Engaging participants in research with self-logged menstrual health data

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Covid-19: First vaccine given in US as roll-out begins

© 14 December 2020

Coronavirus pandemic

The first Covid-19 vaccination in the United States has taken place, as the country gears up for its largest ever immunisation campaign.

Source: BBC
Can the vaccine make your period worse? These women say yes.

No published studies have examined the effects of vaccines on menstrual cycles.
Association Between Menstrual Cycle Length and Coronavirus Disease 2019 (COVID-19) Vaccination
A U.S. Cohort

Edelman, Alison MD, MPH; Boniface, Emily R. MPH; Benhar, Eleonora PhD; Han, Leo MD, MPH; Matteson, Kristen A. MD, MPH; Favaro, Carlotta PhD; Pearson, Jack T. PhD; Darney, Blair G.

METHODS:
We analyzed prospectively tracked menstrual cycle data using the application “Natural Cycles.” We included U.S. residents aged 18–
Daily, weekly, seasonal and menstrual cycles in women’s mood, behaviour and vital signs
Emma Pierson 1, Tim Alteft 1, Daniel Thomas 1, 2, Paula Hillard 1, 2 and June Laskovski 1, 2

Dimensions of human mood, behaviour and vital signs cycle over multiple timescales. However, it remains unclear which dimensions are most cyclical, and how daily, weekly, seasonal and menstrual cycles compare to each other. The menstrual cycle remains particularly understudied because, not being synchronized across the population, it will be averaged out unless menstrual cycles can be aligned before analysis. Here, we analyze 285 million observations from 5.3 million women across 190 countries, treating 16 dimensions of mood, behaviour and vital signs using a women’s health mobile app. Out of the daily, weekly, seasonal and menstrual cycles, the menstrual cycle, while all across countries,

Relationship Between the Menstrual Cycle and Timing of Ovulation Revealed by New App: Analysis of Data from a Self-Tracking Health App
Satoshi Soda 1, Kenta Suzuki 2, 3, Ichiro Igarashi 2

Age-Dependent and Seasonal Changes in Menstrual Cycle Length and Body Temperature Based on Big Data
Tatsuki, Takayuki MD, PhD; Samuel, Malake RN, MPH; Salto, Kazuki MD, PhD; Honda, Yuka
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Obstetrics & Gynecology
doi: 10.1097/AOG.0000000000000000

Identifying Women at Risk for Polycystic Ovary Syndrome Using a Mobile Health App: Virtual Tool Functionality Assessment
Erika Marie Rodriguez 1, 2, MSc; Daniel Thomas 1, Anna Druel 2, Marija Vlajic-Wheeler 2, PhD; Kevin James Lane 2, PhD, MA; Shrutii Mahalingnaia 2, 3, MD, MSc

Time to conception and the menstrual cycle: an observational study of fertility app users who conceived
Danielle Bradley 1, Erin Landau 1, Noreene Jesani 2, Brett Mowry 3, Kenneth Chui 4, Alex Baron 4, Adam Wolfberg 1, 5

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Original Research

Characterizing physiological and symptomatic variation in menstrual cycles using self-tracked mobile-health data
Kathy L. Quayle 1, 2, Virginie Legendre 1, 2, Chris H. Wigglesworth 1, 2, Anna Drew 3, Amanda Shaw 3, Virginia J. Voth 1, 2 and Noemie Chittal 1, 2

The menstrual cycle is a key indicator of overall health for women of reproductive age. Previously, menstruation was primarily studied through survey results; however, as menstrual tracking mobile apps become more widely adopted, they provide an enormous large, content-rich source of menstrual health experiences and behavior over time. By exploring a database of user-tracked observations from the one million (almost) users of over 78,000 users and 41,200 different menstrual cycles, we find that self-reported menstrual health data can reveal statistically significant relationships between per-person cycle length variability and self-reported qualitative symptoms. A concern for self-tracked data is that they reflect not only physiological behaviors, but also the engagement dynamics of app users. To mitigate such potential artifacts, we develop a procedure to exclude cycles leading user-engagement, thereby allowing us to better distinguish true menstrual patterns from tracking anomalies. We observe that women located at different ends of the menstrual variability spectrum, based on the consistency of their cycle length statistics, exhibited large differences in variability. While women with more consistent cycle length statistics are statistically fewer in the app usage timeframe across the variability spectrum. The symptoms that we identify as inversely associated with menstrual health were not statistically significant across data from 38,000 users. The research also aimed to identify the factors that could be linked to symptom variations or as potential health indicators for conditions like endometriosis. Our findings showcase the potential of longitudinal, high-quality self-tracked data to improve understanding of menstruation and women’s health as a whole.

ORIGINAL RESEARCH

Data from a Menstrual Cycle Tracking App Informs our Knowledge of the Menstrual Cycle in Adolescents and Young Adults
Paula J. Adams Hillard, MD • Marija Vlajic-Wheeler, PhD

Membranous Vasa in a Glance
Mobile App Cohort
Jessica A Giagge, BSc, PhD and Robert J Norman, MD, FRANZCOG

600,000 menstrual cycles
Jonathan R. Bull 1, Simon R. Rawland 2, Elena Berglund Schnettler 3, Richard Schnettler 1, Kristina Gemzell Danielsson 3 and Joyce Harper 1

The use of apps that record detailed menstrual cycle data presents a new opportunity to study the menstrual cycle. The aim of this study is to describe menstrual cycle characteristics observed in a large database of cycles recorded through an app and investigate associations of menstrual cycle characteristics with cycle length, age and body mass index (BMI). Menstrual cycle parameters, including menstruation, basal body temperature (BBT) and lasting hormone 3.67–to-wells as age and BMI were collected anonymously from real-world users of the Natural Cycle app. We analyzed k-2.61 variability cycles with a mean length of 20.3 days from 12,664 users. The mean follicular phase length was 15.6 days (95% CI 15.4–15.8). Mean cycle length decreased by 0.17 days/year (95% CI -0.21 to 0.14), and mean follicular phase length decreased by 0.09 days/year (95% CI -0.13 to 0.04) from age 25 to 35 years. Mean variation of cycle length per woman declined in days in 15 higher in women who were over 25 older (0.23) versus younger women with a BMI of 19.3-23. This analysis details variations in menstrual cycle characteristics that are not well studied yet have significant implications for health and wellbeing. Clinicians and women who wish to plan a pregnancy need to have information on their fertile days. In order to identify the fertile period it is important to track physiological parameters such as basal body temperature and not just cycle length.
How can we engage people more directly in research with their personal health data?
Outline

Why would we do that?

What could go wrong?

How do we get there?
Why?

• Participants learn about their health
• Researchers do better research
• Increase people’s **awareness** and **oversight** of what happens with their data
Why not?

- Misinformation & over-diagnosis
- Privacy
- Overemphasis on quantification and norms
How do we get there?
Leverage contextual expertise in data cleaning and analysis
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Convey uncertainty and variability when making comparisons.
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Structure engagement around valid analyses
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Support (asynchronous and anonymous) social engagement and learning

Average cycle lengths

Did you know it’s more common to be irregular when you only just started getting periods?
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Samantha Robertson, HILDA 2022, June 12, 2022

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Acknowledgements

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Dr. Leilani Battle
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Clue collaborators
Dr. Amanda Shea
Charlie Upton

HILDA mentor

Working Draft

https://tinyurl.com/engagecycles