   iv. current trends in that service mix
   v. any implications for community pharmacy or the Pharmaceutical Benefits Scheme
   vi. any implications for private hospitals and private health insurers;
e. Cost structures associated with provision of chemotherapy services – dispensing, support, administration and clinical services;

The aim of CHF’s Project is to engage health consumers in the Review by conducting targeted consultations with consumer organisations and CHF members.

The objectives of this project are to:

• raise consumer awareness of the inquiry; and
• establish an evidence base through consumer consultation to identify community issues related to the Review

This report outlines the key findings of consultations with consumers undertaken by CHF as part of the Review, and makes recommendations to improve future funding and service delivery arrangements.
Consultation Methodology

The information and consumer views presented in this report were obtained through extensive consumer consultations through a number of different methods. These included:

**Distributing a discussion paper** outlining the key issues and describing the consultation process. This paper introduced the Review and asked consultation questions to stimulate discussion. This paper was released on **Monday 22 July 2013** and was available to CHF members. The paper is available at [Attachment A](#).

**Maintaining an online consultation platform** for community members with an interest in cancer treatment issues. This platform went live on **Monday 22 July 2013**.

**Operating an online survey** and consultation to complement the discussion paper. This survey went live on **Monday 22 July 2013**. A brief summary of the results of the survey is at [Attachment B](#).

**Holding face-to-face consultations** to gain a greater understanding of how the Review affects consumers. The consultation program is available at [Attachment C](#).

**Hosting teleconsultations** for consumers and consumer organisations unable to participate in the online consultations. The teleconsultation program is available at [Attachment D](#).

**Inviting written feedback**, including letters, emails, submissions and reports.

**Conducting one-on-one interviews** with consumers and consumer organisations who were unable to participate in other aspects of the consultation.

Contributions to CHF’s consultation closed on **Thursday 29 August 2013**.

Consumers who participated in the consultations had a broad range of experience with chemotherapy, both as patients and as carers for family members undergoing treatment. Some consumers consulted were currently in the process of receiving chemotherapy, while others had received treatment in the past. A number of consumers had experienced more than one type of cancer, and had received chemotherapy treatment in different locations, at different times and in different models of care. In addition to individual CHF members and anonymous survey respondents, a list of consumer organisations and groups participating in CHF’s consultations is provided at [Attachment E](#).
Overview of Consultation Findings and Core Recommendations

For consumers receiving chemotherapy treatment, safety, quality and access are key issues. Participants in CHF’s consultations highlighted the need to ensure that the funding allocated to chemotherapy treatment is used to deliver the highest quality, most accessible and cost effective services. They acknowledged the complexity of the existing funding model, but emphasised the importance of placing consumers at the centre of the funding arrangements.

Existing funding arrangements for chemotherapy were not seen to meet acceptable standards of transparency and accountability, as illustrated by the confusion surrounding the status of chemotherapy funding in the Fifth Community Pharmacy Agreement (5CPA). Consumers also recognised that other funding arrangements impacted on the experiences of consumers undergoing chemotherapy treatment. These include the arrangements between States and Territories and the Commonwealth, and the interaction of arrangements between the public and private health systems.

Overall, participants in CHF’s consultations did not believe that existing funding arrangements represented good value for the investment of public funding, and many consumers raised questions about its role in promoting the quality and safety of chemotherapy provision. They also expressed strong views about the impact of direct out-of-pocket costs of chemotherapy services. There was a consensus among those consulted by CHF that these costs have significant detrimental impacts on consumers at a vulnerable time, and that consumer co-payments should be reconsidered.

Determining the Correct Subsidy for Chemotherapy Drugs

Consumers told CHF that they want chemotherapy funding arrangements that are transparent, equitable and good value for money. Several consumers expressed their concern that the price through the PBS was being used to cover costs other than the drug itself. On this basis, consumers in CHF’s consultations supported the application of Expanded and Accelerated Price Disclosure (EAPD) to chemotherapy drugs, and there was consensus among consultation participants that other aspects of the provision of the drug should not be funded through PBS subsidies.

In light of the consultation findings, CHF recommends that the PBS subsidy for chemotherapy drugs reflect the market price of the medicine. CHF’s consultations have not shown support for the payment inflated costs for chemotherapy drugs in order to cross-subsidise other elements of the delivery of these drugs. Should the delivery of chemotherapy drugs require additional funding, consumers indicated that this should be pursued outside the PBS subsidy, and be based on a transparent costing process.

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<th>Recommendation 1:</th>
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Funding Principles

Through the consultation process, consumers articulated a number of principles which they believed should underpin the development and application of a funding system for chemotherapy. These principles state that a funding system for chemotherapy should:

1. Be consumer-centred, rather than provider-focussed;
2. Be developed and implemented with consumer input;
3. Support equitable access to chemotherapy services, including for consumers in rural, regional and remote areas;
4. Ensure that no consumer experiences a financial barrier to access;
5. Support high standards of safety and quality;
6. Take into account the range of medications required as part of chemotherapy treatment, including ancillary medicines such as anti-nausea drugs;
7. Be based on the actual cost of providing chemotherapy drugs;
8. Be monitored regularly to ensure it delivers the stated outcomes;
9. Take into account the different models of chemotherapy provision within the health system; and
10. Be sustainable over the long-term.

**Recommendation 3:** that the principles outlined above are used to inform any future funding arrangements for the provision of chemotherapy drugs and services.

**Recommendation 4:** that consumers are involved in the development of all future funding arrangements for the provision of chemotherapy to ensure that funding arrangements enhance patient-centred care.

Proposed Future Funding Arrangements

Current arrangements for the funding of chemotherapy have been developed between Government and the Pharmacy Guild of Australia (PGA) with only limited consultation and input from other stakeholders. In recent years, a range of other stakeholders have sought greater involvement in the negotiation of these arrangements, and this has been the subject of some debate.

Many consumers consulted by CHF felt that a global funding agreement, such as the 5CPA, was an inappropriate vehicle for funding chemotherapy. Others felt that chemotherapy could potentially be funded through a similar pharmacy agreement, but that it would need to be substantially changed to meet improved standards of governance, transparency and accountability.

Some consumers believed that long-term global agreements, like the 5CPA, may deliver advantages in the areas of service stability and certainty for pharmacy owners, pharmacists and consumers. Others pointed out that the current 5CPA had resulted in significant uncertainty and anxiety for consumers in relation to the ongoing supply of chemotherapy after the application of price disclosure to Docetaxel.
Participants in CHF’s consultations suggested a number of options to improve current funding arrangements for chemotherapy. Common to all these options was the need for an evidence-based approach to funding the specific chemotherapy services, where payments are attached to the actual provision of the services. This would rely on accurate costing data to reflect the cost of providing the drug and the service, which may depend on the type of drug, the location of the consumer and the model of service provision. Consumers also strongly supported the need for funding to be linked to performance standards, and for this to be actively monitored.

Consumers felt strongly that they needed to be represented in any future negotiations between the Government and the PGA over funding arrangements relating to chemotherapy drugs. Consumers stressed the importance of recognising that funding for chemotherapy, whether through public programs or private health insurance, ultimately comes from taxpayers. As such, this investment needs to reflect value for money. This could be achieved through involving consumer advocacy organisations in the negotiation process. Consumers suggested that this representation should be based on consumer consultation to ensure that peak bodies can accurately reflect consumer experiences, priorities and views.

A number of consumers consulted by CHF felt that a fee-for-service funding model was not well-suited to the provision of chemotherapy services. This is due in part to the role of the pharmacist in the provision of chemotherapy, which differs significantly according to the type of drug being dispensed, the characteristics of the patient, the model of service provision, and the location of the service. For example, consumers reported their experiences of some chemotherapy drugs that required preparation of individual doses, while others could be provided in a standardised, pre-packaged tablet form. A fee-for-service payment system generally provides a standard payment for all services which assumes the cost of providing chemotherapy is always the same. This may result in some providers being overcompensated and others being undercompensated.

Many consumers noted that the costs associated with providing chemotherapy drugs are not dependent on the number of doses dispensed. For example, infrastructure, equipment and training costs remain largely the same regardless of whether the pharmacist is preparing a small or large number of doses. Consumers felt that a fee-for-service payment system may disadvantage pharmacists with a small number of chemotherapy patients, such as those in a rural or regional area, relative to those in urban areas with large patient populations. Consumers were concerned that this may make the provision of chemotherapy less attractive to providers in rural areas, reducing consumer access.

An alternative to a fee-for-service model suggested in the consultation process was a blended payment approach, including specific payments for chemotherapy services, similar to the Practice Incentive Payments (PIPs) or Service Incentive Payments (SIPs) used in general practice. This could involve providing a one-off payment to pharmacists for investing in new equipment necessary for storing chemotherapy medicines and undertaking any additional training required.
Consumers were aware from their own experiences that there are a number of different models for the delivery of chemotherapy drugs. For example, some services involve pharmacists preparing infusions in-house, whereas others contract this role to a third-party, such as Baxter Healthcare. Some consumers raised questions about the relative advantages and disadvantages of these models, particularly in relation to quality, safety, and cost-effectiveness. They felt that from both an individual consumer and general community perspective, the best model should be used in each situation. However, there did not appear to be any data to support a choice of model.

Consumers felt intuitively that using a third-party compounder may be more cost-effective for a large hospital with a high volume of chemotherapy patients, whereas services with a small number of patients may be better suited to in-house preparation and dispensing. In principle, consumers believed that the funding system should support the most cost-effective option, on the proviso that it did not compromise equity of access or quality of care. Some consumers consulted raised questions about the quality associated with third-party, off-site compounders, asking whether they were able to meet the needs for individual targeting of doses sometimes required for chemotherapy patients. A need for standards to be developed and monitored in this area was also identified.

**Recommendation 5:** that the Government, in consultation with consumers and other stakeholders, explore alternative funding models to determine which one would best meet the needs of the community.

**Possible Funding Models**

Over the course of CHF’s consultations, a number of suggestions were made regarding possible alternative funding models. Several consultation participants suggested reviewing international models of chemotherapy funding, and exploring their suitability to the Australian context.

As outlined in the Funding Principles, consumers supported the need for any funding model to be based on an independent assessment of the costs involved in dispensing chemotherapy drugs, and to fund each component individually and transparently. They also stressed the need to consider the longer-term sustainability of funding arrangements to ensure that chemotherapy continues to be accessible. The three alternative funding options discussed during the consultations are as follows.

**Option 1: A global funding agreement that includes chemotherapy drugs**

This option involves retaining the current model of a PBS subsidy alongside a global pharmacy agreement such as the 5CPA. The provision of chemotherapy drugs would be included as a separately defined funding measure, with an outline of the specific services involved in the provision of chemotherapy and attaching funding measures to the identified outcomes. The funding measures would need to be based on data identifying the actual cost of providing specific chemotherapy services and evidence that these services are actually being provided. This option would be dependent on the involvement of consumers in the development and ongoing evaluation of such an agreement.
Option 2: A discrete chemotherapy agreement
This option treats chemotherapy as a separate area of healthcare, funded outside the existing PBS and Medical Benefits Schedule (MBS) structure in a national agreement between relevant stakeholders, including pharmacists, pharmaceutical companies and consumers. This agreement would set out the conditions under which chemotherapy is provided in Australia and the associated funding mechanisms. Implementation of the agreement would be overseen by an independent body, such as a statutory authority. This body would have the authority to enforce sanctions for non-compliance with the agreement and to resolve disputes over funding. This model is similar to the way in which the provision of blood products is funded through the National Blood Agreement.

Option 3: Existing PBS subsidies with additional payments
This option would involve the removal of dispensing payments for the provision of chemotherapy drugs out of a global pharmacy agreement, and replace them with separate payments for specific services through the PBS. This is similar to the incentive payments provided to general practice. These payments would apply to specific services associated with the provision of chemotherapy drugs, and could include the purchase of specialised equipment or the cost of additional training. They could also be dose-specific and attached to PBS payments for chemotherapy medicines. This option would be dependent upon consumer involvement in the development of additional payments. It would also require ongoing monitoring and auditing to ensure compliance with the conditions.

Recommendation 6: that when Government, in consultation with consumers and other stakeholders, explores alternative funding models, the issues and options raised within this consultation process are considered.

Recommendation 7: that international best practice models for chemotherapy funding are reviewed and used to inform future funding arrangements.
Current Funding Issues

“The bottom line needs to be consumer needs. There are so many fingers in the pie at the moment – the system is just a mish-mash. There’s no transparency or accountability.”
Juli, Fleurieu Cancer Network

Consumers who were involved in the consultation process were provided with information about the complex funding arrangements to support the provision of chemotherapy services. These arrangements were explored in the discussion paper that was developed as part of the process. This paper outlined the funding and pricing mechanisms that supported chemotherapy services, explored the stages in the provision of chemotherapy services and explored some of the key issues relevant to the review.

Consumers agreed overwhelmingly that current funding arrangements for chemotherapy did not meet their needs for reliable and high quality supply of chemotherapy. They also questioned whether current arrangements delivered value to them as taxpayers.

Consumers told CHF that funding mechanisms are important in so far as they impact on the nature, availability and location of services. These factors all influence the conditions under which consumers can access chemotherapy. Given the impact of funding arrangements on service delivery, consumers felt that negotiations relating to funding were not simply matters for the funders and providers, but must also involve consumers. Participants in CHF’s consultations also felt that their involvement in funding issues was essential to ensure that any future agreements represented good value for the community.

Many consumers reported feeling disempowered by the current arrangements, with little scope for them to provide input or feedback. They expressed a lack of confidence that their interests were being adequately represented in current negotiations. Consultation participants also reported that they found the current funding arrangements complex and difficult to understand. The role of each of the various funding sources in the provision of chemotherapy drugs was not always clear to them. This complexity was itself considered a barrier to accountability.

Comments on specific aspects of the funding arrangements are outlined in greater detail below.

Fifth Community Pharmacy Agreement

“How can health consumers not be involved in such major negotiations?”
Survey respondent

When discussing the 5CPA, consumers noted that the Agreement contains little detail on the funding arrangements relating to the provision of chemotherapy drugs and this had created significant difficulties around the supply of chemotherapy in recent times.
Some expressed surprise that interim additional funding had been provided to the pharmacy sector given the findings of the recent Senate Community Affairs References Committee inquiry, which found that no further compensation was required beyond the funds committed through the 5CPA.¹

Consumers raised a number of concerns regarding the 5CPA, including:

- **The lack of transparency.** It is difficult, within the terms of the current Agreement, to determine where funding has been allocated. It has proven challenging to determine whether funding was allocated under the Agreement for the provision of chemotherapy drugs, and this has been the subject of uncertainty for both providers and consumers.
- **The lack of accountability.** Consumers noted the difficulty in monitoring whether pharmacists provide relevant chemotherapy services, and no recourse for consumers if this funding is not used for its allocated purpose.
- **The absence of quality and safety mechanisms.** There is no link within the 5CPA between funding and the quality and safety of services provided.
- **The absence of an evidence base to inform remuneration levels.** The funding allocated for the provision of chemotherapy drugs and services under the 5CPA appears arbitrary, and not to be based on the actual costs of providing chemotherapy services.
- **Flaws in the 5CPA evaluation framework.** Consumers consulted by CHF noted the absence of a rigorous and independent evaluation mechanism. This makes it difficult to determine the effectiveness and cost-effectiveness of the provision of chemotherapy services and drugs.
- **The inability of the 5CPA to guarantee supply.** There is no mechanism within the 5CPA to ensure that pharmacists will continue to provide chemotherapy services.

A number of specific issues were raised regarding the development of the 5CPA, particularly the lack of consumer involvement. Consumers participating in the consultations felt strongly that the Government had a number of competing objectives in negotiating the Agreement, and that the interests of consumers were not adequately represented.

Consumers also expressed concern regarding the ambiguity of the 5CPA in relation to the funding arrangements for chemotherapy drugs. They expressed concern that this makes it difficult to validate the claims of the pharmacy sector that additional funding would be required to compensate pharmacists for the application of EAPD to Docetaxel, or the counter claims from the Department of Health and Ageing that this pricing mechanism had been subject to negotiation with the Pharmacy Guild of Australia in 2010.

Consumers participating in CHF’s consultations also acknowledged that there was a lack of available data to support an accurate assessment of the costs associated with the provision of chemotherapy across the spectrum of the health system. They therefore recognised that there may be some pharmacies, particularly those in rural and regional areas, that may no longer consider it commercially viable to continue to dispense chemotherapy drugs. Consumers felt that if there are pharmacies in this situation, they should be able to seek support from the Government through a targeted program. This is outlined in greater detail below.

¹ Senate Community Affairs References Committee (2013) *Supply of chemotherapy drugs such as Docetaxel.* Commonwealth of Australia: Canberra.
Commonwealth, State, and Territory Arrangements

The inconsistency of current funding arrangements across jurisdictions and sectors were identified as a problem for consumers. People reported facing a range of different out-of-pocket-costs depending on where and when they accessed care. This was seen as being a problem, as it was felt that all Australians should receive the same level of care and incur similar costs, while recognising the need to provide a safety net for low-income households.

Consumers reported that some state governments provided chemotherapy as an outpatient service in their public hospitals, resulting in a co-payment for patients. Overall, consumers felt that there was no justification for co-payments for people receiving chemotherapy and supported a commitment from state and territory governments not to impose any co-payments for chemotherapy provided in the public hospital system.

**Recommendation 8:** that the Commonwealth Government seeks agreement from State and Territory Governments that no co-payments will be charged for the provision of chemotherapy in public hospitals.

Care in the Public and Private Sectors

Consumers receive chemotherapy in both the private and the public sectors, and sometimes from both sectors, during the course of a single treatment. For example, a patient in a private hospital may be discharged and then receive treatment as an outpatient from a public hospital. There are differences in the way in which the public and the private systems are funded, which may result in differences in service. Several responses to the Senate Community Affairs References Committee’s *Inquiry into the Supply of Chemotherapy Services such as Docetaxel* raised concerns about the differing public and private systems and their impact on the dispensing of, and claiming for, PBS medicines.

There was a strong consensus among CHF’s consultation participants that chemotherapy services should be a universal service, and that there is a need to ensure that all Australians have the opportunity access chemotherapy within the public system. Consumers were also of the view that regardless of whether treatment is sought in the public or private sector, the accessibility of services should be consistent, equitable and affordable.

Consumers did report that for many cancers there was a need to seek treatment in both the public and private sector. Across both sectors, consumers reported variability in their experience, with the vast majority of people reporting positive experiences in relation to the quality of care they were provided.

With regard to experiences within the private sector, consumers reported a range of experiences with some reporting that they had received high quality care in the private system, and others indicated that they felt that the quality of care had not been adequate. Some stated that they felt that the private sector was promoting over-servicing in the area of cancer treatment, and that they did not feel that the focus was on meeting consumer needs. Others noted the importance of multi-disciplinary care for cancer treatment and questioned whether this was available in smaller private centres.
A number of issues were raised in relation to moving between the public and private sectors. These included the difficulties consumers had in keeping track of treatment records, and recording cost and other information relevant to consumer charges. Some consumers reported not being aware of which sector they had been referred to by their specialist, and only finding out later. Questions regarding potential differences in the safety and quality of care between the sectors were also raised, as was the importance of consumers having accurate data so that consumers can make an informed choice about their treatment location.

Shared standards of care and treatment across both sectors was recommended as a strategy that would help address this problem and ensure a more seamless transition across the public-private interface.

**Recommendation 9:** that the Government obtain data on the provision of chemotherapy in the private sector, including the number of patients treated, the location of treatment, and the associated out-of-pocket costs.
Cost, Location and Other Access Issues

“Cost is an issue for people living on the margin. We know people who don’t eat so that they can afford their medication”
Consumer and cancer support group member, South Australia

Although the cost of medicines is subsidised by the PBS, consumers may incur a range of other costs in accessing chemotherapy medicines and treatments. These may include indirect costs, such as travel or time away from work.

CHF’s consultations suggest that cost issues can impact on access to care, and influence the choices consumers make about their care options, including the location and timing of treatment. Consumers felt that current funding arrangements resulted in an inequitable imposition of costs, and that this was creating barriers to access for some groups in the community. Consumers also agreed that the starting point for the development of an appropriate funding mechanism for chemotherapy should be the impact on consumers, rather than the advantages to providers.

Consumers stressed the importance of understanding all costs associated with chemotherapy when assessing the overall costs of treatment. These costs include ancillary drugs (for example, anti-nausea medication), radiation treatment, doctor visits, allied health services, and transport and accommodation, particularly for consumers who need to travel for treatment.

Out-of-Pocket Expenses for Consumers Accessing Chemotherapy Services

Research commissioned by the Cancer Council NSW has found that the estimated average lifetime out-of-pocket cost for a person with cancer and their family is $47,200. This includes $38,300 in productivity costs such as lost income, $3,900 in non-health costs and $5,000 for healthcare.\(^2\) This is consistent with CHF’s consultation findings, with consumers in CHF’s Adelaide consultation reporting that chemotherapy patients sometimes had to forgo food or other essential expenses in order to afford treatment. Some consumers reported being forced to choose between which prescribed medicines to take, as they could not afford to fill all prescriptions. Consumers repeatedly cited incidents of being forced to choose to fill the prescription for the chemotherapy drug and forego the anti-nausea drug due to financial pressure. While it was recognised that there are some financial assistance programs to support cancer patients undergoing treatment, it was believed that these did not offer adequate levels of support. Consumers also reported low awareness of these programs.

Some consultation participants reported struggling with indirect expenses relating to their treatment. For example, one consumer told CHF that her husband took seven months of leave without pay from his job to care for her during treatment, resulting in significant debts. Other consumers found it difficult to manage ‘one-off’ payments, which can add up to significant expenses over time. For example, one survey respondent reported paying hundreds of dollars in hospital parking costs over the course of a year. The off-label use of medicines on the PBS, and access to drugs not yet listed on the PBS, were also raised. A number of consumers reported relying on medicines for which they did not receive government funding and which could result in increased out-of-pocket costs.

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\(^2\) Access Economics (2007). Cost of Cancer in NSW. NSW.
Informed financial consent was identified as an issue by some consumers who reported that they had not understood the costs they would face prior to treatment. Some consumers reported being referred to private services by specialists working in the public sector, and had not been told that the service was private and would attract out of pocket costs.

There were reports of significant lags of time between the introduction of new arrangements, such as the Australian Government’s Revised Arrangements for the Efficient Funding of Chemotherapy Drugs, which ruled that patients could no longer be charged co-payments for repeat prescriptions, and their implementation. There were reports that some providers have continued to charge co-payments for repeat prescriptions.

While CHF understands that the issue of out-of-pocket costs for healthcare consumers accessing chemotherapy services is outside the Terms of Reference of the current Review. The strength of the feedback from consumers, however, suggests further work on this issue is warranted.

**Recommendation 10**: that the Government commission research for out-of-pocket costs for consumers undergoing chemotherapy, recognising the particular issues facing rural, regional and remote consumers.

**Issues Facing Consumers in Rural, Regional and Remote Areas**

The supply of chemotherapy drugs to consumers in rural and regional areas creates a range of additional challenges, due to the distances involved, the time taken to reach these areas, lower levels of health infrastructure and the smaller and more dispersed population. It is not clear whether these challenges have created cost and other barriers to the delivery of high quality treatment for cancer in rural Australia. There is little available data on the specific costs involved with the provision of chemotherapy in rural areas and the experience of consumers in these areas in accessing chemotherapy.

Consumers consulted by CHF identified a number of specific issues facing people in rural and regional areas who need chemotherapy treatment. These relate to both cost and geographical issues associated with the provision of specialised healthcare in rural and regional areas.

In relation to costs, consumers identified a number of expenses associated with chemotherapy treatments that are higher for people living in rural and regional areas. These include expenses associated with lower levels of competition and higher supply costs. A number of consumers from rural areas also reported that treatments associated with chemotherapy, such as radiation, doctor visits, and allied health services, were significantly higher in rural and regional areas.

A number of additional costs were identified in relation to travel and accommodation requirements. Many consumers reported traveling long distances to receive care. For example, one consumer reported the need to travel from Katherine to Darwin for daily treatment. Consumers stressed that it was important to remember that treatment provided in regional centres may still require travel. While there was recognition of some support for travel costs, such as the Patient Assisted Travel (PATS) scheme, consumers reported that subsidies received under this scheme were inadequate and failed to cover a significant proportion of costs.
There were also a range of additional costs identified by consumers in relation to receiving chemotherapy in rural, regional and remote areas. These included the costs associated with leaving work for extended periods to access care in regional centres or capital cities. Some consumers reported delaying treatment due to the difficulties involved in being away from their homes and families for extended periods.

Several consumers also raised questions about the relative quality of chemotherapy services provided in rural and regional areas. Anecdotal evidence suggests that the outcomes for consumers in larger urban treatment centres are generally superior. Consumers participating in the consultations agreed that those seeking treatment in rural and regional areas deserved the same level of access to the quality care as those in cities, although they recognised that in some cases a trade-off may need to be made between convenience and quality. In these cases, it was important that consumers were able to make informed decisions. It was also suggested that the development of standards for the provision of chemotherapy would assist in driving improvements in quality across rural and regional areas.

**Recommendation 11:** that any future funding agreement recognises rural, regional and remote consumers’ entitlement to equal access.
The Role of Pharmacists

“In my experience the Pharmacy Guild looks after its members to an almost unethical extent – sweeping aside consumer interests for their benefit”
Health consumer at workshop in Adelaide

CHF’s discussion paper provided a background to the role of pharmacists in relation to dispensing chemotherapy medications. Consumers consulted by CHF reported a range of experiences regarding the role of pharmacists in the provision of chemotherapy. Most reported minimal face-to-face contact with pharmacists, although some reported that their pharmacist played a key role in the provision and coordination of services, particularly in the hospital setting.

In general, consumers valued the expertise and advice of pharmacists in relation to chemotherapy and most felt that they would prefer to receive advice on drug interactions from their pharmacist than from their doctor, due to their belief that pharmacists had greater knowledge of this area.

Consumers were aware that much of a pharmacist’s role in the provision of chemotherapy occurred ‘behind the scenes,’ and that they may not be aware of the specific tasks they undertake. They stressed that consumers’ main concern was for the high quality provision of chemotherapy, and it was not the role of consumers’ to assess the performance of individual pharmacists. However, consumers did consider it important that there were standards for the provision of chemotherapy services and drugs by pharmacists, and that these needed to be monitored by an appropriate authority.

It was noted that the role of pharmacists in relation to the dispensing of chemotherapy and other cancer treatments is changing. While some areas are seeing more complexity, the use of some methods, such as oral transition of chemotherapy drugs, can reduce the complexity. As such, consumers suggested that there is the need to understand and respond to changes in treatment regimes and the cost implications of new treatment mechanisms.

Consumers stated repeatedly throughout the consultation process that they respected and valued the role of pharmacists in the health system generally, and specifically in relation to the provision of chemotherapy services and drugs. Many consumers reported positive experiences with pharmacists in the course of their treatment, and said that they valued the expertise of pharmacists, in particular in relation to drug interactions.

Recommendation 12: that an economic analysis is undertaken to assesses the cost of the specific services involved in the provision of chemotherapy services and drugs, including an analysis of the cost-effectiveness of different models of chemotherapy provision.
The Impact of Funding Uncertainty

“I had a lot of patients contacting me who heard something in the media and were terrified that they weren’t going to be able to access their chemotherapy”

Maeve, South Australian consultation participant

Consumers reported a range of reactions to the public statements made about the impact of price disclosure on the supply of chemotherapy. Many described the stress associated with having cancer and receiving treatment, and the additional burden that resulted from the uncertainty surrounding the ongoing supply and affordability of their chemotherapy.

Consumers representing support groups told CHF that many of their members had contacted them and reported distress about the possibility that they may not be able to access chemotherapy in the centre closest to them. Others were concerned about the affordability of treatment if co-payments rose, or if treatment was restricted to large urban centres. Carers of people with cancer also provided feedback, expressing their anxiety on behalf of the person they were caring for when they heard these messages. Consumers stressed that even when the threats of withdrawal of services or price increases are not realised, the threats themselves created an environment of unease for consumers and their families at a difficult time.

Ensuring the Supply of Chemotherapy Drugs

Due to this experience, consultation participants emphasised the importance of future funding policies focussing on ensuring the supply of chemotherapy drugs. While consumers appreciated that there may be supply factors outside the government’s control, they felt that more could be done to minimise the impact of supply threats on consumers. In the case of funding disputes, consumers felt that arrangements should be in place within the context of the funding agreement to ensure that disagreements over funding are addressed without causing unnecessary distress for consumers. In other cases, consumers felt that the government should have been more proactive in predicting and addressing potential problems, such as sourcing alternative sources well in advance if a pharmaceutical company ceases production of a specific chemotherapy drug. Consumers did not believe that it should be left to individual oncologists and consumers to search for suppliers of specific drugs if supply is compromised.

**Recommendation 13:** that future funding agreements for chemotherapy contain dispute resolution provisions to resolve disagreements over funding levels without impacting on consumers.

**Recommendation 14:** that future pharmacy agreements prohibit providers and provider groups from threatening consumers with loss of access to chemotherapy services.

**Recommendation 15:** that the Government take steps to ensure the supply of chemotherapy drugs.

Consumers acknowledged that some providers may be impacted by the application of price disclosure in a way that could compromise the supply of services. In particular in rural areas, consumers understood that providers may face increased costs, and that it would be important to maintain these services.
To address this issue, consumers suggested that the Government invite applications from individual pharmacists who believe that they would be adversely impacted. These applications could be assessed on their individual merits on the basis of the evidence of the costs associated with the provision of chemotherapy in the specific setting.

**Recommendation 16:** should the delivery of chemotherapy drugs require additional funding, it should be pursued separate to the PBS subsidy, and be based on a transparent costing process.
Quality and Safety

“Every patient undergoing chemotherapy deserves the best possible treatment. This requires standards and monitoring.”
Survey respondent

The provision of chemotherapy drugs carries a higher risk, and it is therefore essential to ensure the safe and quality provision of these medicines. There are a number of guidelines and standards relating to chemotherapy medicines. However, there is no agreement on which standards are the most appropriate, how they should be implemented and how compliance with them should be monitored.

Consumers agreed that it must be a key priority of any funding system to ensure the highest standards of quality and safety in the provision of chemotherapy, and expressed concern that the current arrangements do not achieve this aim.

The absence of agreed standards makes it difficult to assess whether or not current funding provision for chemotherapy is likely to achieve good clinical outcomes. Consumers supported the notion of funding being attached to standards of safety and quality. This would rely on the development of national standards for the safe and quality provision of chemotherapy services, agreed on by all stakeholders, and implemented across both the public and private sectors. The development of these standards was seen as essential to ensure best practice wherever consumers receive chemotherapy treatment. This would also enable future funding arrangements to be tied to service providers’ meeting agreed standards.

<table>
<thead>
<tr>
<th>Recommendation 17:</th>
<th>that national clinical standards for the provision of chemotherapy be developed, drawing on the input of consumers and other stakeholders.</th>
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<tr>
<td>Recommendation 18:</td>
<td>that future funding arrangements link funding to the adherence to safety and quality standards.</td>
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</table>
Data and Research Collection

As highlighted above, consumers felt that current funding arrangements were not informed by accurate data on the costs associated with the provision of chemotherapy services. Overall, consumers felt that current funding arrangements were operating in a vacuum, with little understanding of the exact cost of chemotherapy provision in practice.

Consumers identified a number of areas in which additional data collection and research would be necessary to develop more cost-effective funding systems for chemotherapy. These include information relating to:

- Sites where chemotherapy is provided;
- Care in the private sector (including data on the number of people treated, location, out-of-pocket costs);
- Co-payments in the public sector;
- Models of treatment;
- The role of pharmacists;
- The role of third-party compounders;
- The cost-effectiveness of different models of service provision;
- The impact of different models on quality and safety, and outcomes; and
- Qualitative information about consumer experiences and preferences.

**Recommendation 19:** that research on issues surrounding the provision of chemotherapy in Australia is given priority, including where chemotherapy is provided, co-payment arrangements, models of treatment (including the role of pharmacists and third-party compounders), cost effectiveness, quality and safety and consumer experiences. The findings of any research in these areas should be used to inform future funding arrangements for chemotherapy.
Next Steps

CHF’s consultations have highlighted the need to ensure that the funding allocated to chemotherapy treatment is used to deliver them with the highest quality, most accessible and cost effective services. Consumers participating in our consultations acknowledged the complexity of existing funding models, but emphasised the importance of placing consumer needs at the centre of the funding arrangements.

Consumers told CHF that they want chemotherapy funding arrangements that are transparent, equitable and cost-effective. Consumers also noted that it was not the intention of pharmaceutical pricing that the PBS subsidy paid by Government should be used to fund anything other than the cost of the drug. On this basis, consumers in CHF’s consultations supported the application of EAPD to chemotherapy drugs, and there was consensus among consultation participants that other aspects of the provision of the drug should not be funded by PBS subsidies.

In light of the consultation findings, **CHF recommends that the PBS subsidy for chemotherapy drugs reflect the market price of the medicine.** CHF’s consultations have not shown support for the payment of inflated costs for chemotherapy drugs in order to cross-subsidise other elements of the delivery of these drugs.

Should the delivery of chemotherapy drugs require additional funding, consumers indicated that this should be pursued outside the PBS subsidy, and be based on a transparent costing process.

Further Information

Further information about CHF’s work in this area can be found on the CHF website, [www.chf.org.au](http://www.chf.org.au). Alternatively, interested persons can contact CHF Policy Director Rebecca Vassarotti at [r.vassarotti@chf.org.au](mailto:r.vassarotti@chf.org.au) or (02) 6273 5444.

Consumers Health Forum of Australia
PO Box 3099
Manuka ACT 2603
Telephone (02) 6273 5444
Fax (02) 6273 5888
Email [info@chf.org.au](mailto:info@chf.org.au)
[www.chf.org.au](http://www.chf.org.au)
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 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.
Consumer Background and Discussion Paper:
Review of Funding Arrangements for Chemotherapy Services

July 2013
Introduction

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 has been funded by the Department of Health and Ageing to consult with our members on the Review of funding Arrangements for Chemotherapy Services. The initiation of the Review followed talks between the Government and the Pharmacy Guild of Australia over appropriate subsidies for dispensing chemotherapy after the reduction in the PBS subsidy for a key chemotherapy drug, Docetaxel. The Review will investigate and report on:

a. Current arrangements for funding of chemotherapy services;
b. How those arrangements have changed over time;
c. How chemotherapy services are provided, including in relation to:
   i. Different hospital and community settings
   ii. Different business models
   iii. Use of third party compounders
   iv. Integration of hospital, pharmacy and oncology services;

d. The involvement of public and private hospitals in providing chemotherapy services, including:
   i. the extent to which each sector provides services
   ii. differences by state
   iii. how that service mix has changed over time
   iv. current trends in that service mix
   v. any implications for community pharmacy or the Pharmaceutical Benefits Scheme
   vi. any implications for private hospitals and private health insurers;

e. Cost structures associated with provision of chemotherapy services – dispensing, support, administration and clinical services;

The Review will also provide advice on funding arrangements appropriate to the efficient supply of chemotherapy services by community pharmacy; and provide advice on any other relevant matters in relation to securing efficient and effective provision of chemotherapy services.

This Paper outlines the existing arrangements for the provision of chemotherapy services and explores the issues that have arisen in response to the implementation of price disclosure policies on chemotherapy drugs. It also presents consultation questions, which will be complemented by an online survey.
Background

The provision of chemotherapy drugs to Australians with cancer is a complex process involving a number of funding mechanisms, Government policies and programs, and services that operate across both the public and private sectors.

The primary funding sources for chemotherapy drugs are:

- the Pharmaceutical Benefits Scheme (PBS), which funds chemotherapy medicines;
- the Fifth Community Pharmacy Agreement, which funds pharmacists to dispense chemotherapy medicines to consumers;
- private health insurance, which funds aspects of the provision of chemotherapy in private health facilities; and
- consumer co-payments, which contribute a fixed amount to the cost of chemotherapy medicines.

These funding sources work in conjunction with pricing mechanisms that set the conditions for the pricing of chemotherapy medicines and provide pharmacists with additional funding for specific tasks.

The key stages of the provision of chemotherapy to consumers are:

- the manufacture of medicine;
- the distribution of the medicine through a wholesaler;
- the preparation of an infusion, either by a pharmacist or third party compounder;
- the dispensing of the drug;
- clinical care at the point of dispensing (for example, patient interviews, checks of measurements, dosage adjustments); and
- follow-up services (for example, data collection, reporting adverse events).

Health services that are involved in the provision of chemotherapy include:

- community pharmacies;
- public hospitals;
- private hospitals;
- third party compounders; and
- specialist oncology services.

Patients undergoing chemotherapy treatment will likely come into contact with a varied range of health care professionals and settings during the course of treatment, including an oncologist, hospitals, day surgery clinics, clinical pharmacists and nursing staff. The funding for these professional services and the chemotherapy medicines come from a range of sources, including: the Australian Government through the PBS, the Medicare Benefits Schedule (MBS), Private Health Insurers, and State and Territory governments.

The Government pays the full cost of chemotherapy medicines supplied under the PBS. Pharmacists and hospitals cannot charge patients extra for PBS medicines. For cancer drugs, a concessional patient will pay $5.90 and a general patient $36.10 for the first injection/infusion of the drug, but not for repeats. Prices paid by cancer patients for PBS medicines have not been affected by price cuts on the drugs, or the recent interim funding provided to pharmacists by the Government.
The PBS pays for the cost of the medicine and the highly specialised skills and equipment to safely prepare chemotherapy medicines in a form that can be provided to a patient, whilst the clinical services doctors, pharmacists and other health professionals provide in the sector are supported from a range of funding sources.

**Policy Settings**
Government funding for chemotherapy comes from two main sources – the Pharmaceutical Benefits Scheme, and the Fifth Community Pharmacy Agreement. These programs set the framework within which chemotherapy treatments are provided to consumers. Additional policies and targeted initiatives have been introduced in the context of these programs to address specific aspects of chemotherapy funding. These are outlined in greater detail below.

**Pharmaceutical Benefits Scheme**
The Pharmaceutical Benefits Scheme (PBS) is the main funding mechanism for prescription medicines in Australia. Through the PBS, the Government pays a fixed price rebate to the dispensing pharmacist for providing chemotherapy drugs to a consumer. This price is negotiated between the Government and the supplier of the medicine when it is listed on the PBS. If additional preparation is required for dispensing, the PBS can also pay the pharmacist additional charges. Consumers contribute a co-payment for PBS medicines at a general or concessional rate. There is a safety-net which reduces the co-payment once an annual threshold is reached.

**Fifth Community Pharmacy Agreement**
Since 1990, the Government and the Pharmacy Guild of Australia, which represents pharmacy owners, have entered into a series of five year agreements which set out the reimbursements that pharmacists will receive for dispensing PBS medicines. The Fifth Community Pharmacy Agreement (5CPA) commenced in July 2010 and provides $15.4 billion to approximately 5,200 community pharmacies for dispensing PBS medicines and the provision of some pharmacy programs and services.

Under the 5CPA, pharmacists can claim the designated PBS price for each medicine they dispense. They can also claim additional charges associated with the provision of medicines, such as patient consultations. As part of this agreement, there are restrictions on what pharmacists can charge consumers for prescription medicines.

**Pricing Mechanisms**
In conjunction with these funding sources, pricing mechanisms determine the funding of Docetaxel and other chemotherapy drugs. There are:

- Expanded and Accelerated Price Disclosure; and
- Efficient Funding of Chemotherapy Drugs Initiative.

*Expanded and Accelerated Price Disclosure (EAPD)* was introduced in 2010 to address a widespread trend for suppliers to discount the price of medicines to pharmacists. This occurs when the patent protections afforded to the original developers expire, and cheaper products become available. The creation of a competitive market leads to the discounting of prices by manufacturers and wholesalers in order to maximise market share, and reduces the price paid by the pharmacist. This results in pharmacists paying less than the price agreed by the Government and the manufacturer at the time of listing on the PBS.
The savings made through these discounting practices are not passed onto consumers, who are still required to pay the relevant PBS co-payment, or to the Government, which continues to pay the agreed PBS rebate. EAPD aims to address this by bringing Government expenditure on PBS medications in line with the market prices paid by pharmacies. This enables savings to be redistributed to other areas of health need.

Since December 2012, Docetaxel has been subject to a 76.2 percent price cut under EAPD.

*The Revised Arrangements for the Efficient Funding of Chemotherapy Drugs Initiative (EFC)* administers additional funding to support the preparation involved in supplying chemotherapy drugs. The EFC covers chemotherapy drugs administered through infusion or injection, including Docetaxel. Under the EFC, pharmacies can recoup additional fees for the dispensing, preparation, storage, and dilution of chemotherapy drugs.

**Responses to Price Disclosure**

Some representatives of the pharmacy sector did not support the application of EAPD to chemotherapy drugs. They argued that the amount recouped in fees under the EFC is not sufficient to cover the actual costs of preparing chemotherapy drugs for supply to patients, as the processes involved are specialised and complex. Some of the issues raised by pharmacy groups include:

- each dose of chemotherapy drugs must be compounded for the individual patient;
- dosages cannot be stored for long periods so must be prepared when required;
- pharmacists need to undertake clinical consultations with patients;
- pharmacies involved in the supply of chemotherapy need specialised equipment and facilities to ensure that the drugs are safely administered; and
- there are increased regulatory requirements for their handling and storage.

According to some pharmacy groups, the surplus funds received through the PBS rebates for dispensing Docetaxel prior to the application of EAPD were used to subsidise the preparation of chemotherapy drugs. While a number of chemotherapy medicines were affected by price disclosure, Docetaxel is the most significant as it was subject to the largest price cut. Pharmacy groups argued that this price reduction would make it unprofitable for many pharmacists to continue to supply this drug.

Along with other provider groups and stakeholders, some pharmacy groups ran a campaign lobbying the Government to reverse the impact of price disclosure for chemotherapy drugs.

**The Senate Inquiry**

As a result of concerns about the impact of the price reduction of Docetaxel raised by the pharmacy sector, the issue was referred to the Senate Community Affairs Committee for inquiry in February 2013. The inquiry was asked to investigate and report on:

a. the supply of chemotherapy drugs such as Docetaxel, particularly in relation to:
   i. patient access to treatment;
   ii. cost to pharmacies and suppliers; and,
   iii. cost to the private and public hospital systems;

b. any long-term sustainable funding models for the supply of chemotherapy drugs, including Docetaxel; and
c. any related matters.
The Inquiry’s report, released on 10 May 2013 made a single recommendation:

The committee recommends that the Government and industry parties, through the Review, continue the examination of issues in chemotherapy drug pricing to ensure that existing funds under the Fifth Community Pharmacy Agreement as already agreed are appropriately directed to reflect the costs and benefits of the supply of chemotherapy drugs, and to ensure the ongoing supply of these drugs across all services, particularly in rural and regional areas.1

Interim Arrangements and the Review

On 5 May 2013, the Commonwealth Government announced the Increased Funding for Chemotherapy Services initiative. Under this initiative, the Government is providing an additional amount of $60 per chemotherapy infusion prepared between 1 July 2013 and 31 December 2013, while a Review of chemotherapy funding arrangements is undertaken. The interim funding arrangements are in place as the Government undertakes this Review, examining how much it should be paying to support the ongoing viability of the provision of chemotherapy medicines.

The aim of this Review is to maximise the benefits consumers receive from chemotherapy infusions by ensuring efficient clinical processes and appropriate funding arrangements for the preparation and supply of chemotherapy medicine infusions.

1 Senate Community Affairs References Committee (2013) Supply of chemotherapy drugs such as Docetaxel. Commonwealth of Australia: Canberra.
Key Issues and Questions for Consumers

Current Arrangements
The current funding arrangements for chemotherapy are complex, making it difficult to assess whether they are being optimally used. The role of each of the various funding sources in supporting the provision of chemotherapy drugs is not clear. This means that it is difficult to determine whether the current arrangements reflect the most appropriate funding mix.

The 5CPA in particular contains little detail on the funding arrangements relating to the provision of chemotherapy drugs. According to the Department of Health and Ageing, the application of EAPD to Docetaxel had been subject to negotiation with the Pharmacy Guild of Australia in 2010, and resulted in an additional $277 million injection to the 5CPA to compensate the pharmacy sector for its impacts.\(^2\) The Senate inquiry found that no further compensation to the sector was required beyond the funds already committed through the 5CPA.\(^3\)

Despite the inquiry’s findings, the Pharmacy Guild of Australia continues to claim that there was no agreement with the Government on funding for chemotherapy. Although the report from the Senate inquiry and the Department of Health and Ageing have both presented persuasive evidence to the contrary, the lack of detail in the 5CPA makes it difficult to understand the nature or content of these agreements.

Consultation Questions

What is the impact on consumers of the current funding arrangements?

How could the funding system for chemotherapy drugs be made more transparent and accountable?

Given that pharmacists are required to undertake additional tasks in the preparation of chemotherapy drugs and deliver clinical services, how should these be funded?

Is a global agreement with the pharmacy sector, such as the 5CPA, the most appropriate way to fund chemotherapy services? If so, how should future agreements be developed to ensure they reflect the needs and priorities of consumers?

How can changes in price and other factors affecting the provision of chemotherapy be accommodated within a long-term agreement without affecting supply or having other negative impacts on consumers?

Cost, Location, and Other Access Issues
Although the cost of medicines is subsidised by the PBS, consumers may incur a range of other costs in accessing chemotherapy medicines and treatments. These may include indirect costs, such as travel or time away from work.

\(^2\) Ibid.
\(^3\) Ibid.
The supply of chemotherapy drugs to consumers in rural and regional areas may also create additional challenges, due to the distances involved, the time taken to reach these areas, lower levels of health infrastructure and the smaller and more dispersed population. It is not clear whether these challenges have created cost and other barriers to the delivery of high quality treatment for cancer in rural Australia. There is little available data on the specific costs involved with the provision of chemotherapy in rural areas and the experience of consumers in these areas in accessing chemotherapy.

### Consultation Questions

**What are some of the costs incurred in accessing chemotherapy medicines? Do these costs limit access?**

**Do consumers in rural and regional areas incur additional costs compared with consumers in metropolitan areas? If so, what are these costs? Do these costs limit access to services in these areas?**

**How should the increased costs associated with providing chemotherapy services in rural and regional areas be funded?**

### Safety and Quality

The provision of chemotherapy drugs carries a higher risk, and it is therefore essential to ensure the safe and quality provision of these medicines. There are a number of guidelines and standards relating to chemotherapy medicines. However, there is no agreement on which standards are the most appropriate, how they should be implemented and how compliance with them should be monitored.

### Consultation Questions

**Do existing funding arrangements support safety and quality in the provision of chemotherapy medicines? How could this be improved?**

### The Role of Pharmacists

There are significant variations in the definition of the standards of clinical pharmacy services associated with the provision of chemotherapy. Submissions to the Senate Inquiry from key bodies provide differing information on the tasks that pharmacists need to undertake when dispensing chemotherapy drugs.

These submissions, as well as guidelines from the Clinical Oncological Society of Australia (COSA) for the *Safe Prescribing, Dispensing and Administration of Cancer Chemotherapy*[^1] identify the following tasks for pharmacists in the dispensing of chemotherapy drugs:

- clinical verification of the drug order;
- preparation of treatment;
- taking a medication history at the patient’s initial and subsequent cycles;
- documenting previous and current adverse reactions;
- assessing whether additional pathology tests are required;

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Consumer Background and Discussion Paper: Review of funding Arrangements for Chemotherapy Services

July 2013
collecting and assessing current and past patient clinical, drug and family history;
attending chemotherapy write-up to consultation; and
participating in a multidisciplinary team meeting to establish therapeutic goals in collaboration with patient.

In addition, the following tasks were outlined specifically for hospital pharmacists:

- visiting patients in the clinic for assessment of physical signs of drug-related effects;
- providing Patient Care Kits, Cancer Council Kits, and other information to new patients; and
- monitoring compliance with medications, diet, sleeping, nausea, constipation, effect of treatment on lifestyle, medication interactions, liaise with family members.

Many of the tasks outlined above represent an expanded role of pharmacists in relation to chemotherapy compared with most other areas of medicine. It is not clear how these clinical services are currently supported under the existing funding arrangements.

**Consultation Questions**

Which of the above services did you experience when receiving treatment for cancer? Did you receive them from a pharmacist, or another health care provider?

**Care in the Public and Private Sectors**

Consumers receive chemotherapy in both the private and the public sectors and sometimes from both sectors during the course of a single treatment. For example, a patient in a private hospital may be discharged and receives treatment as an outpatient from a public hospital. There are differences in the way in which the public and the private systems are funded, which may result in differences in service. Several responses to the Senate Inquiry raised concerns about the differing public and private systems and their impact on the dispensing of, and claiming for, PBS medicines.

**Consultation Questions**

In your experience, are there differences between the provision of chemotherapy between the public and the private sectors?

Are there problems related to moving between the two sectors? How should these be resolved?

What is the best way to fund chemotherapy in order to maximise the coordination between the public and private sectors?
Impact of Funding Uncertainty
Pharmacy groups and other stakeholders made a number of public statements about the impact of price disclosure on the cost and availability of chemotherapy services. These statements claimed that the impact of the price cuts would result in increased costs to consumers and make some services unsustainable, resulting in their closure. Due to the lack of data on the exact costs associated with the provision of chemotherapy, it is difficult to substantiate these claims or predict the impact of price reductions.

Consultation Questions

Were you aware of these statements regarding the impact of price reductions on services? What impact did these statements have on you during this period?

Long-Term Arrangements
Current arrangements for the funding of chemotherapy have been developed between Government and the pharmacy sector with only limited consultation and input from other stakeholders. In recent years, a range of other stakeholders have sought greater involvement in the negotiation of these arrangements, and this has been the subject of some debate.

Consultation Questions

How should chemotherapy funding arrangements be negotiated in the long-term?

What are the sectors and organisations that should be involved in negotiating these arrangements?
Next Steps

Responses to this paper will add to CHF’s online and face-to-face consultative activities. CHF will report the outcomes of these consultations in our final report on the Review.

The questions asked in this paper are intended as a guide. Comments do not need to be restricted to the questions or points that have been raised. Consumers are encouraged to include examples and provide personal experiences.

As well responding to this paper, consumers are encouraged to respond to the consultation using an online survey, which is available at http://www.surveymonkey.com/s/chemo-funding-survey. Responses are due by Thursday 29 August 2013.

As well as reviewing this paper, consumers are encouraged to review the Department of Health and Ageing’s discussion paper, which is available at http://www.health.gov.au/chemo-review. The Department’s paper contains additional detail on the technical aspects of the pricing mechanisms for chemotherapy drugs. The closing date for responses to the Department’s discussion paper is Monday 29 July 2013.

Further Information

Further information about CHF’s work in this area can be found on the CHF website, www.chf.org.au. Alternatively, interested persons can contact CHF Policy Manager Maiy Azize at m.azize@chf.org.au or (02) 6273 5444.

Consumers Health Forum of Australia
PO Box 3099
Manuka ACT 2603
Telephone (02) 6273 5444
Fax (02) 6273 5888
Email info@chf.org.au
www.chf.org.au
Consumer and Community Input into the Review of Funding Arrangements for Chemotherapy Services:

Survey Results

September 2013
INTRODUCTION

The Consumers Health Forum of Australia (CHF) developed an online survey to support the consultation process being undertaken by CHF to seek community input into the *Review of Funding Arrangements for Chemotherapy Services*.

The survey was developed on the basis of material contained within the discussion paper that was developed to support the consultation processes. It was not designed as a mechanism to collect statistically significant data, but as a mechanism to support consumer input.

The survey went live on **Monday 22 July 2013** and closed on **Thursday 29 August 2013**. The survey was promoted through the CHF member networks and through cancer consumer networks.

WHO PARTICIPATED IN THE SURVEY

The survey was completed by 57 individuals. Respondents represented all states and territories, had a broad age range (but did not include any individuals aged under 18 years) and included a mix of rural and urban respondents. The vast majority of respondents did not come from the health profession. The specific breakdowns are:

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<th>Which state or territory do you live in?</th>
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<td>60 or older</td>
<td>18.2%</td>
</tr>
</tbody>
</table>
Do you live in a rural or urban area?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural</td>
<td>42.4%</td>
</tr>
<tr>
<td>Urban</td>
<td>57.6%</td>
</tr>
</tbody>
</table>

Are you a health professional?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>11.1%</td>
</tr>
<tr>
<td>No</td>
<td>88.9%</td>
</tr>
</tbody>
</table>

**SURVEY RESPONSES**

Survey respondents were asked their views on a range of issues associated with chemotherapy funding. The responses and a brief analysis of results are outlined below.

**QUESTION ONE: Is the funding system for chemotherapy drugs transparent and accountable?**

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15.1%</td>
</tr>
<tr>
<td>No</td>
<td>84.9%</td>
</tr>
</tbody>
</table>

**QUESTION 2: Is a global agreement with the pharmacy sector, such as the 5CPA, the most appropriate way to fund chemotherapy services?**

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>18.5%</td>
</tr>
<tr>
<td>No</td>
<td>81.5%</td>
</tr>
</tbody>
</table>

If you answered yes, how should future agreements be developed to ensure they reflect the needs and priorities of consumers?

As shown in the tables above, a strong majority of survey respondents reported that they did not believe the current funding system for chemotherapy drugs was transparent and accountable. There was also a strong view that a global agreement was not the most effective way to fund these services.
Respondents who did feel that the global agreement was an appropriate mechanism to fund chemotherapy services were asked how future agreements should be developed and they provided a range of suggestions. While some respondents suggested that it was something to be negotiated between the Government and pharmacists, others believed it was important to involve consumer advocacy groups and consumers.

<table>
<thead>
<tr>
<th>QUESTION 3: Do consumers incur any additional costs when accessing chemotherapy medicines?</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Answer Options</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>82.7%</td>
</tr>
<tr>
<td>No</td>
<td>17.3%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QUESTION 4: If you answered 'yes' to the previous question, do you believe these costs limit access?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Answer Options</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

As demonstrated by the responses to the questions above, the vast majority of survey respondents believed that consumers incurred additional costs when accessing chemotherapy medicines. Survey respondents also believed that this did limit access.

<table>
<thead>
<tr>
<th>QUESTION 5: Do consumers in rural and regional areas incur additional costs compared with consumers in metropolitan areas?</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Answer Options</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>83.7%</td>
</tr>
<tr>
<td>No</td>
<td>16.3%</td>
</tr>
<tr>
<td>If you answered yes, what are these costs? Do they limit access to services in these areas?</td>
<td></td>
</tr>
</tbody>
</table>

As outlined above, survey respondents overwhelmingly believed that consumers in rural and regional areas did incur additional costs when accessing chemotherapy services. Travel and accommodation were identified as the most significant costs. The issue of out of pocket costs was raised as was the impact of being dislocated from families.
**QUESTION 6:** Do existing funding arrangements support safety and quality in the provision of chemotherapy medicines?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>17.4%</td>
</tr>
<tr>
<td>No</td>
<td>82.6%</td>
</tr>
<tr>
<td>If you answered no, how do you think this could be improved?</td>
<td></td>
</tr>
</tbody>
</table>

The table provided above shows that survey respondents overwhelmingly reported that existing arrangements do not support safety and quality. Respondents suggested that in order to improve this there was a need to provide additional funding, more work was needed to agree to guidelines and standards, and there was need for more transparency and coordination.

**QUESTION 7:** In your experience, are there differences between the provision of chemotherapy between the public and the private sectors?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>79.5%</td>
</tr>
<tr>
<td>No</td>
<td>20.5%</td>
</tr>
</tbody>
</table>

**QUESTION 8:** Are there problems related to moving between the two sectors?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>72.5%</td>
</tr>
<tr>
<td>No</td>
<td>27.5%</td>
</tr>
</tbody>
</table>

As demonstrated in the tables above, survey respondents identified that there were significant differences between the provision of chemotherapy services across the public and private sectors. In addition, respondents reported significant problems when moving across the two sectors. Key comments appeared to focus around cost, quality of service and communication with consumers.

**QUESTION 9** Were you aware of these statements regarding the impact of price reductions on services?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>36.4%</td>
<td>36.4%</td>
</tr>
<tr>
<td>No</td>
<td>63.6%</td>
<td>63.6%</td>
</tr>
<tr>
<td>If you answered yes, and you were a cancer patient, what impact did these statements have on you?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The table above shows that for the survey respondents there was not a high level of awareness around statements around the impact of price reductions. However, there were strong views expressed within comments by some respondents who were aware of these statements.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>QUESTION 10: How should chemotherapy funding arrangements be negotiated in the long-term?</td>
<td>answered question</td>
<td>16</td>
</tr>
</tbody>
</table>

The table above demonstrates that there was a very low response rate when respondents were asked how funding arrangements should be managed in the future. For those who did respond, there was a variety of views regarding future arrangements for chemotherapy funding. Some respondents believed that the current agreement could produce good results, while others believed there should be a stand-alone agreement. Some respondents suggested that advocacy groups should be involved.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>QUESTION 11: What are the sectors and organisations that should be involved in negotiating these arrangements?</td>
<td>answered question</td>
<td>15</td>
</tr>
</tbody>
</table>

Again, as demonstrated in the table above, there was a very low response rate to the question of who should be involved in negotiating arrangements. While some respondents suggested that it should involve primarily the Pharmacy Guild of Australia and the Government, there was support from others to involve other consumer based groups.

**CONCLUSION**

This survey provided an opportunity for consumers and others to contribute to the CHF consultations on the funding arrangements for chemotherapy services. While the results were largely consistent with the views expressed in face to face consultations and tele-consultations, there was more variety in responses. This potentially reflects the involvement of some health service providers (as distinct from consumers or consumer organisations) in this consultation mechanism. Nevertheless, it is a useful input into the consultation, and provided strong insights into the experiences and views of health consumers who have accessed chemotherapy services.
Chemotherapy Funding Consultation Program
Holiday Inn Potts Point, 203 Victoria Street Potts Point
10.00am-2.00pm, Tuesday 20 August 2013

Facilitator: Jennifer Doggett

<table>
<thead>
<tr>
<th>Timing</th>
<th>Session</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>09.30</td>
<td>Registration</td>
<td></td>
</tr>
<tr>
<td>10.00</td>
<td>Welcome and overview</td>
<td>Carol Bennett, CHF</td>
</tr>
<tr>
<td>10.15</td>
<td>Housekeeping and introductions</td>
<td>Jennifer Doggett</td>
</tr>
</tbody>
</table>

**Session 1: Introduction to Chemotherapy Pricing** (10.30am – 12.00pm)

<table>
<thead>
<tr>
<th>Timing</th>
<th>Session</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.30</td>
<td>Introduction to Chemotherapy Pricing</td>
<td>Jennifer Doggett</td>
</tr>
<tr>
<td></td>
<td>• Overview of CHF consultation paper</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Current arrangements for chemotherapy funding</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Community Pharmacy Agreement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Price disclosure</td>
<td></td>
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<td></td>
<td>• Senate Inquiry</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Key issues being disputed</td>
<td></td>
</tr>
<tr>
<td>11.30</td>
<td>Questions and Answers</td>
<td>Plenary</td>
</tr>
</tbody>
</table>

**Session 2: Current Funding Arrangements and Future Options** (11.45am – 12.30pm)

<table>
<thead>
<tr>
<th>Timing</th>
<th>Session</th>
<th>Course</th>
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</thead>
<tbody>
<tr>
<td>11.45</td>
<td>Consumer views on current funding arrangements</td>
<td>Plenary discussion</td>
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<tr>
<td></td>
<td>and future options</td>
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</tr>
<tr>
<td></td>
<td>• Are there problems with the current global</td>
<td></td>
</tr>
<tr>
<td></td>
<td>funding agreement for chemotherapy?</td>
<td></td>
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<tr>
<td></td>
<td>• How can the current funding system be made</td>
<td></td>
</tr>
<tr>
<td></td>
<td>made more transparent and accountable?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• How should funding arrangements for</td>
<td></td>
</tr>
<tr>
<td></td>
<td>chemotherapy be developed?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Who should be involved?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• How should disputes about funding arrangements</td>
<td></td>
</tr>
<tr>
<td></td>
<td>be resolved?</td>
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<tr>
<td></td>
<td>• What is the role of co-payments?</td>
<td></td>
</tr>
</tbody>
</table>

**Session 3: Other Issues Relating to Chemotherapy Services** (1.00pm – 1.45pm)

<table>
<thead>
<tr>
<th>Timing</th>
<th>Session</th>
<th>Course</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.00</td>
<td>Other issues relevant to the provision of</td>
<td>Plenary discussion</td>
</tr>
<tr>
<td></td>
<td>chemotherapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• The role of the pharmacist</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Access issues</td>
<td></td>
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<tr>
<td></td>
<td>• Public and private sector issues</td>
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<tr>
<td></td>
<td>• Statements from provider groups regarding price</td>
<td></td>
</tr>
<tr>
<td></td>
<td>disclosure</td>
<td></td>
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<tr>
<td></td>
<td>• Quality and safety</td>
<td></td>
</tr>
</tbody>
</table>

**Session 4: Conclusions** (1.45pm – 2.00pm)

<table>
<thead>
<tr>
<th>Timing</th>
<th>Session</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.45</td>
<td>Overview of discussions, major issues and</td>
<td>Maiy Azize, CHF</td>
</tr>
<tr>
<td></td>
<td>priorities</td>
<td></td>
</tr>
<tr>
<td>2.00</td>
<td>Conclusion and evaluation</td>
<td>Jennifer Doggett</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Timing</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.00</td>
<td>Afternoon Tea</td>
</tr>
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</table>
**Chemotherapy Funding Consultation Program**  
Sebel Playford, 120 North Terrace, Adelaide  
10.00am-2.00pm, Friday 23 August 2013

Facilitator: Jennifer Doggett

<table>
<thead>
<tr>
<th>Timing</th>
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<th>Speaker</th>
</tr>
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<tbody>
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</tr>
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</tr>
</tbody>
</table>

**Session 1: Introduction to Chemotherapy Pricing** (10.30am – 12.00pm)

<table>
<thead>
<tr>
<th>10.30</th>
<th>Introduction to Chemotherapy Pricing</th>
<th>Jennifer Doggett</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Overview of CHF consultation paper</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Current arrangements for chemotherapy funding</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Community Pharmacy Agreement</td>
<td></td>
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<td></td>
<td>• Price disclosure</td>
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<td></td>
<td>• Senate Inquiry</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Key issues being disputed</td>
<td></td>
</tr>
<tr>
<td>11.30</td>
<td>Questions and Answers</td>
<td>Plenary</td>
</tr>
</tbody>
</table>

**Session 2: Current Funding Arrangements and Future Options** (11.45am – 12.30pm)

<table>
<thead>
<tr>
<th>11.45</th>
<th>Consumer views on current funding arrangements and future options</th>
<th>Plenary discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Are there problems with the current global funding agreement for chemotherapy?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• How can the current funding system be made more transparent and accountable?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• How should funding arrangements for chemotherapy be developed?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Who should be involved?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• How should disputes about funding arrangements be resolved?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• What is the role of co-payments?</td>
<td></td>
</tr>
<tr>
<td>12.30</td>
<td>Lunch</td>
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</table>

**Session 3: Other Issues Relating to Chemotherapy Services** (1.00pm – 1.45pm)

<table>
<thead>
<tr>
<th>1.00</th>
<th>Other issues relevant to the provision of chemotherapy</th>
<th>Plenary discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• The role of the pharmacist</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Access issues</td>
<td></td>
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<tr>
<td></td>
<td>• Public and private sector issues</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Statements from provider groups regarding price disclosure</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Quality and safety</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**Session 4: Conclusions** (1.45pm – 2.00pm)

<table>
<thead>
<tr>
<th>1.45</th>
<th>Overview of discussions, major issues and priorities</th>
<th>Maia Azize, CHF</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.00</td>
<td>Conclusion and evaluation</td>
<td>Jennifer Doggett</td>
</tr>
</tbody>
</table>

| 2.00    | Afternoon Tea                                                   |                      |
Chemotherapy Funding Teleconsultation Program

**Facilitator:** Maiz Azize

<table>
<thead>
<tr>
<th>Program</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong> Welcome and introductions</td>
</tr>
<tr>
<td><strong>2.</strong> Introduction to chemotherapy pricing (Jennifer Doggett)</td>
</tr>
<tr>
<td><strong>3.</strong> Current funding arrangements (group discussion)</td>
</tr>
<tr>
<td>• Are there problems with the current global funding agreement?</td>
</tr>
<tr>
<td>• Do you think that the current funding system be made more transparent? How?</td>
</tr>
<tr>
<td>• How should funding arrangements for chemotherapy be developed?</td>
</tr>
<tr>
<td>• Who should be involved?</td>
</tr>
<tr>
<td>• How should disputes about funding arrangements be resolved?</td>
</tr>
<tr>
<td>• What is the role of co-payments</td>
</tr>
<tr>
<td><strong>4.</strong> Other issues relating to chemotherapy services (group discussion)</td>
</tr>
<tr>
<td>• The role of the health professionals including pharmacist</td>
</tr>
<tr>
<td>• Access issues</td>
</tr>
<tr>
<td>• Public and private sector issues</td>
</tr>
<tr>
<td>• Statements from provider groups regarding price disclosure</td>
</tr>
<tr>
<td>• Quality and safety</td>
</tr>
<tr>
<td>• Specific issues for rural and regional consumers</td>
</tr>
<tr>
<td><strong>5.</strong> Next steps and further information</td>
</tr>
<tr>
<td><strong>6.</strong> Close</td>
</tr>
</tbody>
</table>
ATTACHMENT E

Participating Organisations in Consumer Consultations conducted by CHF as Part of the Review of Funding Arrangements for Chemotherapy Services

In addition to CHF individual members and anonymous survey respondents, the following consumer organisations and groups participated in CHF’s consultations:

- Association of Independent Retirees
- Breast Cancer Network Australia
- CanSpeak
- Cancer Council NSW
- Cancer Council SA
- Cancer Council Wollongong
- Cancer Voices NSW
- Cancer Voices SA
- Canteen
- Carers NSW
- Central Adelaide and Hills Medicare Local (CAHML) Community Advisory Group
- Fleurieu Cancer Network
- Health Care Consumers Association of the ACT
- Health Consumers Alliance of SA
- Health Consumers NSW
- Health Consumers of Rural and Remote Australia
- Ingham Health District Consumer Group
- Leukaemia Foundation of Australia
- National Breast Cancer Foundation
- National Pain Management Association
- Ovarian Cancer Australia
- Palliative Care Council SA
- Public Health Association of Australia (ACT Branch)
- Prostate Cancer Foundation of Australia
- Southern Adelaide Local Health Network Consumer Council