



Improving Health and Health Care for those Affected by Polycystic Ovary Syndrome: Development of a Provincial Primary Care PCOS Clinical and Patient Pathway

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Rationale

- Polycystic Ovary Syndrome (PCOS) is the most common metabolic-endocrine disorder impacting 15% of females across the lifespan¹.
- PCOS is associated with increased risk of obesity, diabetes, infertility, pregnancy complications, mental illness and cardiovascular disease^{1,2}.
- Our health care survey and focus group studies have shown those with PCOS have concerns about their health care experience including prolonged time to diagnosis and lack of follow up health care for symptoms and co-morbidities³.
- Health care providers in Alberta have expressed the need for direction to provide integrated care for those with PCOS to address their complex health needs.

Aim

To develop a primary care clinical and patient pathway that assists primary care providers and patients to improve the diagnosis and management of PCOS symptoms, and to address the complex health needs of those with PCOS.

Methods

- The pathways were developed in collaboration with the Alberta Health Services Provincial Pathways Unit (AHS PPU) following steps in the Pathway Development Toolkit:
 - Co-define → Co-design → Validate → Implement → Sustain
- A co-design team was established with patient-partners, primary care physicians, researchers, dietitians, endocrinologists and obstetrician-gynecologists.
- The pathway aligns with recommendations from the evidence-based 2023 International Guidelines for Diagnosis and Management of PCOS¹.
- The following elements were considered in the pathway project charter:
 - o no need for additional resources,
 - o usable by most primary care providers,
 - o supported by specialty care providers,
 - o supports patient self-management and shared decision making, and
 - o addresses the challenges in managing the condition identified by patients and health care providers.

Your Journey with Polycystic Ovary Syndrome (PCOS)

For more information scan this QR code or go to myhealth.alberta.ca/pcos-pathway

PCOS is a syndrome that is caused by a hormonal imbalance that impacts health across the lifespan. People with PCOS may have irregular periods and have higher levels of the hormone testosterone. The ovaries may develop enlarged follicles that are often referred to as 'cysts'. You are the most important part of your healthcare team. This guide will help you to know what to expect as you work with your team to manage and treat PCOS. If you have any questions along the way, please ask your healthcare team. Click on the page numbers in blue if you want more information about the step in your journey.

Before your appointment (page 5)

- Write down how you feel, and your questions, symptoms, and concerns.
- Symptoms may include missed or irregular periods, acne, extra hair on the face and body, scalp hair loss, difficulty managing weight, and difficulty in getting pregnant.
- Consider bringing a family member or friend to support you.

Visit your healthcare provider (page 7)

- Your health includes physical, emotional, spiritual, financial, and social elements.
- To better manage your health condition, your healthcare provider needs to hear from you and understand who you are and what matters to you. They will need to ask questions about your past health, family history, and menstrual cycles.

Get your tests (page 9)

- Your healthcare provider will do a physical exam to look for signs of PCOS, such as extra body hair, and signs of insulin resistance. They may measure your blood pressure, weight, and height.
- You will need lab tests to help with the diagnosis.
- Some people may need an internal ultrasound to view the ovaries.

Review your test results (page 10)

- Find your test results on MyHealth Records or MyAHS Connect (myhealth.alberta.ca/myhealthrecords) or ask your healthcare provider to print them for you
- Talk with your healthcare provider so you know what your test results mean.

Review your treatment & management options (page 12)

Your healthcare provider will help you better understand your condition and offer you important strategies to manage your condition. In most cases, nutrition, physical activity, and lifestyle changes should be tried first. This includes:

- having a healthy eating pattern with nourishing foods
- exercising regularly
- having healthy mental health practices
- getting restful sleep
- reducing or quitting smoking and alcohol use

• Some people may benefit from having medication to help with their irregular periods, extra hair growth, body weight, acne, pre-diabetes, and infertility.

• Your symptoms may need other management such as hair removal options, acne treatment, diet, sleep, or mental health supports.

• Discuss the options and decide with your healthcare provider what will work best for you.

Talk with your healthcare provider about a referral (page 18)

- Not all patients need a referral to see a specialist. You may benefit from a referral to a different healthcare provider based on your symptoms, test results, and your history.

Start your treatment & watch your symptoms (page 1)

Visit your healthcare provider if you have any of the following symptoms:

- sudden onset of new and unusual facial and body hair growth
- development of new wide purple stretch marks

If you have a change in symptoms or notice a new symptom, consider keeping a diary to track your symptoms.

Keep taking care of yourself (page 20)

- Keep taking care of your overall health. Look for other healthy lifestyle resources and supports.

Important Tips:

- Need a family doctor? ahs.ca/findadoctor
- Need a translator? Let your healthcare provider know
- Need health advice? Call Health Link at 811
- Need to find programs and services in your community? Call 211 or visit ab.211.ca

Whole-person health (page 2)

Physical, Financial and Social, Emotional, Spiritual

Alberta Health Services

Provincial PCOS Primary Care Clinical Pathway

Quick Links: [Primer & Expanded details](#) [Provider resources](#) [Patient pathway](#) [Provide feedback](#)

This pathway applies to adults and adolescents > 3 years post menarche

Suspect PCOS with a patient who has any of the following symptoms:

- Irregular or no menstrual cycles
- Hyperandrogenism (hirsutism, acne, and hair loss)
- Suggestive ultrasound

1. History

- Evaluate menstrual pattern (abnormal is <21 days or >35 days)
- Reproductive history
- Hyperandrogenism
 - o Hirsutism (consider ethnic variation and hair removal treatments)
 - o Acne (more prevalent in youth, consider if acne is treatment resistant)
 - o Scalp hair loss (more prominent in menopause)
- Metabolic history:
 - o Weight gain or difficulty losing weight, obesity, dyslipidemia, high blood pressure, impaired glucose tolerance and Type II Diabetes
- Family history of PCOS, Type II or gestational diabetes
- Prior or current treatments that affect current menstrual cycles: oral contraceptive pill (OCP), metformin and spironolactone

2. Assessment

- Height, weight, blood pressure
- Physical exam to assess for clinical hyperandrogenism and insulin resistance (skin tags and acanthosis nigricans)

3. Red flags

- Severe and sudden onset of hirsutism
- Signs of Cushing's (wide purple stretch marks, round face, central fat deposition with thin arms and legs)

Red flags present → **7. Urgent Advice or Referral**

No red flags → **4. Investigations**

4. Investigations

Bloodwork: Timing of testing and concurrent combined hormone therapy is important, see expanded details.

- Prolactin
- TSH
- FSH/ LH/ Estradiol
- Lipids
- OGTT
- β-hCG
- Total testosterone, with SHBG to calculate free androgen index
- Free testosterone

Transvaginal ultrasound: If **only one** of the following is present, complete transvaginal ultrasound in adults (if not available/appropriate complete trans abdominal pelvic ultrasound):

- hyperandrogenism or
- acyclic or irregular menstrual cycles

If unusual or unexpected results, or difficulty in interpretation → **7. Non-Urgent Advice**

5. Confirm PCOS diagnosis if other disorders ruled out and if two of the following are present:

- Clinical or biochemical hyperandrogenism
- Acyclic or irregular menstrual cycles
- PCOM follicular morphology

If uncertain about PCOS Diagnosis → **7. Non-Urgent Advice**

6. PCOS Management: Ask the patient about their perception of PCOS related symptoms, impact on quality of life, key concerns, and priorities for management

6a. Consider other Associated Health Risks

- Prediabetes/Diabetes/CVD risks
- Endometrial hyperplasia and cancer
- Psychological: Anxiety, Depression, Body Image, and Eating Disorder
- Metabolic dysfunction-associated fatty liver disease (MAFLD)
- Obstructive Sleep Apnea

6b. For All PCOS Patients Offer Nutrition, Exercise, and Lifestyle Counselling:

- A balanced, healthy diet following [Canada's Food Guide](#).
- Encourage daily physical activity.
- Encourage body weight maintenance, prevent weight gain, and moderate weight loss.
- Encourage reduction or quitting of smoking and alcohol use.

6c. Specific Symptom Management

- For menstrual regulation (amenorrhoea/oligomenorrhoea) Consider hormonal contraceptive options, metformin, and progesterone withdrawal
- For Hirsutism, Acne or Alopecia consider laser hair removal, use of COCP, antiandrogens and encourage management outlined in 6b.
- Pre-diabetes: consider 6b, metformin and other insulin sensitizers
- For fertility: Assess reproductive life plan. Offer education and determine if referral is appropriate.
- For Weight Management: Continue and intensify 6b. Addition of anti-obesity medications can be considered.

8. Consider referral to appropriate provider(s)

Alberta Health Services | Call to Action: We need your feedback during this new pathway's initial testing phase! | Alberta's Pathway Hub | Background | Patient resources | Updated: Apr 25, 2024 | Page 1 of 19

Results

An algorithm with expanded detail for patients and primary care physicians was developed in a provincial co-design approach based on serial consultation. The algorithm was refined by stepwise iteration to meet the project charter outcomes.

Conclusion

The pathway reflects a patient-centered collaborative multidisciplinary team approach to support primary care providers and those affected by PCOS to improve their health care journey. The pathway is in final stages of development and will be released for preliminary review July 2024.

References:

1. Teede HJ et al. International PCOS Network. Recommendations from the 2023 International Evidence-based Guideline for the Assessment and Management of Polycystic Ovary Syndrome. J Clin Endocrinol Metab. 2023;108(10):2447-2469.
2. Vine DF et al. Increased Prevalence of Health Outcomes Across the Lifespan in Those Affected by Polycystic Ovary Syndrome: a Canadian Population Cohort Study. Can J Cardiol. 2023; 6:314-326.
3. Sydora B et al. Challenges in diagnosis and health care in Polycystic Ovary Syndrome in Canada: a patient view to improve health care. BMC Women's Health. 2023;4:59-574.

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