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TO WHOM IT MAY COCNERN

1357-F-18 Fluorodeoxyglucose (FDG) positron emission tomography (PET) for the evaluation of breast cancer

Cancer Voices wishes to make a submission regarding the above protocol proposal before MSAC. Our submission is made from the consumer viewpoint – both through an individual experience and as it affects cancer consumers more broadly.

Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. Cancer Voices networks across Australia work together on national issues identified as important by their members, with consumers working to help others affected by cancer.

Personal story
First, I wish to offer a personal case study as to why PET scans need to be allowed a Medicare rebate for people with metastatic breast cancer (MBC), or suspected of having progressed to MBC. Cancer Voices and other cancer consumer organisations find it difficult to capture consumer experience about using PET technology where rebates do not yet exist. So my own experience in February this year was almost welcome!

My PET scan was ordered by my medical oncologist to ascertain the extent of my progression, if any. This was after an annual CT scan had alerted us to some small spots of concern on my liver, previously (early 2005) successfully resected. This information was needed by my medical team and by me to give us a basis on which to make decisions about a range of treatment options – whether biopsy, surgical intervention, chemotherapy, endocrine therapy and/ or radiotherapy. The PET scan was ordered to show the location and intensity of any new tumours, after a nine year gap without progression. Before having the scan, I, unlike my peer patient group with other cancers whose PET scans are covered through Medicare after MSAC approval, had to pay $590 upfront.

The results were extremely useful to my team and to me. While the liver spots appeared too small to “light up”, useful information in itself, three sets of lymph nodes did. One is above the left axilla and positioned where a biopsy can be safely taken, which will mean we will know if my oestrogen receptor status and HER2 status have changed or not, after the last opportunity to examine tissue following surgery in 2005. Without this information, we would be making decisions in the relative dark. Also, the fact that we now know some accessible lymph nodes are involved means we can

avoid the much more risky and difficult liver biopsy. The biopsy will also provide a little fresh tissue for further profiling, which will add to the knowledge of my cancer profile and may enable me to participate in a clinical trial. Without the PET results, few of these options would be open to me and my medical advisers - we would be flying blind.

Cancer Voices Position

Moving from my own story, I reassume my hat as Spokesperson for Cancer Voices Australia, Chair of Cancer Voices NSW and Founding Chair of the Breast Cancer Action Group NSW. All three cancer consumer organisations have been working for the inclusion of breast cancer and some other cancers where PET is now regularly seen as best practice, but not approved for rebate. Our colleague organisation, the Breast Cancer Network Australia has been, and is, another strong supporter.

We are aware that a number of leading experts, both international and domestic, as well as we patients, are concerned that women with metastatic breast cancer are missing out, unless they can pay upfront, on an extremely effective diagnostic tool. No MSAC approval or Medicare rebate signals a message that that once your cancer has progressed to the metastatic stage, this kind of technology should not be wasted on you – although this is not the case for a suite of cancer drugs which are subsidised via the PBS.

Our view is that if PET has been accepted onto Medicare for a range of cancers, both early and metastatic, and has become a widely accepted part of best practice where more complex diagnosis is needed, how can the same principle not be applied for metastatic breast cancer?

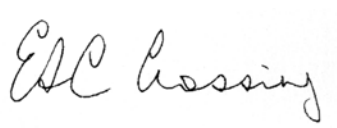
We welcome the opportunity to provide feedback on the proposal before MSAC, recognising that if the outcome is positive, women will have reassurance that they will be able to access PET to inform their treatment decisions. We acknowledge there is a case for some criteria to be attached to ensure that benefits will flow to patients who will most benefit from the knowledge gained via this technology.

Cost effectiveness

PET is an extremely valuable tool in decision-making about best treatment modalities. It is also potentially very cost effective – its cost at around $600 is insignificant compared to the cost of many cancer drugs – the need for which a PET scan may obviate. In my own case, if the PET influenced biopsy shows that my cancer is oestrogen receptor positive, my drug of choice will cost the PBS $1536 pa, of which I will pay $444 as co-payment, i.e. net $1112 pa, rather than the alternative – costly liver surgery, chemotherapy or radiotherapy. This for an investment of $590.

We rest our case; MSAC should approve PET for MBC assessment, or for establishing if MBC is present, its extent and location, because it is a cost effective and clinically effective diagnostic tool. The evidence is in and it is accepted internationally. Approval would mean equity of access for women with MBC to a rebate provided for many other cancers. Please read the accompanying Feedback Survey in conjunction with this letter.

Yours sincerely



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