



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

EMA/637643/2019

Record of data processing activity for individual experts stakeholder database (public)

1.	Last update of this record, version number:	20 December 2019, version 1
2.	Reference number:	S2
3.	Name and contact details of controller:	European Medicines Agency Internally: EMA Head of Stakeholders and Communication Division: S-DataController@ema.europa.eu
4.	Name and contact details of DPO:	dataprotection@ema.europa.eu
5.	Name and contact details of joint controller (where applicable)	N/A
6.	Name and contact details of processor (where applicable)	N/A
7.	Purpose of the processing	<p>Personal data is processed for the purpose of creating and maintaining a database of patients and consumers interested to participate in EMA activities and who may wish to receive targeted information in their defined area of interest.</p> <p>The Database is necessary for the Agency's task and is 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 activities. In particular, Article 78(1) of the Regulation requires that appropriate contacts between the Agency and representatives of consumers and patients shall be developed.</p> <p>Patient and consumer experts provide the Agency with up-to-date, real life experience of living with a condition and the use of medicines. To identify the right person for each of the activities, EMA relies on an extensive network of EU patient/consumer organisations but this needs to be supplemented with a 'pool of interested patients' registered within a database.</p> <p>The information included within the database will be used by the Agency to contact individuals with the aim to invite them</p>

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		to participate in a particular EMA activity, and to send targeted information, based on their pre-defined area(s) of interest.
8.	Description of categories of persons whose data EMA processes and list of data categories	<p>The categories of persons include all members of the public, i.e. patient/consumer representative or carer, who wish to participate in EMA activities.</p> <p>The processing operation relates to the need for a repository of contactable patients/consumers willing to be involved in EMA activities. Therefore, the data categories relate to (i) data concerning health and (ii) data concerning telephone numbers and communications.</p> <p>All those wishing to be included within the database are required to complete an application form with the following information:</p> <p>Name and a) capacity (i.e. patient, consumer representative or carer; b) affiliation (i.e. name of the organisation represented if applicable); c) contact information (address, e-mail address, telephone number); d) country of residence; e) disease area(s) of knowledge/interest; f) activities and targeted disseminations for which they wish to be contacted, and g) previous EMA experience, if any.</p>
9.	Time limit for keeping the data	All individuals whose data is included within the database will be contacted annually and asked if they wish to remain in the database; the data of those who do not want to continue are deleted immediately. In addition, requests for removal can be sent by email to a dedicated email address at any time and these are actioned immediately upon request.
10.	Recipients of the data	Relevant EMA staff members
11.	Are there any transfers of personal data to third countries or international organisations?	N/A
12.	General description of security measures, where possible.	The data is housed within a file maker database stored on the EMA server. It is password protected and only available to EMA staff members, based on need to know and justified basis.
13.	For more information, including how to exercise your rights to access, rectification, object and data portability (where applicable), see the privacy statement:	<p>Details concerning the processing of your personal data are available on the Agency's website at:</p> <p>https://www.ema.europa.eu/en/about-us/legal/general-privacy-statement, where you may find the EMA General Privacy Statement as well as the privacy statements on specific data processing operations.</p>