

August 28, 2012

Mr Gary Morgan
Roy Morgan Research
401 Collins Street
Melbourne Vic 3001

Dear Gary,

Re: Bupa Health Foundation Health & Wellbeing after Breast Cancer Study


I am pleased to enclose a progress report on the Bupa Health Foundation Health & Wellbeing after Breast Cancer Study.

We have 14 manuscripts either published or accepted for publication to-date and analysis and translation of the data collected continues. If you are interested in receiving full copies of any published papers please do not hesitate to contact me or Maria La China of the Women's Health Research Program on 99030832.

We thank you kindly for your continued support of this research project.

With kind regards,

Yours sincerely,



Professor Robin Bell
Deputy Director
Women's Health Research Program

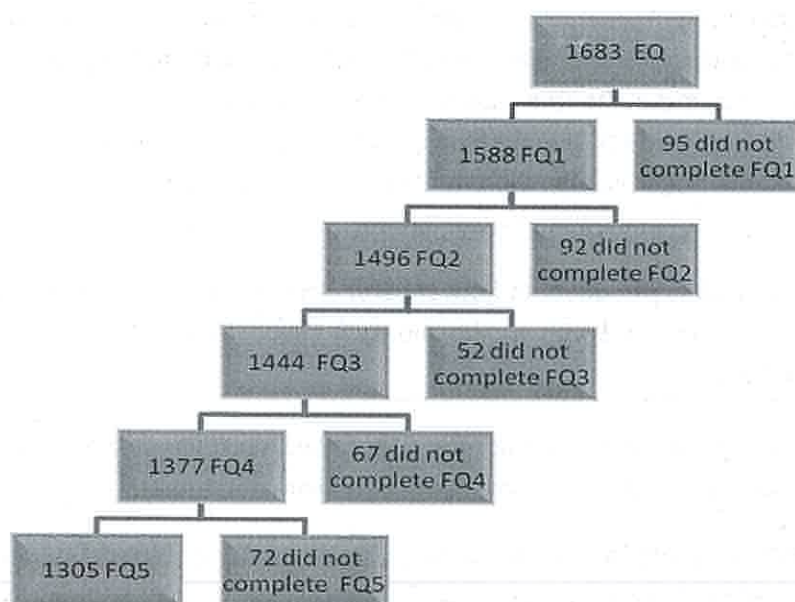
Progress report on the BUPA Health Foundation Health and Wellbeing After Breast Cancer Study

August 2012

Prepared by Robin Bell and Susan Davis on behalf of the BUPA Health Foundation Health and Wellbeing After Breast Cancer team

It is now over 7 years since we started recruiting to this study (commenced June 2004). All women remaining in the study have now completed their fifth and final follow-up questionnaire and all of the questionnaires have been scanned.

The diagram below shows the retention of women in the study:



By the time of completion of the 5th follow-up questionnaire 78% of the 1683 women originally recruited remained in the study. Of the 378 women no longer in the study at the time of the final questionnaire, 122 had died while they were still formal participants of the study but prior to completion of the final questionnaire. The remaining women withdrew from the study (and we know there have been another 34 deaths amongst these women). Of the 1305 women who remained in the study at the time of FQ5, at the time of writing this report there have been another 37 deaths. In total we only lost contact with 10 of our original recruits over the course of the study.

We now have 14 manuscripts either published or accepted for publication. The new publications since our previous report include a paper on breast reconstruction following mastectomy [1] published in 2012 in *The Breast* journal and two papers which have been accepted for publication although are not yet published including a paper on persistence with oral adjuvant endocrine therapy in women 4 years from diagnosis (*Menopause* journal) and a paper reporting on surveillance of breast cancer survivors with mammography 4 years from diagnosis (*Australian and New Zealand Journal of Surgery*). A summary of the findings of these three papers is included at the end of this report.

A further manuscript on lymphedema 4 years from diagnosis is currently under review. A draft manuscript has been written on persistence with oral adjuvant endocrine therapy after completion of the 5th follow-up questionnaire. There are two other draft manuscripts covering women with gestational breast cancer (diagnosed during or in the 12 months following a pregnancy) and women who choose to have a pregnancy following treatment for breast cancer. The analysis of the use of imaging surveillance reported in the 5th follow-up questionnaire is under way as is an analysis of the doctors women continue to consult 5 years from diagnosis. Work is underway on the survival analysis in the study examining factors influencing deaths as well as the emergence of recurrent disease. We will be able to adapt our survival analysis techniques to also examine events such as fracture and venous thrombosis.

Robin Bell was invited to present work from the BUPA Health Foundation Health and Wellbeing After Breast Cancer Study at the annual meeting of the Australian Society for Psychosocial Obstetrics and Gynaecology held in Melbourne in August. The presentation included work from the publications covering women's beliefs about the cause of their breast cancer, their self-reported wellbeing and the lifestyle modifications they make after the diagnosis of breast cancer including the use of complementary and alternative medications and their smoking and alcohol consumption [2-5]. This presentation was awarded the Roger Wurm Award for the best scientific presentation at the conference.

Robin Bell has also been invited to present data from the BUPA Health Foundation study at the 15th International Congress on Hormonal Steroids and Hormones & Cancer to be held in Kanazawa, Japan on November 15th-17th, 2012.

Summaries of the three new papers published/accepted for publication (breast reconstruction, persistence with oral endocrine therapy and surveillance with mammography).

Breast reconstruction following mastectomy for invasive breast cancer is strongly influenced by demographic factors in women in Victoria, Australia[1]

- We found that 25% of women who had a unilateral mastectomy had undergone a reconstruction nearly two years after diagnosis.
- Being younger, educated beyond school, living in the metropolitan area, having private health insurance, not having dependent children and not having radiotherapy explained just over 40% of the variation in reconstruction status. This finding shows that demographic factors strongly influence the likelihood of reconstruction after mastectomy.
- There was a modest difference between women who did and did not have a reconstruction in terms of wellbeing.

Understanding discontinuation of oral adjuvant endocrine therapy by women with hormone receptor positive invasive breast cancer nearly 4 years from diagnosis (in press Menopause journal)

- Use of oral endocrine therapy peaked by 2 years post-diagnosis.
- By 4 years from diagnosis, 18% of women were not taking oral endocrine therapy.
 - Of the 18%, just over half had ceased therapy mainly due to vasomotor symptoms which shows that early discontinuation of these therapies remains an important issue

- 8% of women had never used oral endocrine therapy. although whether this is because treatment was not offered or treatment was refused is not known

Use of imaging in surveillance of women with early stage breast cancer (in press Australian and New Zealand Journal of Surgery)

- There is no evidence of benefit in terms of survival or quality of life for intensive surveillance of women with early breast cancer (BC) and current guidelines reflect this.
 - Four years from the time of diagnosis, of the women who were stage 1 at diagnosis and had not reported evidence of recurrence or a new BC, 89.5% reported having had a mammogram in the previous 12 months and 52.9% of those having a mammogram reported a breast ultrasound. 71% of women reported no other imaging investigations in the previous 12 months
 - Australian practitioners are generally adhering to guidelines about imaging surveillance of BC survivors
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The following statement is typical of the acknowledgement section we include in our publications. It may vary from one publication to another as the requirements of the journals are different.

Acknowledgements:

The authors wish to thank the study participants and the members of our Study Advisory Group: Dr Jacquie Chirgwin, A/Professor John Collins, Professor Graham Giles, Mr Peter Gregory, Mr Stewart Hart, Miss Suzanne Neil and Mrs Avis McPhee. The authors also wish to thank members of the research team of the Health and Wellbeing After Breast Cancer study, without whose hard work this large cohort study would not be possible (Maria La China and Jo Bradbury)

Finally, we thank Ms Helen Farrugia, Director of Information Systems and Professor Graham Giles, Director, of the Victorian Cancer Registry, for their ongoing support of this study.

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None of the funding agencies had any role in determining study design; in the collection, analysis, and interpretation of data; in the writing of the manuscript or in the decision to submit the manuscript for publication.

1. Bell RJ, Robinson PJ, Fradkin P, Schwarz M, Davis SR (2012) Breast reconstruction following mastectomy for invasive breast cancer is strongly influenced by demographic factors in women in Victoria, Australia. *Breast* 21:394-400.
2. Bell RJ, Lijovic M, Fradkin P, Schwarz M, Davis SR (2012) Changes in patterns of use of cigarettes and alcohol in women after a first diagnosis of invasive breast cancer: a cohort study of women from Victoria, Australia. *Support Care Cancer* 20:783-789.
3. Bell RJ, Lijovic M, La China M, Schwarz M, Fradkin P, Bradbury J, Davis SR (2010) Psychological well-being in a cohort of women with invasive breast cancer nearly 2 years after diagnosis. *Support Care Cancer* 18:921-929.
4. Davis SR, Lijovic M, Fradkin P, Bradbury J, La China M, Schwarz M, Bell RJ (2010) Use of complementary and alternative therapy by women in the first 2 years after diagnosis and treatment of invasive breast cancer. *Menopause* 17:1004-1009.
5. Panjari M, Davis SR, Fradkin P, Bell RJ (2012) Breast cancer survivors' beliefs about the causes of breast cancer. *Psychooncology* 21:724-729.