**TEMPLATE FORM – TO BE CUSTOMIZED BY NATIONAL PATIENT ORGANIZATION**

**[This template can be used to collect data from patients that live in Belgium, The Netherlands, Spain, Portugal and Germany.  Should you want to use this consent form in another country, you will need to check if it complies with the data protection rules that apply in that country].**

**Informed consent form**  **Participation in “patient journey” through the EU Survey Platform for [to be completed]**

[ ]  I am a patient

[ ]  I am the authorized representative of a patient

Name

E-mail address

Phone number

[ ]  Yes, I would like to participate in a patient journey through the EU Survey Platform.

If you agree to participate in a patient journey through the EU Survey Platform, [name patient organization] will process certain personal data, as described below, and need to obtain consent as further described below. [Name patient organization] will act as the controller for the processing of those personal data.

**Your data, your rights**

All personal data which is collected in the context of the patient journey through the EU Survey Platform is processed by and on behalf of [name patient organization] as data controller, with its registered office at [address].

[Name patient organization] aims to conduct patient journey surveys in order to enhance the knowledge and available data about the patients’ needs in relation to the provision of healthcare and social services [include the name of the disease(s)].

The following personal data may be collected and processed on the basis of this informed consent form:

* Contact details (name, e-mail address, phone number) of the person(s) signing this informed consent form ("Contact Data");
* Personal data of the patient, including name, contact details, age, date of birth, gender, nationality, data concerning health (including but not limited to disease, symptoms, diagnosis, physical condition, treatments, disease history, quality of life, [other]) ("Patient Data").

The Contact Data and Patient Data will be stored in a secured database which is only accessible for employees and representatives of [name patient organization] on a strict need-to-know basis.

The Contact Data provided via this informed consent form will be used for the following purposes: registering the informed consent and contacting the relevant person in the context of the patient journey through the EU Survey Platform.

The Patient Data collected in the context of the patient journey through the EU Survey Platform, or as otherwise provided to [name patient organization] by the patient or by its authorized representative, will be entered into standard forms, which do not contain identification data of the patient or its authorized representative, such as name, e-mail address and phone number ("worksheets").

[Name patient organization] will use the pseudonymized data included in the worksheets for the following purposes: analysis, scientific and statistical research in connection with the provision of health and social services. The aggregated results thereof may be shared with third parties through conferences, publications, websites, interviews and [other].

The personal data, including both Contact Data and Patient Data, which is collected in the context of the patient journey through the EU Survey Platform is processed on the basis of consent, as expressed in this consent form. The patient or its authorized representative are free to decide whether or not to sign this consent form; if not, then [name patient organization] will not process any personal data that may have already have been provided to [name patient organization] and will immediately delete those personal data.

Any person signing this consent form, is at any time thereafter free to withdraw its consent for the processing of the personal data, without giving any reason, by notifying it by e-mail to [e-mail address] or by mail to [insert address]. Upon the withdrawal of your consent, the processing of your personal data will stop.

If you want to provide Patient Data to [name patient organization] and you are not the patient or the patient's authorized representative, then you need to ensure that the patient or its authorized representative also sign this informed consent form.

The personal data collected in the context of the patient journey through the EU Survey Platform will not be disclosed outside of the European Economic Area. However, the aggregated results of the research which do not include any personal data may be shared with third parties outside of the European Economic Area through conferences, publications, websites, interviews and [other] as described above.

The informed consent forms and the Contact Data contained therein will be stored by [name patient organization] for as long as [name patient organization] needs to be able to prove that it has obtained informed consent for the processing of personal data as described in this form and in accordance with the retention periods required or permitted by law. [Name patient organization] will assess every 10 years which consent forms need to be further retained.

The worksheets are kept as long as necessary to achieve the abovementioned purposes.

Within the limits provided by the General Data Protection Regulation, as a data subject, you have a right to:

* receive a copy of your personal data or to have your personal data rectified, deleted or restricted.
* request to receive the personal data concerning you, which you have provided to us, in a structured, commonly used and machine-readable format and have the right to transmit those data to another controller.
* to object to the processing of your personal data.

Any questions or concerns about the processing of your personal data by [name patient organization] as described in this informed consent form, can be sent by e-mail to [e-mail address] or by mail to [insert address].

You also have the right to file a complaint with the competent supervisory authority (for [insert relevant country] this is [insert name of relevant data protection authority] (insert website of relevant data protection authority)].

For further information about data protection at [name patient organization]: [link to general data protection notice]

By signing this consent form, you agree to the processing of the personal data collected by [name patient organization] as described above.

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| Signature of patient or patient's authorized representative |
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| \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (name) |
| \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (date) |