

# Analysis of the quality, accuracy and readability of patient information on polycystic ovarian syndrome (PCOS) on the internet available in English

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**UNIVERSITY OF SPLIT  
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**ANALYSIS OF THE QUALITY, ACCURACY, AND READABILITY  
OF PATIENT INFORMATION ON POLYCYSTIC OVARIAN  
SYNDROME (PCOS) ON THE INTERNET AVAILABLE IN ENGLISH**

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## **1. INTRODUCTION**

## **1.1 Polycystic ovarian syndrome (PCOS)**

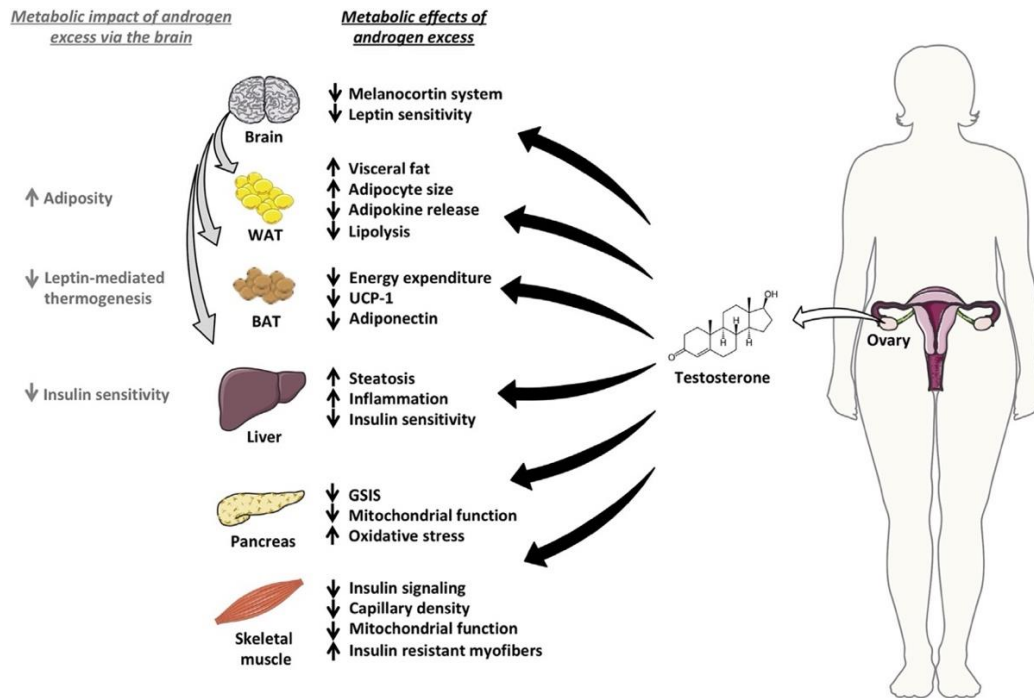
Polycystic ovarian syndrome (PCOS) is a hormonal disorder occurring in women of reproductive age. Presenting with symptoms such as acne, hirsutism, amenorrhea, androgenic alopecia, infertility together with obesity. PCOS causes symptoms that are challenging both physically and mentally for affected patients (1–3). Many women with PCOS experience a lower quality of life due to psychological challenges like anxiety and depression (2,3). These symptoms together with the high prevalence of PCOS makes it a topic frequently searched for on the internet by the public. Behboodi *et al.* in 2018 showed that several of these symptoms were widely reported as an important concern to women with PCOS, especially in adolescents (4). Patients within this age group affected by this disorder predominantly use of internet as a major source of health information (5). The information available online regarding PCOS is however of varying quality (1,4,6).

PCOS affects up to 15%-20% of women of reproductive age, making it a common disorder in this patient group (2,4). PCOS was first described in 1935 by Stein and Leventhal (7). Despite PCOS having a high prevalence in women, the diagnosis and differential diagnosis remain confusing. This is partly due to the lack of a specific test for providing the diagnosis, the prevalence of PCOS varying with diagnostic criteria, and diverse study settings and races (1). With the clinical practice being inconsistent regarding assessment and management of PCOS, women internationally have highlighted delayed diagnosis and dissatisfaction with the care they are receiving (8). There remains limited research synthesizing the broad clinical implications of PCOS which would assist the clinicians working with the management of PCOS, and therefore also benefit patient care (6).

## **1.2 Etiology and pathophysiology of PCOS**

The pathophysiological mechanisms of PCOS are complex and not fully understood. The etiology of PCOS has been suggested by multiple lines of evidence to be related with developmental, environmental, genetic and epigenetic mechanisms (9). It has become evident through recent years that race and ethnicity affects the clinical presentation of PCOS. Due to differences in genetic and environmental predispositions to endocrine and metabolic abnormalities (2). Several studies have suggested that genetic factors have a central role in the etiology of PCOS (9). The most conclusive evidence being from research of genetic factors involving monozygotic and dizygotic twins. Showing a higher concordance of PCOS symptoms in monozygotic twins, as compared to dizygotic twins (10).

Even though there are many aspects of the pathophysiology that remain unclear, it is widely accepted that hyperandrogenism plays a fundamental role. The excess of androgens has a great impact on the metabolic hemostasis in women affected. Acting on different metabolic tissues such as the liver, adipose tissue, pancreas and muscle as well as in the brain. The metabolic impact of androgen excess in PCOS are illustrated in figure 1 (9).



**Figure 1.** Metabolic impact of androgen excess in PCOS (9).

Androgen excess also impairs systemic metabolism through the brain by increasing adiposity and reducing insulin sensitivity (9). Hyperinsulinemia promotes ovarian hyperandrogenism which is present in 60-80% of women affected by PCOS (11). However, the most common biochemical deviation in patients with PCOS is the elevation of circulating testosterone and androstenedione levels (9).

Androgens in women are produced in the ovary as well as in the adrenal gland from a common precursor, cholesterol. After multiple enzymatic reactions, the cholesterol is converted into dehydroepiandrosterone (DHEA) and androstenedione. In the adrenal gland these reactions take place in the adrenal cortex, while in the ovary they occur in theca cells. Androstenedione is the main precursor for the synthesis of estrogen and testosterone in both the adrenal cortex and ovaries. After several additional enzymatic reactions, the production of androgens is regulated by luteinizing hormone (LH) in theca cells. While estrogen is regulated by follicle stimulating hormone (FSH) in granulosa cells. The biosynthesis of both these sex hormones are also modulated by intra and extra-ovarian factors (9).

Convincing evidence suggests that the major source of androgens in women with PCOS is the ovary. While the adrenal gland might also contribute to androgen overproduction in a minority of these patients (9). This androgen excess which predominately is a result of increased synthesis and release of ovarian hormones when seen together with hyperinsulinemia could lead to disrupted follicle growth (11).

PCOS is considered the leading cause of anovulatory infertility, making it clinically associated with subfertility or infertility, combined with an accumulation of immature follicles. A better understanding of the molecular mechanisms underlying the metabolic actions of androgens in PCOS is still needed (9,11,12).

### 1.3 Diagnostic criteria

The major international diagnostic criteria currently proposed are the Rotterdam criteria, together with the National Institutes of Health (NIH), as well as the Androgen Excess Society (AES) criteria (1).

#### 1.3.1 The Rotterdam criteria

Suggested by the European society for Human reproduction and Embryology/American Society for Reproductive Medicine is the diagnostic criteria used in most countries (1). As shown in Table 1, the revised 2003 Rotterdam diagnostic criteria for PCOS requires two out of the three criteria to be met in order to provide the diagnosis (13).

**Table 1.** Revised Rotterdam criteria of PCOS (13).

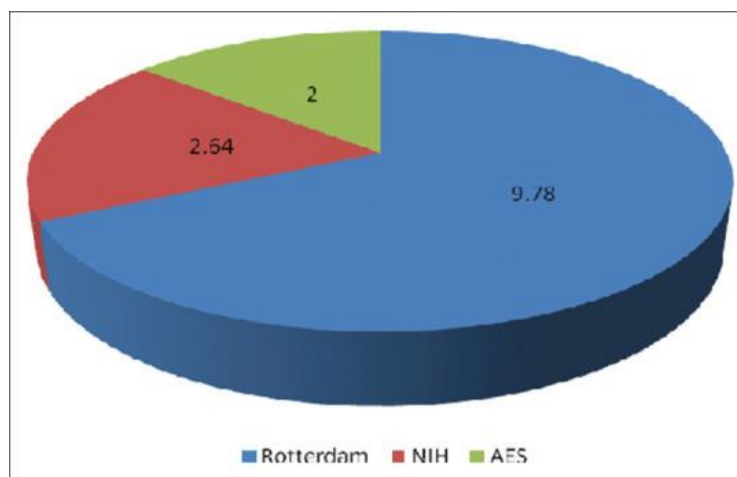
<b>Table 1.</b> Revised diagnostic criteria of PCOS
1999 criteria (both 1 and 2)
1. Chronic anovulation
2. Clinical and/or biochemical signs of hyperandrogenism, and exclusion of other aetiologies
Revised 2003 criteria (2 out of 3)
1. Oligo- and/or anovulation
2. Clinical and/or biochemical signs of hyperandrogenism
3. Polycystic ovaries
and exclusion of other aetiologies (congenital adrenal hyperplasias, androgen-secreting tumours, Cushing's syndrome)



Including oligo- and/or anovulation, clinical and/or biochemical signs of hyperandrogenism, and polycystic ovaries. Polycystic ovaries meaning more than 12 follicles in each ovary measuring 2-9 mm (2).

PCOS remains a syndrome for which no single diagnostic criteria would be sufficient for the clinical diagnosis. Concurrently PCOS is a diagnosis of exclusion, featured as part of the criterium in both the 1999 and the revised 2003 Rotterdam criteria by Fauser *et al.* Therefore, known disorders that mimic the PCOS phenotype must be excluded. These disorders include congenital adrenal hyperplasia, androgen-secreting tumors and Cushing's syndrome (13). The above-described Rotterdam criteria may not be suitable for clinical trials focusing on clinical outcomes in women (2).

As shown in Figure 2, the prevalence of PCOS was significantly higher when using the Rotterdam criteria compared to the NIH and AES criteria (2). Similar overall prevalence has also been described in a systematic review by Bozdag *et al.* (14).



**Figure 2.** Prevalence of PCOS using different diagnostic criteria (2).

These diagnostic criteria are subject to multiple challenges regarding standardization (2). Firstly, the criteria of oligo- and/or anovulation is difficult to assess in early menarche where ovulation is oftentimes irregular. Secondly, there is a lack of consensus on biochemical levels of hyperandrogenism, making the determination of androgen abnormality a complex task. Thirdly, transvaginal ultrasonography would be necessary to assess polycystic ovaries, however this examination is not routinely performed in adolescents. Lastly multifollicular ovaries, which may be present in adolescent girls is clinically challenging to differentiate from polycystic ovaries, making this patient group harder to correctly clinically diagnose when using the Rotterdam criteria (2).

### 1.3.2 National Institutes of Health (NIH) standard

The first attempt to consolidate a clinical definition of PCOS took place in 1990 in a conference sponsored by the National institute of Child Health and Human Development (NICHD). A definition of combined presence of androgen excess, and oligo-anovulation were proposed, resulting in the NIH criteria. Given that there was an absence of all other differential diagnosis for anovulatory infertility (15,16).

It is however important to mention that these criteria were based on majority opinion of those present at the conference, rather than clinical trial evidence. Differing from the Rotterdam criteria, polycystic ovaries are not part of the criteria, but is instead considered suggestive of PCOS (15). In Table 2, the differences in the three criteria are listed (16).

**Table 2.** Diagnostic criteria for PCOS (16).

Criteria	
NIH--NICHD	Both hyperandrogenism and chronic anovulation
Rotterdam	Two of the following: hyperandrogenism, chronic anovulation, and polycystic ovaries
Androgen Excess Society	Hyperandrogenism plus ovarian dysfunction indicated by oligo/amenorrhea and/or polycystic ovaries

### 1.3.3 Androgen Excess Society (AES) criteria.

In 2006, the AES formed a task force to review the existing data on the phenotypic expression of PCOS. They recommended a modification of the Rotterdam criteria to require hyperandrogenism as an essential diagnostic criterion. (15,16). The AES maintains that androgen excess is a central feature of the disease, and therefor PCOS should be defined by the presence of hyperandrogenism (clinical and/or biochemical) in combination with ovarian dysfunction. Ovarian dysfunction meaning oligo-anovulation and/or polycystic ovaries. The AES criteria has however not been widely adopted (17).

## 1.4 A Lack of knowledge

A major obstacle to effective healthcare for woman affected by PCOS is the lack of recognition of the syndrome outside of gynecology and obstetrics. One of the central issues in increasing the awareness around PCOS beyond subspecialty lies in the availability and familiarity with the required diagnostic procedures. An optimal management of PCOS would require a collaboration of a variety of healthcare professionals (16).

In certain medical clinics the syndrome might go unnoticed, such as a gynecological problem in a dermatologist office, or metabolic problems in a family medicine practice. Diagnostic criteria which require ovarian ultrasonography constrains the diagnosis if healthcare providers do not perform their own ovarian ultrasound or are unfamiliar with the criteria. Therefore, they would be unable to recognize and diagnose the morphology associated with the syndrome (16).

With expanded knowledge, primary health care workers can be empowered to recognize and diagnose PCOS even without an available ultrasound, by using criteria such as the NIH. For this to be possible, the physician needs to be familiar with the endocrine features of PCOS in the form of hyperandrogenism and oligoanovulation (16).

A recent 2022 study by Ismayilova *et al.* found through interviews of women in Canada with there is a perceived lack in knowledge on PCOS both from physicians and patients. Highlighting the need for improvement in knowledge and awareness of PCOS in primary health care. They also shed light on the need for more resources, and further PCOS research to be funded and undertaken. As well as the desire for credible doctor-provided information to be made available, especially age-specific support together with mental health support groups (18).

These facts highlight how PCOS is a public health problem, warranting a study on the quality and accuracy of publicly available information on the disorder. A 2018 study conducted by Chiu *et al.* showed that online information about PCOS from mostly commercial sources was poor in quality, thus an updated description regarding publicly available information on the internet on PCOS is warranted (5).

## **1.5 Comorbidities**

PCOS not only causes a series of symptoms and signs affecting the patient, it additionally increases the risk of serious morbidities like endometrial cancer, type II diabetes and cardiovascular disease (1). The risk of type II diabetes is up to four times greater among women with PCOS compared to healthy women, as well as being diagnosed at a younger age (19).

PCOS is well known to be linked to metabolic disorders such as obesity and insulin resistance. In fact, a large proportion of women with PCOS are overweight or obese. On the other side, insulin resistance and hyperinsulinemia are metabolic traits that are found in most lean woman with PCOS as well. Hyperinsulinemia has a prominent role in the development of many of the phenotypical features of PCOS, increasing the risk for metabolic abnormalities.

When PCOS is concurrent with being overweight or obese, the metabolic complications are exacerbated, as well as the reproductive derangements (9). It has also been reported that the risk of obesity itself is four times higher among patients with PCOS, compared to healthy controls (12).

A cohort of studies have suggested that there is an increased rate of particularly breast and endometrial cancer among women diagnosed with PCOS (20). Furthermore, studies looking at the general cancer risk in women with PCOS indicates that cancer may need to be added to the longer-term health consequences of this disease, although more surveillance on the area is needed (21). The increased risks for women affected by this disorder include serious damage not only to fertility, but also to the quality of life both mentally and physically for these patients (1,4).

## **1.6 Therapy**

### **1.6.1 Lifestyle intervention and medical therapy**

Lifestyle interventions such as diet, exercise, behavioral therapy, or combinations of these are the recommended first-line management of PCOS. This includes a large variety of balanced dietary approaches to reduce the daily caloric intake, together with increased physical exercise (12,22).

In a recent 2022 systematic review by Lee *et al.*, it was observed that lifestyle modification displayed significant improvement in reproductive function, compared to the control group. They also found that combination therapy with diet and exercise resulted in improved fasting insulin levels, compared to therapy with either diet or exercise alone. A moderate weight loss as low as 5% of the bodyweight resulted in an improved metabolic index (12). Most obese patients with PCOS fail to achieve a substantial weight loss through lifestyle modifications alone and might need additional medical interventions (9).

Available medical treatments target the biochemical and clinical hyperandrogenism, together with reproductive and metabolic features. Targeted symptomatic treatment includes combination oral contraceptives to improve hyperandrogenism and regulate the menstrual cycles (22). Combined oral contraception decreases gonadotrophin secretion and increases the hepatic secreting of sex hormone-binding hormone and therefore reduces the bioavailability of circulating free testosterone. Additionally, the use of a combined oral contraceptive confers long-term protection against endometrial cancer in the general population (23).

For patients that experience a suboptimal response to therapy with combined oral contraceptives, an anti-androgen can be added. Being effective for cosmetic complaints like hirsutism or acne. Both are therefore considered the first-line treatment for women not seeking pregnancy. On the other hand, using a combined oral contraceptive increases the relative risk of thromboembolic and cardiovascular disease. Which can be worrisome considering some women with PCOS are already at risk for cardiovascular morbidity (23).

Insulin sensitizers have been proposed as a safer therapeutic alternative, despite it being far less effective for hirsutism alone. The patient therefore needs to be well informed of the benefit and risk of their treatment choices. In several studies, metformin has shown benefits like decreasing waist-to-hip ratio, total testosterone levels and fasting glucose and insulin levels in non-obese patients. When combined with lifestyle modification, metformin can increase the number of menstrual cycles (23).

### **1.6.2. Infertility treatment**

Disorders of ovulation in women are a common cause of infertility, with PCOS being the most frequent disorder by far (24). Accounting for up to 30% of infertility in couples seeking treatment (20). Most of the treatment used for PCOS-related anovulatory infertility aims to tilt the balance of intraovarian steroid synthesis away from excessive androgen production (24).

For anovulatory infertility the first-line treatment includes ovulation induction agents, second-line treatment includes gonadotrophins, third-line treatment includes in vitro fertilization (IVF) as well as laparoscopic ovarian surgery (22). The first line ovulation induction agents include insulin sensitizer, selective estrogen receptor modulators and aromatase inhibitors. Out of the ones mentioned, the aromatase inhibitor letrozole and a combination of clomiphene citrate together with metformin have shown the highest rates of ovulation and live birth. The third line treatment with controlled ovarian stimulation by IVF should be considered the last option since it carries the risk of ovarian hyperstimulation syndrome in patients with PCOS (24).

### **1.6.3 Mindful stress management**

With the significant psychological manifestations associated with PCOS in the form of depression, anxiety and an overall reduced quality of life, mindfulness stress management has been proposed as a treatment alternative. The mindfulness technique is a clinical application of

principles involving the key element of non-judgmental acceptance of psychological distress. Aiming to reduce the tendency to ruminate over these experiences (25,26).

Even though mindfulness techniques have not been widely investigated in patients with PCOS exclusively, it has been shown to reduce psychological distress in non-PCOS patients, thereby showing potential as a new additional therapy (25,26). In both PCOS and non-PCOS women, psychological distress could contribute to increased risk of cardiovascular disease and diabetes. By promoting unhealthy behaviors and impeding adherence to medical treatment. It could also contribute to obesity and insulin resistance by altering activities of the hypothalamic-pituitary-adrenal axis and sympathetic nervous system together with increasing chronic inflammation through effects on the immune system (26).

Mindfulness-based stress reduction (MBSR) can be offered as a standardized mindfulness program in medical and health care settings to enhance psychological health and overall well-being (26). With smaller studies assessing the impact of mindfulness stress management having promising results, this could be a beneficial treatment option for women with PCOS, but further research is needed (3).

### **1.7 The DISCERN tool**

Given that information concerning PCOS could vary, we aim to determine the quality of information on PCOS available on the internet using the validated DISCERN tool (27), as well as the EQIP tool (28). We will also assess the reading grade level with eight standardized tests (29). Lastly, we will assess the accuracy of symptoms compared to recent systematic reviews.

Both patients and health consumers are taking on a more active role in decisions regarding health care. Creating a larger demand for high-quality and expanded information about health problems and treatment choices. A well-informed patient is more likely to feel less anxious about consulting their health provider, as compared to a uninformed patient. Patients who participate in their own health care decisions are also more likely to have improved health outcomes. For those who wish to take on an active role in decision-making, high-quality information being available and accessible online would be beneficial (27).

The DISCERN tool enables patients and information providers to judge the quality of written information concerning treatment choices. The DISCERN tool also facilitates the production of new, high-quality evidence-based consumer health information, making it a reliable and valid instrument. The DISCERN instrument was developed through two different stages. In the first stage a panel of experts developed and tested the instrument. The expert panel

was recruited to represent a range of expertise in areas relevant to the production and use of consumer health information. In the second stage a national sample of health information providers and self-help group members tested the instrument on a range of consumer health information regarding treatment choices. The tool consists of 15 questions and an additional overall quality score given through a calculated average of the previous ratings (27).

### **1.8 The EQIP tool**

The Ensuring Quality Information for Patients (EQIP) tool is a checklist used to assess written health care information. The original EQIP tool has been expanded to 36 criteria, providing a more robust and effective analysis of written patient information. The modified EQIP tool sets out to satisfy the British Medical Association (BMA) and the International Patient Decision Aids Standards (IPDAS). The items are classified into three domains: content, identification and structure. Various aspects are considered, such as quality of information, quality of the written work and website design. Similar to this study the EQIP tool was used to rate information online regarding appendicitis in a 2021 study by Ghani and colleagues, where it was found that most sites online were of poor credibility (28). With the current available websites generally having poor quality and providing inadequate health information intended for patients (28,30). The EQIP tool has also been used to evaluate information sources related to transplant surgeries, eczema, gallstone disease and more recently – COVID-19 (28).

### **1.9 Readability and accuracy of written information on the internet**

The internet is becoming an increasingly ubiquitous source regarding health information, with more than 80% of the developed world having access to the internet (31). Readability scores are a way to measure whether written information is likely to be understood by the intended reader, in this case patients seeking medical information regarding PCOS online. Text that scores a readability grade level of 8 or better (8 or below) will be readable for around 85% of the general public (29).

Similar analysis from a 2021 study by Hosseinzadeh *et al.*, found that the readability level for online information on dupuytren's contracture was written above the recommended reading grade level. They also found that the trend in readability of online information on their subject had not shown improvement in the last half decade (31).

The accuracy of symptoms will be checked using four independent recent systematic reviews and scored from 1 to 5, reflecting the percentage of accuracy (2,12,22,32).

In the modern era, there is increasing availability and accessibility of information with the internet as the primary source. Many seek medical information online for their symptoms prior to consulting a medical professional. Many of whom subsequently self-diagnose based on the information found on the internet (28).

Some people find that the method of online self-diagnosis could be reassuring while waiting for a healthcare appointment that might be some time away (33). By patients seeking information of the internet as a primary source, their relationship with healthcare workers can be affected by creating a lack of trust in professionals. At worst, the use of unreliable websites to self-diagnose can lead to poorer outcomes (28). While patients finding information online could benefit their interaction with their primary doctor, there is also a potential that the use of unreliable sources of information could lead to a demand of inadequate diagnostics and treatments from their physician (34). These facts highlight the importance of an assessment of the quality and accuracy as valid research presented in this thesis.



## **2. OBJECTIVES**

## **2.1 Our specific aims**

1. To assess the quality of information on PCOS (accountability, authorship, and transparent reporting of the information) available from Google, Bing, and Yahoo search engines using the DISCERN tool.
2. To assess the clarity of information on PCOS (accountability, authorship, and transparent reporting of the information) available from Google, Bing, and Yahoo search engines using the EQIP tool.
3. To determine the accuracy of the information on PCOS symptoms available from Google, Bing, and Yahoo search engines
4. To assess the readability as the reading grade level of the information on PCOS available from Google, Bing, and Yahoo search engines.
5. To assess the relationship of the quality of PCOS information between commercial and academic webpages.
6. To assess the relationship of the accuracy of PCOS symptoms between commercial and academic webpages.
7. To assess the relationship of the readability of PCOS information between commercial and academic webpages.

## **2.2 Hypotheses**

1. There will be a difference in the quality of the PCOS information as assessed by the DISCERN tool according to search engine.
2. There will be a difference in the clarity of the PCOS information as assessed by the EQIP tool according to search engine.
3. There will be a difference in the quality of the PCOS information as assessed by the DISCERN tool between commercial and academic webpages.
4. There will be a difference in the clarity of the PCOS information as assessed by the EQIP tool between commercial and academic webpages.
5. There will be a difference in the accuracy of the information on PCOS symptoms according to search engine.
6. There will be a difference in the accuracy of the information on PCOS symptoms between commercial and academic webpages.
7. There will be a difference in the median readability level of the PCOS information according to search engine.

8. There will be a difference in the median readability level of the PCOS information between commercial and academic webpages.

### **3. MATERIALS AND METHODS**

### **3.1 Electronic searches**

We will use Google<sup>®</sup>, Bing<sup>®</sup>, Yahoo<sup>®</sup> search engines for separate searches not limited to any specific geographical region to search for webpages describing PCOS information in English. The most updated version of Google Chrome will be used. We will choose the top five keywords directly related to PCOS for the searches from Google Trends at one time point to subsequently conduct our searches in the separate search engines (35). One investigator will perform the search.

### **3.2 Inclusion and exclusion criteria**

We will include any webpage with information describing information about PCOS intended for patients or the lay public (newspaper websites, government and academic institutions, health center or hospital websites, or non-profit institutions), that have text more than 30 sentences or 100 words long, and have identifiable domains (e.g., “.com”, “.edu”, “.gov”, “.info”, “.net”, “.biz”) to allow for their categorization. One investigator copied and pasted webpage text over a two-month period. Another investigator checked the eligibility. Any disagreement about the categorization of the webpages will be discussed until consensus is reached. We will exclude webpages that require subscription, are videos, scientific journal articles, are intended for health care professionals, or are inaccessible.

### **3.3 Data collection**

We will extract the top 10 webpages from each of the three databases in which we will perform five separate searches using the keywords chosen from Google Trends (35). Keywords chosen in search preformed order were polycystic ovary syndrome symptoms, polycystic ovary syndrome treatment, polycystic ovary syndrome causes, polycystic ovary syndrome pregnancy and lastly polycystic ovary syndrome test. Duplicates will be avoided during the extraction process, rendering only unique webpages from each search. The web history log and cookies will be deleted between each search to avoid interference during each search for all search engines used. The text and images will be copied and pasted into Google Word documents marked with the date of download. We will assess the quality of the PCOS information using the 16-item DISCERN tool. When scoring with the above-mentioned tools the webpage will be used directly, given that the date of latest review or update is prior to the downloaded date. Where this is not possible the downloaded copy and pasted information will be used. All

information must be possible to attain within two clicks on the webpage in order for it to be included in the assessment.

### **3.4 The DISCERN tool**

The DISCERN tool assesses the completion of health information in written form with Likert scores of 1 (no), 2, 3 (partially), 4, and 5 (yes) for items 1-15 to judge the presence of (1) clear aims, (2) information that addresses the stated aims, (3) relevant or realistic treatment information, (4) references to the sources used as evidence, (5) dates of the main sources of information, (6) a bias assessment, (7) suggestions for further reading or additional sources of information, (8) acknowledgement of gaps in knowledge, (9) the effectiveness of each treatment, (10) benefits of each treatment, (11) a description of the risks of each treatment, (12) descriptions of disease progression in the absence of treatment, (13) adverse events and the impact on the overall quality of life, (14) description of treatment choice options, (15) suggestions to discuss the health information on the website with family or health practitioners. We will use a Likert-scale with 1 (low or not available), 2 (somewhat low), 3 (moderate), 4 (somewhat high), and 5 (high) to rate these items. Item 16 addresses overall quality as 1 (low), 2, 3 (moderate), 4, and 5 (high). It utilizes four criteria to assess the authorship, attribution, currency of information, and ownership of a publication (website owner and conflict of interest).

### **3.5 The EQIP tool**

We will use the modified 36-item EQIP tool to assess the clarity of the PCOS information. There are 18 items related to content, 6 items for the identification of information, and 12 items regarding the structure of the information. We will respond with yes or no to indicate the presence or absence of information and respond using N/A if the described webpage information is not applicable to an item. Webpages with an EQIP score of greater than 22.0, which corresponds to the 75th percentile, were deemed as high-scoring webpages. Low-scoring webpages were those with an EQIP score less than or equal to 22.0 (28).

From a 10% random sample of selected webpages, two investigators will aim for at least 80% agreement regarding the rating of quality and clarity of the PCOS information with the DISCERN and EQIP tools. One investigator will then rate the remaining webpages independently.

### **3.6 Readability**

Readability will be analyzed using the online readability calculator at [readable.io](https://readable.io) by directly pasting the webpage text into the readability calculator. Grade level readability scores correspond to grade levels from the fourth grade to a doctorate. The readability calculator will use standardized formulas for the readability calculations where the Automated Readability Index uses the formula  $4.71 \times (\text{characters/words}) + 0.5 \times (\text{words/sentences}) - 21.43$ , the Flesch-Kincaid Grade Level relies on  $0.39 \times (\text{words/sentences}) + 11.8 \times (\text{syllables/words}) - 15.59$ , the Coleman-Liau Index, uses  $5.89 \times (\text{characters/words}) - 0.3 \times (\text{sentences/words}) - 15.8$ , the Gunning Fog score uses  $0.4 [(\text{words/sentences}) + 100 (\text{complex words/words})]$ , and the SMOG Index (for sixth grade reading levels relies on  $1.0430 \times \sqrt{(30 \times \text{complex words/sentences})} + 3.1291 (30)$ .

Additionally, we will use the Flesch-Kincaid Reading Ease scored from 0 to 100, where lower scores indicate difficult to understand text and higher scores indicate easier reading. Lower grade levels correspond to easier readability with the Flesch-Kincaid grade (FKG) level (ranges from grade 0 to 18 [college graduate] the Gunning-Fog (GF) score (ranges from grade 0 to 20 [college graduate]. The Coleman-Liau index (CLI) and automated readability index (ARI), ranging from 5 to 22 (college graduate), the New Dale-Chall Readability (NDCR) [ranges from grade level 4 to college graduate], and simple measure of gobbledygook (SMOG) [ranges from grade level 3 to college graduate] scores correspond to the years of education needed to understand written material. We additionally collected word count, syllables per word, words with more than two syllables, words per sentence, and sentence count.

### **3.7 Accuracy of symptoms**

We will assess the accuracy of the symptoms of PCOS using recent systematic reviews to assess the accurate and inaccurate statements. The systematic reviews will be of newer origin being published in 2019 or newer, the most recent being published in 2022 (2,12,22,32). We will base the accuracy of the PCOS information on the proportion of total accurate statements on the symptoms in the webpage text compared to the total number of statements about symptoms. Symptoms not accepted as accurate according to systematic reviews included enlarged clitoris, headache, sleep apnea, sleep problems, pelvic pain, eating disorders, sexual dysfunction, oily skin, deeper voice, decreased breast size, mood changes, insomnia, fatigue, increased appetite, hypertension, swollen belly, endometrial hyperplasia, hidradenitis suppurativa, fatty liver, recurrent miscarriage, hyperkeratosis, inappropriate male features, behavioral changes together with urinary and fecal incontinence. For example, we will assess

the accuracy of each listed symptom in words or in a statement on the website and count the total number of statements or words describing symptoms on a webpage. With the goal of producing one accuracy score for each website, the total number of accurate descriptions across all of the above descriptions will be divided by the total number of statements across all of the above descriptions. Scores will be based on the proportion of accurate data ranging from 1 (lowest) to 5 (highest) (36,37).

A score of 1 would represent less than 25% agreement with evidence-based information, a score of 2 represents 26%-50% agreement with evidence-based information, a score of 3 represents 51%-75% agreement with evidence-based information, a score of 4 represents 76%-99% agreement, and a score of 5 denotes 100% agreement with evidence-based sources on PCOS (36). We will also record our opinions and comments concerning each website. We will assess the accuracy in a 10% random sample to obtain at least an 80% agreement. One investigator will continue with the accuracy ratings for the remainder of the webpages.

### **3.8 Statistical analysis**

The DISCERN, EQIP and readability scores will be treated as continuous variables. The EQIP responses were treated as dichotomous (rated as a (1) for yes or (0) for no) categorical variables, where each item scored as 1 contributed to a total score for each webpage. The accuracy was treated as an ordinal variable. We used the Kolomogorov-Smirnoff test to determine the distribution of the numerical data and used non-parametric tests for non-normally distributed numerical variables. We reported descriptive data as n (%), median (Md), and interquartile range (IQR). Our analysis of webpage quality, clarity, and accuracy involved the assessment of the interrater reliability with Cohen's kappa for agreement along with 95% confidence intervals (CI). The Kruskal-Wallis test was used to determine whether the DISCERN, EQIP, readability, and accuracy scores differ between search engine or webpage category. Post-hoc analyses was used for the Kruskal-Wallis test to determine in which category differences existed. The statistical significance was set at  $P < 0.05$  for all the comparisons. MedCalc version 9.1.2 (MedCalc software bv) and IBM SPSS Statistics for Windows, versions 22.0 (IBM Corp., Armonk, N.Y., USA) were used for all analyses.



## **4. RESULTS**

This study included 150 webpages describing information about PCOS from the searches performed in Google, Bing, and Yahoo. This study was performed to evaluate the quality, clarity, accuracy, and readability of patient information on PCOS on the internet available in English. The quality was assessed by the DISCERN tool. Clarity was assessed by the EQIP tool. Symptom accuracy was checked using multiple new systematic reviews. Lastly the median readability was checked using an online readability calculator. Table 3 shows the overall characteristics of the webpages.

**Table 3.** Producer type and readability scores of PCOS webpages.

Characteristics	Total
<b>Webpage producer type</b>	
Commercial, n (%) <sup>*</sup>	85 (100%)
Non-commercial, n (%) <sup>†</sup>	65 (100%)
<b>Readability scores</b>	
	<b>Median (IQR)<sup>‡</sup></b>
Flesch Reading Ease	48.3 (42.0-54.0)
Flesch-Kincaid Grade Level	10.0 (9.0-11.0)
Gunning Fog Score	12.0 (11.0-13.0)
Coleman Liau Index	12.0 (11.0-13.0)
Simple measure of gobbledygook (SMOG) Index	12.0 (11.0-13.0)
Automated Readability Index	9.0 (8.0-10.0)
Spache Readability Score	4.0 (4.0-5.0)
Dale-Chall Readability Score	7.0 (6.0-7.0)
Word count	1020.0 (730.0-1534.0)
Syllables per word	2.0 (2.0-2.0)
Words with more than four syllables	14.0 (9.0-23.0)
Words per sentence	13.0 (11.0-15.0)
Sentence count	79.0 (58.0-116.0)

<sup>\*</sup>Designated as having .com domain names

<sup>†</sup>Designated as having .edu, .gov, .org, or other domain names.

<sup>‡</sup>Interquartile range (IQR)

Out of the 150 webpages collected for this study, 85 (57%) were found to be commercial, ending with a “.com” domain. While 65 (43%) were described as non-commercial having a “.edu, .gov, .org” or similar domain name.

#### **4.1 Inter-rater reliability**

Inter-rater reliability was assessed by two investigators grading 10% of the 150 webpages independently. Any disagreement was discussed until consensus was reached for all items rated across the different tools were above 80 percent, then one investigator rated the remaining webpages independently. Inter-rater reliability was high for DISCERN items (kappa range 0.826 to 1.00). We resolved through consensus discussion the differences in our interpretation of item 9 “description of how each treatment works”, which had the lowest kappa in any single category of the DISCERN items (0.83, 95% confidence interval (CI) 0.77-0.89), before the full data extraction by HV.

Inter-rater reliability was also high for EQIP items (kappa range 0.83 to 1.00). We resolved through consensus discussion the differences in our interpretation of item 26 “use of generic names”, which had the lowest kappa in any single category of the EQIP items (0.83, 95% confidence interval (CI) 0.77-0.88) before the full data extraction by HV.

Inter-rater reliability was high for accuracy of symptoms with a kappa range 0.891 (95% CI 0.84-0.94) to 1.00. We resolved through consensus discussion the differences in our interpretation before the full data extraction by HV.

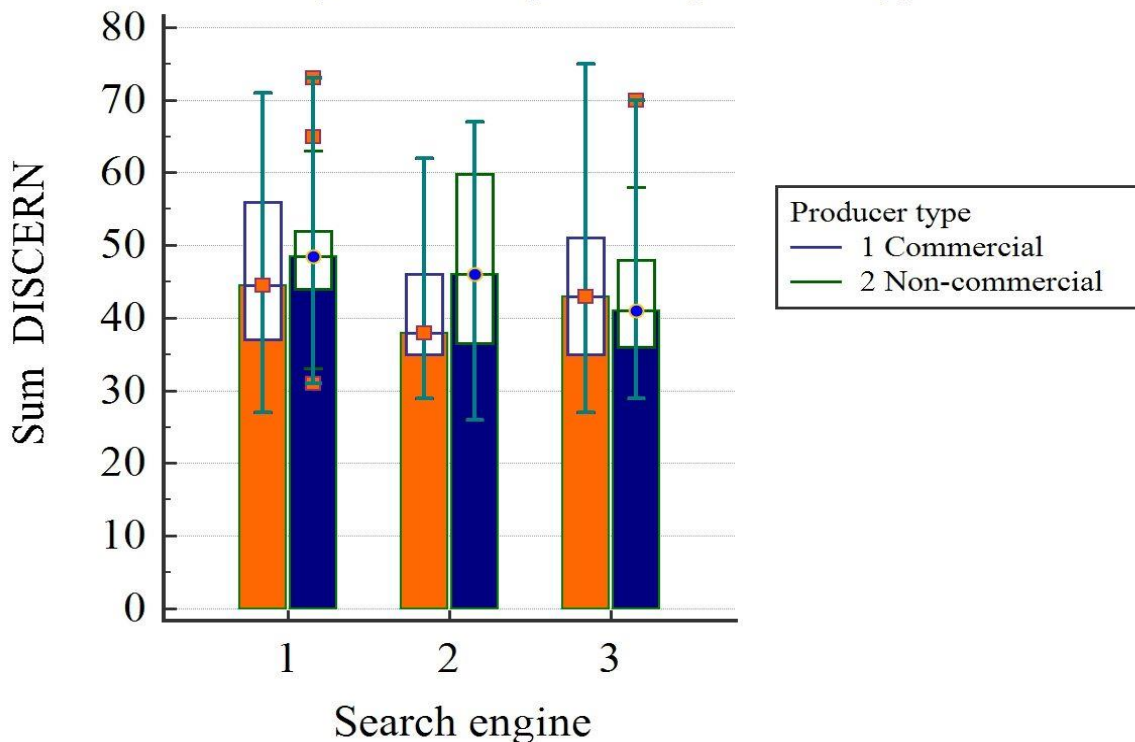
#### **4.2 DISCERN scores**

The overall median DISCERN score for the webpages was 44.0 (IQR 36.0-51.0). Google webpages describing PCOS had a higher median DISCERN score of 47.0 (IQR 39.0-55.0) than webpages from Bing (median 42.0, IQR 35.0-48.0) or Yahoo (median 43.0, IQR 35.0-48.0);  $P=0.023$ . The overall DISCERN score for commercial webpages was 42.0 (IQR 35.0-50.5). For non-commercial webpages the score was 47.0 (IQR 38.0-51.0). The median DISCERN score was higher for non-commercial webpages (median=47.0, IQR 38.0-51.0), but we did not find a significant difference ( $P=0.068$ ).

The quality of the information was classified according to the median score as “excellent” (63 to 80), “good” (51 to 62), “fair” (39 to 50), “poor” (28 to 38), or “very poor” (< 27). Overall, there were 39 (26.0%) webpages rated as good or excellent, and 58 (39.0%) were rated as fair, 53 (35.0%) rated as poor or very poor.

Discern scores by search engine and producer are illustrated in figure 3 with full range.

DISCERN sum by search engine and producer type



**Figure 3.** Discern scores by search engine and producer  
1 - google, 2 - bing, 3 - yahoo

#### 4.3 EQIP scores

The median EQIP score was 20 (IQR 18.0-22.0). Webpages with an EQIP score of greater than 22.0, which corresponds to the 75th percentile, were deemed as high-scoring webpages, while we deemed low-scoring webpages as those with an EQIP score less than or equal to 22.0. A high score was achieved by 36 (24%) of webpages and the remaining 114 (76%) achieved a low score. The lowest score achieved was 5 by 1 webpage obtained from a commercial webpage from Yahoo, whereas the highest score of 30 was obtained by a non-commercial webpage from Bing.

There was no significant difference in the EQIP scores according to Google (median 20.5, IQR 18.0-23.0), Bing (median 20.0, IQR 17.0-22.0), or Yahoo (median 20.0, IQR 18.0-22.0);  $P=0.524$ . According to webpage producer type, the median EQIP score for commercial webpages was 20.00 (IQR 18.0-22.50). For non-commercial webpages it was 21.00 (IQR 18.0-22.0). Showing a higher median for non-commercial webpages with median 21.00 (IQR 18.0-22.0);  $P=0.583$ .

#### 4. 4 Accuracy scores

Symptom accuracy was counted and checked up against several recent systematic reviews. According to webpage producer type the accuracy score was 5.00 (IQR 4-5);  $P=0.202$  for both commercial and non-commercial websites. The accuracy score of webpages across three search engines regardless of the producer type was 5.0 (IQR 4-5);  $P=0.915$ . Table 4 shows the breakdown of the accuracy scores by producer.

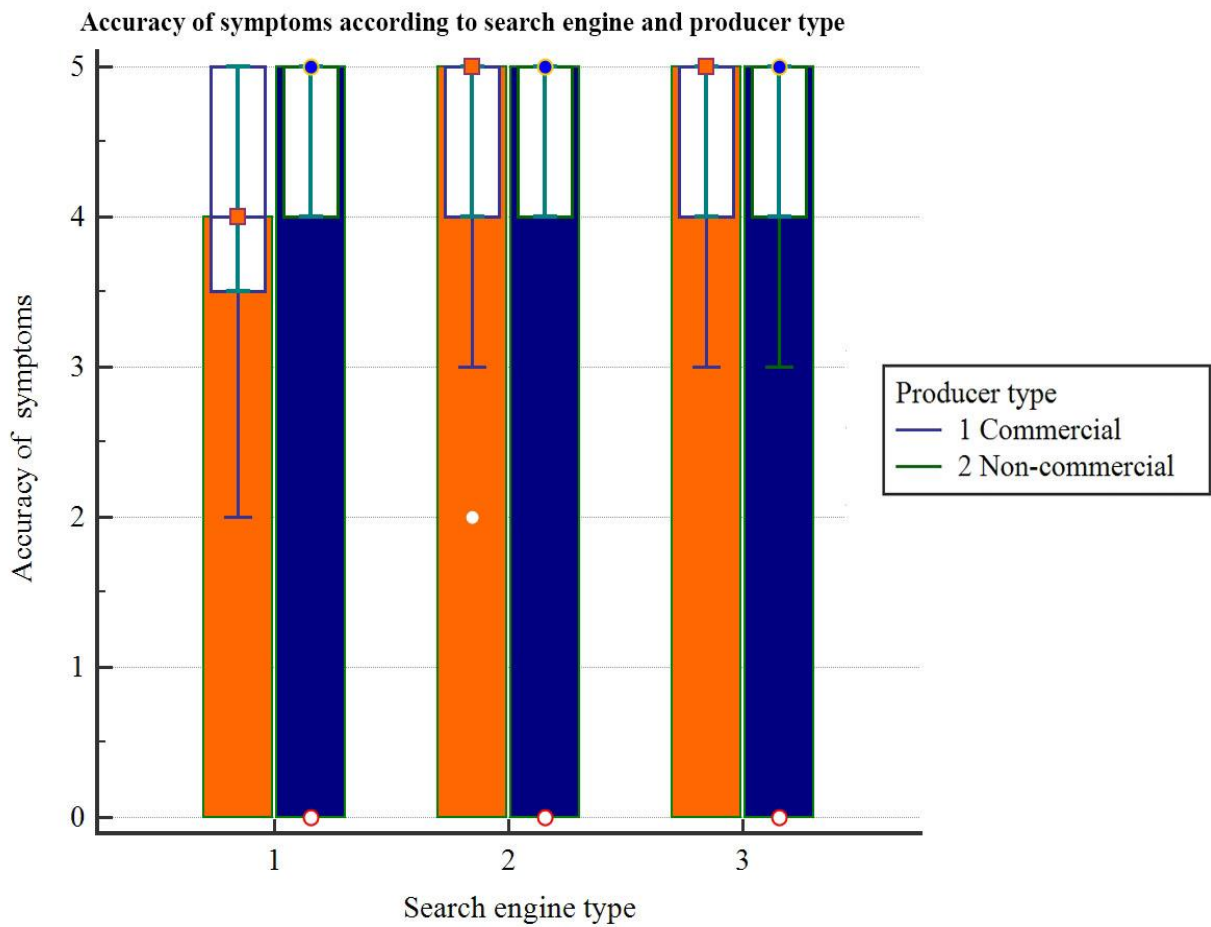
**Table 4.** Accuracy score breakdown by producer.

Accuracy of symptoms	Producer type		
Count (0-5)	Commercial n (%)	Non-Commercial n (%)	Total
0 (N/A*)	0 (0.0%)	3 (4.6%)	3 (2.0%)
1	0 (0.0%)	0 (0.0%)	0 (0.0%)
2	2 (2.4%)	0 (0.0%)	2 (1.3%)
3	8 (9.4%)	2 (3.1%)	10 (6.7%)
4	29 (34.1%)	18 (27.7%)	47 (31.3%)
5	46 (54.1%)	42 (64.4%)	88 (58.7%)
Total	85 (100.0%)	65 (100.0%)	150 (100.0%)

\*N/A – Not applicable

There was no significant difference in the comparison of the specific accuracy ratings by producer ( $P=0.065$ ).

Figure 4 shows the accuracy of symptoms according to search engine and producer type.



**Figure 4.** Accuracy of symptoms according to search engine and producer type. Google-1, Bing-2, Yahoo-3

#### 4.5 Readability scores

Readability was analyzed and collected using the online calculator at [readable.io](http://readable.io). Grade level readability scores correspond to grade levels from fourth grade to a doctorate. Lower grade levels correspond to easier readability. Flesch-Kincaid Reading Ease is scored from 0 to 100, where lower scores indicate difficult to understand text and higher scores indicate easier reading. Table 5 shows the readability scores by search engine.

**Table 5.** Readability scores and text characteristics of webpages describing PCOS information according to Google, Bing, and Yahoo search engines.

<b>Readability scores median (IQR)*</b>	<b>Google (n = 50)</b>	<b>Bing (n = 50)</b>	<b>Yahoo (n =50)</b>	<b>P†</b>
Flesch-Kincaid reading ease	49 (41-56)	48 (42-54)	48 (42-54)	0.787
Flesch-Kincaid grade level	10 (8-11)	10 (9-11)	10 (9-11)	0.787
Gunning-Fog score	12 (11-13)	12 (11-13)	12 (10-13)	0.787
Coleman-Liau	12 (11-13)	12 (11-13)	12 (11-13)	0.571
SMOG‡	12 (11-13)	12 (11-13)	12 (11-13)	0.923
Automated readability index	9 (7-11)	9 (12-13)	9 (11-13)	0.571
Dale-Chall Readability	7 (6-7)	7 (7-7)	7 (6-7)	0.197
Word count	1132 (807-1922)	923 (648-1444)	891 (681-1518)	0.353
Syllables per word	2 (2-2)	2 (2-2)	2 (2-2)	0.580
Words with more than four syllables	15 (8-27)	14 (10-23)	14 (10-23)	0.830
Words per sentence	13 (11-15)	13 (11-15)	13 (11-14)	0.987
Sentence count	89 (65-147)	76 (47-108)	77 (51-113)	0.383

\*IQR – interquartile range

†Kruskal-Wallis test with a P-value set at 0.05.

‡Simple measure of gobbledygook (SMOG) index

Google had a higher Flesch-Kincaid reading ease median 49 (41-56), compared to Bing median 48 (42-54) and Yahoo median 48 (42-56), but the comparison did not reach statistical significance ( $P=0.787$ ). The median Flesch-Kincaid grade level did not differ across the three search engines. The readability scores by producer type are shown in Table 6.

**Table 6.** Readability of webpages describing PCOS information by producer type.

<b>Readability scores median (IQR)*</b>	<b>Commercial</b>	<b>Non-commercial</b>	<b>P †</b>
Flesch-Kincaid reading ease	48 (41-52)	49 (43-57)	0.093
Flesch-Kincaid grade level	10 (9-11)	9 (8-11)	0.061
Gunning-Fog score	12 (11-13)	12 (11-13)	0.195
Coleman-Liau	12 (11-13)	12 (11-13)	0.311
SMOG‡	13 (12-13)	12 (11-13)	0.073
Automated readability index	9 (8-11)	9 (8-10)	0.112
Dale-Chall Readability	7 (6-7)	7 (6-7)	0.201
Word count	1020 (748-1607)	1000 (686-1449)	0.567
Syllables per word	2 (1.70-1.80)	1.70 (1.60-1.80)	0.250
Words with more than four syllables	15 (10-24)	14 (7-22)	0.210
Words per sentence	13 (11-15)	13 (11-14)	0.232
Sentence count	78 (60-120)	80 (53-116)	0.799

\*IQR – interquartile range

†Kruskal-Wallis test with a P-value set at 0.05.

‡Simple measure of gobbledygook (SMOG) index

Non-commercial websites showed a higher Flesch-Kincaid reading ease, median 49 (43-57), compared to commercial websites, median 48 (42-52), but no statistically significant difference was found (0.093). Non-commercial webpages also showed a lower Flesch-Kincaid grade level median 9 (8-11), compared to commercial median 10 (9-11), although there was no statistically significant difference (0.61). These results indicate that most webpages were written at an average of a tenth grade reading level.



## 5. **DISCUSSION**

Polycystic ovarian syndrome (PCOS) is a common yet complex hormonal disorder occurring in women of reproductive age. Women affected by PCOS are expressing dissatisfaction with the care they are receiving and the lack of useful online information on the topic. Underlying a perceived shortage of knowledge from both physicians and patients. (5,18). The internet has become an increasingly ubiquitous source for health information, being a key factor in the relationship between healthcare workers and patients, with positive and negative impacts (28,33,34). This raises concerns for patients seeking health information online due to the information not being regulated and often containing inaccurate or unreliable content (38).

This study used standardized evaluation tools to examine quality, clarity, accuracy, and readability of PCOS information available in English. Quality was investigated using the DISCERN tool and clarity by the EQIP tool. The study also investigated the accuracy of symptoms compared to recent systematic reviews. Lastly the study investigated the level of readability by using a readability calculator. All the information was categorized and compared across website producer and search engine.

Most of the webpages had a commercial domain 85 (57%), with the remaining 65 (43%) being of non-commercial domains. This finding is in concordance with previous similar studies showing a tendency for the greatest part of websites offering health information being commercially produced (38,39). The data suggested that the DISCERN score were higher for non-commercial webpages, but a significant difference was not found. The DISCERN median score was higher for Google as compared to Bing and Yahoo, showing a significant difference in quality, suggesting an advantage in using Google as a search engine.

According to the findings the webpages overall achieved the rating “fair” (median 44, IQR 36.0-51.0) according to the DISCERN tool. Similar findings have been shown in previous studies describing a lack in high-quality information online (5,18,40,41). The analysis done with the EQIP tool deemed the median score across all the websites analyzed below the 75<sup>th</sup> percentile, making them low scoring (median 20, IQR 18.0-22.0), suggesting low clarity overall which are in concordance with previous studies (28,40). The lowest score was achieved by a commercial webpage by Yahoo, while the highest score was obtained by a non-commercial webpage from Bing. Suggesting a higher clarity from non-commercial webpages like we hypothesized. The median for non-commercial webpages was higher as compared to commercial webpages, but no significant difference was established.

The study also did not find a significant difference in clarity between the three search engines: Google, Bing and Yahoo.

The accuracy of symptoms was found to be high across the search engines and producers compared the symptoms reported in recent systematic reviews (2,12,22,32). With only three non-commercial websites not listing any symptoms in their information. Similar research assessing accuracy and readability of pancreatic cancer also showed high levels of accuracy, especially from government webpages. Differing from this study, a previous study was based their accuracy on an expert panel (36). As many patients self-diagnose based on information found on the internet, this data suggests that majority of symptoms on PCOS available online are accurate (42).

The median readability score for commercial webpages were at a tenth grade reading level, while the score for non-commercial webpages were at a ninth grade reading level. Suggesting a better readability level for non-commercial webpages. Even though the results were not found to be statistically significant. This data supports similar findings of the readability level being too advanced to be readable for the majority of the general public, being above a readability of the eighth grade. The joint commission recommends that all patient education materials should be written at or below the fifth grade reading level to meet the health literacy needs of the public, suggesting a need for readability levels to be improved (5,31,43). No significance difference was found between the three search engines. It should also be noted that PCOS is a disorder affecting adolescent girls as well, whom usually read at a sixth, seventh or eighth grade level. Considering the varying literacy of health information, using plain language, substituting complex medical terms with simpler terms, and shortening sentences is of importance.

Despite our findings being in accordance with previous research, our study presented some limitations. The web pages searches were not exhaustive, utilizing only five search terms selected by Google Trends. The identification of search terms with Google Trends only provides the most used search phrases by the wider public, possibly not truly predicting the search patterns of individuals seeking information on PCOS online (42). The study is limited by a small sample size of 150 webpages with an unequal distribution across producer types.

Additionally, only the top ten webpages from each search term was investigated. The study results were also limited to web pages in English, researchers from other countries may evaluate online information on PCOS in other languages. As such, the data from this study may differ from conclusions drawn on patient information in other languages. The study also did not make any differentiations or grouping regarding the origin country of the information analyzed.

Further we did not include video-based material into our study, limiting our study to text. We have utilized the EQIP tool to analyze websites containing information regarding PCOS although the tool was not originally created for this specific purpose, therefore making it a possible limitation (42). Validated quality indicators are needed to help improve the quality and clarity of PCOS information available online as most of them achieved low scores overall. Undermining similar research concluding with a need to improve online resources of health information (5,18,40).

Similar to this study, prior research has found corresponding problems with patient information quality (42). Highlighting the need for establishing high quality websites and specific information evaluation tools to ensure the optimal patient education for a syndrome as common as PCOS. The readability level does not assess the role of previous knowledge, motivation to learn, use of examples and similar and may therefore give a higher reading level regardless of efforts to incorporate an accessible reading level (36).

Health care workers should educate themselves within the topic and strive to educate patients on how to navigate and interpret online-based resources to access the highest quality of information. Finally, it is important to note that the findings of this study acts as a snapshot of a point in time from when the search was performed. However, while search engine results may change over time, this study considers the findings to be representative of the information available to patients on PCOS online in English.

## **6. CONCLUSIONS**

From this study we conclude the following:

- The majority of webpages analyzed were commercial (57%) as compared to non-commercial (43%). This finding is in concordance with previous similar studies.
- Overall, the majority of the webpages achieved fair and low ratings from analysis with the DISCERN tool and EQIP tool. Similar tendencies have also been described in prior research on online health information.
- The quality of PCOS information available online as assessed by the DISCERN tool had a higher median score for Google search engines as compared to Yahoo and Bing.
- The clarity of PCOS information available online as assessed by the EQIP tool showed no significance difference between the search engines Google, Yahoo and Bing.
- The quality of PCOS information available online as assessed by the DISCERN tool showed no significant difference between commercial and non-commercial webpages.
- The clarity of PCOS information available online as assessed by the EQIP tool showed no significant difference between commercial and non-commercial webpages.
- The accuracy of symptoms showed no significant difference between the search engines Google, Yahoo and Bing or between commercial and non-commercial webpages.
- The accuracy of symptoms regardless of search engine and producer suggested high quality overall.
- The readability level did not show a significant difference between the search engines Google, Yahoo and Bing or between commercial and non-commercial webpages.
- High-quality PCOS-related online information available in English within the recommended readability level of the public is lacking and there is a need for high-quality, user-friendly PCOS patient information online within the recommended readability level to be made available for women.

## **7. REFERENCES**

1. Bai X, Zheng L, Li D, Xu Y. TMT-based proteomic and bioinformatic analyses of human granulosa cells from obese and normal-weight female subjects. *Reproductive Biology and Endocrinology* [Internet]. 2021;19:122. Available from: <https://doi.org/10.1186/s12958-021-00802-4>
2. Deswal R, Narwal V, Dang A, Pundir CS. The Prevalence of Polycystic Ovary Syndrome: A Brief Systematic Review. *J Hum Reprod Sci* [Internet]. 2020 Oct 1 [cited 2022 May 31];13(4):261–71. Available from: <https://pubmed.ncbi.nlm.nih.gov/33627974/>
3. Stefanaki C, Bacopoulou F, Livadas S, Kandaraki A, Karachalios A, Chrousos GP, et al. Stress The International Journal on the Biology of Stress Impact of a mindfulness stress management program on stress, anxiety, depression and quality of life in women with polycystic ovary syndrome: a randomized controlled trial. Available from: <https://www.tandfonline.com/action/journalInformation?journalCode=ists20>
4. Behboodi Moghadam Z, Fereidooni B, Saffari M, Montazeri A. Measures of health-related quality of life in pcos women: A systematic review. *International Journal of Women's Health*. 2018;10:397–408.
5. Chiu WL, Kuczynska-Burggraf M, Gibson-Helm M, Teede HJ, Vincent A, Boyle JA. What Can You Find about Polycystic Ovary Syndrome (PCOS) Online? Assessing Online Information on PCOS: Quality, Content, and User-Friendliness. *Seminars in Reproductive Medicine* [Internet]. 2018 Sep 6 [cited 2022 May 19];36(1):50–8. Available from: <http://www.thieme-connect.com/products/ejournals/html/10.1055/s-0038-1667186>
6. Gilbert EW, Tay CT, Hiam DS, Teede HJ, Moran LJ. Comorbidities and complications of polycystic ovary syndrome: An overview of systematic reviews. *Clinical Endocrinology*. 2018;89.
7. Sheehan MT. Polycystic Ovarian Syndrome: Diagnosis and Management [Internet]. Vol. 2, *Clinical Medicine & Research*. 2003. Available from: <http://www.mfldclin.edu/clinmedres>
8. Teede HJ, Misso ML, Costello MF, Dokras A, Laven J, Moran L, et al. Recommendations from the international evidence-based guideline for the assessment and management of polycystic ovary syndrome. *Fertility and Sterility*. 2018;110(3):364–79.
9. Sanchez-Garrido MA, Tena-Sempere M. Metabolic dysfunction in polycystic ovary syndrome: Pathogenic role of androgen excess and potential therapeutic strategies.



- Molecular Metabolism [Internet]. 2020;35(February):100937. Available from: <https://doi.org/10.1016/j.molmet.2020.01.001>
10. Vink JM, Sadrzadeh S, Lambalk CB, Boomsma DI. Heritability of polycystic ovary syndrome in a Dutch twin-family study. *Journal of Clinical Endocrinology and Metabolism*. 2006;91(6):2100–4.
  11. Jeanes YM, Reeves S. Metabolic consequences of obesity and insulin resistance in polycystic ovary syndrome: diagnostic and methodological challenges. 2017; Available from: <https://doi.org/10.1017/S0954422416000287>
  12. Kim CH, Lee SH. Effectiveness of Lifestyle Modification in Polycystic Ovary Syndrome Patients with Obesity: A Systematic Review and Meta-Analysis. *Life*. 2022;12(2).
  13. Fauser BCJM. Revised 2003 consensus on diagnostic criteria and long-term health risks related to polycystic ovary syndrome (PCOS) The Rotterdam ESHRE/ASRM-sponsored PCOS consensus workshop group. Available from: <https://academic.oup.com/humrep/article/19/1/41/690226>
  14. Bozdag G, Mumusoglu S, Zengin D, Karabulut E, Okan Yildiz B. The prevalence and phenotypic features of polycystic ovary syndrome: a systematic review and meta-analysis. *Human Reproduction* [Internet]. 2016;31(12):2841–55. Available from: <https://academic.oup.com/humrep/article/31/12/2841/2730240>
  15. Lujan ME, Chizen DR, Pierson RA. Diagnostic Criteria for Polycystic Ovary Syndrome: Pitfalls and Controversies.
  16. Dunaif A, Fauser BCJM. Renaming PCOS-A Two-State Solution. *J Clin Endocrinol Metab* [Internet]. 2013;98(11):4325–8. Available from: <https://academic.oup.com/jcem/article/98/11/4325/2834812>
  17. March WA, Moore VM, Willson KJ, Phillips DIW, Norman RJ, Davies MJ. The prevalence of polycystic ovary syndrome in a community sample assessed under contrasting diagnostic criteria. Available from: <https://academic.oup.com/humrep/article/25/2/544/673002>
  18. Ismayilova M, Yaya S. What can be done to improve polycystic ovary syndrome (PCOS) healthcare? Insights from semi-structured interviews with women in Canada. 2020; Available from: <https://doi.org/10.1186/s12905-022-01734-w>
  19. Rubin KH, Glinborg D, Nybo M, Abrahamsen B, Andersen M. Development and risk factors of type 2 diabetes in a nationwide population of women with polycystic ovary syndrome. *Journal of Clinical Endocrinology and Metabolism*. 2017;102(10):3848–57.

20. Barthelmess EK, Naz RK. Polycystic ovary syndrome: current status and future perspective. Vol. 6, *Frontiers in Bioscience*. 2014.
21. Medical Association A. Letters Association Between Polycystic Ovary Syndrome and Cancer Risk. 2018; Available from: <https://jamanetwork.com/>
22. Lim SS, Hutchison SK, van Ryswyk E, Norman RJ, Teede HJ, Moran LJ. Lifestyle changes in women with polycystic ovary syndrome. *Cochrane Database of Systematic Reviews*. 2019;2019(3).
23. Luque-Ramírez M, Nattero-Chávez L, Ortiz Flores AE, Escobar-Morreale HF. Combined oral contraceptives and/or antiandrogens versus insulin sensitizers for polycystic ovary syndrome: a systematic review and meta-analysis. *Human Reproduction Update* [Internet]. 2018;24(2):225–41. Available from: <https://academic.oup.com/humupd/article/24/2/225/4779919>
24. Tanbo T, Mellembakken J, Sverre Bjercke |, Ring | Eva, Åbyholm T, Fedorcsak | Peter. Ovulation induction in polycystic ovary syndrome. *Acta Obstet Gynecol Scand*. 2018;97:1162–7.
25. Stefanaki C, Bacopoulou F, Livadas S, Kandaraki A, Karachalios A, Chrousos GP, et al. Stress The International Journal on the Biology of Stress Impact of a mindfulness stress management program on stress, anxiety, depression and quality of life in women with polycystic ovary syndrome: a randomized controlled trial. Available from: <https://www.tandfonline.com/action/journalInformation?journalCode=ists20>
26. Raja-Khan N, Agito K, Shah J, Stetter CM, Gustafson TS, Socolow H, et al. Mindfulness-Based Stress Reduction for Overweight/Obese Women With and Without Polycystic Ovary Syndrome: Design and Methods of a Pilot Randomized Controlled Trial HHS Public Access. *Contemp Clin Trials*. 2015;41:287–97.
27. Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health* [Internet]. 1999;53:105–11. Available from: <http://jech.bmj.com/>
28. Ghani S, Fan KS, Fan KH, Lenti L, Raptis D. Using the ensuring quality information for patients tool to assess patient information on appendicitis websites: Systematic search and evaluation. *Journal of Medical Internet Research*. 2021;23(3):1–12.
29. Measure the Readability of Text - Text Analysis Tools - Unique readability tools to improve your writing! *App.readable.com* [Internet]. [cited 2022 Jun 12]. Available from: <https://app.readable.com/text/>

30. Raptis DA, Sinanyan M, Ghani S, Soggiu F, Gilliland JJ, Imber C. Quality assessment of patient information on the management of gallstone disease in the internet – A systematic analysis using the modified ensuring quality information for patients tool. *Hpb* [Internet]. 2019;21(12):1632–40. Available from: <https://doi.org/10.1016/j.hpb.2019.03.355>
31. Hosseinzadeh S, Blazar P, Earp BE, Zhang D. Dupuytren’s Contracture: The Readability of Online Information. Available from: <https://us.sagepub.com/en-us/nam/open-access-at-sage>
32. Kite C, Lahart IM, Afzal I, Broom DR, Randeva H, Kyrou I, et al. Exercise, or exercise and diet for the management of polycystic ovary syndrome: A systematic review and meta-analysis. *Systematic Reviews*. 2019;8(1):1–28.
33. Farnood A, Johnston B, Mair FS. A mixed methods systematic review of the effects of patient online self-diagnosing in the “smart-phone society” on the healthcare professional-patient relationship and medical authority. Available from: <https://doi.org/10.1186/s12911-020-01243-6>
34. Magdalena Bujnowska-Fedak M, W, P. The Impact of Online Health Information on Patient Health Behaviours and Making Decisions Concerning Health. Available from: [www.mdpi.com/journal/ijerph](http://www.mdpi.com/journal/ijerph)
35. Google Søkretrender [Internet]. [cited 2022 Jul 11]. Available from: <https://trends.google.com/trends/?geo=HR>
36. Storino A, Castillo-Angeles M, Watkins AA, Vargas C, Mancias JD, Bullock A, et al. Assessing the Accuracy and Readability of Online Health Information for Patients With Pancreatic Cancer Supplemental content at [jamasurgery.com](http://jamasurgery.com). *JAMA Surg* [Internet]. 2016;151(9):831–7. Available from: <https://jamanetwork.com/>
37. Dy CJ, Taylor SA, Patel RM, McCarthy MM, Roberts TR, Daluiski A. Does the quality, accuracy, and readability of information about lateral epicondylitis on the internet vary with the search term used? *Hand*. 2012;7(4):420–5.
38. Lovett J, Gordon C, Patton S, Chen CX. Online information on dysmenorrhoea: An evaluation of readability, credibility, quality and usability. *Journal of Clinical Nursing*. 2019;28(19–20):3590–8.
39. Buhi ER, Daley EM, Oberne A, Smith SA, Schneider T, Fuhrmann HJ. Quality and accuracy of sexual health information web sites visited by young people. *Journal of Adolescent Health* [Internet]. 2010;47(2):206–8. Available from: <http://dx.doi.org/10.1016/j.jadohealth.2010.01.002>

40. Fan KS, Ghani SA, MacHairas N, Lenti L, Fan KH, Richardson D, et al. COVID-19 prevention and treatment information on the internet: A systematic analysis and quality assessment. *BMJ Open*. 2020;10(9).
41. Logeswaran A, Chong YJ, Awad J, Edmunds MR. Assessment of the quality of online information on cataract surgery. *JCRS Online Case Reports* [Internet]. 2018;6(4):57–8. Available from: <https://doi.org/10.1016/j.jcro.2018.05.002>
42. Ghani S, Fan KS, Fan KH, Lenti L, Raptis D. Using the ensuring quality information for patients tool to assess patient information on appendicitis websites: Systematic search and evaluation. *Journal of Medical Internet Research*. 2021;23(3):1–12.
43. Stossel LM, Segar N, Gliatto P, Fallar R, Karani R. Readability of Patient Education Materials Available at the Point of Care. *J Gen Intern Med*. 2012;27(9):1165–70.

## **8. SUMMARY**

**Objectives:** The purpose of this study was to analyze the quality, accuracy, and readability of patient information on PCOS available online in English. We hypothesized that there would be a difference in the quality of the PCOS information as assessed by the DISCERN tool according to search engine and producer. As well as a difference in the clarity of the PCOS information as assessed by the EQIP tool according to search engine and producer. We further hypothesized that there would be a difference in accuracy of the information on PCOS symptoms between the different search engines and producer type. Lastly, we hypothesized that there would be a different median readability level of the PCOS information according to both search engine and producer type.

**Materials and methods:** We imitated search strategies of the general public. Using a systematic methodology, we examined the quality, clarity, accuracy, and readability of online information about PCOS available in English. Internet searches were performed with five separate searches using the keywords from Google Trends. The searches were performed using Google, Bing and Yahoo search engines extracting the top 10 webpages from each. A total of 150 unique webpages were evaluated and categorized.

**Results:** The majority of webpages were commercial (n=85, 57%), compared to non-commercial which were the remaining (n=65, 43%). Google webpages describing PCOS had a significant higher median DISCERN score than webpages from Bing and Yahoo. The overall DISCERN score was higher for non-commercial webpages than for commercial, but no scientific significant difference was established. The quality of information showed 39 (26%) webpages rated as good or excellent, 58 (39%) webpages rated as fair and 53 (35%) rated as poor or very poor. According to the EQIP score there was no significant difference between the scores according to Google, Bing or Yahoo. According to webpage producer, non-commercial webpages had a slightly higher score than commercial, with no significant difference being established. An overall high score was achieved by (24%) of the webpages and the remaining (76%) achieved a low score. We found no significant difference in the comparison of the specific accuracy ratings by either producer or search engine. Comparisons in the readability did not reach statistical significance between the three search engines nor between the commercial and non-commercial webpages.

**Conclusion:** High-quality information regarding PCOS with the recommended reading level is lacking. Out of the three search monitors Google showed the best quality. Online information regarding PCOS in English had a high symptom accuracy level. Clarity, accuracy and reading level did not show significant differences between search monitors and producers.

## **9. CROATIAN SUMMARY**



**Naslov:** Analiza kvalitete, točnosti i čitljivosti informacija pacijenticama o sindromu policističnih jajnika (PCOS) na internetu dostupnih na engleskom jeziku.

**Ciljevi:** Svrha ove studije bila je analizirati kvalitetu, točnost i čitljivost informacija pacijentima o PCOS-u, dostupnih na internetu na engleskom jeziku. Pretpostavili smo da će postojati razlika u kvaliteti podataka u PCOS-u prema procjeni alata DISCERN u odnosu na tražilicu i proizvođača. Kao i razlika u jasnoći informacija o PCOS-u prema procjeni alata EQIP u odnosu na tražilicu i proizvođača. Nadalje smo pretpostavili da će postojati razlika u točnosti informacija o simptomima PCOS-a između različitih tražilica i tipa proizvođača. Naposljetku, pretpostavili smo da će postojati različita srednja razina čitljivosti podataka u PCOS-u u odnosu na tražilicu i vrstu proizvođača.

**Materijali i metode:** Imitirali smo strategije pretraživanja opće javnosti. Koristeći sustavnu metodologiju ispitali smo kvalitetu, jasnoću, točnost i čitljivost online informacija o PCOS-u dostupnih na engleskom jeziku. Internetska pretraživanja izvršena su s pet odvojenih pretraga pomoću ključnih riječi iz Google Trends. Pretraživanje je izvršeno pomoću Google, Bing i Yahoo tražilica izdvajajući 10 najpopularnijih web stranica iz svake. Ukupno je ocijenjeno i kategorizirano 150 jedinstvenih web stranica.

**Rezultati:** Većina web stranica bila je komercijalna (n=85, 57%), u usporedbi s nekomercijalnim koje su ostale (n=65, 43%). Googleove web-stranice koje opisuju PCOS imale su značajno višu srednju DISCERN ocjenu od web-stranica Binga i Yahooa. Ukupni DISCERN rezultat bio je viši za nekomercijalne web-stranice nego za komercijalne, ali nije ustanovljena nikakva znanstvena značajna razlika. Kvaliteta informacija pokazala je da je 39 (26%) web stranica ocijenjeno kao dobro ili izvrsno, 58 (39%) web stranica ocijenjeno je kao zadovoljavajuće i 53 (35%) kao loše ili vrlo loše. Prema EQIP rezultatu nije bilo značajne razlike između rezultata prema Googleu, Bingu ili Yahoou. Prema proizvođaču web stranica, nekomercijalne web stranice imale su nešto višu ocjenu od komercijalnih, bez značajne razlike. Ukupnu visoku ocjenu postiglo je (24%) web-stranica, a preostalih (76%) postiglo je nisku ocjenu. Nismo pronašli značajnu razliku u usporedbi specifičnih ocjena točnosti od strane proizvođača ili tražilice. Usporedbe u čitljivosti nisu dosegle statističku značajnost između tri tražilice niti između komercijalnih i nekomercijalnih web stranica.

**Zaključak:** Nedostaju visokokvalitetne informacije u PCOS-u s preporučenom razinom čitanja. Od tri monitora pretraživanja Google je pokazao najbolju kvalitetu. Online informacije o PCOS-u na engleskom jeziku imale su visoku razinu točnosti simptoma. Jasnoća, točnost i razina čitanja nisu pokazale značajne razlike između monitora pretraživanja i proizvođača

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