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Feedback on the Ministerial Taskforce for Cancer, Department of Human Services Consultation on the draft Patient Management Frameworks

Health Issues Centre appreciates the opportunity to provide feedback to the *Draft, Patient Management Frameworks*.

Health Issues Centre is at the forefront of promoting consumer perspectives in the Australian health system. It has been an independent, not-for-profit organisation for over 20 years. It has gained a strong reputation around Australia for its public interest research and its analysis of the health system, particularly promoting awareness of consumer perspectives and needs.

Health Issues Centre congratulates the Department for this policy development. The Draft is very well structured and content thorough, particularly in consideration of consumer needs at all stages of the management. The language used is readable and accessible.

Health Issues Centre is in agreement with the seven steps of the Frameworks. However some issues that are important from our point of view have been overlooked, or not given enough emphasis in the Draft. Our suggestions for specific changes and additions include:

- Family and carers need to have more emphasis in the Frameworks. The current draft states that carer/family must be present at the recurrence of only two tumour streams: Malignant Glioma and Cerebral Metastases. The consumers experience in one of Health Issues Centre's projects, the Clinical Support System Program (CSSP), indicated the need for carer/family support from the point of cancer diagnosis. We recommend that carer/family's presence be encouraged at initial diagnosis of all cancers. Furthermore they should be more involved in the care management process, especially in decisions about palliative care.
- Linkage between acute and non-acute sectors is not apparent in the Frameworks. The implementation of the Frameworks outside the hospital will involve community and primary health care. A collaborative management plan between the hospital and community health needs to be included.
- Although a large number of patients only have access to public health service, the Frameworks should acknowledge the people who use public as well as

private health services and move between the two. The hospital's definition and accreditation of services need to be included in the Frameworks.

- Discussion about advance care planning can be introduced at an earlier stage than at the recurrence of cancer stage. It seems appropriate to initiate this discussion with patients and their carer/family in the follow-up stage. It is evident in our 'Respecting Patient's Choices' collaboration with Austin Health that consumers are prepared to discuss this issue, especially about the Power of Attorney, prior to cancer diagnosis.
- In Head and Neck Tumour Stream, the Frameworks state that the high risk group are difficult to reach and educate because they generally constitute a socially disadvantage group, and that targeted education includes patient advocacy groups, general practitioners, schools, hospitals and government. Centrelink can be added to this list, as it is a government body that makes regular contact with these groups.
- Information support at discharge after surgery in all cancer streams should include existing medication or supplementary medicine that patients may have been using prior to the surgery. Patients will need to know whether they can continue using such medicine.

We thank you for inviting our comment and look forward to the published document.

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