

## Supplementary File 1 Details of the outcomes in the intervention and effectiveness evaluation

Outcome	Outcome measure	Participant of focus	Domains, subscales, items or versions used in the study	Used in study intervention or evaluation	Description	Psychometrics
Generic health-related quality of life	CHU-9D	Child	All items 3 to 5 years (parent proxy) 5 to 7 years (parent proxy) 7 to 8 years (parent proxy) ≥ 8 years version (child)	Evaluation	A measure of health-related quality of life that can be used with child aged 3 years and older. The parent proxy version for children aged 3 to 5 years has 10 items with an additional item on overall health compared to 9-item versions for other versions.	A reliable and valid measure recommended for economic evaluations in paediatric settings [1-3]. 3-5 year version has not yet been validated (personal communication, Katherine Stevens). The item on schoolwork/homework has been modified.
Generic health-related quality of life (primary outcome measure)	Peds-QL 4.0 Generic and Infant Scales	Child	All items 2-4 years (parent proxy) 5-7 years (parent proxy) 8-12 years (child self-report) 13-18 years (child self-report)	Evaluation and intervention	Generic 4.0 scale: 23 items, 4 domains (physical, emotional, social and school functioning), 3 summary scores (psychosocial health, physical health, total score). Scores will be transformed on a 0 to 100 and scored as recommended by the developers (Mapi Research Trust and Varni, 2017, scaling and scoring,	Validation (including reproducibility and responsiveness testing) supported for children with acute and chronic conditions including those in a hospital setting [4,5].

					version 17, available from <a href="http://www.pedsqol.org/PedsQL-Scoring.pdf">http://www.pedsqol.org/PedsQL-Scoring.pdf</a> , accessed 11.05.2020).	
Condition-specific health-related quality of life	The Brisbane Burn Scar Impact Profile	Child and caregiver	All items Children < 8 years (parent proxy) Children 8-18 (child self-report) Parents of children < 8 years (self-report)	Evaluation and intervention	Groups of items measured were overall impact of burn scars; frequency and impact of itch, pain and other sensations; school, play and daily activities (includes mobility and activities of daily living items); friendships and social interactions; appearance; emotional reactions; physical symptoms; and parent and family concerns.	Content validity (children with burn scars and caregiver involvement in development) [6]. Psychometric testing in children and caregivers has largely supported longitudinal validity, reproducibility and responsiveness from around the time of wound healing [7,8].
Condition-specific health-related quality of life	CARe Burn Scales	Caregiver	15 items Parent self-report	Evaluation and intervention	Self-worth and negative mood parent scale items.	Content validity (caregivers of children with burns involved in development). Further validity testing is underway but not yet published (personal communication, Catrin Griffiths).
Condition-specific health-related quality of life	Haemangioma Family Burden Questionnaire	Child and caregiver	4 items Parent proxy and parent	Evaluation and intervention	Four items from the 20-item questionnaire were included. Three items forming the	Structural validity: internal coherence (Cronbach's $\alpha$ : 0.93).

			related quality of life	self-report	relationship and work dimension were included (e.g., time spent with other children, impact of the haemangioma on career and stopping work). In addition the single item on budget and financial resources was included.	Construct validity: correlation with mental dimension of the Short-Form-12 ( $r = -0.75$ ), and Psychological General Well-Being Index ( $r = -0.61$ ). Discriminant validity: significant differences were found according to the size and location of the infantile haemangioma [9].
Condition-specific health-related quality of life	Infantile Haemangioma Quality-of-Life Instrument	Child and caregiver	All items of the final measure Parent proxy and parent self-report	Evaluation and intervention	The 29 final items were included: 5 items targeting the child and the remainder targeting the caregiver. 4 subscales: child physical symptoms, child social interactions, parent emotional functioning, and parent psychosocial functioning.	Content validity (with parents involved in the development), test-retest reliability and structural validity supported [10].
Satisfaction with treatment	Study specific	Caregiver	Single item Parent self-report	Evaluation	An 11-point condition specific numeric rating scale with anchors of very dissatisfied to very satisfied will be asked similar to the numeric rating scale used in a previous study by the authors with children with burn scars and their	N/A

					caregivers [11] at 3-months and 6-months post-baseline.	
Referrals	Study specific	Child and caregiver	N/A	Evaluation	The number and type of referrals for child and caregiver participants to health professionals during 6-month intervention period, including psychosocial referrals. Referrals will be those made by health professional participants receiving result summaries in their consultations. Taken from medical records. Psychosocial referrals include referrals to social work, psychology, a general practitioner, or other health professional; where the referral is clearly for psychosocial support other than that provided by the health professionals delivering consultations in the effectiveness evaluation.	N/A

## References

1. Chen G, Flynn T, Stevens K, et al. Assessing the health-related quality of life of Australian adolescents: An empirical comparison of the Child Health Utility 9D and EQ-5D-Y Instruments. *Value Health* 2015;18(4):432-8.
2. Stevens K. Valuation of the Child Health Utility 9D Index. *PharmacoEconomics* 2012;30(8):729-47.
3. Ratcliffe J, Flynn T, Terlich F, et al. Developing adolescent-specific health state values for economic evaluation. *PharmacoEconomics* 2012;30(8):713-27.

4. Desai AD, Zhou C, Stanford S, et al. Validity and responsiveness of the Pediatric Quality of Life Inventory (PedsQL) 4.0 generic core scales in the pediatric inpatient setting. *JAMA Pediatr* 2014;168(12):1114-21.
5. Varni JW, Seid M, Knight TS, et al. The PedsQLTM 4.0 Generic Core Scales: Sensitivity, responsiveness, and impact on clinical decision-making. *J Behav Med* 2002;25(2):175-93.
6. Tyack Z, Ziviani J, Kimble R, 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(7):1405-19.
7. Simons M, Kimble R, McPhail S, et al. The longitudinal validity, reproducibility and responsiveness of the Brisbane Burn Scar Impact Profile (caregiver report for young children version) for measuring health-related quality of life in children with burn scars. *Burns* 2019;45(8):1792-809.
8. Simons M, Kimble R, McPhail S, et al. The Brisbane Burn Scar Impact Profile (child and young person version) for measuring health-related quality of life in children with burn scars: A longitudinal cohort study of reliability, validity and responsiveness. *Burns* 2019;45(7):1537-52.
9. Boccara O, Meni C, Leaute-Labreze C, et al. Haemangioma family burden: creation of a specific questionnaire. *Acta Derm Venereol* 2015;95(1):78-82.
10. Chamlin SL, Mancini AJ, Lai JS, et al. Development and Validation of a Quality-of-Life Instrument for Infantile Hemangiomas. *J Invest Dermatol* 2015;135(6):1533-39.
11. Wiseman J, Ware RS, Simons M, et al. Effectiveness of topical silicone gel and pressure garment therapy for burn scar prevention and management in children: a randomized controlled trial. *Clin Rehabil* 2019;34(1):120-31.