Participant Information concerning the study "Medication use from a patient’s perspective using Twitter"

Please read this carefully

Dear participant,

in our project, we aim to support the research into medication use from a patient’s perspective (as opposed to a doctor’s perspective).

We would like to create a text collection (text corpus) from texts on social media, such as Twitter, with descriptions of how people use medicine(s) and what they experience when / after taking it. We are interested in dosages, improvement or aggravation of the patient's condition, positive or negative side effects, and other noteworthy things happening during the medical therapy.

The resulting text corpus is subsequently de-identified, annotated by expert annotators, and analyzed by the research team. It is then prepared as “training” material for machine learning models which are later on used to identify medication(s) and their consequences in user-written texts to support pharmacovigilance. The study is conducted in German, French, and English.

Everyone who took or is taking medicine can participate in this study. Also, people who are taking care of someone in a medical therapy are invited to participate and describe their observations.

Data Privacy

The description of a treatment and the associated drug reactions constitutes personal health information. For this reason, we are seeking your consent to include tweets you have authored in our research corpus. If you consent to the use of a tweet, this means that the text will be collected from the Twitter platform and included in an archive for dissemination to researchers in natural language processing and public health (for non-profit research purposes). You will not receive any compensation (financial or otherwise) for your participation. At any time, you can contact us via E-MAIL to change your decision regarding the inclusion of your text in the corpus.

Thank you for your consideration.

For confidentiality reasons, Twitter handles (usernames) will be removed from the texts, which will then be marked with mentions of drugs and adverse drug reactions and shared with the scientific community. The collected data and texts will be stored on institute-owned servers in Germany and France and will be only available within the research community upon signing a data protection agreement.

The study is part of a joint project of the German Research Center for Artificial Intelligence (DFKI,Berlin, Germany), the Nara Institute of Science Technology (NAIST, Nara, Japan) and the

Computer Science Laboratory for Mechanics and Engineering Sciences of the French National Centre for Scientific Research (LISN/CNRS, Orsay, France). The project is funded by The French National Research Agency (ANR, France), Deutsche Forschungsgemeinschaft e.V. (DFG, Germany) and the Japan Science and Technology Agency (JST, Japan).

In case of any questions, please do not hesitate to send an e-mail to E-MAIL (in either German, French or English). We are happy to respond.

Responsible Data Controller: Aurélie Névéol, Lisa Raithel (E-MAIL)

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