



**Participant in Patient Focus Group
Privacy Notice
Last updated: April 2023**

Chugai Pharma Europe Ltd (referred to as “we”, “us” or “our” or “**Chugai**”), the European branch of a Japanese pharmaceutical company, respects your right to privacy and treats all your personal data in accordance with this Privacy Notice and applicable privacy and data protection laws. In collecting and processing this personal data, the Chugai entity you have your relationship with is the controller of your personal data. This Privacy Notice explains who we are, how we collect, share and use personal information about you and how you can exercise your privacy rights.

If you have any questions or concerns about our use of your personal information, please contact us using the contact details provided at the ‘Contact Us’ section of this Privacy Notice.

Scope of this Privacy Notice

This Privacy Notice applies to personal data being collected and processed in relation to Chugai’s patient advocacy focus groups. When you choose to participate, Chugai will collect and process personal data about you, as detailed in this Privacy Notice.

We ask you please read this Privacy Notice carefully to ensure you don’t miss any information that may be relevant to you.

Our Lawful Basis

Chugai has a legitimate interest to conduct this processing relating to its scientific research purposes. The collection and processing of your data is of a research nature.

The purpose of this focus group is to gather information on your disease experience by discussing general information regarding living day to day with the disease. This will aid Chugai’s insight into your unmet medical needs, and also the acceptability of our planned study design. If you have been diagnosed with such disease, you may decide to participate in one of Chugai’s patient focus groups.

Under the UK General Data Protection Regulation (GDPR), the lawful bases we rely on for processing this information are:

- processing is necessary for the purposes of the legitimate interests pursued by Chugai
- the processing of special categories of data, such as health data is necessary for scientific research purposes

How we get the information?

We may receive personal information indirectly from you, via the following sources and in the following scenarios:

- A patient organisation collaborating with Chugai for the advocacy group meeting and because you responded to one of their posts recruiting participants for this event on our behalf
- The platform Chugai uses to hold our virtual meetings (e.g, Zoom Video Communications, Inc), when you have decided to register and participate in one of our meetings

Other personal information we process is provided to us directly by you, for one of the following reasons:

- Your interaction and opinions around the topic of the focus group will be collected directly from you when you enter into discussions during the meeting
- If you decide to complete a survey following the meeting

Why and what type of information will we collect in relation to your participation?

Your privacy is important to us and we take necessary steps to protect your personal data at all times; we would therefore like to collect as little personal information about you as possible.

Please note that Chugai will not necessarily process all data listed below about you. Only adequate, relevant, and limited data in relation to the focus group shall be collected and processed.

Processing Scenario	Categories of Personal Data	Purpose	Legal Basis	Retention Details
Administrative activities relating to meeting registration and coordination	First name You may choose to use a pseudonym/alias to register Email	To register your participation, provide you with meeting details	Legitimate Interest (research purposes, as stated above)	Will be deleted within 3 months
Discussions during the meeting	You may choose to disclose your first name (or a pseudonym/alias), age, medical condition or other personal details and opinions relating to living day to day with the disease	To gather information on any one of our disease areas by discussing general information regarding living day to day with the disease to aid Chugai’s insight into unmet medical needs, and trial acceptability regarding a planned study for that disease	Legitimate Interest (research purposes, as stated above)	Will be anonymised and deleted within 3 months
Recording during the meeting (the use of camera during the meeting is optional, however audio recording will be undertaken at all times)	Audio and image recording	To accurately document the discussions held during the focus group to achieve the goal of the focus group	Consent, participants will be asked to consent before any recording takes place	Image recording will be deleted 2 weeks after the meetings are completed. Audio recording will be deleted within 3 months

Contacting you in relation to the meeting	First name Email	To inform you of the outcome of the meeting and/or to send an anonymous survey	Legitimate Interest (research purposes, as stated above and for Chugai to improve upcoming focus groups)	Will be deleted within 3 months
Meeting minutes for documenting purposes	Does not include personal data. Anonymised and de-identified data	Consolidate all information obtained from the meetings in order to achieve Chugai's goal and purpose from it. All personal data will be removed from the final transcript/report	Legal Obligation (research purposes, as stated above)	Will be retained for 25 years in accordance with legal requirements, but you will not be able to be identified from these minutes

What we will do with the information gathered during the meeting

We will use the information gathered during the meeting to assess whether we need to change our planned clinical trial in order to make it more patient friendly. After the meeting a limited/specialised group of people will assess the data gathered and generate a full report of the meeting. They will use the audio recording to ensure that nothing is missed and draft meeting minutes. After the meeting information is consolidated and anonymised, the recording will be deleted.

Your email address will be retained until this process has been completed so that we can share with you how your contribution has made a difference to our clinical trial process.

Your personal data will then be deleted from our system and we will only maintain anonymised/de-identified records from the meeting. This will occur no longer than 3 months after the date of the meetings.

Sharing of Data

Chugai will retain control of and responsibility for the use of your information; however, we may share the audio recording with our company's headquarters or store that data with them. Whenever Chugai shares your personal data with the company group, this will be done on a need-to-know basis.

Chugai will also share personal data you provided us with, with various outside companies or agents working on our behalf to help fulfil business transactions and to help fulfil business operations. Such is the case of **Zoom Video Communications, Inc**, who Chugai uses to help facilitate our events. We will collect registration information via their registration tool and may host our meetings using their platform. We encourage you to familiarise yourself with how they process data on our behalf [here](#).

All these companies and agents are required to comply with applicable data protection laws.

Chugai will only transfer data to countries outside the UK and EEA when satisfied that both the party which handles the data and the country it is processing it in provide adequate safeguards for personal privacy.

Retention Period

Chugai will only process your personal data for as long as needed and as defined in the table above. We retain personal information we collect from you where we have a genuine business need to do so, once the retention period has been reached we will securely delete your personal data. Even if we delete your personal data it may persist on backup or archival media for an additional period of time for legal, tax or regulatory reasons or for legitimate and lawful business purposes.

Security

Chugai takes precautions to ensure that personal data is protected and that the processing is in accordance with applicable data protection rules, consistent with generally accepted industry standards, including technical, administrative, and physical safeguards to protect the personal data submitted to us from loss, misuse and unauthorised access, disclosure, alteration and destruction.

What happens if you do not provide Chugai with any personal data

Your decision to participate in the focus group and provide any personal data to Chugai is purely voluntary. Chugai would collect and process personal data as stated above. If you do not agree with a processing or do not wish to provide your personal data in connection with the meeting, unfortunately you will not be able to participate in our focus group.

Your Rights

You have the right to be informed, to request access to data we hold about you, to rectification or (in some cases) erasure of personal data held by Chugai and can request that we restrict processing or object to it. If you wish to make use of one of these rights, please email our DPO, using the details below.

If we have asked for your consent in order to process your personal data, you can withdraw this consent in whole or part at any time. To withdraw consent, please email your local contact, who will explain the consequences of doing so in any particular case and initiate proceedings for withdrawing consent.

Your Right to Complain

You also have the right to lodge a complaint at any time to the relevant supervisory authority for data protection issues, the Information Commissioner's Office (ICO). We would, however, appreciate the chance to deal with your concerns before you approach the supervisory authority, so please contact us in the first instance.

Contact us

Chugai has appointed a data protection officer (DPO) who can respond to any enquiries about our use of your personal data. If you have any questions about this policy, including any requests to exercise your legal rights, please contact our DPO using the details set out below:

- **Post:** Data Protection Officer, Chugai Pharma Europe, Mulliner House, Flanders Road, Turnham Green, London, W4 1NN United Kingdom
- **e-mail:** dataprotection@chugai-pharm.co.uk
- **Phone:** +44 (0)208 987 5600