

CABRINI DEPARTMENT OF SURGERY AND THE ALFRED DEPARTMENT OF SURGERY

Patient-Reported Outcome Measures

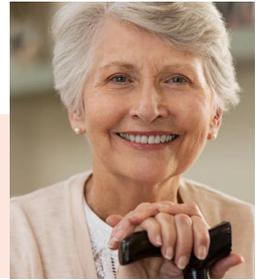
Information about monitoring your treatment outcomes



**How is your condition?
How do you feel?
How effective was your
treatment?**

YOUR VOICE MATTERS

This is YOUR opportunity to let us know how your condition and treatment has affected you, so that we can improve future treatment regimens for all patients.



During your treatment, doctors tell you the expected outcomes of your medical treatment. Traditionally, patient reported feedback has only been subjectively taken into account, without considering it as an integral part of clinical decision making and care provision.

By objectively assessing, recording and analysing this feedback, we can develop techniques and methods to improve your medical outcomes and quality of life. We would like to address 'Patient Reported Outcome Measures' as a means of not only monitoring your progress and the effectiveness of your treatment but also as a way of understanding the outcomes that matter most to you and providing better healthcare.

We are now going to ask you several questions, such as: How are your symptoms? How effective was your treatment? Has your quality of life improved? Are you still experiencing medical problems? If so, in what areas?

Both your health outcomes and the medical data collected from your visit are important. By collecting information about your quality of life, greater insight is gained on the quality of care you have received and how this can be improved.

What are Patient-Reported Outcome Measures?

Patient-Reported Outcome Measures (PROMS) are questionnaires that ask patients about their health before and after treatment. They help to measure the results or outcome of the treatment from a patient's point of view.

The questionnaire we are utilising is part of the colorectal cancer standard set from the International Consortium of Health Outcome Measures (<http://www.ichom.org>). This standard set focuses on your daily functioning, quality of life and your health in relation to your medical problem.

What about privacy?

We take your privacy and the confidentiality of the information you provide very seriously. We will not share your personal details with any third party and all questionnaire data collected will only be used for the purposes of improving clinical care and quality improvement research. Only your treating surgeon and the research team in the Department of Surgery will have access to the data for clinical and research purposes. Any identifiable information will be removed prior to access for quality improvement research purposes.

How do I participate?

Initially, you will receive an SMS and an email with a link to the questionnaire. The online questionnaire should take approximately 10 to 15 minutes to complete. You will receive emails inviting you to complete the questionnaire before treatment, 6 months after treatment and 12 months after treatment. We may also ask you to complete additional questionnaires in the future to monitor your long-term quality of life and treatment outcomes.

What will happen to the information that I give you?

Your treating surgeon may use the information you provide to discuss your concerns during your consultation. Although some of the questions may be confronting or of a highly personal nature, the information you provide will never be used in a judgmental fashion and can only positively influence your treatment and your professional relationship with your doctors. We are interested in hearing what matters to you.

In addition, non-identifiable grouped data may be used to:

- Provide valuable information about the quality of life of patients with bowel polyps and/or cancer, pre- and post-treatment. This information will allow us to improve patient outcomes.
- Allow patients and surgeons to make an informed choice on the course of treatment.
- Allow comparison of quality of life information between hospitals across the country and internationally.

- For quality improvement research purposes. For example, publishing papers in medical journals to provide information to medical staff on the best standards of care.

Am I required to fill in the questionnaire?

You are not required to complete the questionnaire, however, we encourage you to participate. Completing the questionnaire provides important information to your doctor about your condition and treatment and will allow your doctor to provide assistance in responding to your specific concerns.

I get the same questionnaire sent several times, is that correct?

Yes, to get a good overview of your health-related outcomes, you will receive the questionnaire intermittently throughout your treatment and post-treatment period. This allows us to compare how you felt and your quality of life at different points in your journey.

The questions do not apply exactly to my circumstances, what should I do?

Sometimes a question may be difficult to answer because it does not exactly match your circumstances. Try to answer the question by choosing the answer that best suits your circumstances.

I would like the 'not applicable' option in the questionnaire.

The questionnaire was developed by researchers and validated in patients with similar conditions to you, so they do not always contain the option 'not applicable'. Try to answer the question by choosing the answer that best suits your circumstances.

Why are some of the questions personal in nature?

Whilst some of the questions in this questionnaire may be confronting or even a little embarrassing or of a highly personal nature, these questions are highly relevant in ensuring recognition of the issues that matter personally to patients on a day-to-day basis. It is important to ensure that these questions are answered as fully and as honestly as possible so that we can tailor individual patient treatments to best suit the needs of each patient.

I'm not sure if my questionnaire has been sent successfully.

In case of technical problems when completing the questionnaire, please contact Dr Christine Koulis on (03) 9508 3547 or ckoulis@cabrini.com.au. For questions or comments about your own treatment please contact your doctor.

Who makes the questionnaire?

Who sends the questionnaire?

The questionnaire was developed by collaborations between scientists, clinicians, and patient representatives, worldwide, and was sent to you by your treating surgeon.

The patient reported outcome measures program is a Cabrini Health funded initiative and includes participation at both Cabrini and Alfred hospital sites.

HOW TO CONTACT US

If you have any questions or would like more information about the Patient-Reported Outcome Measures program, the questionnaire, confidentiality or how your personal details will be held and/or used, please contact Dr Christine Koulis.

Dr Christine Georges

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If you have any complaints regarding this program, please contact the Complaints Officer at either Cabrini Research Governance (T: (03) 9508 3440, E: researchgovernance@cabrini.com.au) or the Office of Ethics and Research Governance, Alfred Health (T: (03) 9076 3619, E: research@alfred.org.au).

Thank you
for your help

