

# **Engaging participants in research with self-logged menstrual health data**

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**Samantha Robertson, HILDA 2022, June 12, 2022**

# 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.**

Source: BBC

2020

2021

R'S PICKS

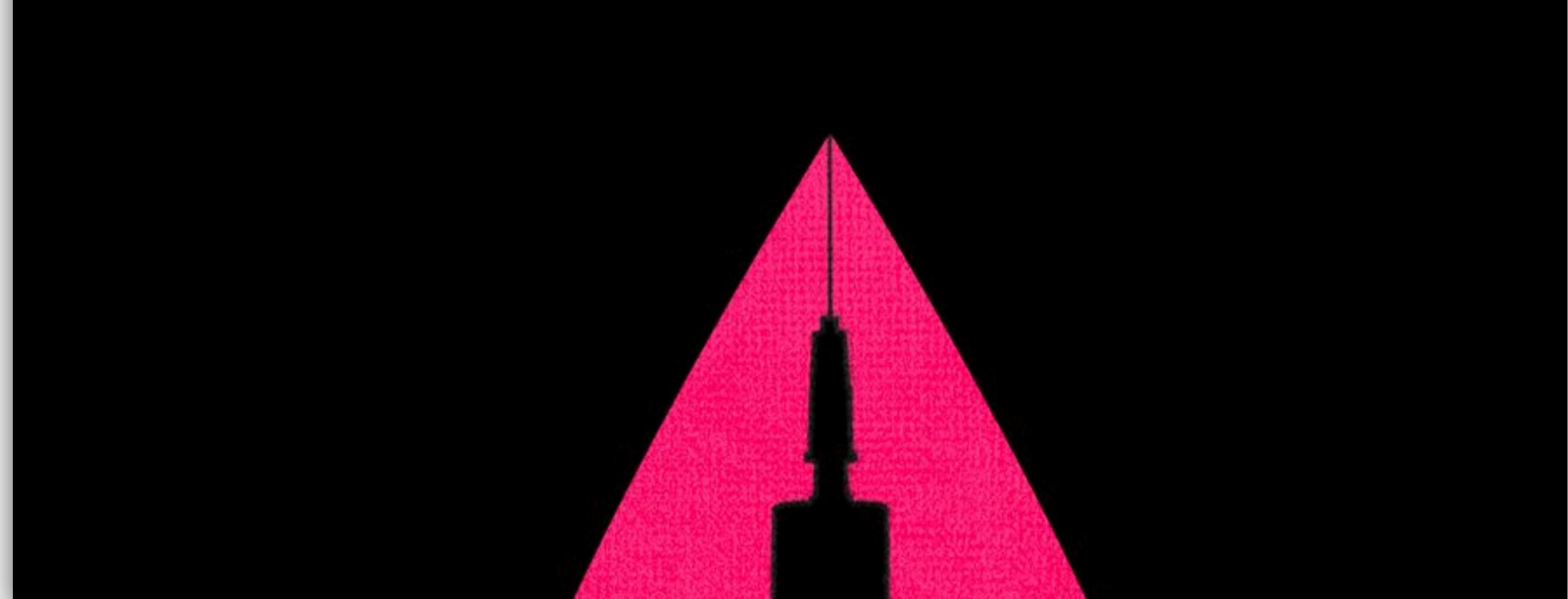
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HEALTH

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

No published studies have examined the effects vaccines on menstrual cycles



Source: Twitter; paraphrased

2020

2021

2022

## METHODS:

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

**OBSTETRICS & GYNECOLOGY**



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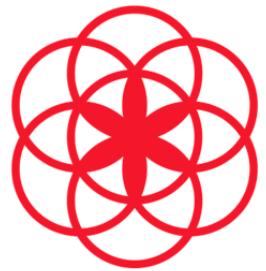
ORIGINAL RESEARCH

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.



LunaLuna



## ARTICLES

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

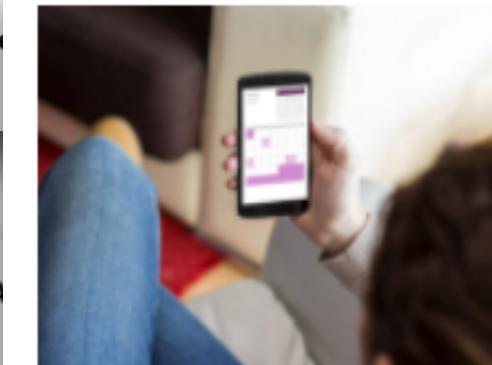
nature  
human behaviour

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

Emma Pierson<sup>1,2</sup>, Tim Althoff<sup>3</sup>, Daniel Thomas<sup>1,4</sup>, Paula Hillard<sup>1,5</sup> and Jure Leskovec<sup>1,6</sup>

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 has the most distinct periodicity. The mood and behaviour dimensions show the most significant periodicity, while vital signs show the least. The menstrual cycle, while showing periodicity, is less distinct than the other dimensions across countries.



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; Araishi, Tomonori MD; Ishikawa, Tomonori MD, PhD

JMIR FORMATIVE RESEARCH

Author Information

Obstetrics & Gynecology: Open Access  
doi: 10.1097/AOG.0000000000000000

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 Bradley<sup>1</sup>, Erin Landau<sup>1</sup>, Noreen Jesani<sup>2</sup>, Brett Mowry<sup>3</sup>, Kenneth Chui<sup>4</sup>, Alex Baron<sup>1</sup>, Adam Wolfberg<sup>1,5</sup>

## 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, Eleonore MPH; Matteson, Kristen A. MD, MPH; Favaro, Carlotta PhD; Pearson, Jacqueline PhD, MPH

Author Information

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

Satoshi Sohda<sup>1</sup> , Kenta Suzuki<sup>2,3</sup> , Ichiro Igari<sup>3</sup>

Journal of  
Pediatric & Adolescent  
Gynecology

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. Bull<sup>1</sup>, Simon P. Rowland<sup>1</sup>, Elina Berglund Scherwitzl<sup>1</sup>, Raoul Scherwitzl<sup>1</sup>, Kristina Gemzell Danielsson<sup>2</sup> and Joyce Harper<sup>3</sup>

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: 0.17–0.20,  $R^2 = 0.99$ ) and mean follicular phase length decreased by 0.19 days (95% CI: 0.19–0.20,  $R^2 = 0.99$ ) 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>

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

MD, FRANZCOG

npj | Digital Medicine

[www.nature.com/npjdigitalmed](http://www.nature.com/npjdigitalmed)

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ARTICLE OPEN

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

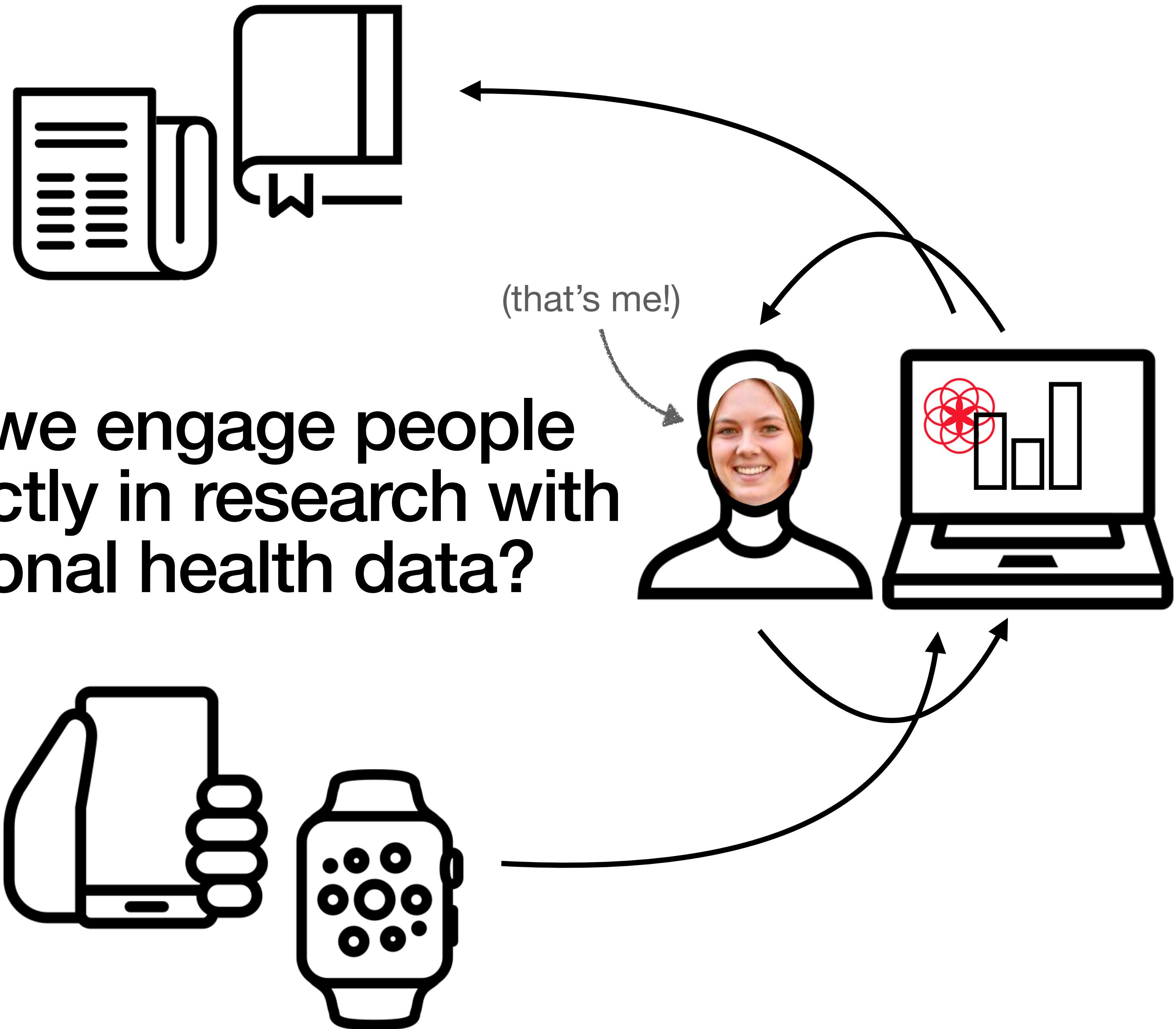
Kathy Li<sup>1,2</sup>, Iñigo Urteaga<sup>1,2</sup>, Chris H. Wiggins<sup>1,2</sup>, Anna Druet<sup>3</sup>, Amanda Shea<sup>3</sup>, Virginia J. Vitzthum<sup>1,3,4</sup> and Noémie Elhadad<sup>1,2,5</sup>

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-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>

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[www.nature.com/npjdigitalmed](http://www.nature.com/npjdigitalmed)



**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

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

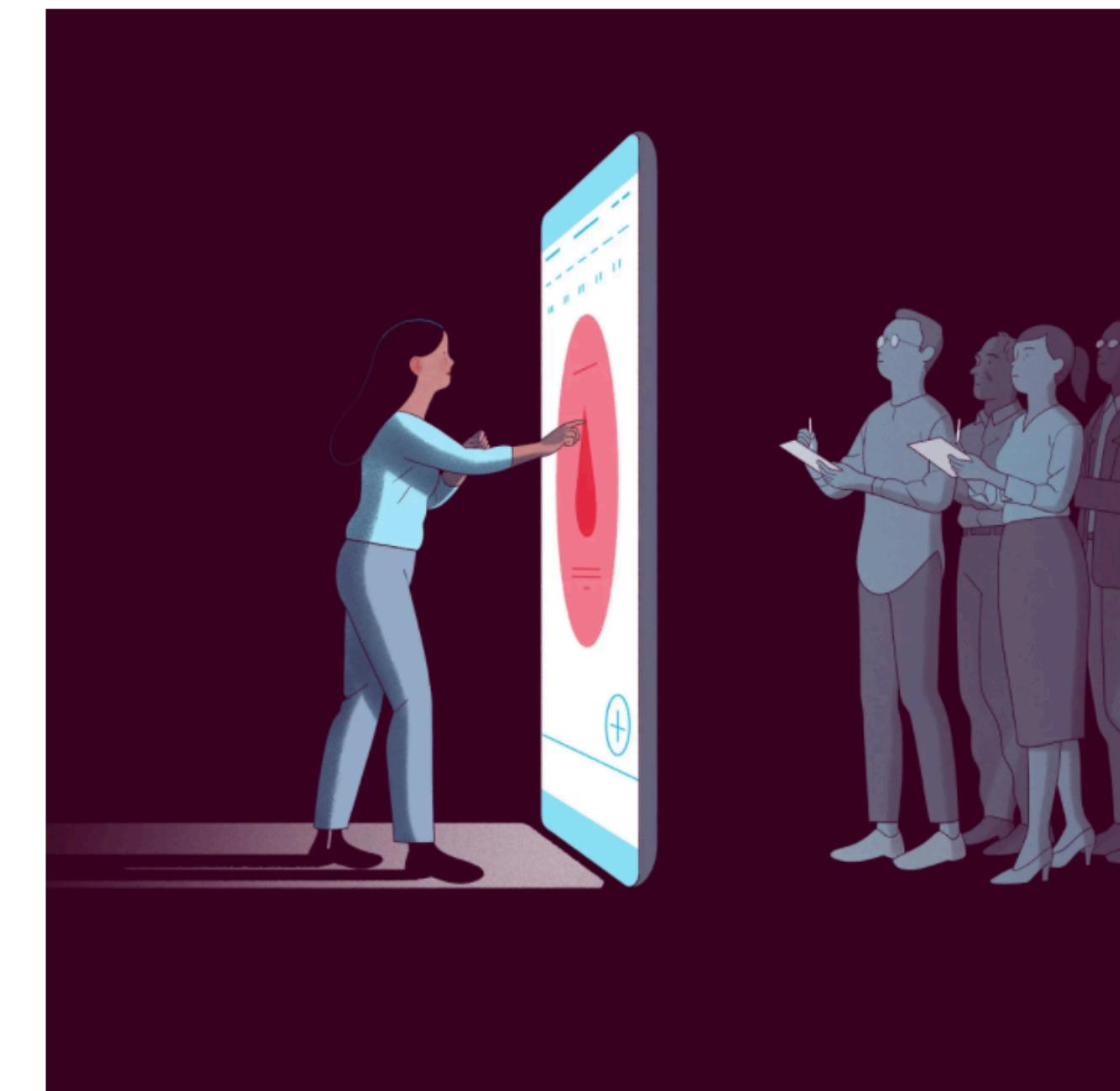
The New York Times

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?**

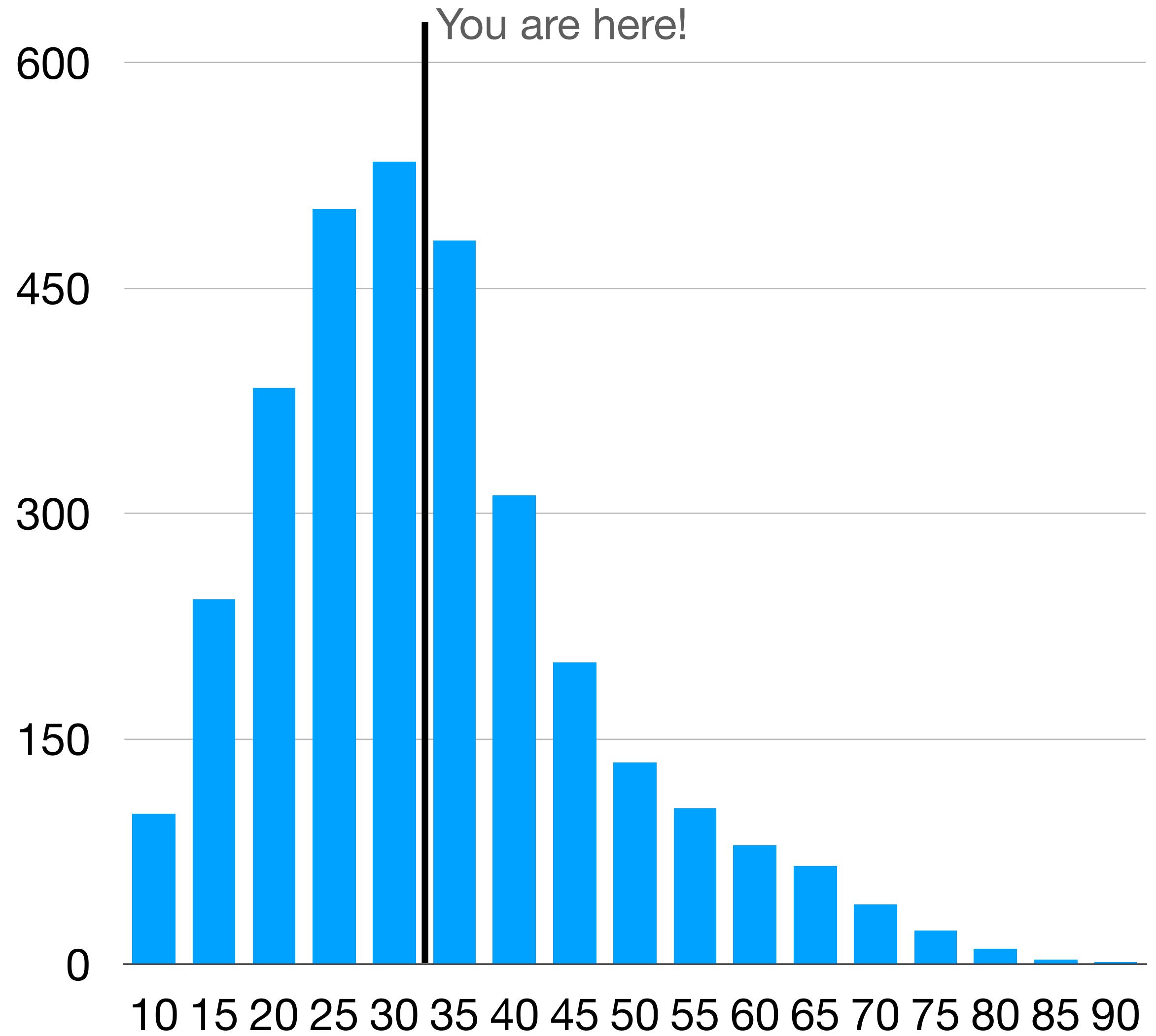


**Leverage contextual  
expertise in data cleaning  
and analysis**



?

Average cycle lengths



R'S PICKS

TheLily

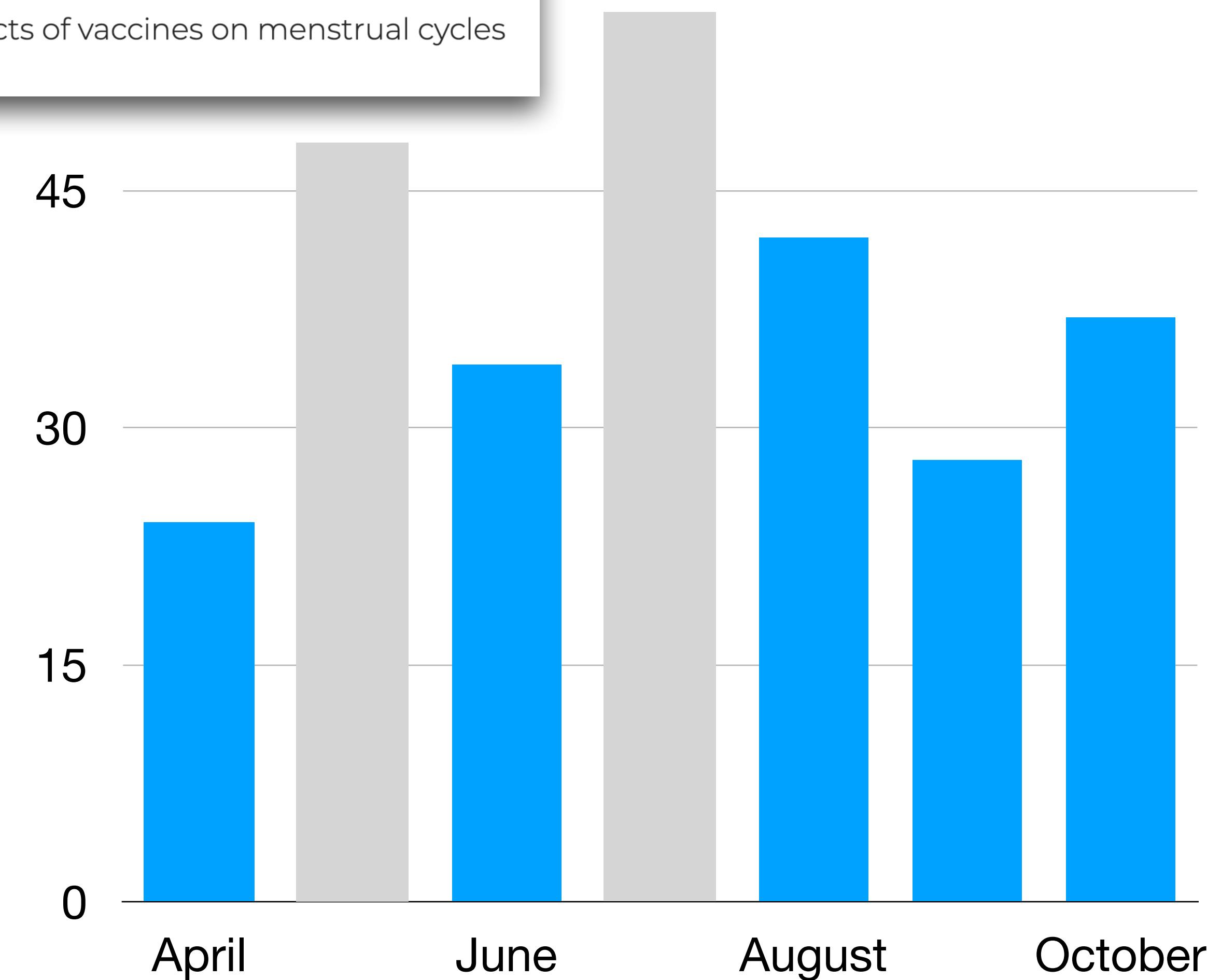
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HEALTH

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

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

Leverage contextual expertise in data cleaning and analysis



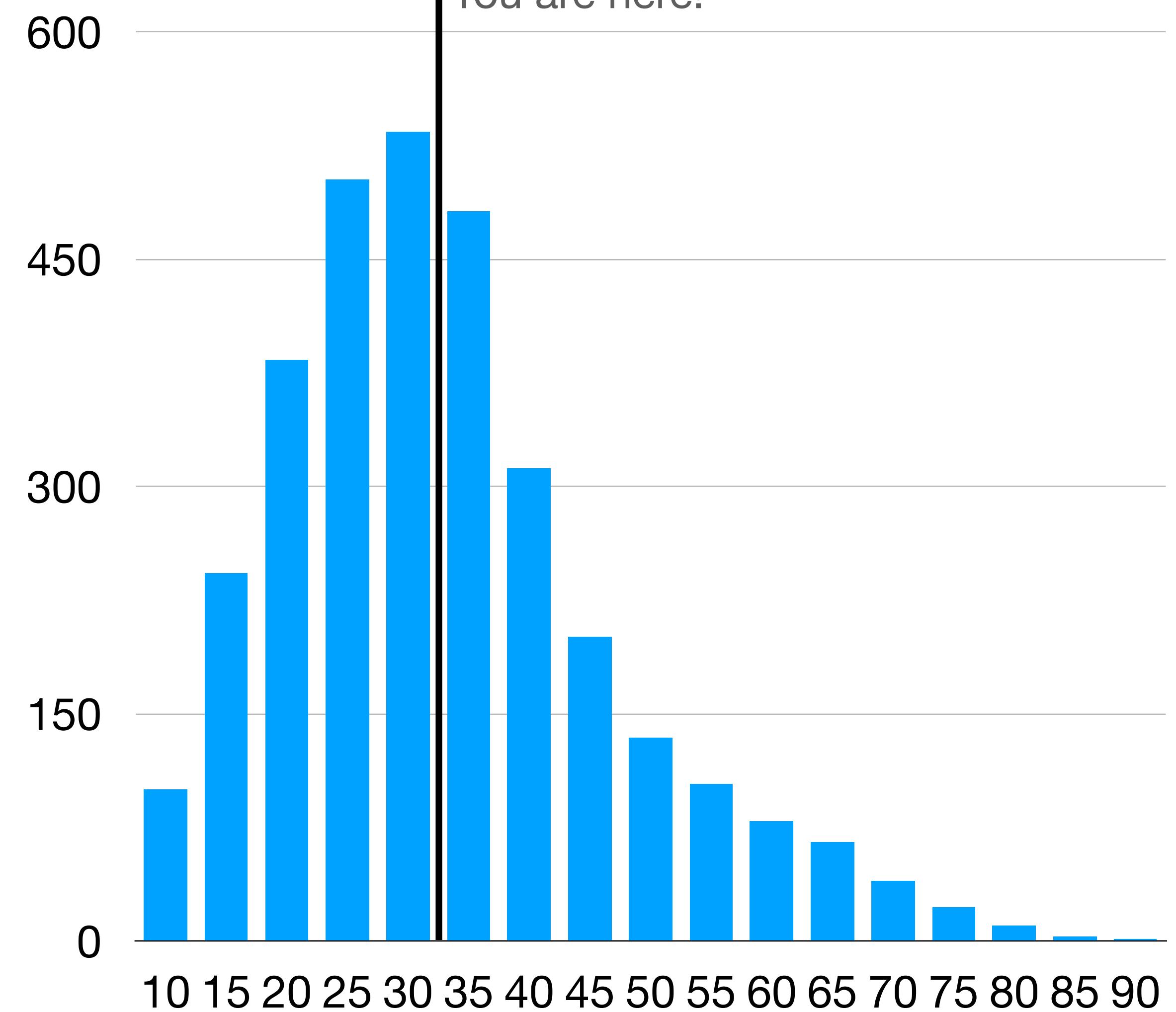
Leverage contextual expertise in data cleaning and analysis

Convey uncertainty and variability when making comparisons



Average cycle lengths

You are here!



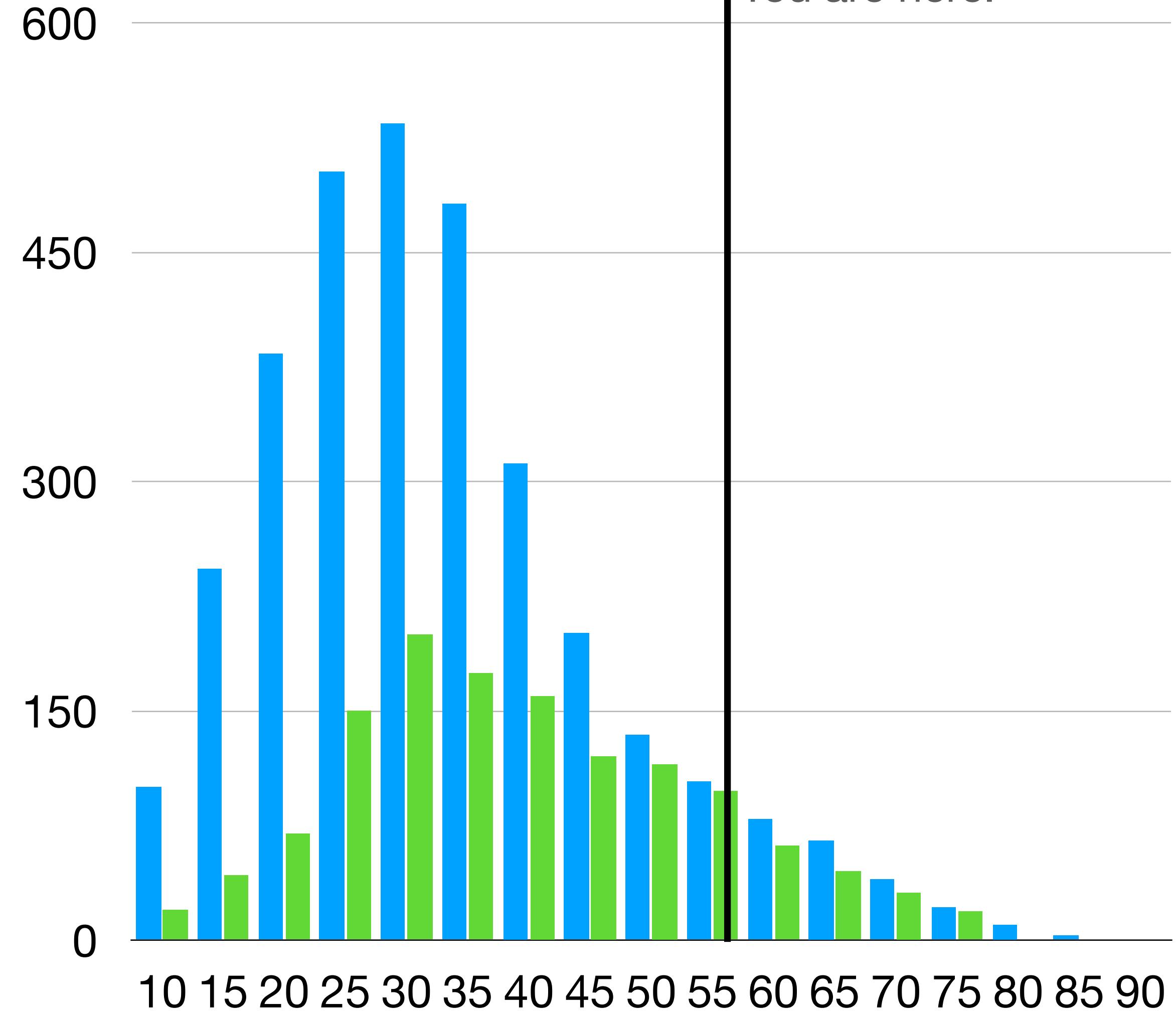
Leverage contextual  
expertise in data cleaning  
and analysis



Convey uncertainty and  
variability when making  
comparisons

Everyone <1 year since first period

You are here!

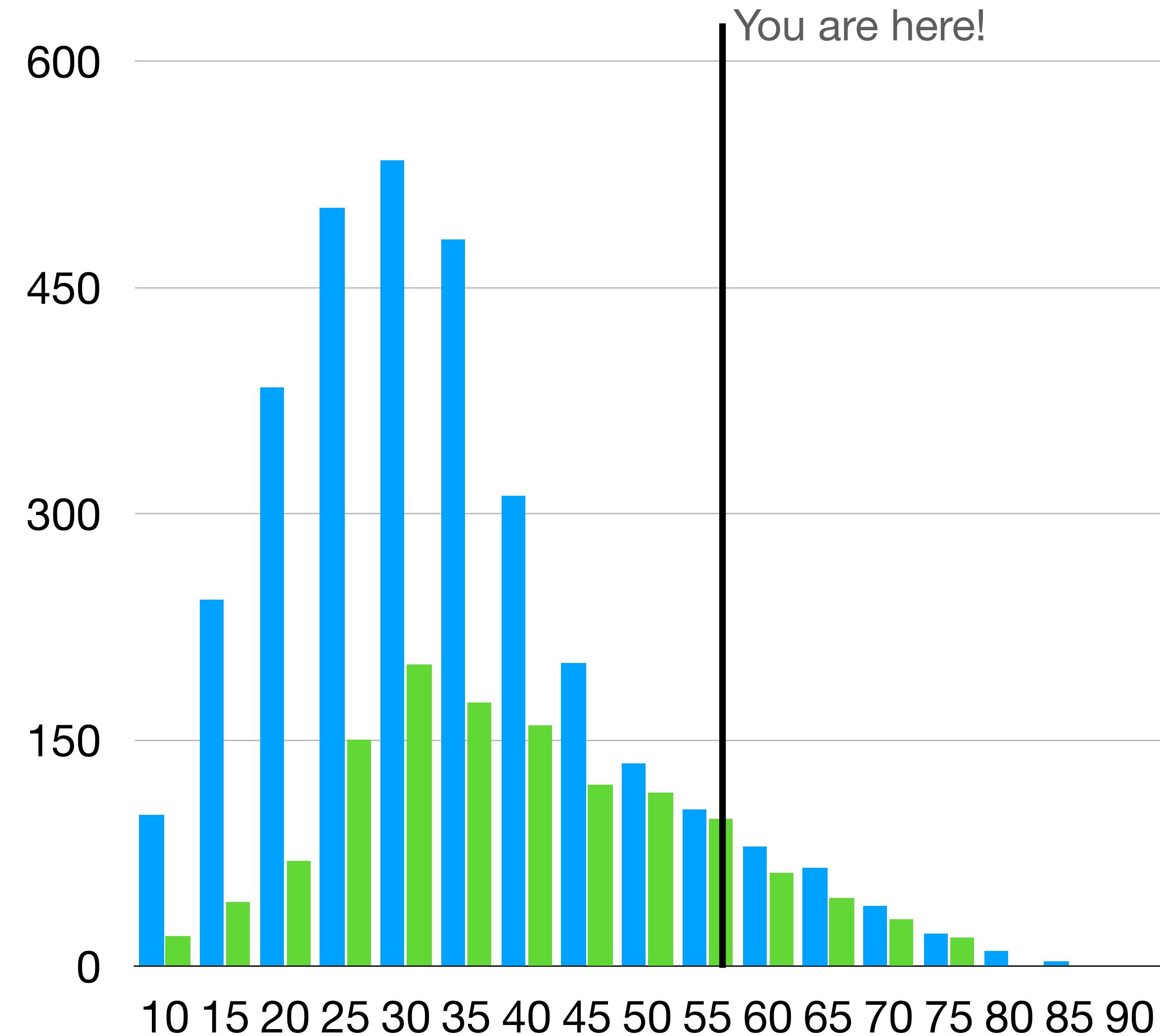


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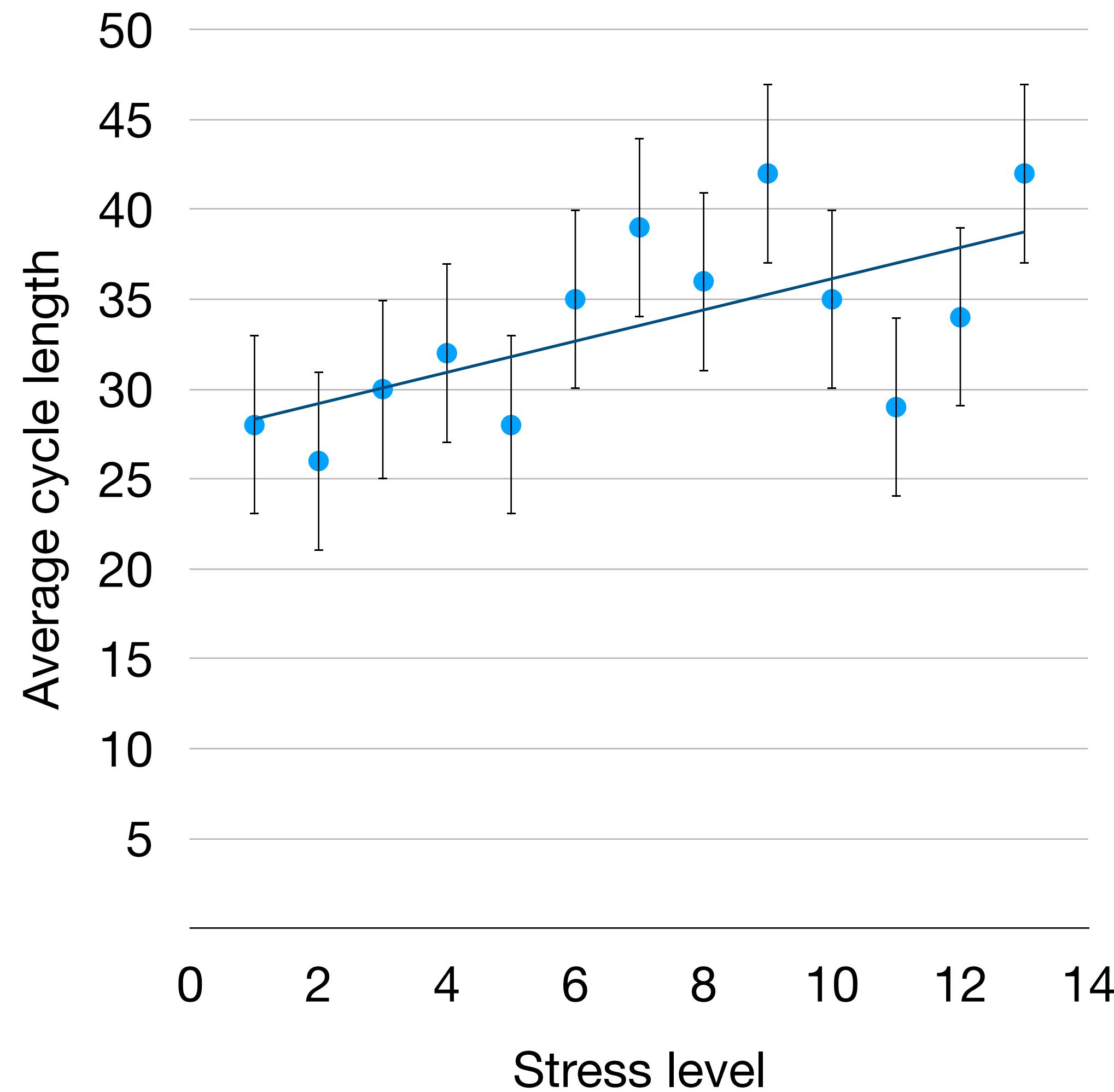
Leverage contextual expertise in data cleaning and analysis

Convey uncertainty and variability when making comparisons

Structure engagement around valid analyses



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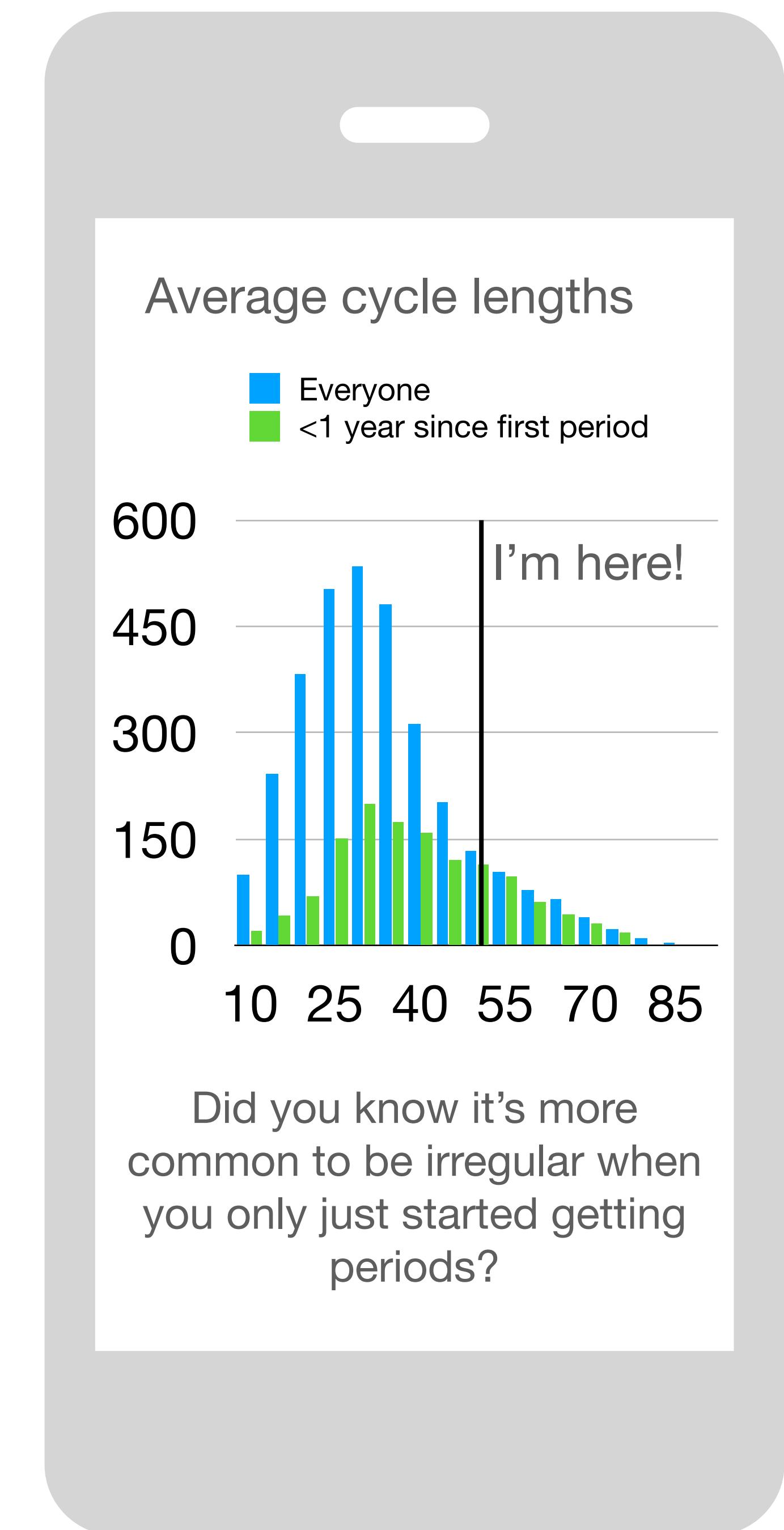


**Leverage contextual expertise in data cleaning and analysis**

**Convey uncertainty and variability when making comparisons**

**Structure engagement around valid analyses**

**Support (asynchronous and anonymous) social engagement and learning**



Leverage contextual expertise in data cleaning and analysis

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



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

## Acknowledgements



# Engaging participants in research with self-logged menstrual health data

**Samantha Robertson, Kim Harley, and Niloufar Salehi**  
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Charlie Upton

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Working Draft

**Samantha Robertson, HILDA 2022, June 12, 2022**

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