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INTRODUCTION

EuRRECa is the affiliated registry of the European Reference Network for Rare Endocrine Conditions (Endo-ERN). It aims to support the needs of the endocrine and bone community by facilitating the collaboration between patients, health care professionals and researchers across Europe and beyond. It consists of two platforms: an electronic reporting tool, e-REC (e-Reporting of Rare Conditions), which collects the number of new cases encountered every month, and the core registry, which collects a set of core data elements and allows the registering of new and existing patients. e-REC has been collecting new cases of endocrine conditions since 2018 and to date. Pituitary adenoma is the most commonly reported condition with over 2400 cases reported so far.

OBJECTIVE

To develop a pituitary tumour module within the EuRRECa core registry. A secondary aim is to detect cases showing aggressive tumour behaviour, including aggressive pituitary tumours and carcinomas.

METHODS

A group of experts from Endo-ERN, ESE, ENEA and ESPE in the field of hypothalamic and pituitary disorders as well as pituitary tumours met remotely on several occasions between December 2020 and June 2021 to develop a consensus on relevant data fields, including aggressive pituitary tumour.

RESULTS

A total of 65 variables were grouped in 13 questionnaires that collect several aspects of the care of patients across all age span with pituitary tumours. Questions aimed at identifying aggressive tumours were included in the imaging section (Fig. 2). The module has been incorporated into EuRRECa's core registry platform and is available to complete if the diagnosis of any form of pituitary tumour is selected. Details of these domains will also be widely disseminated through EuRRECa's data dictionary.

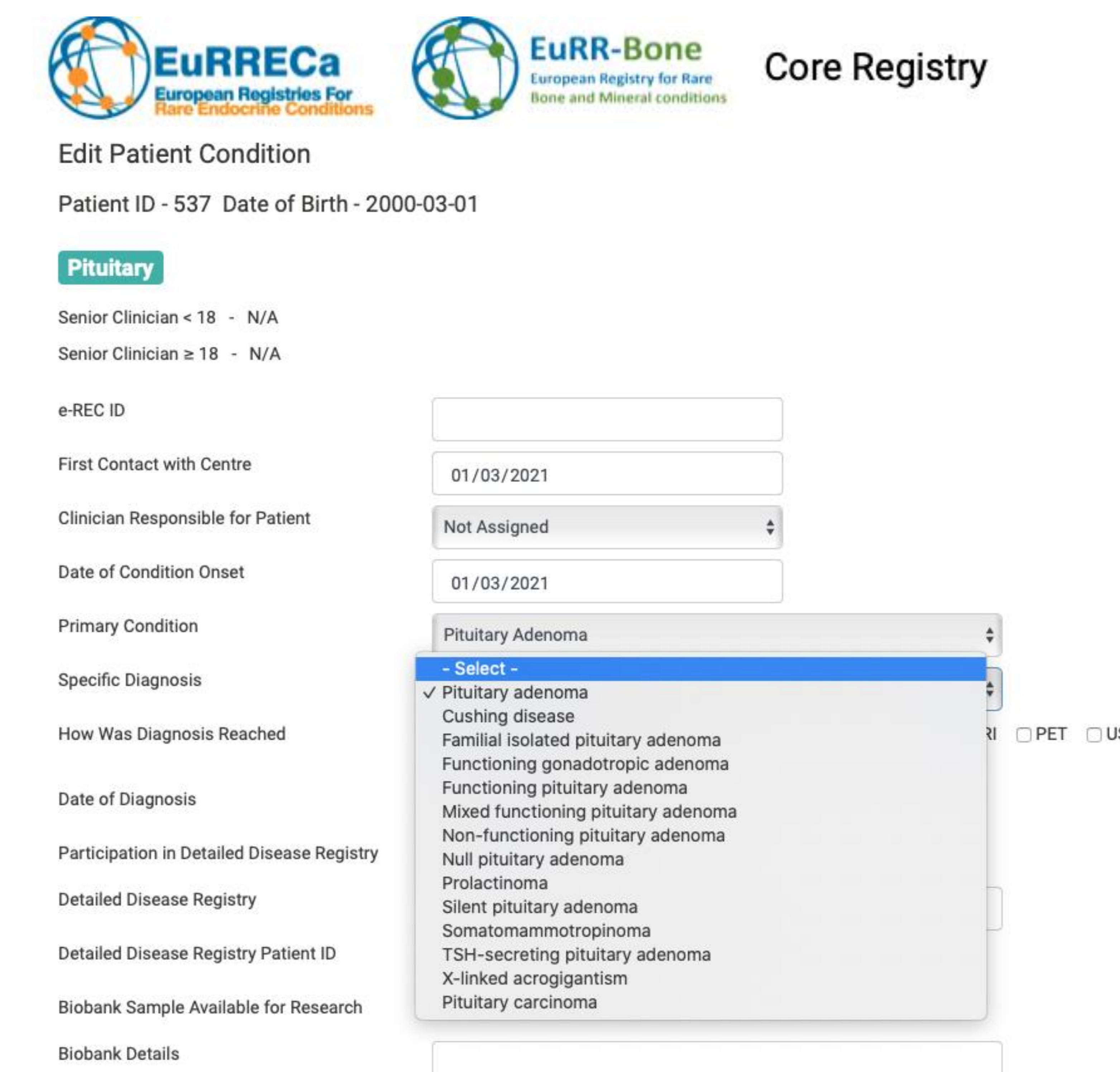


Fig. 1 - Patient condition information in the Core Registry and Pituitary conditions included in the module.

CONCLUSION

Pituitary tumour is the most reported condition in e-REC. The development of a dedicated registry will provide the clinicians with the opportunity of sharing aspects of the disease and care of their patients with health care professionals and the research community. A working group consisting of experts across the patient age span from several centres across Europe proved to be a successful strategy in reaching consensus rapidly.

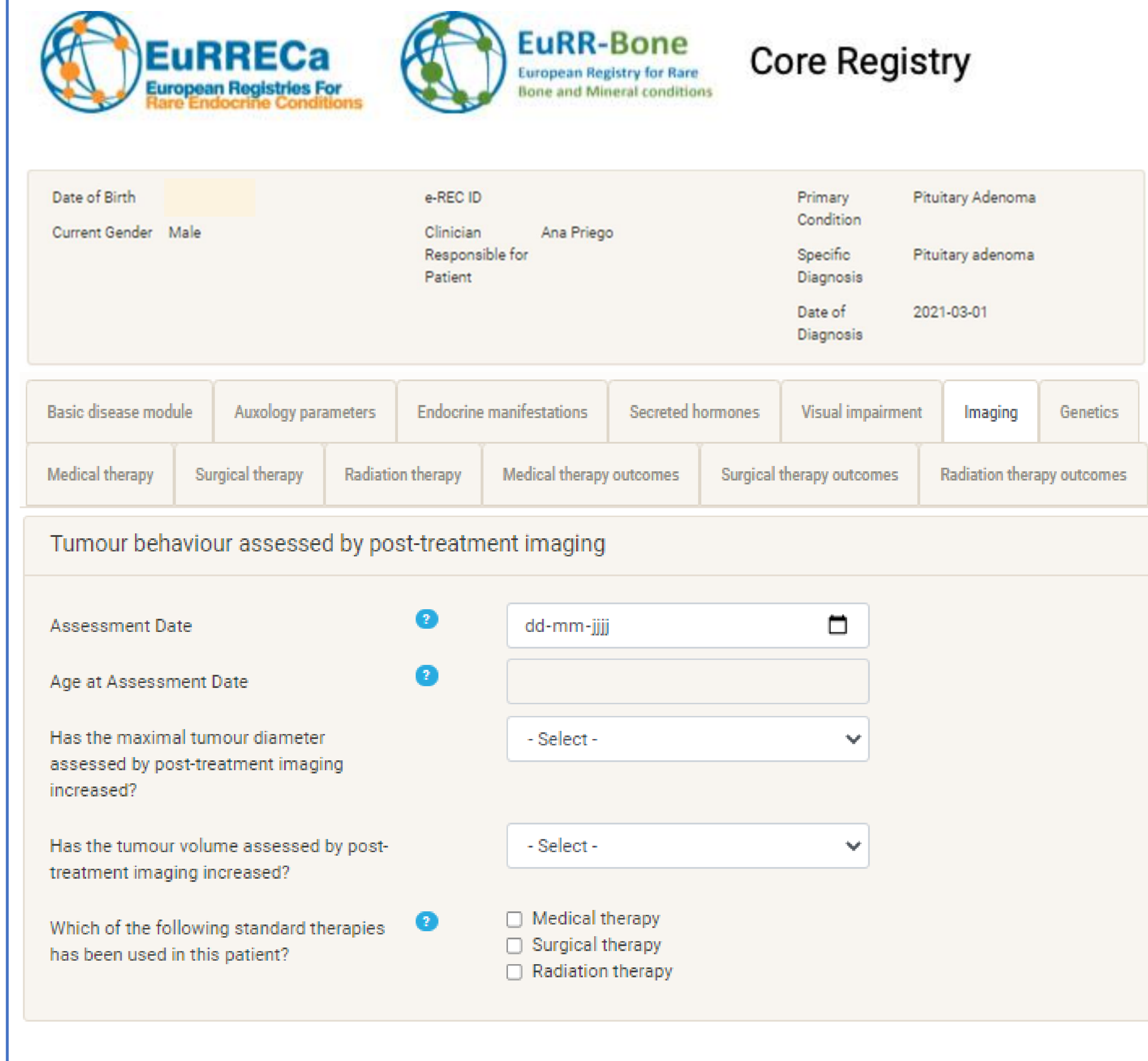


Fig. 2 – Pituitary tumour module and its 13 questionnaires.