

iAsk: A Question Prompt List for PCOS

Background and Rationale

Polycystic Ovary Syndrome (PCOS) is the most common hormone condition affecting women of reproductive age in Australia (9-18%)^{1,2}. Many women have unmet information needs at the time of PCOS diagnosis³. These may have negative impacts on self-management and the ability to improve lifestyle, and on risk perception and participation in regular screening for metabolic complications. These are crucial areas of care to optimise as lifestyle management is the first-line therapy for PCOS⁴ and metabolic complications may be under-appreciated⁵.

Previous research has confirmed that women want to know more about the full range of PCOS features⁶. General practitioners (GPs) are women's initial source of information about PCOS⁷ but women mainly seek PCOS information from specialists and the internet⁶⁻⁸, and perceive that the quality of available PCOS information varies^{6,8,9}.

One way to facilitate provision of consumer information is to use a Question Prompt List (QPL). A QPL is a structured list of questions for consumers to ask health professionals¹⁰. It is designed to encourage consumer participation during health care appointments and to help consumers obtain information relevant to their needs and at their own pace¹⁰. These communication aids have been shown to significantly increase question-asking and consumer satisfaction, and to notably decrease consumer anxiety before and after the appointment¹¹. There is currently no QPL for PCOS but the importance of providing good quality information is suggested by positive associations between enhanced knowledge of PCOS and increased engagement with lifestyle management¹² and between receiving better quality information about PCOS and quality of life⁸.

Aim

To design and pilot a PCOS Question Prompt List to improve consumer-health professional communication and provision of evidence-based PCOS information.

Methods

The target population for this study is women who have already been diagnosed with PCOS.

Phase 1: A survey containing open-ended questions will be distributed to women with PCOS recruited from a range of sources (support groups, women's health websites, general websites, universities, gyms, medical centres) to identify themes (such as menstrual cycles, hair and skin, fertility, weight, mood, long-term health and PCOS management) or questions for inclusion in the QPL. Responses from at least 100 women in different locations and states/territories in Australia will be sought. The project team is very experienced in conducting survey-based PCOS research and consider this recruitment target feasible. A list of possible questions will be compiled based on these data. This list will be the subject of a second online survey (with the same respondents as the first round) to prioritise the key questions to include in the draft QPL.

Phase 2: The draft QPL will then be assessed using focus groups of consumers (3 groups of 4-8) addressing appearance, length, format, readability, legibility, literacy level of the QPL. Linguistic validation will also be conducted with each participant explaining what each question means to them in their own words. One focus group will be conducted specifically with Aboriginal and Torres Strait Islander women to ensure that the QPL is appropriate for this group of women.

Phase 3: The QPL will be piloted in one GP setting and one specialist setting (endocrinology) in Melbourne, Victoria, over a 3-month period. The project team has established relationships that make these settings feasible. All women attending for PCOS care will be invited to participate. Participants will be provided with the QPL immediately before their appointment (with time to identify which questions they would like to cover) and then will be asked to complete a questionnaire following their appointment investigating (i) consumer satisfaction, (ii) acceptability, (iii) knowledge, (iv) what questions they wanted to ask but did not and why, and (v) what questions they asked and why. The health provider will also be surveyed regarding their (i) perception of the QPL and its (ii) impact on the consultation (time and quality). This will inform further refinement of the tool.

Significance

This research project has direct relevance to translating evidence into practice and strong potential for clinical impact. It is expected that this tool will improve health literacy and engagement in self-management, and empower women to participate more actively in their health care. It will also deliver clinical impact by assisting health professionals to provide care consistent with the PCOS evidence-based guideline. Very few QPLs have been developed outside palliative care and oncology, so the learnings from this project will inform other QPLs for women's health and chronic disease management.

Expected outcomes

The publication plan for this project is to prepare an abstract for a national or international conference and to submit a manuscript for publication in a journal. Both primary care and endocrinology conferences/journals are options and final choice will be determined by the project findings.

The translation plan is to make the QPL freely available for download from a variety of health professional and consumer websites. We also intend on making the QPL freely available as an app for both Android and Apple users as well (pending funding). Other associated translation activities will be to develop a FAQ list for health professionals to accompany the QPL, better equipping health professionals to provide evidence-based consumer information.

The longer term research plan is to expand to community health centres and further specialist clinics (gynaecology) and then to assess the effectiveness of the QPL app (impact on self-efficacy, mood and quality of life) in a randomised-controlled trial (pending funding).

Alignment with the CRE New Knowledge Program research activities

1. Improving PCOS diagnosis: A QPL can be included in a suite of resources provided to women at the time of diagnosis to better prepare her for subsequent appointments.
2. Emotional wellbeing in women with PCOS: A QPL has the potential to reduce anxiety and to increase health care satisfaction, engagement with lifestyle management and quality of life.
3. Transfer of research into health policy and practice: Health professional information based on the national evidence-based guideline will be provided to better equip health professionals to deliver evidence-based consumer information in response to QPL questions.
4. Develop the health and medical research workforce: A QPL may assist health professionals to provide evidence-based care.

Budget (prepared using the Monash University project costing model)

1. Research Assistant salary (0.3FTE for 6 months, HEW Level 5, to conduct focus groups/interviews, project administration, data entry and assistance with qualitative data analysis): **\$12,000**
 2. Transcription of focus groups/interviews: **\$2,000**
 3. Focus group/interview costs (venue hire, catering, participant transport): **\$500**
 4. Administration costs (study recruitment, printing): **\$500**
- Total: \$15,000**

References

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