
INCYTE PRIVACY NOTICE STUDY PARTICIPANTS

We use this Privacy Notice to tell you what personal data 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 data:

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

This Privacy Notice was amended on September 15, 2019.

What personal data do we collect and use?

The specific categories of personal data relevant to your study will be made clear to you through additional documentation provided to you during the study. The personal data 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 data?

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 data 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, on the basis of Member State law which provides for specific measures to safeguard the fundamental rights and the interest; or
- your explicit consent

Consent

Use of your personal data will not be based on your consent except where we have expressly obtained consent from you for the purposes of personal data 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 data 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 data 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 data 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 data, we also rely on your consent.

Do you need to provide us with your personal data?

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

Who do we share your personal data 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 data is shared between these parties for purposes connected with conducting the study.

Your personal data is disclosed to ethics committees, health authorities around the world (such as 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 data 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 data, 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 data used or stored?

We transfer your personal data to other countries outside of the European Economic Area. Your personal data is transferred:

1. To Switzerland and Japan: Switzerland and Japan are considered as providing adequate data protection standards (for further details, see here <http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32000D0518&from=EN>).
2. Within the worldwide Incyte group of companies in the United States and United Kingdom: We rely on the Privacy Shield for these transfers. Transfers made in reliance upon Privacy Shield certification are considered as providing adequate data protection standards ((for further details see here for EU-US and UK-US (<http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32016D1250&from=EN>) and here for Switzerland-US: <https://www.admin.ch/gov/en/start/documentation/media-releases.msg-id-65210.html>).

3. To countries where data protection standards have not been determined to be adequate by the European Union: these countries include the United States (where not made under Privacy Shield), United Kingdom, India, and China. In these cases we will ensure that any recipients of your personal data are bound by contract to the European data protection standards (for further details see: <http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELX:32010D0087&from=FR>).

How long is your personal data 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 data concerned. Measures we take include the coding of your information (explained above); ensuring that our staff members and service providers keep personal data confidential; and destroying or permanently anonymising personal data if it is no longer needed for the purposes for which it was collected.

We will store your personal data 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 data. The availability of some of these rights depends upon our lawful basis for processing your personal data 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 data together with information about how and on what basis that personal data is processed;
- to rectify inaccurate personal data (including the right to have incomplete personal data completed);
- to erase your personal data 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 data where:
 - the accuracy of the personal data is contested;
 - the processing is unlawful but you object to the erasure of the personal data;
 - we no longer require the personal data 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 a portable copy of your personal data, or to have a copy transferred to a third party controller;
- to obtain more information as to safeguards under which your personal data is transferred outside of the EEA (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 data is processed is called a Controller. In the context of a study, the Incyte entity responsible for your personal data is the Incyte entity acting as sponsor of a clinical trial. This will be either Incyte Corporation (US) or Incyte Biosciences Sàrl (Switzerland) as represented within the European Union by Incyte Biosciences Distribution B.V. (Netherlands) (a list of all Incyte companies available under: <http://www.incyte.com/contact-us/headquarters.aspx>). 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 data 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 data is processed. More information about how to contact these authorities can be found here: https://edpb.europa.eu/about-edpb/board/members_en.