

Are expanding disease definitions unnecessarily labelling women with PCOS?

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A RESEARCH COLLABORATION FOR REDUCING
OVERDIAGNOSIS AND OVERTREATMENT



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Polycystic ovary syndrome (PCOS)

○ Associated with:

- Adverse reproductive outcomes (e.g. infertility, gestational diabetes)
- Adverse metabolic and cardiovascular outcomes (e.g. metabolic syndrome, insulin resistance and type 2 diabetes mellitus)

○ Symptoms

- anovulation
- menstrual irregularities
- polycystic ovaries
- hirsutism
- Acne
- alopecia

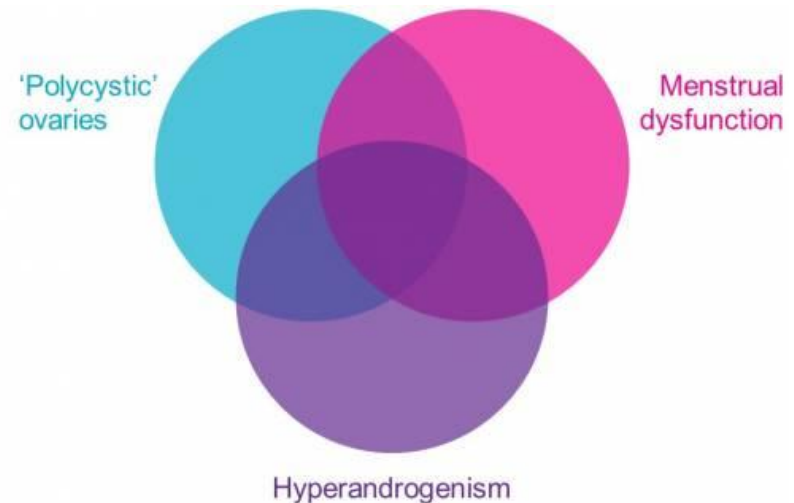


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Diagnostic change and impact on prevalence

Expanding diagnostic criteria

- In 2003, the diagnostic criteria was expanded by including polycystic ovaries on ultrasound, requiring 2 out of the 3 for a diagnosis

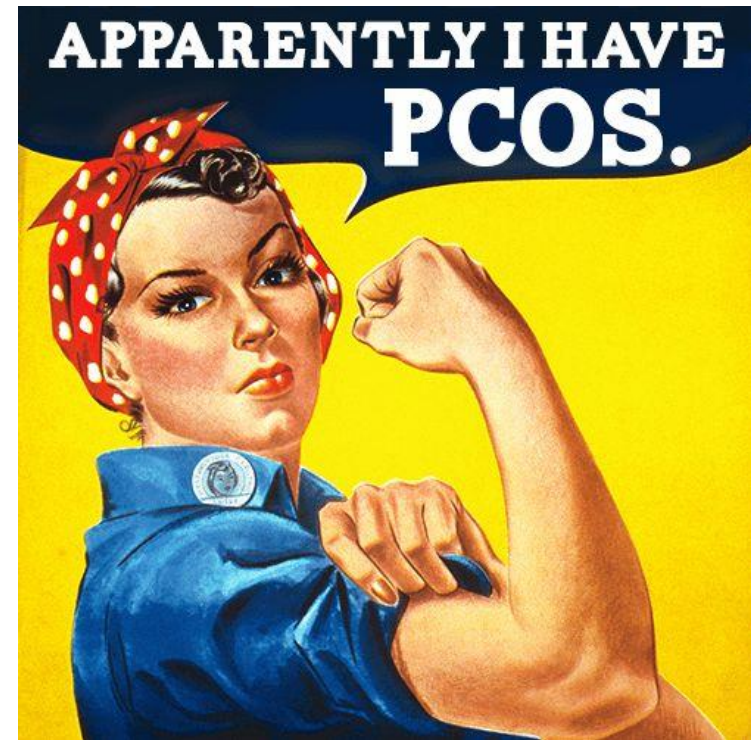
Increasing rate of diagnosis

- Number of women diagnosed has increased from 4-6.6% to up to 21% of reproductive aged women

(Azziz et al., 2004; Boyle et al., 2012)

NIH Diagnostic Criteria (1990)	Rotterdam Diagnostic Criteria (2003)
<p>Both:</p> <ol style="list-style-type: none">1) Oligo- or anovulation; and2) Clinical and/ or biochemical signs of hyperandrogenism <p>And exclusion of other aetiologies</p>	<p>Two of the following:</p> <ol style="list-style-type: none">1) Oligo- or anovulation2) Clinical and/ or biochemical signs of hyperandrogenism3) Polycystic ovaries <p>And exclusion of other aetiologies</p>

Is PCOS being overdiagnosed?



Diagnostic controversy

- Based on expert majority opinion
- Insufficient high quality evidence on long-term follow up or therapeutic benefit to derive an evidence-based definition of the syndrome

(Lizneva et al., 2016)

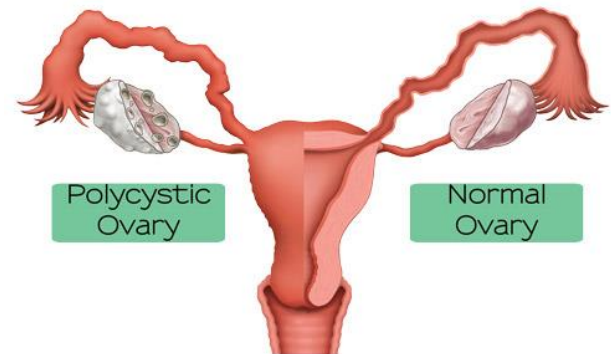
- Polycystic ovaries: a common, age dependent finding
 - Present in 62-84% of women aged 18-30 years from the general population, decreasing to 7% in women aged 41-45

(Johnstone et al., 2010; Duijkers & Klipping, 2010)

Early diagnosis during adolescence

- Features of PCOS overlap with normal symptoms of pubertal development
 - Acne
 - Oligomenorrhea
 - Polycystic ovaries on ultrasound
- No evidence of long-term benefit in identifying PCOS in this age group

Morris et al., 2016



Diagnosis during young adulthood

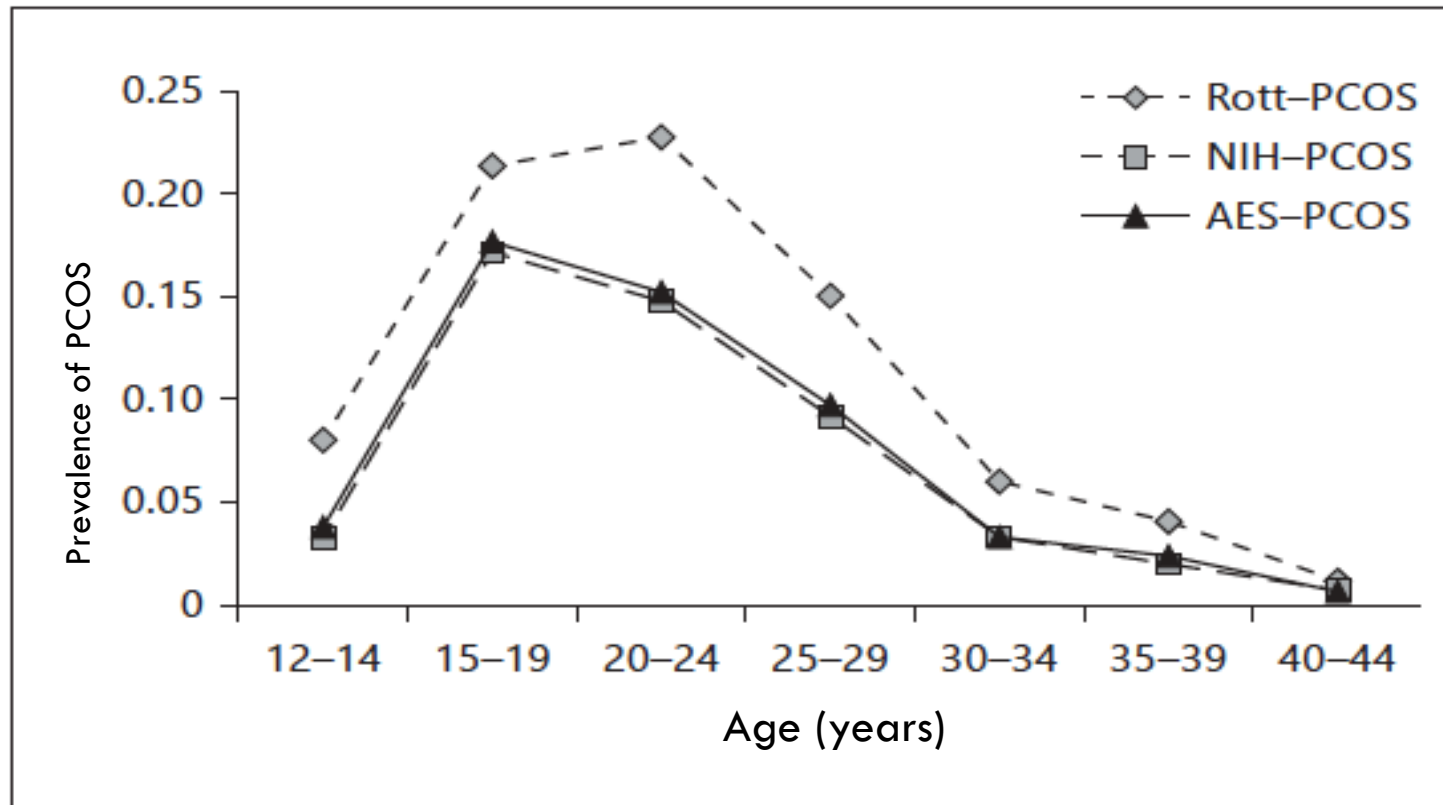


Figure 1. Prevalence of PCOS by age group and diagnostic criteria of a community sample from Chengdu, China (12-44 years; Zhuang et al., 2014)

Diagnosis of non-hyperandrogenic phenotypes

- The non-hyperandrogenic phenotypes introduced by expanded criteria have been found to not have the same increased risk of adverse long-term implications as the original hyperandrogenic phenotypes

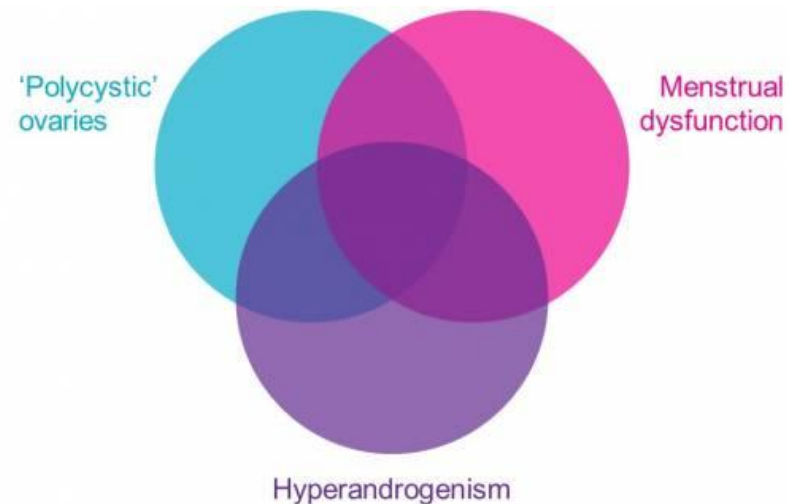


Image from jeanhailes.org.au

Limitations in evidence of treatment benefit

- Existing evidence of low quality
- Referral bias
- No evidence to support rationale of expanding diagnosis

PCOS is associated with psychological burden

Women diagnosed with PCOS have higher levels of:

- Depression and anxiety
- Low self-esteem
- Negative body image
- Disordered eating
- Reduced health related quality of life

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ORIGINAL ARTICLE *Psychology and counselling*

Influence of the disease label 'polycystic ovary syndrome' on intention to have an ultrasound and psychosocial outcomes: a randomised online study in young women

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Ben W.J. Mol^{5,6}, and Jesse Jansen^{1,2,*}

How to move forward

- More adequately powered, carefully phenotyped and multiethnic longitudinal research in unbiased populations
- Focus on improving patient-centred outcomes, not just biochemical markers
- Awareness of the issues in applying a one-size-fits-all diagnostic criteria to heterogeneous presentations of symptoms

Next steps

- Qualitative interviews with clinicians

Aim: To explore the factors that influence decision making around diagnosis and management of PCOS, and examine clinicians' opinions and experiences regarding the benefits and harms of a diagnosis

- Qualitative interviews with women diagnosed with PCOS

Aim: To explore the benefits and harms of receiving a diagnosis from the woman's perspective for those with both mild and more severe manifestations of PCOS

- Quantitative investigation using ALSWH data

Aim: To examine whether there is a significant effect of a new diagnosis of PCOS on health-related behaviour, lifestyle and psychosocial outcomes

THANK YOU

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