**Participant Information Sheet children 12-16 years: Psychology in the ImmunoCOVID19 study**

**Study Title:** Coronavirus infection in immunosuppressed children and adults.

**Chief Investigator:** H. de Graaf

**Principal investigators:** S.N. Faust, C.J. Edwards

**Paediatric clinical teams involved:** Rheumatology, Immunology and Infectious Diseases, Gastroenterology, Renal, Respiratory, Oncology

**Adult clinical team involved:** Rheumatology

**Sponsor ID:** RHM CHI1061

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Dear young person,

The past year has been like no other as we have all had to make a lot of changes in our lives. Things are a bit different when we see family, meet up with our friends and hang out, do sports, or go to school. In the past year you have been very helpful letting us know the symptoms you had each week, the medical care you received, the COVID testing you have done, and when you informed us how the pandemic impacted on your schooling and after school activities. We would like to ask for your help in a new, optional part of the study.

We have all had to make different changes to our daily routines. Sometimes it is nice that you can hang out at home and do your school-work from home, other times you miss school, seeing your friends, or doing your favourite activities like sports, art, music, or dance clubs. Our moods can change depending on what we can do or how we feel, we can feel happy, excited but can also feel lonely or bored. We can even have multiple different feelings at the same time.

In this new part of the study we would like to see how the COVID pandemic has changed the lives of young people like you and how you feel about these changes.

**What would happen if you choose to be in the study?**

If you choose to take part in this new part of the study we will ask you to fill in a form, called the assent form. Your parent will sign another form called the informed consent form. This will be done on the computer.

We will then send your parent an online survey every 3 months to complete. The survey will ask questions about how your parent has been feeling, but will also ask questions about whether you have been able to see your friends, how school has been, whether you have been able to do your favourite activities, and how you have been feeling.

All of the information you give will be kept strictly confidential. The survey you complete has a unique research number and staff will know you only by this number. Your name and address will not be asked on any of the psychology surveys so that you cannot be identified from it.

**Do you have to take part?**

No, it is up to you if you want to take part. We are inviting everyone in the ImmunoCOVID-19 study. It is fine if you do not want to and we would still like your parent to answer our weekly questionnaires reporting the symptoms you have been experiencing every week.

**Why would it be good to take part in the study?**

Being in the study may not help you yourself, but you would be helping us to understand how the pandemic has influenced the lives of young people with chronic illnesses and if there is a need for further support. In this way, we can improve not only your health but also your social care.

**What if I feel sad or worried after answering the questions?**

Completing the questionnaire should not feel much different than talking to a best friend or a family member. However, answering questions can mean difficult feelings like worry or sadness are around. There are some useful websites with lots of resources to help:

<https://youngminds.org.uk/>

<https://www.childrenssociety.org.uk/information/young-people/well-being/resources>

<https://www.mind.org.uk/information-support/for-children-and-young-people/>

www.kooth.com

However, if you are still worried, you or your family can contact Emma Lee, Paediatric Psychologist in the rheumatology department at University Hospital Southampton, at 02381 204657

or reach out to her via email to [e.lee4@nhs.net](mailto:e.lee4@nhs.net) if you are worried or have difficult feelings after completing the questionnaire. She will be able to explain where you can get support locally. Please note, she may be unable to respond to you immediately. If you are really upset, you can talk to your parents who will be able to contact your local GP or CAMHS team, or contact NHS 111 for advice.

**Can I change my mind?**

Yes. If you agree to be in the study but then change your mind that’s fine, you can leave at any time.

**Questions?**

If you have any questions please email us on immunoCOVID19study@uhs.nhs.uk.

Kind regards,

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