
INCYTE PRIVACY NOTICE STUDY PARTICIPANTS CANADA

We use this Privacy Notice to tell you what personal information is collected from you in the course of Incyte pharmaceutical research activities (“study” or “studies”), including clinical trials, non-interventional studies, registration studies, and observational studies conducted by Incyte or by third parties on our behalf. If you are using an Incyte approved product, submitting a medical information request, sharing your patient journey, or otherwise engaging with Incyte as part of Incyte’s obligation to report safety information to a regulatory agency, please see Incyte’s *Privacy Notice for Non-Research Patients* instead.

For clinical trials, this is a high-level summary of Incyte’s data protection processes during studies. Prior to enrolment in the study, you will receive more specific information about these processes. This Privacy Notice is not intended to modify or otherwise change the information provided to you at that time.

When we collect your personal information:

- We take or require appropriate technical, physical, and organisational measures (such as multifactor password authentication, encryption, access restriction, etc.) to protect your personal information from misuse or unauthorized alteration, loss, or access;
- We collect and use your personal information only for the purpose(s) outlined below and as authorized or required by applicable law;
- We only collect the personal information that we need; and
- We keep your personal information up to date and endeavor to ensure that it is accurate.

This Privacy Notice was amended on July 10, 2020.

What personal information do we collect and use?

The specific categories of personal information relevant to your study will be made clear to you through additional documentation provided to you during the study. The personal information collected by Incyte or on Incyte’s behalf by your doctor may include:

- age, gender, and on some occasions if relevant to the study, race or ethnicity, and genetic data;
- your personal medical history (past, present, and future);
- your biological samples collected for the study;
- health data and results from laboratory tests and tests performed on your biological samples, imaging scans, physical exams, or biometric evaluations;
- information learned from you during telephone calls, surveys, questionnaires, and office visits done as part of the study; and
- information in your medical records located in your personal doctor’s office or at other medical facilities you may have received treatment.

The source of this information will include you, your medical records located in your personal doctor's office, and other healthcare facilities where you have received or receive treatment.

During a study, the researcher or "study doctor" or other third party agent acting on behalf of the study doctor, will replace information about you that can be used to directly identify you, such as your name, with a special code prior to transferring information about you to people and organizations involved in the study. The link to your coded information will be retained at the study site and not transferred to Incyte.

Why do we use your personal information?

Your information is used by Incyte for studies to determine whether an investigational drug, medical treatment, or strategy is safe and effective for human beings. Because of this, we may also need to record, store, and report your information for the purposes of complying with studies and associated research laws and regulations.

We will only collect, use, and share your personal information where we are satisfied that we have an appropriate legal basis to do so. The appropriate legal basis is specific to the country in which you reside or participate in the study and you were provided with the basis applying to you during the Informed Consent process. The following are the legal bases Incyte may rely upon depending on that country:

- our legitimate interests as a pharmaceutical company in studying the efficacy and safety of our investigational drugs and treatments, and in conducting safe research, pursued in a way which does not unduly prejudice your rights and freedoms. In these cases we will look after your information at all times in a way that is proportionate and respects your privacy rights and you have a right to object to processing as explained below;
- compliance with a legal obligation, in particular those arising under European Union clinical trials legislation and in regards to safety reporting to local or regional authorities;
- for the purposes of scientific research; or
- your explicit consent

Consent

Use of your personal information will not be based on your consent except where we have expressly obtained consent from you for the purposes of personal information processing. Please note that we still need to obtain consent from you for compliance with ethical standards or procedural obligations, but these are not relevant to data protection law.

Where we have obtained consent for the purposes of personal information processing, you have the right to withdraw that consent at any time by informing your study doctor or chief investigator. If you do so, we will not collect any further personal information from you. This is likely to mean that you will be unable to further participate in the study. Please note that we may need to retain some of your personal information to ensure the integrity of the research and to comply with obligations under applicable laws. Other than the potentially inability for you to continue participating in the study, you will not be penalised for the withdrawal of your consent. In relation to your health data which is considered a 'special category' of personal information, we also rely on your consent.

Do you need to provide us with your personal information?

You are not obliged to provide us with any personal information. Any personal information you share with us is on a voluntary basis as a participant in the study.

Who do we share your personal information with?

There are typically a number of parties involved in a study, including physicians and other medical professionals (who may be operating as study doctors), contract research organisations, laboratories, and vendors who help us manage a study. Your personal information is shared between these parties for purposes connected with conducting the study.

Your personal information is disclosed to ethics committees, health authorities around the world (such as Health Canada, the European Medicines Agency; the United States Food and Drug Administration; etc.), and other regulatory authorities around the world (such as pricing and reimbursement agencies; data protection authorities; etc.), and those organizations who monitor and audit studies for safety and compliance;

We share your personal information with Incyte's affiliates and collaborators (which may include other pharmaceutical companies, academic or healthcare institutions or other partners who help us develop pharmaceutical products and targeted or associated therapies);

We share your personal information, anonymized, with other researchers upon their request to Incyte. These requests are made to Incyte in order to further a particular research topic related to the purpose of an Incyte clinical trial or to further understanding of a medical conditions; and

If, in the future, we sell or transfer some or all of our business or assets to a third party, or invite investment in our company, we may disclose information to a potential or actual third party purchaser of our business or assets.

Where is your personal information used or stored?

We transfer your personal information outside of your country of residence. Your personal information is transferred:

1. Within the worldwide Incyte group of companies in the United States, Europe, Switzerland, Japan, and the United Kingdom.
2. To countries where data protection standards have not been determined to be adequate: these countries include India, and China. In these cases we will ensure that any recipients of your personal information are bound by contract to data protection standards.

How long is your personal information used and stored?

We have implemented and maintain appropriate technical and organisational security measures, policies and procedures designed to reduce the risk of accidental destruction or loss, or the unauthorised disclosure or access to such information appropriate to the nature of the personal information concerned. Measures we take include the coding of your information (explained above); ensuring that our staff members and service providers keep personal information confidential; and destroying or permanently anonymising personal information if it is no longer needed for the purposes for which it was collected.

We will store your personal information for as long as is reasonably necessary for conducting the research study, and for a reasonable period of time thereafter in order to comply with applicable laws regarding the conduct of clinical trials and the marketing of pharmaceutical products. This period is generally up to thirty years after the conclusion of the clinical trial but this time period could vary by the local law in your country

What are your rights?

You have a number of rights which apply to our use of your personal information. The availability of some of these rights depends upon our lawful basis for processing your personal information and your rights may also be subject to certain conditions and restrictions. Please note that, in the context of a research study, we highly recommend that you exercise these rights by contacting the study doctor or chief investigator of the study. They will then co-operate with us in a way which preserves your confidentiality by not disclosing your identity to us (remember, we will normally not know your identity as a result of the coding process described above). If you are happy for your identity to be disclosed to us, you can choose to contact us directly. You may have the right:

- to obtain access to your personal information together with information about how and on what basis that personal information is processed;
- to rectify inaccurate personal information (including the right to have incomplete personal information completed);
- to erase your personal information in limited circumstances where it is no longer necessary in relation to the purposes for which it was collected or processed;
- to restrict processing of your personal information where:
 - the accuracy of the personal information is contested;
 - the processing is unlawful but you object to the erasure of the personal information;
 - we no longer require the personal information for the purposes for which it was collected, but It is required for the establishment, exercise, or defense of a legal claim;
- to challenge processing which we have justified on the basis of a legitimate interest;
- to object to decisions which are based solely on automated processing (to the extent that these are taken);
- to obtain more information as to safeguards under which your personal information is transferred outside of Canada (if relevant); or
- to lodge a complaint with the data protection/supervisory authority noted below.

Who can you contact regarding your rights?

Data Controller: The entity that determines why and how your personal information is processed is called a Controller. In the context of a study, the Incyte entity responsible for your personal information is the Incyte entity acting as sponsor of a clinical trial which is usually Incyte Corporation. In other research contexts, the controller will be the Incyte entity which originally collected information from or about you. Prior to enrolment in a study, you will receive more specific information about the data controller specific to your study. This Privacy Notice is not intended to modify or otherwise change the information provided to you at that time.

Additionally, in the context of each study, and depending on jurisdiction, Incyte may operate as a joint controller with the study doctor responsible for conducting the trial.

Data Protection Officer Incyte: privacy@incyte.com. Please note that, in the context of a pharmaceutical research study, we highly recommend that you first contact the study doctor or chief investigator of the study. They will then co-operate with us in a way which preserves your confidentiality by not disclosing your identity to us (remember, we will normally not know your identity as a result of the coding process described above). If you are happy for your identity to be disclosed to us, you can choose to contact us directly.

Data Protection Authority/Supervisory Authority: The Data Protection Authority/Supervisory Authority for the processing of your personal information is the authority located in the country where the pharmaceutical research activity is being conducted or the country where you live or work or where your personal information is processed. More information about your Data Protection Authority can be found on the Office of the Privacy Commissioner of Canada website: <https://www.priv.gc.ca/en/>.