‘How do you feel?’

Patient Reported Outcomes Survey – Kidney Disease

Information for patients with an appointment at the Kidney Clinic

Queensland Health is inviting patients like you to participate in an online survey about your health outcomes, symptoms and the impact your kidney disease has on your quality of life over time. These are known as Patient Reported Outcome Measures (PROMs).

The survey will ask questions about your general health, symptoms and functional status, such as how much pain you are experiencing, how much you are able to move around and do your usual activities, and how you are feeling. These questions will be asked every three months throughout your treatment.

Who is included in the survey?

A selection of patients will receive an invitation to take part in the survey if they have kidney disease and have an appointment at the Kidney Clinic at the Royal Brisbane and Women's Hospital.

How do I complete the survey?

A link to the survey will be sent in a text message (SMS) to the mobile phone number listed in your hospital record. To complete the survey your phone will need to be connected to the internet.

This is an example of how the SMS will look:

Sender: QLD Health

The xxxxx at the end of both secure links will be replaced with 12 characters that make it unique for you. When you first click on the link, there is an option to provide your email address to receive any future surveys by email. You can also choose to continue to be contacted by SMS.

The link in the SMS and email will take you to the online survey welcome page, where you will be invited to participate in the survey. If you agree, you will be asked to complete two short questionnaires that will take about 5 minutes.

QuestLink survey app

If you receive a SMS, you can complete the survey and track your results on the QuestLink App. The app is available on Google Play (Android) and the App Store for you to download onto your mobile phone or device. Find it by searching for ‘QuestLink’.
**Do I have to take part?**

Taking part in the survey is voluntary and your hospital care and treatment will **not** be affected if you choose not to participate.

**What will the survey results be used for?**

Your survey responses will help us better support your treatment needs and care and will be linked to your health record for clinicians to view. Your participation will also assist us to trial new approaches to collecting patient reported outcome measures via an online survey. This could lead to improvements in care for all kidney patients.

Results from your survey responses will also be available for you to review and these may help you discuss any issues or concerns with your treating team.

**Will the hospital monitor my responses?**

If your survey responses show something that may be of concern, these will be flagged for your treating team to review and they may contact you or advise your GP. However, your responses will not be reviewed in real time and may not align with your clinic appointments. Therefore, if you are experiencing any significant symptoms, please contact your GP or health care provider directly.

**How often will I be sent a survey?**

If you receive the first survey, you will receive a new one to complete every three months. We encourage you to complete any future surveys before your next appointment, so your treating team can review the results, identify any trends and discuss any concerns with you.

**I have already received this information or have already been sent a survey**

If you received this information sheet for a previous appointment, there is nothing you need to do. If you have already received an SMS for a survey that you may have completed, there is no further action required, you will continue to receive surveys every three months.

**Will my personal information and survey responses be kept confidential and secure?**

QuestLink, the system used to survey patients is provided by Philips Electronics Australia Limited. All patient information and survey data are stored securely in Australia and Philips will only access this information if they need to provide technical support. The privacy and confidentiality of any information you provide will be maintained and managed in accordance with the *Hospital and Health Boards Act 2011* and *Information Privacy Act 2009* (Qld).

**What can I do if I do not want to receive a survey?**

If you do not wish to receive an SMS inviting you to complete a survey, or do not want your name and mobile phone number and other information to be provided to Philips, please contact 13 HEALTH (13 43 25 84).

**Where can I find more information?**

For more information about Queensland Health Patient Reported Experience and Outcome Measures visit [www.health.qld.gov.au/preom](http://www.health.qld.gov.au/preom), or for help to complete a survey contact 13 HEALTH (13 43 25 84).