Participant Information Sheet

We would like to invite you to take part in this research study

- Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.
- Joining the study is entirely voluntary. Your decision whether or not to take part in this study will not affect your journey in Conductive Education.
- Please take your time to read this information and think about whether you would like to take part.
- Please ask me if there is anything that is not clear or if you would like more information.

Important things you need to know

- I would like to understand what "hope" means to you and what has influenced your views.
- Taking part in the initial study involves speaking to a researcher (myself) in person for half an hour to an hour.
- Taking part may include taking one or more photographs.
- After this initial interview, I will ask you if you are willing to take a further part in the study.
- You can stop taking part in the research at any time.

How to contact us

If you have any questions about this study, please contact us:

- Researcher: Fiona Holroyd on 07956 309196 or at <u>ttxfh23@nottingham.ac.uk</u>
- Website: www.conductiveeducation.uk
- **Supervisor:** Dr Anne Emerson at ttzae@exmail.nottingham.ac.uk
- In case of a complaint: School of Education Research Ethics Committee, University of Nottingham at <u>educationresearchethics@nottingham.ac.uk</u>

Contents

1. What is the purpose of the study?2
2. Why have I been invited to take part?2
3. Do I have to take part?2
4. What will happen if I decide to take part?2
5. What should I do if I want to take part?4
6. What are the possible benefits or risks of taking part?4
7. Will the information I provide be kept confidential?5
8. What will happen to the results of the research study?5
9. Who has given approval for the study to take place?6
10. Who can I speak to if I have queries or complaints about the study? 6
11. Further Information and Contact Details6
12. Contact Me Form7

To participate in this study please contact me:

Fiona Holroyd on 07956 309196 or at ttxfh23@nottingham.ac.uk

Or post the "**Contact Me**" form to me.

Participant Information Sheet

1. What is the purpose of the study?

Hope is generally accepted as being positive, contributing to our well-being and happiness, and important in understanding how we as humans flourish. However, the meaning of hope may be different for all of us.

There is very little research that has looked at hope in relation to the well-being of parents such as yourself. The objective of this research will be to understand what 'hope' means to you. I would like to find out your views about hope and what has influenced you views. This important information will help me to build a picture of hope and add to the understanding of hope.

I am a senior conductor working at an early years Conductive Education Centre in the East Midlands. I am currently doing my PhD at the University of Nottingham, of which this study is a part. My supervisor, Dr Anne Emerson, is an Associate Professor of Special and Inclusive Education at the University of Nottingham.

2. Why have I been invited to take part?

You have been invited to take part in the study because you are a parent of a child with cerebral palsy (aged 5 and under) who began attending a Conductive Education Centre within the last 6 months. Please tell me if this is not the case.

3. Do I have to take part?

Taking part is entirely voluntary. You don't have to take part or explain why you don't want to. Whether or not you chose to take part, please be assured your journey within Conductive Education will not be affected by your decision.

4. What will happen if I decide to take part?

If you decide to take part, I will contact you for an initial introduction to the study and to arrange an interview at a time and location most convenient for you. The interview will be face to face. Where that is not possible,

Participant Information Sheet

and only in exceptional circumstances eg. a pandemic, the interview can take place online eg. using MS Teams.

Prior to the interview, you will be asked to take some photographs, one or as many as you like, which represent what hope is and/or what it means to you personally. The aim of taking the photographs is to encourage an initial reflection of your experiences of hope – what it is and what it means to you. The images will be shared with me. Any identifiable features in the photographs will be anonymised and images will be stored securely on University of Nottingham computers which are protected by a password.

I will not judge the quality or creativity of the images. Taking photographs is entirely voluntary and until the moment of publication, you can ask that your images not be used, shared, or distributed. Your photographs will then either be destroyed, deleted, or returned to you.

You have complete control over how you take the photographs (disposable camera, Smartphone, or digital camera) and their content. However, I do ask that if you decide to take photographs, please be conscious of not taking photographs of any illegal activity, people who indicated (verbally or nonverbally) that they do not want to be photographed, and photographs that may stigmatize, embarrass, or shame individuals or groups. If you want to take images of people, I encourage you to take photographs that "represent" the person, rather than an image of the person themselves.

I also want to find out about your personal thoughts, feelings, and experiences regarding hope so I will ask you some questions to help you share those with me. During the interview we can use the photographs you have taken, this will make our conversation more personal and images sometimes make it easier to put thoughts into words. The interview will take around half an hour to an hour, although you are free to finish the interview at any time if you no longer want to continue.

I will ask you at the beginning of the interview if you are happy for the interview to be recorded. Recordings will be stored securely on University of Nottingham computers which are protected by a password. The transcript of the interview will be typed out and where possible your details will be removed so that you cannot be identified.

At the end of the interview, I will ask you if you would be willing, at a later date, to take a further part in this study. This will allow me to ask you any follow up questions and for us to talk about any changes in your

Participant Information Sheet

thoughts on hope. If you consent to be contacted again, detailed information about what you will be asked to do will be given to you at the time, so you can make an informed decision whether you wish to continue.

5. What should I do if I want to take part?

I hope that you will be able to take part. If you are interested, please get in touch with me:

- 1. You can contact me by phone or email, my details are on this form.
- 2. You can go to the study website at <u>www.conductiveeducation.uk</u> and complete the Contact Us form.
- 3. You can complete the attached form and return it in the post to me at the following address Steps Conductive Education Centre, 40 Loughborough Road, Shepshed, Loughborough, LE12 9DN.

I will then contact you for an initial introduction to the study. If you agree to take part, together we will then arrange an interview at a time and location most convenient for you.

6. What are the possible benefits or risks of taking part?

As a parent you will be helping to further our understanding of the complexity of hope. With all that is written about hope, there is very little which applies to you, as a specific group of parents. In light of this lack of existing knowledge, you will therefore be contributing towards the creation of a distinctive body of research.

It is anticipated the findings of this study will inform health professionals working in this and other related fields.

Your journey as a parent of a child with cerebral palsy is unique. The interview process may stir up emotions and feelings relating to this journey. That is understandable. I work with parents, just like yourself, on a daily basis. I hope this gives me the familiarity and understanding to conduct the study in a sensitive and compassionate manner. Nevertheless, you may ask for the interview to pause or end at any stage, without giving any reasons.

Participant Information Sheet

7. Will the information I provide be kept confidential?

Yes. I will follow ethical and legal practice and all information collected about you will be kept strictly confidential, secured within the University of Nottingham.

Where possible, all identifying details will be removed from the information you share with me. Where the interview takes place online, it will not be possible to remove all identifying details from the recorded video. However, this information will be linked to your identity only through a unique participant ID number, stored on a separate master list. This master list containing your personal data (name, contact details, your participant ID number for example) will therefore be kept separately from your interview data in OneDrive (encrypted) on a University of Nottingham computer server, also protected by a password. Only the researcher will have access to your personal data. Your personal data will only be used as needed: to contact you about the research study, to make sure that relevant information about the study is recorded for your care, to oversee the quality of the study and for invitations to possible follow-up studies (unless you have let me know that you do not wish to be contacted). Your personal data and identifiable research data (your interviews, photographs etc.) will be kept in OneDrive (encrypted) on a University of Nottingham computer server, protected by a password. Data will be stored according to University of Nottingham's requirements for a minimum of 7 years.

If you withdraw from the study at any stage, you may decide whether or not you want the information you have already provided to be used (with no personally identifiable information) or destroyed.

Regulations on how we use and store your information fall under the General Data Protection Regulations (GDPR). For more information about the University's obligations with respect to your data, who you can get in touch with and your rights as a data subject, please visit:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

8. What will happen to the results of the research study?

Results of the study will be used by myself as part fulfilment of a PhD at the University of Nottingham. Additionally, I may publish the results of this study in the academic press, present the information at academic conferences and on other websites (such as Conductive Education) relevant to the study. Rest

Participant Information Sheet

assured that all information provided by yourself will be anonymised in any publications so it will not be possible for anyone to identify you from the published results.

A summary of the research findings will be available to you at the end of the study if you would like it.

9. Who has given approval for the study to take place?

This research is being supervised by the University of Nottingham. All research in the University of Nottingham is looked at by a group of people, called a Research Ethics Committee (REC), to protect your interests. This study has received full ethical approval by the School of Education Research Ethics Committee.

10. Who can I speak to if I have queries or complaints about the study?

If you have a concern about any aspect of this study, please speak to either Fiona or Anne. We will do our best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the School of Education Research Ethics Officer. All contact details are given below.

11. Further Information and Contact Details

The website for this study is <u>www.conductiveeducation.uk</u> and will be kept up to date with progress.

Researcher: Fiona Holroyd Telephone: 07956 309196 Email: <u>ttxfh23@nottingham.ac.uk</u>

<u>Supervisor:</u> Dr Anne Emerson Email: ttzae@exmail.nottingham.ac.uk.

<u>University of Nottingham School of Education Research Ethics Officer:</u> Email: <u>educationresearchethics@nottingham.ac.uk</u>

Thank you for reading this information sheet and for considering taking part in this research.

Participant Information Sheet

12. Contact Me Form

Thank you for your interest in this research and I hope that you will be able to take part.

If you are interested, please fill in your contact details below:

Your Name:

Your Phone Number:

Your Email Address:

Once you have completed the form, please post it to me at the following address:

Fiona Holroyd

Steps Conductive Education Centre

40 Loughborough Road

Shepshed

Loughborough

LE12 9DN

You can also get in touch with me by phone or email, my details are on this form, or you can go to the study website at <u>www.conductiveeducation.uk</u> and my contact details are online.