

The Hon Paul Green MLC
Chair
Select Committee on Off-Protocol Prescribing of Chemotherapy in NSW
Legislative Council
NSW Parliament
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The voice of people
affected by cancer

Submission by Cancer Voices NSW to the Inquiry into Off-Protocol Prescribing of Chemotherapy in NSW

Cancer Voices NSW, the independent voice of people affected by cancer in our state, congratulates the Legislative Council for instigating this Inquiry. We have been very concerned about the incidents reported, the findings in the Cancer Institute NSW's two Reports and the outcome not only for those cancer patients caught up in this, but for present and future patients in all NSW hospitals. We note that this scenario could occur in either public or private sectors, and that increasingly chemotherapy treatment is being given in the private sector – around 60%. As a result we trust that your recommendations will be applicable to both sectors.

We also note that a Review of Cancer Care in NSW Public Health Facilities is underway which will no doubt inform the recommendations of this Inquiry, and vice versa.

Cancer Voices NSW provides the independent voice of people affected by cancer in NSW, to improve the cancer experience of the 40,000 people who are diagnosed each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with decision makers and providers of these services, ensuring the patient perspective is heard from planning to delivery.

General Comment

Cancer Voices has for some time been calling for a review of clinical practice standards in medical oncology, possibly following the general concept of those produced for radiation oncology practice by the Royal Australian and New Zealand College of Radiologists. We understand that any resulting guidelines would be multi factorial, needing to combine the recommended protocols published online by EviQ, and the ability to individualise patient doses according to their condition, stage of disease and preferences.

We note that not dissimilar incidents have occurred in South Australia, in which our sister consumer organisation, Cancer Voices SA, has been very involved through representing the informed consumer view.

For us, our members and many supporters, the big issue here is maintaining public confidence and trust in the decision-making processes for public, and indeed private, cancer patients. Clear practice standards with appropriate caveats would be most welcome by cancer patients and their organisations. Toxic cancer drugs are very different to drugs used for other serious conditions, and the "primum non nocere" dictum can be difficult to apply.

Comments on the Terms of Reference

(a) The efficacy of electronic prescribing systems, and their capacity to stop or limit off-protocol prescribing of chemotherapy

Cancer Voices supports the introduction of common electronic prescribing systems across the NSW cancer care sector, with the capability to be linked directly to MyHealth Record. This will make it viewable by the patient and their advising clinicians. Accessible electronic systems should enhance the likelihood of unexpected changes to dosing being noticed and discussed.

(b) The value of a potential new patient information sheet on dose adjustment for patients and caregivers' information.

Cancer Voice sees this as essential part of written information about any chemotherapy course, to be included with a signed Consent Form. It follows that any adjustment should also be fully discussed with patient and documented on the clinician's and patient's records.

(c) The process and systems around informed consent for all medical interventions, including chemotherapy.

Accepted processes and systems for informed consent are essential, both in relation to the treatment and side effects, as well as the cost (if private). Consent forms should be developed in consultation with health consumer organisations to ensure they are clear and cover any areas of concern to the patient. They should also be discussed before signing. Copies should be held by both clinician and patient. Preferably the Consent Form will become part of a Cancer Treatment and Care Plan to be held by the patient.

(d) The capacity of the NSW Health system to have all notifiable cancer patients in NSW overseen by a Multidisciplinary Cancer Care Team (MCCT) and if this may prevent off-protocol prescribing.

Cancer Voices strongly supports the policy that all cancer patients should be overseen by a MCCT, wherever practically possible. Distance barriers are being overcome by teleconsultation for this purpose. We believe that in practice this would mean that very few cancer patients would be incorrectly prescribed off-protocol. It should be recognised that the MCCT may agree that particular circumstances for a given patient may require off-protocol prescription, thus individualising cancer care when appropriate and acceptable.

(e) and (f)

Cancer Voices is not in a position to comment meaningfully on these *Terms or Reference*, as they apply directly to St Vincent's Hospital. However we do of course support the ability of staff to raise concerns about practices of clinicians and breaches of the Codes of Conduct. It is also important that patients be notified much earlier than they were in the St Vincent's case, with suitable counselling being provided.

Cancer Voices thanks the Select Committee for the opportunity to make this submission. We hope to see its recommendations being applicable to improving confidence in all NSW cancer care centres.

Yours sincerely



Sally Crossing AM
Chair
2 November 2016