

Annexe n°2 : PaPaS Scale (Bergstraesser et al., 2014)

Table 4 Version 3 of the PaPaS Scale

Domain and Item numbers	Item	Characteristic	Score
Domain 1	Trajectory of disease and impact on daily activities of the child		
1.1	Trajectory of disease and impact on daily activities of the child (in comparison with the child's own baseline) (with reference to the last 4 weeks)	Stable	0 <input type="checkbox"/>
		Slowly deteriorating without impact on daily activities.	1 <input type="checkbox"/>
		Unstable With impact on and restriction of daily activities.	2 <input type="checkbox"/>
		Significant deterioration with severe restriction of daily activities.	4 <input type="checkbox"/>
1.2	Increase of hospital admissions, (> 50% within 3 months, compared to previous periods)	No	0 <input type="checkbox"/>
		Yes	3 <input type="checkbox"/>
Domain 2	Expected outcome of treatment directed at the disease and burden of treatment		
2.1	Treatment directed at the disease, (does not mean treatment of disease related complications, such as pain, dyspnoea or fatigue)	...is curative.	0 <input type="checkbox"/>
		...controls disease and prolongs life with good quality of life.	1 <input type="checkbox"/>
		...does not cure or control but has a positive effect on quality of life.	2 <input type="checkbox"/>
		...does not control and has no effect on quality of life.	4 <input type="checkbox"/>
2.2	Burden of treatment, (Burden means side effects of treatment and additional burdens such as stay in hospital in the patient's or family's view)	No or minimal burden or no treatment is envisioned.	0 <input type="checkbox"/>
		Low level of burden	1 <input type="checkbox"/>
		Medium level of burden	2 <input type="checkbox"/>
		High level of burden	4 <input type="checkbox"/>
Domain 2	Symptoms and nursing burden		

Domain 3 Symptom and problem burden			
3.1	Symptom intensity or difficulty of symptom control (over the last 4 weeks)	Patient is asymptomatic	0 <input type="checkbox"/>
		Symptom(s) are mild and easy to control	1 <input type="checkbox"/>
		Any symptom is moderate and controllable	2 <input type="checkbox"/>
		Any symptom is severe or difficult to control (unplanned hospitalisation or outpatient visits, symptom crises)	4 <input type="checkbox"/>
3.2	Psychological distress of patient related to symptoms	Absent	0 <input type="checkbox"/>
		Mild	1 <input type="checkbox"/>
		Moderate	2 <input type="checkbox"/>
		Significant	4 <input type="checkbox"/>
3.3	Psychological distress of parents or family related to symptoms and suffering of the child	Absent	0 <input type="checkbox"/>
		Mild	1 <input type="checkbox"/>
		Moderate	2 <input type="checkbox"/>
		Significant	4 <input type="checkbox"/>
Domain 4 Preferences/needs of patient or parents			
Preferences of health professional			
4.1	Patient/parents wish to receive palliative care or formulate needs that are best met by palliative care.	No	0 <input type="checkbox"/> please answer 4.2
		Yes	4 <input type="checkbox"/> do not answer 4.2
4.2	You/your team feel that this patient would benefit from palliative care.	No	0 <input type="checkbox"/>
		Yes	4 <input type="checkbox"/>

Table 4 Version 3 of the PaPaS Scale (Continued)

Domain 5 Estimated life expectancy			
5.1	Estimated life expectancy	Several years	0 <input type="checkbox"/> please answer 5.2
		Months to 1–2 years	1 <input type="checkbox"/> please answer 5.2
		Weeks to months	3 <input type="checkbox"/> do not answer 5.2
		Days to weeks	4 <input type="checkbox"/> do not answer 5.2
5.2	"Would you be surprised if this child were to suddenly die in 6 months time?"	Yes	0 <input type="checkbox"/>
		No	2 <input type="checkbox"/>
		Total score:	