Participant information sheet- Healthcare professional

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

You are being invited to take part in this study. Before you decide it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Taking part is completely voluntary, if you do decide to take part, you will be given a copy of this sheet and asked to sign a consent form.

What is the purpose of the project?

General Practitioners (GPs) and the primary care team have an important role to play in the care of children and young people with life-limiting conditions (LLCs) and their family members particularly at the point of transition to adult services. Their involvement has been shown to reduce emergency secondary care use and facilitate person centred continuity of care for this population. Despite this, care during childhood is typically led by specialist services with limited involvement of primary care[1].

This study aims to develop a toolbox of resources to improve engagement of primary care services in the care of young people with LLC with a specific focus on the point of transition to adult services.

Why have I been chosen?

You have been chosen as you are a GP or other member of primary care staff, or other clinician with responsibility in the process of transition of young people between children's and adult services.

We wish to talk to 6 each of;

- Primary care staff including GPs
- Paediatric palliative care clinicians
- Adult palliative care clinicians

We will also be speaking with young people and their family members who have experience of transition from children's hospice care or are expecting to undergo the transition process in the next few years.

What are the benefits of taking part?

Your participation will be a valuable and much appreciated addition to the project, and we hope what we learn from this project will help improve the experience of young people in the future and enable HCPs to provide the most appropriate care. Taking part will give the opportunity for your views and experiences to be heard. Backfill funding will be available to enable your participation if necessary. We will inform you how to claim this at your interview.

Any risks?

We expect that you will find taking part in this research an interesting and rewarding experience. Reflecting upon your clinical practice could raise uncomfortable emotions. However, it is likely that the benefits of increased knowledge will outweigh any risk.

What will I have to do?

Part 1: You would take part in an individual interview at your place of work using Microsoft Teams or face to face. Interviews would last approximately 60 minutes.

Primary care - Interviews will focus on the transition process and explore potential opportunities to engage with young people with LLC and their families at the time of transition, including those that align to existing primary care services such as medication reviews and learning disability checks. Confidence and perceived competence to provide palliative care to young people with LLCs, and training needs, will also be explored. We will discuss documentation currently used to support transition and communication between services.

Palliative care clinicians - Interviews will focus on the current transition process within your organisation, including barriers and enablers to successful transition and opportunities to engage primary care staff in the transition process. We will discuss documentation currently used to support transition and communication between services.

The interview will be audio recorded. Your words from the interview may be used in production of an animation. You will not be identifiable to anyone other than the research team in this animation. The animation may be publicly shared on our website, at research and medical conferences and at workshops with carers, families, young people and healthcare professionals.

Part 2: We will invite you to an online feedback workshop with other healthcare professionals to discuss what we have learnt from the interviews and help identify which parts of the transition process could be made better. This workshop may be online or face to face.

Part 3: We will invite you to a 2nd workshop with young people, healthcare professionals and other family and carers. We will work together to design the HOPSCOTCH toolkit. This workshop may be online or face to face.

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

Do I have to take part?

No, it is entirely up to you to decide whether to take part in this study. If you do decide to take part, you will be given this information sheet to keep. If you complete a 'consent to contact' form, you will be contacted by a researcher to discuss the project and if you wish an interview will be arranged. If you would like to withdraw from the project, this will be possible up to 2 weeks after your individual interview by contacting the research team. It is not possible to withdraw your participation from a workshop.

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, professional role and contact details. 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.

How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

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. Audio data will be destroyed once your interview has been transcribed (written out). We expect this to take no longer than 6 months.

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

What will you do with the interview information?

Analysis will focus on barriers and facilitators to providing quality and equitable care at transition, and how different experiences of transition impact on care and quality of life including opportunities for social interaction psychological support and family support.

Personal information will be pseudoanonymised and be stored securely in accordance with strict University guidelines. Information from interviews would be used in peer reviewed publications, communications to the public and to other professionals.

What if I have concerns about this study?

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

Further Information

Thank you for taking the time to read this information sheet.

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

www.hra.nhs.uk/information-about-patients/

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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1. https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf