# INCYTE PRIVACY NOTICE STUDY PARTICIPANTS, CAREGIVERS AND REPRESENTATIVES

### **UNITED STATES**

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. This Privacy Notice is also applicable to the study participant's caregiver or legal representative who interacts with us. 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 information about how your personal information is treated when it is transferred to another location, please see the applicable Privacy Notice posted on our website for that location.

For clinical trials, this is a high-level summary of Incyte's data protection processes during studies. Prior to enrollment 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 organizational measures (such as multifactor password authentication, encryption, access restriction, etc.) to protect your personal information from misuse or unauthorized alteration, loss, or access; however, we cannot guarantee that your information, whether during transmission or while stored on our systems or otherwise in our care, will be free from unauthorized access or that loss, misuse, destruction or alteration will not occur;
- We collect and use your personal information only for the purpose(s) for which we collect it;
- We only collect the personal information that we need; and
- We keep your personal information up to date and ensure that it is accurate.

This Privacy Notice was amended on April 1, 2022.

## 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, or your caregiver or legal representative, 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 caregiver or legal representative, 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 personal 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.

## 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 and is done so with your consent.

## 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 the United States Food and Drug Administration; the European Medicines Agency; 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?

Depending on your relationship with Incyte, we may transfer your personal information:

- 1) To other countries: your personal information may be transferred to Europe, Switzerland, Japan, the United Kingdom, India, and China; and
- 2) Within the worldwide Incyte group of companies as identified above.

## What are your rights?

You have some rights which apply to our use of your personal information. <u>Please note that, in the context of a research study, we highly recommend that you exercise these rights by contacting the study doctor.</u> 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 using the contact information posted below. These rights include:

#### Consent

As noted above, the use of your personal information is based on your express consent as a study participant. You have the right to withdraw this consent at any time by informing your study doctor. 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.

#### **Right to Access**

You have the right to review your medical records and request changes if any information is incorrect. Please note, however, that during the study, access to your study data and results may be limited if it weakens the integrity of the research. You may request access to the study information help by the study doctor at the end of the study.

## How is your personal information kept secure?

We use a combination of commercially reasonable physical, technical, and administrative safeguards to protect the personal information we collect from you. When your personal information is shared, Incyte will take a reasonable approach to prevent the unauthorized use or disclosure of personal information.

While we use these precautions to safeguard your personal information, please be aware that no security measures are perfect or impenetrable. We cannot guarantee the security of the networks, systems, servers, devices, and databases we operate or that are operated on our behalf. Please use caution when submitting any personal or other sensitive information to us online.

## What if the personal information is relating to a minor?

Incyte does not knowingly collect personal information directly from minors—persons under the age of 16, or another age of a minor as defined by law—other than when required to comply with the law or for safety or security reasons. If you are a parent or guardian of a minor who has provided personal information without your knowledge or consent, you may submit a request to remove the minor's information by emailing us at privacy@incyte.com.

## What if you're an individual with a disability and want to get this Privacy Notice in an alternative format?

Incyte is committed to ensuring that our communications are accessible to individuals with disabilities. To submit accessibility-related requests or report barriers to accessibility, please use the contact information below.

## Who can you contact about Privacy at Incyte?

If you have any questions about our privacy policies or practices, we encourage you to contact the Incyte Privacy Office:

Attn: Privacy Office
Incyte Corporation
1801 Augustine Cut-off
Wilmington, Delaware 19803
833-919-0687
privacy@incyte.com

## CALIFORNIA RESIDENTS ONLY

If you are a resident of California, please read this section to learn more about the California Consumer Privacy Act of 2018 (CCPA) and how it applies to the personal information collected and used by Incyte as described in this Privacy Notice.

## What are my rights?

Individuals who are California residents and whose information is covered by the relevant provisions of the CCPA may have the following privacy rights:

- to request disclosure of personal information we collect and share about you during the 12-month period preceding our receipt of the request, including:
  - the categories of personal information we've collected about you;
  - o the categories of sources from which we collected the personal information;
  - o the business or commercial purposes for which we collected or sold the personal information
  - o the categories of third parties with which we shared the personal information;
  - the categories of personal information that we have shared with service providers who
    provide services to us;
  - o the specific pieces of personal information we collected; and
  - the categories of personal information (if any) that we have sold about you, the categories
    of third parties to which we have sold that information, and the category or categories of
    personal information sold to each third party
- to request deletion of personal information we have collected about you; and
- to request that Incyte not sell your personal information.
  - O Under the CCPA, California consumers also have the right to request that their information not be sold for value. Currently, we do not sell or disclose your information to third parties for monetary or in-kind compensation. However, if this practice changes in the future, we will provide updated information via this Privacy Notice and provide instructions on this page to submit a request to stop selling your personal information.

You also have a right not to be discriminated against for the exercise of the privacy rights conferred by the CCPA. If you exercise any of the rights explained in this Privacy Notice, we will continue to treat you fairly and not discriminate against you on the basis that you have exercised such rights.

There may be some types of personal information that can be associated with a household (a group of people living together in a single home). Requests for access or deletion of household Personal Information must be made by each member of the household. We will verify each member of the household using the verification criteria explained below. If we are unable to verify the identity of each household member with the degree of certainty required, we will not be able to respond to the request. We will notify you to explain the basis of our denial.

## Who can you contact regarding your rights?

If you are a California resident, to exercise your CCPA rights to request access or deletion of personal information that Incyte collects or shares about you, please contact Incyte at <a href="mailto:privacy@incyte.com">privacy@incyte.com</a> or toll free at 833-919-0687. <a href="mailto:Please note that">Please note that</a>, in the context of a research study, we highly recommend that you exercise these rights by contacting the study doctor. 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 using the contact information posted below.

For requests for access or deletion, we will respond to you or your authorized agent's request in writing, or orally if requested, as soon as practicable and in any event generally not more than within 45 days after receipt of your request. We may extend this period to 90 days and, in the event that we do extend the period, we will explain to you or your authorized agent why we did so.

If you are legally entitled to such rights, you may designate an agent to submit a request on your behalf. The agent can be a natural person or a business entity that is registered with the California Secretary of State. If you would like to designate an agent to act on your behalf, you and the agent will need to comply with our agent verification process. You will be required to verify your identity by providing us with certain personal information, depending on the nature of the information you require, which we will endeavor to match with information we maintain about you. Additionally, we will require that you provide us with written confirmation that you have authorized the agent to act on your behalf, and the scope of that authorization. The agent will also be required to provide us with proof of the agency relationship, which may be a declaration attesting to the agent's identity and authorization by you to act on their behalf, signed under penalty of perjury. If the agent is a business entity, it will also need to submit evidence that it is registered and in good standing with the California Secretary of State. Information to identify and verify your agent can be submitted through the same mechanism and at the same time that you submit information to verify your identity. Please note that this subsection does not apply when an agent is authorized to act on your behalf pursuant to a valid power of attorney. Any such requests will be processed in accordance with California law pertaining to powers of attorney.

To respond to your requests, we will ask you for at least two pieces of personal information and, for requests for specific pieces of personal information, we will ask you for at least three pieces of personal information. The information we require may vary depending on your relationship to us, and may include your full legal name, residential address, email address, phone number, as well information we may have on file about you. If you are requesting on behalf of another consumer, we may request additional information from you and/or the consumer to verify their identity. In all cases, we endeavor to match the information we receive for the purpose of verification to information we maintain about you. If we are unable to verify your identity using this process we will provide you with a response explaining so and what additional action you may take to ensure we can successfully verify your request.

## **California Shine the Light**

California Civil Code Section 1798.83, also known as the "Shine The Light" law, permits California residents to annually request, free of charge, information about the personal information (if any) disclosed to third parties for direct marketing purposes in the preceding calendar year. No information is shared with third parties for their own marketing purposes.