

## Project Title: "Our patients' headache narratives"

Recipient: Sabina Maria Rätz

Esteemed members of the Swiss Headache Society,

In November 2023, I had the honor of being awarded the SKG Hansruedi Isler grant. This grant was crucial for the implementation of our project, supporting key project tasks such as the transcription of study data, which serves as the basis of our analyses.

### Project overview

The project *Our patients' headache narrative* is designed to get more insight into pain communication, to improve our understanding of patients' narratives regarding their headache symptoms, and, by exploring which topics are discussed in public forums and comparing those with the topics discussed in the headache consultations, to recognize patient's unmet needs. *Our patients' headache narratives* is part of ComPAIN (Communication about pain in patients with headache), an interdisciplinary research project to systematically study pain communication in patients with primary headaches. It is a prospective, monocentric cross-sectional study undertaken at the University Hospital of Zurich (USZ), Switzerland. It represents primarily explorative, qualitative research. In ComPAIN, conversational data is obtained through audio or videotaping of headache consultations in a natural clinical setting.

### Current status

With the support from the SKG Hansruedi Isler grant, a total of 60 patients, who consented to audio or videotaping of their headache consultations, were included until August 2024. Of these 60 patients, we were able to transcribe 25 video or audio recordings following GAT-2 (1) guidelines and using ELAN software (2).

In our initial analysis of the data, we examined the language patients used to describe their headache and compared their descriptive terms with those in the official ICHD-3 criteria. This was done by extracting descriptive words and phrases from the interview transcripts, assigning each to their respective lemma, and forming the adjective after lemmatization. This allowed for statistical comparison. Secondly, we searched interview transcripts for segments, where headache-attributed disability was discussed during consultations. Thus, we could examine if and how headache-attributed disability was addressed by the clinician and patient. We used our initial findings to draft a manuscript intended for publication this year.

For an analysis of conversation patterns used in headache consultations, we collaborate with our project partners from the University of Zurich from the Department of German studies (Dr. Yvonne Ilg). Video or audio recordings as well as interview transcripts are discussed and analyzed from the perspective of conversation linguistics in a seminar at the Department of German studies, running from August 2024 to July 2025.

In collaboration with Prof Kevin Reuter and his research team, we plan to conduct further analysis of communication in headache consultations combining qualitative and quantitative linguistic approaches. We intend to apply SwissBERT (3), a natural language model, and part-of-speech (POS) tagging models (4) to define the most common descriptions of headache used by patients, and to capture variations in language that patients use when describing different types of headaches. To assess which topics are relevant for people with headaches in peer-discussion, we plan to conduct web-based analysis using semi-supervised topic modeling. So far, we conducted a first explorative analysis using data from the corpora of *r/migraine* on Reddit, a large online forum dedicated to the discussion of migraine and headaches. We plan to conduct these analyses until March 2026. A large DIZH grant (UZH/ ZHAW) was submitted to support this project.

Thanks to the support from the SKG Hansruedi Isler grant, we were able to conduct this research, hopefully enhancing our understanding of headache communication. With our findings, we aim to make consultations at the headache ambulatory unit more satisfactory for our patients an increase diagnostic and therapeutic quality.

Sincerely, Sabina Rätz

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2. ELAN. 6.4 ed. Nijmegen: Max Planck Institute for Psycholinguistics, The Language Archive.; 2022. p. Retrieved from <https://archive.mpi.nl/tla/elan>.
3. Vamvas J, Graën J, Sennrich R. *SwissBERT: The Multilingual Language Model for Switzerland*2023.
4. Aepli N, Sennrich R. *Improving Zero-shot Cross-lingual Transfer between Closely Related Languages by injecting Character-level Noise*2021.