

**Written evidence submitted by Professor Wiebke Arlt and
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***A Case for PolyCystic Ovary Syndrome (PCOS) to be included within the Body Image
Narrative***

Short Summary

Professors Wiebke Arlt and Shakila Thangaratinam alongside colleagues from the Institute of Metabolism & Systems Research (IMSR) and charity partners Cysters and PCOS Vitality, present evidence on why PolyCystic Ovary Syndrome (PCOS) – a lifelong metabolic condition, often dismissed as a ‘reproductive disorder’ – should be considered within the body image narrative.

PCOS is a common condition which affects at least 1 in 10 women in the UK, disproportionately affecting women from Black, Asian and Minority Ethnic (BAME) backgrounds. Physically ‘obvious’ symptoms include weight gain, hair loss on the head, hirsutism (excess hair growth typically on the face, chest, back and buttocks) and acne – all features likely to impact body image in women. Other common, but less publicly ‘overt’ features include infertility and irregular periods, which can also privately compound the way a woman feels about her body. Indeed, PCOS is one of the most common causes of infertility in women. Furthermore, PCOS is correlated with low self-esteem and psychological distress – with evidence from community-led charities suggesting stigma and cultural factors also play a role e.g. hirsutism concerns in women of Sikh religion where hair removal is religiously forbidden for Amritdhari Sikhs.

PCOS goes beyond ‘looks’ and even fertility – it is a lifelong *metabolic* condition linked to other serious health conditions including heart disease, type 2 diabetes and fatty liver disease, amongst others. Professor Arlt’s research seeks to understand these links more clearly through investigating the risks associated with androgen (“male” hormone) excess – a common feature of PCOS^[1]. Our intention with this submission is therefore to bring to the Committee’s attention a common medical disorder, PCOS, which can impact women’s body image.

PCOS is also a condition often dismissed or misunderstood – partly due to a misleading name which suggests a primarily reproductive condition. Given its prevalence, we would urge the Committee to consider how PCOS can become a greater part of the discussion on body image in women, so that awareness of the condition and its health consequences can be raised amongst women themselves as well as their support networks (family, friends, communities etc.). We believe this is an important first step in reducing the longer-term metabolic health implications associated with PCOS, whilst also reducing societal stigma and body-shaming, building greater empathy for those living with the condition.

We are particularly keen to ensure that the medical causes of ‘obvious’ physical symptoms such as acne or hirsutism are explained more transparently within health campaigns or beauty industry advertising, so that alternate explanations (e.g. bad hygiene, self-control or habits) can be myth-busted where appropriate. Advertisers should be encouraged to take a responsible approach when targeting products aimed at alleviating ‘non-desirable’ features – through referencing where these features could also be symptomatic of the underlying metabolic health condition PCOS. This should encourage more women, including BAME women, to come forward to discuss possible desired solutions to symptoms in *medical* settings e.g. by seeing their GPs as the first point of contact. Indeed, earlier diagnosis, education and support present clear opportunities for

improving the experience of women with PCOS[2]. This could potentially facilitate earlier lifestyle and medical interventions, which may subsequently reduce the risk of other health conditions developing later in life. Furthermore, interventions could also play a role in alleviating transgenerational effects of PCOS – new research is currently underway in this area. We hope earlier interventions may also go some way to reducing health inequity for BAME women, who are more likely to have PCOS.

We would welcome the opportunity to discuss our research and clinical experience working with PCOS women further with the Committee, alongside lived experience perspectives from partner charities Cysters, PCOS Vitality and others. Longer-term we hope that a more appropriate name for PCOS can be introduced to underscore the *metabolic* nature of the condition, linking male hormone (androgen) excess to the risk of type 2 diabetes and fatty liver disease. A suitable solution could be the term Female AndroMetabolic Syndrome (FAME) to help further reduce body image, guilt and stigma associated with PCOS and work to consult with affected women is currently under way.

Introduction to the Institute of Metabolism & Systems Research (IMSR)

The **Institute of Metabolism & Systems Research (IMSR)** is a major research institute based within the College of Medical and Dental Sciences at the University of Birmingham. The IMSR conducts world-leading research in metabolism, endocrinology and reproduction, using cutting edge technologies and approaches to understand metabolic, hormonal and reproductive process, with the ultimate goal of positively impacting lives and healthcare provision.

Introduction to the Signatories

Professor Wiebke Arlt is the William Withering Chair of Medicine and Director of the IMSR, providing strategic leadership across the institute's research portfolio, which consists of over 150 researchers. Wiebke also directly leads her own large, multi-disciplinary research group investigating the regulation and role of steroid metabolism and action in health and disease. As an Honorary Consultant Endocrinologist, Wiebke leads specialist services for patients with adrenal and gonadal disorders at the Queen Elizabeth Hospital Birmingham. Wiebke has published over 200 original research articles and her scientific work has attracted several major national and international prizes. In 2010 she was elected Fellow of the UK Academy of Medical Sciences.

Wiebke leads on the Wellcome Trust funded project 'Dissecting Androgen excess and metabolic dysfunction – an Integrated Systems approach to PolyCystic Ovary Sndrome (DAISy-PCOS). DAISy-PCOS is further supported by the involvement of **Dr Punith Kempegowda** – a Wellcome Trust Clinical Research Fellow for the DAISy-PCOS project and a Specialist Registrar in endocrinology, diabetes and general internal medicine. In addition, IMSR's Community and Public Engagement Manager, **Dr Caroline Gillett**, supports Wiebke in delivery of the DAISy-PCOS public engagement initiative, aimed at raising awareness of PCOS as a lifelong metabolic condition.

Mrs Shakila Thangaratnam is the Professor of Maternal and Perinatal Health as well as the Joint Director of the WHO Collaborating Centre for Global Women's Health, a centre of excellence located within the IMSR. As a Consultant obstetrician and gynaecologist, she is involved in the care of high-risk mothers at Birmingham Women's and Children's NHS Foundation Trust. Her work focuses on prediction, prevention and treatment of complications

in mothers with a range of conditions including pre-eclampsia, epilepsy, diabetes and obesity. She has extensive experience supporting women with PCOS through infertility concerns, gestational diabetes and pregnancy.

Maureen Busby is the founder and CEO of **PCOS Vitality**. PCOS Vitality was founded as a non-profit association in 2018 and aims to raise awareness of PCOS and support those with the condition, through social media and through collaboration with other women's health organisations and healthcare professionals. Maureen is a MSc Health Psychology graduate and member of the British Psychological Society. She is also a member of the Royal College of Obstetricians and Gynaecologists (RCOG) Women's Voices Panel, the Patient and Client Council in Northern Ireland and the NI Association for the Study of Obesity Network. She has carried out research in PCOS & Menopause and presented her findings at the British Psychological Society NI Branch Annual Conference in Belfast in April, 2019. She is a published author and is certified in Menopause (Symptoms Remedies).

Neelam Heera the founder of **Cysters**. Cysters was founded to tackle the health inequalities faced by marginalised groups, people of colour and those living under the poverty line. Issues around reproductive wellbeing are often trivialised or sexualised within these communities due to socio-economic background, lack of access to health care and cultural stigma. Cysters works with these groups of individuals to ensure equal access for all through education so that patients can make empowering decision on their healthcare. The work they do in the community challenges the narrative around womens reproductive health. Neelam is a Non-Executive Director for Healthwatch Birmingham, supporting the organisation to remain inclusion and work with grassroots communities, a Member of the RCOG Women's Voices Panel and most recently has joined a Panel on lived experience of obesity for the Obesity Health Alliance and hopes to use this to highlight BAME experiences.

Our collective professional and personal experience in research and clinical support, grassroots advocacy and engagement with women who have PCOS is what we wish to draw to the attention of the Committee as part of this inquiry into body image. In particular, we will provide evidence on why PCOS should be included within the narrative of body image and why this is particularly relevant to the experience of body image in BAME communities.

Introduction to PolyCystic Ovary Syndrome – a lifelong metabolic condition
PCOS is a common health condition which affects between 8-13% of women worldwide^{[3]:[4]} and at least 1 in 10 women in the UK^[5]. It affects how a woman's ovaries function and it is one of the most common reasons for infertility in women^[6].

To be diagnosed with PCOS at least 2 of the following features must be present^[7]:

- Irregular periods – ovulation is disrupted, which means the release of an egg that can be fertilised does not occur monthly, but infrequently or not at all
- Excess androgen – “male” hormone levels are high
- Polycystic ovaries – ultrasound visualises small fluid-filled sacs in the ovary which are ovarian follicles failing to release an egg during the monthly cycle

The name PCOS is misleading. Firstly, because the ovaries in PCOS are not actually filled with ‘cysts’ and secondly, because the ovary reference is suggestive of a condition which is largely reproductive in nature. Whilst PCOS is one of the leading causes of infertility in

women, it is in fact a lifelong *metabolic* condition – not purely a reproductive one. This is important to understand because it has ramifications which go far and beyond fertility.

Research has already shown links between PCOS and obesity, cardiovascular disease, diabetes during pregnancy (= gestational diabetes), type 2 diabetes, Non-alcoholic Fatty Liver Disease and more[[8](#)][[9](#)][[10](#)][[11](#)][[12](#)]. Professor Arlt's current research focuses on identifying 'biological markers' that could indicate women with PCOS who are at a higher risk of developing these metabolic problems. As PCOS is typically diagnosed in late adolescence and early adulthood; effective diagnosis and management interventions *early on* may provide an excellent opportunity to minimize the risk of developing these metabolic health conditions that usually manifest later in life. The collective health, economic and societal impacts of these health conditions is profound, with NHS healthcare provision particularly impacted, alongside quality of life and mental health – making addressing these challenges a major healthcare priority. PCOS may therefore serve as a 'precursor' that allows for proactive targeted interventions to prevent heart disease, liver disease and cancers.

Moreover, there is emerging evidence to suggest that there may also be transgenerational benefits to be had if interventions are used to help those with PCOS. For example, a recent study in *Nature Medicine* showed daughters of women with PCOS are five times more likely to develop the condition compared to those born to women without PCOS[[13](#)]. The same study identified possible candidate genes for the prediction of PCOS in future generations. Therefore, evidence-based interventions in PCOS management might improve broader healthcare in the future both for individuals and future generations.

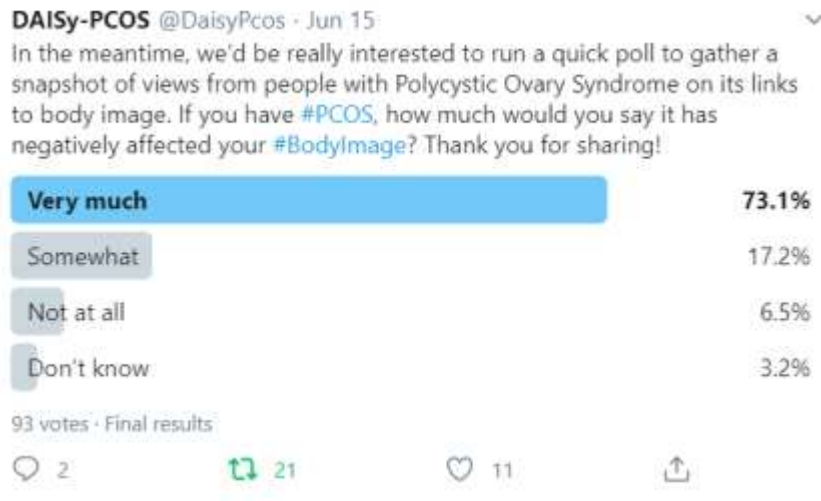
Linking PCOS to Body Image

The symptoms of PCOS typically manifest during adolescence or early adulthood, this means during the late teens or in women's early twenties[[3](#)]. Signs and symptoms can include:

- Irregular or no periods at all
- Difficulty getting pregnant
- Excessive hair growth (hirsutism) – usually on the face, chest, back or buttocks
- Weight gain
- Thinning hair and hair loss from the head
- Oily skin or acne

Many of these signs are understandably likely to cause distress and body image concerns in some women. The symptoms of PCOS can be both overt (e.g. hair loss) and private in nature (e.g. difficulty conceiving), but either way these symptoms can be upsetting for women and impact the way they feel about their body image and confidence.

As part of preparing this document, we ran a short Twitter poll to provide a snapshot of views on the topic. We asked: "If you have #PCOS, how much would you say it has negatively affected your #BodyImage?"[[14](#)].



We received 93 responses with 73.1% indicating “Very much”, 17.2% indicating “Somewhat”, 6.5% indicating “Not at all” and 3.2% indicating “Don’t Know”. Thus, at least 90.3% of those that took part in the poll indicated PCOS did have a negative effect on aspects of their body image. PCOS therefore presents a relevant and often overlooked factor within the existing body image narrative – one which should be given greater visibility and discussion.

Beyond body image, the longer-term emotional well-being of those with PCOS needs to be recognised to prevent mental health problems. Emotional wellbeing and mental health are impaired in women with PCOS, who suffer from higher rates of depression and anxiety^{[15][16]}. Women with PCOS are more likely to have low self-esteem, psychological distress and eating disorders^{[17][18]}.

Self-esteem develops in the context of socio-cultural factors and attitudes towards the body may vary due to cultural issues. For example, some Sikh women with PCOS may feel torn between seeking treatment for hirsutism and their beliefs which forbid hair removal. Body dissatisfaction is also higher in women with PCOS and this has been shown to predict the development of depression and eating disorders^{[19][20]}. Recent research on body image in PCOS suggests that body image distress is linked to the increased rates of anxiety and depression in women with PCOS and that therapeutic interventions targeted at improving body image may decrease depressive and anxiety symptoms^[21].

PCOS and BAME Communities:

The effects of PCOS are further compounded by race. PCOS may have a higher incidence in women from Black, Asian and Minority Ethnic (BAME) backgrounds as these groups are often more prone to metabolic problems and there is recognition that ethnic origin can significantly contribute to differing manifestations of PCOS, to the extent that it has been suggested that ethnically appropriate thresholds are required for metabolic screening in high-risk groups^[22]. For example South Asians in particular have higher prevalence of metabolic syndrome and are at risk for type 2 diabetes^[23], whereas women of African descent are prone to hypertension and cardiovascular disease^[24].

Therefore, PCOS could be a relatively ‘hidden’ and yet significant contributor towards body image concerns in up to 10% of women overall. Moreover, if there are higher rates of body image dissatisfaction in BAME women, this could be at least partly explained through potentially higher rates of PCOS within such communities. We suggest this is a possibility that deserves more detailed exploration in collaboration and consultation with

BAME women. Ethnicity may also be intertwined with aspects of culture, tradition or beliefs – which may also play role in how PCOS is perceived or managed.

PCOS, Culture and Stigma

Through our clinical work with PCOS patients and our involvement work with charity partners, such as Cysters and PCOS Vitality, we have also come to further understand the links between PCOS and mental health. Furthermore, cultural barriers and taboos as well as stigma associated with PCOS symptoms have also been highlighted to us. Some examples of this include, but are not limited to, the following:

- Cultural and societal pressures on women who may be suffering infertility problems to have children and/or to have children ‘naturally’ (as opposed to through assisted reproduction measures such as in vitro fertilization (IVF) or medication support)
- Tension between societal ‘norms’ and cultural beliefs
e.g. some Sikh Amritdhari women feeling torn between seeking treatment for hirsutism and their beliefs which forbid hair removal
- Language barriers which may prevent women whose first language may not be English from presenting to GPs or other community healthcare settings
- Beliefs around PCOS being a sexual function disorder and/or a sexually transmitted disease – creating a taboo around discussion of the condition and dissuading women from seeking healthcare
- Weight stigma (women with PCOS have a higher rate of obesity)

Existing scientific research on the impact of PCOS on body image is still limited. However, our lived experience partner charities would be well placed to provide further illustrations of stigmas, societal and cultural issues related to PCOS and how these impact on body image.

There may well be merit in developing a basic level of schools-based education on PCOS, to raise awareness of the medical nature of the condition in a way that does not single girls with PCOS out during a critical period of adolescence (particularly BAME girls). This would also provide an opportunity to educate male adolescents on PCOS, hopefully reducing stigma and increasing empathy and understanding for those with PCOS longer-term.

We should also be mindful of the need to recognise gender diversity within PCOS, as transmen (born female) and their health needs should be recognised. Transmen with PCOS may experience unique pressures and stigma impacting on their mental health and body image – something which should be explored further as PCOS narratives develop within the body image conversation.

PCOS Public Engagement

We consider public engagement on PCOS to be critical, as there is relatively limited awareness despite the high prevalence of the condition, its symptoms and its links to other significant health conditions. Lack of visibility and public dialogue around the condition:

- Affects the number of women who present within medical settings – reducing opportunities for earlier interventions which could positively impact quality of life and later cases of other linked health conditions. Collectively, these health conditions also pose significant demand on NHS resources.
- Enables societal / cultural stigmas and misinformation associated with the symptoms of PCOS to persist – which undoubtedly can impact on body image

in women with PCOS. Instead we should seek to challenge unhelpful attitudes and build empathy for those with PCOS

- Entrenches health inequity for women and particularly BAME women, who have higher rates of health inequality due to language barriers, socioeconomic factors etc.
- Allows advertisers to (unknowingly) compound body image concerns in women with PCOS (which affects up to 1 in 10 women in the UK) and to continue to offer ‘solutions’ to alleviate ‘non-desirable’ features which may be the first symptomatic presentations of PCOS. Instead we propose advertisers be encouraged to refer to how such features (e.g. acne, hair loss etc.) could also be symptomatic of health condition PCOS so that women are better able to decision-make, including seeking medical advice if desired
- Ignores the role PCOS plays in creating diverse bodies, which can (unknowingly) allow public health campaigns centred on “healthier” weights to create or worsen unhelpful weight stigma

Professor Wiebke Arlt is currently funded through the Wellcome Trust to deliver public engagement linked to her DAISy-PCOS research. Wiebke and colleagues would welcome the prospect of discussing with the Committee further opportunities to raise awareness of PCOS – its causes, symptoms and impacts on body image which are often reported by patients during clinical appointments. Collectively, we are interested in raising awareness of the lifelong metabolic nature of PCOS and its links to longer-term health outcomes. In future we hope that the condition’s name might be changed to reflect its underlying metabolic cause and we have suggested the term ‘Female AndroMEtabolic Syndrome’ (FAME) as an option. Wider consultation with women with PCOS is necessary to progress this longer-term goal.

End Summary

To summarize, our goal with this submission is to:

- Raise awareness of PCOS, a common *metabolic* health condition as a potentially highly significant, but presently ‘invisible’, contributor to body image constructs in up to 10% of women
- Highlight why body image concerns in BAME women may be more pronounced, as BAME women are disproportionately affected by PCOS
- Provide evidence from scientific work on androgen excess as to why increased societal awareness of PCOS is justified – as its symptoms not only impact body image, but the condition itself links to several other significant health conditions that may benefit from earlier interventions i.e. this goes beyond ‘looks’ and impacts women’s physical and mental health
- Encourage advertisers (particularly within the beauty industry) to provide responsible information about the possible alternate medical causes of the ‘undesirable’ features their products or services would look to ‘solve’ – enabling women who may have PCOS to feel encouraged to seek medical advice if they wish to e.g. for hirsutism, hair loss, acne, fertility etc.
- Encourage more weight-neutral public health campaigns to reduce weight stigma in those with PCOS
- Increase empathy for women with PCOS and reduce stigma associated with PCOS symptoms, which may impact these women’s body image and quality of life – this includes transmen with PCOS

- Reduce health inequity for women, particularly BAME women, through making clearer the medical options available to help with symptoms, if treatment is desired
- Provide current understanding on the links between PCOS and other known health conditions (as well as intergenerational effects), so that emerging evidence can inform earlier intervention options – hopefully positively impacting quality of life and cost savings to healthcare services longer-term
- Work towards greater public engagement on PCOS and a potential change in the PCOS name to FAME, to reflect the underlying metabolic nature of the condition

Signatories:

Institute of Metabolism & Systems Research, University of Birmingham:

- Professor Wiebke Arlt, Director of the IMSR and William Withering Chair of Medicine
- Professor Shakila Thangaratinam, Professor of Maternal and Perinatal Health
- Dr Punith Kempegowda, Wellcome Trust Clinical Research Fellow
- Dr Caroline Gillett, Community & Public Engagement Manager

www.birmingham.ac.uk/IMSR

Community-led PCOS Charities

- Neelam Heera, founder of Cysters
- Maureen Busby, founder of PCOS Vitality

www.cysters.org

www.pcosvitality.com

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