

Information sheet- Young people

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

What is the purpose of the project?

The project aims to develop resources to help people working in GP practices to become more involved in the care of young people with life limiting conditions. We are particularly keen to improve care around the time young people move on from children's hospice care (transition).

These resources 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 resources is shaped by their needs.

Why have I been invited?

We aim to speak to a total of 18 young people. We would like to speak with young people (14 years and older) who are in one of these groups:

- Young people who have used children's hospice services within the last 5 years and are now cared for by an adult service.
- Young people who have begun the process of moving between children's and adult services.

We will also be speaking with family members and healthcare professionals who have experience of supporting young people at the time of leaving children's hospice care.

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 in the future. Taking part will give the opportunity for your views and experiences to be heard.

Do I have to take part?

No, it is up to you to decide whether you wish to take part. Your decision will not affect the care you receive in any way.

If I choose to take part, what will I be asked to do?

Part 1: We want to hear about your experiences of changing (or preparing to change) from children's hospice services to adult services.

You will take part in an interview with a researcher. You can choose how you would like to do your interview. We can use Microsoft Teams video or a telephone call. Interviews can also happen face to

face at a place where we can have an undisturbed conversation e.g. your home or the hospice. A friend, carer or relative may accompany you in the interview if you wish.

We will invite you to tell your story regarding your experience of moving from or preparing to move from children's hospice care and your thoughts and feelings about it.

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 in your care.

Interviews will last as long as you like up to a maximum of 60 minutes. You can end the interview at any point and do not have to answer any questions that you do not wish to. With your permission the interview will be recorded for sound and video. Interviews will be written out word-for-word, and these transcripts stored securely on university password-protected computers. We may use your words from the interviews when we share the research but will not say who you are.

The audio or your words from the interview may be used in an animation (film made from moving images or drawings). 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. It is important that you understand this and you are happy that what you say in the interview may be shared.

If you agree to being video recorded, parts of the recording may be combined with clips from other young people interviews to make a short film. The 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 but you will be able to say which parts of your recording can be included or if there are any parts you do not wish to be used. At a workshop (part 3) this film will be shared with the other people who took part in interviews. These will be healthcare professionals, other young people with life limiting conditions and families.

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 film. This workshop may be online or face to face.

Part 3: We will invite you to a second workshop with healthcare professionals, parents, carers and other young people to design the HOPSCOTCH resources.

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

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

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 why we are worried and your contact details with them. This may be someone at the children's hospice if you are currently supported by them, your parent or guardian if you are under 18 or a local Adult Safeguarding team if you are over 18.

How will we use information about you?

University of Leeds is the sponsor of this research. 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 information 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.

The University of Leeds is responsible for looking after your information.

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. When we have done this, the audio recording will be deleted. This will happen within 6 months of your interview.

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
- by sending an email to the University data protection officer at dpo@leeds.ac.uk
- You may also like to watch this short film for young people about General Data Protection Regulations <https://www.youtube.com/watch?v=Vll6V1MgZgY>

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 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 then if you wish to go ahead, 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 after taking part, you change your mind and would like to remove your comments from the project, this will be possible up to 2 weeks after your interview by contacting the research team. Withdrawal or not taking part in the study will not affect your care in any way. If you or your parent or guardian have concerns, please contact the research team. 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 when it is complete.

Thank you for reading this information and considering taking part.

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

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