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Workshop program

Life participation – proposed core outcome measure

BRIEF OUTLINE OF RATIONALE

Life participation was identified as a high priority outcome domain by patients/caregivers and health professionals through the international SONG-Tx Delphi Survey and consensus workshops. Life participation is defined as the ability to participate in key activities of daily living including work, study, family, travel, hobbies, recreational and social activities. This outcome also signifies a return to “normal” life, and having a sense of purpose. Life participation may be affected by the treatment burden including side effects, cognition, and mental health issues.

For feasibility, it's only possible to include a simple core outcome measure that asks a maximum of 3 questions. Based on the previous consensus workshops, we will focus on life participation for this core outcome measure and the other relevant outcomes may be a focus of future work.

EXISTING MEASURES

Based on a preliminary analysis of 271 studies in kidney transplantation, 34 different measures (ie, questionnaires) have been used to assess life participation (Appendix B). Examples of questions include:

SF-36

KDQOL-SF

EQ5D-5L

PROPOSED CORE OUTCOME MEASURE

Severity	or	Frequency	or	EQ5D (existing measure)
During the <u>past week</u> , how much were you limited in participating in your normal activities (eg, work, study, housework, and family or leisure activities)? <input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Somewhat <input type="checkbox"/> Quite a bit <input type="checkbox"/> Extremely		During the <u>past week</u> , how often were you limited in participating in your normal activities (eg, work, study, housework, and family or leisure activities)? <input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> About half of the time <input type="checkbox"/> Most of the time <input type="checkbox"/> All the time		Usual activities (eg, work, study, housework, family, or leisure activities) <input type="checkbox"/> I have no problems doing my usual activities <input type="checkbox"/> I have slight problems doing my usual activities <input type="checkbox"/> I have moderate problems doing my usual activities <input type="checkbox"/> I have severe problems doing my usual activities <input type="checkbox"/> I am unable to do my usual activities

KEY QUESTIONS FOR WORKSHOP DISCUSSION

- How well do these proposed measures capture the concept/idea of life participation?

- Should we make a distinction between “nonmandatory” (eg, holidays, social activities, sport) and “mandatory” tasks (eg, chores, work)?
- What do you think is an appropriate or feasible recall period – what period of time should patients reflect on eg, 1 week, 2 weeks, 3 weeks etc?

What other things are important to consider when choosing a core outcome measure for life participation?

Prompts for Facilitators

Life participation

- How well do these proposed measures capture the concept/idea of life participation?
- Should we make a distinction between “nonmandatory” (eg, holidays, social activities, sport) and “mandatory” tasks (eg, chores, work)?
- What do you think is an appropriate or feasible recall period – what period of time should patients reflect on eg, 1 week, 2 weeks, 3 weeks etc?
- What other things are important to consider when choosing a core outcome measure for life participation?