

PRIVACY STATEMENT

“Call for expression of interest for the IMI2 JU Pool of Patient Experts”

1. Introduction

This privacy statement explains the reason for the processing, the way we collect, handle and ensure protection of all personal data provided, how that information is used and what rights you may exercise in relation to your data.

The Innovative Medicines Initiative 2 Joint Undertaking (IMI2 JU) is committed to protecting and respecting your privacy. As this procedure collects and further processes personal data, Regulation (UE) 2018/1725¹ of 23 October 2018 applies.

This statement concerns the processing operation named “Call for expression of interest for the IMI2 JU Pool of Patient Experts.”

The IMI2 JU Pool of Patient Experts (“the Pool”) is a database containing a list of patient experts/ informal carers that may be invited by the IMI2 JU, in their personal capacity, on an ad hoc basis, to contribute to the Joint Undertaking’s activities, both at strategic and operational levels.

2. Why do we process your data?

Purpose of the processing operation:

Lawfulness

The processing of experts’ personal data is necessary for the performance of a task carried out in the public interest pursuant to point (a) of Article 5(1) of Council Regulation (UE) 2018/1725, since the involvement of patient experts in the IMI2 JU’s strategic and operational activities is essential to the fulfilment of the JU’s objectives.

Furthermore, the persons whose data are processed by the IMI2 JU will be requested to give their consent, as suggested in Article 5.1(d) of Regulation (UE) 2018/1725.

Legal Basis

¹ Regulation (EU) 2018/1725 of the European Parliament and of the Council of 23 October 2018 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, and repealing Regulation (EC) No 45/2001 and Decision No 1247/2002 (OJ L 295, 21.11.2018, p. 39).

The processing operation is based on Article 1(c) of the Statutes of the IMI2 JU annexed to Council Regulation (EU) No 557/2014 of 6 May 2014 establishing the Innovative Medicines Initiative 2 Joint Undertaking, as well as the Minutes of the 23rd meeting of the IMI2 JU Governing Board of 13 November 2018 annexed to Governing Board Decision No IMI2-GB-DEC-2019-02 of 6 February 2019.

Art 39 of Regulation (UE) 2018/1725 is not applicable.

3. Which data do we collect and process?

The personal data collected and further processed may be:

- Name;
- Gender;
- Postal address;
- Email address;
- Occupation;
- Professional profile;
- Whether the data subjects are patients with a chronic and/or lifelong illness/condition or carers of patients with a chronic and/or lifelong illness/condition;
- Disease /condition stated as area of interest;
- Level of education;
- Nationality.

4. How long do we keep your data?

The Data Controller only keeps the data for the time necessary to fulfil the purpose of collection or further processing.

The pool will remain active until 31 December 2021, subject to possible explicit renewal by IMI2 JU.

5. How do we protect your data?

All data in electronic format (e-mails, documents, etc.) are stored either on the servers of the IMI2 JU or of its contractors. The IMI2 JU's contractors are bound by a specific contractual clause for any data processing operations on behalf of the IMI2

JU, and by the confidentiality obligations deriving from Regulation (EU) 2016/679 of 27 April 2016².

6. Who has access to your data and to whom is it disclosed?

Personal data processed by the IMI2 JU may be accessed exclusively by those staff members involved in patient-related matters.

Experts invited to perform tasks and roles associated with the evaluation of project proposals and/or the monitoring of projects will be requested to register in the European Commission's Register of experts, in which case the relevant privacy statement of the European Commission will apply, and the names of experts assigned to such tasks will be published on the general H2020 'Funding and Tenders Portal'.

7. What are your rights and how can you exercise them?

According to Regulation (UE) 2018/1725, you are entitled to access your personal data and rectify and/or block it in case the data is inaccurate or incomplete.

You can exercise your rights by contacting the IMI2 JU or, in case of conflict, the Data Protection Officer and, if necessary, the European Data Protection Supervisor using the contact information below.

8. Contact information

For any questions related to your rights, feel free to contact the Data Controller at Data-Protection@imi.europa.eu by indicating "Data Protection" in the subject and explicitly specifying your request.

The Data Protection Officer (DPO) of the IMI2 JU may be reached at the following email address: Data-Protection@imi.europa.eu

The European Data Protection Supervisor (EDPS) may be reached at the following email address: edps@edps.europa.eu

² Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection regulation) (OJ L 119, 4.5.2016, p. 1).