

# Stakeholder engagement and expert consultation on the EuroQol Toddler and Infant Populations (EQ-TIPS) measure of Health-Related Quality of Life (HRQoL)

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## BACKGROUND & AIMS

The EuroQol Toddler and Infant Populations (EQ-TIPS) is an instrument to measure and value HRQoL in children aged 0–3 years (formerly the TANDI)<sup>1,2</sup>. The initial development of EQ-TIPS took place in South Africa. EQ-TIPS retains the EQ-5D-Y-3L instructions for completion, layout, time frame, levels of report and EQ VAS. The dimensions were however developed *ab initio*. The EQ-TIPS includes six dimensions: movement, play, pain, relationships, communication and eating, which refer to age-appropriate behaviour. The EuroQol Group currently considers the EQ-TIPS an experimental version which requires further development and testing.

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The first phase of this work included international stakeholder engagement and expert consultation which aimed to:

- review the wording and content of the EQ-TIPS descriptive system to ensure suitability for its intended purpose and target age range
- assess the need for additional dimensions
- explore the challenges associated with measuring HRQoL in the youngest populations

## METHODS

The following stakeholder and expert groups were included:

- likely users of EQ-TIPS
- experts in PROMs use and/or development
- experts in child health and development, including paediatricians, educators, allied health and social workers parents and
- caregivers of very young children

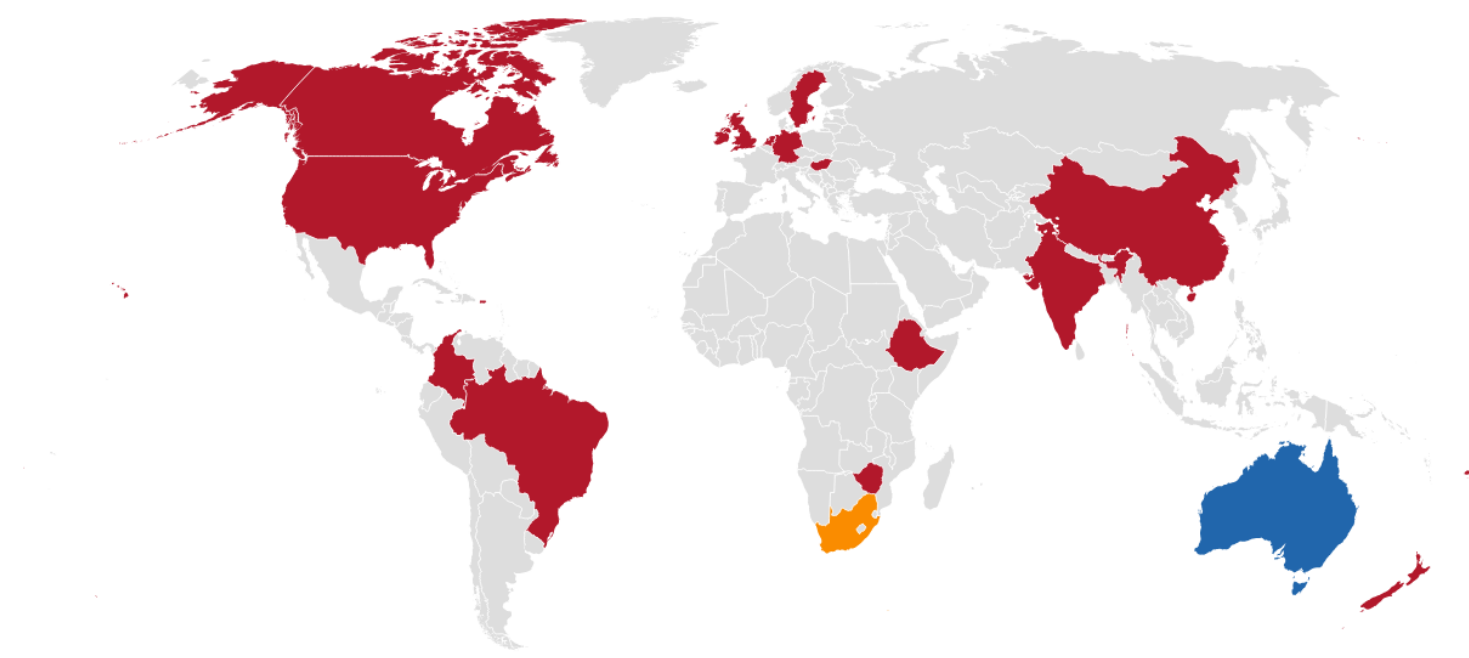
Participants were recruited for the web-based surveys through snowballing and experts consulted online were purposively sampled for their expertise and geographical location. Opinions were sought through an iterative process including three separate web-based surveys and three online expert consultations, respectively. Online consultations were audio-recorded. Data was analysed by thematic analysis for open-ended survey questions and transcripts from the on-line forums.

## RESULTS

### Stakeholder and expert group geographical

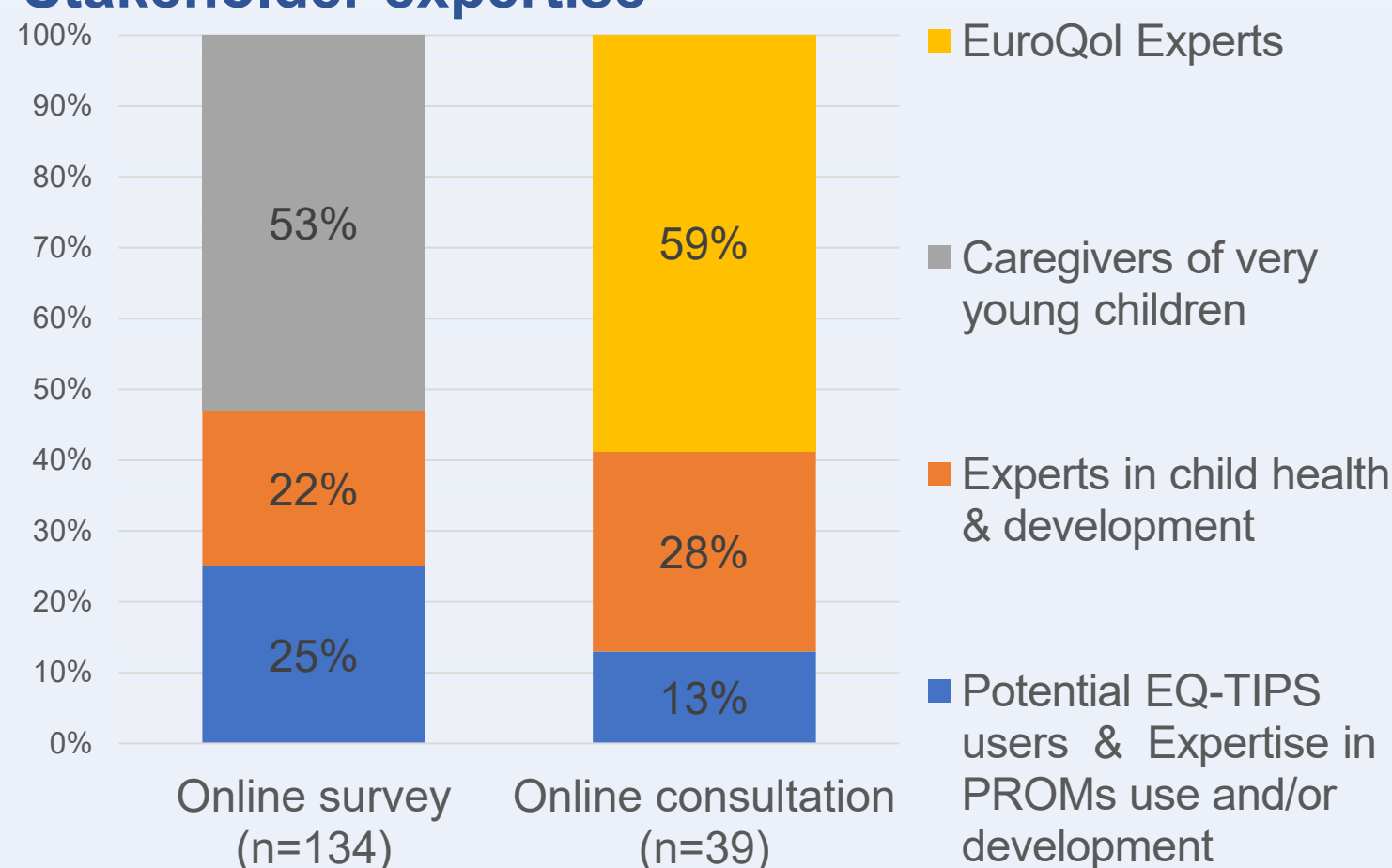
#### Stakeholder geographical representation

■ < 9% ■ 9%–18% ■ 18%–26% ■ 26%–35% ■ ≥ 35%



Grey indicates regions with no participation

#### Stakeholder expertise



## RESULTS

### Overall impression of the EQ-TIPS

*One of the strengths of the EQ measures is that it's very short and that's why, uh, well, people setting up clinical trials are a bit more inclined to accept this into, well, the whole bunch of questionnaires.*

- Well received by stakeholders who noted its potential value in clinical practice, interventional and descriptive health studies, and to inform health decision-making.
- Considered clear, concise and easy to use.

### EQ-TIPS age range

*It's not that these children [0-3 months] don't do any of the things included in there, including eating, moving, playing, experiencing pain. Um, so I definitely don't think you should try and put a lower limit...*

*... where you're going to need to be really careful is around comparing the outcomes in a group from say, naught to three months, compared to three to six months...*

- Experts were uncertain whether the health of very young children (+/- <6months) can be described in the same way as older children, as attributes may be interpreted differently.
- In general problems with health may be interpreted differently according to the age of the child e.g., a child with a deficit in movement at 6 months may be seen as less of a problem to the caregiver than the same deficit in movement at 3 years old.

### Response levels

*...it's not children that are completing the instrument, but parents, so going to five levels doesn't probably add much in the way of burden...*

*...the one thing that, um, is quite striking is there's a relatively small range for, you know, some of the, the domains... and that doesn't give a huge scope for variation. But, perhaps in many ways makes it more simple and easier and to Some extent it's [less] noise.*

- It was suggested that four and five response options be tested
- Reference to problems are considered ableist in nature

### Dimension reference to 'age-appropriate' behaviour

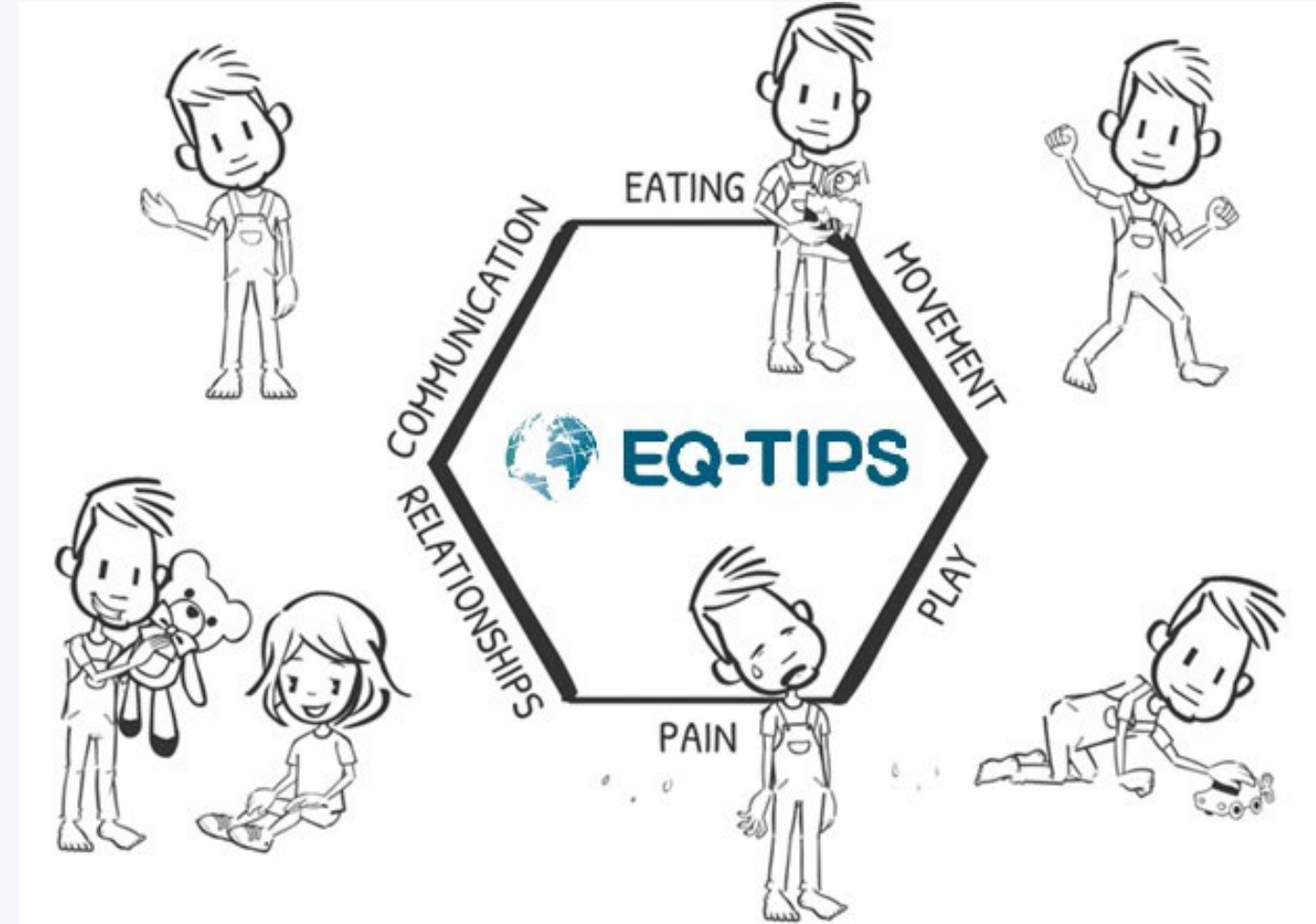
*As long as we've put that proviso of age appropriate, I can see how it can work across all those age groups that we're interested in, including the very young children...*

*... [you] need to try make the options as clear as you can without incorporating some kind of judgement from the person completing the questionnaire...*

There was little consensus as to whether dimensions should refer to 'age-appropriate' behaviour.

- Caregivers/parents reported little concern and could give appropriate examples of age-appropriate behaviour for each dimension.
- The term 'age-appropriate' is thought by some experts to introduces subjectivity as reference to these norms may be context specific.
- There are many behaviours that would not be considered typically 'age-appropriate' but could still be normal. Care needs to be taken that these are not captured as problems.

### EQ-TIPS dimensions



*I was quite interested also by the inclusion of eating and feeding, because that's something I haven't seen before. And considering this is a key let's say, uh, behaviour activity at any age, but particularly between 0-3 years.*

- The EQ-TIPS was considered to include relevant dimensions which were appropriate for the intended age-range.

*...and so, so you say, you know, talking about the example of feeding or eating and picking eating and is this a concern, but it's a concern to the parent, you know, in that context it's not a concern to the child*

*Consideration should be given to better describing social interaction as may be poorly understood by caregivers.*

- Dimensions and wording were well-understood by caregivers/parents who could give appropriate examples of behaviours for each of the dimensions across the age-range.

*I mean it is a bit more difficult to distinguish between them in the younger age group, but I think inherently they mean something different to me when I'm thinking about social interaction versus communication*

- Including examples for communication and social interaction (relationships) may ensure that the dimensions are more distinct.

*I think it's [EQ-TIPS] pretty close to being optimum. Um, I just wonder about sleep, should sleep be included, because it really does impact quality of life of a child. [If] a baby is not getting sufficient sleep apart from the impacting the baby's quality of life, it's the parent's as well.*

*...currently looking at the psychiatric criteria by age group to see if we could add any other emotional aspects into the instrument. But this is actually an incredibly challenging area of health, particularly in the first 2 years of life, and and it really is dependent on interaction with adults.*

- It was suggested that sleep and emotional functioning be considered as additional dimensions.

### Recall Period

*Today is good for acute conditions but two or three days could work too... variability in infant and toddler behaviour does not warrant a change in the time frame. One can consider adding the descriptor of 'unusually persistent' to capture the variability*

*I think the recall of today is probably the best, um, because I mean, it might not be capturing a typical day.*

- The time of day that the EQ-TIPS is completed, and the lability of a very young child may influence completion of HRQoL for 'Today'. Proxy completers may be able to give a more accurate rating of HRQoL over a longer period.

## RESULTS continued

### Considerations for proxy completion

*... how would you, um, uh, accommodate or think about the very young caregiver [or] what about the teenage parent mm-hmm. What about the, um, first time parent who maybe did not have the best rearing themselves and so they are at a loss for what to do, what to look for.*

*I was just thinking ....about the parent's quality of life and whether it's inconvenient for them or whether it's actually impacting their [child's] quality of life.....*

Proxy reporting may be influenced by:

- caregiving experience (e.g., first time parent)
- amount of time dedicated to caregiving
- relationship to the child
- family structure
- health spill-over



*... I would not use the word proxy. I think an adult rater of, a you know a, an infant's health state. They're coming at it with all of their own, as we already identified, potential confounding aspects around experience, expectation, understanding of the child's milestones.... So, the fact that we have someone else other than the individual rating the person, rating their health state. It's certainly a, a complication that is unavoidable here. At least it's consistent.*

*The proxy respondent should be familiar with the child and have spent time with the child on the day of completion*



The best proxy may be the person who spends the most time with the child and not necessarily the parent.

*...include a preamble with, uh, clear instructions for the proxy respondent....include a standardized page so that you can also find out more of the respondent filling it out....*

*...maybe, including some, some examples that clearly define what we are asking for in order, so that the opinions of the parents are closer, uh, between cultures or .... social levels.*

- Subjectivity of completion may be further reduced by including examples of activities or behaviour in each dimension and providing more detailed instructions on completing the instrument.

## DISCUSSION & CONCLUSION

Stakeholders and experts valued the opportunity for their involvement in the development of the EQ-TIPS. Further multi-national development of the EQ-TIPS will be informed by input from both stakeholder and expert groups, e.g., suggested changes to the descriptive system will be tested qualitatively in a multi-national program of work that follows. Future qualitative and quantitative work will target samples across the age range to determine the youngest age which we can reliably measure HRQoL on the EQ-TIPS.

## REFERENCES & DISCLAIMER

- Verstraete J, Ramma L, Jelsma J. Item generation for a proxy health related quality of life measure in very young children. Health and quality of life outcomes. 2020;18(1):11.
- Verstraete J, Ramma L, Jelsma J. Validity and reliability testing of the Toddler and Infant (TIPS) Health Related Quality of Life instrument for very young children. Journal of Patient-Reported Outcomes. 2020;4(1)

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