



Data Protection Notice for the Stakeholder Consultation Activities – *Exploratory study on the provision of care for Adolescent and Young Adult (AYA) cancer patients in the Union (HADEA/2024/OP/0027)*

This Data Protection Notice describes the measures taken to protect your personal data with regard to the action involving the present data processing operation and what rights you have as a data subject.

The European Health and Digital Executive Agency (HaDEA or Agency) protects the fundamental rights and freedoms of natural persons and in particular your right to privacy and the protection of your personal data.

Your personal data¹ are processed in accordance with [Regulation \(EU\) 2018/1725 of the European Parliament and of the Council of 23 October 2018²](#) on the protection of individuals with regard to the processing of personal data by the Union institutions, bodies, offices and agencies and on the free movement of such data.

1. What are the purposes of this processing activity?

The purpose of this DPN is to inform participants of interviews and/or survey as part of the targeted consultation activities (Task 3 interviews and one online survey) for the “Exploratory study on the provision of care for Adolescent and Young Adult (AYA) cancer patients in the Union” about the processing activities related to their personal data.

This includes identifying and contacting relevant stakeholders; collecting their feedback on the state of play of AYA cancer care in the 29 countries in scope; and analysing stakeholder perspectives to inform policy recommendations on AYA cancer care provisions.

This processing activity covers:

- Identifying stakeholders relevant for the consultation activities.
- Carrying out the consultation activities, which will consist in:
 - Sending invitations to take the Survey (Task 3), follow up emails and collection of feedback,
 - Sending invitations and registration of participants to interviews (Task 3) and inclusion in participants’ list,
 - Conducting the interviews and survey,
 - Storing data in our secured servers and conducting the analysis of the data, aggregate data and prepare reports.

You have been identified as a stakeholder to be contacted since it has been concluded that your views are relevant (your contact details were publicly available in your organisation’s website as person of contact and/or shared with your approval by peers and/or you have given your consent to be recontacted for this study from previous tasks (Task 2) and

¹ **Personal data** shall mean any information relating to an identified or identifiable natural person (‘data subject’). An identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

² 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 (OJ L295/39 of 21.11.2018).

necessary for the targeted consultation activities (Task 3 survey and interviews), and because you are part of one of the following stakeholder groups:

- Organisation representing AYA patients and survivors,
- Organisation representing AYA cancer patients' carers and families,
- Relevant national authorities and public health authorities,
- Relevant health and care professionals,
- Clinical trial coordinators and pharma representatives,
- Academia and research institutes.

Your participation in the consultation activities mentioned above is entirely voluntary, so you can refuse to take part if not interested, at any time. You will find further information regarding the consultation process in the **endorsement letter**.

2. Who is the data controller?

The data controller of the processing operation is the **Head of Unit A2 – EU4Health/SMP Food** of the Agency (HaDEA).

3. Who is the data processor?

The following **entities process** your personal data on HaDEA's behalf:

- **ICF S.A.**, Avenue Marnix 17, 1000 Brussels, Belgium (hereinafter referred to as "Data Processor") as the lead contractor for conducting the stakeholder consultations, data collection, analysis, and reporting activities.
- **Spark Legal and Policy Consulting** (hereafter 'Spark') is a company registered and incorporated under the laws of Belgium with its registered office located at Rue Des Comédiens 22, 1000 Brussels, Belgium. Spark will be involved in the following consultation activities, within Task 3: interviews. For the purpose of carrying out these activities, Spark:
 - Conduct the interviews,
 - Record the interviews for accuracy and note taking purposes and only with participants' consent,
 - Store responses,
 - Conduct the analysis of the data,
 - Conduct the clustering and anonymisation of the data before the final reports are submitted,
 - Delete the notes, recordings and any personal data associated with the consultation activities after the final reports are shared with HaDEA. Please read below section for how long we are keeping your data.
- ICF is supported by **Fundacio Privada Recerca I Docencia Sant Joan Deu** (hereafter 'SJD'), is a private research foundation located at Santa Rosa 39-57 4Planta (Edificio PCCB) 08006 Barcelona, Spain. SJD will be involved in the following consultation activities, within Task 3: interviews. For the purpose of carrying out the interviews, SJD will:
 - Conduct the interviews,
 - Record the interview for accuracy and note taking purposes and only with participants' consent,
 - Store interviews' responses,
 - Conduct the analysis of the data,
 - Conduct the clustering and anonymisation of the data before the final reports are submitted,
 - Delete the notes, recordings and any personal data associated with the

consultation activities after the final reports are shared with HaDEA. Please read below section for how long we are keeping your data.

4. Which personal data is collected?

The following of your personal data are collected for the purpose outlined above:

- Full name (first and last names),
- Role or function within your organisation,
- Name of your organisation,
- Professional contact information (email address and phone number, if needed for organisation of the interview),
- Country or region of work,
- Responses and insights shared during consultation activities (Task 3 survey and interviews) related to AYA cancer care provision, through (closed and open questions regarding your knowledge on the matter and professional experience.

Personal data indicated above are mandatory for the purpose(s) outlined above.

In addition, the following non-mandatory personal data may be collected: audio and/or video recordings of interviews. These will only be processed based on your explicit prior consent.³

Before beginning the interview, you will be informed that the data collected through the consultation are treated according to the study's data privacy notice (which is this DPN), attached to the email you received inviting you to take part to the specific consultation.

At the beginning of the interviews, you will be asked if you consent to the recording. The recording will not be publicly available; it will be used only for note taking purposes, and it will be deleted after, accordingly to the maximum period of retention (cf. retention paragraph below).

Furthermore, you may spontaneously provide other, non-requested personal data in the context of your reply to the targeted consultation regarding quality of life of cancer patients and survivors (e.g. personal health related data). If so, we will either disregard or anonymise the received data through a central contact point.

Your personal data will not be disclosed when reporting the consultation results. Thus, the replies to the interviews will be presented anonymously. During the interview, you will be asked to accept this privacy policy to continue with the consultation, and there will be a track in the notes from the interviews of the express or denied consent.

Information will be anonymised before providing the feedback to the contracting authority, and thus stakeholders cannot be identified from their inputs. For the publishable study report, the information will also be anonymised.

5. Who has access to the personal data of data subjects and to whom can they be disclosed?

The recipients of your personal data will be as follows:

- Authorised staff of HaDEA's A2 and the European Commission's (DG SANTE B1 & DG RTD D1) units involved in this study,
- Authorised and need-to know staff of HaDEA contractors responsible for the consultation activities,

³ Processing of **non-compulsory** personal data can only be based on **consent** and individual **tick boxes** have to be provided when data is collected to **document** the consent.

- Bodies charged with monitoring or inspection tasks in application of EU law (e.g. EC internal audit, Court of Auditors, European Anti-fraud Office (OLAF), the European Ombudsman, the European Data Protection Supervisor, the European Public Prosecutor), in compliance with the relevant legislation.

Third party tools used for the organisation of the consultation activities:

- **Microsoft Teams:** for the purpose of hosting the interviews, is a third-party tool under Microsoft O365 which collects email, title, first name, last name, country, company and job, phone number, IP address, and browser-generated information (including device information, operating system, device type, cookies or other technologies used to analyse users' activity). It hosts the collected personal data within the European Union. Nevertheless, data subjects shall be informed that Microsoft is a US-based company but data will be stored only in EU/EEA servers. Data will be securely deleted after the end of retention period (see #8). Microsoft privacy statement can be found at [Microsoft Privacy Statement – Microsoft privacy](#).
- **Forsta:** for the purpose of hosting the survey, is a third-party tool that collects survey responses, including the country and stakeholder group. Forsta does not collect any information other than the responses to the survey questions. It stores data on servers in Germany and has backups within the European Union. Data will be securely deleted after the end of retention period (see #8). Forsta's privacy statement can be found at [Forsta Privacy Notice](#).

Your personal data **will not be transferred** to third countries or international organisations.

The processing of your data will **not include automated decision-making** (such as profiling).

6. Which is the legal basis for processing your personal data?

The legal basis for the processing activities are:

- **Article 5(1)(a)** of Regulation (EU) 2018/1725: processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the Union institution or body⁴, laid down in Union law⁵ for your mandatory personal data indicated above.
- For non-mandatory personal data indicated above, i.e., interview recordings), Article 5(1)(d): processing is based on your informed prior consent.
- The subject matter of the consultation activity will not require you to provide special categories of personal data, and in particular data about your health. However, in case you would voluntarily provide special categories of data, their processing will be based on your explicit consent, in line with Article 10 (2)(a) of Regulation (EU) 2018/1725.

7. How to withdraw your consent and the consequences of doing this

If you provide consent (e.g. for your interview to be recorded, to take part in the interview), you may withdraw it at any time by contacting the study team.

⁴ Act of Establishment: Commission Implementing Decision (EU) 2021/173 of 12 February 2021 establishing the European Health and Digital Executive Agency

⁵ Regulation (EU) 2021/522 establishing a programme for the EU's action in the field of health (EU4health programme) for the period 2021–2027

If you want us to delete the related personal data (e.g. recordings) please contact us at the contact details below and clearly indicate your deletion request, and we will confirm deletion without undue delay and within a month of the receipt of our request.

If you want us to delete your survey responses, please contact us at the contact details below before the survey closes. As the survey platform does not collect any personal information and responses are anonymised in analysis, it will not be possible for the study team to identify your response after the survey has been closed.

Please note that withdrawing your consent does not affect the lawfulness of any processing based on your consent before this consent is withdrawn. Attention is drawn to the consequences of a deletion request, which means that all your contact details will be lost.

8. How long do we keep your personal data?

Your personal data will be kept for a maximum period of 6 months after the end of the project. Data will be securely deleted at the end of this period, on the 31 March 2027.

9. What are your rights regarding your personal data?

You have the right to access your personal data and to request your personal data to be rectified, if the data is inaccurate or incomplete; where applicable, you have the right to request restriction or to object to processing, to request a copy or erasure of your personal data held by the data controller. If processing is based on your consent, you have the right to withdraw your consent at any time, without affecting the lawfulness of the processing based on your consent before its withdrawal.

Your request to exercise one of the above rights will be dealt with without undue delay and within **one month** of its receipt.

If you have any queries concerning the processing of your personal data or wish to exercise any of the rights described above, you contact the data controller via: HADEA-A2-DATA-PROTECTION@ec.europa.eu and HaDEA DPO HADEA-DPO@ec.europa.eu, with the contractor's contact point at: AYAcancerarestudy@icf.com

You shall have right to recourse at any time to the European Data Protection Supervisor at EDPS@edps.europa.eu.

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Consent Form

I confirm that I have read and understood the Data Protection Notice related to my participation in the stakeholder consultation for the “Exploratory Study on the Provision of Care for Adolescent and Young Adult (AYA) Cancer Patients in the Union.

- I consent to participating in this interview / survey.**
- I consent to the audio recording of this interview for the purposes of analysis and reporting under the conditions described.**
- I consent to the video recording of this interview for the purposes of analysis and reporting under the conditions described.**
- I provide my explicit consent with processing of health-related personal data that I provide on a voluntary basis. Please note that the subject matter of this consultation activity will not require you to provide special categories of personal data (e.g., data about your health etc.). However, in case you would voluntarily provide special categories of data, their processing will be based on your explicit consent.**

My participation is voluntary, and I may withdraw my consent at any time without penalty.

For any questions or to exercise my data protection rights, I may contact the data controller (HaDEA) or its Data Protection Officer using the contact details provided in the DPN.