



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

19 June 2019
EMA/351266/2019

Privacy Statement for the EMA individual experts' stakeholder database

This privacy statement provides details on how the European Medicines Agency (hereinafter "EMA" or "Agency") will process your personal data that submitted for the purpose of registering in the EMA individual experts' stakeholder database (hereinafter "Database").

All personal data provided in the application form for registration of interested individuals in the Database (hereinafter "application form") will be processed in accordance with [Regulation \(EU\) 2018/1725 on the protection of natural persons with regard to the processing of personal data by the Union institutions, bodies, offices and agencies and on the free movement of such data](#).

1. Collection of data

EMA will collect the personal data you provide in the application form, such as your name, email address, telephone number, citizenship, representation (patients, consumers, carers), membership/affiliation with patient/consumer organisations or EMA committees or working parties, if any. You will also have to indicate your areas of interest in EMA activities as well as any prior participation in EMA activities, where applicable. Finally, you are also asked to indicate the disease/condition areas of your interest.

If you do not wish to provide your personal data, please note that such refusal might lead to your request for being included in the Database declined.

2. Lawfulness and legal basis of the processing

When you provide your data in the application form, you consent to the processing of that data by the Agency as explained in this privacy statement. You have the right to withdraw your consent later at any time. Please note that such withdrawal does not affect the lawfulness of processing carried out by the Agency before the withdrawal of your consent.

Official address Domenico Scarlattilaan 6 • 1083 HS Amsterdam • The Netherlands

Address for visits and deliveries Refer to www.ema.europa.eu/how-to-find-us

Send us a question Go to www.ema.europa.eu/contact **Telephone** +31 (0)88 781 6000

An agency of the European Union



In addition, the processing of your data in relation to the setting up and maintenance of the Database is necessary for the Agency's task carried out in the public interest. This processing is based on the legal provisions of [Regulation \(EC\) No 726/2004](#) regarding the involvement of stakeholder representatives in the Agency's activity. In particular, Article 78(1) of the Regulation requires that appropriate contacts between the Agency and the representatives of the industry, consumers and patients and the health professions shall be developed. These contacts may include the participation of observers in certain aspects of the Agency's work. In this regard, the EMA Management Board had adopted the [EMA stakeholder relations management framework](#) and the [Revised framework on the interaction of the Agency with patients and consumers and their organisations](#).

Further specific details on the setting up and maintenance of the Database are provided in the [Frequently Asked Questions - EMA individual experts' stakeholder database: patients and consumers](#).

3. Who is the data controller?

The Agency is ultimately responsible to comply with your data protection rights and freedoms. On behalf of EMA, Head of Communication and Stakeholders Division is appointed as a 'Data Controller' to ensure the proper implementation of the processing operation. You may contact the Data Controller through the Public Engagement Department at S-DataController@ema.europa.eu.

4. Start of data processing

EMA will commence the processing of your personal data as soon as the application form is received.

5. Purpose of data processing

The information collected in the application form will only be used by EMA staff members for the purpose of informing and involving patients and other interested parties in the regulatory activities of EMA. No further processing of your personal data for any other purposes outside the scope of this specific context is envisaged.

6. Location of data storage and recipients of the data

All data is stored within a secure data centre within the EMA premises which is password protected and only available to EMA staff members. All data will be processed internally by EMA staff authorised by senior management to carry out the maintenance of the Database and to contact the experts included in the context of their involvement in the regulatory activities of EMA.

7. Publication of data

None of the data included in the application form, and in the database will be published or shared outside of the EMA.

8. Retention period

Once included in the database, you will be asked on an annual basis if you wish your details to remain in the database, this is also necessary to ensure current contact details and interests are up to date. If at this time, you advise you wish to 'unsubscribe' then all of your data will be immediately removed. Removal from the database can additionally always be requested at any time by email.

9. Your rights

As data subject, you have a number of rights:

- **Right to be informed** – This privacy statement is aimed at informing you on how EMA collects and uses your personal data.
- **Right to access** – You have the right to access your personal data. You have the right to request and obtain a copy of the personal data held by EMA. Requests for other information, such as information on recipients may also be directed to the Data Controller.
- **Right to rectification** – Data subjects have the right to obtain without undue delay the rectification of inaccurate personal data concerning him or her.
- **Right to withdraw consent** – You have the right to withdraw your consent to the processing of your personal data at any time. However, this will not affect the lawfulness of any processing carried out before consent is withdrawn.
- **Right to erasure** – You have the right to require EMA to delete or stop processing your data, for example where the data is no longer necessary for the purposes of processing.
- **Right to object** – When EMA processes your data based on the fact that it is necessary for the performance of the Agency's tasks in the public interest, you may object to such processing on grounds relating to your particular situation.
- **Right to portability** - Where personal data was directly given to EMA by the data subject and the processing is carried out with his/her consent and by automated means; the data subject has the right to receive their personal data in a machine-readable format. In these cases, data subjects may also request that such data is directly transferred to another controller.

You can exercise your rights by contacting the Public Engagement Department at

S-DataController@ema.europa.eu.

The rights of the data subject can be exercised in accordance with the provisions of Regulation (EU) 2018/1725.

If you have any complaints about the processing of your personal data, you can contact the EMA Data Protection Officer: dataprotection@ema.europa.eu.

You also have the right to lodge a complaint with the European Data Protection Supervisor:

- Email: edps@edps.europa.eu
- Website: www.edps.europa.eu
- Further contact information: www.edps.europa.eu/about-edps/contact_en

To find out more about how EMA processes personal data in general, please view the [Privacy Statement on EMA's website](#).