

## **CHESS – Family Faculty Working Group (2) 6 Nov 2024**

### ***CHESS stands for Children's Early Self-care Support***

Organisers: Jen McAnuff, Richard Sutton, Bel McDonald, Phill Harniess

Attendees: Julia, Lisa, Catarina, Becky, Sam

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1) Bel started off the meeting by sharing the ground rules and the link to [PenCRU's policy on involvement payments and expenses](#).

2) Then Jen led us into introductions and a warm-up game: Hug, Marry, Avoid.

3) Richard gave feedback from our previous (first) meeting in June 2024:

- Family Faculty members gave us a steer on some of the key words and ideas we have been using: like “self-care” and whether other words like “life skills” and “independence” are better. But also, what do “life skills” and “independence” mean for children with complex needs?” We have taken this on board and it’s feeding into all our materials.
- Members also gave us a steer on the CHESS intervention – it should emphasise a positive mindset for the future, building up sustainable habits over time, choosing your battles. Again, we have taken this on board and it’s feeding into all our materials.
- Members also reviewed one of the questionnaires in the study – the one about what services that study participants and their child have accessed in the previous six months (e.g. therapy, hospital, private, charity etc). This feeds directly into the health economics part of the study where we look at the cost-effectiveness of the new approach (CHESS) versus the usual therapy approach. This was incredibly helpful. If you’re interested, you’ll get to see it with all the other questionnaires when we have the online portal set-up, see how it turned out. We’d like you to do some further testing of that online portal with all the questionnaires.

- We talked a bit about our big challenge: recruiting 960 parents and their 0–5-year-olds from across the UK (it’s actually 12 months old to 5-year-olds – Jen got mixed up). That’s what we asked for more help with in today’s meeting.

4) Jen gave a quick background and update to the CHESSE study:

- CHESSE is a £2.5million piece of research. That’s a lot of money and investment, especially in the current climate. We did a quick recap on where CHESSE has come from and why we got that funding.
- The headline is that CHESSE has come from PPI – two PPI projects in particular. [One project](#) was from 2016. We published a small PPI project that we did with young people with neurodisability, parents, and health professionals. Self-care was their top priority for future research. PDF of the project attached to these notes.
- The other was a [PenCRU project](#) led by Chris Morris. It was published in 2014. Working with parents and professionals, they came up with the top ten list of research priorities in childhood neurodisability.
- These PPI projects are the main reason why we were able to influence the research funder and get that investment in CHESSE.

Since last we met, CHESSE has achieved two big milestones:

- (1) We’ve got approval for the study from the Research Ethics Committee. That’s the independent expert committee that judges whether they are happy with the ethics of the CHESSE study.
- (2) Plus, we are in talks with 52 NHS services across the four UK nations saying they are going to take part in the CHESSE study. We need about 40 services, so that’s looking good.

5) The main task in the meeting was about recruitment.

- We need to recruit 960 parents and young children into the study – that’s 24 from each NHS service that joins.

- Most people we invite will receive a recruitment pack through their letterbox. That'll be a little bit different for a small minority who can't access a pack, but we're not going to get into that today.
- At the last workshop, Family Faculty members started telling us about what the recruitment pack should look like. we've also been talking to parent groups in West Yorkshire about this.
- In this meeting, we took you through the structure of the recruitment pack – it's not really drafted yet because we need to get this structure right. In the pack, we're trying to take that “layered, bit-by-bit” approach that Family Faculty members talked about. We will need to set out the “essential elements”, like you recommended. And we will need to direct people on “how to dive deeper”, like you advised.
- We presented this to Family Faculty members bit-by-bit and you listened, read, and thought aloud/reacted/questioned/challenged.
- We took detailed notes on everybody's views and these have fed directly into the first draft of the CHES recruitment materials. After the meeting, we collated everyone's comments and put them together with the comments we have had from another group of parents we are working with – you can see pictures of the summary of comments below.

**Actions:**

Several people said they would be able and willing to comment on the draft recruitment materials. Jen and Bel will be in touch about this separately towards the end of November 2024.

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**Thank you for coming to the session. We hope you will join us for the next one.**

## INVITATION LETTER – ORIENTATION

### *Who is contacting you and why?*

Make it immediately clear which service the invitation is coming from (e.g. local NHS occupational therapy service).

Make it immediately clear which child(ren) this relates to, because parent may have more than one child aged <5 years.

Make the child's position in the service immediately clear (e.g. currently known to x named therapist; or referred onto the waiting list in month/year, by x professional, and due to be seen in next x weeks).

Make the headline focus of the invitation immediately clear:

- Service is taking part in a large national NHS research study (1).
- Research is evaluating NHS therapy approaches for young children aged 12 months to starting full-time school.
- Invitation to support the research by sharing anonymous and confidential information about parent and child.
- Please read this recruitment pack to help you decide whether you would like to take part in the research.

## INVITATION LETTER – ORIENTATION

### *Why are we doing this research?*

The research is evaluating NHS therapy approaches for supporting young children's life skills, independence, and development.

The research is focusing on children aged 12 months to starting full-time school.

Parents and research have told us that this is one of the most important times for laying strong foundations and building children's skills for the future. They want therapists to pay more attention to young children's life skills and independence, including children with very complex needs.

We are taking part in/doing this research because we want to help all young children reach their full potential.

If you decide to take part, you will be contributing to vital research that will improve NHS therapy services for young children in the future.

## INVITATION LETTER – ORIENTATION

### *What will happen in the research?*

This is a large national NHS research study.

40 NHS services are involved across the UK. They are comparing two modern therapy approaches.

In the next x weeks, your local therapy service will be randomly chosen to provide one of these two approaches.

Every therapist in your local service will be fully trained to use this approach. Every child in the service will receive the same approach.

We need to recruit 24 parents to share anonymous and confidential information about their child and themselves.

This information will help us to compare the benefits of the two therapy approaches.

Once we know the benefits, this information can be used to help improve services for parents and their young children across the country.

## INVITATION LETTER – PERSONALISATION

### *Why are we inviting you and your child?*

We need to recruit 24 local parents to share anonymous and confidential information about their child and themselves.

We are inviting you and your child because:

- Your child is within the age range for the research.
- We want to include a mix of children who are at different stages of development and who are experiencing different challenges.
- We want to include a mix of people from different backgrounds and different locations in our area.

## INVITATION LETTER – CREDIBILITY

### *Why can you trust this research?*

Independent researchers from named universities. Reassuring for some people, will not mean much to others and will not be enough for them, unlikely to put anyone off.

Local groups (e.g. parent groups). Reassuring for some people (maybe underserved groups in particular e.g. religious groups), will not mean much to others and will not be enough for them, unlikely to put anyone off.

Expert therapists. Reassuring for most people, unlikely to put anyone off.

Independent ethics committee. Reassuring for some people, unlikely to put anyone off.

Research funded and endorsed by the NIHR and NHS. Reassuring for some people, may raise issues of trust for some people because of current national and local issues with the NHS and will not be enough for them, but unlikely to actively put anyone off.

Local therapists and paediatrician(s). A double-edged sword. Reassuring for many people if they already know and trust the local services. Not meaningful to others if they do not yet know the therapists and paediatrician well. Might put some people off if they are on a long waiting list and/or relations are strained with local services. Might appeal to some people if they are on a long waiting list (e.g. might believe it will help things, something is going to happen after waiting all this time).

Information geared towards trust and credibility must be alongside an answer to the question: what's in this for me? How is it going to help me?

Photographs of the researcher(s) might make the research seem more approachable. (Should the photograph be of the local trustworthy person that parents can contact about the study?)

## STUDY INFORMATION – WORK INVOLVED FOR PARENTS

### *What are we asking parents to do?*

Must make it clear up front that we are asking people to make a decision about whether to get involved / whether to help the research.

Must be very clear about what people would have to do, when, where, how long it will take, and what is the deadline. Be accurate and honest.

There must be flexibility and clarity in all of the above – people are overwhelmed with people and appointments.

The options need to be set out in a very concrete and simple / non-distracting way – people liked the analogy of different options you see when booking an Easyjet or Ryanair flight. Something like the following:

- Option 1 = 4 sets of questionnaires (at the start, 6 months after the start, 9 months after the start, and 12 months after the start)
- Option 2 = option 1 + PE
- Option 3 = option 1 + DCE
- Option 4 = option 1, 2 + 3
- Option 5 = don't take part but have a conversation with us about your decision, so we can improve the way we are approaching parents

The layout and wording should convey that all options / contributions are equally valued.

Indicate that people can drop out at any point and refer to the specific FAQ that gives people more information about this (e.g. that we will retain data etc).

We have had separate advice about how to do reminders (notes attached at end of this slide deck).

## BENEFITS AND RISKS/DISADVANTAGES OF TAKING PART

### *How is the research going to help parents?*

The headline benefits must come first. These should be expressed in terms of helping other people in the future. The following benefits were important to people:

- Making a difference, helping future generations, helping communities, being part of large research study, giving parents a voice, improving services, having a role in working together to make a positive impact, the research has a genuine interest in helping children, being specific about the sorts of positive impact the research is trying to make, getting to hear about the progress of the research and the results.

Although we need to convey that there is no direct benefit to the individual parent and child right now, it is essential to avoid negativity. If we do not emphasise the benefits above, it risks putting people off by thinking, “why would I waste my time for someone else?”

Thought: The main disadvantage is that we are asking people to give up time to take part, complete the questionnaires etc. It seems reasonable to reinforce this in a way that acknowledges how busy people are dealing with services. Shows empathy and insight to their situation.

People can find it difficult to take risks, so it's important to emphasise that we do not see any risks to the child and we will be monitoring safety closely throughout the study.

Would be helpful to again address the fact that we are comparing the benefits of two modern therapy approaches. Every child in the service will receive the same approach regardless of whether the parent is taking part in the research. There is no known advantage of one approach over the other. The child will not be missing out on anything they would usually get from the NHS.