

[Parent/carer to give additional information for questions below]

Introduction

Thanks for seeing me today. My name is XXX.

We can play, draw can talk together. XX (PARENT/CARER) will be with us as well.

I spend lots of time talking and playing with different children. While we are playing together I would really like to find out more about what you like doing, and what makes you feel happy.

If you get tired or want to take a rest please tell me. Is that OK?

We can start now and I will switch on this machine. It will keep what we have talked about so that I can listen to it later so that I can think about what you have said.

Guide

First of all I'd like to get to know you a little better. Can you tell me how old you are? And what do you enjoy doing? What kinds are things do you think are fun? Is there anything you'd like to know about me?

That's great- now I'd like you to tell me about when you see the doctors and nurses. What sort of things you tell them about?

Do you have anywhere in your body that hurts you? Where on your body, how does it feel?

And how does that make you feel?

How about inside, do you ever feel worried about anything? Do you tell anyone?

Do you like going out to play? Who with? Where do you like to go? Does feeling poorly ever stop you from playing?

Of all the things you've just told me, what do you think matters most to you? What would you like doctors and nurses to do for you to help you?

Does anybody ever ask you about that? Would you like them to? Would it be OK if a doctor or nurse asked you about these things?

Who would you like to ask you (prompt staff, family others)?

If someone was feeling poorly how would you tell them? What do you say to tell a grown up so that you know that you are feeling poorly?

Introduction

Thanks for seeing me today. We can talk and play together, and I'll ask you to tell me about the things that matter to you and what are the things you care about when you are feeling poorly. We can talk, play and draw to help you tell me. Your (PARENT/CARER) can join us as well if you want. If you get tired or want to take a rest please tell me. Is that OK?

We can start now and I will switch on this machine.

Guide

First of all I'd like to get to know you a little better. Can you tell me how old you are? And what do you enjoy doing? What kinds of things do you think are fun? Is there anything you'd like to know about me?

That's great- now I'd like to learn a little more about your illness. What sort of things does it do to you- probe:

Any problems it gives with your body? Where on your body, how does it feel?

And how does that make you feel?

How about inside, do you ever feel worried about anything? Do you tell anyone- why?

How about how your illness affects other parts of your life, like seeing friends, going out to do things, school?

Of all the things you've just told me, what do you think matters most to you?

Does anybody ever ask you about that? Would you like them to?

Do you think it would help if your care team (doctors, nurses and others that help look after you) asked you about some of the things you have told me about? Would it be OK if they asked you each time they saw you? Or how often? And if they asked you about a problem, how far back do you think it would be best to remember, so perhaps how has this bothered you in the last day, 3 days, week- what is easiest to remember?

Who would you like to ask you (prompt staff, family others)?

And who could have that information you share about the things that bother you and matter to you- just your care team, you, your family? Why?

I'd really like to hear your ideas about how we could best ask what matters to you, if we were trying to find out how much of a problem something was for you from maybe not at all to bothering you very much, how could we ask that? Some ideas might be pictures showing things getting better or worse, or numbers from very low to high, you could mark it with a pen, you could do it on an iPad screen- what do you think you'd like to do?

The last thing I'd like to ask is what you think would be a good way to ask someone in a sentence if they are feeling better or worse than the last time they saw their team- what could we ask?

Introduction

Thanks for seeing me today. We can talk and we can also play together if that would help, and I'll ask you to tell me about the things that matter to you and what are the things you care about when you are feeling poorly. We can talk, play and draw to help you tell me if that would be easier for you. Your (PARENT/CARER) can join us as well if you want. If you get tired or want to take a rest please tell me. Is that OK?

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Any problems it gives with your body? Where on your body, how does it feel?

And how does that make you feel?

How about inside, do you ever feel worried about anything? Do you tell anyone- why?

How about how your illness affects other parts of your life, like seeing friends, going out to do things, school? Can you tell me about your friendships- what is good about them and what could be better? What could help you with your social life?

What about the things you might wonder about- do you have questions about your illness and how you are cared for? Although I am not the right person to answer them for you, I'd like to know what your questions might be? Have you tried asking anyone? Why?

Of all the things you've just told me, what do you think matters most to you? Anything else?

Does anybody ever ask you about that? Would you like them to?

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Topic guide – Child aged 11-15

Version 5.1.- 18th December 2018 C-POS Protocol Tool

IRAS project ID: 250470

I'd really like to hear your ideas about how we could best measure what matters to you, if we were trying to find out how much of a problem something was for you from maybe not at all to bothering you very much, how could we ask that? Some ideas might be pictures showing things getting better or worse, or numbers from very low to high, you could mark it with a pen, you could do it on an ipad screen- what do you think you'd like to do?

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Is there anything else you'd like to ask me or tell me?

Thank you.

Introduction

Thanks for seeing me today. I'll ask you to tell me about the things that matter to you and what are the things related to your health that you care about. Your (PARENT/CARER) can join us as well if you want, it's up to you. If you get tired or want to take a rest please tell me. Is that OK?

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Any problems it gives with your body? Where on your body, what kind of problems do you have?

And how does that make you feel in yourself?

How about inside, do you ever feel worried about anything? Do you tell anyone- why?

How about how your illness affects other parts of your life, like seeing friends, going out to do things, school? Can you tell me about your friendships- what is good about them and what could be better? What could help you with your social life?

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