

SONG

STANDARDISED OUTCOMES IN NEPHROLOGY

Life participation in patients with chronic kidney disease

What do we aim to do?

We would like to invite you to participate the SONG Life Participation (LP) validation survey. The Standardised Outcomes in Nephrology (SONG) Initiative aims to establish core outcomes to be measure in all trials in chronic kidney disease.

Life participation has been identified by patients, caregivers and health professionals as a critical outcome of importance. Life participation refers to the ability to participate in activities that are meaningful and important to patients.

We aim to assess life participation in a way that is meaningful to patients with CKD, their families and health professionals. To do this we have created the SONG LP measure.

Can I participate in the study?

You can participate in the study if you:

- have chronic kidney disease not yet requiring kidney replacement therapy (and have not received a transplant);
- are currently receiving dialysis (haemodialysis or peritoneal dialysis).

What does the study involve?

You will be asked to complete an **online questionnaire** with brief questions about yourself, and meaningful activities. The survey will be completed at three time points (baseline [15 minutes to complete], one-week [2 minutes to complete], and 12- months [10 minutes to complete]).

Yes, I want to be involved.

Please go to the link below or scan the QR code to complete the consent from. You will then be sent the first questionnaire.

Link: <https://redcap.sydney.edu.au/surveys/?s=P7YP73FKTDFN7AR>

If you have any questions please email Anastasia at anastasia.hughes@sydney.edu.au

