PROTECTION OF YOUR PERSONAL DATA

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

**Processing operation:** Collecting ideas for identifying potential IHI JU topics

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

**Record reference:** DPO – SO - 04

**Table of Contents**

1. Introduction
2. Why and how do we process your personal data?
3. On what legal ground(s) do we process your personal data?
4. Which personal data do we collect and further process?
5. How long do we keep your personal data?
6. How do we protect and safeguard your personal data?
7. Who has access to your personal data and to whom is it disclosed?
8. What are your rights and how can you exercise them?
9. Contact information
10. Where to find more detailed information?
1 Introduction

The Innovative Health Initiative Joint Undertaking (hereafter ‘IHI JU’) is committed to protect 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 this information is used and what rights you have in relation to your personal data. It also specifies the contact details of the responsible Data Controller 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 “Collecting ideas for identifying potential IHI JU topics” undertaken by the IHI JU is presented below.

2 Why and how do we collect your personal data?

**Purpose of the processing operation:** The IHI JU gathers ideas from a wide range of stakeholders, IHI JU founding members and Science and Innovation Panel (SIP) members to help IHI JU define its annual scientific priorities and areas for future calls for proposals. Any stakeholder may submit an idea for an IHI JU topic using an online form, through which, the IHI JU will collect your personal data (first name, last name, email and country). The IHI JU may use this information to get in contact with you as the submitter, if needed. The country data shall be further processed by IHI JU for the purposes of IHI JU reporting metrics.

The form is checked for completeness and quality of the content by the IHI JU Programme Office. For those that are complete, they are then reviewed by the SIP which identifies those ideas that merit further consideration (i.e. they are aligned with IHI JU’s objectives and have the potential to be developed further as all or part of an IHI JU call topic) and the SIP sends feedback to the IHI JU Governing Board (GB). The forms are processed via two online private IHI JU platforms (the Topic Ideas platform and the SIP platform) which are maintained by a company contracted by the IHI JU. For all ideas reviewed by the SIP, an extract of the form without any personal data is published on the IHI JU website along with the SIP opinion. This process aims to ensure transparency, openness, inclusiveness and benefits to society in line with the Single Basic Act1.

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

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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) 2018/1725** 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)(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.

4 Which personal data do we collect and further process?

In order to carry out this processing operation, IHI JU collects the following categories of personal data:

- First name, last name
- E-mail address
- Country

The provision of personal data is mandatory to meet a contractual requirement of submitting the online form, to allow the IHI JU to get in touch with the submitter if needed. Please note country data shall be further processed by IHI JU for the purposes of IHI JU reporting metrics.

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 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.

In order 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 the 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.

- **Scientific operations team**: management of the online private Topic Idea platform through which the ideas are submitted; quality and completeness check of the idea submitted; contact of submitter, if needed.

- **Governance team in charge of the SIP**: management of the review of the ideas at the SIP level and of the online private SIP platform through which the ideas are shared with the SIP members.

- **Information technology team and company contracted by IHI JU**: responsible for the development and maintenance of the online private platforms, *i.e.* Topic Ideas platform and the SIP platform.

In addition, your personal data will be accessed and disclosed to IHI JU governance bodies whose members abide by specific confidentiality agreements.

- **SIP**: review of the submitted ideas that passed the completeness and quality check.

- **IHI JU GB**: reception of the idea and SIP feedback following the review of the idea.

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.

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 (DPO) at 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 as a result of the processing of your personal data by the IHI JU.

10 Where to find more detailed information?

The IHI JU DPO publishes the register of all processing operations on personal data by IHI JU, which have been documented and notified to the DPO. 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 - 04.