

PROTECTION OF YOUR PERSONAL DATA

This privacy statement provides information about the processing and the protection of your personal data.

Processing operation: IHI JU Patient Pool

Data Controller: Innovative Health Initiative Joint Undertaking (IHI JU)

Record reference: DPO-SO-05.

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1 Introduction

The Innovative Health Initiative Joint Undertaking (hereafter 'IHI JU') is committed to protecting your personal data and to respect your privacy. IHI JU collects and further processes personal data pursuant to [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 (repealing Regulation (EC) 45/2001).

This privacy statement explains the reason for the processing of your personal data, the way we collect, handle, and ensure protection of all personal data provided, how that information is used and what rights you have in relation to your personal data. It also specifies the contact details of the Data Controller responsible with whom you may exercise your rights, the Data Protection Officer, and the European Data Protection Supervisor.

The information in relation to the processing operation "IHI JU Patient Pool" undertaken by IHI JU is presented below.

2 Why and how do we collect your personal data?

Purpose of the processing operation:

IHI JU collects and uses your personal data (as specified in the section 4 of this privacy statement) in the context of the IHI Patient Pool to involve you as patient/caregiver to support its activities with your perspectives and experience.

The IHI JU may use your personal data to select and contact with you when needed to

- a. act as patient experts for the evaluation of scientific proposals or for the review of ongoing projects improving their quality from a patient perspective;
- b. provide advice on scientific ideas for future calls, scientific portfolio strategy, annual scientific priorities, or to review the content of documents prepared for public events organised by IHI JU;
- c. participate in project meetings, scientific events, webinars, trainings, workshops organised by the IHI Programme Office alone or jointly with the IHI members or other EU bodies/initiatives.

Any patient/caregiver may submit the application to IHI JU using an online form, through which, the IHI JU will collect your personal data. The applications are processed via an online private IHI JU platform (the IHI JU Patient Pool platform) which is maintained by the IT company currently contracted by the IHI JU.

Aggregated information of your personal data (e. g. country, disease area, knowledge, and experience in scientific and innovative health areas) may be used by the IHI JU staff (as listed in the section 7 of this privacy statement) for eventual future statistical analysis for the purpose of IHI JU reporting metrics.

Your personal data will not be used for any automated decision-making including profiling.

3 On what legal ground(s) do we process your personal data

We process your personal data because the processing operations carried out in this context are necessary and lawful under the following legal basis:

- Regulation (EU) 2018/1725¹ more specifically:
 - Article 5(1)(a) “processing is necessary for the performance of a task carried out in public interest or in the exercise of official authority vested in the Union Institution or body”
 - Article 5(1)(b) “processing is necessary for compliance with a legal obligation to which the controller is subject”
 - Article 5(1)(d) “the data subject has given consent to the processing of his or her personal data for one or more specific purposes”.
- [Council Regulation \(EU\) 2021/2085](#) establishing the Joint Undertakings under Horizon Europe;
- [Regulation No 31 \(EEC\), 11 \(EAEC\)](#), the “Staff Regulation”², more specifically Articles 11(1), 11a, 14 and 16;
- IHI Internal Control Framework as adopted by the Governing Board on 16.12.2021 (GB-DEC-2021_03)³;
- ED Decision No 23/2022⁴ on the Adoption of a revised guidance on sensitive functions within IHI JU.

4 Which personal data do we collect and further process?

To carry out this processing operation IHI JU collects the following categories of personal data:

- Personal details (title, first name, family name, patient/caregiver, gender, address, email, phone number, nationality, date of birth, occupation);
- Education (working knowledge of English, level of education);
- Country of residence;
- Member of patient’s organisations;
- Health data (disease/condition area of interest);
- Other additional information regarding your knowledge and experience in different scientific and innovative health development areas, patient engagement and/or patient involvement activities, IMI2/IHI and its activities, ethics, and regulatory processes (as listed in the section 4.3 of the Call text).

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/EC.

² Regulation No 31 (EEC), 11 (EAEC), laying down the Staff Regulations of Officials and the Conditions of Employment of Other Servants of the European Economic Community and the European Atomic Energy Community.

³ Further readopted by the Governing Board by its amended Decision No 14/2023 of 23 June 2023.

⁴ ARES(2022)6226499 of 08/09/2022

5 How long do we keep your data?

IHI JU only keeps your personal data for the time necessary to fulfil the purpose of collection or further processing namely as from your submission date until the end of the duration of IHI JU (2031).

6 How do we protect and safeguard your personal data?

All personal data in electronic format (e-mails, documents, databases, uploaded batches of data, etc.) are stored either on the servers of IHI JU. All processing operations (including process of personal data collected on paper) are carried out pursuant to the [IHI JU Decision Nr 19/2021 on Record Management of 6 of September 2021](#) that adopts by analogy the [Commission Decision \(EU\) 2020/4482 of 6 of July 2020](#) on the security of communication and information systems in the European Commission.

To protect your personal data, the IHI JU has put in place a number of technical and organisational measures. Technical measures include appropriate actions to address online security, risk of data loss, alteration of data or unauthorised access, taking into consideration the risk presented by the processing and the nature of the personal data being processed. Organisational measures include restricting access to personal data solely to authorised persons with a legitimate need to know for the purposes of this processing operation.

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

Access to your personal data is provided to the IHI JU staff responsible for carrying out this processing operation and to authorised staff according to the “need to know” principle. Such staff abide by statutory, and when required, additional confidentiality agreements.

In addition, when necessary and in accordance with the legal requirements, your personal data may be disclosed to external IHI JU data recipients which are bounded by specific confidentiality agreements:

- IHI JU public and private members, including the European Commission, the European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry (COCIR), the European Federation of Pharmaceutical Industries and Associations (EFPIA), EuropaBio, MedTech Europe, and Vaccines Europe;
- Science and Innovation Panel (SIP);
- States Representatives Group (SRG);
- IT company contractor managing the online private IHI JU Patient Pool platform.

The information we collect will not be given to any third party, except to the extent and for the purpose we may be required to do so by law including legal requests from public authorities e.g., from the Internal Audit Service (IAS), the European Court of Auditors (ECA), European Public Prosecutor’s Office (EPPO), European Data Protection Supervisor (EDPS), Anti-Fraud Office (OLAF), External auditors, and those other European Union Institutions, Bodies and Agencies (EUIBA)s as determined by specific need.

8 What are your rights and how can you exercise them?

You have specific rights as a ‘data subject’ under Chapter III (Articles 14-25) of Regulation (EU) 2018/1725, in particular the right to access, rectify or erase your personal data and the right to restrict the processing of

your personal data. Where applicable, you also have the right to object to the processing or the right to data portability.

You have the right to object to the processing of your personal data, which is lawfully carried out on grounds relating to your particular situation.

You have consented to provide your personal data to IHI JU for the present processing operation. You can withdraw your consent at any time by notifying the Data Controller (IHI JU). The withdrawal will not affect the lawfulness of the processing carried out before you have withdrawn the consent.

You can exercise your rights by contacting the IHI JU Data Protection Officer. If necessary, you can also address the European Data Protection Supervisor. Their contact information is given under Heading 9 below.

Where you wish to exercise your rights in the context of one or several specific processing operations, please provide their description (i.e. their Record reference(s) as specified under Heading 10 below) in your request.

9 Contact information

The Data Protection Officer of IHI JU

If you would like to exercise your rights under Regulation (EU) 2018/1725, or if you have comments, questions or concerns, or if you would like to submit a complaint regarding the collection and use of your personal data, please feel free to contact the IHI JU Data Protection Officer (data-protection@ihi.europa.eu) with regard to issues related to the processing of your personal data under Regulation (EU) 2018/1725.

The European Data Protection Supervisor (EDPS)

You have the right to have recourse (i.e., you can lodge a complaint) to the European Data Protection Supervisor, https://edps.europa.eu/data-protection/our-role-supervisor/complaints_en or edps@edps.europa.eu if you consider that your rights under Regulation (EU) 2018/1725 have been infringed because of the processing of your personal data by the IHI JU.

10 Where to find more detailed information?

The IHI JU Data Protection Officer (DPO) publishes the register of all processing operations on personal data by IHI JU, which have been documented and notified to him. You may access the register via the following link: <https://www.ihi.europa.eu/legal-notice-and-privacy>

This specific processing operation has been included in the IHI JU DPO's public register with the following record reference: DPO- SO-05.