Participant information sheet- Parent, Carer or Guardian participant.

Study title: HOPSCOTCH: Helping Optimise Primary Care Support During Transition From Children's Hospice Care

We would like to invite you to take part in this research study. To help you decide whether you would like to take part or not, it is important that you understand why the study is being done and what it will involve. Please carefully read the information.

What is the purpose of the study?

The study aims to develop a toolbox of resources to help people working in GP practices to become more involved in the care of young people with life limiting conditions, particularly at the point when young people leave children's hospice and move into adult services (transition).

This will improve the quality of care received by young people and their families. We want to work in partnership with young people and their families so that the design of the toolbox is shaped by their needs.

Why have I been invited?

We would like to speak with family member/carers with experience of supporting a young person who:

- Has transitioned from children's hospice services to adult services within the last 5 years.
- Has started the process of transitioning from children's hospice services to adult services.

We aim to speak to a minimum of 18 people including young people and family/carers. We will also be speaking with healthcare professionals who have experience of supporting young people at the time of leaving children's hospice care.

Do I have to take part?

No, it is up to you to decide whether you wish to take part. Withdrawal or not taking part will not affect your or your young person's care in any way. If you change your mind and would like to remove your comments from the study, this will be possible up to 2 weeks after your interview by contacting the research team.

What will I be asked to do?

Part 1: We want to hear about your experiences of supporting a young person who has or is preparing to change from children's hospice services to adult services.

You would take part in an interview with a researcher. You would choose how you would like to do your interview. We can use Microsoft Teams video or telephone call. Interviews can also happen face to face at a place where we can have an undisturbed conversation e.g. home, hospice. A friend, carer or relative may accompany you in the interview if you wish.

We will invite you to tell your story regarding the experience and/or thoughts of the transition process. We will also ask questions to help us understand in more detail. We are particularly interested in whether your GP and other staff from the GP practice have been involved.

Interviews will last around 60 minutes. You can end the interview at any point and do not have to answer any questions that you do not wish to. The interview will be recorded for sound and also video (if you give us permission)

Your words from the interview will be written out and may be used in development of an animation. The animation will be shared with the public on websites, at research and medical conferences and at workshops with carers, families, young people and healthcare professionals. You will not be identifiable other to people involved in running the research. It is important that you understand this and, you are happy that your words may be shared.

If you agree to being video recorded, parts of the recording may be combined with film from the interviews with other family members and young people to make a 'catalyst film'. You will be able to say which parts of your recording can be included in the film and say if there are any parts you do not wish to be used. The catalyst film will be made up of young people and families talking about key points about going through or expecting the transition process and how they felt about this. People will be able to see who you are in this film. The film will be used in workshops (part 2 and 3) with other families, young people and healthcare professionals taking part in the research.

If you agree to video recording, you will be asked whether you also give permission for the film to be publicly shared e.g. at conferences, on websites and in presentations and journals.

Part 2: We will invite you and other participants (young people and families) to a feedback workshop to discuss what we learned from the interviews and help identify which parts of the transition process could be made better. We will watch and discuss the catalyst film and/or animation. This workshop may be online or face to face.

Part 3: We will invite you to a 2nd workshop with healthcare professionals, families and young people. The film and/or animation developed from part 1 will be shared with the other people who took part in interviews. These will be healthcare professionals, young people with life limiting conditions and families. We will work together to design the HOPSCOTCH resources.

Part 4: You may meet with a researcher and other family members in a small group to help design parts of the resources. We will meet online.

Taking part in an interview does not mean that you have to take parts 2, 3 and 4. We would like you to be involved in as much as possible but how many activities you wish to be involved in will be your choice.

What are the benefits of taking part?

There is no payment for taking part. Your participation will be a valuable and much appreciated addition to improving care. We hope what we learn will improve the experience of other young people and families in the future. Taking part will give the opportunity for your views and experiences to be heard.

What are the possible risks of taking part?

It is possible talking about your experiences may be upsetting. If this is the case, we will make some suggestions who you might like to talk about this with. If during your interview or workshop you tell us about something that suggests you or someone else is at risk of serious harm, we will contact an appropriate person to help. We would need to share your contact details with them. This may be someone at the children's hospice if you are currently supported by them, or a local Adult Safeguarding team.

How will we use information about you?

University of Leeds is the sponsor of this research.

The University of Leeds is responsible for looking after your information We work in accordance with the Data Protection Act 2018 and University of Leeds policies. Your identifiable data will not be shared outside the UK.

The link to the University Privacy Notice for Research is:

https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf

We will need to use information from you for this research project. This will include your name, age, gender, ethnicity, medical condition, postcode and contact details. Your full name or contact details will not be used other than for arranging the research.

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure by:

- Giving your data a study code number which will be used in most instances instead of your name.
- Securely storing data where it can only be accessed by the research team.
- Only publicly sharing data that you have given us permission to share.

If you agree to your words or film from your interview (from part 1) being used to develop an animation or a film, we will need to share these with professional external companies who help us to produce these. A confidentiality agreement will be in place to say what they may use your film and words for. We will not share personal details such as your name or contact details with these companies.

We will keep your study data for a maximum of 3 years after the study ends. The study data will then be fully anonymised and securely archived or destroyed.

Interviews will be written out word-for-word, and these transcripts stored securely on university password-protected computers. We may use direct quotations from the interviews when we share the research.

What are your choices about how your information is used?

- you can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have
- you have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this

Where can I find out more about how your information is used?

You can find out more about how we use your information:

- **www.hra.nhs.uk/patientdataandresearch**
- by asking one of the research team or by sending an email to the University data protection officer at dpo@leeds.ac.uk

Who is running and paying for the project?

This work is funded by the National Institute for Health and Care Research (NIHR159019) and is led by Professor Lucy Ziegler from the Academic Unit of Palliative Care, School of Medicine at the University of Leeds.

How do I take part?
If you complete a 'consent to contact' form, a researcher will call or email you to tell you more about the project and if you wish an interview will be arranged. This form will be provided at the same time as this information sheet.

What if I have concerns about this project?
If you have any concerns, please contact the research team in the first instance. For independent advice or complaints contact The University of Leeds Sponsor Representative at governance-ethics@leeds.ac.uk

You can ask the researchers to send you a summary of the results of the project.

Thank you for reading this information and considering taking part in the study.

If you need further information or have any questions, please get in touch.

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