



## **Information to research subjects – parents/guardians of pupils 13–14 years**

We would like to ask you to participate in a research study. Here is some information about the study and the implications of participation as a youth and 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 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, and you in your capacity as their parent/guardian, will be asked to respond to a series of digital questionnaires. In order for you to be able to participate you need to consent the research below. If you wish for your youth not to participate in the study, please let us know below. In otherwise, your youth will be asked for consent on the day we do the surveys at school. The questionnaires concern young people's mental health, the possible causes of mental health problems, and any need for support. Your child will complete the questionnaire during school hours. A member of school staff will be present while your child answers the questions, but the staff will not look at your child's answers. If your child is

unable to attend school on the day in question, the child can complete the questionnaire at home. It takes between 45 and 120 minutes to complete the questionnaire. After your child has completed the questionnaire, you will receive a link to your questionnaire via email and text message. We estimate that it will take between 45 and 120 minutes to complete the questionnaire. You can pause whenever you like and continue later. Your child and 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 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 45–120 minutes). To supplement the questionnaires, the researchers will follow your child in national registers until they are 30 years of age. This will involve collecting data on the child's country of birth, past and future mental health care, and future data on education, employment, income and criminal record.

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 that you may find difficult to address.

Your child will be informed about how to contact school health services to access support should they find it unsettling to participate in the study. If you find it uncomfortable to answer the questions, please bear in mind that participation is voluntary and that you can choose to end your involvement at any time. Neither your nor your child's answers will be seen

by other pupils or school staff. You will not have access to your child's answers. However, if, based on your child's answers, we feel that there is a serious risk of life-threatening injury, we have an obligation to breach our duty of confidentiality. We will then get in touch to tell you how you can access the help and support that you and your child may need.

### **What happens to my and my child's data?**

For the purposes of the study, we will collect and process personal data about you and your child. This data is collected via questionnaires and national registers for the purpose of studying the prevalence of mental health problems, its potential causes, and support needs among youth. 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 and your child 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. 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. The coded (pseudonymised) data may be shared both within and outside the EU/EEA in accordance with applicable 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**

Your child is covered by the municipality's insurance. As remuneration for participating in the study, the child will receive a cinema ticket once they consent to take part, and then a gift card worth SEK 200 on each occasion they respond to a follow-up questionnaire after one and two years. You will not receive any remuneration for your participation.

### **Participation is voluntary**

Your participation is voluntary, and you may choose to cancel your participation 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 cancel your participation, please contact the person responsible for the project (see below).

### **Project manager**

The project manager is: Christina Dalman, email: [christina.dalman@ki.se](mailto:christina.dalman@ki.se)  
Mobile: 072 242 68 92