**PCOS Vitality submission of evidence for the Women’s Health Strategy**

PCOS Vitality is a non-profitable organisation (awaiting charitable status) which supports women and people with PCOS in the UK & Ireland. We welcome the current call for evidence to help women’s voices be included in improving the health and wellbeing of women and girls. We agree there is a need for greater focus on women’s health. Below are points that we feel need to be addressed particularly in relation to PCOS.

**1.Women’s voices** – In our experience, people with PCOS often go undiagnosed, experience delays in diagnosis and are dissatisfied with their care. Often there are delays in getting appointments with Gynaecologists. There is a lack of support for these women especially in relation to the psychological effects of the condition (anxiety & depression & eating disorders). There are currently no treatments (only drugs prescribed off-licence) and there is no Management Plan or care pathway at present[1]. There is also lack of treatment for symptoms of PCOS ie. hirsutism (need for hair removal ie. Laser) and obesity treatments and bariatric surgery for Obesity which puts women at increased risk of cardiovascular disease[2] There is a need to address weight stigma in the treatment of women with PCOS as this leads to poorer health outcomes and a disengagement with healthcare[3]. PCOS is shrouded in stigma because of a lack of openness for discussions of menstruation in general[4] We believe there is a gender bias in healthcare in relation to PCOS and because of this it has traditionally been regarded solely as a reproductive disorder and so has been neglected which has resulted in the lack of treatments & support[1].

**2.Information & education on women’s health** There are International Guidelines that were published in 2018 and these are not being followed[5]. They are the best evidence we have to date regarding PCOS. GPs and other healthcare professionals need training in PCOS. PCOS also needs to be included on the National Curriculum. There needs to be a life-course approach to PCOS too to enable proactive healthcare as oppose to reactive as there is an opportunity to prevent serious health problems in later life such as Type 2 Diabetes, Cardiovascular Disease and Womb Cancer[6]

**3.** **Lifelong –** PCOS is not limited to reproductive age as it is in fact a metabolic endocrine disorder which is linked to 2 Diabetes, Cardiovascular Disease, Anxiety, Depression, Womb Cancer, Obstructive Sleep Apnoea, Non-alcoholic Fatty Liver Disease[7]. It is now well established that Menstrual Health is a vital sign for general health in later life. Menopause has an additional adverse effect on aging especially with relation to cardiovascular risk, which has the highest mortality in women[8].There is also a need to consider the transgenerational impact of PCOS as research is emerging of a potential link to ADHD and Autism[9].

**4 Women’s health in the workplace** – There needs to be consideration for paid leave in terms of attending doctor’s or specialist appointments including for IVF or other fertility treatments. There is also a need for awareness of the increased rates of miscarriage in those with PCOS so there may be a need for consideration at least at the discretion of employers for additional bereavement leave[10].

**5**. **Research evidence & data** - We also need more research on PCOS in post reproductive life[6]. Also, Ethnic Minorities, LGBTQIA and pregnant women are often underrepresented in research[11][12][13].

**6. impacts of COVID-19 on women’s health** – Some evidence suggests an increased risk for those with PCOS so further research is needed that can provide evidence-based advice to those with PCOS[14]. There are also concerns about Covid-19 and vaccination effects on pregnancy and fertility which couples need support with[15]

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