



## **Information to research subjects – parents/guardians of 15–17 year students**

We would like to inform you about a research study. Here is some information about the study and the implications of participation as a parent/guardian.

### **What kind of study is PEDALS and what are we studying?**

The PEDALS research project studies the prevalence of emotional distress and mental disorders among teenagers in Sweden. The study examines both milder mental distress such as worries and low mood, as well as diagnoses such as major depressive disorder. The study also looks at what kind of support young people would like to have to help them deal with mental health problems, as well as the opinions of parents, psychologists, and doctors. Finally, the study examines possible causes of mental health problems, such as sleep problems, bullying and how young people use social media.

Your child's school class has been randomly selected to participate in the study. The public authority responsible for the research is Karolinska Institutet (KI). The Swedish Ethical Review Authority has approved the study (ref. no. 2023-05934-01)

### **How is the study conducted?**

Your child will be asked to participate in the study. Pursuant to the Section 18 of the Swedish Ethical Review Act (SFS 2003:460), it is your child who must give consent for their participation in the study.

Your child will also be asked to consent that you (as their parent/guardian) can participate in the study. If your child consents to your participation, you will be sent a link via email and text message to fill out questions about your child. We estimate that it will take between 45 and 120 minutes to complete this questionnaire. You can pause whenever you like and continue later.

You will later be asked to complete follow-up questionnaires. The first follow-up questionnaire will be sent one year after the initial questionnaire, and the second follow-up questionnaire will be sent two years after the initial questionnaire. The follow-up questionnaire after one year is short (approximately 15 minutes), while the questionnaire after two years is the same as the initial questionnaire (and takes approximately 120-45 minutes).

To supplement the questionnaires, the researchers will also collect data from national registers. To better understand mental health problems among young people, and the potential causes of these problems, we need to understand the environment in which young people grow up. For this purpose, we will collect certain data about you from national registers. This includes data on your country of birth, place of residence, income, education, and any history of mental illness.

### **Potential consequences and risks of participating in the study**

In our assessment, there are no health risks associated with participating in this study. However, some of the questions you will be asked to answer deal with difficult events, violence, self-harm, and other sensitive subjects. It may be difficult for you to answer such questions about your child. Please bear in mind that your participation is voluntary, and you can choose to end your involvement in the study at any time.

### **What happens to my data?**

For the purposes of the study, we will collect and process personal data about you. This data will be collected from national registers so that we can understand the environment in which your child is being raised. The legal basis for processing personal data is the performance of a task in the public interest. The data will be stored in a system approved by KI, which has a security classification appropriate to the processing of sensitive personal data, and your answers and results will be processed in a manner that prevents unauthorised access. The data will be stored pursuant to applicable legislation and KI's internal rules.

Your identity will be protected by replacing your name and personal identity number with a code. The code key that links the data to you will be stored securely to prevent unauthorised access. The results of the

study will only be presented at group level; at no time will any individual be described.

Encoded data may be shared both within and outside EU/EEA and is then done in accordance with current legislation. Karolinska Institutet (KI) is the controller of your personal data. Pursuant to the EU's General Data Protection Regulation (GDPR), as the data subject you have the right to know what data concerning you is being processed for the purposes of the study, and to have any inaccuracies rectified. You can also request that information about you be erased and that the processing of your personal data be restricted. The right to erasure and to restriction of the processing of personal data does not, however, apply when the data is necessary for the research in question. If you would like to know what data concerning you is being processed, please contact project manager Christina Dalman by emailing [christina.dalman@ki.se](mailto:christina.dalman@ki.se) or calling 072 242 68 92. KI's data protection officer, Mats Gustavsson, can be contacted by email at [dataskyddsbud@ki.se](mailto:dataskyddsbud@ki.se) or by calling 08 524 864 73. If you are dissatisfied with the way your personal data is processed, you have the right to make a complaint to the supervisory authority, the Swedish Authority for Privacy Protection (IMY). You can learn more about the complaints procedure on the IMY website at <https://www.imy.se/klagomal>, by emailing [imuy@imy.se](mailto:imuy@imy.se) or calling 08 657 61 00.

### **How can I get information about the results of the project?**

Results will be presented in scientific journals, on the project page on the Karolinska Institutet website and via collaborating partners Bris – Children's Rights in Society, TILIA, Friends and MIND.

### **Insurance and compensation**

You are covered by your own insurance. No additional policies will be taken out due to your participation in the study. You will not receive any remuneration for your participation. Participation is voluntary. Your participation is voluntary, and you may choose to end your involvement at any time. If you choose not to participate, or if you wish to end your participation, you do not need to give any reason for doing so. If you wish to end your participation, please contact the project manager (see below).

**Project manager**

The project manager is: Christina Dalman, email: [christina.dalman@ki.se](mailto:christina.dalman@ki.se)

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