

Information on collecting data for Participation in “Patient Journey”

If you agree to participate in a Patient Journey either as a patient or as the authorized representative of a patient, Work Package 4, working group under Endo-ERN, will process personal data, as described below, and need to obtain consent as further described below. Work Package 4 (WP4) consisting of two health care providers (Dr. Susan Webb of Hospital de la Santa Creu I Sant Pau, Barcelona and Dr. Anna Nordenström of Karolinska University Hospital, Stockholm, and two patient representatives, Diana Vitali, chair of SOD Italia and Jette Kristensen, chair of Addison Foreningen i Danmark), will act as the controllers for the processing of those personal data.

Your data, your rights

All personal data which are collected in the context of the Patient Journey are processed by and on behalf of WP4 as data controller.

WP4 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.

The following personal data may be collected and processed on the basis of this information sheet:

- Contact details (name, e-mail address) of the person(s) signing this informed consent form ("Contact Data");
- Personal data of the patient, including name, contact details, 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 members of WP4 and representatives of Endo-ERN on a strict need-to-know basis.

The Contact Data provided via the Patient Journey will solely be used for contacting the relevant person in the context of the Patient Journey.

The Patient Data collected in the context of the Patient Journey 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").

WP4 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.

The personal data, including both Contact Data and Patient Data, which are collected in the context of the Patient Journey are processed on the basis of consent. The patient or his/her authorized representative are free to decide whether or not to give their consent; if not, then WP4 will not process any personal data that may already have been provided and will immediately delete those personal data.

Any person giving his/her consent, is at any time thereafter free to withdraw the consent for the processing of the personal data, without giving any reason, by notifying WP4. Upon the withdrawal of your consent, the processing of your personal data will stop.

The personal data collected in the context of the Patient Journey 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 as described above.

The Patient Journey and the Contact Data contained therein will be stored by WP4 for as long as WP4 needs to be able to prove that it has obtained consent for the processing of personal data as described in this information sheet and in accordance with the retention periods required or permitted by law. 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 WP4 as described in this informed consent form, can be sent to WP4.

You also have the right to file a complaint with the competent supervisory authority of your country.