

# PROTECTION OF YOUR PERSONAL DATA

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

**Processing operation:** SOFIA (Submission of Information Application)

**Data Controller:** Innovative Health Initiative Joint Undertaking

**Record reference:** DPO – SO – 03

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# 1 Introduction

The Innovative Health Initiative Joint Undertaking (hereafter 'IHI JU') is committed to protecting your personal data and to respecting 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 Protection Officer and the European Data Protection Supervisor.

The information in relation to the processing operation “*SOFIA (Submission of Information Application)*” undertaken by IHI JU is presented below.

## 2 Who are the data subjects?

Data subjects concerned by this processing operation are the following:

- The project legal representative,
- The project coordinator and contact persons,
- The responsible for scientific aspects,
- IMI1 JU, IMI2 JU independent experts,
- IHI JU Staff member involved in the project.

## 3 Why and how do we collect your personal data?

Purpose of the processing operation:

SOFIA (Submission of Information Application) is a project management tool used by the JU to process your personal data related to the consortia of IMI1 JU, IMI2 JU and IHI JU projects in order to:

- proceed with amendments of Grant Agreements,
- proceed with in-kind contribution reporting\* and related payments,
- fulfil the reporting obligations of all the three iterative programs (IMI1/IMI2/IHI) as determined by their respective legal bases.

- monitor the Key Performance Indicator (hereinafter 'KPI') to fulfil our reporting obligations,
- monitor and promote the impact of the projects through communication and dissemination activities,
- any other activity related to the project management.

\*The reporting of in-kind contribution in IMI2 projects is done via the SOFIA tool and personal data of EFPIA companies and associated partners are collected through their audit certificates and financial statements.

	GA Amendment	GA Payments	In-kind contribution reporting	KPIs	Communication & Dissemination
IMI1 JU	Yes	Yes	Yes	Yes	Yes
IMI2 JU	Yes	Yes	Yes	Yes	Yes
IHI JU	No	No	No	Yes	Yes

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

## 4 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<sup>1</sup> 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*”,

These legal basis are:

[Council Regulation \(EU\) 2021/2085](#) establishing the Joint Undertakings under Horizon Europe.

<sup>1</sup> 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.

## 5 Which personal data do we collect and further process?

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

- First and second name,
- Current work organisation name,
- Job title,
- Gender,
- Nationality,
- Contact address,
- Phone number,
- Fax,
- E-mail.

## 6 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:

- For unsuccessful proposals: personal data are retained for up to 5 years after the closure of the call for which the data have been collected or updated.  
Pursuant to Article 4(1)(e) of the Regulation, and subject to the implementation of appropriate safeguards in accordance with Article 13, we may retain limited categories of personal data of unsuccessful applicants for scientific research and/or statistical purposes for up to 25 years, unless you exercise your right to object under Article 23 of the Regulation.
- For successful proposals, personal data are retained for 10 years after the end of the year following closure of the action.  
Pursuant to Article 4(1)(e) of the Regulation, and subject to the implementation of appropriate safeguards in accordance with Article 13, we may retain limited categories of personal data of beneficiaries for scientific research and/or statistical purposes for 6 up to 25 years, unless you exercise your right to object under Article 23 of the Regulation.

## 7 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 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.

The IHI JU's contractors are bound by a specific contractual clause for any processing operations of your data on behalf of IHI JU, and by the confidentiality obligations deriving from the transposition of the General Data Protection Regulation in the EU Member States ('GDPR') [Regulation \(EU\) 2016/679](#).

In order to protect your personal data, IHI JU has put in place a number of technical and organisational measures in place. 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.

## **8 Who has access to your data and to whom is it disclosed?**

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

Access to personal data can also be shared with other recipients other than the IHI JU, according to the "need to know" principle. In particular:

- The European Commission;
- Members of the IHI JU other than the Union;
- IT software development contractor.

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), External auditors and other European Union institutions, bodies, and agencies ('EUIBA's) as required.

## **9 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 pursuant to Article 5(1)(a) on grounds relating to your particular situation.

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 10 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 11 below) in your request.

## 10 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](mailto: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](https://edps.europa.eu/data-protection/our-role-supervisor/complaints_en) or [edps@edps.europa.eu](mailto: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.

## 11 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 - 03