

Institute for Biomedical Ethics and **History of Medicine**

Young hemato-oncological Patients Health Experiences - DIPEx.ch

We are looking for people aged between 15 and 34 with a hemato-oncological disease who are willing to share their experiences with other people.

We are part of a research group based at the University of Zurich that aims to understand the point of view of patients. We would like to talk to you about your experience with the disease, how it affects your everyday life, and we would like to hear your thoughts on it.

With your consent, this information will be used anonymously for scientific purposes to improve the understanding and thus the treatment of hemato-oncological diseases.

In parallel, we would like to use the results of the study to create an online platform, called "Database of Individual Patient Experiences" (DIPEx). The main purpose of this website is to provide support to people who have to deal with a hemato-oncological disease every day.

This includes:

- (1) other affected people, who can thus have an idea of how others manage their lives;
- (2) physicians, therapists and other healthcare professionals, who can better understand the experiences and needs of the patients and what is important to them;
- (3) students and scientists, who can learn a lot from the patients' perspective.

The idea for DIPEx.ch originates from the University of Oxford, which in 1998 developed the "Database of Individual Patient Experiences" (DIPEx) and the website "healthtalk.org", which currently covers and maintains over one hundred health-related topics.

How does it work?

The first step in participating in this study is to complete an online questionnaire. It only takes ten

minutes, and can also be done with a smartphone. The second step is an interview, which will be done in person, at your home or in a place of your choice, with a researcher from our Institute. It will then be possible to decide whether to allow its publication on the website and if you prefer that we use the video, the audio or only the written text.

How can I participate?

Simple: just visit this website and follow all the instructions. If you prefer, you can also scan the QR code.

https://dipex.ch/illness/young-hematooncological-patients/



Do you know other people who might be interested in participating? Then you can also send them the link.

Thank you for your interest, and for your help!



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