

Engaging participants in research with self-logged menstrual health data

**Samantha Robertson, Kim Harley, and Niloufar Salehi
U.C., Berkeley**

2020

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

🕒 14 December 2020



Coronavirus pandemic



| The day the US began Covid vaccinations

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

2020

2021





ORIGINAL RESEARCH

☰
Outline

🖼️
Images

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.

2020

2021

2022

METHODS:

We analyzed prospectively tracked menstrual cycle data using the application “Natural Cycles.” We included U.S. residents aged 18–



LunaLuna

AVA



ARTICLES

https://doi.org/10.1038/s41562-020-01046-9

nature human behaviour

Check for updates

Daily, weekly, seasonal and menstrual cycles in women's mood, behaviour and vital signs

Emma Pierson^{1,2}, Tim Althoff³, Daniel Thomas⁴, Paula Hillard⁵ and Jure Leskovec^{1,6}✉

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 in magnitude. 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 analyse 241 million observations from 3.3 million women across 109 countries, tracking 15 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 had the most pronounced magnitude for most of the measured dimensions of mood, behaviour and vital signs. The menstrual cycle, while slightly out of phase with the seasonal cycle, is the most cyclical across countries.



Relationship Between the Menstrual Cycle and Timing of Ovulation Revealed by New Protocols: Analysis of Data from a Self-Tracking Health App

Satoshi Sohda¹✉; Kenta Suzuki^{2,3}✉; Ichiro Igari³✉

CONTENTS: ORIGINAL

Age-Dependent and Seasonal Changes in Menstrual Cycle Length and Body Temperature Based on Big Data

Tatsumi, Takayuki MD, PhD; Sampei, Makiko RN, MPH; Saito, Kazuki MD, PhD; Honda, Yuka PhD; Okazaki, Yuka MD; Arai, Yuki MD; Ishikawa, Tomonori MD, PhD

Author Information

Obstetrics & Gynecology: 0
doi: 10.1097/AOG.000000000

JMIR FORMATIVE RESEARCH

Original Paper

Identifying Women at Risk for Polycystic Ovary Syndrome Using a Mobile Health App: Virtual Tool Functionality Assessment

Erika Marie Rodriguez^{1,2}, MSc; Daniel Thomas³; Anna Druet³; Marija Vlajic-Wheeler³, PhD; Kevin James Lane⁴, PhD, MA; Shruthi Mahalingaiah^{1,2,5}, MD, MSc

Observational Study

doi: 10.1080/14647273.2019.1613680. Epub 2019 May 16.

Time to conception and the menstrual cycle: an observational study of fertility app users who conceived

Danielle Bradley¹, Erin Landau¹, Noreen Jesani², Brett Mowry³, Kenneth Chui⁴, Alex Baron¹, Adam Wolfberg^{1,5}

ORIGINAL RESEARCH

Association Between Menstrual Length and Coronavirus Disease (COVID-19) Vaccination

A U.S. Cohort

Edelman, Alison MD, MPH; Boniface, Emily R. MPH; Benhar, Eleonora MD, MPH; Matteson, Kristen A. MD, MPH; Favaro, Carlotta PhD; Pearson, Jack PhD, MPH

Author Information

npj | Digital Medicine

www.nature.com/npjdigitalmed

ARTICLE OPEN

Check for updates

Characterizing physiological and symptomatic variation in menstrual cycles using self-tracked mobile-health data

Kathy Li^{1,2}, Inigo Urteaga^{1,2}, Chris H. Wiggins^{1,2}, Anna Druet³, Amanda Shea³, Virginia J. Vitzthum^{3,4} and Noémie Elhadad^{2,5}✉

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 increasingly large, content-rich source of menstrual health experiences and behaviors over time. By exploring a database of user-tracked observations from the Clue app by BioWink GmbH of over 378,000 users and 4.9 million natural cycles, we show that self-reported menstrual tracker 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 lacking user engagement, thereby allowing us to better distinguish true menstrual patterns from tracking anomalies. We uncover that women located at different ends of the menstrual variability spectrum, based on the consistency of their cycle length statistics, exhibit statistically significant differences in their cycle characteristics and symptom tracking patterns. We also find that cycle and period length statistics are stationary over the app usage timeline across the variability spectrum. The symptoms that we identify as showing statistically significant association with timing data can be useful to clinicians and users for predicting cycle variability from symptoms, or as potential health indicators for conditions like endometriosis. Our findings showcase the potential of longitudinal, high-resolution self-tracked data to improve understanding of menstruation and women's health as a whole.
npj Digital Medicine (2020)3:79; https://doi.org/10.1038/s41746-020-0269-8

Journal of Pediatric & Adolescent Gynecology

Log in



ABSTRACT ONLY | VOLUME 30, ISSUE 2, P269-270, APRIL 01, 2017

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

Real-world Menstrual Cycle Characteristics of more than 600,000 menstrual cycles

Jonathan R. Bull¹✉, Simon P. Rowland¹, Elina Berglund Scherwitzl¹, Raoul Scherwitzl¹, Kristina Gemzell Danielsson² and Joyce Harper³

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 from a large database of cycles collected 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 luteinising hormone (LH) tests as well as age and BMI were collected anonymously from real-world users of the Natural Cycles app. We analysed 612,613 ovulatory cycles with a mean length of 29.3 days from 124,648 users. The mean follicular phase length was 16.9 days (95% CI: 10–30) and mean luteal phase length was 12.4 days (95% CI: 7–17). Mean cycle length decreased by 0.18 days (95% CI: 0.17–0.18, R² = 0.99) and mean follicular phase length decreased by 0.19 days (95% CI: 0.19–0.20, R² = 0.99) per year of age from 25 to 45 years. Mean variation of cycle length per woman was 0.4 days or 14% higher in women with a BMI of over 35 relative to women with a BMI of 18.5–25. This analysis details variations in menstrual cycle characteristics that are not widely known yet have significant implications for health and well-being. Clinically, women who wish to plan a pregnancy need to have intercourse 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.
npj Digital Medicine (2019)2:83; https://doi.org/10.1038/s41746-019-0152-7

Menstrual Cycle in a Global Mobile Health Cohort

Jessica A Grieger, BSc, PhD and Robert J Norman, MD, FRANZCOG



How can we engage people more directly in research with their personal health data?

(that's me!)

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

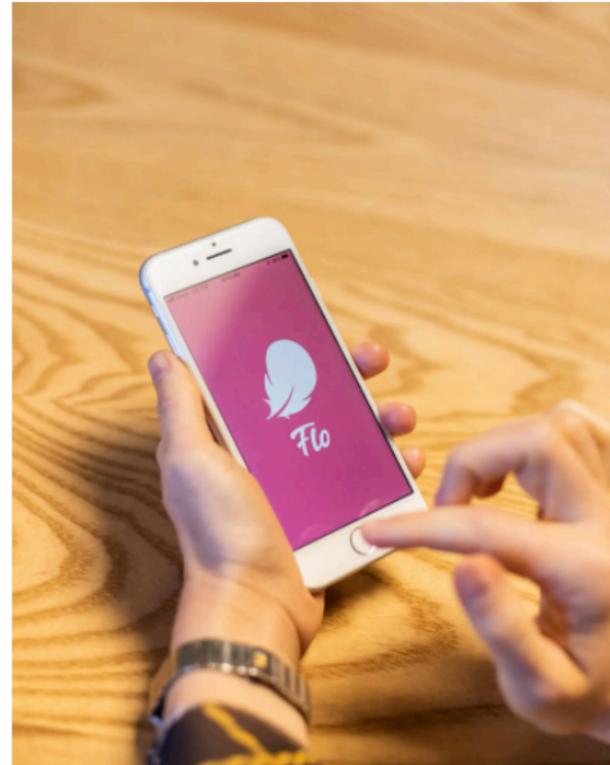
Why not?

- Misinformation & over-diagnosis
- Privacy
- Overemphasis on quantification and norms

The New York Times

Period-Tracking Apps Say You May Have a Disorder. What if They're Wrong?

Give this article    11



The Flo period-tracking app, which has more than 30 million active monthly users, recently introduced a health tool that tells women if their irregular periods may be symptomatic of a hormonal disorder. Cayce Clifford for The New York Times

By **Natasha Singer**

Oct. 27, 2019

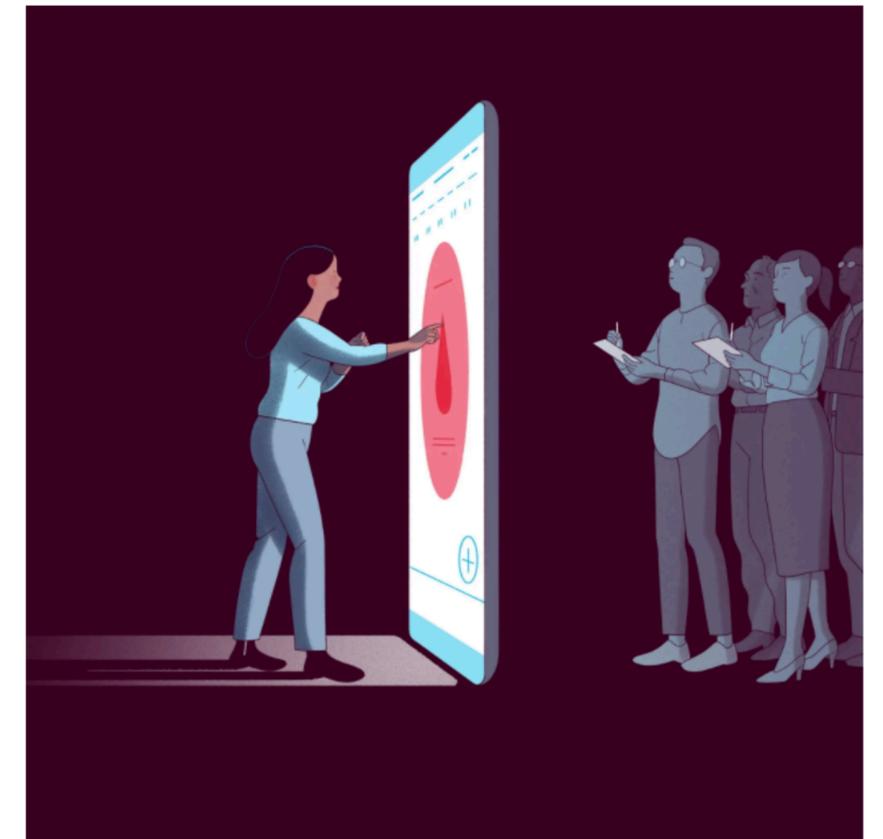
The New York Times

IN HER WORDS

Your App Knows You Got Your Period. Guess Who It Told?

Millions of women use apps to track their cycles, and that data is often passed on to third-party companies, like Facebook and Google. But what if that data could be used to help women's health research?

Give this article  



Bianca Bagnarelli

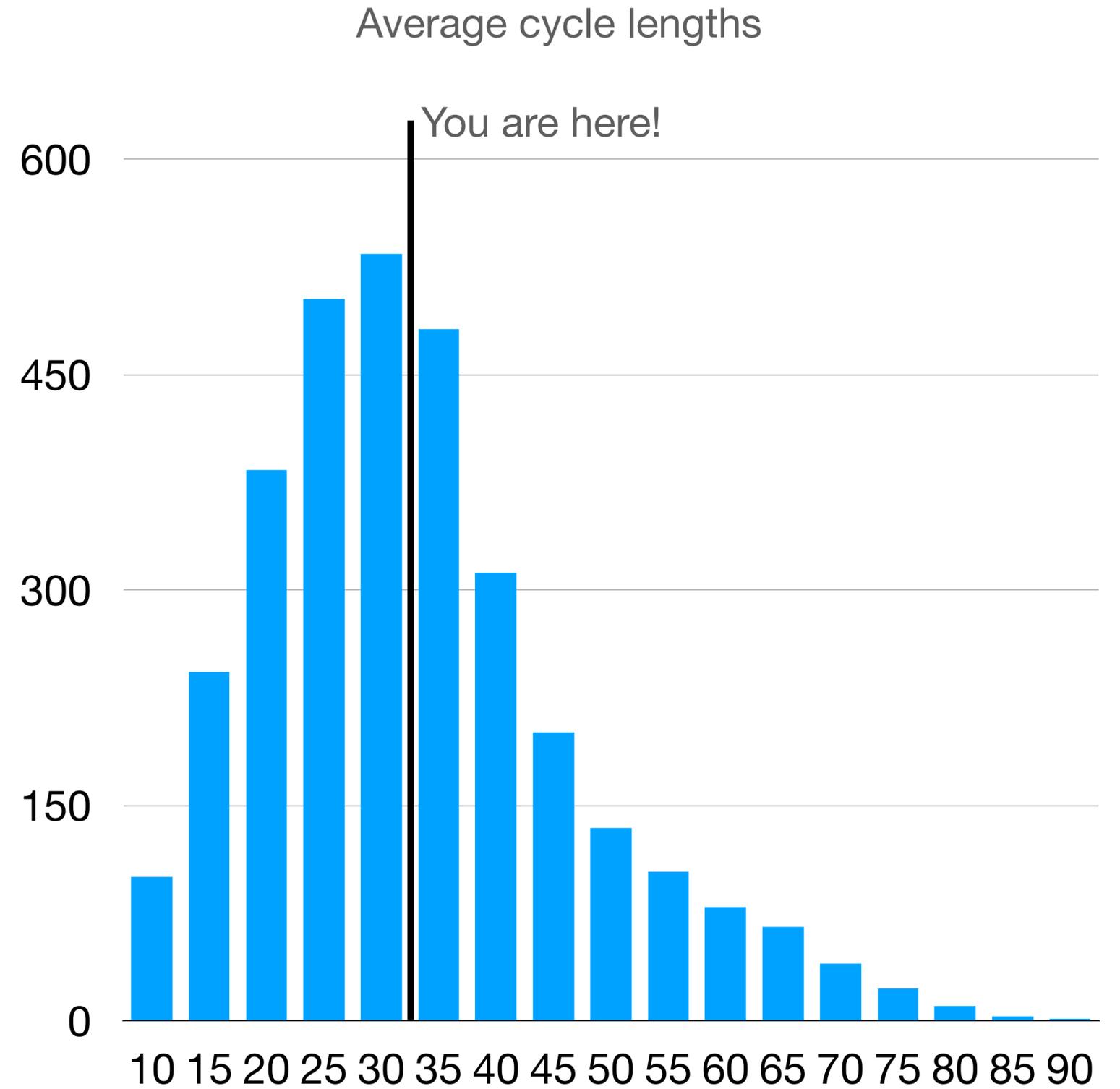
By **Alisha Haridasani Gupta and Natasha Singer**

Jan. 28, 2021

How do we get there?



Leverage contextual expertise in data cleaning and analysis



WOMEN'S PICKS TheLily

We're moving! Get our latest gender and identity coverage on [washingtonpost.com](https://www.washingtonpost.com).

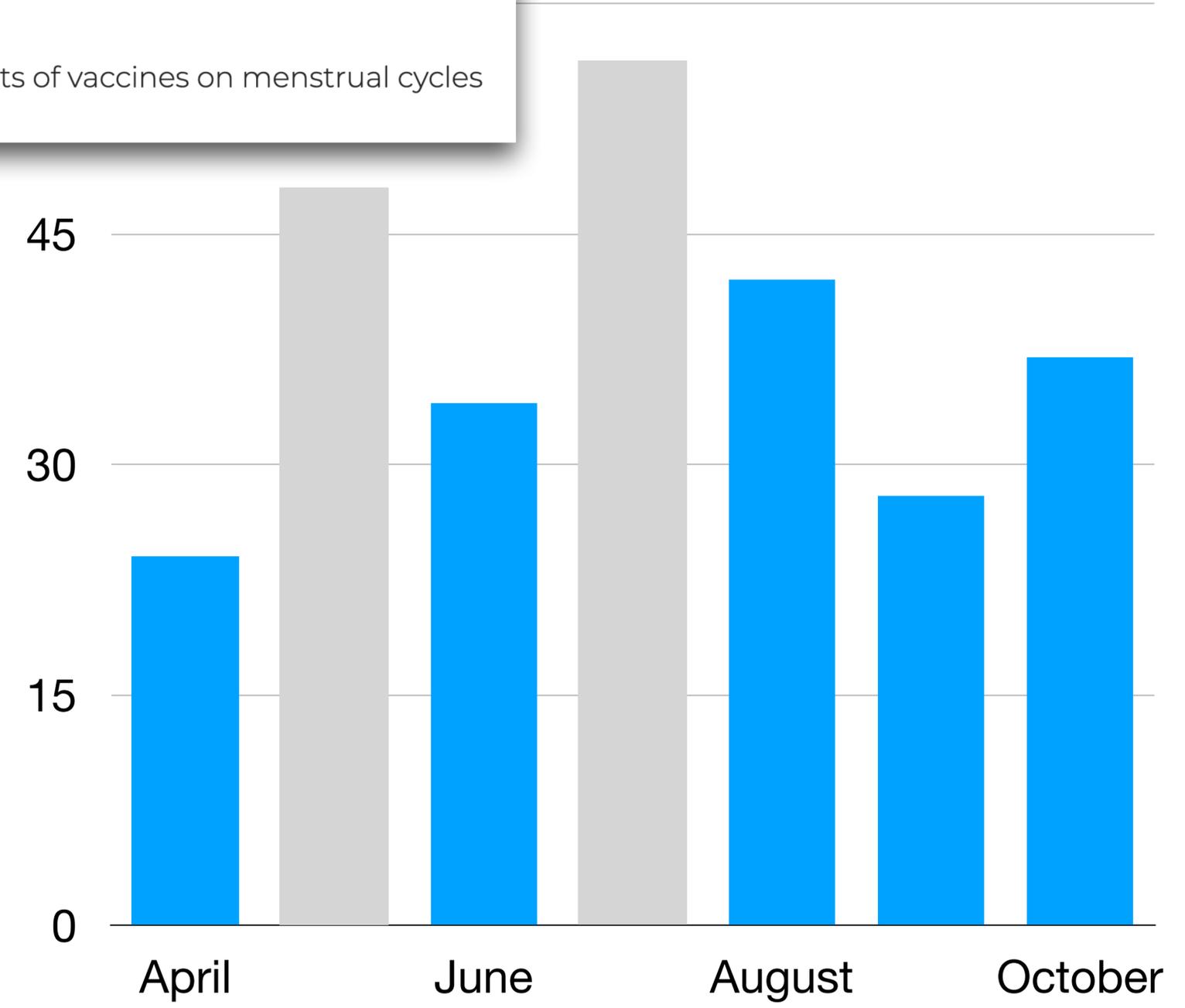
HEALTH

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

No published studies have examined the effects of vaccines on menstrual cycles

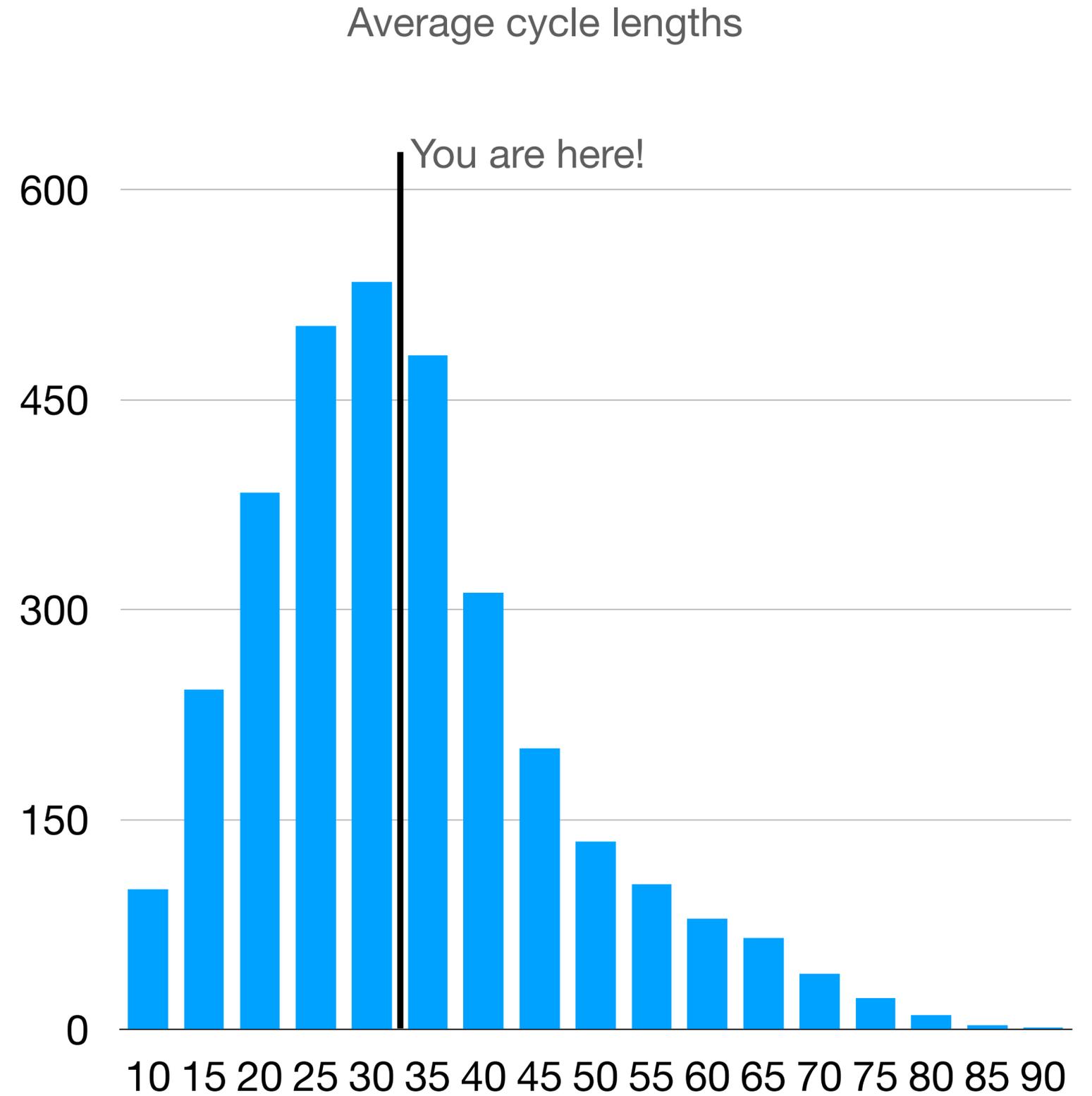
our cycles

Leverage contextual expertise in data cleaning and analysis



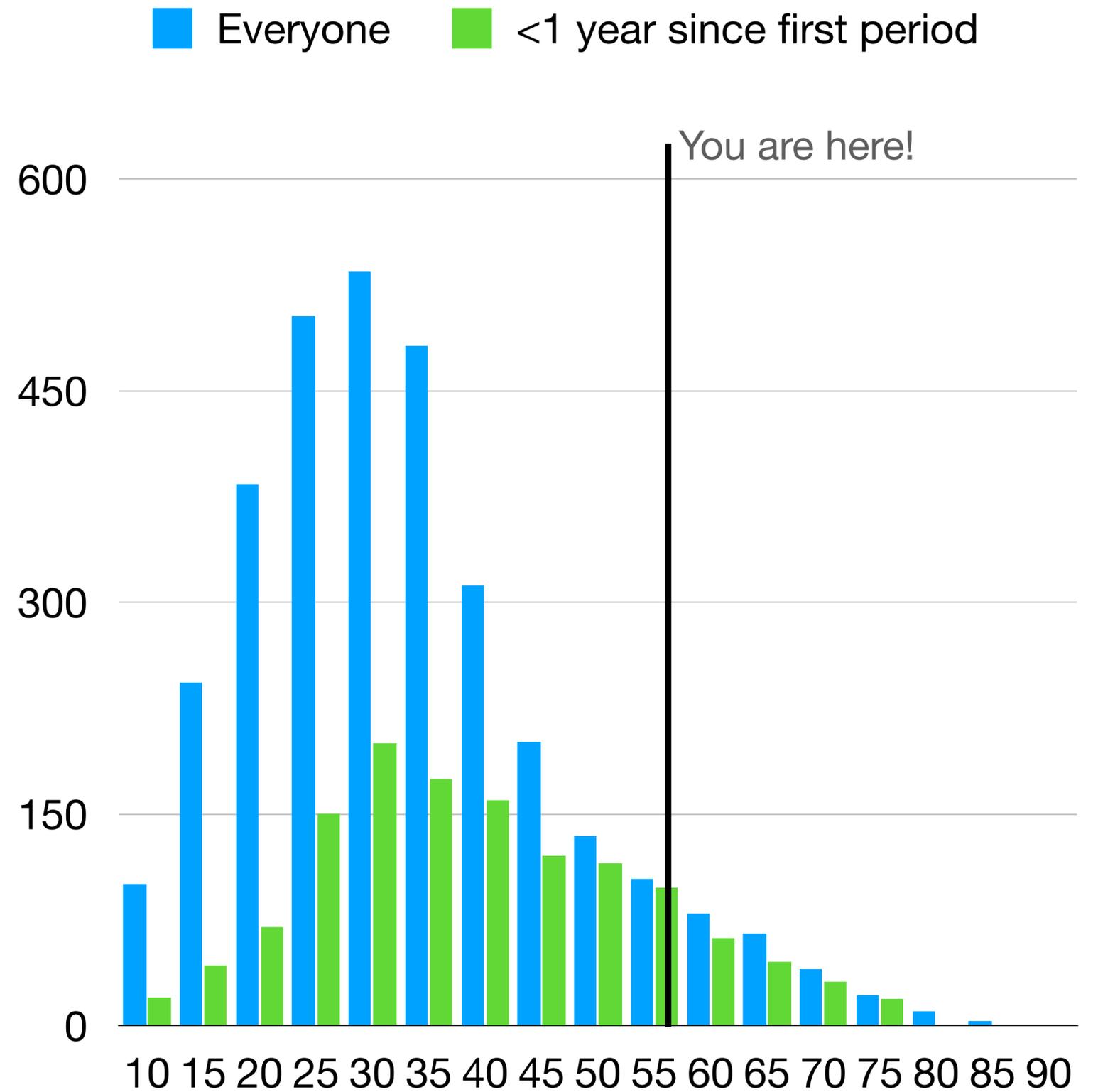
Leverage contextual expertise in data cleaning and analysis

Convey uncertainty and variability when making comparisons



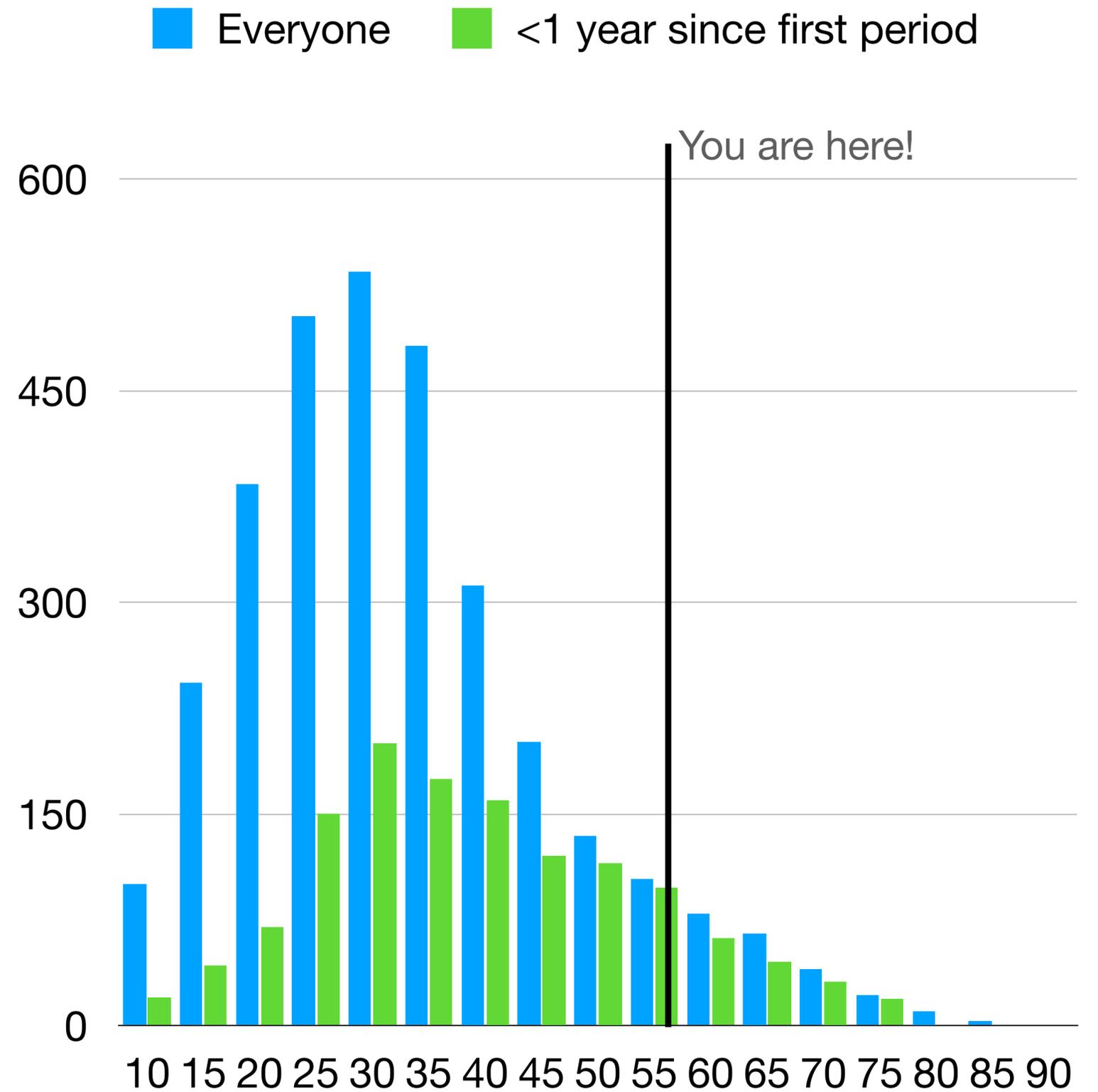
Leverage contextual expertise in data cleaning and analysis

Convey uncertainty and variability when making comparisons



Leverage contextual expertise in data cleaning and analysis

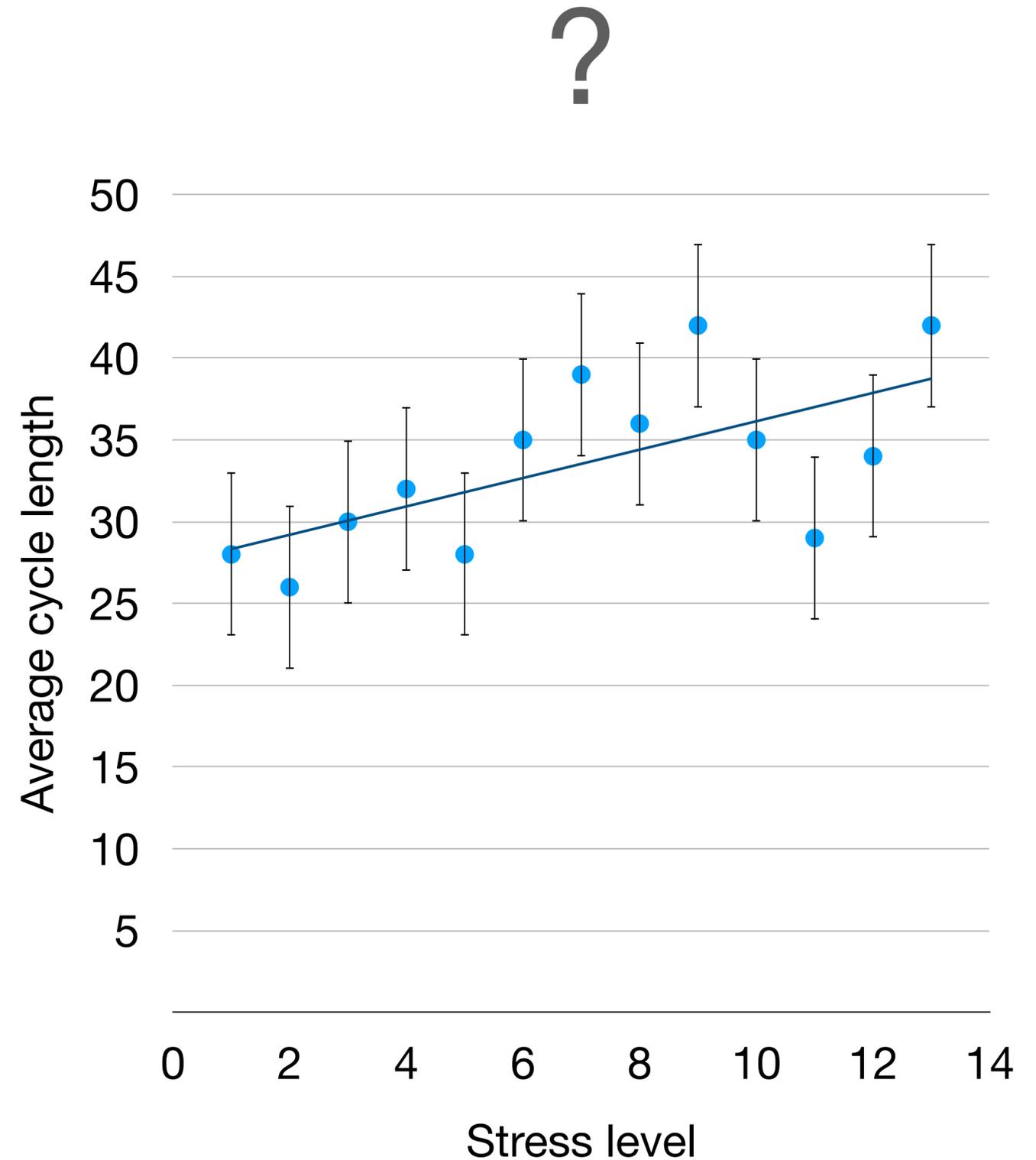
Convey uncertainty and variability when making comparisons



Leverage contextual expertise in data cleaning and analysis

Convey uncertainty and variability when making comparisons

Structure engagement around valid analyses

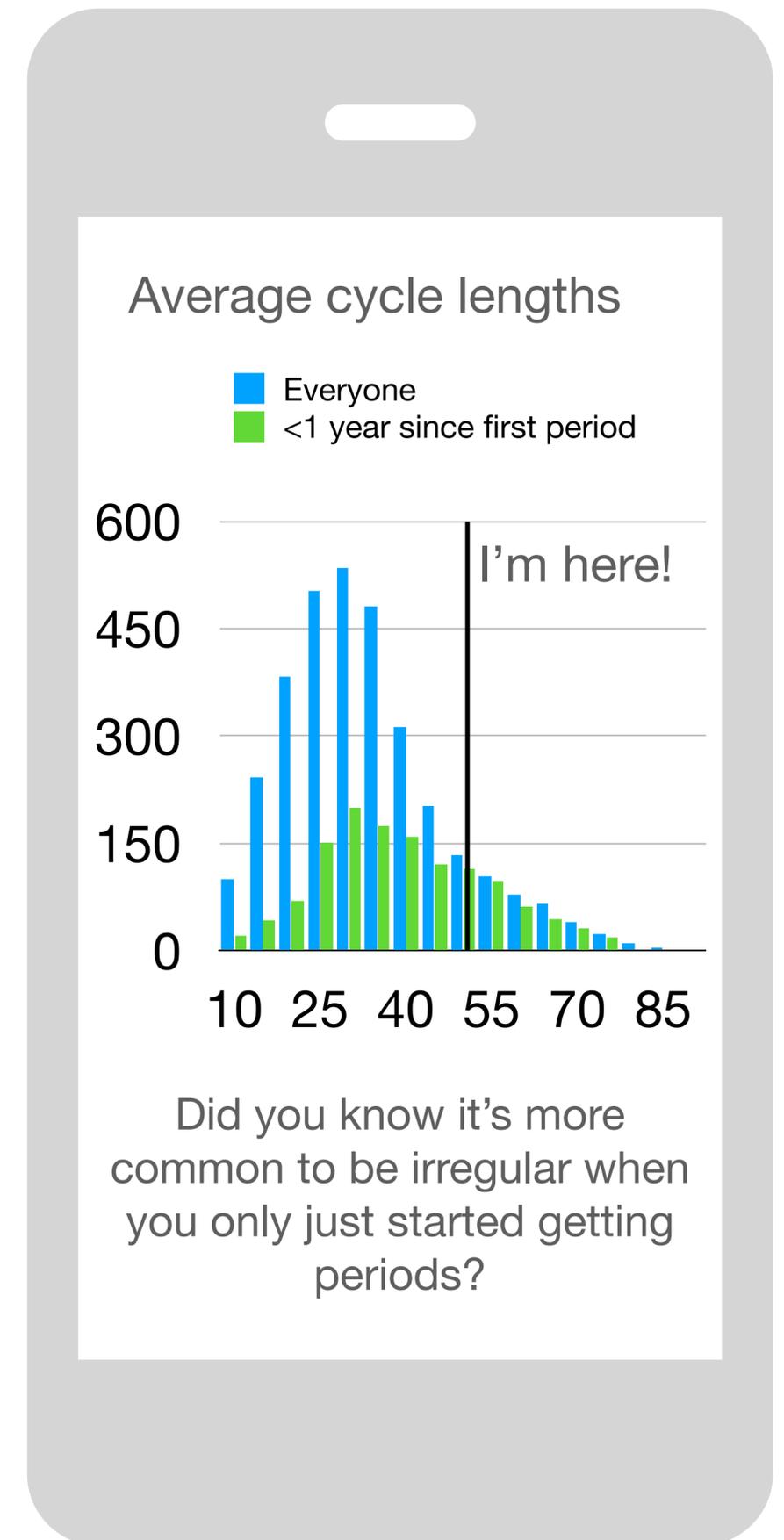


Leverage contextual expertise in data cleaning and analysis

Convey uncertainty and variability when making comparisons

Structure engagement around valid analyses

Support (asynchronous and anonymous) social engagement and learning



How can we engage people more directly in research with their personal health data?



Leverage contextual expertise in data cleaning and analysis

Convey uncertainty and variability when making comparisons

Structure engagement around valid analyses

Support (asynchronous and anonymous) social engagement and learning

How can we engage (with limited technical & domain expertise) people more directly ~~in research~~ with their ~~personal health~~ data?

Leverage contextual
expertise in data cleaning
and analysis

Convey uncertainty and
variability when making
comparisons

Structure engagement around
valid analyses

Support (asynchronous and anonymous)
social engagement and learning



Engaging participants in research with self-logged menstrual health data

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Samantha Robertson, HILDA 2022, June 12, 2022

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Acknowledgements



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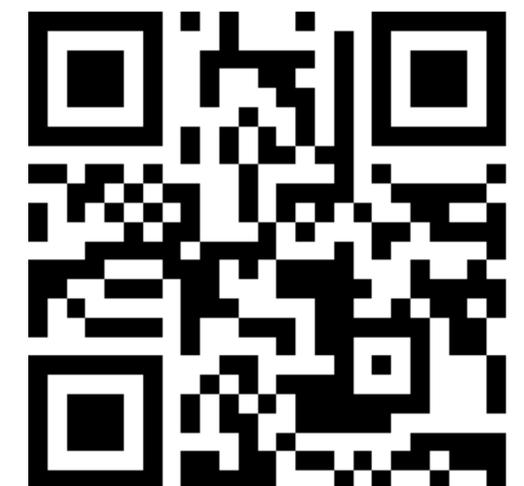
Clue collaborators

Dr. Amanda Shea
Charlie Upton

HILDA mentor

Dr. Leilani Battle
University of Washington

Working Draft



<https://tinyurl.com/engagecycles>