

TABLE 1: INFORMATION FOR THE PATIENTS AND TEMPLATE TO COLLECT DATA (ENGLISH VERSION)

PATIENT JOURNEY

Introduction

The European Reference Network for Rare Endocrine Diseases (EndoERN) aims at collecting information on how patients have experienced their disease. We as leaders of the work package 4 (WP4) focusing on patient care and quality of life, would like to ask you to participate in this pilot study, by reflecting your experience with your/your child's disease. Our over-all aim is to improve patient outcome.

Description

Patient Journeys (PJ) represent the collective perspective on the burden of the disease and the needs of people with first-hand experience of living with a rare disease. They map the natural history and needs of patients along their life journey, through the patients' or parents' eyes.

The PJ can be used as a key tool to engage with the clinicians, to highlight the different needs of the patient community and identify how clinicians can respond to these needs. They can also be used for information to the patient community and to lay persons, like general practitioners and other healthcare workers.

The PJ shows in a comprehensive way the goals that are recognized by both patients and clinical experts. Therefore, it can be used by both these parties to explain the clinical pathway: professional experts can explain to newly identified patients how the clinical pathway generally looks like, whereas their patients can identify their specific needs within these pathways.

Suggested process

Please complete the table below including the different stages of the PJ that are relevant for you. Do not hesitate to adapt or modify the stages if needed **but please do not delete or insert columns**. Then, outline the clinical presentation and patient needs at each of the stages of the PJ and add a recommendation, or state what 'good care' and support would be, in the last column.

1. Complete the table template with you your own experience, expectation, view and needs
2. Share this first version with your family and your patient community (e.g. members of your patient organizations and ask for feedback
3. Feel free to discuss the clinical presentation of your journey with your clinician / health care provider, if you wish.
4. Send back the filled in form by end January 2022.
5. WP4 will discuss these pilot PJ results with the Endo-ERN community to identify key common needs or priorities of patients with rare endocrine conditions, so the network can take positive action, for the benefit of the patients.

INDICATE THE NAME OF THE RARE DISEASE/ CONDITION/ SYNDROME _____

DATE _____ COUNTRY OF RESIDENCE _____

INDICATE THE NUMBER OF PATIENTS/FAMILIES WHO CONTRIBUTED TO THIS PATIENT JOURNEY _____

"I have read and understood the attached "Informed Consent Privacy Statement related to collecting Information on Patient Journeys" and consent to the processing of the reported data as described therein". [] (Please mark with an "x")

Stage of Journey Please adapt or modify stages if needed	Timeline	Clinical Symptoms	Presentation/	Patient/Family Needs (collective view)	Ideal Outcome/Support (how to address the needs)
Pre-diagnosis					
First symptom					
Diagnosis					
First treatment					
Surgery					
Follow up care					
..					