



Interested in Sharing Your Thoughts on Clinical Research?

The Center for Information and Study on Clinical Research Participation ([CISCRP](#)), an independent nonprofit organization, is working with Takeda Pharmaceuticals to organize a virtual Patient Advisory Council where participants will talk about how clinical trials can be best designed to include and support LGBTQ+ and racially and ethnically diverse communities. The results will help improve experiences and promote greater inclusion of diverse communities in clinical trials.

Participation* in the Patient Advisory Council will include:

- 5 to 7 virtual meetings over the course of 1 year
- Each meeting will last between 1 to 3 hours
- Both healthy individuals and those with a health condition are eligible to participate

**Participants will be paid for their time by Takeda.*

If you or anyone you know is interested in participating, please review the privacy language that follows and then contact Rebecca Nordland at:



617-725-2750 ext. 406



rnordland@ciscrp.org

To learn more about CISCRP and Takeda, please visit:

CISCRP www.ciscrp.org | Takeda www.takeda.com/en-us/



Privacy Notice & Consent for Patient Advisor Screening

Your privacy is important to us. Takeda recognizes and respects the privacy rights of individuals with regard to their personal data. This Privacy Notice and Consent form (“Form”) explains what type of personal data we may collect from you and how we use it when you participate in this activity to identify potential patient advisors (the “Screening”).

Before participating in the Screening, you should read this entire Form. Prior to participating in the Screening, you will be asked to make an available choice with respect to the processing of your personal data and to consent to the processing of your personal data by providing your verbal consent.

For more detailed information on how Takeda processes personal data, please refer to Takeda’s Privacy Notice at www.Takeda.com.

Patient Advisory Activities

CISCRP is a company assisting Takeda with identifying patients and/or caregivers of patients for potential longitudinal advisory panel participation.

What personal data will be collected?

During the Screening, your personal data will be collected by CISCRP and includes your contact information and information you share about your condition, including your experience of the condition, diagnosis, treatment, unmet needs of the patient community, meaningful outcomes, and considerations for designing patient-friendly clinical trials.

What happens with my personal data?

If you decide to participate in the Screening, your personal data, including health related information will be processed (e.g. collected, used, disclosed, stored, and disposed) by CISCRP and/or Takeda as described based on your consent. Your personal data may be sent to countries around the world where Takeda has an affiliate or business partner. The data protection and privacy laws in these countries may not provide the same level of data protection as the laws in your home country or the country where you are participating in the Screening. With respect to transfers to its affiliates and business partners located outside of your home country, Takeda has entered or will enter into specific agreements with these parties to provide appropriate protections for your transferred information (e.g., “EU Standard Contractual Clauses”), where required.

How will your personal data be protected?

Takeda and CISCRP will protect your personal data in accordance with all applicable data protection and privacy laws. Your personal data is secured against unauthorized access. Security measures reduce the risk of unauthorized individuals accessing your personal data, but such risks cannot be eliminated. If your personal data were to be accessed by unauthorized individuals, information about you could be used to make decisions which may be unfavorable to you. Many, but not all, possible unfavorable uses of your re-identified or improperly disclosed information are prohibited by medical ethics, law or regulation.

How long will my personal data be retained?

Your personal data will be retained by CISCRP and Takeda for the period of time necessary to identify patients for potential participation in patient advisory activities. After this period, your personal data will be securely destroyed.

Your rights regarding your personal data

You have the right to request access to your personal data, request corrections of any errors in recorded personal data, or where personal data may be missing or incomplete ask that it be completed. You also have the right to ask that your personal data collected and used for the Screening to be erased or that its use be restricted. A local supervisory authority is responsible for making sure that privacy laws are followed. If you have a complaint about how your personal data is being processed, you may contact your supervisory authority.

How to contact us?

CISCRP can be contacted by emailing Rebecca Nordland of CISCRP. Advisors: rnordland@ciscrp.org

Takeda, the sponsor of this Screening activity and Takeda’s Data Protection Officer can be contacted at Takeda Pharmaceuticals International AG, Thurgauerstrasse 130, 8152 Glattpark-Opfikon (Zurich), Switzerland, Tel.: +41 044 555 10 00; fax: +41 44 55 51250; e-mail: PrivacyOffice@takeda.com. Additionally, In the United States, you may contact Takeda at 1-800-676-8975.