

DIAGNOSIS AND SUPPORT NEEDS OF INDIVIDUALS LIVING WITH POLYCYSTIC OVARY SYNDROME (PCOS)

Author/PI: Sharon Manship (MA, MSc) / Email: S.Manship@kent.ac.uk / RA: Kate Day (MSc, GMBPsS)
Centre for Health Services Studies, University of Kent

Introduction

- Women make up 51% of the population, yet historically their health has not been a priority (1)
- Historically, the health and care system uses a 'male as default' approach, leading to gaps in the data and evidence base, meaning that not enough is known about conditions that only affect women (2)
- The Women's Health Strategy for England was implemented in 2022 -> 10-year ambitions and actions to improve the health and wellbeing of women and girls (2)
- **PCOS** is the most common endocrine disorder affecting between 8% and 13% of individuals assigned female at birth, yet up to 70% still remain undiagnosed (3). The condition has broad manifestations requiring personalised diagnosis and treatment (4) and a wide range of associated symptoms and comorbidities



Study Aims and Design

- **Research Question:** What are the diagnosis experiences of individuals living with PCOS in Kent, Surrey and Sussex and what support is needed in relation to post-diagnosis care and pathways?
- **Aims:** Understand the current evidence regarding experiences of PCOS diagnosis and care pathways, both globally and in the UK; Explore the experiences of individuals living with PCOS in Kent, Surrey and Sussex in relation to diagnosis and post-diagnosis care pathways; Co-develop recommendations and implementation plan for those involved in the care of individuals with PCOS
- **Methods:** Scoping review of the literature, semi-structured one-to-one interviews with individuals with PCOS (n=12)

Findings - scoping review

- 15 peer reviewed journal articles/1 PhD thesis included
- Positive and negative experiences
- Range of unmet support needs
- HCP approach is key to patient experience, requiring communication, compassion, knowledge, holistic, person-centred and culturally sensitive approach
- Mental health screening recommended on diagnosis
- Ongoing professional education and training required
- Care & information resources should be accessible and underpinned by best practice guidelines
- Lack of referrals to specialist allied health professionals and support groups
- Further research needed regarding lived experiences

Preliminary Findings - interviews

- n=12 (Kent n=4, Surrey n=4, Sussex n=4), mean age 33
- Interview data broadly echoes literature
- Negative experiences of care - delayed diagnoses, lack of knowledge/compassion of GPs/HCPs, repeated and short appointments
- Lack of symptom management guidance from experts
- Impact on mental health exacerbated
- A need for PCOS specialists

For the gynaecologist...I think it was at least six months and then when I went he said "Well, you're not overweight so what is the problem?". I explained the problem and then he said that I should come back if I wanted to get pregnant and I couldn't get pregnant, but that that they wouldn't do anything in the meantime"
Surrey participant

They referred me back the GP, who Googled PCOS in front of me and just told me to lose weight. And I've also had an eating disorder before, so telling me to lose weight was...I was a bit like please don't
Kent participant

Next Steps

- Finish data analysis
- Work with Expert Advisory Group (PPI) to develop recommendations for a resource to support those living with/caring for individuals with PCOS - to raise awareness and improve diagnosis and support experiences
- Disseminate findings for further impact:
 - Inform future service provision and care pathways for PCOS
 - Plan follow-up study

1. Cleghorn E. Unwell women: A Journey Through Medicine and Myth in a Man-made World. Weidenfeld & Nicolson; 2022.
2. DHSC. Women's Health Strategy for England [Internet]. Available from: <https://www.gov.uk/government/publications/womens-health-strategy-for-england-2022>
3. WHO. Polycystic ovary syndrome: Key facts. [Internet]. Available from: <https://www.who.int/news-room/fact-sheets/detail/polycystic-ovary-syndrome>; 2023
4. Sharma S, Mahajan N. Polycystic ovarian syndrome and menopause in forty plus women. Journal of Mid-life Health. 2021 Jan 1;12(1):3-7

