

## Supplementary Box S1

### GPPCOS Questionnaire

Please read the information below carefully:

This questionnaire invites women with a diagnosis of polycystic ovarian syndrome (PCOS) to share their experiences of how their condition has been managed by their General Practitioner(s) (GP).

It is being conducted by the University of Warwick in partnership with Verity the UK PCOS charity and the fertility charities; fertility network and fertility friends. The findings will be used to raise awareness of PCOS and in particular, women's concerns so that these can be better supported in future. We will produce a report and publications from this research.

Taking part in the research is entirely voluntary.

The questionnaire involves several questions about how your PCOS was diagnosed and has been managed, and some questions requesting demographic information such as your age. We appreciate that you may have seen more than one GP about PCOS; unless specifically asked about the first or last GP you saw, the questions are about any of the GPs you have seen and your overall experience.

You do not have to answer any questions which you do not want to. All responses will be completely anonymous and confidential – you will not be asked to disclose your name or address.

Only the research team will have access to the data from this survey and the data will be held securely by the research team and used for the purposes detailed above.

The questionnaire has received ethical approval from the University of Warwick. If you have any questions about the questionnaire you can contact the research team [Lead Researcher: Dr Sarah Hillman, Warwick Primary Care, Medical School, University of Warwick Coventry CV4 7AL email [s.hillman@warwick.ac.uk](mailto:s.hillman@warwick.ac.uk)]

If the questionnaire raises any issues for you, you can seek independent advice or support from Verity, the online charity aimed at supporting women with PCOS <http://www.verity-pcos.org.uk/> or fertility network for support with fertility related issues <http://fertilitynetworkuk.org/>. Thank you for your participation. Through raising awareness of PCOS we can help women in the future.

To begin the survey, read the following statements, and check the appropriate boxes:

I have read and understood the information describing the aims and content of this survey and have been given enough information to help me decide to take part

I am 16 years or older

I understand that by completing this survey (submitting my answers electronically) I consent to take part in this research under the terms detailed above

1. Have you experienced any problems with your fertility?

- a. Yes
- b. No

If Yes, have you discussed this with you GP?

- a. Yes
- b. No

If Yes what happened and did you find this helpful? *free text box*

If No why do you think it hasn't been discussed? *Text box*

2. Did your GP ever discuss any health conditions that may be associated with PCOS?

- a. Yes
- b. no

If so what conditions? *Free text box*

3. Do you feel having PCOS has affected your mental health?

- a. Yes
- b. No

If yes could you please describe in what ways. *Free text box*

If yes was this something you ever discussed with your GP?

- a. Yes
- b. No

If you did discuss your mental health with your GP, what happened and did you find this helpful? *Free text box*

If no, why was that? *Free text box*

4. Do you think your GP(s) could have done anything more to help with your PCOS?

- a. Yes
- b. no

If yes what would you like them to have done? *Free text box*

5. Think about the last GP you saw about your PCOS did you feel

- a. Listened to? LIKERT scale
- b. Supported? LIKERT scale
- c. Confident in their explanation? LIKERT scale
- d. Confident in their management? LIKERT scale

6. Are you a member of any support networks that support womens with PCOS?

7. If yes which support networks?

8. a. What symptom of PCOS did you *first* present to your GP with and what age were you?

Acne

Irregular or no periods

Hair growth

Problems with weight

Problems getting pregnant

Diabetes

Other *free text box*

b. Age at first symptom

9. How old were you when you were given a diagnosis of PCOS?

*Free text box*

10. What was the time lag between first having symptoms and being given a diagnosis of PCOS?

a. Less than a week

b. Less than a month

c. 1-3 months

d. 3-6 months

e. 6-12 months

f. 1-3yrs

g. 3-5yrs

h. 5-10yrs

i. >10yrs

11. Who first suggested you may have PCOS?

a. Me

b. GP

c. Friend

d. relative

e. specialist

f. other (free text box)

12. Was weight reduction ever explored as a treatment option for PCOS by your GP(s)

a. Yes

b. No

If Yes what options were discussed?

a. Dietary advice

b. Exercise

c. Subscription to weight watchers /slimming world

d. metformin

e. orlistat

f. gastric surgery band/sleeve

g. other [free text box]

h.

Demographics: Age, Ethnicity, Most recent weight, Height, Region of UK:

Finally, would you be willing to participate in either an informal interview about how your PCOS has been managed in general practice to help us understand more about your experience and views. Please e-mail me [s.hillman@warwick.ac.uk](mailto:s.hillman@warwick.ac.uk) if you would be happy to take part.

## Supplementary Box S2

### **GP-PCOS semi structured interview Schedule**

Thank you for agreeing to speak to me about your experiences of having PCOS. I am particularly interested to hear of the experiences you have had with your general practitioner.

**How old were you when you first went to see your GP with a symptom or problem that was subsequently linked to having PCOS?**

**Tell me about that first appointment**

What symptoms did you first present with?

**What happened subsequently?**

Did you have any tests or investigations?

How long did it take before you had a diagnosis?

Who first suggested the diagnosis?

Was any medication considered or started?

**How was the diagnosis first explained to you?**

What information, if any, were you given?

**How did you feel?**

**What else have you done to gain support or discover information about PCOS?**

Did you join any support groups?

**If you told friends and family what was their reaction?**

Were they supportive?

**Was weight loss ever advised?**

If you have tried to lose weight what is your experience?

Was any help or medication suggested?

**Were any other health conditions discussed that you maybe at increased risk of because of PCOS?**

How about diabetes? Do you have any monitoring for diabetes?

How about regular bleeds/periods? What is the longest you have gone without a period/bleed?

**Do you think that PCOS has affected your mental health?**

In what way?

Did you discuss this with your GP?

What support/medication was offered if any?

**Have you had any problems with trying to become pregnant, and have you discussed this with your GP?**

How helpful was this?

**How do you think can we best educate doctors, patients and family and friends on PCOS?**

How do you feel about online support groups/charities?

Do you think it's helpful when celebrities come forward as having the condition?

**What more could your GP have done or be doing to help you?**

**Finally, what does PCOS mean to you?**

Do you think it would help if the condition had a different name?

Is there anything further that you would like to add?

### Supplementary table S3

Analysis of demographics and response to binary outcome questions within survey.

*p value is significant	Ethnicity	Area of UK	Age first had symptoms	Lag time between first symptoms and diagnosis	Years since diagnosis
Did you discuss your fertility with your GP?	0.038*	0.586	0.442	0.372	0.527
Did you discuss associated health condition with your GP?	0.233	0.445	0.320	0.406	0.24
Does having PCOS affect your mental health?	0.119	0.916	0.632	0.75	0.532
Did you discuss your mental health with your GP?	0.021* ^OR 1.66; 95% CI 1.04-2.63	0.977	0.011* ^OR 0.64; 95%CI 0.41-0.98	0.132	0.168
Could you GP have done more to help?	0.733	0.869	0.063	0.305	0.458

\*Bivariate analysis was significant

^Logistic regression was performed.