

## Supplementary Table 1

### Patient-related outcomes for assessment of quality of life

Outcome	Questionnaire	Component	Scope	Min Score	Max Score
Perceived health status and Satisfaction of life	VR-12	Mental Health	Emotions, vitality, mental and social functioning	0	100
		Physical Health	Physical functioning, pain	0	100
	EQ-5D-5L	VAS	Mobility, self-care, usual activities, pain, anxiety/depression	-0.661	1
			Perceived health status	0	100
SWLS		Life satisfaction, subjective well-being	5	35	
Psychological functioning	PHQ-8		Depression	0	24
	SOC-13		Orientation to life (stress management, coping, resilience)	13	91
Health risk behaviors	HBS-CHD	Substance use	Alcohol drinking, smoking, drug abuse	0	100
		Dental hygiene	Annual dental visit, daily brush, teeth floss	0	100
		Overall risk	Substance use, dental hygiene, sport participation	0	100
Illness perception	IPQ-R	Consequences	Illness impact on one's life	1	5
		Emotional representations	Negative emotions related to the illness	1	5
		Identity	Attribution of symptoms specific to the illness	0	28
		Coherence	Understanding of the illness (cause, treatment)	1	5
		Personal Control	Self-efficacy to control symptoms	1	5
		Timeline acute/chronic	Perceived duration of illness (short $\frac{1}{2}$ long)	1	5
Timeline cyclical	Perceived duration of illness (cyclical)	1	5		

VR-12: Veterans RAND 12-item mental and physical scores, EQ-5D-5L: EuroQol 5-Dimension Level, SWLS: Satisfaction with Life Scale, PHQ-8: Patient Health Questionnaire, SOC-13: Sense of Coherence 13, HBS-CHD: Health-Behavior Scale–Congenital Heart Disease, IPQ-R: Illness Perception Questionnaire-Revised, VAS: visual analog scale. Blue and red values represent the best and worst scores, respectively, for each component of the questionnaires.

