

PARTICIPANT INFORMATION SHEET for family members

Vulnerable young people living with life-limiting or life-threatening conditions and their families: A study of the non-intended consequences of epidemic control decisions

The Open University in collaboration with *Together for Short Lives*, *Hospice UK* and the *International Children's Palliative Care Network* would like to learn more about your life during the COVID-19 pandemic. This research may inform future policy and practice.

This information sheet provides you with more information about this study

Who are we?

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What is the aim of this project?

The Open University supports research which has the potential to improve people's lives. In this project we would like to learn more about your life during the COVID-19 pandemic so that we can better support families like you. We are interested in:

- Understanding your experiences and needs and those of your family member
- Developing information that would be useful to you and your family
- Exploring what needs to change in the future so that young people with life-limiting or life-threatening conditions and their families are well-supported.

What is involved?

We would like you to participate in an online interview which will last up to 1 ½ hours (using video conferencing software on your computer or smartphone). You will be able to take breaks during the interview, or schedule your interview over more than one day, if you need to.

The research questions will focus on your personal experiences during the pandemic as someone who lives with, supports or cares for a young person with a life-limiting or life-threatening condition. We will ask you about how you are coping with staying at home and how your life has changed because of COVID. We will ask you about your family member and about any changes they have experienced such as changes to their care, their wishes about end-of-life, and their wellbeing.

We will then transcribe and analyse the interview data and prepare reports, articles and presentations about the issues that have been raised.

If you wish, we will send you copies of reports and articles that we write.

If you choose to participate you will be given a £40 Amazon voucher to thank you for your time.

Do I have to take part?

No. We are relying on your voluntary consent. No one is taking part in this study who does not want to. Even if you say yes to begin with, you are free to withdraw from the study before and during the interview and up to one month after your interview. If you withdraw from the study your data will be destroyed. You can let us know whether you want us to use your data in the event of your death.

If you decide to take part but then you change your mind please get in touch with a member of the research team to let them know. We will not tell anyone that you have done this.

Is it confidential?

Yes. No personal information will be published or passed on to anyone outside of the research team. (This would include things such as your name, where you live or details of very rare conditions that could identify you or your family member personally).

However, if we thought you were in immediate danger, we would call emergency services to assist you. If we think that a child or vulnerable person is at risk, we may contact Social Services to ensure that appropriate support can be given but we would discuss this with you first if possible.

No individual will be publicly identifiable from the publications.

This project has been reviewed by, and received a favourable opinion from, The Open University Human Research Ethics Committee, reference HREC/3595/Earle

Our responsibilities to you

We guard and respect your privacy: your participation will be treated in strict confidence in accordance with the Data Protection Act 2018 (UK). As per the General Data Protection Regulation (GDPR), your contribution will be used for research purposes only but for this to happen we will obtain your written consent. Nobody will be individually identified in any publications. You will have the opportunity to withdraw from the project before, during and for up to one month after your interview. Nobody will be informed about whether you are participating, or refuse to participate, or if you withdraw from the project.

We securely store the data: the data we collect will be kept securely at the Open University for 10 years. The data will be available to other researchers so it can be used for future research and learning. We will destroy the data after 10 years.

We respect your wishes: participation in the study is voluntary and you are not obliged to answer any questions you do not wish to. At any time, you have the right to ask us for access to the data we have collected from you.

We answer your questions: we will be happy to answer any questions you may have about the research.

What happens now?

You will be asked to read and complete an online consent form. In the meantime, if you have any queries at all about the study, please contact the Principal Investigator (Dr Sarah Earle) or another member of the research team listed on this form.

If you have a concern about this research project, please contact: Professor Regine Hampel, Associate Dean for Research ☎+44 (0)1908 858704 ✉regine.hampel@open.ac.uk

Thank you!

We really do appreciate your time and your contribution to valuable research during the COVID-19 pandemic.