

PATIENT INFORMATION SHEET

A Guide to Completing PROMs Questionnaires *Patient Reported Outcome Measures*

As part of the B-EAGER Research Capacity Building & Quality Improvement Initiative the Bowen therapy and Oncology Massage professions have introduced several questionnaires called Patient Reported Outcome Measure (PROMs) to help improve your clinical care and outcomes. The B-EAGER initiative also aims to build research capacity and to broaden the integration of these therapies in healthcare settings.

Collecting good quality information about you and how your symptoms or condition affects your health and wellbeing is important in helping your practitioner develop the right treatment approach for you.

Alongside other forms of information gathering, questionnaires are routinely used in healthcare settings to collect information. There are many different types of questionnaires that are used for different purposes.

What are these questionnaires for?

PROMs ask about how your condition and healthcare affects your wellbeing or your experience of care.

This helps your practitioner measure both how you feel and function as well as your health outcomes. It also helps them better understand your perspective about your health and care and how treatments are affecting you.

Why do my answers matter?

Your experience and answers will help your practitioner understand and support you, and other patients, better in the future. They will help guide treatment options in your care.

Your answers may also help develop a Case Report or Case Series, highlighting ways that Bowen therapy or Oncology massage is helpful for patients like you in managing their condition.

What kind of questions will I be asked?

PROMs questionnaires commonly ask about:

- **Symptoms**, like pain, tiredness

- **Physical wellbeing**, such as your ability to move around, undertake your daily tasks, engage in hobbies
- **Emotional wellbeing**, such as levels of worry, sadness, stress
- **Social wellbeing**, such as your ability to spend time with family and friends
- **Everyday activity and roles**, such as your ability to work, enjoy hobbies.

How do I answer the questions?

You may be asked to answer questions on paper, on an electronic device or in person (depending on your preference). Your practitioner will discuss these options with you.

There are no ‘right’ or ‘wrong’ answers – just answer as honestly and completely as possible. Questions may ask you to tick a box, circle a number on a scale, or mark an X on a scale.

For example:

Please circle the number that best applied to you.
During the past week, did you worry?

1	2	3	4
Not at all	a little	quite a bit	very much

Please mark an **X** on the scale to indicate how your health is **TODAY**

WORST health you can imagine **BEST health you can imagine**

0	10	20	30	40	50	60	70	80	90	100

Can I ask for help with answering?

Your answers should reflect your thoughts and feelings rather than anyone else’s. If needed, you can ask someone to read out the questions to you or record your answers.

If you aren’t sure what a question means just answer according to what the question means to you, rather than ask someone else for their opinion. These types of questionnaires are designed to accept many types of meanings.

Who will see my answers?

Usually only your practitioner will see your answers. PROMs information will be used by your practitioner to enhance their understand of how you are responding to treatment(s), what your health goals and preferences etc.

As with all other information you provide to your practitioner during your consultations, all answers you provide in PROMs must be treated privately and confidentially, according to the ethical standards practitioners are required to work within.

Occasionally information may be used in developing a Case Report or Case Series. If this were going to happen your practitioner will discuss this with you and gain your signed permission to use the information for this purpose (informed consent). If this happens

your practitioner will go through a Consent process with you and have you sign a Consent Form if you decide to participate.

Participating in a Case Report is entirely voluntary. Case Report and Series information is deidentified, meaning identifying information, such as your name, date of birth, condition etc., is de-linked from your answers. You may withdraw your consent at any time up to the completion of the Case Report without explanation. Withdrawal of consent can be written or verbal.

What if questions aren't relevant to me?

When a PROMs question asks about something this is not a problem for you, please say this rather than just leave the answer blank. For example, if you do not have pain, choose 'none' 'not at all' or '0'. If you leave the question blank your practitioner will wonder whether you missed the question by mistake, rather than learn that you didn't have pain.

Will not answering a PROMs questionnaire affect my treatment?

NO, definitely not, completing a questionnaire is completely voluntary, and at your discretion. Your treatment will not change because you declined to participate in completing a questionnaire.

Why am I being asked the same questions repeatedly?

Some questionnaires ask similar questions on multiple occasions. This can help practitioners to understand how people are affected by a treatment over time. This can seem repetitive, especially if nothing has changed for you. However, it's equally important for your practitioner to know whether your health has stayed the same as it is to understand if it has changed.

Where can I find out more information?

Your practitioner can give you more information about the PROMs you are completing and how they will use the information you give them.

For further information about the B-EAGER Initiative, and the use of PROMs, please visit <http://www.b-eager.org.au>.

If you would like to speak to someone other than your practitioner about the Initiative or questionnaire you can email the B-EAGER initiative at info@b-eager.org.au.