

## **PATIENT INFORMATION SHEET**

The Illawarra Shoalhaven Local Health District (ISLHD) is currently working on a project aimed at better understanding the outcomes of patients diagnosed with rectal cancer. The ISLHD Colorectal Cancer Multidisciplinary Team (of which your doctor is a member) supports and participates in this project. The aim of this project is to introduce outcome measurements into routine clinical care for rectal cancer patients in ISLHD. Outcome measurements allow us to measure the quality of care we provide and identify areas where we can improve. The type of questions we are seeking answers to include:

- How does rectal cancer and its treatments affect our patients' quality of life and daily functioning
- How many rectal patients experience side-effects of treatment
- How do our services and our patient outcomes compare with those around the world

Measuring the effectiveness of cancer treatment is good clinical practice, and will contribute to the improvement of care for patients in ISLHD and allows us to contribute to the international evidence on cancer care.

## **WE WOULD LIKE TO INVITE YOU TO TAKE PART IN OUR RESEARCH PROJECT**

### **What does participation in this research involve?**

Participation in this project will involve completing three (3) questionnaires at the start of your treatment and then two (2) questionnaires 6 months after treatment and then every year as part of your normal follow-up care for your cancer. The questionnaires will coincide with your follow-up appointments. Questionnaires can be completed on paper or electronically (online).

The duration of study participation is five (5) years (approx.) and it will take about 5-10 minutes to complete each questionnaire.

There are no costs associated with participating in this research project, nor will you be paid. You will not be required to travel or attend any special appointments for the research.

### **Do I have to take part in this research project?**

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your care or relationship with your doctor or the researchers at ISLHD.

### **What are the possible benefits of taking part?**

This study will investigate how the treatment and interventions for rectal cancer affect your daily functioning, what symptoms trouble you and how your symptoms affect your wellbeing. You may not derive any personal benefit from this study, but it is hoped that the study as a whole will contribute to a better understanding of the impact of rectal cancer on patients and better patient outcomes.

### **What are the possible risks and disadvantages of taking part?**

There are no anticipated risks for participating in this project. You can refuse to answer any questions that make you feel uncomfortable. If you have any questions or concerns, please discuss these with your doctor or other health care providers. You can also contact support services such as the Cancer Council's Support and Information service (13 11 20).

### **What information will be gathered and what will happen to that information?**

The study will gather information about patients' rectal cancer, the treatments they have and their follow-up care. The study will also gather information about how rectal cancer and its treatment affects patients' quality of life.

Your personal identifying information is confidential and will not be disclosed to a third parties without your consent, except as part of normal clinical care, or to meet government, legal or regulatory authority requirements. Information collected that might identify you will be stored in a password protected file at ISLHD Cancer Services.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. Reports will summarise information across large numbers of patients rather than individuals.

In accordance with relevant Australian and/or NSW privacy and other relevant laws, you have the right to request access to the information collected and stored by the research team about you. You also have the right to request that any information with which you disagree be corrected. Please contact the research team member named at the end of this document if you would like to access your information.

### **Who is organising and funding the research?**

This research is being conducted by a research group of health professionals who treat and manage rectal cancer in the Illawarra Shoalhaven Local Health District (ISLHD). This research is funded by the Cancer Institute of NSW.

## Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project has been reviewed and approved by the HREC of the UOW and ISLHD, reference 2017/557.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

## Further information and who to contact

If you have any questions about participating in the project or you would like more information, please contact the Project Officer at [ISLHD-RectalCancerOutcomes@health.nsw.gov.au](mailto:ISLHD-RectalCancerOutcomes@health.nsw.gov.au). If you have any concerns about this project, please contact the Ethics & Integrity Manager on 4421 4457 or email [rso-ethics@uow.edu.au](mailto:rso-ethics@uow.edu.au).

**If you are happy to be included in the Rectal Cancer Outcome Measurement research, you do not need to do anything.**

**If you would prefer NOT to participate, then please complete the form below and send to [ISLHD-RectalCancerOutcomes@health.nsw.gov.au](mailto:ISLHD-RectalCancerOutcomes@health.nsw.gov.au)**

I would like to be excluded from the Rectal Cancer Outcomes study

Name: \_\_\_\_\_

Date: \_\_\_\_\_

## VERSION CONTROL

Version	DATE	OFFICER	DESIGNATION
1	July 2018	Brooke Selby	Project Officer
2	Jan 2019	Kathryn Mulligan	Cancer Systems Innovation Manager



**YOUR CONTINUED SUPPORT OF THIS PROJECT IS GREATLY APPRECIATED AS THIS WILL HELP US TO MEASURE THE QUALITY OF OUR CARE AND IDENTIFY AREAS WHERE WE CAN IMPROVE**

**PLEASE INCLUDE THIS PAGE WITH YOUR RETURNED SURVEYS**

**COULD YOU PLEASE TICK YOUR FUTURE PREFERENCE FOR HOW YOU WOULD LIKE TO RECEIVE THESE SURVEYS IN THE FUTURE**

	<b>SEND TO MY HOME ADDRESS</b>
	<b>SEND VIA EMAIL</b> <b>CONFIRM EMAIL ADDRESS:</b>
	<b>SEND VIA SMS</b> <b>CONFIRM MOBILE PHONE NO:</b>

**PLEASE DO NOT HESITATE TO SEND ANY QUERIES TO THE PROJECT OFFICER**  
[ISLHD-RectalCancerOutcomes@health.nsw.gov.au](mailto:ISLHD-RectalCancerOutcomes@health.nsw.gov.au)