PCOS Patient Survey

Thank you for your interest in this study. Your participation in this survey is voluntary. The purpose of this research survey is to better understand the experiences and needs of patients with polycystic ovary syndrome (PCOS). If you agree to participate, we will ask you to complete the survey either online or on paper. It is estimated that it will take approximately 10 minutes to complete the questions. You are also invited to complete a section with your comments. It is up to you how much time you wish to spend on the comments section.

In order to protect your confidentiality, the survey does not include any of your personal identifying information. If you have any questions, please feel free to contact Dr. Daniel Dumesic or a member of his study team by email at uclaobgynresearch@mednet.ucla.edu or by phone at (310) 825-0580. If you have any questions regarding research at UCLA, please feel free to contact the UCLA Office of the Human Research Protection Program (OHRPP) by phone at (310) 825-5344; by email at mirb@research.ucla.edu; or US mail at UCLA OHRPP, 11000 Kinross Ave, Suite 211, Box 951694, Los Angeles, CA 90095-1694. The confidentiality of emails cannot be guaranteed. Please do not include any sensitive information in email communications.

Only women 18 years of age or older are eligible to complete this survey.

- By checking this box, I am providing my assurance that I am 18 years of age or older.
- 1. At what age (in years) did you first begin experiencing symptoms of PCOS?
 - 1. <10
 - 2. 10-15
 - 3. 16-25
 - 4. 26-35
 - 5. >36
- 2. Are you presently experiencing any of the following symptoms? (indicate all that apply)
 - 1. Irregular menstrual periods
 - 2. Excessive facial or body hair
 - 3. Acne
 - 4. Excess weight gain
 - 5. Infertility
 - 6. None of the above
- 3. Have you received a formal diagnosis of PCOS by a health care professional?
 - 1. Yes
 - 2. No
 - 3. Not Sure

- 4. If yes, how old were you (in years) when you were diagnosed with PCOS?

 <10
 10-15
 16-25
 26-35
 36+

 5. What was the specialty of the doctor who diagnosed you with PCOS?
 - 1. Family Practice
 - 2. Internal Medicine
 - 3. Medical Endocrinologist
 - 4. Obstetrician/Gynecologist
 - 5. Pediatrician
 - 6. Pediatric Endocrinologist
 - 7. Reproductive Endocrinologist
 - 8. Other
- 6. How many doctors did you see for your symptoms before you received a diagnosis of PCOS?
 - 1. 1
 - 2. 2
 - 3. 3
 - 4. 4
 - 5. 5
 - 6. 6 or more
- 7. Did you receive a pelvic ultrasound at the time of your diagnosis?
 - 1. Yes
 - 2. No
 - 3. Not Sure
- 8. Did you receive a blood test for male hormone levels at the time of your diagnosis?
 - 1. Yes
 - 2. No
 - 3. Not Sure
- 9. At the time of your diagnosis, how satisfied were you with the explanation you received about the cause of PCOS?
 - 1. Completely satisfied
 - 2. Mostly satisfied
 - 3. Satisfied
 - 4. Not Satisfied

- 10. At the time of your diagnosis, how satisfied were you with the initial explanation of your treatment options for managing your PCOS symptoms?
 - 1. Completely satisfied
 - 2. Mostly satisfied
 - 3. Satisfied
 - 4. Not Satisfied
- 11. Are you presently taking any of the following prescription drugs to treat your PCOS symptoms? (indicate all that apply)
 - 1. Birth control pills
 - 2. Progestins (including Mirena IUD)
 - 3. Insulin sensitizers (i.e. metformin or glitazones)
 - 4. Spironolactone
 - 5. Anabolic steroids
 - 5. Blood pressure medications
 - 6. Cholesterol-lowering medications
- 12. Are you presently using any interventions for removal of facial or body hair (i.e. creams, laser hair removal, electrolysis)?
 - 1. Yes
 - 2. No
- 13. At the present time, how satisfied are you with the medical care you are receiving for your PCOS?
 - 1. Completely satisfied
 - 2. Mostly satisfied
 - 3. Satisfied
 - 4. Not Satisfied
- 14. Since your diagnosis, have you sought medical care for PCOS from a health care provider other than the one who diagnosed your PCOS?
 - 1. Yes
 - 2. No
- 15. What is your race?
 - 1. American Indian or Alaska Native
 - 2. East Asian
 - 3. South Asian
 - 4. Black or African American
 - 5. Native Hawaiian or other Pacific Islander
 - 6. Caucasian
 - 7. Mixed
 - 8. Other

16.	What is your ethnic background?	
	1.	Hispanic or Latino (Latina?)
	2.	Not Hispanic or Latino (Latina?)
17.	What is your current age (years)?	
	1.	18-25
	2.	26-35
	3.	36-50
	4.	51+
18.	What state do you live in?	
19.	Have you searched the internet for information about PCOS?	
		Yes
	2.	No
20.	Have you joined an <u>in-person</u> PCOS support group?	
		Yes
	2.	No
21.	If yes, h	now many in-person PCOS support groups, have you joined?
	1.	
	2.	
	3.	
	4.	•
	5.	5 or more
22.	Have you joined an online PCOS support group or forum?	
		Yes
	2.	No
23.	If yes, how many online support groups have you joined?	
	1.	
	2.	2
		3
	4.	
	5.	5 or more



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COMMENTS: Please let us know how you think the health care system could be improved to better support women with PCOS (text is limited to 2000 characters including spaces)		
If you would like to know if you qualify for a research study, please feel free to contact us by email at uclaobgynresearch@mednet.ucla.edu or by phone at (310) 825-0580. The confidentiality of emails cannot be guaranteed. Please do not include any sensitive information in email communications.		
Thank you for taking the time to participate in this survey!		
To return this survey by mail, please send to:		
Daniel Dumesic, MD UCLA Department OB/GYN 10833 Le Conte Ave, Room 22-188 CHS Los Angeles, CA 90095-1740		