

Patient-Reported Measures for Solid Organ Transplant Recipients

A Development Roadmap

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- Patient-reported measures can help identify supportive care needs in post-transplant follow-up or areas for improvement in healthcare provision.
- For meaningful data to be collected, these measures must be rigorously developed with consistent patient and professional involvement throughout.



Phase one: Identify and evaluate existing measures



Phase one key messages:

- Methodological quality was poor in all existing quality of life PROMs for solid organ transplant recipients.
- There are no existing measures of patient experience for cardiothoracic transplant recipients.
- Insufficient patient and professional involvement in the development of existing PROMs and PREMs, so relevance, comprehensiveness and comprehensibility is largely unclear.

Phase two: Concept elicitation

Aim: To identify and understand the quality of life outcomes and healthcare experiences of solid organ transplant recipients.

Actions:

1. Systematic review of qualitative studies on lived experiences of quality of life in solid organ transplant recipients (*ongoing*).
2. Semi-structured interviews with solid organ transplant recipients (>1-year post-transplant) about their post-transplant lived experiences.
 - a. Sample size n=32 (planned n=40); seeking to maximise diversity (e.g. ethnicity, organ type).

Phase three: Item generation and refinement

Aim: To generate and refine items to develop drafts of each measure, ready to be piloted.

Actions:

1. Team meetings to review Phase one and two findings and consider the broad domains to be captured by the measure.
2. Group workshops with patients and professionals to examine the relevance and comprehensiveness of the generated items.
3. Cognitive interviews with patients to further examine relevance, and the comprehensibility of instructions, item wording, and response options.
4. Iteratively refine the measure following identified problems/areas for change.

WE
ARE
HERE

GAS STATION

Planned PROM/PREM development

PROM: Quality of life measure for all solid organ transplant recipients (*Lead: Rimmer*)

PREM: Measure of healthcare experiences for cardiothoracic transplant recipients (*Lead: Rimmer*)

PREM: Measure of healthcare experiences for kidney transplant recipients (*Lead: Jenkins*)

If you have any questions, or for further updates on our progress, please contact me:

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Phase four: Pilot and finalise

Aim: To pilot each measure with a sample of the target population for an indication of its feasibility, reliability, measurement error, and known-groups validity.

Action: Small-scale survey (n≥50) with repeat administration following a two-week interval.

Outcome: Final refinement of each measure ready for a large-scale survey (n~250) to fully evaluate the measurement properties (e.g. internal consistency, structural validity).