

## Feasibility and acceptability of quality of life measures used in the paediatric burn outpatient clinic.

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### Background

Paediatric burn injury has significant physical and psychological sequelae. Patient-reported quality of life (QoL) outcome measures are important tools to monitor recovery and identify problems that might go undetected<sup>1</sup>. These measures can be collected routinely in outpatient clinics; however, they may be a burden to patients<sup>2,3</sup>.

### Methods

Three QoL questionnaires were completed by patients and parents to assess acceptability and feasibility at  $\geq 6$  weeks postburn. The PedsQL was administered as part of routine clinical practice to all attending the burn outpatient clinic (n=159). The burn specific QoLs were administered to a small number of willing (and native English-speaking) parents/patients to assess suitability (n=14).

### Measures

1. The Paediatric Quality of Life Inventory (PedsQL): a generic age-specific QoL measure used in many areas of health, including burns.
2. The Brisbane Burn Scar Impact Scale (BBSIP): a burn-specific outcome measure that focuses on burn scarring.
3. The CARE Burns Scale: a burn-specific outcome measure that focuses on all aspects of burn recovery.

### Results

#### PedsQL

*Acceptability*: No-one refused participation or objected to items.

*Feasibility*: Some double negative items created confusion sometimes requiring explanation. Completion time was 2 to 5 minutes for English speakers and up to 15 minutes for those for whom English was a second language.

#### BBSIP

*Acceptability*: No one refused participation or objected to items. However, there were complaints about time for completion (15-20 min)

*Feasibility*: Some questions required full attention for respondents to understand what was wanted. Response format changes added to the time and effort burden. There were occasional missed responses. Comprehensive assessment of scar impact likely to be useful for research outcomes.

#### CARE Burns Scale

*Acceptability*: No one refused participation. Some objections to romantic relationship domain.

*Feasibility*: Easy to understand. Includes a section on burden of scar management. Missed responses from some participants. Section 9 asks about romantic relationships for teens, which may cause stress. Also includes a parent report about themselves. Time to complete was 9-10 min.

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### Conclusion

The PedsQL was quick and easy to complete, but wording can cause confusion. The BBSIP was acceptable in content, but was a time and effort burden to patients and parents. The CARE was quicker and easier than the BBSIP to complete, but the romantic relationship domain was deemed to be potentially stressful to patients. The CARE assessed the burden of scar management, which was not assessed by the BBSIP.

### References

- 1 Griffiths C, Armstrong-James L, White P, Rumsey N, Pleat J, Harcourt D. A systematic review of patient reported outcome measures (PROMs) used in child and adolescent burn research. *Burns*. 2015;41:212-24.
- 2 Tyack Z, Wasiak J, Spinks A, Kimble R, Simons M. A guide to choosing a burn scar rating scale for clinical or research use. *Burns*. 2013;39(7).
3. Tyack Z, Ziviani J, Kimble R, Plaza A, Jones A, Cuttle L, et al. Measuring the impact of burn scarring on health-related quality of life: Development and preliminary content validation of the Brisbane Burn Scar Impact Profile (BBSIP) for children and adults. *Burns*. 2015;41:1405-19.