Introduction
The increasing number of QoL studies in patients with pituitary diseases suggest a growing interest in the patient’s perspective on QoL and patient reported outcome (PRO). However, until now no measure is available assessing the patient perceived burden of these impairments and their needs for help for these issues.

Objective
To develop and validate a disease-specific burdens and needs questionnaire for patients with a pituitary disease.

Methods
Patients: A total of 337 patients with pituitary diseases completed the questionnaires (response rate 63%).

Development questionnaire: Items for the Leiden Burdens and Needs Questionnaire for patients with pituitary diseases (LBNQ-Pituitary) were formulated based on results of a recent focus group study. Each item on the LBNQ-Pituitary consisted of three parts (figure 1):

a) Whether a certain complaint was present (Yes/No);
b) The extent to which the patient is bothered (burden) by the complaint which was scored on a 5-point Likert scale (0=not at all - 4=extremely);
c) The extent of importance that patients placed on the attention they received from their healthcare provider for their complaint (needs for help), scored on a 5-point Likert scale (0=not important - 4=extremely important).

For each item the burden en needs for help were separately scored.

Validation: Construct validity of the LBNQ-P was examined by using an exploratory factor analysis on the burden part of all items. Reliabilities of the subscales were calculated with Cronbach’s α, and concurrent validity was measured assessed by calculating Spearman correlations between the dimensions of the LBNQ-Pituitary and the other questionnaires (EuroQol-5D, SF-36, MFI-20, HADS, UCL, GSE, IPA).

Conclusions and future directions
The LBNQ-Pituitary is a valid and reliable instrument to measure pituitary-related burden and potential unmet needs. Future research is needed to further establish the psychometric properties, for instance by using a confirmatory factory analysis in another cohort of patients with a pituitary disease.

We postulate that the LBNQ-Pituitary can be used in clinical research (e.g. comparing burden and needs between groups, evaluate the effect of interventions). It can also be used to facilitate the assessment of potential unmet needs in clinical practice (LBNQ-Pituitary Needs Index, Figure 2), but further work is needed to evaluate this.

References