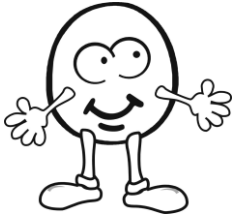


Your initials: _____ Your DOB: _____

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)

Child Self-Report of Quality of Life

INSTRUCTIONS

On the next two pages, there are questions that ask you **about this past week**. We know that ITP has mattered to you from when you first came to hospital, but **for this study, we really need you to focus on what you thought about and did over the past week**. You may have done things at home, at the hospital, at school and with your friends. Record your answer by putting a tick (✓) in the box of the most correct choice.

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

In general, over the past week ...	Never	Rarely	Sometimes	Often	Always
1. I felt poorly...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I had a headache...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I felt tired...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I felt upset (sad or angry)...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I felt cranky (bad tempered or moody)...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I felt anxious (worried or nervous or afraid)...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I 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. I was bothered that I could not do things with my friends...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I was bothered because I could not do the activities I like...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I was more frustrated with my parents than usual...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I was bothered by how much my parents watched me...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I was bothered because I did not know enough about ITP...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I was bothered that I didn't know how long my ITP would last...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I was bothered that I could not do anything to get better...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Over the past week ...	Never	Rarely	Sometimes	Often	Always
15. I worried about my platelet count...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I worried about my ITP getting worse...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I 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.

Over the past week ...	Never	Rarely	Sometimes	Often	Always
18. I was bothered by my 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"/>
or <input type="checkbox"/> I did not have any bruises in the past week.					
19. I was bothered by changes in how I 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"/>
or <input type="checkbox"/> I did not have any changes in how I looked in the past week.					
20. Having blood taken bothered me...	<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"/>
or <input type="checkbox"/> I did not have blood taken in the past week.					
21. Staying overnight in the hospital bothered me...	<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"/>
or <input type="checkbox"/> I did not stay overnight in hospital in the past week.					
22. Going to clinic bothered me...	<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"/>
or <input type="checkbox"/> I did not go to clinic in the past week.					
23. Having my treatment through a drip bothered me...	<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"/>
or <input type="checkbox"/> I did not have treatment through a drip in the past week.					
24. Taking medicine by mouth bothered me...	<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"/>
or <input type="checkbox"/> I did not take medicine by mouth in the past week.					
25. I 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"/>
or <input type="checkbox"/> I did not miss school in the past week.					
26. I worried that I 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. Have you ever had a bone marrow test?	<input type="checkbox"/> yes	<input type="checkbox"/> no			

Was there anything else that bothered you?

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 ITP, please talk to your doctor or nurse.

Please return this form to:

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Royal Manchester Children's Hospital
Oxford Road
Manchester
M13 9WL**