Polycystic ovary syndrome (PCOS), self help and complementary medicine; the...

This survey is part of a study is being carried out by the University of Western Sydney with the support of the Polycystic Ovary Association of Australia (POSAA) to provide a clearer understanding of the use of self prescribed therapies and complementary medicine or therapies by women with polycystic ovary syndrome (PCOS). Your answers will help to better understand the experiences of women with PCOS and for health providers to provide better care. The main therapies in this questionnaire include diet, exercise and physical activity and complementary medicine and therapies. Many complementary medicines do not have a clear evidence base for their effectiveness and this study does not in any way imply that POSAA endorse or refute the use of these therapies.

Your help would be appreciated in the completion of this anonymous survey. Your involvement is voluntary and returning the completed questionnaire will indicate your consent to participate in this study. It should take about 20 minutes to complete the questionnaire. Please note that after submission, your survey cannot be withdrawn. The survey is confidential and the answers given by you are not identifiable.

When completing the survey please click on the box which best represents your answer. When you finish the survey, please click on the submit button. There are no right or wrong answers. The results will be published on the Polycystic Ovary Syndrome Association of Australia (POSAA) website.

This study is being carried out by a PhD student at the Centre for Complementary Medicine Research at the University of Western Sydney. It has been approved by the Human Research Ethics Committee of the University of Western Sydney, approval number H9341.

If you have any questions regarding the survey please contact the researcher, Susan Arentz on 0403 044 247 or email s.arentz@uws.edu.au. If you have any concerns or complaints about the ethical conduct or content of the survey, please contact the Office of Research Services at humanethics@uws.edu.au Thank you for your participation.

What is Complementary Medicine?

Complementary alternative or natural medicine or therapies includes herbal tablets or capsules, vitamins and/or mineral supplements, food supplements such as fish oil or barley greens or visiting a complementary, traditional medicine or alternative practitioner. In this survey, complementary medicine or therapies is referred to as CM.

IO Sta	art we would like to ask you some questions about your general health and the way you expelence PCOS.
1. I	n general, would you say that your physical health is (choose one only)
0	Excellent
0	Very good
0	Good
0	Fair
0	Poor
2. [Oo you experience any signs or symptoms that may be associated with PCOS?
0	Yes
0	No (please go to question 4)

3. Do you experience any of the following signs or symptoms that may be associated with PCOS (choose as many as needed)

	All of the time	Most of the time	Some of the time	A little of the time	Hardly any of the time	Not any of the time
A late menstrual period	0	0	0	0	0	0
Menstrual cramps	0	0	O	0	O	O
Skin breakouts or skin irritation on the face, back or chest	С	O	С	О	О	О
Depressed as a result of having PCOS	0	O	0	O	0	0
Growth of visible hair on chin or body	0	O	0	0	0	0
Waist larger than hips	0	O	\circ	0	0	0
Overweight	0	0	0	0	0	0
Very overweight	0	0	O	0	0	O
Metabolic syndrome or insulin or sugar imbalances	O	O	0	O	0	0
Infertility, or taking longer than 12 months to get pregnant	0	O	0	O	0	0
	record of yo	our menstrua	al cycle?			
Other (please specify) 4. Do you keep a I Yes - always Yes - sometimes	record of yo	our menstru	al cycle?			
4. Do you keep a I	record of yo	our menstru	al cycle?			
4. Do you keep a I Yes - always Yes - sometimes	any of the f	allawina 4a y		ınage PCOS	symptoms	(please
4. Do you keep a l Yes - always Yes - sometimes No No The individual of the ind	any of the f	allawina 4a y		nage PCOS	symptoms	(please
4. Do you keep a l Yes - always Yes - sometimes No 5. Have you tried at tick as many as no Exercise/physical activ	any of the f eeded)	ollowing to ı		nage PCOS	symptoms	(please
4. Do you keep a l Yes - always Yes - sometimes No 5. Have you tried attick as many as no Exercise/physical activ	any of the feeded) Writy Sine or natural the	ollowing to I	reduce or ma	nage PCOS	symptoms	(please
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4. Do you keep a Paragram of the oral contraceptive Fertility drugs as part of the paragram of	any of the feeded) wity cine or natural the ugs such as Metfore pill of an IVF cycle h as laparoscopic	ollowing to I	reduce or ma		symptoms	(please

Self help and complementary medicine or natural therapies for PCOS

Now we want to ask you in more detail about ways, if any, that you have tried to keep yourself well or to manage the symptoms of PCOS. First some questions about complementary medicine or natural therapies, followed by some questions about diet and lastly some questions about exercise or physical activity.

Yes				
No (please go to question	on 8)			

Polycystic ovary syndrome (PCOS), self help and complementary 7. In the past 12 months or do you currently use or take any of the following complementary medicines or natural therapies (tick as many as needed) How often? Vitamins such as multivitamins, or vitamin C, not prescribed by a doctor Other natural medicines ▼ | from fish, plants or animals Herbal teas, for therapeutic reasons Mineral supplements not prescribed by a doctor Food supplements such as spirilina, barley greens etc Mineral supplements prescribed by a doctor Herbal medicines such as Vitex agnes castus (chaste tree), dong quai, Echinacea etc Other herbal medicines Traditional Chinese herbal tablets or teas Indigenous or other traditional medicines such as Ayevedic medicine Vitamins prescribed by a doctor Aromatherapy oils for therapeutic reasons Homoeopathic medicines No complementary medicines or natural health supplements used in the last 12 months Other (please specify)

	lave you ever visited or are you currently seeing any of the following complementary ctitioners or therapists (please tick as many as needed)
	Acupuncturist
	Chiropractor
	Naturopath/western herbalist
	Osteopath
	Homoeopath
	Traditional Chinese Medicine practitioner
	Reflexologist
	Massage or Bowen therapist
	Aromatherapist
	Iridologist
	Kinesiologist
	A medical doctor for acupuncture
	A medical doctor for integrative medicine
com	No I have not visited a complementary practitioner or therapist. If you have not used, are not currently using and have not visited a plementary practitioner or therapist please go to question 13.
Othe	er (please specify)

Polycystic ovary syndrome (PCOS), self help and complementary 9. For what area of your health have you used, currently use complementary medicines or therapies or see a complementary therapist or practitioner (please tick as many as needed) PCOS Increase energy Period pain PMS ☐ Fertility Sleep Digestion Constipation Acne Colds and flu prevention Stay healthy Depression Anxiety General well-being Other (please specify) 10. Have you found complementary medicines or therapies effective for (please tick as many as required) Reducing PCOS symptoms such as regulating menstruation or reducing acne Improving PCOS in combination with diet and exercise Improving PCOS in combination with drugs Reducing period pain Reducing PMS Improving general health Improving fertility Improving sleep Enhancing weight loss No not effective at all Other (please specify)

	nplementary therapies (please tick as many as needed)
	I self prescribed
	Internet
	Retail assistant
	Family or friends
	Medical doctor
	Complementary medicine practitioner such as a naturopath, herbalist or acupuncturist
	Health professional such as a nurse, chemist, psychologist, physiotherapist or other health provider
	Vitamin company hotline
	Magazines or books
	TV
Othe	er (please specify)
12.	What do you think are the advantages of CM's (please tick as many as needed)
	It's more natural
	Lack of side effects
	Safe
	Effective, it seems to work
	Lasting effects
	Holistic effects
	Not addictive
	Can complement existing health care
	Can't do any harm
	I can be responsible for my own health and well-being
	I have not tried, so not sure
Othe	er (please specify)

Polycystic ovary syndrome (PCOS), self help and complementary 13. What do you think are the main disadvantages of using CM's (please tick as many as needed) ☐ I don't think there are any Expensive ☐ Takes longer to work ☐ Lack of research on whether or not it works Lack of research on safety such as no warnings ☐ Not sure if it will work ■ Not enough information ☐ Taste or smell of preparations $\hfill \square$ Not confident to use in conjunction with other drugs $\hfill \square$ Not prescribed or recommended by my doctor ☐ Don't know Other (please specify) 14. Have you ever had a negative reaction or unwanted side-effects to any complementary medicine or therapies? Yes No (please go to question 17)

15. If you have experienced negative or unwanted side effects, to which complementary

me	dicines or therapies (please tick as many as needed)
	Vitamins such as multivitamins or vitamin C, not prescribed by a doctor
	Other natural medicines from fish, plants or animals
	Herbal teas for therapeutic reasons
	Mineral supplements not prescribed by a doctor
	Food supplements such as spirilina, barley greens etc
	Mineral supplements prescribed by a doctor
	Herbal medicines such as Vitex agnes castus (chaste tree), dong quai, Echinacea etc
	Other herbal medicines
	Traditional Chinese herbal tablets or teas
	Indigenous or other traditional medicines such as Ayevedic medicine
	Vitamins prescribed by a doctor
	Acupuncture
	Reflexology
	Kinesiology
	Iridology
	Massage or Bowen therapy
	Aromatherapy oils for therapeutic reasons
	Homoeopathy or homoeopathic medicines
Othe	or (please specify)

16. If yes, what was the nature of the negative or unwanted side-effects you experienced (please tick as many as needed)

	Temporary and I continued to use	Temporary, side-effects went after I stopped taking the CM	Unwanted side-effects continued afte I stopped taking the CM
Menstrual cycle lengthened	С	O	О
Menstrual cycle changed in a way I didn't want	O	C	0
Changes in bowel habits either looser or constipated	С	O	С
Headaches	O	0	O
Vomitting	O	О	O
Skin rashes	O	0	O
Sleep changes	0	0	O
Heart beating fast	0	0	O
Excessive sweating	0	0	O
An anaphylactic reaction	0	0	O
Other (please specify)			

Diet or food choices

ext we want to know if you have tried any diets to improve the symptoms of PCOS or to help with weight loss	or
neral well-being.	

gen	eral well-being.
17.	In the past 5 years have you used any diets to improve PCOS?
0	Yes
0	I eat a special diet but not specifically to manage or improve PCOS
0	I eat a healthy diet but not for any particular reason (please go to question 20)
0	No, I'm not interested in diets (please go to question 20)
18.	What was the purpose or reason for using the diet (tick as many as needed)
	To lose weight
	To improve body composition (eg build muscle mass)
	To improve health
	To address a health concern (such as high blood sugar, food allergy or high cholesterol)
	For social reasons, that is to enjoy with family or friends for example to encourage a family member to eat a particular diet
Othe	er (please specify)

Polycystic ovary syndrome (PCOS), self help and complementary 19. Have you tried any of the following diets (tick as many as needed) Low glycaemic (low GI) as in foods that lower blood sugar or glucose or lower insulin Low calorie Low fat Energy restricting diet A whole food diet Healthy eating plan such as the government endorsed lifescripts High protein Low carbohydrate CSIRO Weight Watchers Liver detox diet Palm Beach diet Blood group diet Anti-candida diet Lean cuisine Lite and Easy Protein powders Meal replacement Very low calorie diet Low allergy diet (gluten or dairy free for example) Other (please specify) 20. If you were or currently eat a special diet, for a particular reason, do you feel you achieve or achieved your goals? Yes Partly 0 No O Don't know

Polycystic ovary syndrome (PCOS), self help and complementary 21. Have you experienced weight loss or weight management (prevention of weight gain) as a result of making dietary changes? No but I have experienced positive changes other than weight loss No, no weight loss, no prevention of weight gain and no other positive changes Other (please specify)

	Sylidion	1e (PCC	DS), self	help an	d comple	ementa	ry
exercise or phys	sical activ	ity					
Next are some questio is movement that caus brisk walk, mowing the	es a slight incre	ease in you	r breathing ar	nd heart rate,	but you shou		
22. Do you partici _l	pate in mod	erate or	vigorous e	xercise or	physical a	activity?	
○ Yes							
C No (please go to quest	tion 30)						
23. How many day	/s per week	do you p	articipate	in exercis	e or physic	al activit	у
	more than once per day	every day	5-6 times per week	2-4 times per week	once per week	once or twice	I don't do this type of exercise
moderate activity (such as walking)	0	O	0	0	0	0	O
vigorous activity (such as aerobics, circuit training and running)	© d	0	O	O	0	O	0
would you underta			3				
 I don't do moderate ph About a quarter of an h About half an hour (30 About one hour (60 mi More than an hour Other (please specify) 	hour (15 minutes)						
About a quarter of an half an hour (30) About one hour (60 min) More than an hour	hour (15 minutes) o minutes) inutes) orous activi ur exercise ysical activity	• •	as aerobic	s, circuit	training an	nd running	j), for how
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Lift weights
Brisk walking up hills or stairs (where your breathing is heavy, panting and puffing)
Run
Group fitness classes at gym eg. spinn, zumba, pump
Swim
Yoga
Pilates
Personal trainer
Dance
Cycle
Team sports such as netball, hockey etc
Tennis (including table tennis)
ncidental exercise (as part of a busy lifestyle for example walking up stairs instead of taking the lift, parking the car a long way from lestination, gardening etc)
(please specify)
lestination, gardening etc)
(please specify) Why do you undertake these forms of physical activity (please tick as many as
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physical activity (please tick one) C Yes C Parily C No C Don't know Other (please specify) 29. If physical activity is an ongoing part of your lifestyle, do you expect to be exercising this time next year (please choose one) C yes C no C don't know 30. If you do not participate in moderate or vigorous activity, is there a particular reason (please tick as many as needed) Limited time Not done before Physical injury Feel self conscious or embarrassed No difference to my health No difference to my weight Increased my weight Trying to get pregnant I am pregnant Not convinced of the benefits Limited money Other (please specify)	40.	. Do you feel that you have achieved your he	alth goals with your exercise and
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 □ Not convinced of the benefits □ Limited money 		Trying to get pregnant	
☐ Limited money		I am pregnant	
		Not convinced of the benefits	
Other (please specify)		Limited money	
	Othe	ner (please specify)	

Describe yourself Finally some questions about you, to help us describe the women who have taken part in the survey. 31. Are you aged between 17 or less than 17 O 18 - 19 O 20-24 C 25-29 O 30-34 35-40 O 40-44 O 45+ 32. Did you finish high school O yes O no Still completing high school education 33. Have you completed any tertiary education O yes Currently completing tertiary education 34. If yes indicate if the qualification was (tick as many as needed) A qualification from TAFE or similar

Diploma

Australia

Other (please specify)

University degree

35. In which country were you born?

Polycystic ovary syndrome (PCOS), self help and complementary 36. Which of the following best describes your working activities (tick as many as required) ☐ Home duties ☐ Self employed ☐ Student ☐ Employed part-time ☐ Employed full-time Other (please specify) 37. Do you have private health insurance? O yes O no Thank you for your help. Please remember to click on the submit button at the bottom of this page.