

Public Health Research

EARLY: Evaluating, Identifying and Reducing determinants for Mental Health Conditions in Youth

Request to participate in a research project

Good day

We would like to ask you to willingly to participate in our research project.

Your participation is voluntary. All data collected in this research project is subject to strict data protection regulations.

The research project is being carried out by the Zurich University of Applied Sciences (ZHAW). If you are interested, we will be happy to inform you about the results of this research project.

So that you can already get an idea, here is the most important information first. This will be followed by further, detailed information.

Why are we conducting this research project?

In our research project, we want to learn more about the mental health and psychological stress of adolescents and young adults as well as about associated risk and protective factors. For this purpose, we have prepared an online questionnaire for you.

What do I have to do to participate? – What happens to me if I participate?

- If you participate, we will send you personalized access to the online questionnaire. All your data will be treated confidentially at all times.
- If you decide to participate, please answer all questions in the questionnaire as truthfully as possible. In total, you will need about 45 to 60 minutes to answer all the questions of the EARLY study.
- If you participate, we ask you to register and provide us with your e-mail. Your email is only needed to send you a personalized link and will be deleted after the data collection is complete. You can fill out the questionnaire online at any time, take a break and come back later or stop.

What are the benefits and risks associated with this?

Benefit

- You have no direct benefit if you participate in this research project.
- With your participation, you help other young people by learning more about mental health and stress and possible influencing factors.

Risk and burden

- There are no risks associated with participation. Answering some of the questions in the questionnaire may trigger questions or cause bad feelings. You can find a list of helplines on our Swiss EARLY website (www.zhaw.ch/early).

By participating, you testify that you are participating voluntarily and that you have understood the contents of the entire document.

Detailed information on the EARLY study

1. Objective and selection

In this brochure, we refer to our research project as a research project. If you participate in this research project, you are a participant.

The research project is carried out to learn more about the mental health and stress as well as risk and protective factors of adolescents and young adults. EARLY is interested in your life prospects and your mental health.

The results of the research project will be shared with policymakers and mental and public health professionals. It will provide information for future mental health and well-being activities and interventions. We are asking you because all people aged 15 – 24 who live in Switzerland can participate.

2. General information

The research project is important because we still know little about risk and protective factors of mental health and stress on adolescents and young adults in Europe and Switzerland. We want to learn more about this in order to inform professionals and policymakers and to develop future activities and interventions.

- By participating, you will contribute to a better understanding of the mental health of young people today. The EARLY research project is a European study involving study teams from Albania, Belgium, Israel, Italy, Germany, Moldova, Poland, Portugal, Romania, Serbia, Spain and Switzerland. In Switzerland, the ZHAW Zurich University of Applied Sciences is conducting the study. We aim to motivate about 1600 young people to participate.
- We are doing this research project in accordance with the laws in Switzerland. We also comply with all internationally recognised guidelines. The Ethics Committee, which is responsible for Switzerland, has reviewed and approved the data collection for Switzerland.

3. Expiration

You can register to participate in the study and then receive a personalized link to the study information and questionnaire by e-mail. The e-mail serves only this purpose and will be deleted after the data collection has been completed. Please read the study information carefully, it contains more information about the study, data protection and the rights of the participants. Participation is voluntary. We ask you to confirm your consent to participate in the study before filling out the questionnaire. Please answer the questions in the questionnaire as truthfully as possible. In total, you will need about 45 to 60 minutes to answer all the questions of the EARLY research project. You can fill out the questionnaire online at any time, take a break and come back later or stop.

4. Benefit

You will not personally benefit from participation, in particular there will be no financial compensation. However, the results may be important for other young people, as they contribute to a better understanding of the mental health of adolescents and young adults in the participating countries.

5. Voluntariness and obligations

They participate voluntarily. If you do not want to participate in this research project or later withdraw your participation, you do not have to justify this. You will not be disadvantaged if you decide not to participate. If you participate in this research project, you will be asked to answer all questions as truthfully as possible. Your answers are important!

6. Risks and burdens

The research project does not expose you to any risks. Answering some of the questions in the questionnaire can trigger questions and perhaps also cause bad feelings. You can find a list of offers of help on our Swiss EARLY website.

7. Results

There are final results of the entire research project.

We will be happy to send you a short report of the results if you wish. Please let us know by ticking the box at the end of the EARLY questionnaire: "I would like to receive information about the results of the EARLY study". In this case, we will delete your email as soon as the report is sent.

8. Data processing and encryption

For this research project, data about your person and mental health will be collected and processed. In addition, in addition to health data, socio-demographic information, as well as information on age, gender, religion, ethnicity and place of residence (zip code) are collected. This data is collected exclusively for research purposes.

Data processing is carried out on the basis of your free consent in accordance with the Swiss Human Research Act and the General Data Protection Regulation (GDPR) in conjunction with § 13 of the Lower Saxony Data Protection Act. The personal data collected for the conduct of the study will be stored and deleted 10 years after completion or termination of the study.

Your personal data will be treated confidentially at all times. When data is collected, your data is encrypted. Encryption means that all reference data that could identify you (name, date of birth, etc.) is deleted and replaced by a numerical and/or letter code. The key list always remains at the Emden/Leer Study Center and the EARLY Study Director (Prof. Dr. Jutta Lindert, University of Applied Sciences Emden/Leer, Germany). This key list is stored separately at the Emden/Leer Study Centre and is subject to technical and organisational measures to ensure that the personal data cannot be viewed by unauthorised persons. Backup copies of the encrypted data are stored on two encrypted physical data carriers (external hard drives) in a secured steel cabinet. Decryption only takes place if you want the data to be deleted.

The encrypted data is stored separately from the identifying data on secured data carriers and evaluated at the respective study sites.

After the evaluations in the study centers, all data is transmitted in encrypted form to the study center of the lead organization (University of Applied Sciences Emden / Leer). Only the responsible persons at Emden / Leer University of Applied Sciences have access to the personal data. Very few professionals will see your unencrypted data, and only to perform tasks within the scope of the research project. These persons are subject to confidentiality. As a participant, you have the right to inspect your data.

9. Privacy

All data protection requirements are strictly adhered to. It is possible that your data may have to be transmitted in encrypted form, for example to Emden/Leer University of Applied Sciences or bodies commissioned by it for the purpose of scientific evaluation and, in the event of adverse events, to the responsible ethics committee and the European Commission. The data will not be passed on to countries outside the European Union.

The Director of Studies is responsible for ensuring that the same standards are met abroad as in Switzerland and the EU. Research results are published in the usual scientific form on the basis of encrypted data, so that no conclusions can be drawn about your person.

Any collection, storage, use and transmission of data involves confidentiality risks (e.g. the possibility of identifying the data subject). These risks cannot be completely eliminated and increase as more data can be linked. We assure you that we will do everything we can to protect your privacy according to the state of the art and will only pass on encrypted data to institutions that can demonstrate a suitable data protection concept. A data management and sharing plan is part of the study and will be continuously revised by the research

consortium, consisting of all institutions involved in the research project, should this be necessary due to technological or other developments. There are no health risks associated with data processing.

10. Inspection rights during inspections

This research project can be reviewed by the responsible ethics committee and by the project management. The country-specific project managers must then disclose your data for such checks. Everyone must maintain absolute confidentiality.

11. Withdrawal

You can withdraw from the research project at any time. In this case, however, the data collected up to then will still be evaluated in encrypted form.

12. Compensation

If you participate in this research project, you will not receive any compensation. There are no costs for you or your health insurance company to participate.

13. Liability

If you suffer damage as a result of the research project, the ZHAW Zurich University of Applied Sciences, which initiated the research project and is responsible for its implementation, is liable. The requirements and the procedure are regulated by law

14. Financing

The EARLY research project is mainly funded by the EU as part of the EU's Horizon research programme, with Switzerland's participation being paid for by SERI.

15. Contact person(s)

You may ask questions about participating in the project at any time. Also, if you have any uncertainties that arise during or after the research project, please contact:

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EARLY

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