

PATIENT INFORMATION SHEET

The Waikato Breast Care Register

You are invited to join the Waikato Breast Care Register (WBCR). The WBCR is a comprehensive computerised database established to monitor breast care in the greater Waikato region with the goal of improving breast care services. This was also established to evaluate information about the treatment and survival of women and men with breast cancer and to improve future management of breast cancer. The WBCR has received ethical approval from the Northern Y Ethics Committee.

The Royal Australasian College of Surgeons - National Breast Cancer Audit

In addition to the Waikato audit of breast care services, local surgeons are participating in a New Zealand and Australian audit called the **Royal Australasian College of Surgeons National Breast Cancer Audit (RACS – NBCA)**. This audit collects data on surgery performed on breast cancer patients in New Zealand and Australia. Its purpose is to:

- Improve breast cancer treatment by providing information to surgeons and to the Breast Section of the RACS.
- Monitor surgeons practice through audit of their cases – participation in the audit is a requirement for surgeons to maintain full membership of the Breast Section of the RACS and for surgeons practicing in Breast Screen Aotearoa.
- Allow for compilation of national statistics.

Since August 2002, this audit has been managed by the Australian Safety and Efficacy Register of New Interventional Procedures - Surgical (ASERNIP - S).

More information about the audit can be obtained at: 0061 8 8363-7513 (Adelaide, Australia) or <http://www.surgeons.org/asernips>

Participation in the Waikato Register and National Breast Cancer Audit

Your participation is entirely voluntary (your choice). If you do not want to take part in either the WBCR or the RACS - NBCA, please inform your doctor or nurse. You do not have to take part in either project and if you choose not to take part this will not affect any future care or treatment.

If you do take part you are free to withdraw from either project at any time without having to give a reason and this will not affect your continuing health care.

If you agree to participate in the WBCR and the RACS – NBCA, information about you will be collected from your routine clinical and follow-up notes, and then entered into the databases.

Why is my information being recorded?

In the Waikato approximately 300 women are diagnosed with breast cancer each year and approximately 1,500 women are diagnosed with benign (non cancerous) breast conditions. The WBCR and the RACS – NBCA are tools which allow at both a local and international level evaluation of the effectiveness of local breast care services.

By monitoring the care and outcome of all women with breast problems the quality of Waikato breast care services can be properly assessed and the quality of breast care services maintained and improved.

How will information about me be kept private?

All aspects of the project, including results, will be strictly confidential and only your doctor and the staff involved in the study will have access to information on participants.

Confidentiality of your personal information is maintained at all times through the practice of using a code rather than your name for both databases.

You have the right to see and, if necessary, correct the information held about you.

How will my information be used now and in the future?

Your breast health information will be combined together with the breast health information of other women and men receiving care and treatment through Waikato breast care services. Information about diagnosis, treatment and outcome will be recorded.

At a local level, data from the WBCR will be analysed and submitted for publication and/or presented at appropriate meetings or conferences. Individual participants will not be identifiable in any reports or presentations.

Similarly, the RACS – NBCA data will help ASERNIP-S compile Australasian statistics about breast surgery and create a practice profile for surgeons practicing at Waikato hospitals.

What is involved for me?

Information about you will be collected from your routine medical records. You will not have to attend extra appointments and there will be no financial cost to you. As these are long-term projects (all of your life) the database co-ordinator may request follow-up information annually from your specialist or GP.

For further information:

If you require any further information about either the Waikato Breast Care Register or the RACS Australasian National Breast Cancer Audit please do not hesitate to ask your doctor or contact:

Mary-Ann Hamilton, Nurse Co-ordinator, WBCR Ph (07) 839 8899 Ext 7503

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Consumer Advocate on telephone 0800 423 638.

If you wish, you may also contact:

The Manager, Te Puna Oranga and Waikato District Health Board's Kaumatua Kaunihera representative group on telephone: **(07) 834 3664**

Thank you for taking the time to read this information sheet and to consider participating in these projects.