

Family-Centered Multidimensional Outcome Measure For Pediatric Palliative Care (FACETS-OF-PPC)

Professional caregiver version

Please always answer ALL questions on this questionnaire.

If an answer option does not fit exactly, please mark the one that applies best.

Today's date: _____._____.20____

Date of birth: _____._____._____

First name: _____

Surname: _____

or patient stickers

Universität Witten/Herdecke

Kinderpalliativzentrum
Vestische Kinder- und Jugendklinik Datteln

Dr.-Friedrich-Steiner-Str. 5, 45711 Datteln

Tel.: 02363 975-700

Fax: 02363 975-701

E-Mail: info@kinderpalliativzentrum.de

Web: kinderpalliativzentrum.de
facebook.com/kinderpalliativzentrum

FACETS-OF-PPC

© Prof. Dr. Boris Zernikow, Datteln

Layout:

Ceyda Şimşek, Münster c.simsek@mail.de

Content:

Sophie Pelke

Dr. Mandira Reuther

PD Dr. Julia Wager

Prof. Dr. Boris Zernikow

A: We would first like to ask you some questions about the family's current situation.

	Completely disagree	Mostly disagree	stimme eher nicht zu	stimme eher zu	Mostly agree	Completely agree
1. The family feels safe in providing care to the child at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. The family knows the child's symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. The family has ideas on how to keep their child occupied in daily life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Besides his/her limitations, the family also recognizes his/her abilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. The family can accept their child's illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. If necessary, the family is able to independently take measures to alleviate the child's symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. The family is prepared for the child's crises.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. The family has a clear idea of what should be done for the child in a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. The family is overwhelmed by their child's care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. The family feels guilty for their child's illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The family can assess the child's needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. In assessing the child, the family trusts their gut feeling.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Although the child suffers from a serious illness, there are times at which the family members are well.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. The family despairs at the question of why their child is affected.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. The family is convinced that they make the right decisions for the child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B: How pronounced were the following symptoms of your child in the last 7 days?

	Not present	Very weakly pronounced	Weakly pronounced	Moderately pronounced	Very pronounced	Very strongly pronounced
1. Secretion problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Respiratory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Agitation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Sleep disturbances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Seizures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Spasticity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Has the child experienced another relevant **symptom** in the last 7 days?
If yes, please describe it below and indicate its' severity.

<div><div></div><div>-----</div><div>(e.g. itchiness, problems with urination)</div><div><input type="checkbox"/> No additional symptom present</div></div>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
---	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

C: The following questions concern your assessment of the family's everyday life in the last 7 days.

	Completely disagree	Mostly disagree	Somewhat disagree	Somewhat agree	Mostly agree	Completely agree
1. The child took part in social life according to his/her abilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. In certain situations, the child was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. The family was alone in dealing with their child's illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. The family members had time to do the things that make them happy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. The family members had time to themselves.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Despite the child's illness, the family was able to maintain social contacts.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. The family was alone with their grief.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. The family's everyday life was predictable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. The family could talk openly about their child's illness in their social environment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. The family was constantly worried about their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The family spent sufficient time together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. A normal family life was possible.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. The sick child's siblings had an age appropriate everyday life. <input type="checkbox"/> There are no siblings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. The parents were there for the sick child's siblings as a mother/father. <input type="checkbox"/> There are no siblings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. The parents were good spouses/partners for each other. <input type="checkbox"/> There is no spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. The parents were satisfied with their relationship. <input type="checkbox"/> There is no spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>