

# Current Methods of Assessing Health-Related Quality of Life (HRQoL) in Informal Carers of Children With Rare Progressive Life-Limiting Conditions Are Inadequate: Findings From a Collaborative Project Hercules Workshop

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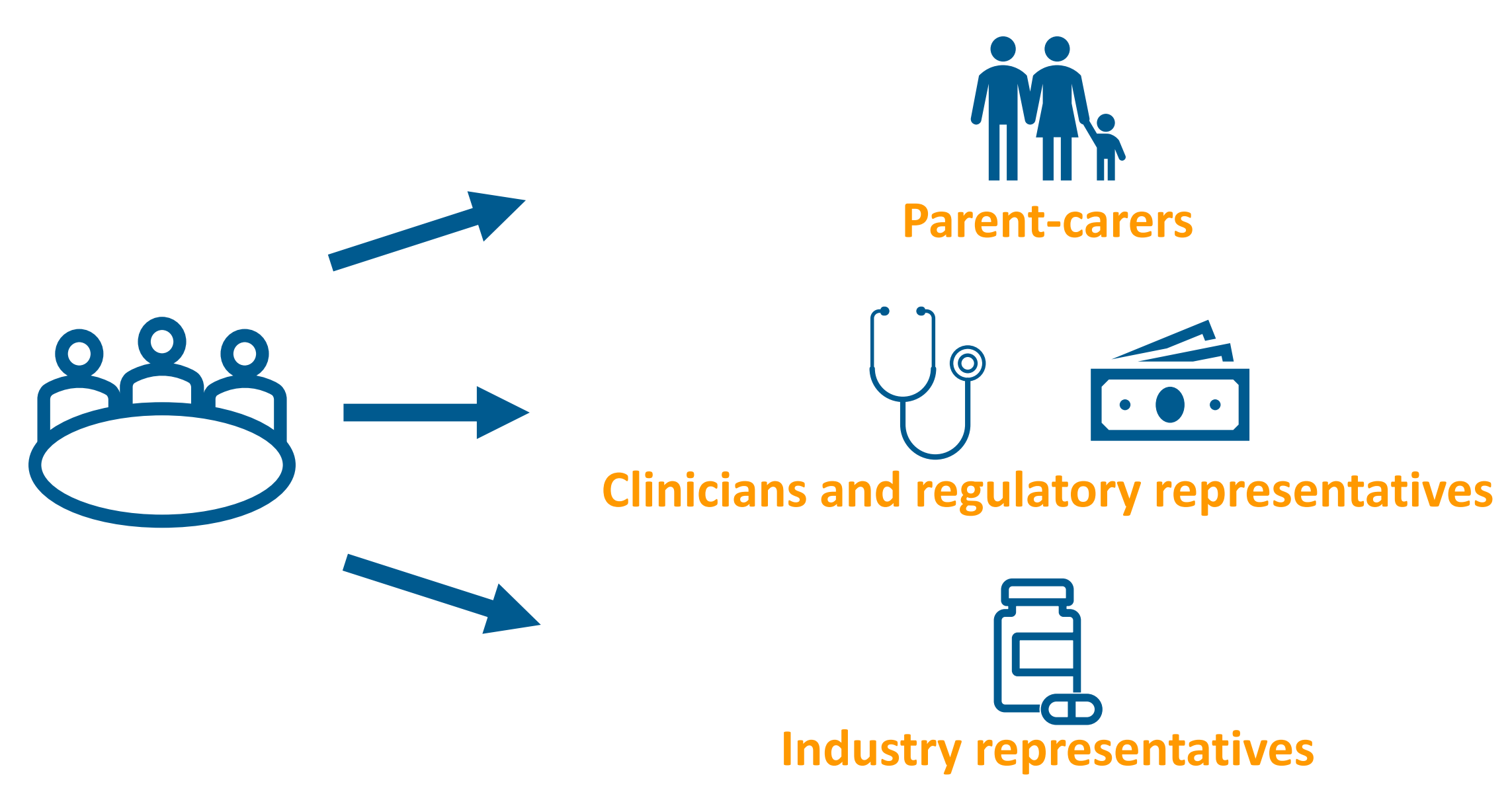
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## AIMS AND OBJECTIVES

There are methodological challenges in assessing carer health-related quality of life (HRQoL) and incorporating this into economic models for health technology assessment (HTA). These challenges are magnified for informal carers of children living with rare, progressive, life-limiting conditions (RPLC). A recent multi-stakeholder collaborative workshop explored (i) how HRQoL of informal carers of children living with RPLC differed from a generic framework; and (ii) research priorities to support future HTA submissions.

## METHODS

Seven parent-carers of children with RPLC; seven industry representatives; and five clinical and regulatory representatives attended a collaborative workshop event. Discussions were facilitated within each group and focused on (i) defining HRQoL for informal carers of children with RPLC; and (ii) research priorities for generating evidence to support future HTA submissions. Whole-group discussions reflected on individual group considerations.



-  What is the HRQoL impact of caring for someone with a RPLC?
-  How can we evidence this?
-  What are the research priorities for carer HRQoL in RPLC?

## RESULTS

Parent-carers described how a bespoke (as opposed to generic) model was required to characterise HRQoL in informal caregivers of children with RPLC. This included stronger descriptive vocabulary (e.g., ‘despair’ instead of ‘hopelessness’) and the inclusion of attributes not normally captured (e.g., ‘anticipatory grief’ and ‘psychological exhaustion’). Research priorities for all attendees included qualitative research to better evidence unique impacts for this informal carer group; an understanding of change over time and affects on multiple family members; and methodological work to better understand how to model carer HRQoL in cost-effectiveness models.



**Figure legend:** Initial framework informed by EQ-HWB framework, adapted from Mukuria et al. (2022). Bold text denotes high-level themes. New sub-themes are shown in lighter colours and italic font. Underline italicised font indicates additional subtheme to existing theme. Irrelevant themes are indicated by strikethrough.

## CONCLUSIONS

A collaborative workshop empowering the voice of parent-carers and other key stakeholders suggests that a generic framework is insufficient for understanding HRQoL in informal carers of children living with RPLC. There is a gap in the evidence base on the HRQoL impacts in this group of informal caregivers. Focused qualitative studies, including those that investigate beyond the primary caregiver to include other family members, and methodological studies that enable appropriate incorporation of carer HRQoL data to HTA are needed.

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## REFERENCES

Mukuria, C., et al., Qualitative Review on Domains of Quality of Life Important for Patients, Social Care Users, and Informal Carers to Inform the Development of the EQ-HWB. Value Health, 2022. 25(4): p. 492-511

