

Survey Privacy Notice

The aim of this survey is to understand what kind of information about medicine use before or during pregnancy and breastfeeding women need, and how you and other women prefer to receive that information. We collect your data for the purpose of conducting this survey and to analyse the results of this survey as part of our research project. Since ConcePTION aims at understanding your information needs and preferences about the safety of medicines during your pregnancy and breastfeeding, we collect personal data relating to your health. But we do so only with your explicit consent.

Your answers will be saved for the duration of the project, until March, 2024, and analysed by ConcePTION's researchers. We (the members of the ConcePTION project) your data as joint data controllers.

If you have any questions or comments on how we handle your personal data or wish to exercise any of the rights listed in said Notice, please contact Helena Harnik helena@thesynergist.org.

Last updated: 13 January 2020

1. About this Notice

- 1. This Privacy Notice ("Notice") explains how we (as defined below) collect, share and use any information that, alone or in combination with other information, relates to you ("Personal Data") in your capacity as a respondent of surveys or participant to studies ("you" and "your"), conducted as part of the ConcePTION consortium ("ConcePTION Members", "we" and "our"). The ConcePTION consortium unites a number of partners, who act as joint data controllers when they process Personal Data in the context of the consortium. The full list of ConcePTION Members, as well as their respective contact details, is available <u>here</u>.
- 2. We use this Personal Data collected through surveys and studies in a de-identified aggregate form to generate research reports. In other words, your name will not appear in such final reports.
- 3. This Notice also sets out the rights that you have in relation to the Personal Data that we process about you and how you can exercise them.
- 4. ConcePTION Members treat compliance with their privacy obligations seriously. This is why we have developed this Notice, which describes the standards that ConcePTION Members apply to protect Personal Data.
- 5. As joint data controllers, ConcePTION Members are responsible for ensuring that the processing of Personal Data complies with applicable data protection law, and specifically with the General Data Protection Regulation.
- 6. Please take the time to read this Notice carefully. If you have any questions or comments, please contact us using the "Contact" section of the ConcePTION's website, available at https://www.imi-conception.eu/contact/.



2. What Personal Data do ConcePTION Members process and why?

1. The types of Personal Data that we may collect about you, and the reasons why we process it, include:

Why we collect it	Types of Personal Data	Legal basis
-Establishing and maintaining a pool of potential respondents for future surveys or studies;	-Identification data: name, contact details such as email; -Professional data: job title, department, information about your practice;	- Legitimate interest of the ConcePTION Members to carry out the ConcePTION's research project;
-Conducting surveys or studies; -Publishing aggregate results.	 The answers you provide in the survey or studies may include personal data; The answers may also include health data relating to your pregnancy and breastfeeding. 	-Your explicit consent in compliance with article 9 of the GDPR.

If we ask you to provide any other Personal Data not described above, then that specific Personal Data and the reason for our asking will be made clear to you at the point we collect that Personal Data.

2. We can also collect certain information automatically from your device when you receive an email about our surveys or studies, fill out surveys or participate in a study online. Specifically, the information we collect automatically may include information such as your IP address, device type, unique device identification numbers, browser-type, broad geographic location (e.g. country or city-level location) and other technical information. We may also collect information about how your device has interacted with the survey or study webpages, including the pages accessed and links clicked.

Collecting this information enables us to better understand the behaviour of survey respondents and study participants, where they come from, and what content on our website is of interest to them. We use this information for our internal analytics purposes.

- 3. It is technically possible for us to receive Personal Data about you from third party sources (incl. Survey Monkey), but only where we have checked that these third parties either have your consent or are otherwise legally permitted or required to disclose your Personal Data to us.
- 4. The types of Personal Data we collect from third parties include responses to surveys or studies, analyses, reports and statistics and we use this Personal Data we receive from these third parties to collect, generate and disseminate information regarding effects of medications used during pregnancy and breastfeeding to women and their healthcare providers, as stated in the mission of the <u>ConcePTION</u> project. We can also receive some information automatically collected from your device (please see above) by third-party service providers such as Survey Monkey.

3. Who do ConcePTION Members share your Personal Data with?

1. Besides the exchange of Data between ConcePTION Members, we may disclose your Personal Data to the following categories of recipients:

a. to **our third-party researchers and third-party partners** for purposes consistent with this Notice. Such researchers analyse the results and draw up a report or publication about such results. Our third-party partners are listed <u>here</u>.



b. to **our third party vendors and services providers** who provide data processing services to us, or who otherwise process Personal Data for purposes that are described in this Notice or notified to you when we collect your Personal Data. This may include disclosures to third party vendors and other service providers we use in connection with the ConcePTION project including to support us in areas such as online survey providers (such as SurveyMonkey), IT platform management or support services, infrastructure and application services, data analytics;

c. to **any competent law enforcement body, regulatory, government agency, court or other third party** where we believe disclosure is necessary (i) as a matter of applicable law or regulation, (ii) to exercise, establish or defend our legal rights, or (iii) to protect your vital interests or those of any other person;

d. to **our auditors, advisors, legal representatives and similar agents** in connection with the advisory services they provide to us for legitimate purposes and under contractual prohibition of using the Personal Data for any other purpose;

4. How we protect your privacy

1. We will process Personal Data in accordance with this Notice and in compliance with the following principles:

a. Fairness: We will process Personal Data fairly. This means that we are transparent about how we process Personal Data and that we will process it in accordance with applicable law.

b. Purpose limitation: We will process Personal Data for specified and lawful purposes, and will not process it in a manner that is incompatible with those purposes.

c. Proportionality: We will process Personal Data in a way that is proportionate to the purposes which the processing is intended to achieve.

d. Data accuracy: We take appropriate measures to ensure that the Personal Data that we hold is accurate, complete and, where necessary, kept up to date. However, it is also your responsibility to ensure that your Personal Data is kept as accurate, complete and current as possible by informing us of any changes or errors, using the contact below.

e. Data security: We use appropriate technical and organisational measures to protect the Personal Data that we collect and process about you. The measures we use are designed to provide a level of security appropriate to the risk of processing your Personal Data. Specific measures we use include storing data on a server with restricted access.

f. Data processors: We may engage third parties to process Personal Data for and on our behalf. We require such data processors to process Personal Data and act strictly on our instructions and to take appropriate steps to ensure that Personal Data remains protected.

g. International data transfers: Your Personal Data may be transferred to, and processed in, countries other than the country in which you are resident. These countries may have data protection laws that are different to the laws of your country and, in some cases, may not be as protective. However, we have taken appropriate safeguards to require that your Personal Data will remain protected in accordance with this Notice.

h. Data Retention: We retain your Personal Data where we have an ongoing legitimate need to do so. We will retain the answers to the survey for the duration of the research project until March 2024.



When we have no ongoing legitimate need to process your Personal Data, we will either delete or anonymise it or, if this is not possible (for example, because your Personal Data has been stored in backup archives), then we will securely store your Personal Data and isolate it from any further processing until deletion is possible.

5. Your data protection rights

1. You have the following data protection rights:

a. If you wish to **access, correct, update or request deletion** of your Personal Data, you can do so at any time by contacting us via the "Contact" section of the ConcePTION's website, available at <u>https://www.imi-conception.eu/contact/</u> or contact maximiliane@thesynergist.org

b. In addition, in certain circumstances, as stipulated in the applicable data protection legislation, you can **object to the processing** of your Personal Data, ask us to **restrict processing** of your Personal Data or **request portability** of your Personal Data. Again, you can exercise these rights by contacting us via the "Contact" section of the ConcePTION's website, available at <u>https://www.imi-conception.eu/contact/</u> or contact maximiliane@thesynergist.org

c. If we have collected and processed your Personal Data with your consent, then you can **withdraw your consent** at any time. Withdrawing your consent will not affect the lawfulness of any processing we conducted prior to your withdrawal, nor will it affect the processing of your Personal Data conducted in reliance on lawful processing grounds other than consent.

d. If you have a complaint or concern about how we are processing your Personal Data then we will endeavour to address such concern(s). If you feel we have not sufficiently addressed your complaint or concern, you have the **right to complain to a data protection authority** about our collection and use of your Personal Data. For more information, please contact your local data protection authority. (Contact details for data protection authorities in the European Economic Area, Switzerland and certain non-European countries (including the US and Canada) are available <u>here</u>.)

2. We respond to all requests we receive from individuals wishing to exercise their data protection rights in accordance with applicable data protection laws.

6. Updates to this Notice

- 1. We may update this Notice from time to time in response to changing legal or technical developments. When we update our Notice, we will take appropriate measures to inform you, consistent with the significance of the changes we make. We will obtain your consent to any material Notice changes if and where this is required by applicable data protection laws.
- 2. You can see when this Privacy Notice was last updated by checking the "last updated" date displayed at the top of this Notice.