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**Children and Young People Quality of Life Study**

 **Information Sheet for Parents/Guardians**

**What is the Children and Young People Quality of Life Study?**

This study is about helping researchers and decision-makers to learn about what is important to children and young people. We are interested in the views of parents/guardians in addition to young people themselves. The study is funded by Wellcome and has been approved by the University of Bristol Ethics Committee.

**Why have I been asked to take part?**

You have been asked to take part in the study because you have a child aged 0-18. We would like to speak to you about what you think is important in your child’s life, both now and in the future. If your child is aged 6-18 years old, we would also like your permission to talk to your child about what is important to them. The findings from the research will help decision-makers to decide how healthcare is funded for children and young people.

**What will I have to do?**

We would like you to take part in an interview about what you think is important to your child now, and in the future. If you are happy, the interview will be undertaken online using a secure online platform. With your permission, we will record the interview. The interview will last around 1 hour. We would also like to talk to your child about what is important to them. With your permission, we will interview your child on the same day we interview you. You can be present for your child’s interview if you wish. Your child will be given a £10 voucher as a thank you for taking part. We might also ask you to take part in a follow-up interview in the future.

**Do I have to take part?**

No, you don’t have to take part. If you decide to take part and then change your mind, you can withdraw from the research at any time. If you don’t want to take part in the research but are happy for your child to, that is also fine. A member of the research team will go through the study information with your child and ensure they know that they are free to withdraw from the study at any time. If you decide to withdraw from the research after the interview, please ensure to notify us within a week of the interview; the data you have provided will then be destroyed. If you notify us after this time period it is possible the data may already have been analysed and used to inform future interviews.

**What will happen to our data?**

Yours and your child’s data will be analysed and stored electronically on a secure computer network at the University of Bristol. Any hard copies of this information will be locked in a secure filing cabinet at the research base (University of Bristol). Your personal data will be stored separately from research findings, and will only be accessed by the research team. Any information that could identify you or your child will be removed from the data before the findings are seen by others, and personal data will not be used in research reports. The handling, processing, storage, and destruction of these data are compliant with the Data Protection Act 1998.Quotes from interviews may be used in research reports and presentations. At the end of the study your research data will be made “Controlled Access”, which means your data will be stored in an online database and can be accessed and used by other researchers through requests to a Data Access Committee. However, there will be no way to identify you or your child from these data.

**What do I do next?**

If you and/or your child would like to take part in the study, please complete and return the questionnaire on the back of the study invitation letter. A member of the research team will be in touch to arrange the interview.

**Can I have more information?**

If you have any questions, please feel free to contact the research team using the details below:

Dr Sam Husbands

Population Health Sciences, Bristol Medical School

University of Bristol, 1-5 Whiteladies Road

Bristol, BS8 1NU

Telephone: 0117 428 3121

Email: Samantha.husbands@bristol.ac.uk

**What if there is a problem?**

In the event that a safeguarding issue concerning your child arises, the researcher will stop the interview and inform your child that what they have said will be passed on to an appropriate organisation or professional. The researcher will contact the principal investigator (Professor Joanna Coast) in the first instance, who will make contact as soon as possible with the relevant safeguarding persons and/or organisation.

If you have any concerns about this project, please contact Professor Joanna Coast: *Address:* Population Health Sciences, Bristol Medical School, University of Bristol, 1-5 Whiteladies Road, Bristol, BS8 1NU. *Telephone:* 0117 428 3134. *Email:* Jo.coast@bristol.ac.uk or research-governance@bristol.ac.uk for independent complaints.