

Acknowledgement of Country

Jean Hailes acknowledges the Traditional Owners of Country throughout Australia and recognises their continuing connection to land, waters and culture. We pay respect to Elders past, present and emerging.

Managing PCOS in Indigenous Communities: a community-led approach

- Partnership between Jean Hailes and Alukura Women's Health Service
- Aimed to create accessible and culturally appropriate resources about PCOS for Aboriginal women and health professionals in Central Australia
- Health professional and community consultations
- Resources for health professionals and community launched October 2022

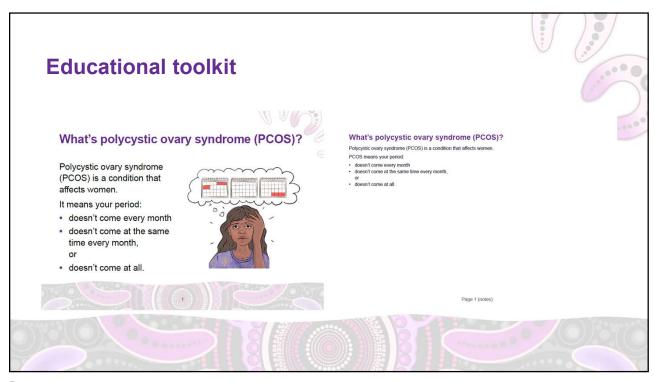
3

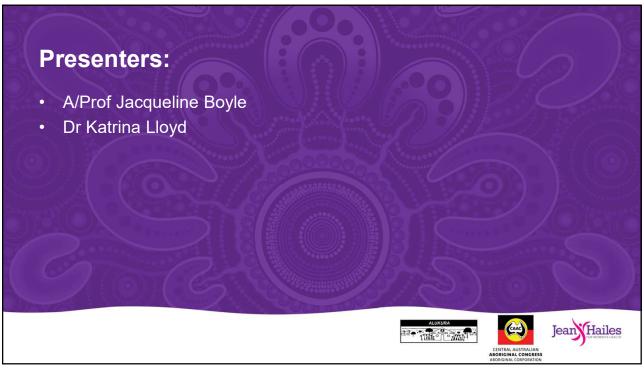
Managing PCOS in Indigenous communities: a community-led approach

- Resources developed include:
 - brochures and animations for community members
 - educational toolkit for health professionals to use when discussing periods and PCOS with Aboriginal women









What is polycystic ovary syndrome (PCOS)?

- A hormonal problem in women, affecting 8-13% women of reproductive age
- Aboriginal and Torres Strait Islander women may be disproportionately impacted, up to 1 in 5 affected
- Testosterone and insulin

How common is PCOS?

PCOS is common.
Up to 1 in 5 Aboriginal and
Torres Strait Islander women
and girls have PCOS.



Jean Hailes, Polycystic ovary syndrome (PCOS) educational toolkit, 2022

7

What symptoms or conditions are related to PCOS?

Reproductive

irregular menstrual cycles, hirsutism, infertility, pregnancy complications

Metabolic

 insulin resistance, metabolic syndrome, obesity, prediabetes, type 2 diabetes, CVD risk factors

Psychological

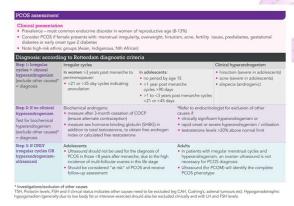
anxiety, depression, body image

Diagnosis: two out of three

Rotterdam diagnostic criteria

Requires two of:

- 1. Oligo- or anovulation
- Clinical and/or biochemical signs of hyperandrogenism
- 3. Polycystic ovaries



Jean Hailes, Polycystic ovary syndrom (PCOS) HP tool, 2018

С

Oligo/anovulation

Irregular cycles: Adult women or women >3 years post menarche

- <21 or > 35 days
- < 8 cycles per year or >90 day cycle

Care needs to be taken in assessing young women

- Irregular cycles are normal the first year post menarche
- 1-3 post menarche still often not as regular
 - <21 or > 45 days
- > 1 year post menarche > 90 days for any one cycle
- Primary amenorrhea by age 15 or > 3 years post thelarche (breast development)

Note: Ovulatory dysfunction may occur with regular cycles and may need luteal serum progesterone



Clinical hyperandrogenism

Adults

- acne
- alopecia
- hirsutism

Adolescents

- severe acne
- hirsutism
 - Rapid onset may signal androgen secreting tumour
 - Assess with modified Ferriman-Gallwey Score (score >4-6)

Practice point: women are often treating any hair growth so difficult to assess clinically









Biochemical hyperandrogenism

- ↑ Calculated free testosterone, free androgen index or calculated bioavailable testosterone
- **↓** SHBG
 - Not able to assess if on hormonal contraception
 - Very high levels may indicate an androgen secreting tumour

Androgens - levels

Testosterone

- 5.2-6.9 nmol/L
 - Consider ovarian tumour

DHEAS

- >20µmol/L
 - Consider adrenal tumour
- 10.5-20 µmol/L
 - Consider congenital adrenal hyperplasia

Thomas J et al Exp Rev

13

Ultrasound

- Transvaginal ultrasound: follicle number ≥20 or an ovarian volume ≥10ml
- Transabdominal ultrasound: ovarian volume ≥10ml

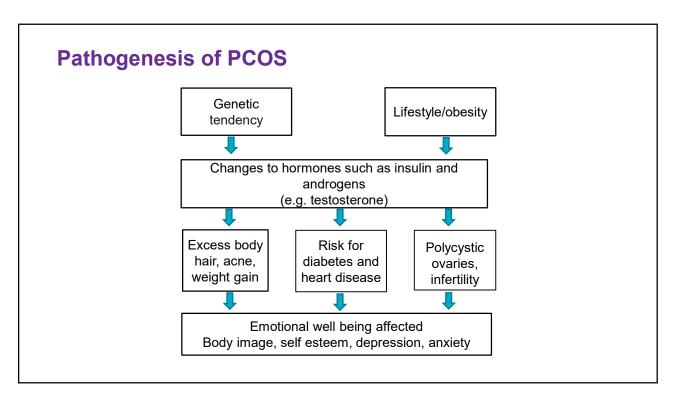
Note:

- There should not be corpus luteum, cysts or dominant follicles
- Not able to use ultrasound for diagnosis if less than 8 years since first period - ovaries commonly look multi-follicular or "polycystic" in these years in normal women

Exclude secondary causes

- Of irregular periods:
 - thyroid disease, hyperprolactinaemia, premature menopause, Cushing's
- Of hyperandrogenism:
 - non-classical adrenal hyperplasia more common in Ashkenazi Jews, Hispanics, Italians
 - androgen secreting tumours rapid progression/virilization
 - Cushing's syndrome
 - medication valproate

15



PCOS management areas

- Lifestyle nutrition, physical activity, weight management
- Clinical hyperandrogenism
- Menstrual cycle regulation
 - Be aware of risk of endometrial hyperplasia
- Fertility
- Screen for and manage Metabolic Syndrome and diabetes
- Sleep apnoea
- Mental and emotional health

PCOS management should be considered across the lifespar and individualised, making sure that patient priorities are identified.

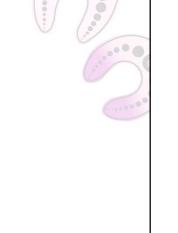
A team/multidisciplinary approach with GP coordinatic should be considered, where appropriate and available.

Jean Hailes, Polycystic ovary syndrome (PCOS) HP tool, 2018

17

PCOS management – care team approach

- General practitioner
- Nurse
- Dietitian
- Aboriginal Health Worker/Practitioner
- **Psychologist**
- Endocrinologist
- Gynaecologist
- Exercise physiologist



Lifestyle – primary management

- 1. Healthy eating
- 2. Regular physical activity
- 3. Weight management +/- reduction

Use of behavioural strategies:

· goal setting



19

Management of hirsutism

Physical removal

- Cosmetic treatments such as waxing, depilatory creams, shaving, threading
- Electrolysis
- Laser hair removal is recommended as a safe method to reduce excess hair growth

Topical Treatment

Eflornithine cream (Vaniqa) – prescription only

Oral medication

- · Oral combined contraceptive pill
- Metformin

Note: Anti-androgens – e.g. spironolactone (only used after 6 months of failed treatment, contraindicated in pregnancy)

OCP with

RD0

RD0 Jacqui - is there a word missing?

Rose Dupleix, 2022-10-27T06:16:30.900

Management of acne

- Standard dermatological acne treatment i.e. dual therapy (topical and oral antibiotics)
- Oral contraceptive pill
- Anti-androgens e.g. spironolactone (contraindicated in pregnancy)

21

Management of irregular periods

- Weight loss 5-10%
- Oral contraceptive pill
 - regular bleeding cycle and endometrial protection
 - contraception
 - positive effect on hirsutism and acne
 - 20-30 mcg E pill
- etonogestrel, ethinyl estradiol vaginal ring (Nuvaring)

- Metformin
 - improves ovulation and cycles
- Progestins
 - levonorgestrel intrauterine system (Mirena)
 - etonogestrel implant (Implanon)
 - drospirenone (Slinda)
 - intermittent progestogen to induce bleed four times a year



Screen for Metabolic Syndrome and diabetes

- Increased blood pressure
- High blood sugar
- Increased waist circumference (abdominal obesity)
- High triglyceride levels
- Low HDL
- Increases risk of diabetes and risk factors for heart disease and stroke

PCOS can lead to other health issues

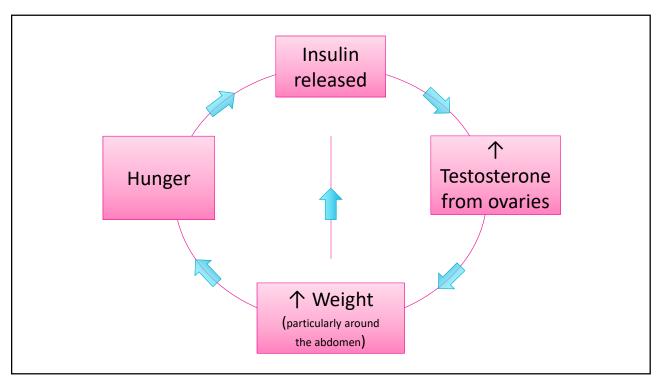
PCOS can impact your health and lead to serious health conditions. You might get:

- diabetes
- high blood pressure
- high cholesterol.



Jean Hailes, Polycystic ovary syndrome (PCOS) educational toolkit, 2023

23



Metformin

- Increases sensitivity to insulin in liver, skeletal muscle, fat and the ovaries
- May help regulate ovulation and menstrual cycles, and may help fertility
- In addition to lifestyle management, may assist in weight loss
- Helps prevent progression to diabetes
- Greater benefit in high metabolic risk groups
- Side-effects are mild diarrhoea, nausea short term dose related

25

PCOS and fertility

- · PCOS limits fertility, but can be treated
- Infertility risk increases for women over 35 years
- Advise early family initiation (<35 years) where practicable
- BMI >30 limits fertility
- Prevent weight gain and aim for weight loss if needed
- Increased risk of gestational diabetes, preterm birth, pre-eclampsia, miscarriage, stillbirth



Fertility management

- If anovulatory no need to wait for treatment
- Letrozole or clomiphene are 1st line pharmacological therapies for infertility
- Metformin can be started before fertility specialist referral or used as an alternative understanding limitations
- Laparoscopic ovarian drilling may be considered in some circumstances

27

Mental and emotional wellbeing

- Research shows women with PCOS have higher levels of anxiety and depression
- Adverse impact of PCOS on
 - quality of life
 - depressive and anxiety symptoms
 - body image and self esteem issues
 - disordered eating
 - psychosexual issues
- Consider screening tool PCOSQ and offer appropriate support, care and referral
- Consider life stage, culture and preferred language

Feeling sad

PCOS can make you feel sad, unhappy, worried or nervous. If you feel like this, talking can help. Talk to:

- friends, family, Elders
- your health carer
- · a counsellor or psychologist

Jean Hailes, Polycystic ovary syndrome (PCOS) educational toolkit, 202



Case study 1 – 34 yo female

- G1P0T1
- BMI 39.7
- Hb A1c 5.5% no OGTT done but have referred to dietitian, patient looking at weight loss options
- Irregular periods since she was a teenager and since stopping Implanon 12 months ago (Had been on Implanon for > 15 years prior)
- Planning pregnancy in 2023

29

Case study 1 – assessments

Androgen studies - ? time in cycle
 = unremarkable

Testosterone	SHBG	Free Testo.	FAI
(0.3 - 1.8)	(25 - 120)) (6 - 28)	
nmol/L	nmol/L	pmol/L	
1.1	46	16	2.4

FSH / LH / Prolactin = OK

FSH								:	9	IU/L	(see below)
LH								:	9	IU/L	(see below)
Prog	ge:	ste	er	on	е			:	4	nmol/L	(see below)
Prol	lad	ct:	in		•			:	220	mIU/L	(< 500)

TSH = OK

```
TSH (mIU/L) FT4 (pmol/L) FT3 (pmol/L) (0.40 - 4.00) FT3 (pmol/L) (13/01/20 2.33 (30/11/21 3.86 12/05/22 1.62
```

 D24 progesterone = consistent with ovulation

```
HORMONES (Serum) DAY 24

Progesterone . . . . : 29 nmol/L
```

LFTs abnormal, USS = fatty liver

Case study 1 – assessments

- Pelvic ultrasound: TA and TV scans performed
- Clinical details: irregular menses for investigation
- The uterus is anteverted and is normal in size with a volume of 34cc
 - No focal lesion
 - Mildly heterogeneous myometrium noted
 - Endometrial thickness is 2mm
 - Normal appearance

31

Case study 1 – assessments

- Right ovary volume is 8.2cc
 - There is a 16 x 13mm simple parapelvic cyst
- Left ovary is normal with a volume of 4.9cc
- · No adnexal masses or free fluid
 - There was non-specific moderate tenderness of both ovaries
- Conclusion
 - Simple right parapelvic cyst
 - Non-specific ovarian tenderness bilaterally

Questions for case study 1

- Patient has risk factors for PCOS (raised BMI, fatty liver suggests metabolic syndrome) and has irregular periods
- But USS / androgen studies don't confirm diagnosis of PCOS
- Are there management options (other than lifestyle advice and weight loss) given she doesn't fulfil criteria for PCOS but is at high risk?

33

Case study 2 – 21 yo female

- BMI 23
- Periods regular
- Low abdominal pain with recurrence after PID treatment three months ago
 - ?hydrosalpinx or other abnormality
- USS done to investigate lower abdo pain no PCOS concerns

Case study 2 – assessments

- Pelvic ultrasound: TA and TV scans performed
 - The uterus is anteverted and normal in size with a volume of 62cc
 - Endometrial thickness is 12mm
 - No focal lesion
 - Both ovaries are normal measuring 10cc in volume on the right and 14cc on the left
 - Multiple small follicles noted bilaterally at the periphery
 - No free fluid or adnexal masses
- Conclusion
 - No evidence of hydrosalpinx or other focal pathology
 - There was non-specific tenderness on TV scanning of the ovaries

35

Questions for case study 2

- Issue incidental follicles on USS are they consistent with PCOS? Should we do anything?
- Are the follicles as reported on the USS normal?

Case study 3 – 20 yo female

- Oligomenorrhoea
- BMI 36
- HbA1c 4.6%
- Irregular periods and not conceived since Implanon removed 2018
- Not particularly hirsute
- Has missed appointments for pelvic USS

37

Case study 3 – assessments

- Pathology
 - Low SHBG (testosterone and calculated free testosterone within normal limits)
 - Pathology comments "decreased SHBG may occur in obesity, PCOS, or hypothyroidism"
- Hormones (Serum)
 - FSH: 8 IU/L
 - LH: 9 IU/L
 - Progesterone: 1 nmol/L
 - Prolactin: 220 mIU/L (< 500)
- Cumulative thyroid function test (Serum)

TSH (mIU/L) FT4 (pmol/L) (10 - 20)

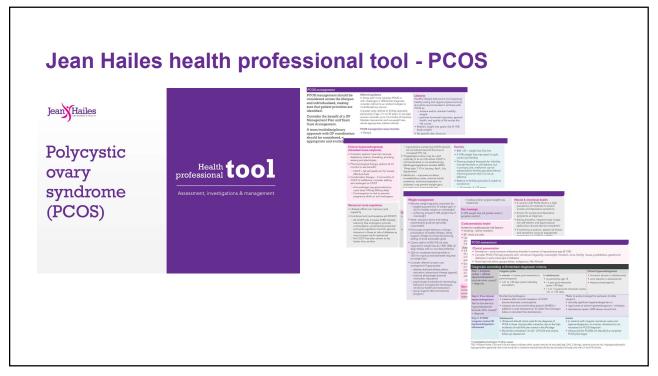
12/09/20 3.07 18
07/12/21 3.23 17



Question for case study 3

 Issue – interpreting androgen studies – should we diagnose PCOS on the information that we have below and commence metformin?

39



Health professional resources







Weight, obesity and women's health

Polycystic ovary syndrome (PCOS): the consultation

In this video, Dr Rosie Worsley discusses what might alert a clinician to undiagnosed PCOS and also some of the key points for consideration in a consultation, once a woman has a diagnosis of PCOS,

Watch now (video)



- Resource tools
 - https://jeanhailes.org.au/health-professionals/tools
- Health professional learning activities
 - e-Learning courses
 - Webinars
 - Practice points

https://jeanhailes.org.au/health-professionals

41

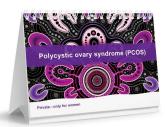
Resources for Aboriginal and Torres Strait Islander communities

Animations, booklets and educational toolkit available at: jeanhailes.org.au/resources/aboriginal-and-torres-strait-islander-resources











What do you think about the resources developed to support diagnosis and management of PCOS among Aboriginal women in Mparntwe (Alice Springs) and surrounding communities?

The final phase of the project is to evaluate the process undertaken to develop the resources, as well as the usefulness and appropriateness of the resources – culturally and clinically. The evaluation includes an online survey of health care professionals.

This survey will take approximately 15 minutes.

The project has been approved by the Charles Darwin University Human Research Ethics Committee (approval number H22075).



Participant information sheet

Access the survey here, or scan the QR code

For questions please contact:

Emily.gilbert@cdu.edu.au







43

Thank you

Go to **jeanhailes.org.au** for more resources, videos and articles











