

PARTICIPANT INFORMATION

Study Title:

The CoRonavIruS Health Impact Survey (CRISIS).

Research Team:

- Prof. Louise Gallagher – Consultant Child Psychiatrist and Chair in Child and Adolescent Psychiatry, Trinity College Dublin
- Prof. Jane McGrath - Consultant Child Psychiatrist and Associate Professor in Child and Adolescent Psychiatry, Trinity College Dublin
- Dr. Nadia Bolshakova – Research Project Manager, Discipline of Psychiatry, Trinity College Dublin.

Why is this study being done?

- The current COVID-19 pandemic is a major emergency.
- Across the world public health measures have been taken to stop the virus spreading and minimise the risk to health and life.
- This includes social distancing, school and workplace closure, limitations on travel and leisure activities.
- This might effect mental health and behaviour in children and young people of young people with mental health or behavioural needs.
- We are doing this research together with researchers in other countries (e.g. USA, Canada, Taiwan and Greece). Other researchers will also be invited to join this study over the coming months.

Why am I being asked to take part?

- We are asking parents of children or young people aged 3-18 years with either a mental health disorder, autism or another developmental disability to complete this survey to let us know how their child/ young person has been affected.

You have been invited to participate if your child/ young person:

- Attends clinical mental health services in Linn Dara CAMHS or Beechpark Autism services
OR
- Previously participated in our research studies in the Autism Research Group in Trinity College Dublin
OR
- Agreed to be contacted for research purposes through the AsIAm website.
OR
- If you joined the survey through social media.

Do I have to take part?`

You do not have to take part in the study. Your rights to clinical services will not be affected if you don't take part.

How will the study be carried out?

- If you agree to take part, you be asked to answer a survey about your child/ young person. It will take around 20 minutes. The questions are related to the COVID-19 pandemic, mental health and behaviour.
- If you attend clinical services (specifically Linn Dara CAMHS or Beechpark Autism Services), we will ask for your permission to access your child/ young person's clinical data. We will get information about his/ her age, gender, cognitive ability, mental health diagnosis and mental health and behavioural symptoms.
- If you previously participated in one of our research studies, we will also ask for your permission to use the information we collected before.
- This will help us to understand how mental health and behaviour are affected in the current situation.

- You will also be invited to participate in a follow up survey in six weeks to evaluate the ongoing impact of the pandemic and restrictions and we will invite you to participate in surveys a number of times over the next two years. You do not have to take part in the follow up surveys, but it will give us more information about how your child/ young person has been affected.

How will my data or my child's data be used in this study?

We will use your personal data and your child/ young person's data to link your survey responses to the clinical information if you agree. Your personal data also helps us to link between the surveys that you complete.

All data that are collected will be coded. Only the researchers named here can access the key that connects your personal data to the survey and clinical data we collect.

Any information about you or your child that we collect during this study will be kept private. We have a duty to protect your personal data. (i.e. the General Data Protection Regulation (GDPR) and local laws on data protection).

If you consent, we will share the data anonymously with our research collaborators in the International CRISIS consortium. This means that we can compare the different effects of COVID-19 on mental health and behaviour between countries.

When the study is finished, we will keep your data for 10 years. After that we will anonymise the data which means that we will no longer be able to connect the data with your personal details.

What are the risks and benefits from participating in the survey?

You or your child will not benefit directly from taking part in the study. However your responses will help us to understand the impacts on young people's mental health and behaviour. These data may help us develop our services.

There is always a minor risk that someone could access your data illegally. This is a very low risk as we take many measures to protect your data, including coding your data as explained.

Is the study confidential?

All data collected for this study will be treated as confidential according to the Trinity College Dublin and Linn Dara CAMHS policies, except in such cases required by law where information emerges that raises a concern for the safety or well-being of any individual.

What is the lawful basis to use my personal data?

Your data or your child/ young person's personal data will only be used for scientific research which is in the public interest (Article 6 (e) and Article 9(2) (j) of General Data Protection Regulation (GDPR)).

Data protection information

What are my rights?

Under the GDPR, you are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

You can tell us if you want to withdraw from this study or want your data deleted. You can send an email to either of the researchers below. We will delete your data if we can, unless the data have already been used in research, and has been published anonymously, or if it would seriously impair the research, to remove the data. Your data will be not be included in any future research.

Who is funding the study?

This study is not currently funded.

What happens if I wish to make a complaint?

If you have concerns or questions about the study or if you wish to make a complaint, please contact the study's principal investigators (Prof. Gallagher/ Prof. McGrath).

Will I be contacted again?

You will be asked to consent for contact for a shorter follow up questionnaire(s) in around 6-8 weeks and for follow up surveys over the next two years. If you agree to these surveys, you will be sent a link to complete the survey online.

Ethical approval:

This study has been approved by the research ethics committee of the Faculty of Health Sciences, Trinity College Dublin on 15/05/2020 and by the Linn Dara CAMHS Research Ethics Committee on 25/5/2020.

If you would like more information about the ethics committee's approval of this study, please contact Prof Louise Gallagher / Prof Jane McGrath / Dr Nadia Bolshakova.

Where can I get further information?

You can get further information from our research team at Trinity College.

Principal Investigator

Prof. Louise Gallagher
Dept. of Psychiatry
Trinity Centre for Health Sciences
St James's Hospital
Dublin 8
lgallagh@tcd.ie
(01) 896 2144

Prof Jane McGrath
Dept. of Psychiatry
Trinity Centre for Health Sciences
St James's Hospital
Dublin 8
sandersj@tcd.ie
(01) 896 2144

Dr Nadia Bolshakova
Dept. of Psychiatry
Trinity Centre for Health Sciences
St James's Hospital
Dublin 8
bolshakn@tcd.ie
(01) 8962144

The data controllers for this study are: Trinity College Dublin and the Health Service Executive services (Linn Dara CAMHS)

The data processors for this study are: Research IT in Trinity College Dublin and Qualtrics Online Survey Software, the CRISIS Consortium

The CRISIS Consortium is led by Dr. Kathleen Merikangas/ Dr. Argyris Stringaris, National Institute of Mental Health, USA and Dr. Mike Milham/ Dr. Adriana di Martino, New York University. It includes also researchers from McMaster University, Ontario, University of Toronto, University of Taiwan and the University of Athens.

For more information about your data protection rights, please contact:

Data Protection Officer
Secretary's Office, Trinity College Dublin,
Dublin 2, Ireland.
dataprotection@tcd.ie