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CORRELATES OF COMPLETION RATE AND QUESTION COMPREHENSION FOR A MULTI-ETHNICITY ONLINE STUDY OF OVULATION AND MENSTRUATION HEALTH

by

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CORRELATES OF COMPLETION RATE AND QUESTION COMPREHENSION FOR A MULTI-ETHNICITY ONLINE STUDY OF OVULATION AND MENSTRUATION HEALTH

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ABSTRACT

Background

Polycystic ovary syndrome (PCOS), a diagnosis of exclusion, is considered the most common endocrinopathy in females of reproductive age. Current cohorts of individuals with PCOS exist but are limited, specifically in racial/ethnic diversity, due to the complexity of multiple choice survey questions and difficulty to obtain data.

Methods

After examining existing cohorts and their questionnaires, an online survey was designed specifically to assess PCOS characteristics in a diverse population. The survey was field tested for cognitive understanding and usability in a diverse population, with respect to race/ethnicity and education. After cognitive testing, the survey was launched online and participants were recruited to complete the survey.

Survey completion rates by level of education, race/ethnicity, and birthplace were established by determining the proportion of participants in each subgroup to complete the entire survey. We also looked at the average percentage of the survey participants in each subgroup completed before discontinuing the survey. Univariate regression analyses were performed to evaluate these results.

Question comprehension was determined by evaluating all survey questions by length and complexity. The survey question asking participants to report their typical menstrual cycle length (MCL) was selected to assess participants' question comprehension. Responses that fell outside of the normal range for MCL were examined and those that may have been inaccurate were isolated. Level of education and birthplace reported by participants who may have responded to the MCL question inaccurately were noted and assessed collectively.

Results

Two-hundred and forty-eight participants, aged 18-53 years, began the survey between August 9, 2017 and October 23, 2017. Of these participants, 71.7% identified as White; 11.7% as Hispanic, Latina, or of Spanish Origin; 12.6% as Black or African American; 13.2% as other races/ethnicities; and 9.2% as more than one race/ethnicity.

Of the participants with some high school education, a high school diploma, or a GED, 74% completed the entire survey; of those with some college education or a 2-year degree, 81% completed the entire survey; and of those with a 4-year college degree or more, 90% completed the entire survey. On average, participants with a high school education completed 86% of the survey before discontinuing; those with some college education completed 91% of the survey before discontinuing; and those with a college degree or more completed 95% of the survey before discontinuing.

Of the participants who identified as White, 92% completed the entire survey; of those who identified as Hispanic, Latina, or of Spanish Origin, 68% completed the entire

survey; and of those who identified as Black or African American, 70% completed the entire survey, with statistical significance ($p = 0.002$). On average, participants who identified as White completed 96% of the survey before discontinuing; those who identified as Hispanic, Latina, or of Spanish Origin completed 82% of the survey before discontinuing; and those who identified as Black or African American completed 86% of the survey before discontinuing, with statistical significance ($p = 0.002$).

Of the participants who were born in the United States, 92% completed the entire survey, and of the participants who were not born in the United States, 66% completed the entire survey, with statistical significance ($p < 0.0001$). On average, participants who were born in the United States completed 96% of the survey before discontinuing and participants who were not born in the United States completed 81% of the survey before discontinuing, with statistical significance ($p < 0.0001$).

When asked to report their typical MCL, 66 participants (28.1%) responded with irregular answers and 20 (8.5%) may have responded inaccurately. Of these 20 participants, 18 (90%) completed at least some amount of college and 16 (80%) were born in the United States.

Discussion

This pilot study succeeds in establishing a cohort that is more racially/ethnically diverse than existing cohorts of individuals with PCOS. In order to gather more information on the ways in which PCOS manifests across different groups, future recruitment efforts ought to be more targeted towards individuals belonging to different

racial/ethnic groups and socioeconomic statuses. Additionally, the baseline survey and future modules can be made more accessible to diverse groups through language translation. Furthermore, the addition of a menstrual cycle tracker component to the survey may increase the accuracy of information on participants' menstrual cycle patterns.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ACTH ..... adrenocorticotropic hormone

AES ..... Androgen Excess Society

BMC ..... Boston Medical Center

BUCRC ..... Boston University Charles River Campus

BUMC ..... Boston University Medical Campus

BUSM ..... Boston University School of Medicine

BUSPH ..... Boston University School of Public Health

CCHS ..... Cape Cod Health Study

CRH ..... corticotropin-releasing hormone

CVD ..... cardiovascular disease

DOB ..... Doctor's Office Building

DHEA ..... dehydroepiandrosterone

DHEAS ..... dehydroepiandrosterone sulfate

E1 ..... estrone

E2 ..... estradiol

FHS/OMNI ..... Framingham Heart Study and Omni Cohorts

FSH ..... follicle-stimulating hormone

GUTS ..... Growing Up Today Study

GnRH ..... gonadotropin-releasing hormone

IRB ..... Institutional Review Board

LH ..... luteinizing hormone

MCL ..... menstrual cycle length

NHS2 ..... Nurses' Health Study 2

NIH ..... National Institutes of Health

OM Health Study ..... Ovulation and Menstruation Health Study

PCOS ..... polycystic ovary syndrome

PRESTO ..... Pregnancy Study Online

QR code ..... Quick Response Code

SHBG ..... sex hormone-binding globulin

T ..... testosterone

T2DM ..... type 2 diabetes mellitus

INTRODUCTION

Polycystic Ovary Syndrome

Criteria. Polycystic ovary syndrome (PCOS), a diagnosis of exclusion, is considered the most common endocrinopathy in females of reproductive age; however, a consensus on diagnostic criteria for the syndrome has yet to be established (Azziz 2004; Chang 2004; Franks 1995; Kauffman 2008; Toulis 2009; Wood 2007). According to the National Institutes of Health (NIH), PCOS should be diagnosed in the presence of chronic oligo- or anovulation and clinical or biochemical hyperandrogenism, with the exclusion of related disorders (Zawadzki 1992). In 2004, the Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group revised the NIH definition of PCOS, concluding that the syndrome should be diagnosed in the case that at least two of the following three symptoms are present in the individual: 1.) chronic oligo- or anovulation, 2.) clinical or biochemical hyperandrogenism, and 3.) polycystic ovaries on ultrasound (Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group). The Androgen Excess Society (AES) subsequently declared that clinical or biochemical hyperandrogenism is an essential component of the syndrome, concluding that PCOS should only be diagnosed in the presence of both hyperandrogenism (clinical or biochemical) and ovarian dysfunction (chronic oligo- or anovulation and/or polycystic ovaries) (Azziz 2006; Azziz 2009).

Prevalence. A number of studies have aimed to ascertain the prevalence of PCOS. In a study on 728 females aged 27-34 years born in Adelaide, South Australia, who were

predominantly Caucasian (94% had European ancestry), PCOS prevalence was 8.7 ± 2.0% according to the NIH criteria, 11.9 ± 2.4% according to the Rotterdam criteria (17.8 ± 2.8% when imputed), and 10.2 ± 2.2% according to the AES criteria (12.0 ± 2.4% when imputed) (March 2010). In a study on 1126 females aged 18-45 years from various regions of Iran, PCOS prevalence was 7.1% according to the NIH criteria, 14.6% according to the Rotterdam criteria, and 11.7% according to the AES criteria (Tehrani 2011). In a study on 15,924 females aged 19-45 years from various regions of China, PCOS prevalence was 5.6% according to the Rotterdam criteria (Li 2013). In a study on 863 females aged 20-40 years, who were employees of Copenhagen University Hospital, Rigshospitalet, in Copenhagen, Denmark, PCOS prevalence was 16.6% according to the Rotterdam criteria (Lauritsen 2014). In a systematic review and meta-analysis of 24 studies reporting PCOS prevalence, overall PCOS prevalence was 6% (5-8%) according to the NIH criteria, 10% (8-13%) according to the Rotterdam criteria, and 10% (7-13%) according to the AES criteria (Bozdag 2016) (Table 1).

Table 1. Summary of PCOS Prevalence of Different Populations by Diagnostic Criteria. Data for Australia from March 2010; for Iran from Tehrani 2011; for China from Li 2013; for Denmark from Lauristen 2014; for Review from Bozdag 2016.

	PCOS Prevalence by Criteria		
Study	**NIH Criteria**	**Rotterdam Criteria**	**AES Criteria**
Australia	8.7 ± 2.0%	11.9 ± 2.4% 17.8 ± 2.8%*	10.2 ± 2.2% 12.0 ± 2.4%*
Iran	7.1%	14.6%	11.7%
China	-	5.6%	-
Denmark	-	16.6%	-
Review	6% (5-8%)	10% (8-13%)	10% (7-13%)

*Imputed result for the presence of polycystic ovaries in participants who did not consent to ultrasound

PCOS prevalence estimates range from as low as 2.2% to as high as 26% due to the application of different diagnostic criteria on a variety of populations (Asuncion 2000; Azziz 2004; Barth 2007; Chen 2008; Diamanti-Kandarakis 1999; Farah 1999; Franks 1995; Goodarzi 2005; Knochenhauer 1998; Kumarapeli 2008; March 2010; Michelmore 1999; Teimuraz 2005; Wang 2011). This wide range illustrates both the difference in PCOS prevalence across races/ethnicities and the result of implementing the different criteria (for instance, PCOS prevalence can double when implementing the Rotterdam criteria over the NIH or AES criteria) (Broekmans 2006; Lowe 2005). Figure 1 portrays this.

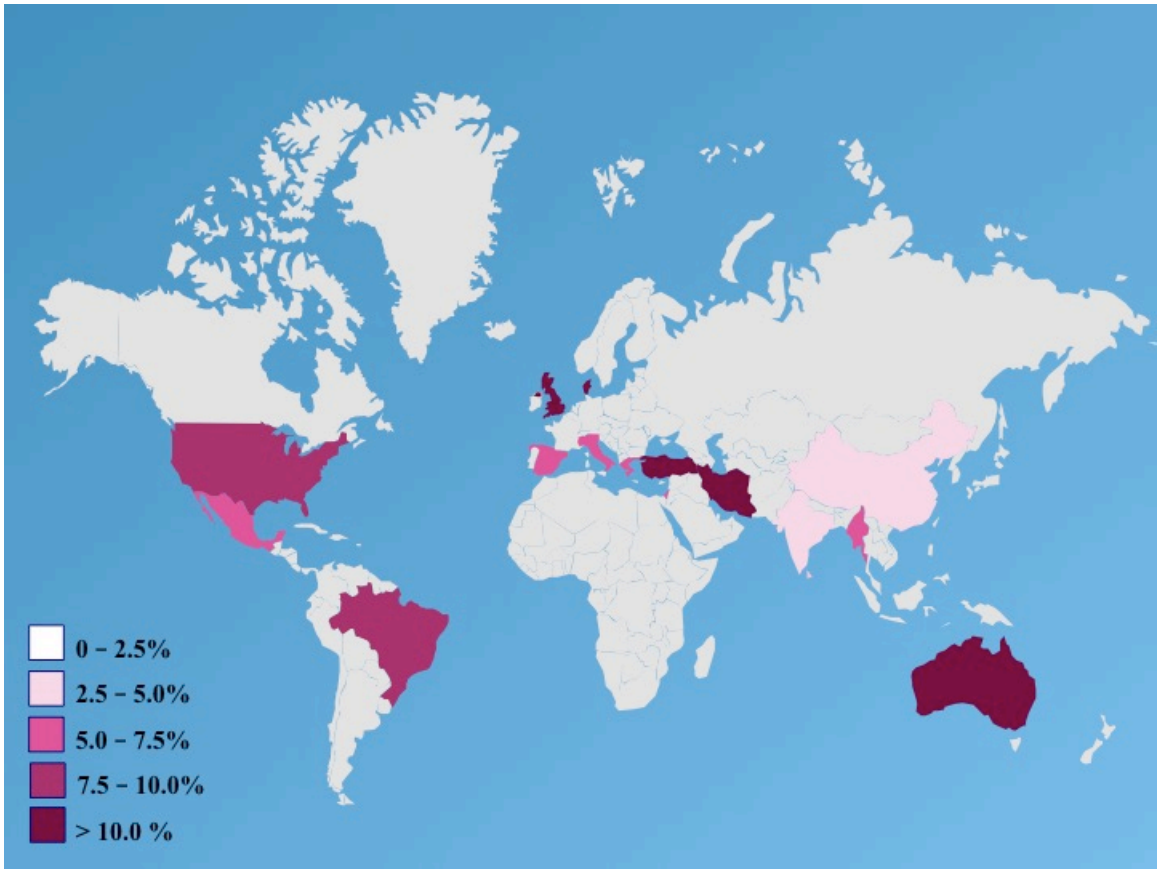

Figure 1. Global Prevalence of PCOS. Data for Australia from Boyle 2012, March 2010; for Brazil from Gabrielli 2012; for China from Chen 2008, Li 2013, Ma 2010; for Denmark from Lauritsen 2014; for Greece from Diamanti-Kandarakis 1999; for India from Gill 2012; for Iran from Mehrabian 2011, Rashidi 2014, Tehrani 2011; for Italy from Sanchón 2012; for Mexico from Moran 2010; for Palestine from Musmar 2013; for Spain from Asunción 2000; for Sri Lanka from Kumarapeli 2008; for Thailand from Vutyavanich 2007; for United Kingdom from Michelmore 1999; for United States from Azziz 2004, Goodarzi 2005.

Pathophysiology. There are multiple etiologies of PCOS. In one case, the hypothalamus releases increased levels of gonadotropin-releasing hormone (GnRH). When GnRH is hypersecreted, it selectively stimulates the release of luteinizing hormone (LH) over follicle-stimulating hormone (FSH) by the anterior pituitary. Higher levels of

LH than FSH (35 ± 4.6 mIU/mL and 10.3 ± 0.7 mIU/mL, respectively) result in greater stimulation of the theca cells (by LH) than the granulosa cells (by FSH) in the ovaries (DeVane 1975). Increased stimulation of the theca cells results in increased androgen production. Meanwhile, comparably decreased stimulation of the granulosa cells results in granulosa cell atresia and consequently decreased aromatase production (Diamanti-Kandarakis 2012).

Decreased aromatase levels prevent the conversion of androgen to estrogen, causing androgen levels to remain elevated (with testosterone, T, levels at 468 ± 41 pg/mL vs. normal T levels at 325 ± 34 pg/mL, and androstenedione levels at 2083 ± 138 pg/mL vs. normal androstenedione levels at 1123 ± 153 pg/mL) (DeVane 1975). Furthermore, obesity and hyperinsulinemia (components of metabolic syndrome, which is frequently seen in individuals with PCOS) decrease the availability of sex hormone-binding globulin (SHBG), thus decreasing inhibition of androgen activity. It is also theorized that high levels of dehydroepiandrosterone (DHEA) are released by the adrenal cortex in individuals with PCOS due to hyper-responsiveness of the adrenal cortex to adrenocorticotropic hormone (ACTH), which is produced by the anterior pituitary upon stimulation by corticotropin-releasing hormone (CRH) from the hypothalamus. Increased DHEA (11.3 ± 1.7 mμg/mL vs. normal levels at 7.5 ± 1.2 mμg/mL) perpetuates elevated levels of androgen (DeVane 1975; Lachelin 1979; Yildiz 2007). Decreased estrogen (with estradiol, E2, levels at 58 ± 4 pg/mL vs. normal E2 levels at 63 ± 8 pg/mL) results in decreased follicular growth or follicular arrest. A low ratio of estrogen to androgen results in decreased sensitivity of the hypothalamus to estrogen and progesterone. This

decreased sensitivity prevents negative feedback by estrogen and progesterone on the hypothalamus to decrease GnRH release. Resultantly, hypersecretion of GnRH by the hypothalamus continues (Diamanti-Kandarakis 2012) (Table 2).

Table 2. Hormone Levels in Non-PCOS and PCOS Females on Days 2-4 of the Menstrual Cycle. Data from DeVane 1975.

Hormone	Non-PCOS	PCOS
Luteinizing Hormone (LH)*	12.7 ± 2.6 mIU/mL	35 ± 4.6 mIU/mL
Follicle-Stimulating Hormone (FSH)	8.7 ± 0.9 mIU/mL	10.3 ± 0.7 mIU/mL
Estrone (E1)*	52 ± 5 pg/mL	92 ± 4 pg/mL
Estradiol (E2)	63 ± 8 pg/mL	58 ± 4 pg/mL
Testosterone (T)*	325 ± 34 pg/mL	468 ± 41 pg/mL
Androstenedione*	1123 ± 153 pg/mL	2083 ± 138 pg/mL
Dehydroepiandrosterone Sulfate (DHEAS)*	2.0 ± 0.37 mμg/mL	3.4 ± 0.4 mμg/mL
Dehydroepiandrosterone (DHEA)	7.5 ± 1.2 mμg/mL	11.3 ± 1.7 mμg/mL

*Statistically significant differences

Hyperandrogenism may manifest in the form of hirsutism, increased acne, and/or alopecia (Diamanti-Kandarakis 2012; Goodarzi 2011). Follicular arrest results in infrequent ovulation and/or the formation of ovarian cysts (eventually, polycystic ovaries) (Hull 1987; Jonard 2003; Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group).

Health implications. The reproductive health implications of PCOS include infertility and endometrial cancer (Balen 1995; Dahlgren 1991; Mulders 2004; Navaratnarajah 2008; Tehrani 2010). Metabolic risk factors include obesity, insulin resistance, type 2 diabetes mellitus (T2DM), metabolic syndrome, dyslipidemia, cardiovascular diseases (CVD), and sleep apnea (Amowitz 1999; Christakou 2008; Chun-Sen 2010; Dokras 2008; Ehrmann 2006; El-Mazny 2010; Essah 2007; Shaw 2008; Stepto 2013; Talbott 2004; Teede 2010). Psychological implications include depression, anxiety, and low self-esteem (Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group; Teede 2007; Meyer 2005).

Existing cohorts. The Cape Cod Health Study (CCHS), the Framingham Heart Study and Omni Cohorts (FHS/OMNI), and the Nurses' Health Study 2 (NHS2) are large population-based cohorts that were established without aiming to ascertain PCOS prevalence but report PCOS-related findings. Limitations of these include lack of thorough PCOS phenotyping, too few reported cases of menstrual irregularity, and poor correlation between PCOS self-reporting and PCOS in medical records (Chavarro 2016; Mahalingaiah 2016; Mahalingaiah 2017). Furthermore, these cohorts lack racial/ethnic diversity, with over 90% of participants being Caucasian. As a result of these limitations, the various phenotypes of PCOS, and the ways in which these phenotypes present themselves across varying races/ethnicities, the global burden of PCOS cannot be assessed accurately. A cohort designed specifically to evaluate PCOS characteristics is needed.

Specific Aims

We designed an online survey, the Ovulation and Menstruation Health Study (OM Health Study) to establish a multi-ethnicity cohort of individuals with PCOS and a comparison cohort of healthy females. In order to determine correlates for survey completion rate and question comprehension of the baseline questionnaire, this thesis aims to:

1. Evaluate the relationship between survey completion rate and
    a. Level of education
    b. Race/ethnicity
    c. Birthplace
2. Determine participants' ability to comprehend menstrual cycle length and respond to questions regarding menstrual cycle length by
    a. Level of education
    b. Birthplace

METHODS

Survey Design

In an effort to establish a multi-ethnicity cohort of individuals with PCOS, the Mahalingaiah Lab at Boston University School of Medicine (BUSM) designed an online survey, the OM Health Study. The survey was written after examining existing cohorts and their questionnaires, including the CCHS, the Growing Up Today Study (GUTS), the FHS, the LIFE Health Care Study, the NHS2, the Pregnancy Study Online (PRESTO), and Project Viva. The OM Health Study survey was developed by a board-certified reproductive endocrinology/infertility physician-scientist and includes questions concerning demographics, anthropometrics, menstrual cycle health, contraceptive use, medication and supplement use, PCOS status, reproductive health, general health, diet and lifestyle, and pregnancy and birth history. A licensed medical illustrator created images for questions on body shape and hair growth. The survey was written at an 8th-grade reading level and tested for cognitive understanding and usability for a diverse population, with respect to race/ethnicity and education.

Eligibility

Individuals were deemed eligible to participate in the study if they were 18 years of age or older and identified as female, trans male, or “other” gender. Individuals were deemed ineligible to participate if they were under 18 years of age, identified as male,

were pregnant at the time of participation, had a hysterectomy, or had been exposed to radiation or chemotherapy.

Recruitment

After cognitive testing, the survey was launched online and made available to the public. The survey could be accessed through the study website, which also exhibited a two-minute animated video on ovulation and menstruation to introduce the study. Flyers for the study with the hyperlink and a Quick Response Code (QR code) to the study website were posted around the Boston Medical Center (BMC) campus, the BUSM campus, the Boston University School of Public Health (BUSPH) building, and the Boston University Charles River Campus (BUCRC). Recruitment letters were sent to patients with OB/GYN and endocrinology appointments at BMC during scheduled recruitment hours. The recruitment letters introduced recipients to the OM Health Study and explained that study staff might be recruiting participants for the study in the clinic waiting room during their visit. The letters provided recipients with a hyperlink to the study website and an email address to contact the research team.

The study staff recruited participants in-person in OB/GYN and endocrinology waiting rooms at BMC and at the Boston Women's Market, a community fair, in the Jamaica Plain neighborhood of Boston, MA. In-person recruitment was achieved by having participants complete a consent form and screener on an electronic tablet. If participants were eligible to complete the survey, the form asked the participant to provide an email address. A link to the survey was then sent to the participant's email.

Participants recruited at BMC were given the option to begin the survey in the waiting room while waiting for their appointment. A return code was provided to participants who started but did not complete the survey. Participants recruited at the Boston Women's Market were encouraged to complete the survey at home.

The study staff also recruited participants for the study online using Facebook. A Facebook Page for the study was created and the study staff posted information on the study in various Facebook Groups. While recruiting, the study staff posted related articles on the Facebook Page to maintain interest and to remind Followers of the survey. Furthermore, information on the study appeared in the weekly Boston University Medical Campus (BUMC) News and Events email with Institutional Review Board (IRB) approval by BUMC.

Assessment of Completion Rate

Survey completion rates by level of education, race/ethnicity, and birthplace were established by determining the proportion of participants in each subgroup to complete the entire survey. We also looked at the average percentage of the survey participants in each subgroup completed before discontinuing the survey.

Assessment of Question Comprehension

Question comprehension was determined by evaluating all survey questions by length and complexity. The survey question asking participants to report their typical

menstrual cycle length (MCL) was selected to assess participants' question comprehension.

Participants were provided with a definition of MCL (the number of days from the first day of one menstrual period to the first day of the next menstrual period) and a normal range for MCL (21 to 35 days) (Figure 2). They were subsequently asked to report their typical MCL. Participants who selected "don't know" when asked to report MCL were asked to take a guess.

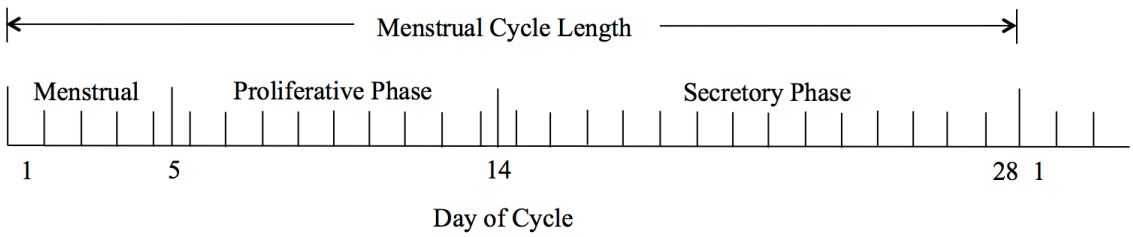

Figure 2. Menstrual Cycle Diagram. Menstrual cycle length (MCL) is defined as the number of days from the first day of one menstrual period to the first day of the next menstrual period. The normal range for MCL is 21-35 days.

Irregularities. We defined a "short" MCL as less than 21 days, a "normal" MCL as 21 to 35 days, and a "long" MCL as greater than 35 days. The following were considered "irregular" responses to the MCL question:

1. Less than 21 days (short)
2. 21 days
3. More than 35 days (long)
4. "Don't know"

While an MCL of 21 days is "normal," reporting 21 days was considered irregular because participants may have responded with 21 days, having misinterpreted the definition of MCL as the number of days from the *last* day of one menstrual period to the first day of the next menstrual period, rather than as the number of days from the *first* day of one menstrual period to the first day of the next menstrual period.

Inaccuracies. The following were considered potentially "inaccurate" responses to the MCL question:

1. Reporting an MCL of < 21 days, 21 days, or > 35 days without reporting any other menstrual irregularities
2. Selecting "don't know" and then selecting a normal range
3. Selecting "don't know" and then selecting an irregular range without reporting any other menstrual irregularities
4. Selecting "don't know" and then selecting "still not sure" without reporting any other menstrual irregularities

Responses that may have been inaccurate (based on the participants' responses to questions in the menstrual cycle health, contraceptive use, PCOS status, and reproductive health sections of the survey) were further evaluated (Appendix 1). Level of education and birthplace reported by participants who may have responded to the MCL question inaccurately were noted and assessed collectively.

Statistical Analysis

Univariate analyses were performed to evaluate completion rate. Fisher's Exact test was used to compare the proportion of participants to complete the entire survey in each subgroup for level of education and race/ethnicity. The Kruskal-Wallace test was used to compare the average percentage of the survey participants responded to before discontinuing the survey in each subgroup for level of education and race/ethnicity. The Chi-squared test was used to compare the proportion of participants to complete the entire survey between participants born in the United States and those born outside of the United States. The Wilcoxon Rank-Sum test was used to compare the average percentage of the survey participants responded to before discontinuing the survey between participants born in the United States and those born outside of the United States.

RESULTS

Demographics

Between August 9, 2017 and October 23, 2017, 389 participants approached the survey consent form. Of those participants, 99.0% completed the consent form and 98.7% started the screener. Of the 384 participants who started the screener, 355 completed it and 316 screened in. Two-hundred and forty-eight (63.8% of those who approached the consent form) began the survey and 214 (55.0%) completed the entire survey (Table 3).

Table 3. Summary of Survey Completion

Survey Completion	Participants
Approached Consent Form	389 (100%)
Completed Consent Form	385 (99.0%)
Consented	384 (98.7%)
Approached Screener	384 (98.7%)
Completed Screener	355 (91.3%)
Screened In	316 (81.2%)
Approached Survey	248 (63.8%)
Completed Survey	214 (55.0%)

The 248 participants who began the pilot survey after completing the consent form and screener were aged 18-53 years, 27.6 years on average. Nearly all participants identified as female (99.2%) and reported currently living in the United States (98.0%). Of those who reported currently living in the United States, 68.6% lived in the Northeast and 25.8% lived in the Midwest. One hundred and ninety-nine participants (80.9%) were born in the United States and 47 participants (19.1%) were not born in the United States. One hundred and seventy-seven participants (71.7%) identified as White; 29 participants (11.7%) identified as Hispanic, Latina, or of Spanish Origin; 31 participants (12.6%) identified as Black or African American; 33 participants (13.2%) identified as other races/ethnicities; and 23 participants (9.2%) as more than one race/ethnicity. Nineteen participants (7.8%) had only completed some amount of high school, graduated from high school, or passed the GED; 36 participants (14.8%) had only completed some amount of college or had completed a 2-year degree; and 189 participants (77.5%) had graduated from a 4-year college or more (Table 4).

Table 4. Summary of Pilot Sample Demographics

Age (years)	
Range Mean (standard deviation) Median (25th percentile, 75th percentile)	18-53 27.6 (6.6) 25.0 (23, 31)
Gender	
Female Trans male Other	246 (99.2%) 0 2 (0.8%)

Residence by Country	
United States	242 (98.0%)
Other	5 (2.0%)
Residence by Region of the United States	
Northeast[a]	162 (68.6%)
Midwest[b]	61 (25.8%)
South[c]	7 (3.0%)
West[d]	6 (2.5%)
Birthplace	
United States	199 (80.9%)
Other	47 (19.1%)
Race/Ethnicity[e]	
White	177 (71.7%)
Hispanic, Latina, or Spanish Origin	29 (11.7%)
Black or African American	31 (12.6%)
East Asian	7 (2.8%)
Southeast Asian	8 (3.2%)
South Asian	5 (2.0%)
American Indian or Alaskan Native	5 (2.0%)
Middle Eastern or North African	3 (1.2%)
Native Hawaiian or Other Pacific Islander	1 (0.4%)
Some other race, ethnicity, or origin	4 (1.6%)
> 1 race/ethnicity	23 (9.2%)
Level of Education	
Some high school, high school graduate, or GED	19 (7.8%)
Some college or 2-year degree	36 (14.8%)
4-year college graduate or more	189 (77.5%)

Annual Household Income[f]	
Below $15,000	25 (10.2%)
$15,000 – $24,999	28 (11.5%)
$25,000 – $49,999	62 (25.4%)
$50,000 – $74,999	41 (16.8%)
$75,000 – $99,999	16 (6.6%)
$100,000 – $124,999	12 (4.9%)
$125,000 – $149,999	4 (1.6%)
$150,000 – $199,999	7 (2.9%)
≥$200,000	14 (5.7%)
Prefer not to answer	16 (6.6%)
Don't know	19 (7.8%)

[a]The Northeast was defined as New England (CT, ME, MA, NH, RI, VT) and the Mid-Atlantic (NJ, NY, PA)
[b]The Midwest was defined as the East North Central region (IL, IN, MI, OH, WI) and the West North Central region (IA, KS, MN, MO, NE, ND, SD)
[c]The South was defined as the South Atlantic region (DE, FL, GA, MD, NC, SC, VA, DC, WV), the East South Central region (AL, KY, MS, and TN), and the West South Central region (AR, LA, OK, TX)
[d]The West was defined as the Mountain region (AZ, CO, ID, MT, NV, NM, UT, WY) and the Pacific region (AK, CA, HI, OR, WA)
[e]Participants could report more than one race. As a result, the sum of the percent frequencies reported in this section of Table 4 exceeds 100%.
[f]Individual household income could not be calculated using annual household income and number of individuals per household because annual household income was reported as a range.

Completion Rate

Level of education. Of the participants with some high school education, a high school diploma, or a GED, 74% completed the entire survey; of those with some college education or a 2-year degree, 81% completed the survey; and of those with a 4-year college degree or more, 90% completed the survey (Table 5). This comparison did not reach statistical significance using Fisher's Exact test. On average, participants with some high school education, a high school diploma, or a GED completed 86% of the survey

before discontinuing; those with some college education or a 2-year degree completed 91% of the survey before discontinuing; and those with a 4-year college degree or more completed 95% of the survey before discontinuing (Table 5). This comparison did not reach statistical significance using the Kruskal-Wallace test.

Table 5. Completion Rate by Level of Education

Level of Education	Participants Who Completed Entire Survey	Average % of Survey Completed Before Discontinuing
Some high school, high school graduate, or GED (n = 19)	14 (74%)	86%
Some college or 2-year degree (n = 36)	29 (81%)	91%
4-year college graduate or more (n = 189)	170 (90%)	95%

Race/ethnicity. Of the participants who identified as White, 92% completed the entire survey; of those who identified as Hispanic, Latina, or of Spanish Origin, 68% completed the entire survey; of those who identified as Black or African American, 70% completed the survey; of those who identified as East Asian or Southeast Asian, 100% completed the survey; of those who identified as South Asian, 80% completed the survey; and of those who identified as more than one race, 91% completed the survey (Table 6). This comparison reached statistical significance using Fisher's Exact test ($p = 0.002$). On average, participants who identified as White completed 96% of the survey before discontinuing; those who identified as Hispanic, Latina, or of Spanish Origin completed

82% of the survey before discontinuing; those who identified as Black or African American completed 86% of the survey before discontinuing; those who identified as East Asian or Southeast Asian completed 100% of the survey before discontinuing; those who identified as South Asian completed 91% of the survey before discontinuing; and those who identified as more than one race/ethnicity completed 98% of the survey before discontinuing (Table 6). This comparison reached statistical significance using the Kruskal-Wallace test ($p = 0.002$).

Table 6. Completion Rate by Race/Ethnicity

Race/Ethnicity	Participants Who Completed Entire Survey	Average % of Survey Completed Before Discontinuing
White (n = 177)	163 (92%)	96%
Hispanic, Latina, or Spanish Origin (n = 29)	20 (68%)	82%
Black or African American (n = 31)	22 (70%)	86%
East Asian (n = 7)	7 (100%)	100%
Southeast Asian (n = 8)	8 (100%)	100%
South Asian (n = 5)	4 (80%)	91%
> 1 race/ethnicity (n = 23)	21 (91%)	98%

Birthplace. Of the participants who were born in the United States, 92% completed the entire survey, and of the participants who were not born in the United States, 66% completed the entire survey (Table 7). This comparison reached statistical

significance using the Chi-squared test ($p < 0.0001$). On average, participants who were born in the United States completed 96% of the survey before discontinuing and participants who were not born in the United States completed 81% of the survey before discontinuing (Table 7). This comparison reached statistical significance using the Wilcoxon Rank-Sum test ($p < 0.0001$).

Table 7. Completion Rate by Birthplace

Birthplace	Participants Who Completed Entire Survey	Average % of Survey Completed Before Discontinuing
United States (n = 199)	183 (92%)	96%
Other (n = 47)	31 (66%)	81%

Question Comprehension

Menstrual cycle length. Of the 248 participants who began the pilot survey, 235 (94.8%) responded when asked to report their typical MCL. One participant (0.4%) reported a short MCL (less than 21 days), 180 participants (76.6%) reported a normal MCL (21 to 35 days), and 16 participants (6.8%) reported a long MCL (greater than 35 days). Thirty-eight participants (16.2%) initially selected "don't know" (Table 8).

Table 8. Short, Normal, and Long Menstrual Cycle Length Responses

	Self-Reported MCL	Participants
Short	< 21 days	1 (0.4%)
Normal	21-25 days 26-29 days 30-35 days	29 (12.3%) 93 (39.6%) 58 (24.7%)
Long	> 35 days	16 (6.8%)
	"Don't Know"	38 (16.2%)

Irregularities. Of the 235 participants who responded when asked to report their typical MCL, 66 (28.1%) responded with irregular answers (less than 21 days, 21 days, more than 35 days, or "don't know"). One participant reported an MCL of less than 21 days, 11 participants reported an MCL of 21 days, 16 participants reported an MCL of more than 35 days, and 38 participants initially selected "don't know" (Table 9).

Table 9. Irregular Responses to Menstrual Cycle Length Question

Irregular Response	Participants
< 21 days (short)	1 (2%)
21 days	11 (17%)
> 35 days (long)	16 (24%)
"Don't know"	38 (58%)

Inaccuracies. Of the 66 participants who responded with irregular answers, 20 participants may have responded with inaccurate answers (Table 10).

Table 10. Potentially Inaccurate Responses to Menstrual Cycle Length Question

ID	Age	Birthplace	Education[a]	MCL[b] (days)	Menstrual Irregularity[c]
242	27	United States	College graduate	21	No
385	23	Indonesia	More than college	21	No
22	22	United States	College graduate	DK → 30-31	No
51	24	United States	More than college	DK → 21-25	Yes
56	22	United States	Some college	DK → 26-29	Yes
63	22	United States	College graduate	DK → 26-29	Yes
77	24	United States	College graduate	DK → 26-29	Yes
93	27	Costa Rica	College graduate	DK → 26-29	No
98	19	United States	High school graduate	DK → 30-31	No
105	25	United States	More than college	DK → 26-29	Yes
114	23	United States	More than college	DK → 21-25	Yes
121	22	United States	More than college	DK → 21-25	Yes
145	22	United States	College graduate	DK → 26-29	No
183	24	Canada	*No response*	DK → 26-29	Yes
189	26	United States	More than college	DK → 26-29	Yes
221	31	United States	College graduate	DK → 26-29	No
249	23	United States	College graduate	DK → 21-25	No
277	35	Haiti	More than college	DK → 30-31	Yes

351	33	United States	Some college	DK → 32-35	Yes
343	26	United States	College graduate	DK → NS	No

[a]"High school graduate" denotes "high school graduate or GED," "some college" denotes "some college or 2-year degree," "college graduate" denotes "4-year college graduate," and "more than college" denotes "more than 4-year college degree."
[b]DK denotes "don't know" and NS denotes "I'm still not sure"
[c]The presence of menstrual irregularities were determined by participants' responses to questions in the menstrual cycle health, contraceptive use, PCOS status, and reproductive health sections of the survey (Appendix 1).

Of the 20 participants who may have responded with inaccurate answers when asked to report their typical MCL, 16 (80%) were born in the United States, while the remaining four were born in countries whose official language is not English (with the exception of Canada, whose official languages are both English and French). Eighteen (90%) of these participants have completed at least some amount of college (Table 11).

Table 11. Birthplace and Level of Education of Participants Who Provided Potentially Inaccurate Responses to Menstrual Cycle Length Question

Birthplace	
United States Other	16 (80%) 4 (20%)
Level of Education	
Some high school, high school graduate, or GED Some college or 2-year degree 4-year college graduate or more *No response*	1 (5%) 2 (10%) 16 (80%) 1 (5%)

DISCUSSION

The Pilot Sample

This pilot study was successful in establishing a cohort that is more racially/ethnically diverse than existing cohorts of individuals with PCOS (Table 12). This success can be attributed to the study staff's in-person recruitment efforts in OB/GYN clinic waiting rooms at BMC, due to the diverse profile of the patients who attend these clinics. Of the clinics that the study staff recruited from, the Doctor's Office Building (DOB) was the most successful site because of the waiting room environment. The DOB OB/GYN clinic waiting room was relatively small—compared to that of the Yawkey Ambulatory Care Center, another site of in-person recruitment—and thus had fewer patients at any given time, creating a calmer environment that allowed the study staff to more readily approach patients (Figures 3 and 4). Furthermore, patients in the DOB OB/GYN clinic waiting room typically had longer wait times than patients in the Yawkey OB/GYN clinic waiting room, giving DOB patients the opportunity to complete the survey while in the clinic, rather than having to return to it later on. The study staff also recruited participants in-person in BMC's Contraceptive Clinic, a smaller area within the Yawkey OB/GYN clinic. Recruitment in the Contraceptive Clinic was more successful than recruitment in the Yawkey OB/GYN clinic waiting room because patients attending the Contraceptive Clinic were more likely to be eligible to participate in the study. Patients attending the Contraceptive Clinic, however, had extremely short wait times, making it difficult to fully engage participants in the survey while in clinic.

Table 12. Racial/Ethnic Profiles of Existing Cohorts of Individuals with PCOS and the OM Health Study. Data for Australia from March 2010; for Iran from Tehrani 2011; for China from Li 2013; for Denmark from Lauristen 2014.

Study	Racial/Ethnic Profile
Australia	94% White
Iran	100% Middle Eastern
China	100% East Asian
Denmark	97.3% White
OM Health Study	71.7% White 11.7% Hispanic, Latina, or Spanish Origin 12.6% Black or African American 2.8% East Asian 3.2% Southeast Asian 2.0% South Asian 2.0% American Indian or Alaskan Native 1.2% Middle Eastern or North African 0.4% Native Hawaiian or Other Pacific Islander 1.6% Some other race, ethnicity, or origin 9.4% More than one race

Figure 3. Doctor's Office Building OB/GYN Clinic Waiting Room. Photos of the DOB OB/GYN clinic entrance (top) and waiting room (bottom). Photos taken by Alicia Peterson, Operations Manager at BMC.

Figure 4. Yawkey Ambulatory Care Center OB/GYN Clinic Waiting Room. Photos of the Yawkey OB/GYN clinic entrance (top) and waiting room (bottom). Photos taken by Jill MacRae, Project Manager for Research, Recruitment, and Retention at Boston University Clinical and Translational Science Institute.

While the racial/ethnic diversity of the pilot sample can be attributed to in-person recruitment in OB/GYN clinic waiting rooms at BMC, the study staff was successful in creating a sizeable pilot sample due to in-person recruitment efforts at the Boston Women's Market. Individuals who chose to attend the Market were interested in learning about ongoing research in Women's Health and felt an obligation to contribute to medical research. As a result, a significant number of individuals who the study staff approached at the Market were eager to participate in the OM Health Study and felt compelled to complete the survey later on.

While this pilot sample is more racially/ethnically diverse than existing cohorts of individuals with PCOS, it is a convenience sample, primarily due to the online recruitment efforts of the study staff. In an effort to establish a sizeable pilot cohort, the study staff recruited participants from personal networks, which yielded a sample composed primarily of individuals currently living in the United States (particularly in the Northeast and Midwest regions of the country), individuals who were born in the United States, individuals who identify as White, and individuals who have graduated from a 4-year college or completed higher education.

In order to gather more information on the ways in which PCOS manifests across different groups, future recruitment efforts may be more targeted towards individuals with lower socioeconomic statuses. For instance, in-person recruitment should be continued at BMC—while focusing on clinics that provide an appropriate environment for recruitment—and expanded to neighboring healthcare facilities to reach low-income patients belonging to diverse racial/ethnic categories. Furthermore, recruitment efforts

should target racially-/ethnically-focused community events, similar to the Boston Women's Market in Jamaica Plain, but with greater racial/ethnic diversity.

Variable Selection

Level of education, race/ethnicity, and birthplace were selected as variables to determine the accessibility of the pilot survey to diverse populations. Birthplace was selected as a variable as it indicates participants' primary language and thus ability to read and comprehend the English language version of the survey. Because birthplace is not an entirely reliable indication of primary language, a question asking participants to indicate primary language ought to be added to the baseline survey. Income was not selected as a variable in this study due to the difficulty of assessing the income of younger participants who may be under the care or support of family. While participants were asked to report annual household income and the number of individuals per household, younger participants may have provided their parents' household income while belonging to a different household. As a result, a question whose response can better summarize participant income and socioeconomic status ought to be added to the baseline survey.

Completion Rate

There may be an association between factors such as level of education and birthplace, and survey completion. Participants identifying as White, East Asian, Southeast Asian, and South Asian had greater rates of completion compared to those identifying as Hispanic, Latina, of Spanish Origin, Black, and African American, within

their own racial/ethnic category. Participants who were born in the United States had greater completion compared to those who were not born in the United States. These findings indicate the importance of translating the baseline survey and future modules into multiple languages.

Question Comprehension

Level of education and birthplace did not affect participants' ability to comprehend MCL and respond to questions regarding MCL. A large number of participants, however, may have responded to the question inaccurately, even after being provided with a definition of MCL and a normal range for MCL. In order to gain accurate information on MCL, an alternate measure ought to be implemented, such as a menstrual cycle tracker app that participants can update daily as they progress through their menstrual cycle. Furthermore, a menstrual cycle tracker app would reveal any discrepancies between one cycle and the next, rather than simply requesting averages or "typical" menstrual cycle details.

Conclusion

This pilot study succeeds in establishing a cohort that is more racially/ethnically diverse than existing cohorts of individuals with PCOS. In order to gather more information on the ways in which PCOS manifests across different groups, future recruitment efforts ought to be more targeted towards individuals belonging to different racial/ethnic groups and socioeconomic statuses. Additionally, the baseline survey and

future modules can be made more accessible to diverse groups through language translation. Furthermore, the addition of a menstrual cycle tracker component to the survey may increase the accuracy of information on participants' menstrual cycle patterns.

APPENDIX 1: QUESTIONS USED TO DETERMINE POTENTIALLY INACCURATE RESPONSES TO MENSTRUAL CYCLE LENGTH QUESTION

1. At what age did you have your first menstrual period?
2. Sometimes when a woman first gets her period, it's not on a regular schedule and she may go months between periods. Thinking back to when you first got your period, how long did it take for your menstrual periods to become regular?
3. Did your period become regular on its own—that means without taking the Pill or using any other hormonal contraceptives (patch, implants, or injectables)?
4. Has there ever been a time when your menstrual period was NOT regular or predicable for more than a 3 month window of time?
5. Why do you think were your periods were irregular?
    a. Stress
    b. Polycystic ovary syndrome (PCOS)
    c. Hormonal abnormality
    d. Too much exercise and not eating enough
    e. Overweight/obesity
    f. Pregnancy/breastfeeding
    g. Other, please specify
    h. Don't know
6. We are interested in whether your menstrual period is regular now—that means you can usually predict about when the next period will start. Would you say that your period is usually regular?

7. Now we want to know about how long your period usually lasts. Counting only the days when you were bleeding and not when you were spotting, in the last year about how many days did your period usually last?
8. In the last 12 months, how many menstrual periods did you have?
9. Hormonal contraceptives include the pill, patch, implants, or injectables. Have you ever used hormonal contraceptives?
10. Do you currently use any hormonal contraceptives?
11. Are you currently taking hormonal contraceptives to help regulate your menstrual periods so they are more regular and predictable?
12. Polycystic Ovary Syndrome is a health condition involving irregular periods, excess testosterone, increased acne, body and facial hair, and many small cysts in the ovaries. Some women also experience hair loss on the scalp. Has a doctor ever diagnosed you?
13. Do you think you might have PCOS?

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CURRICULUM VITAE

ANNA S. WILLIAMS

1994

CONTACT INFORMATION

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EDUCATION

Boston University School of Medicine | Boston, MA
Master of Science in Medical Sciences, Expected Spring '18

Bates College | Lewiston, ME
Bachelor of Science in English, Fall '12 – Spring '16

EXPERIENCE

Boston University School of Medicine, Mahalingaiah Lab | Boston, MA
Research Assistant, Summer '17 – Present

- Research assistant to Dr. Shruthi Mahalingaiah in fulfillment of the thesis component of the M.S. in Medical Sciences degree
- Recruit participants in-person and online for the lab's Ovulation and Menstruation Health Study (OM Health Study)
- Facilitate collaboration with companies and other research teams to expand the OM Health Study
- Contribute to survey design for the OM Health Study

Leonard Morse Hospital, Surgical Day Care & Endoscopy Unit | Natick, MA
Volunteer, Summer '16

- Prepared patient charts for surgeons, anesthesiologists, and surgical day care nurses
- Checked patients in for surgery preparation and transported patients to hospital exits for pick-up after surgery
- Cleaned and made patient beds and restocked medical supplies for physicians and nurses

Bates College Harward Center for Community Partnerships | Lewiston, ME
Short Term Action/Research Team Leader, Museum L-A, Spring '16

- Engaged in a community partnership with a local museum, Museum L-A
- Organized museum stock, carried out academic research, and conducted in-person interviews
- Met with other research team members twice a week to discuss research progress and setbacks

Bates College "Cats Against Cancer" Club | Lewiston, ME
Co-President, Fall '15 – Spring '16

- Co-led weekly meetings and co-organized events that educated students on cancer awareness and detection
- Club member from Fall 2013 to Spring 2016

Big Brothers Big Sisters | Sabattus, ME
Program Coordinator, Fall '15 – Spring '16

- Recruited and interviewed "Big" candidates
- Supervised Big-Little matches at Oak Hill Middle School
- Big Sister at Longley Elementary School in Lewiston, ME from Winter 2014 to Spring 2016

Bates College Education Club | Lewiston, ME
Secretary, Winter '15 – Spring '16

- Took minutes at weekly meetings on non-traditional methods of schooling, such as place-based, Socratic, and IB approaches

Bates College Senior Gift Committee | Lewiston, ME
Committee Member, Fall '15 – Spring '16

- Attended monthly meetings regarding fundraising events
- Managed the fundraising table at fundraising events

Bates College, Department of English | Lewiston, ME
Senior Honors English Thesis, Spring '15 – Spring '16

- Examined the ways in which contemporary novelists convey the importance of empathy for patients among health care professionals and the resultant importance of health care workers reading literature toward this end
- Evaluated literature programs designed to develop empathy among medical students and practicing health care professionals

Pilgrim Church Senior High Youth Group | Sherborn, MA
Work Camp Advisor, Spring '15

- Spent a week in New Orleans, LA acting as an advisor to 24 high school students
- Students and advisors painted, gardened, and did construction on churches and homes of people affected by Hurricane Katrina

Bates College Residence Life | Lewiston, ME
Junior Advisor, Fall '14 – Spring '15

- Acted as a resident peer advisor to 18 first-year students
- Assisted students making academic and social decisions during the transition from secondary school to college
- Organized and produced social, educational, and community-engaged programs

Muscular Dystrophy Association Camp Waban | Sanford, ME
Volunteer Counselor, Summer '13

- Tended to the physical and emotional needs of children with muscular dystrophy

SKILLS & INTERESTS

- Strong interpersonal and organizational skills
- Speaks conversational French
- Enjoys reading, writing, skiing, and travelling