

## Information sheet- Young people

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

#### **What does this have to do with me?**

Care around the time young people move on from children's hospice support (transition) needs improving. HOPSCOTCH will design resources to help people working in GP practices to become more involved in the care of young people with life limiting conditions.

These resources will improve the care received by young people and their families. We need to work with young people and their families so that the resources are shaped by what they want.

We want to speak with to up to 18 young people (age 14 years and above).

- Young people who have used children's hospice services within the last 5 years but do not now.
- Young people who are expecting to move from children's hospice support.

We will also speak with family members and healthcare staff.

#### **What are the benefits of taking part?**

There is no payment for taking part. What you tell us will improve care for other young people in the future. Taking part will allow you to tell us about your views and experiences.

#### **Do I have to take part?**

You do not have to take part. Taking part or not taking part will not affect your care

#### **What will I have to do?**

##### **Part 1: We want to hear about leaving (or preparing to leave) children's hospice.**

You will have an interview with a researcher. You will be asked whether your interview may be recorded for sound and video. The researcher will ask you questions. You can choose how you would like to do this. We can use Microsoft Teams video or a phone call. Interviews can also be face to face at somewhere where we can have a quiet talk e.g. your home or hospice. A friend, carer or relative can also be there if you like. Interviews can be as short or long as you like. We plan that interviews will not be longer than an hour. You can end the interview whenever you like. You do not have to answer all questions.

We will ask you to tell us about moving from or thinking about moving from children's hospice care. We will ask about your feelings around this. We would like to hear about how much your GP and other staff from the GP practice have been involved in your care.

The audio (sound) or your words from the interview may be used in an animation. An animation is a film made from moving images or drawings. The animation will be shared at workshops and with the public. It is important that you know that what you say in the interview may be shared. If we share your words or audio, we will not say who you are. The whole recording of your interview will be stored for up to 6 months and then deleted.

If you are video recorded, parts of your recording may be put with parts of other interviews to make a short film. It will be possible to see who you are in this film. You can say which parts of your recording can be used and which cannot. The film will be shared in workshops with the others who did interviews. These will be healthcare staff, other young people with life limiting conditions and families.

You will be asked whether it is OK for us to share the film where anyone in the world may see it e.g. at meetings, on websites and in talks.

Interviews will be typed out word-for-word. These documents will be 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.

**Part 2: We will invite you to a feedback workshop.** The workshop will be with other people taking part (young people and families). We will talk about what everyone said in the interviews and see how leaving children's hospice could be made better. We will watch and talk about the film. This workshop may be online or face to face.

**Part 3: We will invite you to a second workshop.** This will be with other young people, healthcare staff, parents, carers. We will work together to plan the HOPSCOTCH resources.

**Part 4: You may attend a small online group with other young people.** You will work with a researcher to help plan parts of the resources.

We would like you to be involved as much as you can but how many parts you do is up to you.

### **What are the risks of taking part?**

Talking about your experiences may be upsetting. If this happens, 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 makes us think you or someone else is at risk of serious harm, we will contact someone 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, 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?**

The University of Leeds runs the research and is responsible for looking after your information.

We follow the Data Protection Act 2018 and University of Leeds policies. Your identifiable data will not be shared outside the UK.

More information is found here: <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf>

We will use information from you for this research. This will include your name, age, gender, ethnicity, medical condition, postcode and contact details. Your full name or contact details will only be used for arranging the research.

People will use this information to make sure that the research is being done properly.

Only people who need to know who you are will 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.

- We give your data a code number which is mostly used instead of your name.
- We securely store data where it can only be seen by the research team.
- We only publicly sharing data that you said we could.

If you agree to words or film from your interview being used in the animation or film, we will share these with companies who help us to make these. The company will only use your film and words for this project. We will not share your name or contact details with companies.

We will keep your data for a maximum of **3** years after the study ends. The data will then be anonymised (this means we cannot link who you are to the data) and securely stored or destroyed.

#### **What are my choices about how information about me is used?**

- you can stop being part of the study at any time, without giving a reason. We will keep information about you that we already have
- you can ask us to see, change or remove data we have about you. You can say that you do not want us to process 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.

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

- [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- by asking the researcher
- by sending an email to the University data protection officer at [dpo@leeds.ac.uk](mailto:dpo@leeds.ac.uk)
- This is a short film for young people about General Data Protection rules  
<https://www.youtube.com/watch?v=Vll6V1MgZgY>

#### **Who is running and paying for the project?**

This work is paid for by the National Institute for Health and Care Research (NIHR159019). Professor Lucy Ziegler from the University of Leeds is in charge of the project.

### **How do I take part?**

If you fill in a 'Consent to Contact' form, a researcher will call or email you. We will tell you more about the project and answer any questions. If you want to take part, we will book an interview.

### **What if I have concerns about this project?**

If you change your mind about being involved in the project, please contact the researcher. This is possible for up to 2 weeks after your interview. If you do not take part or leave the project, this will not affect your care in any way.

If you or your parent or guardian have concerns, please contact the researcher. If you need advice or want to complain please contact The University of Leeds at [governance-ethics@leeds.ac.uk](mailto:governance-ethics@leeds.ac.uk)  
You can ask the researcher to send you a summary of the results of the project.

Thank you for reading this information and thinking about taking part.

If you have any questions,  
please get in touch.

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