

Women dissatisfied with long process to diagnose polycystic ovary syndrome

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A large international survey of women with a common condition called polycystic ovary syndrome (PCOS), which is characterized by reproductive and metabolic problems, found nearly two in three were dissatisfied with the length of time they waited and the number of healthcare professionals they had to see before they received a diagnosis, according to a new study published in the Endocrine Society's *Journal of Clinical Endocrinology & Metabolism*.

Nearly half of the 1,385 women surveyed internationally saw three or more healthcare providers before they were diagnosed. The diagnostic process took more than two years for a third of the survey respondents.

PCOS is a chronic disorder that impacts numerous aspects of a woman's health. Women who have the condition face an increased risk of developing [metabolic problems](#) such as diabetes, reproductive issues such as infertility, and psychological issues including anxiety and depression. Women are diagnosed when they have at least two of the three key features of the condition:

- Increased numbers of immature eggs in the ovaries (called polycystic ovaries) seen on ultrasound;
- Slightly higher levels of testosterone or clinical symptoms of higher testosterone with excess body hair; and
- Irregular or no menstrual periods.

Between 9 percent and 18 percent of women of childbearing age have

PCOS, according to currently accepted Rotterdam [diagnosis](#), international prevalence studies and guidelines.

"Given the prevalence of PCOS, it is important for women and healthcare professionals to be more aware of the condition," said one of the study's authors, Helena Teede, FRACP, PhD, of Monash University in Melbourne, Australia. "Despite the misleading name, PCOS is not primarily an ovarian condition, but instead is a hormonal disturbance with diverse health effects that is largely inherited. The process of diagnosing PCOS needs to be improved, and the diverse set of metabolic, reproductive and psychological features need to be understood and addressed."

In the cross-sectional study, women with PCOS who were at least 18 years old and had been diagnosed with the condition by a physician were asked to complete an online questionnaire. Researchers built on initial studies in Australia and worked with two large PCOS patient support groups—U.S.-based PCOS Challenge and U.K.-based Verity—to distribute the questionnaire to their website visitors, mailing lists and social media followers with an international reach.

"We were interested in women's diagnosis experience and satisfaction with information and educational materials they received at the time of diagnosis," Teede said.

A total of 1,550 women responded to the survey, but 165 were excluded because they didn't meet the eligibility criteria or they completed less than half of the questions. Respondents lived in 32 countries.

Reports of months- or years-long waits for a diagnosis and visits to multiple [healthcare professionals](#) were common among the survey respondents. Women who waited more than six months for a diagnosis were more likely to report being dissatisfied with the process than those

who were diagnosed in a shorter period.

Less than a quarter of the survey respondents were satisfied with the information they received about common treatments for PCOS, including lifestyle management and medications, when they were diagnosed with the condition. More than half reported that they didn't receive any information about long-term PCOS complications or emotional counseling or support.

"Our findings show women are dissatisfied with the diagnosis experience and that there are clear opportunities to improve awareness, diagnosis and health outcomes for [women](#) with PCOS," Teede said. "The survey results, along with a new international guideline and awareness ad education initiative, will be used to inform international efforts to improve PCOS education and care."

More information: "Delayed Diagnosis and a Lack of Information Associated with Dissatisfaction in Women with Polycystic Ovary Syndrome," press.endocrine.org/doi/10.1210/jc.2016-2963

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