

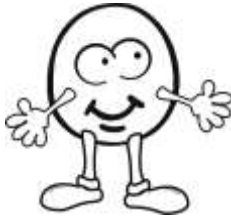
Your child's initials: \_\_\_\_\_ Your child's DOB: \_\_\_\_\_

Study ID: \_\_\_\_\_

Date: \_\_\_\_\_

**Time points for completion:**

- within the first 2 weeks of diagnosis
- at 6 weeks
- at 6 months
- yearly (if ITP persisting)



# KIDS' ITP TOOLS

(UK – English)

## Parent Report of Child's Quality of Life

### INSTRUCTIONS

For this questionnaire, we are asking: **How much of a problem has this been for your child over the past week?** Mark the answers that you think your child would select. We know that ITP has had an impact on your child since diagnosis, but for this study, we need you to **focus on what your child would have answered about the past week.** Record the answer by putting a tick (✓) in the box of the most correct choice. **Answer in general, don't worry if an answer is not because of ITP.**

**It is important that you answer all questions about this past week.**

### What do the answers mean?

#### Answers

#### Meaning

Never	=	none of the time
Rarely	=	almost none of the time
Sometimes	=	once in a while
Often	=	almost all of the time
Always	=	all of the time

**Note: You may provide other comments about your child's ITP at the end of the questionnaire**

## Please answer as your child would.

In general, over the past week ...	Never	Rarely	Sometimes	Often	Always
1. My child felt poorly...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My child had a headache...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My child felt tired...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My child felt upset (sad or angry)...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My child felt cranky...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My child felt anxious (worried, nervous or afraid)...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My child was more hungry than usual...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In general, over the past week ...	Never	Rarely	Sometimes	Often	Always
8. My child was bothered that she/he could not do things with friends...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. My child was bothered because he/she could not do the activities he/she likes...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My child was more frustrated with me than usual...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My child was bothered by how much I watched her/him...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My child was bothered because she/he did not know enough about ITP...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. My child was bothered that he/she didn't know how long the ITP would last...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. My child was bothered that she/he could not do anything to get better...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In general, over the past week ...	Never	Rarely	Sometimes	Often	Always
15. My child worried about his/her platelet count...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. My child worried about the ITP getting worse...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. My child worried about having a more serious disease...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please Note: the next set of questions have an **additional** answer.

In general, over the past week ...	Never	Rarely	Sometimes	Often	Always
18. My child was bothered by her/his bruises...	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>or <input type="checkbox"/> My child did not have any bruises in the past week.</b>					
19. My child was bothered by changes in how he/she looked...	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>or <input type="checkbox"/> My child did not have any changes in how he/she looked in the past week.</b>					
20. Having blood taken bothered my child...	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>or <input type="checkbox"/> My child did not have blood taken in the past week.</b>					
21. Staying overnight in the hospital bothered my child...	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>or <input type="checkbox"/> My child did not stay overnight in hospital in the past week.</b>					
22. Going to clinic bothered my child...	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>or <input type="checkbox"/> My child did not go to clinic in the past week.</b>					
23. Having treatment through a drip bothered my child...	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>or <input type="checkbox"/> My child did not have treatment through a drip in the past week.</b>					
24. Taking medicine by mouth bothered my child...	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>or <input type="checkbox"/> My child did not take medicine by mouth in the past week.</b>					
25. My child was bothered by missing school...	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>or <input type="checkbox"/> My child did not miss any school in the past week.</b>					
26. My child worried that she/he might need to have a bone marrow test...	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Has your child ever had a bone marrow test?	<input type="checkbox"/> yes	<input type="checkbox"/> no			

**Was there anything else that bothered your child?**

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**Thank you!**

**If you have any questions about these forms, please talk to the person who gave them to you. If you have any questions about your child's ITP, please talk to your child's doctor or nurse.**

**Please return this form to:**

**Marie Reeves  
UK Paediatric ITP Registry Data Manager  
Paediatric Oncology / Haematology  
Room 207, Ward 84  
Royal Manchester Children's Hospital  
Oxford Road  
Manchester. M13 9WL**