

## **Managed Access Programs / Post-Study Drug Supplies Patient Privacy Notice and Consent Template**

Dear Patient,

Your treating physician is submitting a request to Novartis for your treatment or your child's/ward's treatment. This privacy notice describes how Novartis Healthcare Private Limited at Inspire BKC 701, Bandra Kurla Complex, Bandra (East), 400 051 Mumbai, India (hereinafter referred to as "Novartis"), uses and otherwise processes your data as controller.

In this privacy notice, references to "we" or "us" mean Novartis. "You" means the patient whose data is processed as described in this document. If you receive this document because your treating physician has submitted a request for access to treatment for your child or ward, the term 'you' refers to your child or ward for whom the request is being made.

Where you are not comfortable with English, the notice and / or Consent Form and related Program information may be made available in another language, including a language specified in the Eighth Schedule to the Constitution of India, upon request, within a reasonable period. Consent will be obtained or confirmed only after the Consent Form has been explained or provided in a language the data subject understands

### **What data do we collect and what happens with it?**

When submitting the request for access to your treatment, your treating physician is required to share certain data about you with Novartis (hereinafter referred to as "your data").

Novartis solely receives information about your gender, month and year of birth and information about your health, such as your medical condition and the information about the treatment you have received so far. In case your treating physician requests a re-supply of the treatment for you, additional information about the treatment efficacy may also be requested. Other data, such as your initials, may be collected only if required by local laws or regulatory authorities. Novartis does not receive your directly identifiable information such as your name or address unless it is required for the shipment of your treatment as per the country requirements – in such case your name and contact details may be required for the shipment.

Novartis needs your data to:

- manage the request, e.g., evaluate your eligibility for the treatment,
- manage the shipment: in countries where we are required to ship your treatment directly to you,
- comply with legal or regulatory requirements, for example, in case of safety events.

Novartis may also further anonymize your data, which means that the data can no longer be linked back to you. Anonymized data may be used by Novartis for other purposes such as writing scientific publications and educational papers and may share it with others including external partners or health authorities.

### **Who can see your data?**

Your data can be seen by:

- Institutional review boards or ethics committees,
- Novartis and their representatives,
- Third parties hired by Novartis to provide services related to the management of the request and other purposes outlined in this document,
- Health Authorities.

The people and organizations listed in the section above are required to keep your data confidential.

Novartis representatives and third parties hired by Novartis may be located in countries that do not provide the same level of data protection, however Novartis will protect the privacy of your data by applying safeguards required by law.

Novartis collects and uses your data based on your consent and to meet its legal obligations. Novartis will keep your data for 15 years.

### **What are your privacy rights?**

- Right to access information about personal data.
- Right to correction and erasure of personal data.
- Right of grievance redressal.
- Right to nominate
- Right to withdraw any consent you provided, without affecting the lawfulness of the processing prior to such withdrawal

If you want to exercise the above rights, [click here](#).

In addition to the rights above, you may have the right, under applicable law, to file a complaint with the Data Protection Board.

Novartis may be restricted by law in following requests related to your privacy rights, it may e.g. not be possible to erase certain data, where data needs to be available for health authority purposes.

If you have any questions about your data or want to exercise the above rights, please contact your treating physician.

If you reach out directly to Novartis, and not through your physician, Novartis may know your identity.

This form will be retained by your physician.

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By signing below, I agree to the sharing and use of my data, as described in this privacy notice.

\_\_\_\_\_  
Typed/printed name of  
**Patient / Parent/Guardian**

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date