

Polycystic ovary syndrome: Panel recommends changing name of common disorder in women

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An independent panel convened by the National Institutes of Health has concluded that the name of a common hormone disorder in women, polycystic ovary syndrome (PCOS), causes confusion and is a barrier to research progress and effective patient care. The current name focuses on a criterion—ovarian cysts—which is neither necessary nor sufficient to diagnose the syndrome. In a report released today, the panel recommended assigning a new name that more accurately reflects the disorder.

"The name PCOS is a distraction that impedes progress. It is time to assign a name that reflects the complex interactions that characterize the syndrome. The right name will enhance recognition of this issue and assist in expanding research support," said Dr. Robert A. Rizza, panel member and professor of medicine at the Mayo Clinic in Rochester, Minn.

PCOS is a common disorder that affects approximately 5 million reproductive-aged <u>women</u> in the United States. Women with PCOS have difficulty becoming pregnant due to hormone imbalances. They often have other symptoms as well, such as irregular or no <u>menstrual periods</u>, acne, weight gain, excess hair growth on the face or body, thinning scalp hair, and <u>ovarian cysts</u>. Women with PCOS are also at risk for <u>type 2</u> <u>diabetes</u>, <u>high cholesterol</u>, and <u>high blood pressure</u>. Costs to the U.S. <u>healthcare system</u> to identify and manage PCOS are approximately \$4



billion annually.

The causes of PCOS are not well understood. Some studies suggest a strong genetic component, while others find that environmental factors play an important role. The panel recommended that well-designed, multiethnic studies be conducted to determine factors, such as obesity, that exacerbate a genetic predisposition. The panel also determined the need for additional research to identify risks and treatments for complications and how to manage to common symptoms.

"Additional studies are needed to identify new treatments that address the most common symptoms women face, such as weight gain and difficulty becoming pregnant. We also need studies to determine a woman's risk for cardiovascular and other complications and if treatment can reduce these risks," said Dr. Pamela Ouyang, panel member and director of the Women's Cardiovascular Health Center at Johns Hopkins Bayview Medical Center in Baltimore.

Three diagnostic classification systems are currently in use for PCOS: the NIH Criteria, the Rotterdam Criteria, and the Androgen Excess and PCOS Society Criteria. The panel found that the use of multiple systems hinders the ability of clinicians to successfully partner with women in addressing the health issues that concern them.

"To resolve any confusion created by different diagnostic systems, we recommend using the broad, inclusionary Rotterdam Criteria, while also specifying a woman's particular phenotype (or observable clinical characteristics). We also recommend that key components of the Rotterdam Criteria be clearly defined and have normal ranges established across age groups and populations," said Dr. Timothy Johnson, panel member and obstetrician-gynecologist-in-chief at the University of Michigan in Ann Arbor.



The panel also determined that models for involving consumers, such as the one developed by the Australian PCOS Alliance, are worthy of imitation. "Creating multidisciplinary teams—that engage women and their health care providers—is critical to promoting patient education, increasing public awareness, and successfully managing the syndrome," said Lorrie Kline Kaplan, executive director of the American College of Nurse-Midwives in Silver Spring, Md.

More information: <u>prevention.nih.gov/workshops/2 ...</u> <u>/pcos/resources.aspx</u>

Provided by National Institutes of Health

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