EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

23 June 2016
EMA/441045/2016
Stakeholders and Communication Division

EMA individual experts' stakeholder database: patients and consumers

Frequently asked questions

Background:

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

These patient and consumer experts provide the Agency with up-to-date, real life experience of living with a disease or the use of medicines, and in turn they can be directly involved in regulatory discussions on medicines for use in the EU.

Identifying the right person for each of the activities requires the use of a database; therefore the 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 experts' stakeholder database?

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

By maintaining a database with patients interested in participating in EMA activities representing different indications, the EMA hopes to increase further involvement of patients and consumers in its activities, which is consistent with the transparency practices of the 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.

30 Churchill Place ● Canary Wharf ● London E14 5EU ● United Kingdom
Telephone +44 (0)20 3660 6000 **Facsimile** +44 (0)20 3660 5550
Send a question via our website www.ema.europa.eu/contact

Is this the only way that the EMA can identify patients?

No, in fact the Agency's first port of call when looking for patients is via their list of registered eligible patients' and consumers' organisations. However the increasing demand and diversity of activities requires a broader approach.

Is anyone able to be part of the database?

Yes, patients, carers and consumers are all invited to register in the individual experts' stakeholder database.

Is a background in medicine or regulatory affairs necessary?

Patients and consumers are invited because they can contribute valuable information based on their real-life experiences. A background in medicine or regulatory affairs is not necessary. The EMA provides support and educational material to prepare patients and consumers invited to EMA to participate in an activity.

In what language will the communication and activities be?

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

What kinds of activities are patients and consumers involved in at the EMA?

There are many ways to be involved at the Agency and we recommend that you consult our Patients and Consumers pages as well as our Annual Report on interactions with patients and consumers.

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 the EMA strives to involve patients or consumers 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 the EMA offices in London, experts receive a travel expense allowance. Further details on the expense allowance will be explained when the activity is discussed.

Which contact information has to be provided?

To be included in the database you will only have to provide your name, email address and telephone number so that the EMA can contact you if an opportunity arises for you to be involved.

How will your personal data be protected?

Your personal information will be processed and stored in accordance with European law. Your information will not be shared with anyone outside of the European Medicines Agency.

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 to reconfirm inclusion in the database. This is necessary to ensure current contact details and interests are up to date. If inclusion is not reconfirmed, you will be removed from the database.

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?

Every time you are involved in an activity at the EMA this will be tracked on your page for future reference.