



Woman to Woman



Breast Cancer
Research to Reality
~
Easier Said than
Done?

Evaluation report
April 2008

April 2008

This evaluation was conducted by Kate Cuss of Women's Health Goulburn North East (WHGNE). Women's Health Goulburn North East was established in July 2000. Previously known as NEWomen, WHGNE is the government funded specialist women's health service for the Goulburn Valley and North-East Victoria. The vision is to lead the Hume region in creating opportunities for women to experience a positive sense of self, health, safety and wellbeing.

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Executive Summary

The incidence of breast cancer continues to rise in Australia with over 2,500 women dying each year¹. However, survival rates are rising, with 86 per cent of women diagnosed with the disease being expected to be living five years after their diagnosis².

Addressing the issue from a holistic perspective, Women's Health Goulburn North East (WHGNE), in partnership with BreastScreen Victoria (BSV) and many regional health services, has since 2006 conducted a multifaceted approach to breast health in the Hume region of Victoria. This initiative, the *BreastScreen Van Women's Cancers Project* (previously known as the BreastScreen Van project), emerged from the recommendations in the *Woman to Woman* breast cancer research which was published by WHGNE in 2004³.

This report evaluates the initiatives of the *BreastScreen Van Women's Cancers Project* occurring between March 2006 and November 2007. It follows on from work recorded in two previous reports⁴.

The specific objectives set for the *BreastScreen Van Women's Cancers Project* were:

- ⊗ Improved health literacy for women and health care professionals (health related knowledge, attitudes, motivation, confidence and behavioural intentions)
- ⊗ Improvement in knowledge of where to go (locally, state and nationally) and what to do to obtain health services for women and health care professionals
- ⊗ Improved capacity within organisations to develop sustainable skills, organisational structures, resources and commitment to improving women's health
- ⊗ Stronger relationships with partner organisations.

Methodology

¹ National Breast Cancer Centre <http://www.breasthealth.com.au/statisticsresearch/> accessed 9/1/08 @ 11:05 am

² National Breast Cancer Centre http://www.nbcc.org.au/media/nbcc-aihw_2006report.html accessed 1/4/08 @ 3:14 pm

³ Verde A, Cuss K and Parkinson D. October 2004, *Woman to Woman: A research report on the experience of rural women with breast cancer and implications for the provision of health services and Woman to Woman: Insights from rural women with breast cancer*, Victorian Government Department of Human Services Hume region, Hume Breast Services Enhancement Program and Women's Health Goulburn North East, Wangaratta

⁴ Cuss K. November 6, 2005, *Woman to Woman, Implementations of the recommendations, Work in Progress Draft Version 1*, and Cuss K. November 20, 2005, *Woman to Woman, Implementations of the recommendations Work in Progress Draft Version 2*, Women's Health Goulburn North East, Wangaratta.

Women and workers from nine rural towns were involved in establishing locally appropriate events, and in the development and provision of localised information. There were three key elements to the project:

- (1) holistic health promotion was provided to well women who attended BreastScreen for mammograms in the form of health promotion (HP) packs and women's health promotion passports tailored to each community {Appendix # 1};
- (2) supportive care was provided for women who had experienced breast cancer; and
- (3) professional education was conducted for health care workers.

The evaluation methodology included statistics kept on numbers of passports copied, health promotion packs distributed and numbers attending events; evaluation surveys at events and enclosed in the health promotion packs. Qualitative interviews were conducted by telephone or in person using a structured questionnaire.

Project results

Over the two years of the project, involvement of women and workers was high with more than 13,180 participants.

Community events and health care professional education

In relation to community events and health care professional (HCP) education, 27 project events were held by WHGNE and its partners. These were well attended:

- 8631 women received HP packs and/or passports through attending BreastScreen vans at Myrtleford, Wangaratta, Yarrawonga, Mansfield, Alexandra, Seymour and Tallangatta or through the fixed imaging site for mammograms at Shepparton.
- 2620 women attended and received HP packs with passports at related events.
- 1936 health care professionals (HCPs) attended educational events where *Woman to Woman* was featured, including conference presentations, WHGNE forums and workshops hosted with partner agencies. 196 HCPs received HP packs at these events.

Partners in coordinating the community forums felt:

- The events were well organised, with excellent delegation;
- The events served as reminders of what needed to be done; and
- It was valuable that the events were held in their local communities.

Passports and health promotion packs

The total number of health promotion packs distributed was 10,120. In addition, 1347 passports only were also distributed. Because agencies had electronic copies of their passport, it is unknown exactly how many passports these agencies have distributed, however anecdotally it is estimated to be in the many hundreds.

Each of the HP packs contained a reply paid questionnaire. Fifty-one women took the opportunity to post back their feedback. Forty-seven women indicated they had learned something new from information in the pack, and 46 read about a service they didn't previously know about. Forty women had already told someone else or passed information on, whilst two indicated 'not yet', which would appear they intend to. On the important question of whether the women had taken action as a result of the information in pack, 30 said 'yes', 12 indicated 'no' and three 'not yet'.

While the number of respondents to this survey was small, there is evidence to indicate that one letter or phone call about an issue is said to equate to 100 concerned constituents, and one visit equates to 1,000. Even individual letters, emails and phone calls from community members carry impact. There are many examples of public opinion directly influencing government policies, because politicians know that for every person who took time to write, many more have the same opinion⁵. Therefore it may be that while only a few returned the survey in their HP pack, many more benefited.

Project achievements

The importance of partnerships

The importance of partnership development and maintenance was central to the success of the project. Many partnerships were fostered throughout the region during the planning and implementation of this project. Consumer involvement⁶ was one of the major philosophies of the project and entailed working closely in each community with women who had experienced breast cancer. National (such as National Breast Cancer Centre) and state-wide agencies (such as BreaCan and Cancer Council Victoria), major regional health services, rural community health centres, breast and cancer support groups and isolated sole workers were partners in various events and communities.

While many of the outcomes from working in partnership can be quite intangible, there is much evidence in this report to suggest that our partners have valued the opportunities to work together towards improved women's and breast health in the region, and in doing so raised their profile or enhanced their service.

The state-wide breast cancer service BreaCan viewed our partnership as a way to transfer our project model to other parts of rural regions of the state, and to reach rural women and health care professionals.

BreastScreen Victoria (BSV) valued the partnership and the opportunities it offered to broaden their image from a breast cancer screening program to one of women's wellness.

⁵ Flannery Tim http://www.psychology.org.au:80/publications/inpsych/saving_april viewed at 5:32 pm 3/4/08

⁶ The word consumer is used here to mean women who are equal partners in their health care with their care team. WHGNE's preference is to generally refer to them as 'women'

Breast Cancer Support Groups (BCSGs) valued their involvement with this project as they were able to take their learnings and insights back to help other members of their groups.

Partnerships rely heavily on a collegiate mentality to work together and share, and this can be difficult when one partner does not see the value added to their organisation or feels threatened by the partnership. This is what happened with two organisations during the implementation of this project which resulted in less than optimal outcomes.

Through the partnerships developed for this project, provision of information to women was able to be undertaken on a large scale, and this was seen as the most positive aspect of the project. This information contained data about available services and their contact details, with all information collated into one pack.

The project also produced significant benefits for the various groups involved in the project. These are listed below:

Health care professionals

Health care professionals and workers experienced a number of benefits as a result of being involved in the project:

- Distributing valuable information, which contained useful resources and updated contacts, to women via a resource pack or an event was mentioned most often by HCPs as the most beneficial aspect of the project. HCPs felt it was also an opportunity to raise their personal and agency profiles, to pool resources and network and partner with other agencies.
- Capacity building for HCPs, through learning new skills and information, increasing public speaking experience and realising the rewards of coordinating events were important to many workers. Breast care nurses in particular expressed their gratitude for the work being undertaken within this project, and the networking and education they have been able to obtain locally.
- The process of developing the passport was also seen as a positive experience for most workers, as they learned a lot about available services and found it a collaborative and inclusive process.
- Some HCPs reported an increase in community members attending or utilising their services as a result of their exposure as partners or speakers at events.

Project participants

Benefits to the women participating in community events were acknowledged as:

- Not having to travel to regional centres or Melbourne to access the expertise, networking and support;
- Easy access to local services and workers; and
- The motivation to see services they may not have otherwise accessed.

Volunteers

Feeling useful, putting back into the community, advancing women's health and assisting WHGNE staff by freeing up their time so they could achieve something else were all noted by volunteers as benefits of the project. Other rewards included having something to do, learning and access to information, and the fun of meeting new people.

Agencies

The benefits to WHGNE were:

- Greater exposure and understanding by others of the role of WHGNE; and
- Increased partnerships and health promotion with a significant number of women in a variety of rural communities.

Partnering agency workers felt their services benefited from involvement in the project through:

- Broadening their expertise;
- Making updated resources available to the whole agency;
- Bringing events to their rural communities;
- Networking;
- Having another connection to their community; and
- Provision of more holistic health services to women.

Project challenges

The major project challenges centred around:

- The amount of photocopying that needed to be undertaken;
- Poor photocopy quality of some passports and some materials in the HP packs;
- Relevance of some of the materials;
- Collation, transportation, storage and distribution of the HP packs;
- Trying to fit in the breast cancer work as well as all other workloads; and
- Lack of consultation and collaboration with some agencies.

BreastScreen recognised that there would be opportunities to better educate their staff about how their role fit within the project and the benefits of collaboration.

Next steps

The findings from this project will be valuable in the planning and development of the next phase of the project. This coincides with the BreastScreen mobile screening service two-year schedule.

Introduction

Since 2006 Women's Health Goulburn North East (WHGNE) in partnership with BreastScreen Victoria (BSV) and many regional health services, has conducted a multifaceted approach to breast health in the Hume region of Victoria. Women and workers from nine communities were involved in establishing locally appropriate events, and in the development and provision of localised information. This includes:

1. **Supportive care for women who have experienced breast cancer.** Local service providers and health professionals were engaged in a concerted effort to inform women about health and available services, and there were public forums for women with breast cancer, their families and carers
2. **Holistic health promotion to well women who attend BreastScreen for mammograms.** WHGNE 'value added' to the services of BreastScreen to share information distribution, so that WHGNE have women's health information on the BreastScreen mobile vans and in screening centres, and BreastScreen information is available at WHGNE and distributed through networks, e.g. in newsletters and mail outs, both by email and mail. There are around 40 well women going into the van and screening centres each day, aged between 50 and 69+. This was a great opportunity to reach women in this age group to improve their knowledge of health issues and local health services.
3. **Health care professional education.** Professional development sessions were offered to health workers, particularly around communication with women with cancers, the unique needs of younger women, sexual and reproductive health and psychosocial support.

This initiative, the *BreastScreen Van Women's Cancers Project* (previously known as the BreastScreen Van project), emerged from the recommendations in the *Woman to Woman* breast cancer research published by WHGNE in 2004³. The vision for that qualitative research was for *increased awareness of rural women's experiences of breast cancer, resulting in informed policy and improved services.*

After implementation of this project, it is timely to evaluate the work of the project, so that the process for the next two-year cycle beginning in mid-2008 can be planned and improved. This coincides with the BreastScreen mobile screening service two-year schedule.

Rationale for the project

The diagnosis of breast cancer is usually a traumatic event in a woman's life, and the impact of breast cancer and its demands can be significant. The incidence of breast cancer continues to rise in Australia, and more women are surviving the disease.

The number of women diagnosed with breast cancer has more than doubled in the past 20 years – increasing from 5,318 women in 1983 to 12,027 women in 2002² (the increase in incidence in the 50-69 year old age group in 1993 and 1994 was most likely the result of the introduction of the national breast cancer screening program, given that this has been the main target age group¹). It is estimated that over 13,000 women and about 100 men will be diagnosed with breast cancer in Australia each year. The risk of a diagnosis by age 85 years has increased to one in eight for women, up from one in 12 in 1983².

The Ovens-Murray Statistical Division of ABS, which loosely correlates to Central Hume and Upper Hume (particularly Alpine Shire region), has the highest incidence of breast cancer in Victoria, linked by a Monash University study to high organochloride pesticide use of many decades in the tobacco and grape crops^{7 8}.

There is a growing body of evidence showing that the 670,000+ Australians who live outside state capital cities are at risk of significantly poorer survival rates following a cancer diagnosis than people with similar diagnoses in the major metropolitan centres⁹. The limited evidence on cancer in indigenous people in non-metropolitan areas indicates significantly poorer treatment outcomes than non-Aboriginal Australians¹⁰.

A woman's risk of dying from breast cancer before the age of 75 years has been declining, from a one in 43 risk in 1983 to a one in 56 risk in 2004². While over 2,600 women a year die each year in Australia from the disease¹, overall 86 per cent of women diagnosed with breast cancer today can expect to be living five years after their diagnosis, compared to only 71 per cent in the period 1982-1986².

For the first time, information has been reported on the number of people living in Australia after a diagnosis of breast cancer: 113,801 women and 730 men alive who have been diagnosed in the past 20 years. The significant improvement in survival rates means our next challenge is to ensure we expand our focus to include life beyond breast cancer or 'survivorship'. Many women who have experienced breast cancer feel high levels of stress and anxiety associated with the fear that cancer may return, and can also experience a range of problems about body image after surgery, loss of fertility for younger women, fatigue, financial, work and relationship

⁷ Khanjani N, English DR and Sim MR. September 2005, *Epidemiology*, Abstracts, Vol 16, No 5, p. S23.

⁸ Khanjani N. January 2005 <http://www.monash.edu.au/news/releases/2005/jan05-pesticide2.html> accessed 25/10/05 @ 4:12 pm.

⁹ ABS in Clinical Oncological Society Australia March 2006: Australian Bureau of Statistics. Australian social trends. Canberra: ABS, 2003. (ABS Catalogue No. 4102.0) and Australian Institute of Health and Welfare and Australasian Association of Cancer Registries. Cancer survival in Australia 1992.1997: geographic categories and socioeconomic status. Canberra: AIHW, 2003. (Cancer Series No. 22. AIHW Catalogue No. CAN 17)

¹⁰ Condon JR, Barnes A, Cunningham J, Armstrong BK, Long-term trends in cancer mortality for Indigenous Australians in the Northern Territory, Medical Journal Australia, 2004. in COSA March 2006

issues. These issues traditionally coincide with a time when there is reduced contact with the health care team².

Women in the middle years and those approaching older age are known to have high needs for health information as they face menopause and ageing issues. Conversely, younger women experiencing breast and gynaecological cancers are proven to have unique needs. The Hume region is one fifth the size of Victoria and the challenge for WHGNE is to effectively reach these women to provide them with health information.

This report evaluates the initiatives of the BreastScreen Van Women's Cancers Project occurring between March 2006 and November 2007. It follows on from work since 2004 recorded in two previous reports¹¹. This project has built the capacity of local organisations and health professionals to offer women better access to health services and information. The resources of BreastScreen Victoria, WHGNE and other partners were used to implement this project.

Objectives

A clear set of objectives informs the development, implementation and evaluation of any program.

Health information interventions aim to increase people's capacity to make informed choices about their health and wellbeing. This includes providing opportunities for preventive care, by improving their understanding about the causes of health and illness, the services and support available to help maintain or improve health, and personal responsibility for actions affecting their health¹² (pg 18).

The specific objectives set for the BreastScreen Van Women's Cancers project were:

- Ⓢ Improved health literacy for women and health care professionals (health related knowledge, attitudes, motivation, confidence and behavioural intentions)
- Ⓢ Improvement in knowledge of where to go (locally, state and nationally) and what to do to obtain health services for women and health care professionals

¹¹ Cuss K. November 6, 2005, Woman to Woman, Implementations of the recommendations, Work in Progress Draft Version 1, and Cuss K. November 20, 2005, Woman to Woman, Implementations of the recommendations Work in Progress Draft Version 2, Women's Health Goulburn North East, Wangaratta.

¹² DHS. April 2003, *Measuring Health promotion Impacts: A Guide to Impact Evaluation in Health Promotion*, Rural and Regional Health and Aged Care Services Division, Victorian Government Department of Human Services, Melbourne

- ② Improved capacity within organisations to develop sustainable skills, organisational structures, resources and commitment to improving women's health
- ② Stronger relationships with partner organisations.

Methodology

The evaluation methodology included statistics kept on numbers of passports copied, health promotion packs distributed and numbers attending events; evaluation surveys at events and enclosed in the health promotion packs. Qualitative interviews were conducted by telephone or in person using a structured questionnaire.

Evaluation forms were issued at most community and HCP events, with the exception of some partner activities where the lead agency did not evaluate. Responses were collated and distributed to partners and speakers for reflection and action where appropriate.

Short evaluation surveys were enclosed in the health promotion packs, 51 were returned.

A meta-analysis of events, passports and health promotion packs was developed for a snapshot of the overall concept and data, refer to Tables 1 - 7.

Qualitative interviews using a structured questionnaire were conducted by the Project Manager by telephone or in person with 26 respondents, of which 16 were health care professionals, 6 WHGNE volunteers, a WHGNE staff member and 3 women with breast cancer or members of breast cancer support groups. To maintain the integrity of the internal evaluation and ensure respondents were free to provide honest feedback, they were offered a choice of interviewer, either the Project Manager or a WHGNE staff member who was not aligned with this project.

How many participated?

In excess of 13,180 women, family, carers and health care professionals either attended events or received health promotion packs and/or passports in the Hume region between March 2006 and November 2007. The list of numbers of women and health care professionals is detailed in Table # 1 and further detail is found within relevant sections of the report.

Women attended and received HP packs with passport at WHGNE and partner events	920
Women received HP packs with passport from BreastScreen Radiographers, in the following towns and approximate numbers:	7284
@ Yarrowonga	750
@ Tallangatta	125
@ Myrtleford	900
@ Wangaratta	3000
@ Seymour	800
@ Mansfield	923
@ Alexandra	786
Women received passport only via Shepparton BreastScreen Goulburn Valley Imaging	1347
Women received health promotion packs and passports at other agencies' events	1700
Health care professionals attended events where <i>Woman to Woman</i> was featured (of which 196 received HP packs)	1936
Total #s people participated	13,187
Additionally, some Hume agencies (in towns such as Albury/Wodonga, Cobram and Benalla) obtained electronic copies of their specific local passports and have copied them for their own purposes (as opposed to the above which were copied and distributed by WHGNE). It is unknown exactly how many passports these agencies have distributed, however anecdotally it is estimated to be in the many hundreds.	

Table # 1

Events, health promotion packs and passports

Events

The total number of events held by WHGNE and partners was 27 (Table # 2 and # 3). Ten of these events were for health care professionals, 17 for women who have experienced breast cancer or breast health events.

Table # 2 Total number of WHGNE lead agency sponsored events held:

For women, partners, family and carers:	5	For Health Care Professionals:	3
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Table # 3 Total number of events held where WHGNE partnered:

For women, partners, family and carers:	12	For Health Care Professionals:	7
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A meta-analysis was developed of the five of WHGNE lead agency sponsored community events, as seen in Table # 4.

	For the women				
Events:	<i>'Breast Health, Boats and Beautiful Women'</i> Myrtleford June 2006	<i>Now What? What to do when you have completed Rx for cancer</i> Wangaratta Oct 2006	<i>Women's Health Forum</i> Yarrowonga July 2006	Year 7-10 girls Yarrowonga High School <i>Young Women's Health and Healthy Relationships</i> July 2006	<i>TOWN Health Trivia Night</i> Tallangatta Sept 2006
Numbers attended	90	53	40	125	18
Liked	<ul style="list-style-type: none"> Ⓢ Excellent speakers Ⓢ Very informative 	<ul style="list-style-type: none"> Ⓢ The speakers helped to validate and 'normalise' all 	<ul style="list-style-type: none"> Ⓢ The accessibility of senator Lyn Allison to 	Not formally evaluated	Not formally

	<p>afternoon</p> <ul style="list-style-type: none"> Ⓢ Eclectic mix of presentations Ⓢ Opportunity to light a candle Ⓢ Singing 	<p>the feelings I have!</p> <ul style="list-style-type: none"> Ⓢ As a supporter of my sister I can go away hopefully a lot better able to help her and support her Ⓢ I am currently going through chemo and it gives me courage and inspiration when I hear others who have coped and survived Ⓢ Very informative speakers; so much was so true 	<p>the public</p> <ul style="list-style-type: none"> Ⓢ Quality of the speakers Ⓢ Being informed about networks we don't always have 		evaluated
Didn't like	<ul style="list-style-type: none"> Ⓢ I had more time to talk Ⓢ I was warmer! 	<ul style="list-style-type: none"> Ⓢ More people attended or even were aware of the benefits to each other of coming along Ⓢ If I had spoken of my own experience Ⓢ Could not be faulted Ⓢ There was more time to hear more speakers 	<ul style="list-style-type: none"> Ⓢ First section not relevant to age of audience Ⓢ Poor use of microphone by some speakers 		
Future actions	<ul style="list-style-type: none"> Ⓢ Be happy, be healthy and move on Ⓢ Take care of myself so I can continue to care for family and friends and enjoy my life 	<ul style="list-style-type: none"> Ⓢ Talk more about our feelings to each other Ⓢ Focus on my needs a bit more Ⓢ Not to be so hard on myself 			

	<ul style="list-style-type: none"> Ⓢ Update my handouts (for today!) Ⓢ Stay positive and keep exercising Ⓢ Live life to the fullest. Enjoy every moment and be inspired by people's everyday experiences 	<ul style="list-style-type: none"> Ⓢ Use the info and resources available; nurture and take care of myself Ⓢ Set more life goals Ⓢ "Gunna" do some more of the things I've always been 'gunna' do!! 83 year old Judy Ⓢ Stay positive and to appreciate the support 			
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Table # 4

A meta-analysis was developed of the three WHGNE lead agency sponsored health care professional events, as seen in Table # 5.

	For Health Care Professionals		
Events:	<i>Now What? Working with people who have finished treatment for cancer</i> Wangaratta Oct 2006	<i>Breast Cancer Screening and Treatment Update</i> Yarrowonga March 2006	National Breast Cancer Centre and Cancer Council Victoria ' <i>Delivering Bad News</i> ' Communication Skills Workshop Wangaratta May 2007
Numbers attended	23	27	16
Liked	<ul style="list-style-type: none"> ⊕ Look forward to presenting some of these ideas to my patients ⊕ Great to go away with resources we can use to assist people following tx of cancer ⊕ It was great to have the importance of after treatment life expressed ⊕ I had not previously equated my own major traumatic life events with this, but it really made me think! ⊕ Like the way in which transition theory was used. The concept of post treatment well established 	<ul style="list-style-type: none"> ⊕ Well facilitated. Answered questions well. ⊕ A positive, proactive presenter thanks! ⊕ It is very interesting to learn what happens across the region and what treatment options are available to woman ⊕ Great to see experts dispelling "myths" to GPs. ⊕ Extremely positive having up-to-date info in regional centre – instead of travelling to Melbourne ⊕ Very beneficial to have local and metro speakers ⊕ Great to be invited as a Breast Care Nurse 	<ul style="list-style-type: none"> ⊕ The professional actor as the patient ⊕ Role play – actor provided 'reality' ⊕ Positivity and validation ⊕ Encouraging me in the adventure of communication ⊕ Affirming my own knowledge ⊕ Experiencing others skills

Events:	<i>Now What? Working with people who have finished treatment for cancer Wangaratta Oct 2006</i>	<i>Breast Cancer Screening and Treatment Update Yarrowonga March 2006</i>	<i>National Breast Cancer Centre and Cancer Council Victoria 'Delivering Bad News' Communication Skills Workshop Wangaratta May 2007</i>
Didn't like	<ul style="list-style-type: none"> Ⓢ Presentation a little unorganised – acknowledged and apology given Ⓢ Don't like the concept "move on". Would love to see the workshop as I am sure it would be beneficial. Didn't like how it was presented Ⓢ I question your "automatic <u>negative</u> thoughts" concept, i.e., labelling "<u>negative</u>" comes from a judgement – could bring outcomes opposite to goal 	<ul style="list-style-type: none"> Ⓢ Worried that maybe benefits of sentinel node biopsy understated. Ⓢ It would be appreciated if RN 1, CNS, Breast Care Nurse could be invited to these presentation in the future instead of filling the gaps for the lack of G.P. involvement. Ⓢ Need to start the talks earlier. No point having one hour before talk starts – makes for a late night 	<ul style="list-style-type: none"> Ⓢ Difficulty doing role play, but do understand the importance of it Ⓢ As stated before it probably didn't go into quite enough depth for me but this is difficult in the short timeframe available Ⓢ Could be longer – more information! Ⓢ Little opportunity to identify flaws and ways of improving existing skills
Future workshops and topics		<ul style="list-style-type: none"> Ⓢ Do treatments differ rural areas, e.g. Wangaratta to Melbourne? OR Doctor's choice? OR Experience? Ⓢ I think it would be very beneficial to have a BCN speaking on their experience and role following assessment clinic and positive result Ⓢ Herceptin updates 	

Table # 5

Community events

Of the 27 project events held by WHGNE and partners, 17 were for women who have experienced breast cancer or breast health events. Total people attending WHGNE lead agency sponsored events was 326 in Myrtleford, Wangaratta, Yarrawonga and Tallangatta. Events hosted by other agencies of which WHGNE partnered had 2294 women attend and receive HP packs at 35 other partnership events.

Event partners were interviewed regarding their participation in the community forums, how they found the process of coordinating the events and what worked well. The most common responses were how well organised the events were, excellent delegation, reminders of what needed to be done and valued that the events were held in their local communities. It was generally agreed that there needed to be a paid person in the overall coordination role.

- Ⓢ *'How engaged we all were, good team, common focus of interest, passion for consumers, introverts that have a voice, hear what people are saying as well as a voice, know what each others strengths and weaknesses are, no intimidation, sharing doesn't diminish power. We care for each other, supported each other, we needed to be OK personally to do that'* (Breast Care Nurse BCN)
- Ⓢ *'Very well organised, we always knew what we had to do, did what we were told, we would need someone in the role of coordination, a paid person, otherwise we volunteers wouldn't have pulled it together; we help out, come along for the drive. If you are doing a section of it, rather than overall coordination, you can focus on it. Well delegated.'* (Breast Cancer Support Group Coordinator)
- Ⓢ *'Done exceptionally well and keeping us informed in terms of tasks/responsibilities we had, sponsorship and support at local level was really critical, venue, local knowledge, really well important in terms of credibility. Whole format excellent. People came along and thought a really well run event. Media coverage locally important. Organisation really professionally done, other stalls/displays really good.'* (State-wide service Manager)

When asked what they would change next time, there were few changes to be made: *'nothing, we worked very well together and the outcomes show that despite thinking we could have done better, the evaluation comments were all worthwhile'* (BCN). One rural town attempted to engage other community groups in event planning, which were not successful: *'we fell down by not linking with football/netball, shame we didn't get it to the wider community, but again lack of communication'*. (Women's Health Nurse).

When asked if they remembered seeing the evaluation summary of their local event, the challenge for many was that their event had been held 6 to 18 months previously, and they had trouble recalling the specifics. Of those interviewed who had partnered on events, none said 'No' they could not recall having seen it, one

was 'Unsure' and six said 'Yes, they could recall. Of those that did recall the evaluation summary, they were pleased and validated by the positive responses and that action was taken as a result of attending a workshop *'Finding out about services they didn't know existed and some taking steps they couldn't otherwise – making them stop and think about their health'*. Another HCP utilised the evaluation results to show a need for future initiatives.

Health Care Professional Events

Health education and skills development aims to improve knowledge, attitudes, self-efficacy and individual capacity to change¹² Through this project, professional development sessions were offered to health workers as a result of the recommendations of the *Woman to Woman* breast cancer research, particularly around communication with women with cancers, the unique needs of younger women, sexual and reproductive health and psychosocial support.

The HCP event evaluations asked how well the objectives for the educational workshops were achieved and the findings show that the vast majority of HCPs were 'quite a lot' and 'very well' satisfied with the education events achieving their objectives. Tables # 6 and # 7, and the theory to practice responses, detail the comments received from the HCPs at the event and in a four months follow-up of one event.

Event Now What? Working with people who have finished treatment for cancer - Wangaratta	Satisfactory/Pleasing*	Unsatisfactory^
<u>Objective 1:</u> Present a conceptual framework to consider the experience of a cancer diagnosis and beyond	17/19 89%	2/19 11%
<u>Objective 2:</u> Illustrate the ways in which the experience of cancer is like other major traumatic life experiences – a useful way to understand the residual psychological impact of cancer – after treatment ends	17/19 89%	2/19 11%
<u>Objective 3:</u> provide practical ways in which you can assist the people that you work with to process, debrief and move on from the trauma of cancer	16/19 84%	3/19 16%

* Satisfactory/pleasing is where responses given were 'quite a lot' and 'very well'

^ Unsatisfactory is where responses given were 'not at all', 'not much' or 'somewhat' (great!)

Table # 6

An important component of this work is to ensure transfer of theory to practice. A further evaluation was conducted four months later to assess the transfer from theory to practice of the strategies learned at the '*Now What? Working with people who have finished treatment for cancer*' seminar. We surveyed 10 HCPs and five responses were returned.

Four out of five said they used the strategies they learned in the seminar in their professional practice. '*The session emphasised the importance of post-cancer treatment follow-up. With a couple of clients many issues have arisen post-treatment; with phoning and keeping in contact, feel they have been supported even though not great involvement with medical team post Rx*'.

Four out of five respondents indicated they had shared or taught the knowledge and skills they learned at the seminar with others, i.e. colleagues and significant others. '*I liked the empowerment the education gave me in reinforcing the need for patients to not have the oncology office number as their only post treatment support number*'.

One respondent appeared to have a conflict with the philosophical framework of the workshop, '*I didn't actually learn that much. What concerns me is the notion of survivors, I do not believe it is a useful concept for people who have finished treatment. It victimises them, it's not about survivorship, it's about how we live. So the concept is negative, I'm getting this from the people themselves. Think they would do well to change that – negative for people who are trying to learn to live again. It's not about poking, existing, how do we live with the knowledge that we are going to die (which we all do). It separates them, it's not useful. It's about understanding that when bad things come, it's not to punish us, it just happens and makes us stronger*'.

The HCP event held in Yarrawonga in partnership with BreastScreen indicated an overall 89% satisfaction rate of achieving the objectives.

Event: Breast Cancer Screening and Treatment Update - Yarrawonga	Satisfactory/Pleasing	Unsatisfactory
<u>Objective 1:</u> To provide an overview and update of breast cancer screening and treatment	100%	0%
<u>Objective 2:</u> To identify the specific issues in the treatment of breast cancer	100%	0%
<u>Objective 3:</u> To enable peer discussions and case review with specialist input	69%	31%

* Satisfactory/pleasing is where responses given were 'quite a lot' and 'very well'

^ Unsatisfactory is where responses given were 'not at all', 'not much' or 'somewhat'

Table # 7

Passports and Health Promotion Packs

Women's health promotion passports

The total number of Health Promotion packs with passports distributed was 10,120 and an additional 1347 passports only. Agencies had electronic copies of their passport, and some reported copying additional passports for their clients. It is unknown exactly how many passports these agencies have distributed, however anecdotally it is estimated to be in the many hundreds.

Local workers were co-opted to assist with tailoring the women's health promotion passport specific to each community. A framework of the passport was provided electronically and they supplied the local service contact details and could add or edit any other details as appropriate. WHGNE administration staff did the passport final formatting and it was returned back in PDF format to be used by the agency, and in most cases photocopied by WHGNE for the HP packs.

The process of developing the passport tailored to each community was seen as a positive experience for most workers, as they learned a lot about available services, found it a collaborative and inclusive process, especially since the format was set up and they just had to provide the local content and contacts. *'Communication was good, the prompt nature of suggestions being taken up by the Project Manager, overall very positive. The comprehensive nature very good, desire to include so much shows in the document. It has given us another avenue, another way of presenting info, the passport has merit, people look for information that is compact, succinct, not too much blurb, just enough'*. (Community and Allied Health Manager)

When the health care professional partners were asked what they would change next time they were working on the passport, their requests were for it to arrive earlier for completing and distributing the local information and further consultation with colleagues. Some practical suggestions were received to improve the document itself, such as the addition of a wallet sized card to record dates as a constant reminder of check-ups needed, and eliciting evaluation feedback directly on the passport, not just through a separate survey.

- Ⓢ *'Passport was excellent, unfortunately arrived at the end of the van so not everyone got one, due to delay of going back and forth and van cutting short'*. (Women's Health Nurse)
- Ⓢ *'Next time I would take it to my direct manager and a meeting and the HP worker, dietitian, get more input from colleagues, they might think of some other things we could include in it – good to include family violence'*. (Community Health Nurse)
- Ⓢ *'Probably put a lot more thought into consulting other people, silos within our own agency that may have resources I don't know about'*. (Health Promotion Officer)

In one instance, a service was not included in an agency's passport, and a request was received to be included: *'I have just received a copy of this great resource. I would like to work with you in any future editions to include dental health. Dental health has been shown to be extremely important for people with cancer, heart disease and diabetes, all of these diseases or their treatments can be significantly compromised with poor oral health. And of course oral health is a good part of general health'*. (Dental Health Service Manager)

Action was taken as a result of the feedback received anecdotally and from the evaluations, and further recommendations appear in this report. The passports continually evolved as more services were added, and clearer language was suggested. The East Hume Regional Communication Service based at Ovens and King Community Health Service was consulted to ensure clear, concise language was used and appropriate to the majority of readers. The passport was also sent to BreastScreen Victoria for feedback, and they suggested some wording and logo changes, particularly within the section on breast health. A Health Promotion Officer at a major health service within the region was consulted for feedback on the HP packs, passport and evaluation methodology, and suggestions implemented.

The women who received the passport benefited from the comprehensive health information and contact details for their local community and elsewhere.

- Ⓢ *' "Passport to good health" a novel and useful approach and presentation to issues of health we need to be aware of, well done'.*
- Ⓢ *'I thought all the information was valuable. I enjoyed reading the different information and getting an overview of what is available'.*
- Ⓢ *'There was a wide range of information-something for everyone. Contact numbers for further information/help are very useful'.*
- Ⓢ *'If something is in writing in front of you, you are more likely to ring up and do something about it'.*

It was challenging in some communities to engage local workers to assist with developing a passport specifically tailored to their community, and due to time constraints, a generic passport was included in the HP packs in those instances. The women attending BreastScreen and local community events were disappointed not to receive a more personalised health information resource.

- Ⓢ *'Make the info more local-nothing much for Seymour'.*
- Ⓢ *'Why no Seymour GPs listed? Suggest alternatives also e.g. naturopath, chiro, dietician etc'.*
- Ⓢ *'A little more info for southern area, this area often misses out'.*

Women's health promotion packs

The total number of Health Promotion packs distributed was 10,120.

Collation and distribution of the HP packs either worked extremely well as local workers utilised them in numerous ways within their agencies, or was problematic due to personalities, transport and storage. Those workers that embraced the concept of the HP packs found them an incredibly valuable resource for their practice:

- Ⓢ *'Thank you very much for the production of them, a gift well received by so many people'. (Oncology Nurse)*
- Ⓢ *'...even their body language was amazing, after some women feeling so vulnerable naked having their mammogram, when I gave them their pack at the end as they were leaving they clutched it to their chest, it was like their security blanket, not feeling so exposed, feeling whole, and empowered to go out and face the world again'. (BreastScreen Radiographer)*
- Ⓢ *'Women liked the fact that they didn't come for just one thing – they liked that we gave them something, more community involvement, not just put boob on and out the door, they get to know women who return and this helped'. (BreastScreen Staff)*
- Ⓢ *'Our brains are programmed to "every event we go to, we take the packs as they are just so valuable"'. (Cancer coordinator)*
- Ⓢ *'...used packs quite a bit, whenever we did something here, linking people into services, letting them know what's available'. (Community Health Nurse {CHN})*
- Ⓢ *'I have distributed the left over packs in my HP role to my wider community. Everyone thought they were a really good idea. I promoted that if they couldn't use the info to pass it along to another woman'. (Women's Health Nurse)*
- Ⓢ *'Let me know if you're happy for me to give the packs out to clients/groups that I see. I don't want to run out! They have been really well received'. (CHN).*

When the magnitude of the workload of collating the necessary number of HP packs was realised, an advertisement was run in the local paper seeking volunteers to assist. Twenty-one women responded and 18 attended on the first day, which proved a challenge to coordinate all those volunteers into a system at the same time. Two thirds of the women failed to come back. One possible reason for this could have been many thought there were more women than needed to put the packs together. On average about 3-5 women attend each week to collate the packs¹³**Error! Bookmark not defined.**

The actual logistics of gathering the brochures, photocopying pages and collating enough health promotion packs to meet demand was a constant challenge, particularly for the volunteer coordinators and WHGNE staff who oversee this production¹³. Getting the HP packs to rural communities and distributing them once there often relied on the goodwill of others, with variable results. Transporting the

¹³ Howard Faylene. Undated, *Breast Screen Volunteers Report*, Women's Health Goulburn North East, Wangaratta.

bags from WHGNE to other towns often relied on convoluted transport methods, including husbands, partners and colleagues of workers.

Storage space within the BreastScreen van was limited and this posed a challenge to the Radiographers for housing hundreds of HP packs which were to be distributed to the 40 women per day who presented for their mammograms. While almost all the BreastScreen staff appeared positive about the partnership, some individuals were negative towards the initiative and were uncooperative, i.e. when the boxes were delivered and in the manner in which the packs were offered to the women. The challenge of embedding systems and processes which are not reliant on personalities remains a challenge.

- Ⓢ *'It was difficult in Alexandra, getting bags to hospital, nurses not real keen on delivering, ...and the radiographers weren't happy to get them – storage, etc; one week the nurses forgot them.'* (WHGNE worker)
- Ⓢ *'It didn't affect me, the radiographers handed them out – sometimes getting them to do something extra is a challenge.'* (BreastScreen Staff)

Numerous comments were made about the professionalism of the WHGNE staff and the way in which the collation and distribution of the packs was done.

- Ⓢ *'Karen is good about organising people who weren't sure what to do, very patient, very efficient, very well coordinated in that regard.'* (Volunteer)
- Ⓢ *'Karen has a way of being peaceful, seems to sum up a situation and do it quite well, others are friendly and enthusiastic.'* (Volunteer)
- Ⓢ *'Someone reminding us in advance of events to check stock of bags – helps planning. We could send our calendar of events to Women's Health admin in advance and they could get them organised for us. Availability, despite our chaos, when we spoke to the ladies on the telephone, they couldn't do enough, went above and beyond – service exceptional. Amenable to our chaos!'* (BCN)

Having such varied and comprehensive information together in a 'show bag' which could also hold other event-specific or issue-specific or agency-related brochures was viewed as a plus by the women.

- Ⓢ *'I thought all the information was valuable. I enjoyed reading the different information and getting an overview of what is available.'* (Women Respondent)
- Ⓢ *'Everything in a bag, not carrying bits of paper, added bits during the day so they didn't get lost'.* (BCSG coordinator)
- Ⓢ *'This pack is very good. Instead of trying to gather information from lots of different sources it is altogether in one place. Great!'* (Woman Respondent)

The information was used by the women themselves and passed along to family and friends.

- Ⓢ *'I used the abuse and violence in relationships and in the family information, for a friend who is having problems in her marriage'.* (Women Respondent)
- Ⓢ *'I think information about women's health issues is important for everyone. I am a mother with two daughters and discussed many issues with them, particularly breast examinations and pap smears'.* (Women Respondent)
- Ⓢ *'The women loved them – the little bag, loved fact there were leaflets in there, when you're having a cup of tea, read them. If they said I don't need it, I'd ask, do you have a daughter, give it to them – oh, that's a good idea! They felt they were getting a little gift, felt happier when they left'.* (BreastScreen Radiographer)

Approximately 10,120 HP packs were distributed, each containing a reply paid questionnaire. Fifty-one women took the opportunity to post back their feedback. Forty-seven women indicated they had learned something new from information in the pack, and 46 read about a service they didn't previously know about. Forty women already told someone else or passed the information on, and two indicated 'not yet', which would appear they intend to. On the important question of whether the women had taken action as a result of the information in pack, 30 said 'yes', 12 indicated 'no' and three 'not yet'.

While the number of respondents to this survey was small, there is evidence to indicate that one letter or phone call about an issue is said to equate to 100 concerned constituents, and one visit equates to 1,000. Even individual letters, emails and phone calls from community members carry impact. There are many examples of public opinion directly influencing government policies, because politicians know that for every person who took time to write, many more have the same opinion¹⁴. That evidence indicates that while only a few returned the survey in their HP pack, many more benefited.

There were differing opinions about whether the fabric or paper bags were better. One agency liked the paper so they could then stamp their logo on it as more of a partnership, others felt the cloth bag was reusable and therefore eco friendly. Volunteers collating the packs and the accessibility of the packs for use outside of BreastScreen van worked particularly well.

¹⁴ Flannery Tim http://www.psychology.org.au:80/publications/inpsych/saving_april viewed at 5:32 pm 3/4/08.

Suggestions for improving the HP pack and its distribution included making them look more professional with less photocopies and more colour pages, including other types of information, such as on STD, and ensuring inserts are appropriate for the area, i.e. *'I took out the Koori brochure, as very few in this area, perhaps send 20 with the packs to be inserted in appropriate bags, rather than in every bag – waste of resources and if people get too much stuff that isn't relevant they won't read any of it; it's like putting a rural brochure in a city bag'*. (Women's Health Nurse)

Qualitative survey

The qualitative survey which was conducted by telephone or in person asked 22 women to identify what they perceived their role to be in the BreastScreen van project. This ranged from WHGNE administering and coordinating the project, to volunteers collating the health promotion packs, Breast Cancer Support Group coordinators informing women where to get information and education, through to health care professionals providing the local content to the passport, distributing the HP packs, coordinating events, providing resources and working as BreastScreen Information Officers where the van visited.

Overwhelmingly the most positive aspect of the project was providing information to women in the community about what services are available with contact details, with all the information collated into one pack. Several commented on the partnerships and networks that were formed, the importance of initiatives in the rural areas, and having events local, central and accessible to women. One cancer worker commented *'The whole HP concept, love that. Giving that information to the consumer so they have control over their own health – empowerment. Providing people with free knowledge to access services – knowledge is power! Two women said to me at one function "I really liked what was in that brown bag".'*

Benefits to workers, volunteers, women and agencies

Numerous benefits were cited by those surveyed, whether they were health care professionals, volunteers, women receiving the information or the agencies themselves.

Benefits to workers

Getting valuable information out to women in a great resource pack and via events were the most mentioned benefits to the workers *'really great realising the women were getting info they didn't know existed and that came from the evaluations'*, followed by useful resources for themselves and their agencies with updated contacts, etc. They felt it was also an opportunity to raise their personal and agency profiles, to pool resources and network and partner with other agencies. The HP packs were seen as a resource all in one place, where they could also put their agency specific or relevant information and use them for their other events too, as one cancer worker identified: *'when you provide that information to large numbers*

of groups, efficiency, reaching a greater number – like 'play it forward' all that info goes to so many people indirectly – HP, rather than dealing with diseases in the end – that's why I love this so much, try and stop it from the starting point'.

Capacity building for the workers, in learning new skills and information, increased public speaking experience and the rewards of coordinating events were important to some workers.

Some HCPs have reported an increase in community attending or utilising their services as a result of their exposure as partners or speakers at events, including one private practitioner gaining 12-15 new lymphoedema clients as a direct result of speaking at a community forum. One state-wide provider noted *'I would like it if more health professionals and women were calling {our service} – my expectation is probably too high, people will think of the organisation and link rural women in, not happening enough as standard practice – don't know how we shift that practice in terms of linking women in. What happened afterwards though, we did get calls from BCNs so spin off/multiplier, we showed our face, a greater sense of understanding of our role, a rapport established. It gave us an insight into some of the issues rural women were facing and it never hurts for us to be reminded of those – awareness raising of the issues of access and isolation women feel.'*

Breast Care Nurses particularly have expressed their gratitude for the work being undertaken within this project, and the networking and education they have been able to obtain locally. Breast Care Nurses (BCNs) are required to undertake 12 hours of professional development per year to maintain their accredited status. Accredited BCN hours were applied for and obtained for many of the community and health care professional events, which benefited the BCNs by not having to travel to the city for face to face professional development.

The initiatives were seen as a conversation starter, a way to introduce more health promotion to women. One Breast Care Nurse had a woman say to her: *'I was also wondering about i.e. my daughter is not sexually active @ 30, does she need a pap smear?'* The BCN valued that she had the HP pack to offer to this woman, *'The fact that you are giving something - written information that they can refer back to – their own resource library – we can talk to it, then they walk away with it.'*

Benefits to volunteers

The volunteers received many benefits being involved in the project. Their roles mainly consisted of collating the HP packs and assisting with coordinating the community events. Feeling useful, putting back into the community, advancing women's health and assisting the staff by freeing up their time so they could achieve something else were all noted. Other rewards included having something to do, learning and access to information, and the fun of meeting new people. *'I have been through quite a bit of trauma and what have you over the last few years – them {WHGNE} offering me something to do, a lot of people think that when you are old and you can't do things. It's important for people to learn and let them do what they can do'.*

When the volunteers were asked what their barriers to participation may be, they cited lack of free parking, getting paid work, life issues and dealing with their own circumstances, e.g. depression. *'...how I am feeling within myself, although I know I'm better off going when I feel like that, most women truly believed they were doing something for their community, really important to them, nothing too taxing, people with disabilities, we worked around that, felt a part of it – everybody was included'.*

Benefits to women

The women who participated in community events and/or received passports and HP packs cited many benefits they received as a result. The workers interviewed were quick to point out how much reward they received from benefiting their women clients, such as reinforcing health promotion messages and early detection leading to improvement in health and better survival, and *'All in one place in the passport and health promotion pack with a good range of contacts: local, regional, crisis, resource lines and 1-800 numbers'.* (Allied and Community Health Manager).

With health promotion and education comes knowledge and empowerment, and this was valued by the women themselves and by the workers for the women.

- Ⓢ *'Knowledge, power, confidence, referral point – you don't know what opens it up to them – like an oyster'.* (BCN)
- Ⓢ *'The way you made me feel that all my feelings are not "silly" – but normal – and that I'm not on my own going through breast cancer!'*

Benefits to the women participating in community events were acknowledged as not having to travel to regional centres or Melbourne to access the expertise, networking and support, easy access to local services and workers and the motivation to see services they may not have otherwise.

- Ⓢ *'Let's people out there know there's a life after diagnosis, you can help yourself and there is support'.* BCSG coordinator
- Ⓢ *'It brought women and informed them of other services – things are quite private, don't want to share it around in a small town, so finding someone that could be a support for them, i.e. we had 3 diagnosed in a school and we were able to link them together'.*
BreastScreen Staff

Benefits to agencies

The benefits to WHGNE were more exposure and a greater understanding by others of what the agency does, increased partnerships and health promotion to a vast number of women, *'I didn't realize that there was a body in Wangaratta so proactive concerning women's health. I enjoyed reading the pamphlets on breast care and pelvic floor exercises. Information that I had not read in such detail before'.* One

example of the raised profile was the increase in the library patronage as a result of the WHGNE bookmarks in each HP pack.

Workers felt their partnering agencies benefited from involvement in the project through broadening their expertise and resources available to the whole agency, bringing events to their rural communities, networking, another connection to their community and more holistic health service to women.

- Ⓢ *'Promotes the agency, the reputation of the agency, evaluations always 'wow, tell me more', advertising for the agency. Always an opportunity to show your professionalism, integrity, more networks'. Cancer worker*
- Ⓢ *'For a rural community, the availability of the project, especially drought and petrol costs, networking. While it was a new service to {XX town}, so many services go from the country and don't return, refreshing to have a new service come to us'. (Women's and Community Health Nurse)*
- Ⓢ *'Women now don't just see BreastScreen as an isolated service, not just breast health – public's image that we are breast health specialists, but working with you at Women's Health, that we are more broadly women's health'. (BreastScreen Staff)*

One service has adopted the passport as an official consumer information resource, having passed through their rigorous process: *'part of the {XX health service} mission is to work with partner organisations, anything to help relationships. What we've done due to having our logo on the passport, is the Continuum of Care committee vet and check all consumer documents – it will become an endorsed patient item and in doing that a wider range of management has had access and input to it'. (Community and Allied Health Manager)*

What was not so good about the project?

When asked what was not so good about the project, the major themes centred around the amount of photocopying, poor photocopy quality of some passports and some materials in the HP packs, relevance of some of the materials, collation, transportation storage and distribution of the HP packs, trying to fit in the breast cancer work as well as all the other workload and lack of consultation/collaboration with some agencies.

- Ⓢ *'I would have liked the passport to be colour printed and not crooked – such a great little piece, it loses its importance in the pack, not even necessarily glossy. Maybe if bigger, easier to read and write in. On some occasions looks like it was copied from a copy – use double sided printer'. (Cancer worker)*
- Ⓢ *'One member of staff went for breast check and was recipient – photocopy of photocopy quality wasn't good'. (Allied and Community Health Manager)*

BreastScreen recognised that there would be opportunities to better educate their staff about how their role fit within the project and the benefits of collaboration.

- Ⓢ *'One radiographer was adamant it wasn't her role, we need to train them better. Our fault – we need to do better educating, she didn't like the distraction. Our participation lacked some planning – maybe we should take a few hours out, education, information of the benefits what it means to the women when they get a kit – would be happy to take them off van for ½ day or start ½ day later. We have new radiographers and there's a need to understand how it all fits in'* BreastScreen Staff
- Ⓢ *'Size of the packaging, limited space, the fact they are here with only one room to put anything in. A bit of bulk on top of the X-Ray machine, but we did get it down to a nice routine. Did work with one girl who didn't like handing them out, so that slows you down when one isn't doing it – it was a personal thing with her – I can't see anything wrong with it, she just had a bee in her bonnet. In discussions with women, often get around to pap smears, etc, great to have info in pack to give to women with details on women's health clinics, BCNs, etc, local bits, it's all there.'* BreastScreen Radiographer
- Ⓢ *'Only adverse comment – BreastScreen didn't appear to give the pack to everyone, some of my friends didn't get one.'* (Volunteer)
- Ⓢ *'Storage may be an issue at the van, the radiographers would roll their eyes and say 'where are we going to put them?'*. (CHN)

Other outcomes and pending workplan tasks

In addition to the three key strategies within the BreastScreen Van Women's Cancer's project, a number of other outcomes were achieved and work undertaken, which included presenting at national conferences; participation and inputting to a feasibility study, mapping exercise and a Hume region cancer stakeholder reference group; lobbying, advocacy and publicity. The outcomes and work tasks are listed here.

- Ⓢ Contributed to directories of psychosocial cancer services
- Ⓢ Lobbied HRICS to re-establish BCN and Oncology Nurses networking days and professional development forums
- Ⓢ Accredited BCN professional development hours received for all project events
- Ⓢ Input to HRICS Strengthening Support for Rural Women with Breast Cancer (SSWBC) mapping exercise into psychosocial services
- Ⓢ Attended National Breast Cancer Centre (NBCC) workshop 'Breast Cancer in Indigenous women' in Albury March 2007
- Ⓢ Input to BreastScreen Maroondah feasibility study of a fixed screening and assessment service in Wangaratta
- Ⓢ Contributed to the foundations of the Wangaratta multidisciplinary cancer team monthly meetings established by HRICS

- Ⓢ Secured a full-time BCN position in Albury-Wodonga through the McGrath Foundation with Border Cancer Care Collaboration and Upper Hume Community Health Service
- Ⓢ Accepted an invitation by Hume RICS to become a member of their Stakeholders Reference Group
- Ⓢ Generated publicity and presented at national and regional conferences (refer Appendix # 2)
- Ⓢ Advocated to BreastScreen following the policy decision not to recall women over 70
- Ⓢ Participated in 'The Challenge of Research and Supportive Care in Cancer', Ministerial Taskforce for Cancer, DHS, Melbourne Nov 05. The objectives of the seminar were to identify current and emerging research in supportive care, facilitate the translation of supportive care research into policy and practice, and inform strategic directions for future research in supportive care.
- Ⓢ BCN funding application written and submitted to McGrath Foundation for the Alpine Shire in partnership with Alpine Health and Alpine Healthy Communities Group
- Ⓢ Partnering with NE Victorian Division of GPs to explore funding options for BCNs in the Alpine and Hume regions e.g. a Bendigo Bank Foundation

Funding the project

The Project Manager is contracted to WHGNE one day per week, her wages budgeted within core funding.

The Health Promotion packs cost about \$2.00 each to produce. This cost includes WHGNE staff time, the bag, paper and photocopying, purchase of some brochures and electricity. As volunteers collate the packs, the production cost is significantly reduced.

The project was successful in receiving funding grants and donations to stage the events. Brave Hearts on the Murray Inc donated \$1500.00, BreaCan \$600.00, Curves Fitness Centre and other donations through the Northeast Health Wangaratta BCN \$1300.00 and Albury-Wodonga Cancer Foundation \$500.00 towards conducting the series of cancer forums and information dissemination for women and health care professionals in the region. These generous donations enabled 234 people and HCPs to benefit from attending five forums in four communities.

The National Breast Cancer Centre (NBCC) and Cancer Council Victoria partnered with WHGNE, HRICS and NHW to deliver one NBCC/CCV funded HCP workshop in Wangaratta, entitled '*How to deliver bad news to cancer patients and their families*'. There were some issues with miscommunication and changes to funding arrangements which posed some challenges for the local organisers. The workshop itself was deemed successful, although some respondents would have preferred

more constructive feedback on their communication exercises¹⁵. This partnership worked through the issues and as a result three more workshops were conducted with 30 participants.

Events were either free to attend or a nominal entry fee was charged to help cover costs. Additional sponsorship was obtained in-kind and in cash from a range of businesses and agencies. These are listed in Appendix # 2.

Partnerships

Many partnerships were fostered throughout the region during the planning and implementation of this project. These varied from working closely with women who had experienced breast cancer (one of the major philosophies of the project – consumer involvement), through to national (such as National Breast Cancer Centre) and state-wide agencies (i.e. BreaCan and Cancer Council Victoria), major regional health services, rural community health centres, breast and cancer support groups and isolated sole workers.

While many of the outcomes from working in partnership can be quite intangible, there is much evidence to suggest that our partners have valued the opportunities to work together towards improved women's and breast health in the region, and in doing so raised their profile or enhanced their service.

- Ⓢ *'It helped us rethink from a community sector what we offer women – sparked off, trigger for this group to develop services and partnerships'. (Community and Allied Health Manager)*
- Ⓢ *'It's a good thing to tell people you are working in partnership with other groups who have the same goal'. (BreastScreen Staff)*

The state-wide breast cancer service BreaCan viewed our partnership as a way to transfer our project and successful events model to other parts of the state. *'It worked really well as a model for how we can work in with other rural regions and we used same process in Gippsland. The way you took the lead coordination at a regional level and utilised the networks/coordination at that level and we brought our knowledge from a state-wide perspective. What was interesting and positive was the very proactive way you coordinated and got local support, very professional, numbers really good, feedback very positive, Health Care Professionals had access to a really high skilled professional they wouldn't have access to on their own turf. Collaborative effort between Women's Health, BreaCan and local, nice combo, very beneficial.'* BreaCan Staff

¹⁵ Finlayson J, Kerr R, and Cuss K. June 2007, Final evaluation report National Breast Cancer Centre (NBCC) Communication Skills Grant, Northeast Health Wangaratta, Hume Regional Integrated Cancer Services and WHGNE, Wangaratta.

BreastScreen Victoria really valued the partnership and the opportunities to broaden their image from a breast cancer screening program to one of women's wellness.

- Ⓢ *'We are a conduit to share info, people come on the van for reason of a mammogram and we have a responsibility to other health service's promotion. Our radiology screening doesn't have to have a lot of knowledge about anything else, wellness. We need to look at a broader role for them if we are going to continue to partner. I think it's important we are seen as a wholeness approach to wellness, preventative stuff together with you. To raise awareness, not necessarily just breast screening, other services and support groups in their area'. (BreastScreen Staff)*
- Ⓢ *'BreastScreen Victoria has always welcomed working with community groups to promote women's health. Our partnership with Women's Health Goulburn North East has given us an opportunity raise awareness to women in the target age group (50 - 69). This partnership has created a sense of 'belonging' and 'caring' within the women's community and we have heard anecdotally that women requiring follow-up treatment 'found each other' through their connection with Women's Health have by default developed a support group. Overall, we saw this exercise as an excellent opportunity to work with another organisation concerned about well women'. (BreastScreen Staff)*

Breast Cancer Support Groups have benefited and valued the involvement of this project in their groups. One young women's breast cancer support group coordinator commented after a community event, *'People who would not have approached me before now speak to me about breast cancer support, etc. Increase community awareness, helping women with other cancers, who are in a minority and don't have anyone/group to fall back on, dealing with grief, etc so many of same issues'. Women who are members of these groups who attended for their needs are now also able to take their learnings and insights back to the other members: 'A survivor of seven years and I will now spread a lot of thoughts with other survivors in my support group – our future is right now so get on with life'.*

One partnership that hasn't been as collaborative as it could be was with Hume Regional Integrated Cancer Services (HRICS), despite repeatedly WHGNE fostering an alliance and agreements in principle to partner. One area in particular has been the lack of support for Breast Care Nurses, despite rigorous evidence of the need and desire in the region. An invitation was extended to the WHGNE BreastVan Project Manager to have a seat at the table on the HRICS Stakeholder's Reference Group, but meetings were cancelled, agendas not delivered and this has generally not been a positive partnership.

Partnerships rely heavily on a collegiate mentality to work together and share, and this can be difficult when one partner does not see the value added to their organisation or feels threatened by the partnership. Working together with another agency towards one community event and trying to develop an evaluation form

which would suit both services, the Project Manager was told *'this is OUR event and we will not use your logo or evaluation'*. This attitude resulted in no evaluation being done, which is a great disservice to quality improvement processes.

Sustainability

The flawed nature of non-recurrent project funding means sustainability is always an issue. Respondents to the qualitative survey were asked for their suggestions on how these initiatives could be made sustainable if WHGNE were not to take the lead on the project. Finding alternative funding sources; utilising more free brochures in the HP packs and agencies copying their own passports; putting the passports on regional websites; getting other groups involved i.e. Primary Care Partnerships (PCPs) and HRICS were all suggestions for funding sources and cost reduction.

Workers in rural and regional areas know that the outcomes of their work often rely on networking, knowing people in their rural communities and the good will of community members, evidenced by the unique modes of transporting the HP packs, for example. There is also a need to embed more processes and find more local champions so systems are in place and the outcomes are not so reliant on individuals or personalities, *'I don't really see too many barriers, perhaps change of staff, need to ensure a system is in place and good linkages so it doesn't get left'*. (Allied and Community Health Manager)

Two workers felt that there was a possibility that they could do some of this work in a limited capacity within their existing role.

- Ⓢ *'Now that there's a template for us to keep as an ongoing document the passport is certainly sustainable, taking it onboard as part of our HP so funding could come from within'*. (Community Health Nurse)
- Ⓢ *'My women's health program could pick it up in our region but wouldn't be on the grand scale, I'm limited in my time'*. (Women's Health Nurse)

Overall the feeling was that WHGNE should continue to take the lead on this project.

- Ⓢ *'If not for Women's Health, a lot of things for women wouldn't happen. You'd have to hire someone, couldn't rely solely on volunteers'*. (Volunteer)
- Ⓢ *'Always needs to be a lead agency, would Women's Health fund another one to do it? Things just disappear if there isn't the passionate person – Women's Health has proved themselves to be such a great organisation in this project'*. (Breast Care Nurse)
- Ⓢ *'Groups could volunteer to put packs together, you still need someone at the top of the tree to coordinate it all, keep it up to date'*. (Breast Cancer Support Group Coordinator)

- Ⓢ *'Don't know how you can without a control body like Women's Health, who would be passionate, disciplined and interested enough to do it?'* (Volunteer)

Reflection on progress towards the objectives

What was clear from the evaluation data was how many women and health care professionals benefited from the passports, health promotion packs and events. This evaluation reports on the triangulated evidence which demonstrates the project has achieved its objectives of:

- Ⓢ Improved health literacy: *'I enjoyed reading the pamphlets on breast care and pelvic floor exercises. Information that I had not read in such detail before.'* (Woman respondent)
- Ⓢ Improvement in knowledge of where to and what to do to obtain health services:
 - *'I didn't realize that there was a body in Wangaratta so proactive concerning Women's health.'* (Woman respondent)
 - *'I thought all the information was valuable. I enjoyed reading the different information and getting an overview of what is available.'* (Woman respondent)
- Ⓢ Improved capacity within organisations:
 - *'Gave me a bit more info and education for these women, that's what our group is all about, a bit more info I could pass on to them.'* (Breast Cancer Support Group Coordinator)
 - *'Work with local service providers together to enhance what they do as well to enhance women's health. Linking other local workers together.'* (BreastScreen staff)

Conclusion and Recommendations

The BreastScreen mobile screening is about to re-commence its two year service to the Hume region in 2008. At time of printing, the schedule is Yarrawonga late Aug-early Oct, Corryong early Oct - mid Oct, Tallangatta mid Oct – late Oct, Myrtleford is late Oct – mid Dec, Wangaratta Jan - April 2009, (at this stage Wangaratta will continue to be a mobile site for the next visit).

The evidence presented points toward a recommendation to continue the BreastScreen Van Women's Cancer's project for the next two year screening cycle within Hume region. The following recommendations, broadly grouped into three categories, give further direction to progress this project.

Sustainability

WHGNE remain as the lead agency for the BreastScreen Van Women's Cancer's Project

The workers and volunteers involved in the project felt that these initiatives would best progress with WHGNE as the lead agency. Overall responsibility for the project needs to be held with one worker. Administration time needs to be allocated into a staff member's workplan to oversee HP pack collation and distribution, assist the overall Project Manager and oversee volunteers.

Utilise and foster volunteers within the project

The volunteers felt engaged and knew they were contributing to holistic women's health in the region. This utilisation of volunteers can be expanded by another recruitment campaign and fostering their roles with training, increased responsibility and recognition of their efforts at key points throughout the year. If a volunteer is going to be utilised to oversee the volunteers, as was previously done, they need to be provided with the resources to do so, i.e. policy documents and authority to conduct their role.

Develop an evaluation framework that can be used at all events

To assess the effectiveness of the next phase of the project, an evaluation framework should be developed at the beginning of the phase, to be collecting data on every initiative. Having a well developed evaluation methodology allows for easier collation and analysis of the data with more comprehensive meta-analysis if similar evaluation surveys are used at each event, for example.

Events

Work more closely with state-wide providers to bring more speakers to Hume region

Attendees at the events valued that speakers with expertise were brought to their community, rather than having to travel to regional or metropolitan centres to access the learning and support. It was agreed that by bringing these speakers to a rural area, they better understood more rural issues and could then advocate more effectively for, or better provide, services to the country.

Invite BreastScreen van staff to attend events

Often the community events are held while the BreastScreen mobile screening service is in town. BreastScreen Radiographers should be invited to participate in these functions, possibly as guest speakers, or at an information table. This may assist the Radiographers to feel more rewards for their job and understand how pivotal their role in the project is.

Broaden the appeal of the events

While breast cancer is the leading cause of cancer death in Australian women and should remain the focus of these interventions, the project could be further broadened to include other women's cancers such as gynaecological. And while this is a Women's Health service, the males who did attend the various events, either as partners of women with breast cancer, or as men who are experiencing cancer, valued the opportunity to learn from the expert speakers and avail themselves of local HCPs, and this should be encouraged.

Development and distribution of resources

Conduct education sessions with BreastScreen staff and management

BreastScreen Radiographers need more opportunity to understand their role in this overall project, and have more opportunity to input to how we can make the distribution of the HP packs from the van more streamlined. Conducting education sessions with the BreastScreen Radiographers and management on how pivotal their role is to the entire project should be done when the van recommences its Hume schedule. This gives BreastScreen managers the opportunity to champion their involvement, WHGNE to explain the project philosophy and operation, and the Radiographers to assist us to streamline the delivery, storage and distribution of the HP packs.

Maximise access to passports while maintaining quality and reducing costs

To maximise access to passports, they can be put on websites, such as WHGNE, HRICS and Border Cancer Collaboration, for example. This provides easy access for a large volume of people to obtain their local community information, without any cost to WHGNE, and they can be updated as new information is edited into the passport. Funding could be sought to either colour photocopy or print quantities of the passports, bearing in mind that they are an evolving document and regularly need to be updated. As much as practicable, agencies are to be encouraged to photocopy their own passports for their agency use, with an understanding that the quality of the reproduction be maintained at an acceptable standard.

Passports need to be updated to ensure consistency of information in each community version, and amended to reflect the clear language guidelines from Ovens and King Community Health Service Specialist Communication Service and BreastScreen logo and wording requirements.

More lead time needs to be given to each community worker when requesting them to complete or update their passport information, so that the workers can fit it into their workload and take it to team meetings for further input.

If not already identified, relationships with local champions within each community need to be developed, so that we have assistance with compiling the local contact details so each community does have their own tailored version of the passport.

Passports should have a section which invites feedback from the women and workers on how to improve the document, or if there are other services which could be included. Including a separate survey in each HP pack did not elicit enough responses to warrant the photocopying or paper consumed.

Producing other versions of the passport could be considered, such as having them translated into emerging languages within the communities, such as Arabic, Chinese, Turkish, Sudanese, and consideration of an Indigenous version. A younger women's version could be investigated, for distribution at ante-natal classes, for example.

In conclusion, this report has described the evaluation process and findings of the Women's Health Goulburn North East BreastScreen Van Women's Cancer's initiatives.

Appendices

Appendix # 1 Sample of Passport

Cardiovascular

Heart and blood vessel disease is the number one killer of Australian men and women. Women are particularly vulnerable post menopause. Risk factors include smoking, diet, lack of exercise.

Please contact:

Your local GP

Ovens & King Community Health Service – 0357 23 2 000-
(Blood Sugars/Blood Pressure checks)

Heart Foundation Information Line – 1300 362 588

<http://www.heartfoundation.org.au>

- Cholesterol Check
- Blood Pressure
- Other

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Appointment Date

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Diabetes

Diabetes is caused by either the decreased production of insulin, or ability of the body to use insulin. If you are feeling tired, sleepy because you lack energy, have increased thirst, blurry vision, weight loss or gain, skin infections, itching in the genital area or tingling/numbness in your feet, get it checked. If you are overweight, over 40 and/or have a family history of diabetes, a screening is important.

Please contact:

Your local GP

Diabetes Educator (Helen O'Donohue or Josie Hill) –
Northeast Health Wangaratta – 0357 220 129

Diabetes Australia- 1300 136 588

<http://www.dav.org.au/content.asp?rid=495>

Better Health Channel

<http://www.betterhealth.vic.gov.au/>

- Fasting Blood Sugar check
- Health Service Provider Review

Appointment Date

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Feet

Your feet are an essential transport item and need to be looked after. Bunions, corns and calluses need to be checked by a Health Professional. If you have Diabetes, get to know your feet and check for change. Shoes should be deep, wide and long. Nails should be level with the end of your toes.

Please contact:

Ovens & King Community Health Service 0357 232 000
(Limited to frail elderly & people with a disability)

Northeast Podiatry – 0357 212 533

Wangaratta Podiatry – 0357 229 500

The Foot Centre – 0357 215 100

Footworks – 0357 222 678

Australian Podiatry Association (Vic) – 0398 665 906

www.podiatryvic.com.au

- Foot check with Health Service
- Personal Foot check

Appointment Date

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Background and Context to this Health Passport

Women's Health Goulburn North East has been actively implementing the recommendations from their "Woman to Woman"¹ Rural Breast Cancer Research. Strategies have included health promotion, consumer forums and health care professional education in the 5 towns in Hume region where the BreastScreen mobile service has been operating in 2006. This health passport, one of the health promotion strategies, is for all women who want to strive for optimal wellness. We trust you find it a useful tool for prompting you to contact some local health services and recording your appointments and results.

A Bit About Our "Woman to Woman" Research:

A partnership was established between Women's Health Goulburn North East, Hume Breast Services Enhancement Program and Department of Human Services Hume Region, to undertake research into the experiences of rural women with a breast cancer diagnosis.

The diagnosis of breast cancer is usually a traumatic event in a woman's life, and the impact of breast cancer and its demands, can be significant. Up to 30% of Australian women diagnosed with breast cancer live in rural or remote areas where there is often limited access to specialists and diagnostic, supportive and therapeutic services².

This research was designed to qualitatively explore the effects of breast cancer and breast cancer treatment on rural women. The research documented the experiences of women in the Hume Region of Victoria who had been diagnosed and treated for breast cancer within the previous three years. Focused, in-depth interviews were undertaken with 20 women. The women were asked to reflect on the effect of breast cancer on their lives generally and on the nature and quality of the services they received. They were also asked about what was helpful to them and about their views regarding how services may be further enhanced. The study was unique, in that the researcher herself shared the experience of having breast cancer.

Results were presented¹ around the themes of medical interventions (diagnosis & treatment), health system and financial issues, women's perceptions of their experience of health services, effects and issues of breast cancer, the impact of rurality, and strategies that were useful.

This research report has a companion volume of excerpts from the 20 interviews, entitled, "Woman to Woman: Insights from Rural Women with Breast Cancer"¹.

The data obtained serves to provide a richness of information to assist health practitioners, managers, planners and funders of breast cancer services in terms of future decision-making and practice.

¹ Verde, Cuss K & Parkinson D. 2004 "Woman to Woman – A Research Report on the Experience of Rural Women with Breast Cancer and Implications for the Provision of Health Services", and "Woman to Woman: Insights from Rural Women with Breast Cancer" Women's Health Goulburn North East, Wangaratta, Victoria.

² Zorbas H, Barraclough B, Rainbird K, Luxford K & Redman S. 17 November 2003, MJA, "Multidisciplinary Care for Women with Early Breast Cancer in the Australian Context: What Does it Mean?", Vol 179, pp528-531.

Stress and Mental Well Being Someone to Talk to

For all of us at different times in our lives, things can seem overwhelming. Sometimes the reasons are not clear. If you are feeling overwhelmingly tired, flat, sad, sleepless and/or irritable, there are things you can do.

Talking to someone is a good start. If you have a trusted friend, this could be a help. There are people trained to provide support – they are free and confidential.

Please contact:

Ovens & King Community Health Service – 0357 23 2 000

Integrated Primary Mental Health Service – 0357 222 677

Community Psychiatry – 0357 220 347

GROW Mental Health Support – 1800 558 268

Crisis Line-Life Line 131 114 www.lifeline.org.au

Beyond Blue Depression Information Line 1300 224 636

<http://www.beyondblue.org.au/>

Family Violence

Everyone has arguments or disagreements. In a respectful and equal relationship, both partners feel free to state their opinions, to make their own decisions, to be themselves and to say no to unwanted sex. But this is not the case when someone is abusive. In an abusive relationship, one partner tries to dominate the other through physical harm, criticisms, demands, threats or sexual pressure. For the victim, this behaviour can be dangerous, frightening, confusing and damaging.

You can get some help –

Please contact:

Domestic Violence National Helpline – 1800 200 526

Upper Murray Centre Against Sexual Assault – 1800 806 292

Cooroonya Domestic Violence Service – 1800 721 100

Women's Domestic Violence Crisis Service – 1800 015 188

Rural Women Domestic Violence Service – 1800 755 988

Rape Crisis Centre – 1800 424 017

Domestic Violence & Incest Resource Centre

<http://www.dvirc.org.au/>

Teenagers & Domestic Violence-Bursting the bubble

www.burstingthebubble.com

Victims of Crime Helpline- 1800 819 817

Lab Tests Online

Designed to help you to better understand any lab tests that are part of routine care as well as diagnosis and treatment of a broad range of conditions and diseases.

<http://www.labtestsonline.org.au>

Nurse On Call

24 Hour Health Advice- 7 days a week- 1300 60 60 24

Grief and Loss

Ovens & King Community Health Service- (Home visits avail.) 0357 232 000

National Association for Grief & Loss (Vic) 1800100 023

Griefline (Vic)– 9596 7799

Osteoporosis

Osteoporosis occurs when bones lose density and strength because of calcium loss. Particularly affects women in middle and later years. Risk factors include lack of exercise, diet and some medications.

Please contact: Your local GP

Osteoporosis Victoria- 0385 318 000

<http://www.arthritisvic.gov.au/>

Dementia

National Dementia Help Line- 1800 100 500

Dementia Telephone Outreach Program- 0398 15 7 800

- Discuss with Service Provider
- Bone density scan if indicated

Appointment Date

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Skin

Skin cancer is most often found in fair skinned people who are exposed to too much sun. These are three main types of skin cancer: **Basal** – most common and the least dangerous, usually on the face or neck; **Squamous Cell** – which is quite dangerous, usually appears on face, forearms, hands, neck; **Melanoma** – the rarest and most dangerous, usually starts as a mole – it can be found ANYWHERE on the body.

Signs

Crusty non-healing sores or “sunspots”. Persistent small lump that is red, pale or pearl in colour. A new freckle or mole that has changed colour, thickness or shape over months. **Dark spots need special care.**

Please contact: Your local GP.

Cancer Info and Support Line – 13 11 20

Sunsmart <http://www.sunsmart.com.au/>

- Self check
- Health Service Provider check

Appointment Date

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Vision

The major causes of vision loss are ageing, diabetes, glaucoma and cataracts. About 80,000 Victorians are vision impaired. Please contact:

Wangaratta Eye Care – 0357 219 733

Holloway Vision Centre – 0357 221 322

OPSM – 35 7213 119

Vision Australia – 1300 847 466

<http://www.visionaustralia.org.au>

- Optometrist
- General Practitioner

Appointment Date

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Dental

Good oral health is essential to general health. Decayed teeth and poor gums can cause general health to deteriorate and also have the potential to be a risk factor in heart disease and diabetes. Regular check ups can assist in maintaining oral health. Please contact:

Your local dentist.

Community Dentist at North East Health Wangaratta-

0357 220 325 (Health Care Card Holders Only)

Breasts

The vast majority of breast changes are not breast cancer. Women with a strong family history of breast cancer may have an increased chance of breast cancer. 75% of breast cancers occur in women over 50.

Please contact: Your local GP. Breast Screen – 13 20 50
Ovens & King Women's Health Nurse – 0357 232 000
Breast Care Nurse Wangaratta Jodie Finlayson- 0357 220 473

Cancer Info and Support Service Line – 13 11 20

Cancer Council Aust- www.cancer.org.au

National Breast Cancer Centre-

<http://nbcc.org.au>- Calculate your risk of breast cancer with the new tool on this website.

<http://www.breasthealth.com.au>

Breacon Support- Queen Vic Women's Centre-1300 781 500

- Self check
- Health Service Provider check
- Mammogram – if indicated ie – age or history or concern

Appointment Date

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Cervical Health

About 250 Victorian women are diagnosed with cancer of the cervix each year. About 70% are women over 40. Sometimes changes occur and abnormal cells develop, known as Dysplasia. This is not cancer, however, if left it could develop into cancer. Regular pap tests can detect these cells and they can be treated before cancer has a chance to develop. Please contact:

Ovens & King Community Health Service – Bulk Billing. (Female GP and Nurse Pap Test Provider) – 0357 23 2 000

Women's Health Info Line at the Royal Women's Hospital- 0393442007

Cancer Info & Support Line – 13 11 20

Cancer Council Aust- www.cancer.org.au

Cervical Cancer Vaccine (Aboriginal)-1300 882 008

Papscreen Victoria <http://www.papscreen.org.au>

National Ovarian Cancer Network- 1300 660 334

www.ovca.org

- Pap test
- Check of ovaries and uterus

Appointment Date

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Disability

Ovens & King Health Service- 0357 232 000, Central Access Wangaratta- 0357 214 840

CRS Australia- 0357 234 700. Comm Support North East- 0357 220 888

Disability Advocacy and Information Service- 1300 886 388 or 0260 562 420

Noah's Ark Family Resource & Toy Library- 0357 216 201

Scope – 0357 218 467

Wang disAbility Action Group- 1300 886 388 or 0260 246 809

Wang Community Mental Health – 1300 783 347 (Emer) or 0357 220 347

Disability Services – DHS- www.dhs.vic.gov.au/disability/

Aust Disability Abuse and Neglect Hotline- 1800 880 052

www.disabilityhotline.org

Other Issues

Smoking

For advice on how to stop smoking –

Please contact:

Ovens & King Community Health Service –0357 232 000

QUIT – 13 18 48 <http://www.quit.org.au>

Legal Issues

Women's Legal Services Victoria – 1800 133 302

Victoria Legal Aid Helpline – 1800 677 402

WIRE 1300 134 130 <http://www.wire.org.au/>

Victorian Legal Aid – 1800 677 402

Refugee & Immigration Legal Centre-9483 1140, 9483 1144

Consumer Affairs Vic- 1300 558 181 www.consumer.vic.gov

Drug and Alcohol

If you are concerned about your alcohol or drug use, help is available through local and national services.

Please contact:

Ovens & King Comm Service – Counsellors & Nurses available-0357 232 000

Alcoholics Anonymous Wangaratta- 0357 221 430 (meet Thurs 8pm Ovens & King Comm Service)

Drug and Alcohol Line – 1800 888 236.

<http://www.health.vic.gov.au/drugs/directline.htm>

Gambling

Gambling Help Hot Line- 1800 156 789

Ovens & King Community Health Service – 0357 232 000

Ethnic Issues

North East Multicultural Association- (03) 5722 0726

Ethnic Communities Council of Vic. – (03) 9349 4122

Refugee & Immigration Legal Centre-9483 1140, 9483 1144

Translating & Interpreting Service- 13 14 50

Multicultural Cancer Information Service- 02 9334 1758

Stretched to the Limit – Need a Break?

Carers often experience poor health, in fact, carers can die before the person they are caring for. It is important not to reach a crisis point. There are services that can help. Talk to them about your needs – they can point you in the right direction or help you.

Please contact:: Commonwealth Carelink Centre – 1800 052 222

Community Support North East/Homecare – 0357 220 888

Carer Support Options Wangaratta – 03 57 234 000

Family Care 1800 663 107

Home & Comm Care Services- Assessment Team- 0357 220 875

Case Management Services – 0357 220 888

Carer's Victoria Helpline 1800 242 636 <http://www.carersvic.org.au/index.htm>

SANE Helpline – 1800 187 263 – www.sane.org

Relationships

Having difficulties and challenges is a normal part of sharing your life with others. The way we deal with these challenges will affect our relationships. Sometimes it is difficult to talk to your partner about some issues. You may need outside help to resolve problems and ensure your relationship stays healthy and strong.

Relationships Australia – 1300 364 277

Relationships Aust Telephone Counselling- 1800 817 569

Gay & Lesbian Counselling Service – 1800 631 493

Same Sex Attracted Support Line – 03 95105488

Rape Crisis Centre – 1800 424 017

Lesbians in the North East- 0408 466 770

Family Relationships Advice Hot Line- 1800 050 321

www.familyrelationships.gov.au

Midwifery Care

Pregnancy and the arrival of a new baby can present a range of challenges for a woman and her family. Community based midwives in Wangaratta are available to support pregnant women and mothers by providing antenatal care, postnatal home visits, lactation or breastfeeding advice and assistance with baby settling concerns.

Please contact:

Your Local GP

Wangaratta Maternal Child Health Centre-0357 220 868

Domiciliary Nurse at NE Health- 0357 220 494

Lactation Consultant & Clinic at NE Health- 0357 220 487

Ante natal Clinic (Tues AM)- 0357 220 111

Community Midwife Program at NE Health- 0357 220 256

Continence

Over 2 million Australian's have difficulty controlling their bladder or bowel and 1 in 3 women who ever have had a baby are likely to wet themselves.

If you: Leak urine when you laugh, cough, sneeze or play sport. Leak urine during intercourse. Go to the toilet frequently during the day. Get up to pass urine more than twice overnight. Feel your bladder hasn't completely emptied. Have uncontrolled loss of wind or difficulty with bowel motions. Then you should seek help.

The NE Health Continence Service have specially trained Continence Nurse Advisors, Physiotherapist and Medical Advisors who offer comprehensive assessment, advice and management strategies to assist clients who are experiencing bladder and bowel control issues. Please contact: Your local GP

Please contact the Continence Nurse at North East Health – 0357 220 388

Continence Nurse at Ovens & King - 0357 232 000

National Continence Helpline- 1800 330 066 www.continence.org.au

Continence Foundation of Australia- 039347 2522- www.confound.org.au

Produced by:

Women's Health Goulburn North East – (03) 5722 3009;

Ovens & King Community Health Service – (03) 5723 2000;

Northeast Health Wangaratta – (03) 5722 0111

(Every effort has been made to provide accurate and current information. Please notify WHGNE with any changes or corrections, in particular organization's details.)



BreastScreen
Victoria

Caring about Women

Women's Health Goulburn North East in partnership with Northeast Health Wangaratta and Ovens & King Community Health Service



Be Breast Aware

Nine out of 10 breast changes are not breast cancer, however it is always important to have any changes checked out straight away by your doctor. Don't delay.

Our breasts change throughout our lives. Being aware of the changes and learning how your breasts feel at different times will help you understand what is normal for you. If you are familiar with your breasts you may be more likely to notice any unusual changes that could be a sign of breast cancer.

1. Get to know your breasts and what's normal for you by looking at them and feeling them
2. See a doctor if you notice any unusual changes
3. If you are aged 50 or over, have a mammogram (breast x-ray) at BreastScreen every two years.

Reference: Cancer Council Victoria, May 2007, *Breast awareness for all women: getting to know what is normal for you* brochure.

Overweight and Obesity

Australia has one of the highest rates of overweight and obesity in the developed world. Aside from genetic factors, overweight and obesity is caused by an energy imbalance, where energy intake exceeds energy expenditure over a considerable period of time. Hence good nutrition and adequate levels of physical activity play an important role in the prevention of further weight gain throughout the life cycle. Overweight and obesity have recently overtaken tobacco smoking as the leading risk factor for premature death and disease in Australia. Being overweight or obese can lead to an increased cancer risk as well as a decreased life expectancy and reduced quality of life as a result of cardiovascular disease, type 2 diabetes, sleep apnoea, osteoarthritis, psychological disorders and social problems. Many of these are often preventable through a healthy and active lifestyle. Overweight and obesity is measured at the population level for adults using the Body Mass Index (BMI), which is calculated by dividing weight in kilograms by height in metres squared. You can calculate your BMI on line at www.health.gov.au If you are concerned about your weight please contact:

Your Local GP

Women's Health Information Line at the Royal Women's Hospital-1800 442 007

<http://www.thewomens.org.au>

Jean Hailes Foundation – 0395 627 555

<http://www.jeanhailes.org.au/>

Go For Your Life Info Line- 1300 739 899

www.goforyourlife.vic.gov.au

Healthy Active Info Line- 1800 020 103

www.healthyaactive.gov.au

Obesity Prevention Program- The Cancer Council of Victoria-

www.cancervic.org.au

Cancer Council Aust- www.cancer.org.au

Better Health Channel <http://www.betterhealth.vic.gov.au/>

Ageing

While women are living longer they are not always living healthier. Ageing well is about emotional wellbeing, as well as good mental and physical function. Socialising and participating in physical activity and eating healthy foods are good for both your emotional and physical health. Chronic health conditions, common in older age, can often be related to lifestyle risk factors, such as lack of physical activity and poor nutrition. The good news is that lifestyle risk factors can be reduced: all it takes is commitment and Remember: ageing can be a positive experience.

IMPORTANT TIPS

- It is never too late to start "healthy bone habits," but the earlier in life, the better for your bones.
- It is important to see your health practitioner before starting an exercise program.
- Exercises that promote balance such as Tai Chi and exercises that strengthen muscles, such as walking, will help prevent falls.
- There are plenty of inspirational older people who remain physically active as they age.
- As you age, you need more calcium as your body becomes less efficient at absorbing calcium. If you find that you can not get 3-4 service of dairy products per day you may need to talk to a health practitioner about your individual calcium supplements.
- Vitamin D is required for healthy bones. The main source of vitamin D comes from the sun. If you find it difficult to get outdoors, vitamin D supplements may need to be discussed with your health practitioner.
- Healthy eating and an active lifestyle can help both in the prevention and management of osteoporosis.

(courtesy of Jean Hailes Fact Sheet- Information on Ageing Well)

For more information and advice please contact:

Your local GP

Aged Care Assessment Service-Ovens &King Comm Service- 0357 232 000

Jean Hailes Foundation – 0395 62 7 555

<http://www.jeanhailes.org.au/>

Women's Health Information Line at the Royal Women's Hospital-1800 442 007

<http://www.thewomens.org.au>

Aged/Community Care Info Line- 1800 500 853

www.seniors.gov.au

Hearing

Once hearing is damaged it often cannot be restored. Some of the causes of hearing loss include noise, trauma, certain drugs and diseases.

Please contact:

Your local GP

Better Hearing Victoria- 0395 101 577

Better Hearing Australia <http://www.hearing.com.au>

Parenting

Wangaratta Maternal Child Health Centre-0357 220 868

Parenting Groups at Ovens & King Comm Service- 0357 232 000

MCHN Line (0-5 Years) 13 22 29

Parentline 13 22 89 <http://www.parentline.vic.gov.au/>

Victorian Parenting Research Centre <http://www.parentingrc.org.au/vp/index.php>

Raising Children <http://www.raisingchildren.net.au>

Sexuality and Sexual Health

Sexuality contributes significantly to our quality of life, our personal fulfilment and our emotional and physical health. Libido and sexual desire change at various life stages or due to illness, and can become problematic in relationships. It is important to remember that your sexuality belongs to you and is for your pleasure. Confidential support is available for you, or you and your partner. Please contact:

Ovens & King Community Health Service (Diane Hourigan) – 0357232 067- for counselling, Morning After Pill, contraception advice and referral, STI checks, Pap smears and breast health.

Upper Murray Centre Against Sexual Assault- 1800 806 292

Gay & Lesbian Counselling Service 1800 631 493

Same Sex Attracted Support Line 03 95105488

Rape Crisis Centre 1800 424 017

Lesbians in the North East 0408 466 770

Services for lesbian women- Peer based counselling (NSW, Vic, WA, Qld)- 1800 184 527

Family Planning Victoria – 1800 013 952

<http://www.sexlife.net.au/>

Melbourne Sexual Health Centre- 1800 032 017

<http://www.mshc.org.au>

Communicable Diseases Service-Royal Women's Hospital- 93427000

HIV/Sexual Health Connect- 1800 038 125

HepC infoline- 1800 703 003

STD Clinic- Vermont St Health Clinic-Wodonga- 0260 561 589

Road Trauma Support

Counselling and support services provided free of charge for people who have been affected by road trauma- 1300 367 797

LOOK GOOD.... FEEL BETTER

National helpline 1800 650 960

A Community service sponsored by the Cosmetic, Toiletry and Fragrance Association of Aust Inc. to help women undergoing cancer treatment restore their appearance and self-image during chemotherapy and radiotherapy.

CANTEEN

Australia wide 1800 639 614

A national organisation that supports people aged 12-24 with cancer, or who have relatives or friends with cancer.

Women's Health Information

Please contact:

Women's Health Nurse at Ovens & King Community Health Service-0357 232 000

Women's Health Information Line at the Royal Women's Hospital-1800 442 007

<http://www.thewomens.org.au>

Jean Hailes Foundation – 0395 627 555

<http://www.jeanhailes.org.au/>

WIRE – Women's Information – 1300134 130

www.wire.org.au

Women's Health Goulburn North East – 0357 223 Ovens & King Community Health Service 009

<http://www.whealth.com.au/>

Better Health Channel <http://www.betterhealth.vic.gov.au/>

Nurse On Call – 1300 60 60 24

Rights and Complaints

In Victoria individuals have a right of access to their health information and to make complaints about health service providers. The Health Services Commissioner (HSC) is an independent statutory authority established to receive and resolve complaints about health service providers. The HSC also handles complaints about disclosure of health information and access to health information. Whenever possible make a complaint with the health service provider. If your complaint involves a hospital, you can contact the complaint liaison officer or patient representative. If this does not work, you can make a written complaint to the HSC. If you need help to put your complaint in writing, ring the HSC telephone advice line: 9am-5pm Monday to Friday. A complaint can be made against any person or organisation that collects and/or handles health information, including doctors, pharmacists, alternative therapists, dentists, hospitals, physiotherapists, ambulance services, nurses, psychiatric services, optometrists, chiropractors and counsellors.

Health Services Commissioner Complaints and Information Telephone- 8601 5200

Or Toll Free-1800 136 066

The Health Report

Questions you should ask health professionals. During September 2006 the ABC broadcast a special report, Facing the evidence. This two-part series looked at the importance of asking health professionals for evidence based health care: Karen Carey-Hazell, consumer advocate, suggested asking your healthcare provider the following three questions:

Question 1: What are my treatment options?

Question 2: What are the possible outcomes of those options?

Question 3: How likely is each of the outcomes to occur?

Thanks to Karen Carey-Hazell.

Appendix # 2 List of events, sponsors and publicity

Appendix 2

List of events and publicity BreastScreen Van Women's Cancer's project

Partner activities where HP packs/passports were distributed Consumer WHGNE lead agency sponsored with partners

<u>Partner activities where HP packs/passports were distributed</u> <u>Consumer WHGNE lead agency sponsored with partners</u>	<u>Numbers</u>	<u>Date</u>	<u>Town</u>	<u>Partners</u>
Now What? What to do when you have completed treatment for cancer Plus EXPO stalls	44 9	Oct-06	Wangaratta	BreaCan, NHW, HRICS, Curves, St Vincent's, Brave Hearts, A/W Cancer Foundation and Reality Clothing
Women's Health Forum	40	Jul-06	Yarrowonga	Yarrowonga Community Health Service Spirited Sisters & Ovens & King Breast Cancer Support Groups, NHW, HRICS, Brave Hearts, A/W Cancer Foundation
Breast Health Boats & Beautiful Women	90	Jun-06	Myrtleford	Yarrowonga Community Health Service
Year 7-10 girls @ High School Young Women's Health & Healthy Relationships	125	Jul-06	Yarrowonga	Tallangatta Health Service
TOWN Health Trivia Night	<u>18</u>	Sep-06	Tallangatta	
	326			
<u>Consumer WHGNE and partners</u>				
Australia's Biggest Morning Tea	63	May-07	Wangaratta	Northeast Health Wangaratta (NHW) Westmead Hospital, Leukemia Foundation
Surviving cancer in rural & regional Australia Survivorship forum	17 30	Sep-06 Oct-06	Albury/Wodonga Shepparton	Cancer Council Victoria (CCV) McGrath Foundation, Brave Hearts on the Murray
McGrath Foundation BCN launch (Nov 06) & breakfast (Feb 07)	20		Albury/Wodonga	BreastScreen
Breast health awareness	34	Feb-07	Seymour	Delatite Community Health Service (DCHS)
Breast Health		Jul-07	Woods Point	DCHS
Breast Health	35	Jul-07	Mansfield	Cobram Community Health Centre
Australian Breast Cancer Day	20	Aug-07	Cobram	A/W Breast Cancer Support Group
Australian Breast Cancer Day	150	Oct-07	Albury/Wodonga	A/W Cancer Foundation
A/W Cancer Foundation Forum	50	Nov-06	Albury/Wodonga	Breast Cancer Network Australia, AWBCSG
Breast Cancer Network Australia Wodonga Forum	130	Aug-07	Albury/Wodonga	NHW, HRICS, National Breast Cancer Centre, CCV
Cancer and Sexuality	<u>45</u>	Aug-07	Wangaratta	
	594			

Appendix 2 continued - page 2

List of events and publicity BreastScreen Van Women's Cancer's project

Women attending and HP packs distributed at other WHGNE events
other than *Woman to Woman* BreastScreen Van
Project

1700

HCP events WHGNE lead agency sponsored with partners

Now What? Working with people who have finished treatment for cancer	23	Oct-06	Wangaratta	BreaCan, NHW, HRICS, Curves, St Vincent's, Brave Hearts, Albury/Wodonga Cancer Foundation
Breast Cancer Screening & Treatment Update	27	Mar-06	Yarrowonga	BreastScreen, NEVicDivGPs, Astra Zeneca
Delivering Bad News Communication Skills module	<u>16</u>	May-07	Wangaratta	NHW, HRICS, National Breast Cancer Centre, CCV
	66			

HCP events WHGNE and partners

A Rich Tapestry of Excellence in Allied Health conference	100	May-07	Beechworth	NHW, Central Hume Primary Care Partnership, Hume DHS,
Eliciting & Responding to Emotional Cues Communication skills module	10	Oct-07	Wangaratta	HRICS, NHW, CCV
Discussing Sexuality with Cancer Patients communication skills training	20	July&Sept 07	Wangaratta	HRICS, NHW, CCV
PHCRED conference W2W poster presentation	100	Nov-07	Shepparton	Dept Rural Health University of Melbourne
Statewide Rural Health Week launch W2W poster presentation	90	May-06	Shepparton	Victorian Healthcare Association, DHS
9th National Rural Health conference W2W poster presentation	1100	Mar-07	Albury	National Rural Health Alliance
Oral and poster presentations National Breast Care Nurse Conference	<u>450</u>	Feb-07	Melbourne	CCV
	1870			

Appendix 2 continued - page 3

List of events and publicity BreastScreen Van Women's Cancer's project

Health Promotion packs/passports distributed by BreastScreen Radiographers March 2006 - November 2007

Yarrawonga	750
Tallangatta	125
Myrtleford	900
Wang	3000
Seymour	800
Mansfield	923
Alexandra	786
Shepparton Goulburn Valley Imaging	1347
	8631

Others passports distributed numbers

unknown

Goulburn Valley Health (GVH)
Goulburn Valley Community Health Service (GVCHS)
Delatite Community Health Service (DCHS)
Upper Hume Community Health Service (UHCHS)

List of publicity for BreastScreen Van Women's Cancer's project

Radio

Live radio interviews ABC Riverina and ABC state-wide rural report
News reports on regional radio ie 3NE & ABC promoting events

Newspapers

Contributed to Wangaratta Chronicle article on 'What Next' seminars
& Myrtleford consumer event

Newsletters

NEVicDivGPs Issue 75 pg 8 1 page breast cancer-breast health article
GVGPs News 1/2 page article BCN service & BreastScreen
WHGNE members and NHW staff newsletter articles on 'What Next' seminars & Myrtleford consumer event
Info Tree electronic newsletters - various articles on events
NEVicDivGPs Friday Faxes promoting various events for HCPs