

# Exploring the benefits and harms of a PCOS diagnosis: women's views

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A RESEARCH COLLABORATION FOR REDUCING  
OVERDIAGNOSIS AND OVERTREATMENT



# 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 appearing ovaries
- Hirsutism
- Acne
- Alopecia

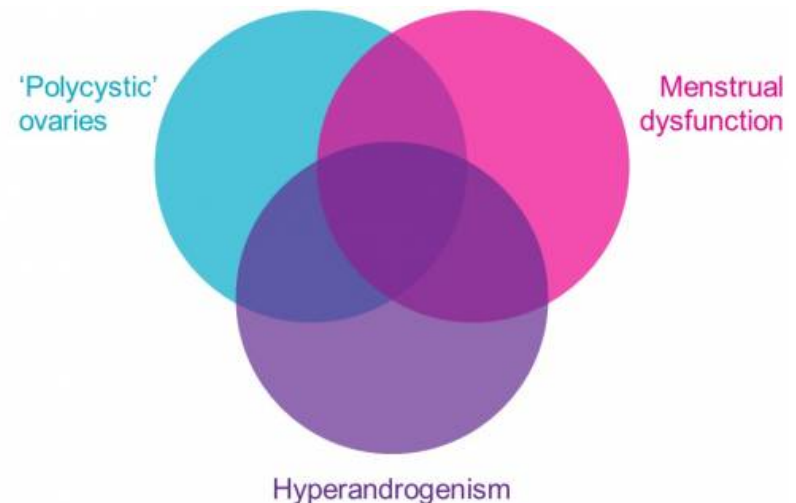


Image from [jeanhailes.org.au](http://jeanhailes.org.au)

# Multiple criteria, phenotypes and diagnostic uncertainty

	All possible potential PCOS phenotypes									
	A	B	C	D	E	F	G	H	I	J
<b>Features</b>										
Hyperandrogenaemia (biochemical androgen excess)	+	-	+	+	-	+	+	-	+	-
Hirsutism (androgen excess)	+	+	-	+	+	-	+	+	-	-
Oligo-anovulation (irregular ovulation)	+	+	+	+	+	+	-	-	-	+
Polycystic ovaries	+	+	+	-	-	-	+	+	+	+
<b>Diagnostic criteria</b>										
NIH (1990)	X	X	X	X	X	X				
Rotterdam (2003)	X	X	X	X	X	X	X	X	X	X
AE-PCOS (2006)	X	X	X	X	X	X	X	X	X	

Modified from Azziz et al.<sup>11</sup> and an NIH evidence based workshop.<sup>10</sup>

# Underdiagnosis of PCOS

- Populations with limited access to healthcare or at high risk of obesity and diabetes, such as Indigenous populations, are less likely to receive a diagnosis (Boyle et al., 2012)
- Some women report delays to diagnosis and seeing multiple providers before receiving a diagnosis (Gibson-Helm et al., 2017)
- An accurate and timely diagnosis is considered important to provide access to healthcare and implement healthy lifestyle interventions
- A study screening for PCOS in a community setting found that 68% of women with PCOS were undiagnosed (March et al., 2010)

# Overdiagnosis of PCOS

- Diagnostic criteria have expanded to include women with milder variants of the syndrome → increased diagnoses
- Are criteria appropriate in adolescence and young women?
- The 'newer' non-hyperandrogenic phenotypes of PCOS do not have the same risk of associated adverse implications
- Potential psychosocial harms of an unnecessary disease label associated with infertility and adverse metabolic outcomes
- Can the label provide more harm than benefit for some women? (Copp et al., *BMJ*, 2017)

## Study aims

- To explore the benefits and harms of receiving a diagnosis for those across the spectrum of symptom severity
- To explore the impact of the diagnosis on psychological wellbeing, lifestyle and behaviour



# Method

- Qualitative study using semi-structured face-to-face & phone interviews
- Women in Australia aged 18-45 years diagnosed with PCOS, recruited through Facebook advertising
- Interviews were audio-recorded, transcribed and analysed thematically

# Demographic characteristics

Characteristic	Number of women (n=26)
<b>Current age</b>	
18-25	9
26-30	6
31-35	6
36-40	2
41-45	3
<b>Age at diagnosis (dx.)</b>	
12-15	3
16-20	8
21-25	12
26-30	3
<b>Education</b>	
Completed Yr 10	1
HSC (Yr 12)	3
Diploma/ Trade certificate	6
Bachelors degree or above	16
<b>Relationship status</b>	
Single	8
In a relationship	7
Married	11



# Preliminary results

## Key themes

Benefits of a diagnosis

Harms of a diagnosis



## Benefits of the label

- Explanation, increased understanding and clarity
- Diagnosis enables management plan
- Increased awareness of the importance of a healthy lifestyle
- Motivates some into action, but not all
- Validation of symptoms
- Shift in responsibility

“...I felt like medically I was being blamed for a lot of my symptoms, which started to impact me in a way that I’d... you know, I’d start questioning myself. Like maybe I am making this up? Or maybe this is my fault? So I guess it, it was a change to sort of have, I guess, being absolved from some of that responsibility.” (ID9, 24yrs, age dx: 19)

# Harms of the label

- Psychological distress
  - Stress and anxiety
  - Worry about the future
  - Loss of control over situation
- Identity related harms
  - Self-esteem, embarrassment, confidence
  - Changes in self identity

“I think it’s made me... probably a bit more anxious. It’s like challenged my whole idea of like... what I wanted for my future. Like it’s like that idea has been shaken a bit... I really just don’t know what’s going to happen. Like what will happen if I can’t have a baby at all? And the thought just like absolutely petrifies me.”  
(ID13, 29yrs, age dx: 29)

## Harms of the label cont.

- Impact on relationships
  - Feel obligated to communicate risk of reduced fertility upfront
- Impact on life decisions
  - Putting career on hold to start a family earlier than planned
- Impact on behaviour
  - Risk taking with contraception
  - Unplanned pregnancies

“That diagnosis absolutely affected my decision to, um, to continue with my pregnancy, which was unexpected and, and become a parent at age 20, a single parent at age 20. So yeah, I guess my understanding of my fertility from that diagnosis, yeah, absolutely it impacted that decision.” (ID9, 24yrs, age dx: 19)

# Importance of weighing up the benefits and harms for each individual woman

- Some reported overwhelming benefit and limited or no harms
- Some reported a 50:50 balance of benefits and harms
- Some reported receiving more harm than benefit

“I see it as being more detrimental than being beneficial... I think mainly because I don't have as many symptoms as, as... other people might do, um so I, yeah... it just puts more, as I said before, it plays on your mind. So it doesn't, I don't see really any benefit to having the diagnosis.”  
(ID10, 28yrs, age dx: 21)

# Discussion

- The diagnosis had various positive and negative impacts, which were influenced by a number of factors, but were also highly individualised
  - What led to diagnosis
  - Symptom severity
  - Age at diagnosis
  - Communication at diagnosis
- Fear of infertility was a universal theme → important to provide accurate information and reassurance
- In addition to the harms that may result from delayed diagnosis, significant harms can arise from receiving the diagnosis, which can have serious consequences

# Thank you!

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# Topics in interview guide

- Experience with diagnosis and management
- Doctor-patient communication
- Information provision and diagnostic satisfaction
- Perceived benefits and harms of a diagnosis
- Impact of diagnosis in psychosocial wellbeing, life decisions and behaviour



# Impact of uncertainty surrounding fertility

“...like ever since that day I’m just like what if I do want kids? Like when is the right time to start trying to work hard for kids? ‘Cause, um, yeah, to this day I’m like, do I still want kids or not? Or... shall we even try if, if you know my chances are decreased already? Yeah, I’m still questioning to this day (laughs).” (ID11, 25yrs, age dx: 18)

“I’m concerned that by having PCOS I’m not going to be able to have a baby, even though no one has said that. That’s my worst fear and that’s what I... am worried about.” (ID13, 29yrs, age dx: 29)

## Diagnosis impact on life

“I truly thought that I wouldn’t be having any kids. But I think, I think that probably affected my attachment a little bit with my, my first son because I just wasn’t even on the planet for having a baby.”  
(ID4, 42yrs, age dx:18)

“I basically thought that I would never get pregnant, so the unplanned pregnancy happened.... you really do get that argument in your head that, you know, look it’s not easy for me, I may never get pregnant, so you know, you’re not always that careful. So that’s definitely a negative thing. And, and obviously a lot of lack of understanding. Um, and I think doctors shouldn’t say you may never get pregnant. I think that gives the wrong impression at that stage when you don’t really understand” (ID3, 43yrs, age dx: 15)

# Limitations

- Highly educated sample
- Self-reported PCOS diagnosis & symptoms

# Overdiagnosis of PCOS

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## Are expanding disease definitions unnecessarily labelling women with polycystic ovary syndrome?

Since polycystic ovary syndrome was described in the 1930s, the diagnostic criteria have expanded and prevalence has risen, explain **Tessa Copp and colleagues**. But to what extent do women today benefit from their diagnosis, particularly younger women and those with milder symptoms?

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