

Participant Information
Regarding the Project DIPEX.ch Health Experiences
Module „COVID-19“

Project Leader

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Project Team

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Dear Sir/Madam,

We warmly invite you to participate in our project "DIPEX" (Database of Individual Patients' Experiences) and would like to gain your insight as an interview partner.

Goal of DIPEX.ch:

In our project, we would like to explore and understand what people experience with COVID-19. We would like to talk to you about how the disease has changed your life, how it affects your family, your friends and your work, how you deal with it and/or what treatments you have tried.

We would also like to publish the interview in video, audio and/or text excerpts on the "dipex.ch" website, where you will find more stories such as yours. We conduct interviews on various illnesses and other health topics with 40 to 50 people each in selected sections on the website.

The Interview:

The interview can be held at your home, or at a location of your choice, or with an online video-conferencing system and is recorded either in audio only, or in audio and video, depending on your preferences. The interviewer will ask you to tell the story of your condition, and to mention anything that is important to you. Following this, he or she will ask some more in-depth or broadening questions.

The interview takes approximately 2 hours.

We will transcribe the interview and will delete all references to your identity such as names and places. The transcript will then be sent to you, and we ask you to decide upon the following questions:

- whether you agree to publish excerpts of your interview on the Website,
- whether certain excerpts may not be published,
- in which form your interview excerpts are published on the Website (video and/or audio and/or text file),

The Project DIPEX.ch

This project is a long-term study, on whose website DIPEX.ch people who may be going through a similar health experience can find out how other people live with and experience the same disease. It is also available for training and further education purposes. Medical students and health care professions and people who work in the health care system can better comprehend what patient's experience are and what is important to them. The scientific evaluation of the interviews also contributes to improve patient care and supports quality improvement in healthcare.

Our project is part of the international DIPEX network that was founded almost 20 years ago in the United Kingdom. The English website (www.healthtalkonline.org) features over 100 health conditions.

In Switzerland, we are currently in the process of setting up the website www.DIPEX.ch with the help of public research funds and funds from private foundations. DIPEX.ch is a collaboration between the Institute of Biomedical Ethics and History of Medicine (IBME) at the University of Zurich, and the Department of Health at the Zurich University of Applied Sciences (ZHAW) in Winterthur.

Participation:

Participation in our project is completely voluntary. Choosing not to participate will not affect the quality of the medical



care that you will receive. You confirm your willingness to participate by a written declaration of consent. If you sign this form, you give copyright of the interview to the University of Zurich, Institute of Biomedical Ethics and History of Medicine (IBME).

The material on the website is protected by copyright and third parties are not allowed to copy or record the material. You can revoke your participation at any time, even after consent has been given, in which case all recordings and transcripts of your interview will be destroyed. We will also remove all contributions from your interview to the website. If you decide to withdraw after your interview has been published on the website, DIPEX.ch cannot guarantee that copies have not been made by third parties. DIPEX.ch has no access to the archives of search engines, which may still provide access to data although it has been removed from the website.

The study is conducted in agreement with the Swiss Law and international guidelines. The ethics committee of the Kanton of Zurich has reviewed the study as not harmful to participants "Nichtzuständigkeitserklärung" (BASEC- Nr. Req-2018-00050). In addition, the "CEBES" (Checklist for the Ethics Review Process of Empirical Studies) Commission of the University of Zurich has approved the project.

Data Protection:

The interview will be done online on video.meeting.uzh.ch, a safe videoconferencing platform set up by the University of Zurich. The servers are located in Zurich, in the University's own data centres. The data stream is end-to-end encrypted, so no one can intercept the conversation. The stream is recorded locally by the interviewer on his computer, then uploaded on the University's server and deleted from the computer of the interviewer. No third parties are involved.

The audio or video file as well as the written interview are provided with a number and stored on computers of the University of Zurich. Your consent form, with your name, will be stored separately from your interview data. The list attributing codes to interview participants will be kept securely, and is accessible only by internal project members. All data related to your interview, including consent forms, are only accessible to staff members. All staff members are obliged to secrecy.

The interviews are transcribed without your name. If you agree to the interview being published as a video or audio file, all references to your person will be muted, so that they are not audible.

On the website, your name will be replaced by a pseudonym, without any personal information such as your name or place of residence, etc. However, if you have agreed to the interview being published as a video or audio file, you will be recognisable through your image or voice. Publication on the Internet implies that third parties can use the data. The recordings and/or still images can thus be used in the press, radio and television. In the case of scientific use, analysis of information from your interview will also be done on anonymized transcripts, with all personal identifiers removed prior to analysis.

Contact:

If you can imagine participating in our project, please contact us so that we can arrange an interview. We would be glad for your support with the DIPEX.ch project. If you have further questions, please feel free to contact us, and we will do our best to answer them for you.

Of course, you can also contact us at any time after the interview if you have any further questions.

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