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 the following sections:

section 1 is your views about research trials generally

section 2 is your views about three possible ways to evaluate therapy treatments

section 3 asks for some background details about you and your child 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 your child, therapy interventions for them, and your everyday life. 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 your child, their therapy, and your everyday life. By therapy we mean physiotherapy, occupational therapy, and speech and language therapy.*

*Imagine this situation:* Your child is receiving therapy. You have recently received a letter from your child’s therapist. The letter tells you about a cluster trial to evaluate some aspect of your child's therapy. The trial is carried out by an independent university research team and funded by an independent reputable national funder. The letter invites you to discuss the trial with someone who knows more about the study. The discussion will give you an overview of the study, benefits and harms of taking part and what you will be asked to do. The discussion will also answer any questions you may have.

 For this discussion, you can:

 1) Discuss the trial with your child’s therapist. The discussion will happen face-to-face at your next routine appointment. The therapist may or may not be directly involved in the trial, but has some information about the trial.

**or**

 2) Discuss the trial with a member of the research team who is trained in research and has detailed information about the trial. You can choose for the discussion to happen over the phone, at your home, or at your local healthcare clinic.

Regardless of who you have the discussion with, the key content will be the same: information about the trial; why it is happening; what you and your child will be asked to do; and the potential benefits and harms. In both options, at the end of the discussion you will be asked whether you would like to take part. You can choose to take part, not to take part, or go away and think about it.

 **What are your initial thoughts and feelings about the situation?**

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**How confident are you that you can discuss the trial *with your therapist at a routine appointment?***

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

**How confident are you that you can discuss the trial *with a research team member over the phone, at home, or at an extra session at the local healthcare clinic*?**

* 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 *with your therapist* will take from you?**

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

**How much effort and resource do you think discussing the trial *with a research team member* will take from you?**

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

*Imagine this situation:* Your child is receiving therapy. You have recently received a letter from your child’s therapist. The letter tells you about a cluster trial to evaluate some aspect of your child's therapy. You have two weeks to consider the information and to speak to someone about the trial. After the two weeks, you need to decide whether or not you want to take part. Your decision does not affect your child's therapy. If you do decide to take part in the trial, your child’s therapist will share information about your child with the research team, e.g. information about your child’s health, difficulties and therapy. You will be told in advance what information will be shared, and any information shared will be kept confidential and secure. If you decide not take part then no information is shared with the research team. *Taking part in the trial means you agree to share information – you are not asked to agree to any changes to your child’s therapy.*

 There are two ways you can tell the research team about your decision:

1) **Opt-out:** It will be assumed that you are willing for information about your child to be shared for the trial. The researchers will not be able to identify your child from the information shared. You will need to opt-out to stop information about your child being shared. You can opt-out by posting a pre-paid reply slip, emailing, or phoning the team, or by informing your child’s therapist. You can opt-out anytime.

2) **Opt-in:** You actively opt-in to take part by telling the research team that you want your child's information to be shared. You can do this by posting a reply slip, emailing, or phoning the research team, or by informing your child’s therapist. If the research team does not hear from you, they will assume you do not want to take part in the trial. You can change your decision at any time and exit the trial if you no longer want to take part.

 **What are your initial thoughts and feelings about the situation?**

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**On balance, would you choose to:**

* Allow information to be shared, unless I specifically opt-out
* Actively opt-in for my chosen trials, and no information to be shared otherwise
* I have no preference

**How confident are you in your choice?**

* 1 Not at all confident (0-20% confident)
* 2
* 3 Somewhat confident (40-60% confident)
* 4
* 5 Very confident (80-100% confident)

**In a situation where you want to take part in the trial, and the only option is to opt-in, how confident are you that you can *opt-in* to the trial?**

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

**In a situation where you do not want information about your child to be shared, and the only option to avoid this to opt-out of the trial, how confident are you that you can *opt-out* of the trial?**

* 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 the action of *replying to the clinical research team* will take from you?**

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

*Imagine this situation:* You have recently opted-in to take part in a cluster trial to evaluate some aspect of your child's therapy. The research is carried out by an independent university-based research team and will take three years to complete. Throughout the study you will be asked to share information about yourself and your child with the research team. This decision is about how you would like the research team to access your child’s health information.

 You can share information:

 1) Directly with the research team, e.g. by completing questionnaires, taking part in interviews or being observed in everyday situations or therapy appointments. You will share information directly with trained researchers who may or may not be healthcare professionals. The research team will keep you and your child’s details (name, address, date of birth, phone number) on file to contact you for the questionnaires etc.

 2) By giving permission for the research team to access existing health information in your child’s therapy record. This information will be included in the trial using an ID number. Your child’s name and exact street address will not be used, but e.g. their postcode and date of birth could be used. The ID number could be later used to contact you about the trial, via the NHS. How you choose to share information will not affect your child's therapy. You can contact the research team at any time to withdraw from the trial. Information will be kept securely at all times, and your information will be protected.

      **What are your initial thoughts and feelings about this situation?**

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**On balance, I would choose to:**

* Share information directly with the research team by completing questionnaires, taking part in interviews and being observed.
* Give permission for the research team to access existing health information stored in my child’s therapy record
* I have no preference

**How confident are you in your choice?**

* 1 Not at all confident (0-20% confident)
* 2
* 3 Somewhat confident (40-60% confident)
* 4
* 5 Very confident (80-100% confident)

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

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

**How confident are you that you can agree to a healthcare professional sharing information from your child's therapy record?**

* 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 directly* with the research team by completing questionnaires, taking part in interviews and being observed will take from you?**

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

Now just some brief information about you and your child and we’ll be done!

*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 gender?**

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**What language do you speak at home?**

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**How old is your child?**

**Does your child have any diagnosed health conditions?**

* Yes
* No

**What diagnosed health conditions does your child have?**

* developmental coordination disorder, dyspraxia or verbal dyspraxia
* autistic spectrum disorder, Asperger’s Syndrome, or specific language impairment (SLI)
* cerebral palsy
* developmental delay, or speech delay
* cognitive delay, learning disability
* other (e.g. attention disorders/ spina bifida,muscular dystrophy, Tourette, dysarthria, Cleft palette, a rare genetic syndrome)

**Who is the main carer for your child?**

* Mother
* Father
* Grandparent
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**What is the main carer's highest educational qualification?**

* Secondary education certificate (O-level/GCE/GCSE)
* College level qualification (HSC/A-Level)
* University Bachelors degree
* University Masters degree
* University Doctorate
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* None of the above

**What is the name of the NHS Trust that provides services to your child?**

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