

Supplemental material

**Appendix 7: Assessment schedule for the psychosocial component****Assessment schedule for the psychosocial component**

Measure	Intake	Case report form	T0	T1	T2-T4	T2b	Brief Q
Semi-structured interview	-	-	-	X	X	-	-
Demographic data	-	X	X	-	-	-	-
Decision to participate <sup>1</sup>	-	-	X	-	-	-	-
PIPseqKQ adapted[21]	-	-	X	-	-	-	-
Distress ratings	-	-	X	X	-	-	-
Family communication	-	-	X	X	X	-	-
Family surveillance	-	-	-	X	X	-	-
Trust in Physician scale[22]	-	-	X	X	X	-	-
Understanding <sup>2</sup>	-	-	X	-	-	-	-
Hopes and concerns <sup>2</sup> [14]	-	-	X	X	X	-	-
Perceived benefit <sup>2</sup> [14]	-	-	X	-	-	-	-
Who will benefit most <sup>2</sup>	-	-	X	X	X	X	-
Satisfaction with Decision scale	-	-	X	X	X	X	-
Satisfaction rating <sup>2</sup>	-	-	X	X	X	X	-
Decisional Regret scale[23]	-	-	-	X	X	X	-
Patient QoL EQ-5D-5L <sup>2</sup> [24]	-	-	X	X	X	-	X
Parent wellbeing[24]	-	-	X	X	X	-	X
Emotion Thermometers Tool <sup>2</sup> [25]	X	-	X	X	X	X	X
Change to health status	-	-	X	X	X	-	X
Impact of participation <sup>1</sup>	-	-	X	X	-	-	-
Impact of COVID-19	-	-	X	X	X	-	-
Recommend to others <sup>2</sup>	-	-	X	X	X	X	-
Open-ended comments <sup>2</sup>	-	-	X	X	X	X	-

T0 = Baseline; T1 = following receipt of results; T2 – T4 = annually following enrolment; Brief Q= Quarterly.

<sup>1</sup>Assessed in patient questionnaires only.

<sup>2</sup>Assessed in patient questionnaires (T0 and T1 only) and parent questionnaires.

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