

## Managed Access Programs / Post-Study Drug Supplies

### Patient Privacy Notice/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 Pharma AG, at Lichtstrasse 35, 4056 Basel, Switzerland]/ [insert details of the relevant gulf entity across UAE, Oman, Bahrain, Qatar, Kuwait as applicable] (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.

#### **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.

Your personal data may be transferred to Novartis group companies, service providers, or health authorities located outside your country of residence.

Such transfers will be carried out in accordance with applicable data protection laws and subject to appropriate safeguards, as required under applicable regulations.

Novartis processes your personal data in accordance with applicable data protection laws in the country of operation by using 'binding corporate rules' and 'standard contractual clauses', including where necessary to manage access to treatment, comply with regulatory and pharmacovigilance obligations, and, where required, based on your consent.

Novartis will retain your personal data for no longer than necessary to fulfill the purposes described in this notice and in accordance with applicable legal, regulatory, and pharmacovigilance retention requirements under local law.

**What are your privacy rights?**

Subject to applicable laws, you have the right to access your personal data, request correction of inaccurate data, and request deletion where permitted under applicable laws.

Requests may be submitted through your treating physician or directly to Novartis using the [link](#) and will be handled in accordance with applicable data protection laws and regulatory requirements.

Where processing is based on consent, you may withdraw your consent at any time. However, withdrawal of consent will not affect the processing or retention of personal data where continued processing is required under applicable laws, including obligations related to health, patient safety, or pharmacovigilance

You can contact the Novartis data protection officer at the email address [\[dataprivacy.gulf@novartis.com\]](mailto:dataprivacy.gulf@novartis.com) / [global.privacy\\_office@novartis.com](mailto:global.privacy_office@novartis.com) or writing per post mail to "Global Data Privacy Office, Novartis Pharma AG, Lichtstrasse 35, 4056 Basel, Switzerland". If you reach out directly to Novartis, and not through your physician, Novartis may know your identity. In addition to the rights above, you may have the right under applicable law to file a complaint with the competent supervisory authority.

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. I have read this document / had its contents explained to me.

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

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date