iAsk: Developing effective electronic platforms for women with PCOS and health care providers

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 remain undiagnosed or take significant time to diagnosis and often have unmet information needs at the time of PCOS diagnosis[3]. The delay to diagnosis and lack of evidence-based information can affect knowledge of the associated complications of PCOS and appropriate self-management. This can lead to lack of engagement in healthy lifestyle management and participation in regular screening for metabolic complications.

Women are seeking information through increasing arrays of electronic platforms. According to the Pew Research Internet Project, in the USA in 2013: half of smartphone owners have used their phone to look up health information and one in 5 have downloaded a health app; 59% of US adults have looked for health information online; and 7 in 10 adults track a health indicator for themselves or a loved one and report it has changed their approach to health[4]. Women also seek information on PCOS on the internet and the quality and helpfulness of information varies. Sometimes the information found is just what was needed. Other searches end in frustration or retrieval of inaccurate, even dangerous, information[5]. Facilitating access to evidence-based information about diagnosis and management of PCOS for health care providers and consumers is vital and there is exciting potential for undertaking health interventions through these platforms.

Aim

To use a rigorous methodological framework to identify and evaluate websites and apps for women and health care providers on PCOS diagnosis and management.

Objectives

To identify gaps in the provision of readily available evidence-based, user-friendly information in apps and websites to health care providers and women on PCOS.

Methods
1. An internet search for PCOS or Polycystic Ovary Syndrome on
- apps for women and health care providers on the apple and android platforms
- four of the major internet search engines including google, BING, yahoo and Ask.com will be searched to find websites for women and health care providers on PCOS. The top 20 most commonly identified and highest ranked web pages will then be evaluated further. This is based on data that reports that 90% of people do not go past page 1 of search results and over 50% do not go past the first three results on page 1.

2. Evaluation of the identified websites and apps will be undertaken by two reviewers following previously tested, pre-defined criteria (Appendix1)[7,8] that assess
- Technical criteria (general domain independent criteria such as transparency)
- Design
- Readability
- Accuracy
- Completeness/comprehensiveness

3. Development of a survey for women and health care providers about common apps and websites used and what their needs are. This will then be administered as part of a larger future grant (see below).

4. Development and evaluation of an app and linked website providing evidence-based information at a later phase of the project and will be the subject of planned NHMRC funding proposals.

Significance and Alignment with the CRE New Knowledge Program

This project will **improve clinical care** through easily accessible evidence-based information on diagnosis and management on electronic platforms for health care providers and women with PCOS. It will therefore facilitate **research transfer into practice** providing guidance for health care providers and improving health literacy for women with the potential to therefore raise awareness and **improve diagnosis** and management. It is also **building collaborations** between research groups skilled in ehealth, mhealth (Deakin University), clinical sciences and implementation (Monash University).

Translation and dissemination

Translation and dissemination plans will include a manuscript for submission in a peer reviewed journal and abstract submission for presentation at a national or international conference. The app and website ultimately developed will be freely available on both Apple and Android platforms.

Budget (prepared using the Monash University project costing model)

1. Research Assistant salary (0.3FTE for 3.5 months, HEW Level 5, to conduct internet search and assist with app and website evaluation, project administration and data entry): **$7,300**

2. Administration costs (printing): **$200**

Total: $7,500

References

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Appendix 1.0 Criteria to assess websites and Apps[1]

Website/App					
URL					
Date accessed					
Type C-commercial, NFP-not for profit, G-Government, MS- medical society, S-support group					
Authorship Yes/no					
Author's qualifications A=academic B=biomedical C=commercial N=news D=doctors P=patients/ consumers U=unidentified					
Ownership/credentials Yes/no					
sources of information identified Yes/no					
disclosure of sponsorship Yes/no					
disclosure of advertising Yes/no					
statement of purpose Yes/no					
Audience c-consumer HP- health professional					
General disclosures Yes/no					
currency/ date of creation					
date of last update provided					

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[1] Soot et al 1999

credentials of physicians					
interactivity yes/no					
navigability 1-5					
internal search engine yes/no					
links provided yes/no					
balance- controversial statements supported by data yes/no					
references provided yes/no					
language					
hierarchy of evidence clear yes/no					
writing style appropriate yes/no					
Glossary Yes/no					
illustrations yes/no					
info on RX yes/no					
audio versions yes/no					
audio versions					
culturally appropriate yes/no					
readability score					
Soot score/ completeness					
contact details provided					
disclaimer					
Independence sponsors/funders					
copyright					
Editorial review process					
HON approved					