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**Parent/Guardian Information Sheet for taking part in study**

**Study title:** Quality of life for young people living with illness

**Researcher name:** Isabella Floredin

This is an invitation to take part in an interview for a research study.

**Please take time to read the following information and feel free to ask for more information if something is not clear.**

**What is the study about?**

This study aims to explore the things that are important to young people (14-25 years old) who are seriously ill and/or expected to live a shorter life. This will include asking parents/guardians of young people who are currently not able to take part in the study directly about the things that matter to their child.

The study findings may help inform the way care for young people is funded based on their needs and what young people view as important.

**Am I eligible to take part?**

We would like you to participate in the study if you are a parent/guardian of:

a young person, 14 – 25 years old, who is seriously ill and/or expected to live a shorter life and who is currently not able to take part in the study directly.

**What does taking part involve?**

* We will ask you to complete and return the questionnaire and consent form enclosed.
* Then, the study researcher will be in touch with you to arrange a virtual interview, for example via Skype or a similar online platform, at a time that is most convenient to you. If you do not have access to an electronic device to use for the interview, please let the researcher know.
* The interview will last for up to an hour but with breaks if needed and with your permission it will be audio and video recorded.
* You are free to ask for the interview or recording to stop at any time. You can withdraw from the study at any time if you change your mind and you do not have to answer all the questions if you do not want to.
* The researcher will give you a £10 voucher as a thank you
* The interviewer may invite you to take part in a second interview at a later date but you do not have to take part.
* If you would like to withdraw from the study after your interview, please let us know within a week of the interview and your data will then be destroyed. If you notify us after this time period, it is possible that the data may already have been analysed and used to inform future interviews and thus it will not be possible to withdraw your data from the study
* We may not be able to interview all those interested in taking part in the study. In that case, the researcher will contact you following receipt of your questionnaire and consent form to let you know and your questionnaire and consent form will be securely destroyed by the researcher.

**What will the interview be about?**

In the interview you will be asked about the things that you feel are important to your child.

During the interview, it is possible that sensitive topics may arise that are upsetting or difficult to answer. If you feel uncomfortable in any way during or after the interview, please let the interviewer know.

**Will my participation and personal information be kept confidential?**

* All personal information collected from you will be kept confidential and your name will be removed from any information connected to you. Any names and places you mention will be anonymised so that you cannot be recognised from this.
* The interview will be written up and anonymised and the interview audio and video recording will be kept on a secure computer network at the University of Bristol. Only those directly involved in the study will be able to access this information, that is Isabella Floredin and her academic supervisors.
* Any paper copies including your personal information will be uploaded electronically and then paper copies will be destroyed.
* If you tell us that you are at risk to yourself or others then it is a statutory requirement to report this as part of safeguarding measures

**If I decide I would like to take part:**

* **Please complete and return the questionnaire and consent form enclosed. This information sheet is for you to keep**
* Then, Isabella will get in touch with you to arrange a time for the interview.

**What if I have a concern or complaint?**

If you have a concern or complaint as a participant in this study, you may contact the Faculty of Health Science Research Ethics Committee, via the Research Governance Team, research-governance@bristol.ac.uk

**Where can I get more information?**

If you would like more information about this study or a copy of your interview transcript, please contact Isabella Floredin at - Address: Population health sciences, Bristol Medical School, University of Bristol, 1-5 Whiteladies Road, Bristol, BS8 1NU, Tel: +441174282096, Email: isabella.floredin@bristol.ac.uk

**This study is part of a University of Bristol project funded by the Wellcome Trust and has been approved by the University of Bristol Research Ethics Committee.**