Greetings from the Queensland Thyroid Cancer Study team

We would like to provide you with an update about the progress of our study and would also like to thank you for your valuable contribution to our project.

Why are we doing this study?
Very little research has been done in Australia to try to understand the causes of thyroid cancer, even though the number of people being diagnosed has been increasing for at least 25 years. As the graph to the upper right shows, that increase has been seen in many countries across the world although the size of the increase varies from country to country and is not the result of ageing of the population. The size of the increase in Australia has been amongst the highest in the world and we would like to try and understand why that might be.

Who has taken part?
The Queensland Thyroid Cancer Study has been underway for two years now, with one year left to go. Thus far, 1300 people have taken part; 1,150 questionnaires have been completed, and a further 150 questionnaires are still out with participants. So a big THANK YOU to all of you who have contributed so far.

The graph to the lower right shows who has taken part by age group and sex. You can see that women in their middle years make up the biggest group of people affected by thyroid cancer - men are less commonly affected and tend to develop the disease at an older age.

The reasons for these differences are not clear but are areas we will explore when we have collected all the data for the study. We are inviting people from the general population without thyroid cancer (controls) to balance the numbers of cases by age and sex of people with thyroid cancer.
Working together with other researchers. Some of you completed an extra survey about your quality of life after a diagnosis of thyroid cancer. This extra part of the study is being conducted in collaboration with researchers based in Germany. The aim is to develop an effective questionnaire that addresses issues of specific concern to people with thyroid cancer. So far, apart from those of you who have participated, this research includes people from 11 European countries as well as Japan, Egypt and India. Results are expected next year.

We have also started doing some work with researchers from the University of Sydney. That group is very interested in the communication between doctors, nurses and patients around the time of diagnosis of thyroid cancer and how decisions are made about the type of treatment that is recommended. This will only be a small study and is very new, so only a few people are being asked if those researchers can make contact with them.

For any new studies such as those mentioned, we will always ask your specific permission to either provide us with extra information or to provide your contact details to other researchers. We take your confidentiality very seriously and would never pass on any of your details without your express permission.

What do we hope to learn from looking at thyroid tumour tissue samples? Those of you who have a diagnosis of thyroid cancer have been asked to consent to the release of a sample of your stored tumour tissue held by the pathologists that made the original diagnosis. The sample will be tested for certain changes in genes within the tumour. All cancers have a variety of genetic changes. We hope that we will be better able to determine factors that increase the risk of developing thyroid cancer if we can look at cancers with specific gene changes separately. We have just started this process and expect some preliminary results in the next few months.

Do we have your email address? If you have received this newsletter by post, please consider providing us with an email address, if you have one, for future newsletters. We want to keep you up-to-date with study progress and results in future newsletters. With postage possibly rising to $1 per letter soon, it would really help if we can send more of the newsletters by email. Please email your name and current postal address to QTCS@qimrberghofer.edu.au and we will update your records.

What happens to your information? Did you notice that there is no personal identifying information on the questionnaire we send you? It only has your study number. Your answers are entered into our database identified only by this code. Your personal details such as name, address and phone number are stored completely separately from the questionnaires.

Do you still have questionnaires to complete? The information you give us in your questionnaires is essential to the success of our research. We understand that the questionnaires are quite detailed and filling them out can be time-consuming, so if you need any assistance in completing them please contact either:

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If you would like us to update your contact details on our database please contact either Andrea or Emily as above or email us at:

QTCS@qimrberghofer.edu.au

Once again we wish to THANK YOU for the generous contribution of your time and information.