

## Patient reported experience measures for solid organ transplantation: protocol for a scoping review

**Authors:** Rebeka Jenkins, Ben Rimmer, Lorna Marson, Andrew Fisher, Linda Sharp, Catherine Exley

### Background

The patient's perspective is integral to the planning, evaluation and delivery of good quality transplantation care. This is made clear by the strategic vision for organ transplantation in the UK, in which patient reported outcomes measures (PROMs) and patient reported experience measures (PREMs) are presented as key indicators of person-centred transplant care (1,2).

The concept of patient experience of healthcare has been variously defined (3) and understanding continues to evolve (4). The most consistently adopted definitions describe a range of interactions along the patient's pathway of care, both relational (e.g. communication, respect) and functional (e.g. continuity of care, environment) (5–8). The Beryl Institute, for example, defines patient experience as “the sum of all interactions, shaped by an organisation's culture, that influence patient perceptions across the continuum of care” (9) whilst the Picker Institute describes eight principles of person-centred care (10).

Patient Reported Experience Measures (PREMs) are standardised tools designed to capture the patient's views of their experience of receiving health care; their perception of what happened and how it happened (11). PREMs generate quantitative metrics that relate to the systems and processes by which health care is delivered, and thus complement patient-centred outcome measures in evaluations of care quality (6). PREMs are considered central indicators of overall care quality (5,12) and are being developed across a wide range of conditions, interventions, and care settings (13–18). It is acknowledged that national-level analysis of patient-derived data, including PREMs has the potential to generate novel insights (19). PREMs can, for example, highlight (i) specific areas (e.g. information, communication) where improvements may be needed nationally, (ii) variations in care experience between providers, and/or (ii) inequalities in care experience (e.g. identifying particular groups of patients who are less well served by care) (20).

It is necessary to identify any existing PREMs for solid organ transplantation potentially appropriate for implementation across the UK. Thus, in this review, a candidate PREM is one that captures the patient's perspective of the multiple relational and functional aspects of how standard transplantation care is currently being delivered and can be used to support the evaluation of equitable delivery of standard care.

A systematic review by Bull *et al* in 2019 assessed the validity and reliability of PREMs regardless of context and did not identify any PREMs for transplantation (21). That search focused on validity and reliability of measures, excluded grey literature sources, acknowledged that there were PREMs still in development, and preceded the shift in healthcare delivery to include more routine use of telemedicine in response to the COVID-19 pandemic. To date, there are only evidence syntheses of purely qualitative research on patients' lived experiences of having or preparing for organ transplantation (22–27).

This is to our knowledge the first attempt to synthesise evidence regarding PREMs for solid organ transplantation and comes at a time of great interest in the topic. A scoping review is an appropriate methodology, drawing out a range of pertinent theoretical and practical features of PREMs from across the spectrum of solid organ transplantation care. It will identify measures and structures for administering and acting on PREMs, highlighting areas requiring further input. This provides a foundation to guide further work to deliver on the UK's strategic vision for solid organ transplantation.

## Aim

This scoping review aims to identify and describe the available Patient-Reported Experience Measures (PREMs) for solid organ transplantation.

## Objectives

1. Identify and describe PREMs that have been developed specifically for completion by those actively preparing for, or having received, a solid organ transplant (kidney, pancreas, liver, heart, lung, intestine, or combinations of these).
2. Map the aspects of patient experience/care journey covered by the PREMs.
3. Map the settings and contexts in which the PREMs have been used.
4. Broadly describe any development and validation work reported for identified PREMs.
5. Identify the gaps in existing PREMs (e.g., patient groups, health care settings or aspects of patient experience that are not covered by existing PREMs).

## Eligibility criteria

### Inclusion criteria

This review is designed to capture quantitative measures of the patient's perspective of the multiple relational and functional aspects of how standard transplantation care is currently being delivered. Papers will be eligible

if they describe (i) a quantitative measure of patient experience of healthcare; (ii) the PREM is designed for candidates actively preparing for, or recipients of, a solid organ transplant (kidney, liver, pancreas, heart, lung, intestine); (iii) the PREM is focused on the experience of the candidate or recipient, and is completed with or without support; (iv) the PREM items are available in English; (v) the PREM reports on multiple aspects of standard transplantation care.

Measures will primarily generate quantitative metrics; they may invite some additional free-text responses but not be designed exclusively with free-text answers. Eligible measures may offer the patient the option of seeking support in completing the measure. It is recognised, however, that the experience of the carer or family member themselves is a distinct construct and measures designed only for completion by proxy, or focusing on carer or donor experience, are excluded.

### Exclusion criteria

A measure will be excluded if: (i) it is designed to capture only the experience of those other than solid organ transplant recipients or candidates e.g. organ donors, carers or family members, health-care professionals or is designed for completion only by proxy; (ii) the measure is a PROM primarily designed to measure a patient's health-related outcomes (including PROMs with a small number of embedded items relating to healthcare experience); (iii) the measure primarily reports patient preferences relating to hypothetical scenarios; (iv) the measure primarily reports evaluative ratings of global satisfaction, or satisfaction with specific interventions e.g. medications, surgical techniques; (v) the measure reports the experience of something other than of standard healthcare e.g. community events, clinical trials; (vi) the measure is generic and does not reference any part of the transplantation journey.

Although the term satisfaction measure is often used synonymously with PREMs (28), the concepts are distinct. Patient satisfaction, arguably an outcome (6), is influenced by a patient's existing expectations, and satisfaction measures fail to identify reasons for different levels of satisfaction (29). Evaluative "satisfaction" ratings of a specific technical intervention, more properly assessing their acceptability and usually used with a trial setting, are fulfilling a different purpose to eligible measures which report on the process of delivering standard transplantation care. Global satisfaction ratings of overall care are considered too broad to meaningfully capture the multiple aspects of health experience. Conversely, measures reporting on a single domain of patient healthcare experience are considered too narrow to give a rounded account of the patient's perspective.

## Search Strategy

A three-step search strategy will be followed as per recommendations from the Joanna Briggs Institute (30). An initial limited search of MEDLINE (OVID) and CINAHL (EBSCO) will be followed by an analysis of the key words to inform a further search of seven bibliographic databases from inception: MEDLINE (OVID), Embase (OVID), CINAHL (EBSCO), PsycINFO (OVID), Cochrane CENTRAL (Wiley), Scopus and Web of Science. The search strategy will encompass the key concepts of *organ*, *transplant*, *patient experience* and *measurement tools* and includes “satisfaction” to ensure that measures labelled with the term are captured and scrutinised for their content, rather than name. Search terms will be informed by previous published search strategies (14,21) and supported by specialist librarian services to tailor key words and controlled vocabulary searches to each database. Additional hand searches of references and forward citations of key eligible articles and relevant reviews will aim to achieve comprehensive subject matter coverage. A search of relevant grey literature repositories with less advanced search capabilities will be undertaken using key word searches (including Google advanced search, EThOS, UK Health Security Agency grey literature index, targeted website searches eg. The Health Foundation, The King’s Fund).

## Paper selection

A screening strategy will be developed a priori. Two independent reviewers will, after piloting the screening strategy, double-screen all the papers identified by the above searches using Rayyan software. Firstly, titles and abstracts will be viewed, and potentially eligible papers retained for subsequent full text screening. Papers excluded at full text screening will have coded reasons for exclusion reported following PRISMA recommendations (31). Any disagreements will be resolved by consensus discussion involving a third reviewer if necessary.

## Data Abstraction

This review will use a structured dedicated form to abstract data. Data relating to specific measures will include name and type of the measure, who developed it, date of publication, country of origin, number of items, overview of purpose, context of use (organisation, respondents, timeframe, impact of results), design and content. Information will be abstracted on any formal development and/or validation of the measure.

## Data Synthesis

This will take the form of a narrative synthesis informed by guidelines for systematic reviews (32) and tabulation and visual mapping. Synthesis will include description of general characteristics, content and presence of development and validation processes. Any gaps in coverage will be discussed.

## Patient and Public Involvement

The scope of this review draws directly on the patient perspective that is actively integrated into the research strategies of NHS Blood and Transplant, the Organ Utilisation Group and the Blood and Transplant Research Unit in Organ Donation and Transplantation (1,2,33).

## Dissemination

This work contributes to a doctoral research thesis. The findings will be submitted for publication and presentation at meetings of professional societies. The results will underpin the engagement of patient and professional stakeholders in the subsequent phases of developing a strategy to integrate PREMs within the UK Transplant Registry.

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