

Experience with medical side effects

Dear participant,

thank you for taking the time to respond to our survey.

P.S.: At the end of the survey you will find the respective codes for SurveyCircle or SurveySwap users.

There are 15 questions in this survey.

Information for Participants

Information for Participants

Welcome to the study "Experiences with Medical Side Effects"!

This study is conducted at Quality and Usability Lab (<https://www.tu.berlin/qu>) of Technischen Universität Berlin, DFKI Berlin (<https://www.dfki.de/web/forschung/forschungsbereiche/speech-and-language-technology>) and LISN, CNRS, Orsay (<https://www.lisn.upsaclay.fr/recherche/departements-et-equipes/sciences-et-technologies-des-langues/>). The aim of the study is to gain knowledge about experiences with medical side effects in an online community.

Further information in the project can be found on the project's website: https://keepha.lisn.upsaclay.fr/wiki/doku.php?id=info_en (https://keepha.lisn.upsaclay.fr/wiki/doku.php?id=info_en)

The study consists of answering a questionnaire that takes about 10 minutes.

Privacy Information:

Personal data will be collected in this study, such as your gender, age, and answers to the questions. Your data will only be used for scientific purposes and will only be stored anonymously. You can request deletion of your data at any time using the personal code you created at the beginning of the study.

You will have the option to have your data deleted after the trial. This option will last for at least 30 days from the date of your participation and will end upon submission of the data as part of a scientific publication. If you have further questions, please contact survey.medication.use@gmail.com (<mailto:survey.medication.use@gmail.com?subject=%5BSurvey%20Medication%20Use%5D>).

Compensation:

Unfortunately, no financial compensation can be offered for this study.

- I have read and understood the study information provided in the "Information for Participants" provided above.
- I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact <mailto:survey.medication.use@gmail.com?subject=%5BMedication%20Use%20Survey%5D>).
- I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions.
- I can withdraw from the study at any time, without having to give a reason.
- I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication.
- I understand that my user token will only be used for deleting my data in case I ask for it.
- I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project.
- I agree to joint copyright of the written texts to the project's researchers.

*

● Choose one of the following answers

Please choose **only one** of the following:

yes, I consent

no, I do not consent

Personal Code

Personal Code

Please follow the instructions below to create the personal code:

(If information is not known, please insert an X).

1. The first letter of your mother's first name
2. The first letter of your father's first name
3. The first letter of the place of your birth
4. The last digit of the year of your birth
5. The last digit of the day of your birth

*Please enter your personal code here: **

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question '[general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

Please write your answer here:

Your personal code is made out of 3 letters and 2 digits as follows:

1. The first letter of your mother's first name
2. The first letter of your father's first name
3. The first letter of the place of your birth
4. The last digit of the year of your birth
5. The last digit of the day of your birth

General Questions

Please answer some more general questions first.

Required fields are marked with an asterisk (*).

In case of questions, please do not hesitate to send an e-mail to survey.medication.use@gmail.com
(mailto:survey.medication.use@gmail.com%20?subject=%5BSurvey%20Medication%20Use%5D).

Are you going to report your own experience or the experience of another person (child, partner, parent, ...)? *

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question '[general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

🗨 Choose one of the following answers

Please choose **only one** of the following:

- I am going to report my own experience.
- I am going to report the experience of another person.

What is the birth year of the person whose experience you are reporting?

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question ' [general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

🗳️ Choose one of the following answers

Please choose **only one** of the following:

- 2022
- 2021
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- 2019
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- 1922
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Gender: How do you identify? *

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question '[general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

🗨 Choose one of the following answers

Please choose **only one** of the following:

- female
- male
- non-binary
- prefer not to say
- Other

Information on Medication Use

This is the main part of the survey.

Please note: The answers you are giving will be de-identified to prevent any inference to you. However, please DO NOT share any personal information (names, addresses) identifying you.

Which medication(s) did you take / are you taking? *

*

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question '[general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

Please write your answer here:

You can use whatever description of the medication that comes to your mind. It does not have to be the official brand name. If you want to add more than one medication name, please separate them by a comma.

Example: Ibuprofen, Aspirin, pain medication

Was the medication prescribed by a doctor? *

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question ' [general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

● Choose one of the following answers

Please choose **only one** of the following:

- yes
- no
- partly yes / partly no
- prefer not so say

Make a comment on your choice here:

In case you have a comment on your prescription, please add it to the blank field on the right side.

Why did you take / are you taking the medication? What was / is your diagnosis?

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question ' [general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

Please write your answer here:

What was / is the dosage of the medication?

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question ' [general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

Please write your answer here:

Example: "two takings daily, morning and evening, for one week" OR "whenever I felt like it"

Description of Experiences

Please describe your experience with the above drug(s) as if you were talking to a friend (not a doctor).

Do not write in bullet points, but in continuous text.

How did you feel after taking the medication(s)? Did you feel better or worse?

*

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question ' [general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

Please write your answer here:

Please rate (approximately) the number of different side effects you experienced.

*

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question ' [general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

Please choose the appropriate response for each item:

	no side effects at all	little side effects	few side effects	many side effects	a great many side effects
Approximate number of side effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you have experienced any side effects, please describe them as accurately as possible. *

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question ' [general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

Please write your answer here:

Will you continue to use the drug and if so, would you recommend it to other patients? *

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question ' [general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

Please write your answer here:

This is the last question!

If you have any further information that you think might be interesting for us, please let us know!
You can also give us feedback concerning this survey on the next page.

Only answer this question if the following conditions are met:

Answer was 'yes, I consent' at question ' [general]' (I have read and understood the study information provided in the "Information for Participants" provided above. I have been able to ask questions about the study and my questions have been answered to my satisfaction (contact). I consent voluntarily to be a participant in this study and understand that I can refuse to respond to questions. I can withdraw from the study at any time, without having to give a reason. I understand that taking part in the study involves providing personal information about the use of medicine and the written description of my experiences when taking medication. I understand that my user token will only be used for deleting my data in case I ask for it. I understand that personal information collected about me that can identify me, such as my name or where I live, will be de-identified and will not be shared beyond the researchers in this project. I agree to joint copyright of the written texts to the project's researchers.)

Please write your answer here:

Thank you!

Thank you for participating in our survey!

We aim to create a collection of texts describing patients' experiences with medication. In contrast to patient records which are usually written by medical staff, the collection is focused on the patient's perspective. For this, we first need to collect enough reports about the use of medicine. Then, these texts can be annotated and analyzed.

The text collection that we are going to compile will only be accessible to researchers who registered at our institutes.

In case you filled in optional fields, this will help us to specify your experiences: for example, we have to handle side effects of elderly people differently than those of younger ones.

All answers will be stored on an institute-owned server in either France or Germany and de-identified before publication, thus there will be no possibility to trace your answers back to you.

In case of questions, do not hesitate to send an e-mail to survey.medication.use@gmail.com (<http://gmail.com>).

In case you want us to remove your answers from our dataset, please send the code you generated at the beginning of the survey to survey.medication.use@gmail.com (<http://gmail.com>).

We welcome your feedback and would appreciate your help in further improving the survey.

Please write your answer here:

Thank you for participating in this survey and for supporting our research! Have a great day!

For SurveyCircle users (www.surveycircle.com): The survey code is: KVK4-VDTS-E1YF-924R

For SurveySwap users (www.surveyswap.io): The code is 1V7M-LWOX-DUIR

Submit your survey.

Thank you for completing this survey.