



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

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Stakeholders and Communication Division

## EMA's individual stakeholder database: patients, consumers, healthcare professionals and academia

### Frequently asked questions

#### Background:

The European Medicines Agency ([EMA](#)) collaborates with a large number of patients, consumers, healthcare professionals and academia, and their organisations on aspects such as information on medicines, consultation on product-specific issues and participation in workshops and meetings.

These experts provide the Agency with up-to-date, real-life experience of living with a disease, the context of clinical practice and/or the use of medicines in different EU countries, and new medical technologies to address unmet medical needs. In turn they can be directly involved in regulatory discussions related with the development and evaluation of medicines for use in the EU.

Identifying the right person for each of the activities requires the use of a database; therefore, EMA is expanding its internal database of stakeholders, which currently contains information on organisations, to also include individuals and their areas of interest across Agency activities.

#### What is the purpose of the individual stakeholder database?

The database's main purpose is to identify patients, consumers, healthcare professionals and academia to participate in EMA activities. In addition, those registering will receive information in their area of interest.

By maintaining a database with individual experts interested in participating in EMA activities representing different indications, EMA hopes to complement [EMA's public list of European experts](#) and increase further the involvement of patients and consumers, healthcare professionals and academia in its activities, which is consistent with the transparency practices of EMA with respect to its decisions.

#### How do I register to be in the database?

In order to register to be included in the database, please click [here](#) and fill the application form. You will receive an automatic acknowledgement followed by a confirmation email once validated.

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## **Is this the only way that EMA can identify experts?**

No. The Agency can use the [list of European experts](#) or its list of eligible [patient and consumer](#) and [healthcare professional organisations](#). However, the increasing demand and diversity of activities requires a broader approach.

## **Is anyone able to be part of the database?**

Yes, patients, consumers, healthcare professionals and academia are all invited to register in the individual stakeholder database.

## **Is a scientific background in medicines research or medicines regulation necessary?**

Patients and consumers bring a unique and critical input based on the real-life perspective of living with a condition and its current therapeutic environment. This element complements the scientific information and fills a gap that other scientific experts cannot fill, and which has proven to be critical for achieving the best possible results within the regulatory process. The role of patients is not expected to be of a scientific nature and experience has demonstrated that patients can frequently contribute scientifically to the discussion. Their added value is to bring their unique real-life perspective as end-users of medicines. EMA provides support and educational material to prepare patients and consumers invited to the Agency to participate in an activity.

Healthcare professionals bring their expertise and the views of the wider community of practicing specialists, general practitioners, nurses and pharmacists. European healthcare professionals support and reinforce existing knowledge within the European Regulatory Network with additional input from day-to-day clinical practice; including at the level of prescribing, dispensing and/or administering medicines and provide valuable insight on the potential impact of regulatory decisions. Healthcare professionals are not expected to bring regulatory expertise.

Academics/ researchers are expected to have a demonstrable professional interest to be included in our stakeholder database. Interests may lay in the fields of regulatory science, clinical and non-clinical translational research, novel methodologies, including non-animal models, medical devices or medicines development.

## **In what language will the communication and activities be?**

All communication and activities organised and arranged by EMA are in English. Unfortunately, there is no possibility for a translator during the activities.

## **What kinds of activities are experts involved in at EMA?**

There are many ways to be involved at the Agency and we recommend that you consult our dedicated pages ([Patients and Consumers](#), [Healthcare Professionals](#), [Academia](#)) as well as our [Engagement Report](#) on stakeholder interactions.

## **When and how often will I be involved in EMA activities?**

It is impossible to indicate when and how often an activity in your area of interest will arise, however EMA strives to involve experts whenever it would be of added value. Opportunities for involvement are also dependent on the dossiers submitted by developers of medicines.

## **Is participation in EMA activities paid?**

Participation, in EMA activities, is on a voluntary basis. If the activity involves travelling to EMA offices in Amsterdam, experts receive a travel expense allowance. Further details on the expense allowance will be explained when the activity is discussed.

## **Which personal information has to be provided?**

To be included in the database you will have to provide your name, email address and telephone number so that EMA can contact you if an opportunity arises for you to be involved. It also means EMA can send you targeted information, based on your pre-selected preferences.

In addition, you will have to indicate your citizenship, representation (patients, consumers, carers, healthcare professional, academia) and membership/affiliation with patient/consumer organisations or professional organisations/ learned societies. 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 research or interest.

## **How will your personal data be protected?**

Your personal information will be processed and stored 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](#). Your information will not be shared with anyone outside of EMA.

For detailed information on how the Agency processes your personal data included in the EMA individual stakeholder database, please read our specific privacy statement which may be found here: [link](#). You may also find this privacy statement on the online application form for registration in the database. By submitting the application form, you declare that you have read and understood the privacy statement, and that you consent to the processing of your personal data as explained in the privacy statement.

## **Is it possible to update my data?**

Everyone included in the database will receive a personalised link enabling them to change their settings and data at any time.

## **How long will my data be held in the database?**

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.

## **Can I request to be removed from the database?**

Yes, you can withdraw from the database at any time.

## **How will my activities be recorded in the database?**

If you are involved in an EMA activity this will be recorded on your page for future reference. When you are removed from the database this data will also be deleted however information regarding your involvement in certain EMA activities may be retained in the records of those particular activities (e.g., list of participants, meeting minutes) in accordance with the retention policy applicable to those documents.