A national survey: parents’ and therapists’ views about how to evaluate therapy interventions for children

**Are you completing the questionnaire as a healthcare professional or a parent?**

* Healthcare professional
* Parent

This survey consists of three sections:

section 1 is your views about research trials

section 2 is your views about three possible ways to evaluate therapy treatments in a trial section 3 asks for some background details about you to help us know the key characteristics of the people who have completed the survey.

In completing the survey, we ask you to think about children on your caseload, therapy interventions for them, and your everyday clinical practice. By therapy interventions we mean physiotherapy, occupational therapy, and speech and language therapy. This survey does not focus on medicines or surgery.

**It is clear to me how research trials improve children’s therapies and outcomes**

* 1 (disagree)
* 2
* 3
* 4
* 5
* 6
* 7 (agree)

Trials to evaluate treatments involve assigning (‘allocating’) people to treatments by random (e.g. a ‘toss of a coin’), and then seeing how the people assigned to different treatments fare on different health measures. A common way to assign people is to assign individuals as they come to receive treatment. However, for some treatments it is not practical to assign individuals and we need to assign groups of people instead. For example, for a school health trial whole schools may be assigned to either receive the new treatment or not. Or whole therapy teams may be assigned to provide certain types of treatments for all children who are seen by that team. Trials where groups of people are assigned to treatments are called cluster trials, where the word ‘cluster’ means a group. There are many reasons why it may be necessary to assign groups rather than individuals. All the questions below refer to cluster trials (also called cluster randomised controlled trials by a more formal name).

**It makes sense to me how a cluster trial might work in my therapy situation**

* 1 (agree)
* 2
* 3
* 4
* 5
* 6
* 7 (disagree)

**A cluster trial is likely to inform the actual treatments that children receive.**

* 1 (agree)
* 2
* 3
* 4
* 5
* 6
* 7 (disagree)

*Please think about children 0-13 years old, and about the everyday context of your practice*

*Consider this scenario:* You have received information about a cluster trial to evaluate the potential benefits and harms of a children’s therapy treatment. The trial is carried out by an independent university research team and funded by an independent reputable national funder. It has all the necessary research governance and ethics approvals. A member of the research team has attended one of your therapy team meetings to discuss the trial with you. The trial is a cluster trial and will take three years to complete. Your manager has agreed for you to be involved in the trial. The research team now asks you and your therapy colleagues to agree to take part in the trial. As part of the trial, you and your team will be randomly assigned to provide a specific treatment to eligible children on your caseload. The treatment may be usual care or a new treatment that you have not provided before. You will be asked to follow a protocol and instructions about how to provide the assigned treatment (whether it is usual care or a new treatment). You will receive support from the research team and your NHS Trust to take part in the trial, and training to provide the assigned treatment.

**What do you like and dislike about the scenario?**

* Likes \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Dislikes \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**How confident are you that you can agree to take part in the trial?**

* 1 (can not do at all)
* 2
* 3
* 4
* 5
* 6
* 7
* 8
* 9
* 10 ( can definitely do)

**Continuing to think about children 0-13 years old, and the everyday context of your practice, how much effort and resource do you think taking part in a cluster trial will take from you?**

* 1 (a little)
* 2
* 3
* 4
* 5 ( a lot)

**In this scenario, how likely are to take part in the trial?**

* Extremely unlikely
* very unlikely
* unlikely
* Maybe
* Likely
* Very likely
* Extremely likely

*Please continue to think about children 0-13 years old, and about the everyday context of your practice.*

*Consider this scenario:* Today you are seeing a child on your caseload and their parent. The parent and child have recently received a letter about a cluster trial related to some aspects of the child’s treatments. The trial is being carried out by an independent university team, but the letter for the parent has come from your team. You know about the trial and have received training in how to discuss the trial with parents and children. You will discuss the trial with them face-to-face at today’s appointment. You have extra time at the appointment to do this. You will give the parent and child a general overview of the trial, discuss the potential benefits and harms to them, explain what they will be asked to do in the trial, and answer any questions they may have. At the end of the discussion you will ask the parent whether they would like to take part in the trial. The parent can choose to take part, not to take part, or go away and think about it. If the parent chooses to take part, you will complete a consent form with the parent and send the consent form to the research team.

 **What do you like and dislike about the scenario?**

* Likes \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Dislikes \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**How confident are you that you can discuss the trial with the parent and child at the appointment?**

* 1 (can not do at all)
* 2
* 3
* 4
* 5
* 6
* 7
* 8
* 9
* 10 (can definitely do)

**How much effort and resource do you think discussing the trial will take from you?**

* 1 (a little)
* 2
* 3
* 4
* 5 (a lot)

*Please continue to think about children 0-13 years old, and about the everyday context of your practice.*

*Consider this scenario:* You have agreed to take part in a cluster trial – as has a child on your caseload, and their parent. The child and parent have also agreed for you to share information about the child with the research team – including information about the child’s health, difficulties and development extracted from their health records. The relevant governance and ethics permissions are in place, as are consents. As part of the trial, you will also be asked to share practice-related information about yourself with the research team. Specifically, over the coming three years you are asked to complete short questionnaires about your practice, your professional training, and your experiences. The research team may also ask to observe your practice to better understand how the trial intervention is being delivered and how it works in real life. You can choose how much information you share about yourself and whether or not you agree to being observed. You will be invited to share information at different times throughout the three years. All information you agree to share will be transferred securely and protected appropriately.

**What do you like and dislike about the scenario?**

* Likes \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Dislikes \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**How confident are you that you can share information with the research team?**

* 1 (can not do at all)
* 2
* 3
* 4
* 5
* 6
* 7
* 8
* 9
* 10 (can definitely do)

**How much effort and resource do you think sharing information will take from you?**

* 1 (a little)
* 2
* 3
* 4
* 5 ( a lot)

This is the final section which asks some information about you. This information tells us a little bit about the people completing the questionnaire. The information is confidential, and we will not be able to identify you from the information you give.

**What is your profession?**

* Physiotherapist
* Occupational therapist
* Speech and language therapist
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**How many years have you been qualified as a therapist?**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**What is your primary professional role?**

* Therapist
* Service manager
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Are you employed by the NHS?**

* Yes
* No

**What is the name of your employer?**