

Breast Cancer Network Australia
Submission to the Medical Services Advisory Council
Application 1098.1 Public Comment Submission



7 March 2012

About Breast Cancer Network Australia

Breast Cancer Network Australia is the peak national organisation for Australians personally affected by breast cancer. We empower, inform, represent and link together people whose lives have been affected by breast cancer.

BCNA represents more than 67,000 individual members and 305 Member Groups from across Australia.

BCNA works to ensure that women diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible – no matter who they are or where they live. BCNA is represented by the pink lady silhouette. The pink lady depicts the organisation's focus – women diagnosed with breast cancer.

Introduction

Breast Cancer Network Australia welcomes the opportunity to provide feedback to the Medical Services Advisory Committee's Consultation Decision Analytical Protocol regarding Breast Magnetic Resonance Imaging (MRI) for screening of high-risk women.

As an organisation representing more than 67,000 Australians affected by breast cancer, BCNA is often contacted by women asking why their breast MRI does not attract a Medicare rebate. Women with a personal history of breast cancer, particularly younger women, are often referred for regular follow-up MRI by their health professionals.

As you are aware, younger women with a strong family history of breast cancer are able to access a rebate for breast MRI. Currently, women who have a *personal* history of breast cancer are unable to access this rebate. This represents a fundamentally inequitable situation between these groups of women. BCNA supports the inclusion of women with a personal history of breast cancer women in the eligible population for Medicare rebates, and therefore welcomes this review of the current MBS item numbers for breast MRI.

BCNA is a consumer advocacy group, representing the views of people affected by breast cancer. For this reason, not all questions in the survey fall within the ambit of our expertise. These questions, particularly those that require clinical expertise, have therefore not been answered in this submission.

Response to Survey Questions

Question 1: What is your experience with the medical condition (disease) and/or proposed intervention relating to the draft protocol?

As stated above, BCNA is the peak national organisation for Australians personally affected by breast cancer. BCNA connects more than 350 member groups and over 67 000 individuals across the country. We work to ensure that women diagnosed with breast cancer

receive the very best information, treatment, care and support – no matter who they are or where they live.

To this end, BCNA draws directly on the experience of women who have, or have had, breast cancer.

In 2009, BCNA conducted a survey involving 160 participants of The BCNA Review and Survey Group¹. 'The out-of-pocket cost of follow-up care: Mammogram, ultrasound and MRI' (the Survey) investigated the various costs associated with (among other imaging techniques) MRI for follow-up breast cancer care.

"I think most people realise there will be some cost involved when you have a serious illness, however the cost of MRI is prohibitive for some people. I have top private cover and I still had to pay upfront and there was no rebate. \$600 is a lot of money to pay when you are already paying so many other medical expenses. I wonder how many women miss out on this due to the high costs. It seems very unfair". – Woman with breast cancer, participant in the Survey.

2. What do you see as the *benefits of this proposed intervention for the person involved and/or their family and carers?*

A rebate for MRI services would represent a significant cost saving for women and their families. Women with breast cancer face a significant range of out-of-pocket costs relating to their diagnosis, treatment and ongoing care. These are not solely medical in nature. Whilst the medical expenses add up (for example, specialist and GP fees, imaging fees, and other associated costs), women and their families face other financial burdens as a direct result of their breast cancer diagnosis. This may include travel and accommodation costs, loss of income, childcare and myriad other expenses.

BCNA knows that, as yet another added cost, some women may forfeit necessary testing:

"Because of the costs... I feel less inclined to continue. The costs of what should be regarded as a necessary part of ongoing surveillance for women who have been diagnosed with breast cancer can be prohibitive, and consideration must be given to making these services totally rebatable or free of charge.

It is also worthwhile noting that in many Australian states, women who have a personal history of breast cancer are ineligible to participate in the free BreastScreen program. The cost of private mammography is yet another additional cost, which creates significant inequity and disparity between women with a history of breast cancer (and therefore at greater risk) and women without.

"Add the costs of hormone therapy and other medication, blood tests, pelvic scans, follow up visits with the surgeons, GPs, day charges in hospital etc. to mammograms and ultrasounds and you have a very high ongoing cost..."

¹ The BCNA Review and Survey Group consists of over 1000 women nationally (including women from rural and regional areas across the country), who have nominated themselves to consider participation opportunities in research relevant to breast cancer treatment and support. These women are actively sought out by researchers to participate in research, focus groups, reviews and more. Further, BCNA often uses the Group to assist in the development of position statements and policy. Surveys are widely used to establish a strong evidence base for BCNA's position on particular issues.

In the Survey, 57% of women reported having had an MRI. Most (52%) paid between \$100 and \$500 out-of-pocket for each MRI, with many paying more. BCNA is aware, anecdotally, that the costs since 2009 for MRI have reduced somewhat. A member recently informed us she paid \$350 out-of-pocket for her MRI. However, as stated, once factored in with all other costs and associated sundry expenses, these annual fees add up.

With this in mind, BCNA sees the following benefits of the proposed intervention:

- (a) Reduced out-of-pocket expenses for women and their families who are already at a financial disadvantage due to their personal history of breast cancer;
- (b) Improved compliance with MRI referrals (i.e. less women will forgo the imaging due to the cost);
- (c) Medical professionals will be better placed to make referral decisions based on therapeutic and clinical need, rather than the economic circumstances of their patients; and
- (d) Less inequity between women with a personal history of breast cancer, and those without.

Question 3: What do you see as the disadvantages of this proposed intervention for the person involved and/or their family and carers?

BCNA does not see any potential disadvantages with the proposal.

Question 4: How do you think a person's life and that of their family and/or carers can be improved by this proposed intervention?

“Breast MRI was considered, by my treating team, to be the most effective screening tool for my young dense breast tissue. I was offered it as a “Mastercard moment”. In 2005 my first MRI cost \$800- (my out of pocket expenses for a radical mastectomy was \$1200). Over the next the few years I had another three MRIs, until my breast tissue was considered to be “less dense and safely readable by mammogram and ultrasound”. It was a significant additional cost, on top of all the other expenses, but my husband and I felt that we had to follow the medical recommendations of the team, to do all we could. I’m glad I was given the option.”

As stated above in our response to Question 2, the benefits for women affected by this proposed intervention are:

- (a) Financial. An MRI rebate for the identified high-risk population (women with a personal history of breast cancer, and those with a diagnosis of DCIS and LCIS) will reduce the cost burden on them and their families;
- (b) Medical. BCNA understands that younger women are generally better suited to MRI due to dense breast tissue. Young women with a history of breast cancer may have significantly dense tissue due to radiography treatment and scarring from surgery. Mammography for these women is not only not clinically recommended, but painful. An MRI rebate for these women may increase the rate of compliance with MRI referrals, thereby ensuring these women receive the best possible imaging technique for their circumstances; and
- (c) Emotional. The emotional benefits of receiving a rebate for breast MRI are significant, for a number of reasons. For a woman with a personal history of breast cancer, these include:

- a. Less anxiety and stress related to the financial burden of her breast cancer treatment.
- b. Significantly less anxiety about the quality of her treatment and follow-up care. Women who are unable to afford the out-of-pocket MRI costs (or are not referred to MRI by doctors who believe they can't afford MRI) have the additional burden of worrying whether they are doing everything medically appropriate to detect a recurrence of their breast cancer.

BCNA is aware that the fear of recurrence is a significant emotional burden affecting women with a personal history of breast cancer. The ability to access the best scanning technique for their circumstances (i.e. MRI for younger women) gives these women confidence that all is being done to detect a recurrence. This in turn may go some way to relieve the associated stress and anxiety.

I know of women, with young dense breast tissue, whose doctors did not initially discuss or offer the option of a MRI scan, or another who choose to forgo the recommended MRI screening due to financial hardship. This appeared to have consequences to their prognosis and the emotional health of themselves and their family and friends. Blame, guilt and questions hinging on "what if you / I had had the MRI..." were added to the existing stressors of the breast cancer journey."

"My surgeon did discuss the possibility of MRI instead of mammogram/ultrasound but advised that the cost is prohibitive and not yet medicare funded – he did state that he'd refer me if I was prepared to pay approximately \$500 for the pleasure!"

Questions 5 – 11

BCNA does not have the clinical expertise to answer these questions, and respectfully decline to answer for this reason.

Question 12

BCNA suggests that 'financial impact be recorded against "Patient Outcomes", to reflect the comments above.

BCNA thanks the Medical Services Advisory Committee for the opportunity to provide comment on this proposal. Should you have any concerns or questions related to this comment, please contact Nicca Grant, Senior Policy Officer on (03) 9805 2585 or at ngrant@bcna.org.au.

Yours faithfully

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