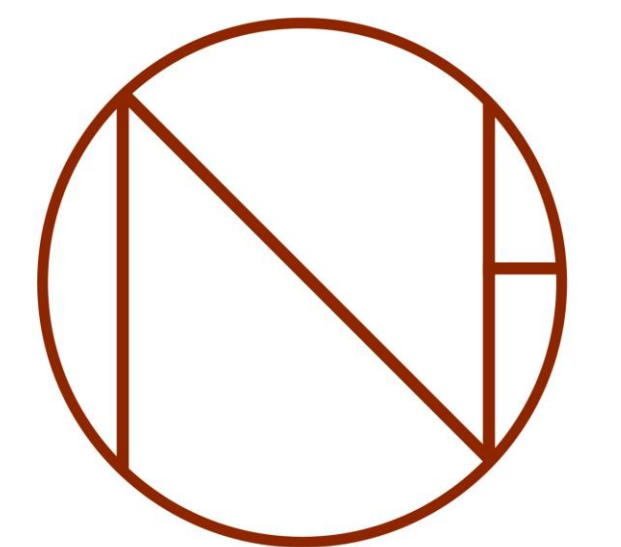


# Developing a Set of Patient-Centered Outcome Measures for Endometriosis: An International Delphi Study



ONE CLINIC



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## Introduction

There is a large variation in individual patient care for endometriosis. A standardized approach to measure patient-centered outcomes could be incorporated into routine clinical practice to monitor treatment effects and potentially improve the quality of care. Furthermore, if tailored to specific timepoints of clinical decision-making, standardized outcome metrics could help establish benchmarks for best practices across different groups and institutions, contributing towards improving endometriosis care and transitioning towards a more patient-centered care. The aim of the present study was to identify patient- and clinician-important Patient Reported Outcome Measures (PROMs) and Clinician Reported Outcome Measures (CROMs) for use in routine endometriosis care which are relevant to any patient to encompass: those with either pain or infertility, and clinical or imaging elements suggestive of endometriosis before its diagnosis; and, for those with complex or severe disease.

## Methods

By means of a two-round Delphi study with international representation (51 participants, 16 countries) followed by a consensus discussion (21 participants, 10 countries), we developed a set of patient-centered measurements. Healthcare professionals and researched specialized in endometriosis care, and patient representatives from endometriosis associations were invited to be part of the expert panel. During the two rounds, participants evaluated 47 PROMs and 30 CROMs according to their feasibility and relevance for their use in routine endometriosis care. After the two rounds, meetings of the experts were convened to finalize the included measures.

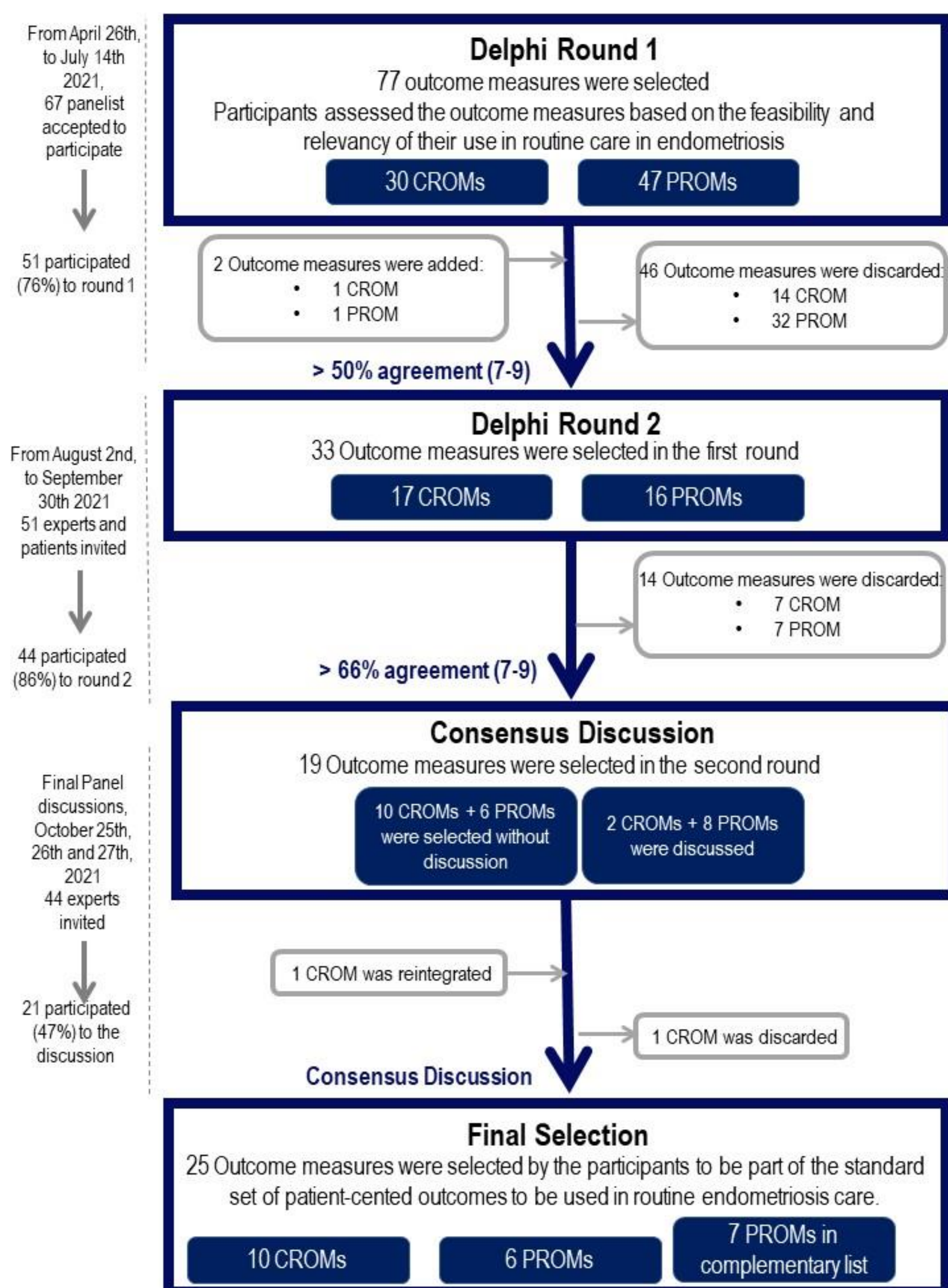


Figure 1. A two-round modified Delphi consensus study to determine a set of patient-centered outcome measurements for routine use in endometriosis care.

## Conclusion

The selected set of patient – centered outcome measures covers the common features of all patients suffering from endometriosis and is adapted to its implementation in routine care. It can be used as a decision support tool to evaluate care and improve communication between patient and physician. It could also contribute to the transition towards value-based endometriosis care, where outcomes that are important to patients will be used as main indicators to determine the most relevant care strategy. In addition, the need for development of specific tools (PROMs) measuring the psychological impact and the impact in sexual activity of endometriosis was highlighted.

## Results

Overall, 166 experts and patient representatives were contacted to participate in the study, 51 participated. Figure 2 show the characteristics of the participants.

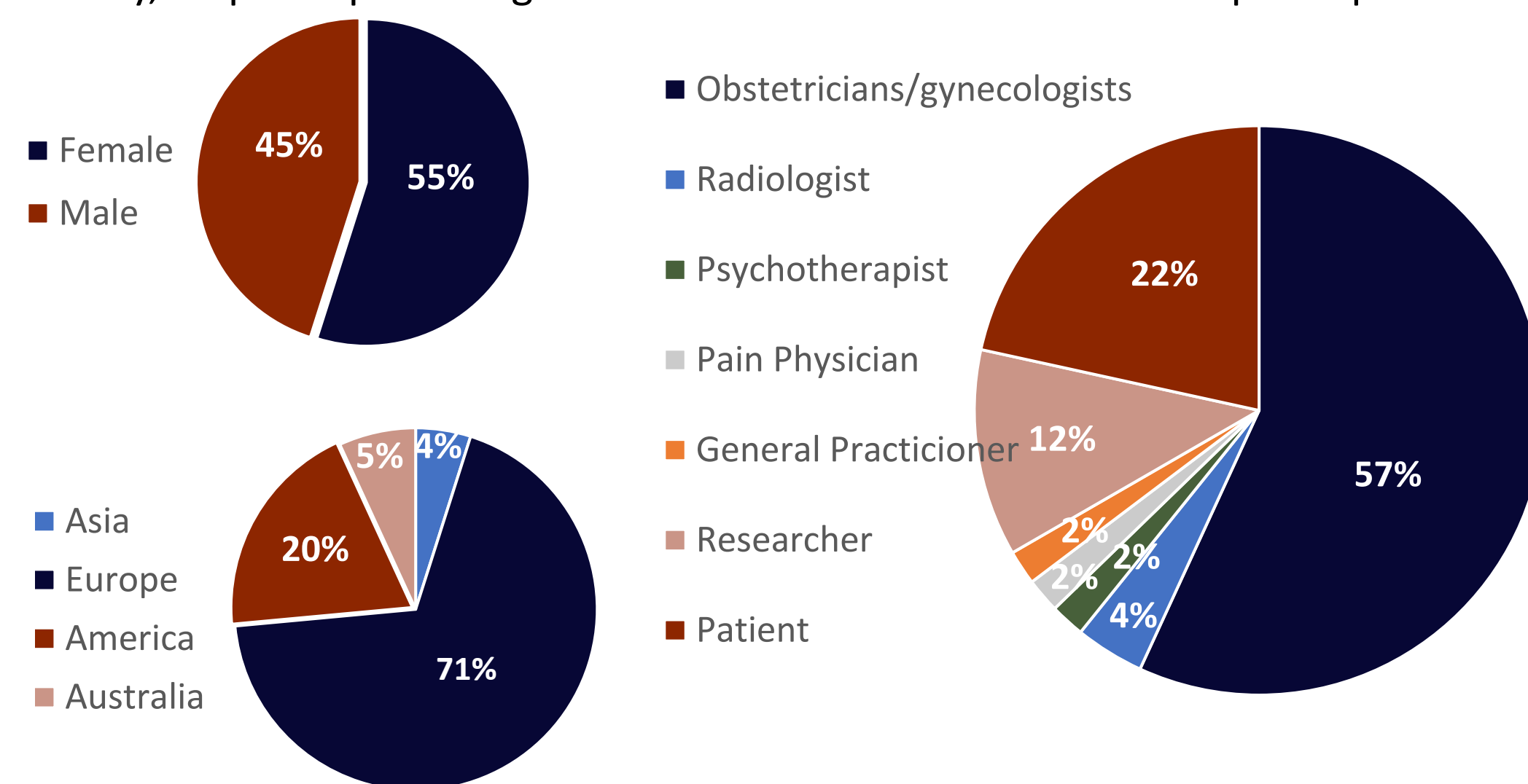


Figure 2. Characteristics of participants in the different rounds of the Delphi study.

The final set of patient-centered outcome measures includes six PROMs (measuring symptomatic impact, pain, work productivity and quality of life) and ten CROMs (measuring clinical, imaging and surgical indicators). A supplementary list of outcome measures was added to include important dimensions that were considered essential by the expert panel but are not relevant to all patients due to the heterogenous symptomatology in endometriosis. This list includes seven additional PROMs measuring symptomatic impact, sexual activity, gastrointestinal symptoms and psychological impact.

### 6 PROMs

**Symptomatic impact:** Endometriosis Impact Questionnaire (EIQ)  
Menstrual Distress Questionnaire (MDQ)  
**Pain:** Endometriosis Associated Pelvic Pain (EAPP) + ENDOL-4D  
**Work Productivity:** Work Productivity and Activity Impairment Questionnaire (WPAI – SHP).  
**Quality of Life:** Endometriosis Health Profile 5 (EHP-5)

### 10 CROMs

**Clinical indicators:** NSAID consumption, Oxycodone/Opioids consumption, identification of black-blurish nodule at vaginal fornix examination, assessment of cul-de-sac nodularity by bimanual pelvic examination, duration of infertility  
**Imaging indicators:** Deep pelvic endometriosis index (dPEI) classification, IDEA consensus for MRI, IDEA consensus for ultrasound  
**Surgical indicators:** #Enzian classification

Supplementary list (7 PROMs ): measuring symptomatic impact, sexual activity, gastrointestinal symptoms and psychological impact

### Ethics approval

This study has received ethics approval from the *Comité d’Ethique de la Recherche en Obstétrique et Gynécologie (CEROG)* in 2021 (number 2021-GYN-0409)