

Welcome to my EDAV Community Contribution Zoom Discussion on Visualization in Biomedical Research

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Agenda

- 1) Present my work on patient-provider qualitative research, where goal was to identify needs for interactive visualization tool for patient-generated data
- 2) High-level glance at Phendo data, alongside the prototype of early heatmap & summary tool, plus brainstorming for how to improve & apply principles from class
- 3) Open discussion about research, graduate programs, careers, or viz in healthcare & beyond

Land Acknowledgement

To begin, I wish to acknowledge the Indigenous Peoples as the traditional stewards of the land where I work, study, and conduct research, which is the unceded territory of the Lenape people. On the land we occupy, there is a longstanding history of colonialism that is ongoing and has painful effects that persist today; Indigenous Peoples still live on this land and I want to acknowledge their contributions to science and society.

*Thanks to Oliver Bear Don't Walk IV for help with this statement

Today is Transgender Day of Remembrance



Divided We Stand: The Collaborative Work of Patients and Providers in an Enigmatic Chronic Disease

Adrienne Pichon, Kayla Schiffer, Emma Horan, Bria Massey, Suzanne Bakken, Lena Mamykina, and Noémie Elhadad. 2020. Divided We Stand: The Collaborative Work of Patients and Providers in an Enigmatic Chronic Disease. Proc. ACM Hum.-Comput. Interact. 4, CSCW3, Article 261 (December 2020), 24 pages. <https://doi.org/10.1145/3434170>

*Also thanks to Megan Houterloot for implementing the design of the early D3 prototype

Enigmatic Chronic Diseases

No biomarkers to rely on &
unclear which symptoms to rely on

No established guidelines

Obstacles to communication

Monitoring is difficult

Treatment is difficult

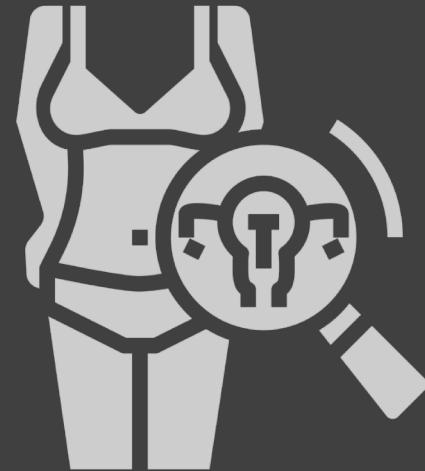
Partnership & understanding
are difficult for both
patients & providers



Endometriosis

Debilitating illness impacting 6-10%
of reproductive-age women

No biomarkers, no clear treatment
guidelines, & no cure



"Remains a riddle wrapped in a mystery inside an enigma." Emery Wilson

Research Questions

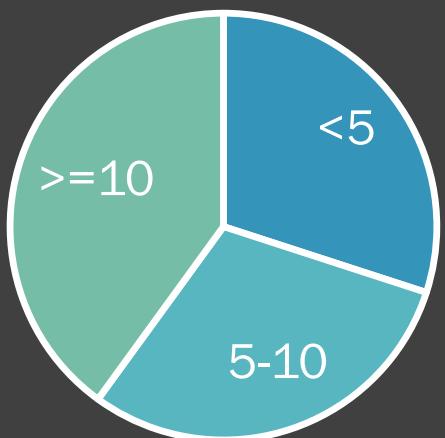
- (1) In the work of patients and providers when caring for endometriosis, what **aspects of their work** pertain specifically to such a complex condition?

- (2) What **role does technology play** in facilitating the partnership and the success of endometriosis care, and what **opportunities** are envisioned?

Study & Participants

Interviews (n = 10)

Years Experience



Specialists:

- 3 Surgeons
- 2 Gynecologists
- 2 Psychiatrists
- 2 Pelvic physical therapists
- 1 Pain specialist

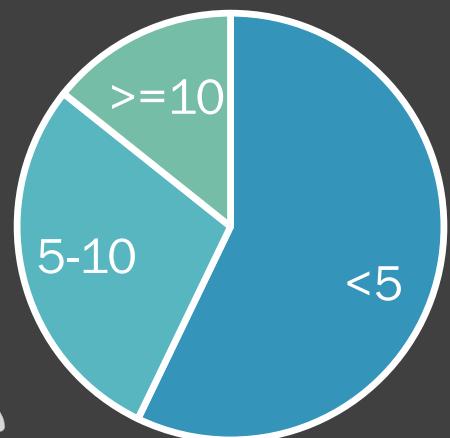
Focus Groups (n = 21, 5 groups)

Race: 1/3 non-white

Age:

- 7 Younger than 30
- 14 30 or older

Years Diagnosed



Analysis

- thematic analysis of interview & focus group transcripts

Findings

- insights about the work of patients & providers in caring for enigmatic conditions
- insights about how patients & providers use & want to use data & technology to support care

Discussion

- design implications

We found that **patients want to use their records & data** to...

- Construct a holistic picture of their illness trajectory
- Reflect & make sense of their illness experiences
 - Short-term health status
 - Long-term journey
- Facilitate care & self-management



→ Patients on their own

- For self-care
- To prepare for clinical visits



→ Patients & Providers together

BUT, the **complexities** of endometriosis as an enigmatic condition **complicate care**

Patients & providers told us about...

[THEMES]

enigmatic nature (lack of medical guidance)

... means uncertainty & frustration in care

chronic & temporal dynamics

... adds confusion

multi-factorial & systemic features

... overwhelms patients & providers
working together for comprehensive care

negotiation of knowledge & expertise

... necessary & beneficial, but potential for
significant patient-provider misalignment

BUT, the **complexities** of endometriosis as an enigmatic condition **complicate care**

Patients & providers told us about...

[THEMES]

chronic & temporal dynamics

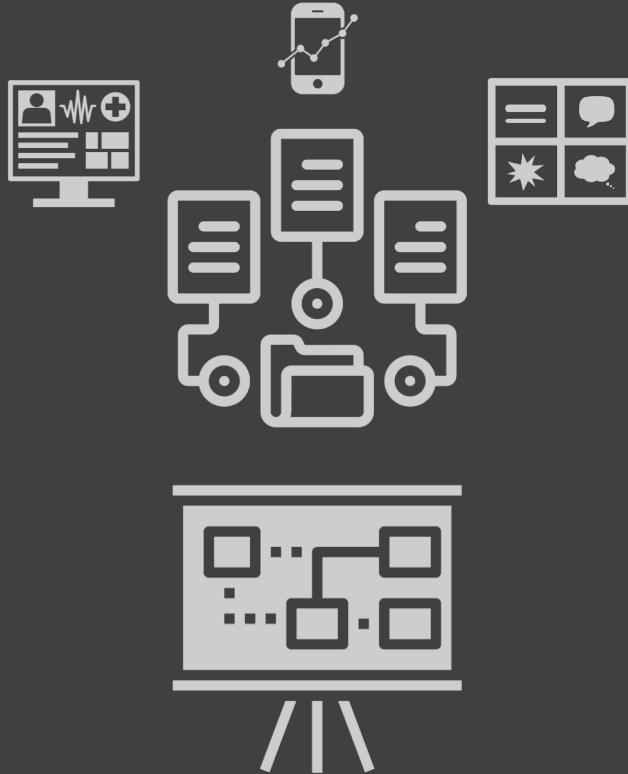
... adds confusion

"It can be really hard to sort through, if [the patient is] like 'and on this hour I felt this way and that way.' Most of us think in terms of weeks instead of days." [provider]

"It's such a daily thing, hour-by-hour, day-by-day. When a physician asks me three months, that's a tricky answer." [patient]

At the other extreme, [patients] talked about their experiences "as an adventure," "journey," & in terms of "stages of life"

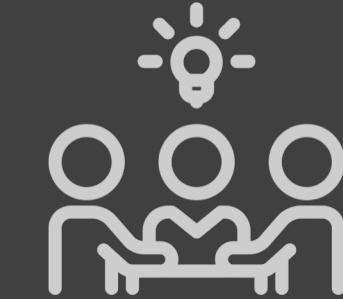
Design Opportunities Identified



(1) Construct & Curate Holistic Representation of Illness Trajectory & Health Status

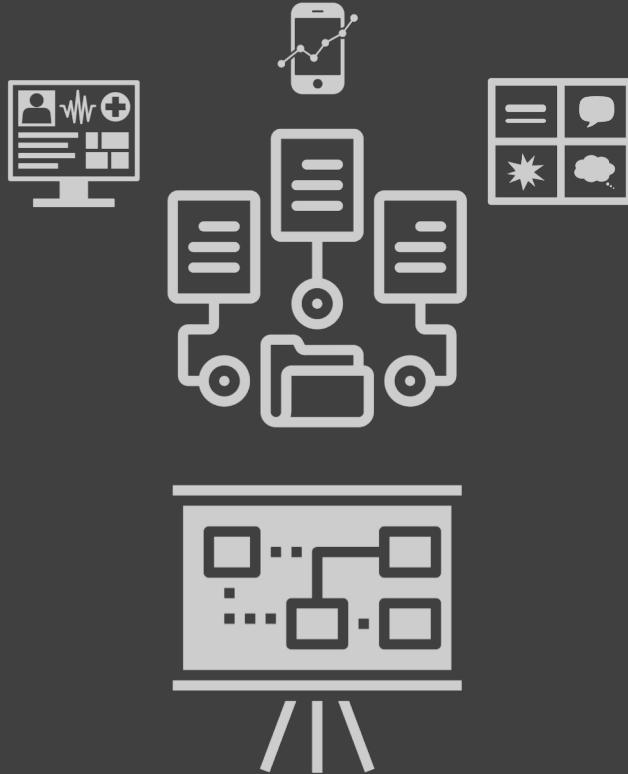


(2) Help Reflect & Make Sense of Illness Experience



(3) Scaffold Collaborative Work & Actively Correct Misalignments

Design Opportunities Identified



(1) Construct & Curate Holistic Representation of Illness Trajectory & Health Status

link & synthesize clinical + raw, daily self-tracking data into a comprehensive timeline with multiple/flexible views, leveraging FHIR standards for interoperability

tools for data curation to transform artifacts for independent use into artifacts for collaborative use to support care

leverage narrative to tell the patient's story

in the absence of medical guidelines, integrate data-driven solutions with annotations & storytelling to reflect on & craft representations of a patient's personal illness trajectory

Data-powered stories

[Bach]

A Specific Example: Data Comics

The Emerging Genre of Data Comics

Benjamin Bach

Harvard University

Nathalie Henry Riche

Microsoft Research

Sheelagh Carpendale

University of Calgary

Hanspeter Pfister

Harvard University

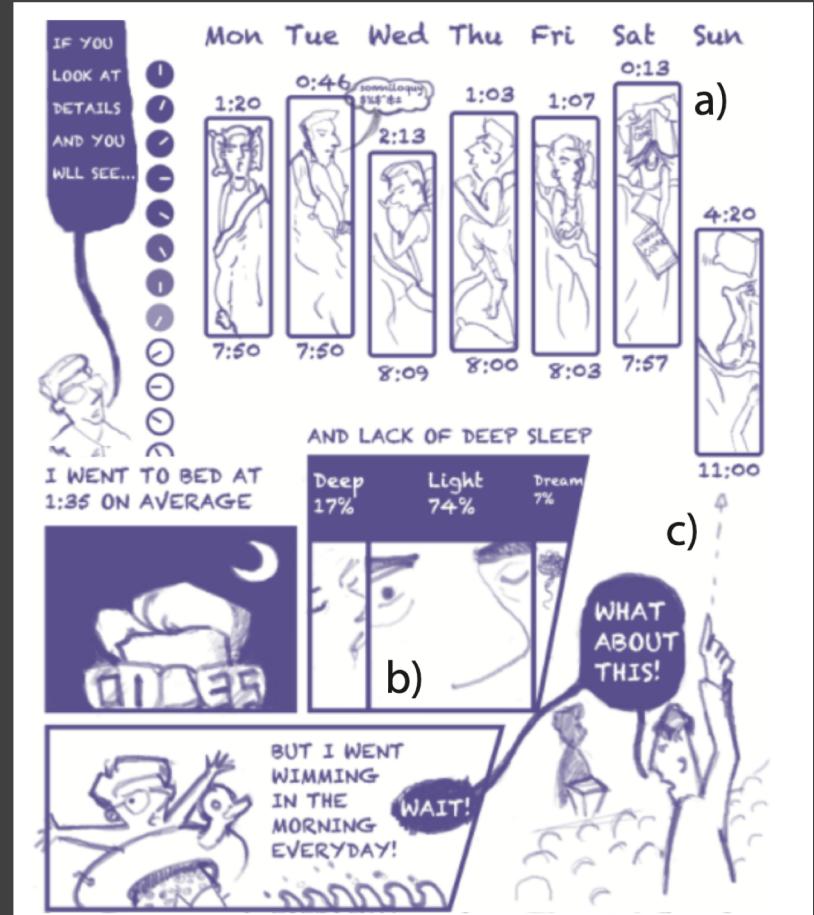
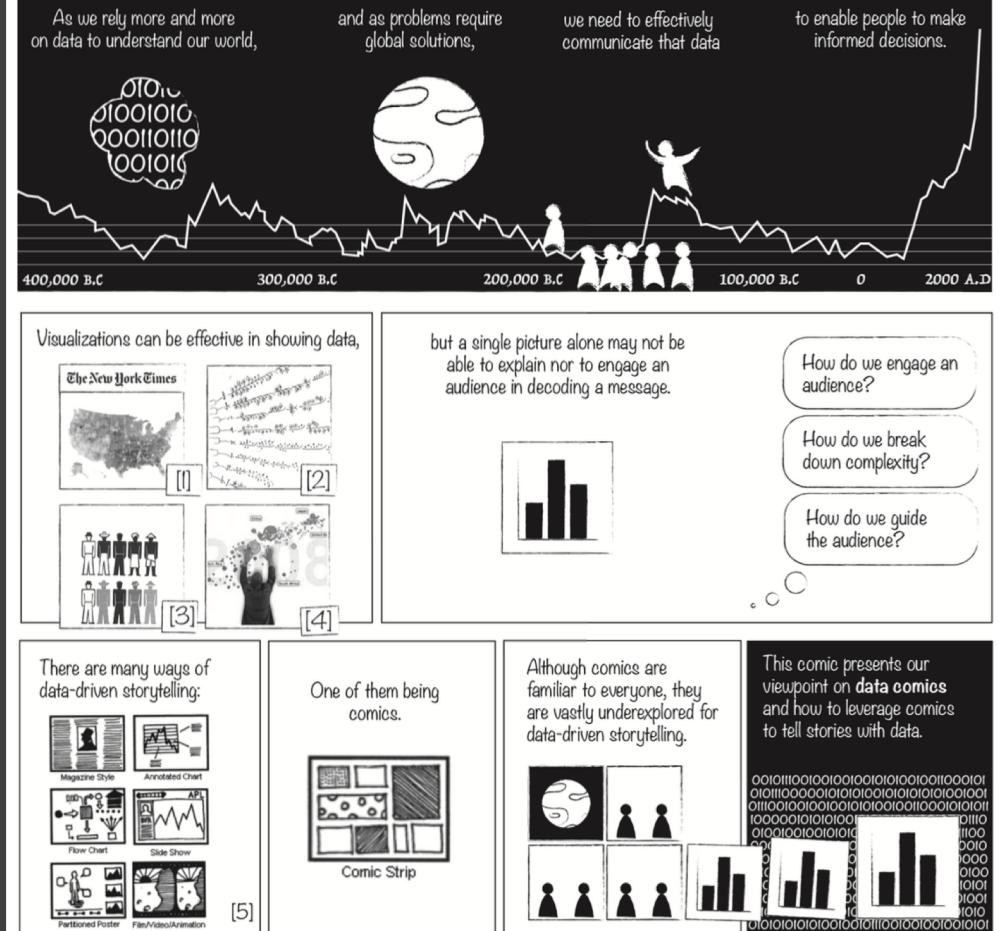


Figure 1. Data comic example employing design patterns: a) temporal sequence, b) bar-chart panel, and c) flashback. (©Zehzhong Wang)

Bach, B., Wang, Z., Farinella, M., Murray-Rust, D., & Henry Riche, N. (2018). Design Patterns for Data Comics. Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems, 38:1–38:12. <https://doi.org/10.1145/3173574.3173612>

Bach, B., Riche, N. H., Carpendale, S., & Pfister, H. (2017). The Emerging Genre of Data Comics. IEEE Computer Graphics and Applications, 37(3), 6–13. <https://doi.org/10.1109/MCG.2017.33>

Design Opportunities Identified



(2) Help Reflect & Make Sense
of Illness Experience

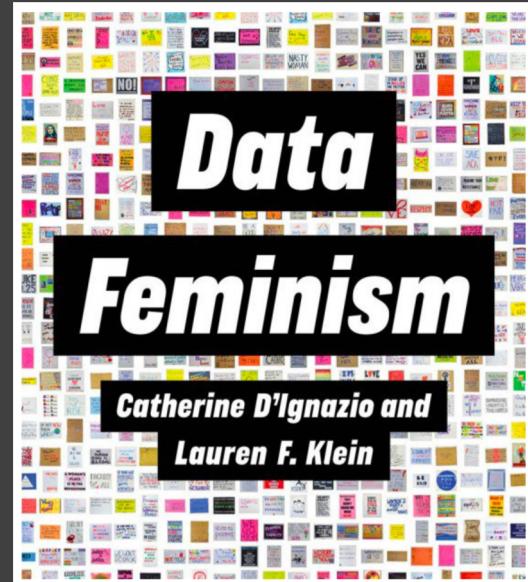
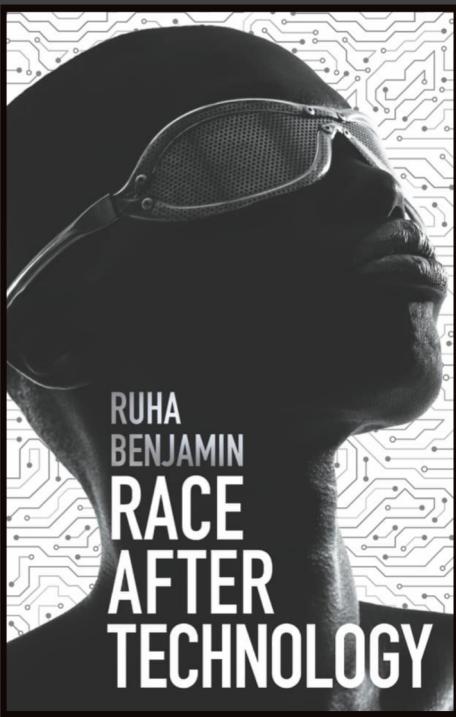
visualizing, exploring, and engaging with the data can help generate insights useful for clinical discussions or directly integrating into care activities

computational approaches (modern time series analysis, reinforcement learning) combined with visual analytics techniques could support patients and providers in tasks that are impossible without assistance: resolving different temporal resolutions, identifying trends within lots of data, and figuring out which strategies might be useful

human-centered computing, for things like trust and control over automated processes (eg, data-point level consent/permissions)

Some Specific Resources

with a focus on
human-centered
computing



D'Ignazio, C., & Klein, L. F. (2020). *Data Feminism*. MIT Press.
[open access, free online; also webinar recordings and sketchnotes from sessions with the authors: <http://datafeminism.io/>]

Benjamin, R. (2019). *Race After Technology: Abolitionist Tools for the New Jim Code*. John Wiley & Sons.
[<https://www.ruhabenjamin.com/race-after-technology>]

Costanza-Chock, S. (2018). *Design Justice: Towards an Intersectional Feminist Framework for Design Theory and Practice* (SSRN Scholarly Paper ID 3189696). Social Science Research Network.
[<https://designjustice.org/>]

Design Opportunities Identified



(3) Scaffold Collaborative Work & Actively Correct Misalignments

explicit scaffolding & mechanisms for collaborative review of data

interactive visualizations for collaborative reflection & sensemaking... to craft self-reflections & act as an objective measure to bridge the discussions between a clinical understanding of the disease and the patient's experience

self-tracking prescriptions to decide about what & how to track

Current & Future Work

****Implement design features identified in this study****

Iteratively update prototype with **usability testing**

Pilot test with end-users in a real-world setting



Project website:
CitizenEndo.org

**Thanks to research
participants for their input**

Phendo App & Prototype

Now to design the tool.... eventually will include clinical data also,
but for now just self-tracking data from Phendo

The Phendo App: self-tracking endometriosis

Research app for self-tracking
experience of endometriosis, from
patient perspective

12,000+ users; >25% log for at least 1 month

Initially designed for phenotyping the disease, to produce much needed medical knowledge... see prior work:

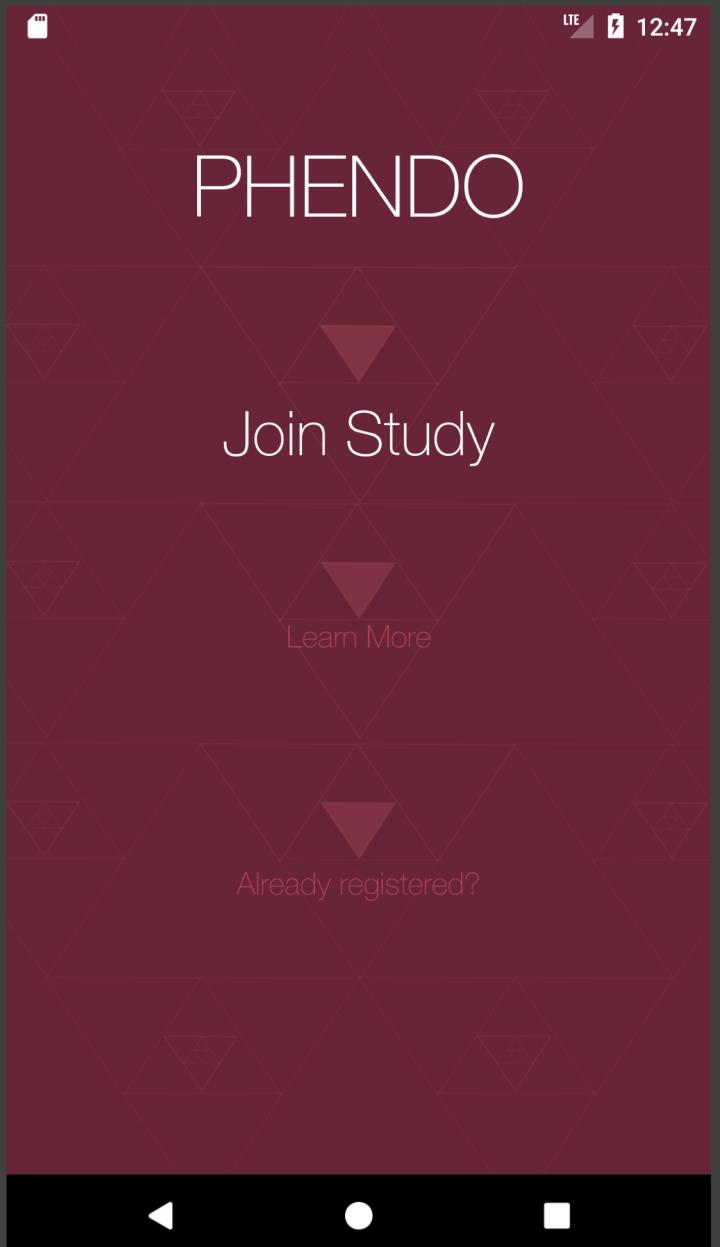
McKillop, M. (2019). Phenotyping Endometriosis from Observational Health Data [Ph.D., Columbia University].

<https://search.proquest.com/docview/2197685272/abstract/8E1610F24E8C4765PQ/1>

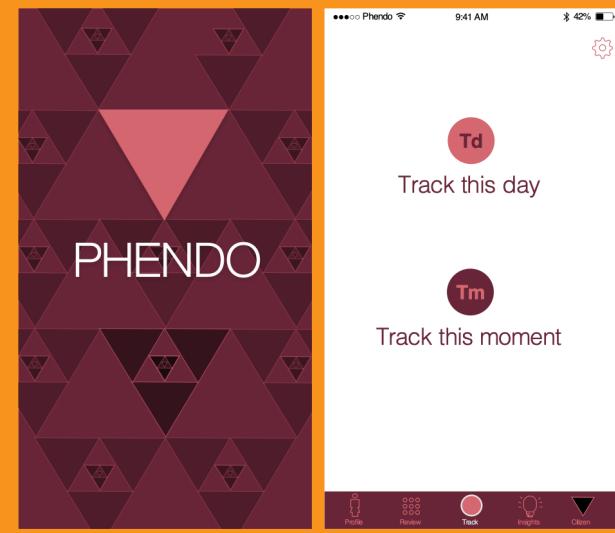
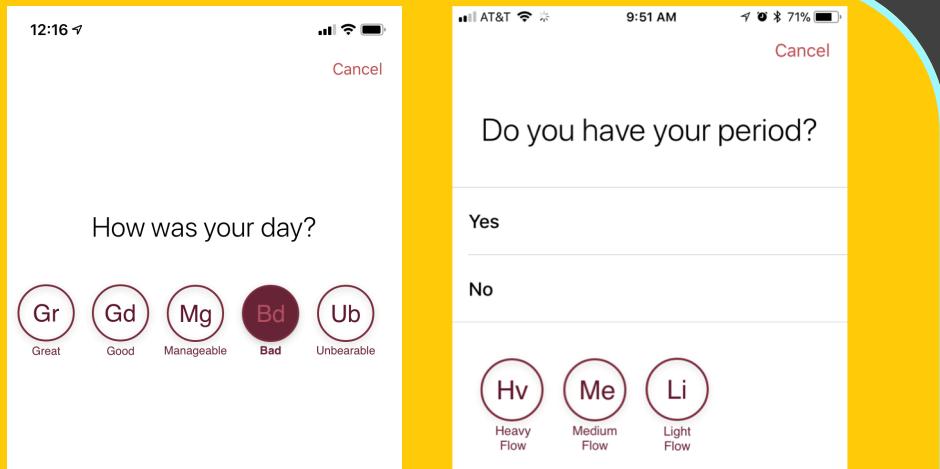
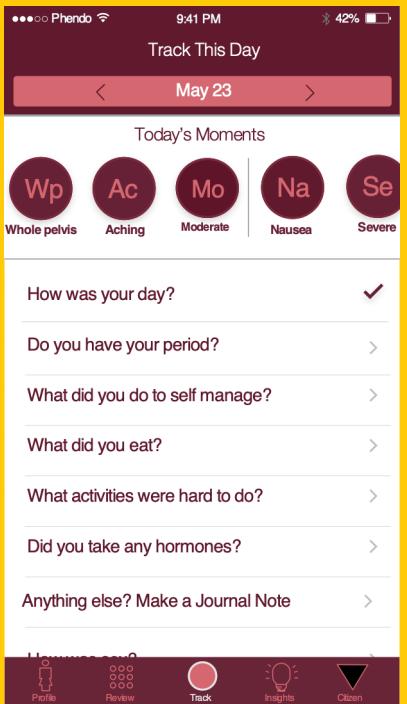
McKillop, M., Mamykina, L., & Elhadad, N. (2018). Designing in the Dark: Eliciting Self-tracking Dimensions for Understanding Enigmatic Disease. Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems, 565:1–565:15.

<https://doi.org/10.1145/3173574.3174139>

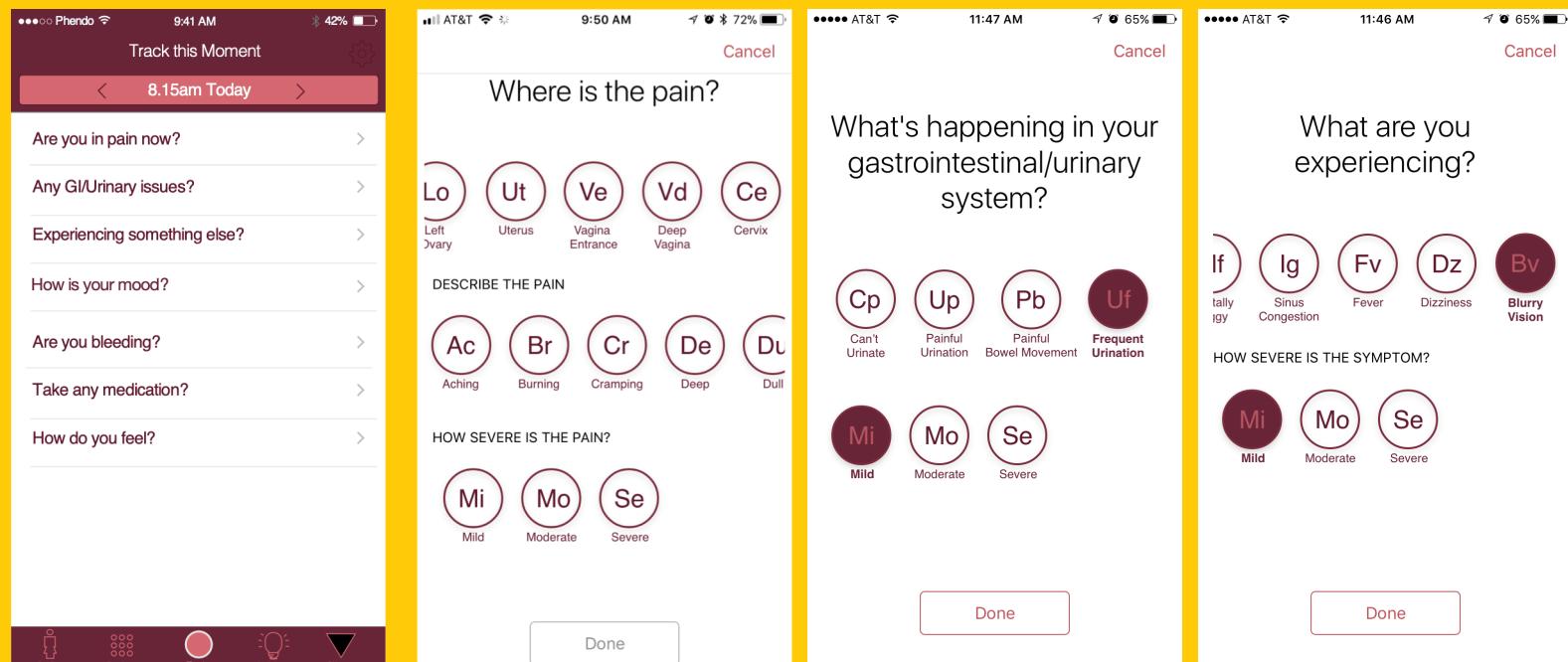
Urteaga, I., McKillop, M., Lipsky-Gorman, S., & Elhadad, N. (2018). Phenotyping Endometriosis through Mixed Membership Models of Self-Tracking Data. Proceedings of Machine Learning for Health Care, 1–22. <http://arxiv.org/abs/1811.03431>



DAY Variables



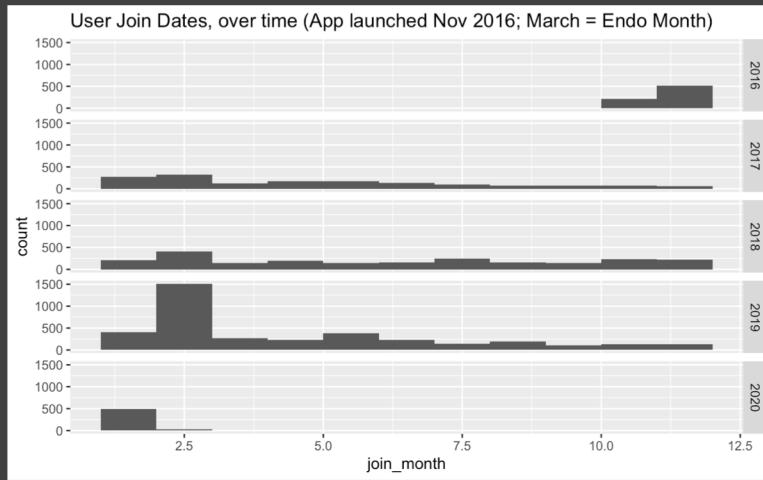
MOMENT Variables



Phendo data at-a-glance

Who uses the app? How do they use it?

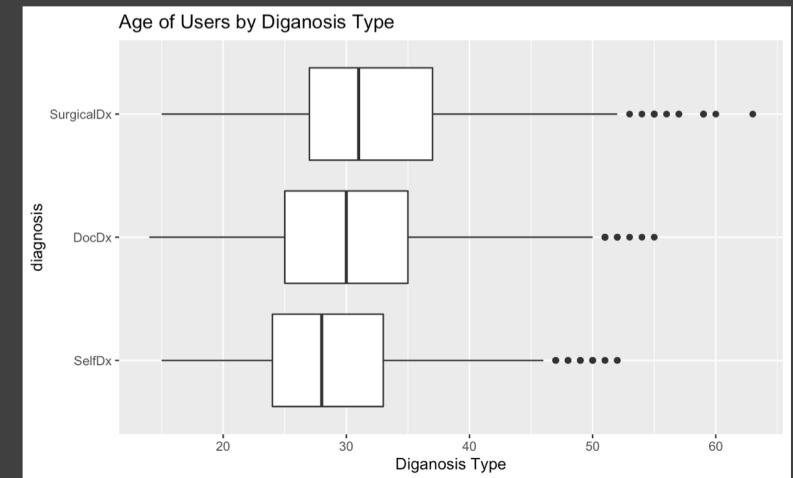
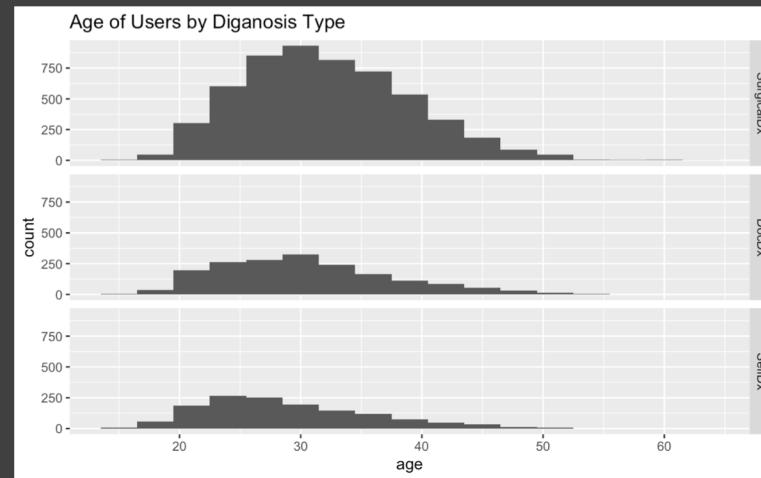
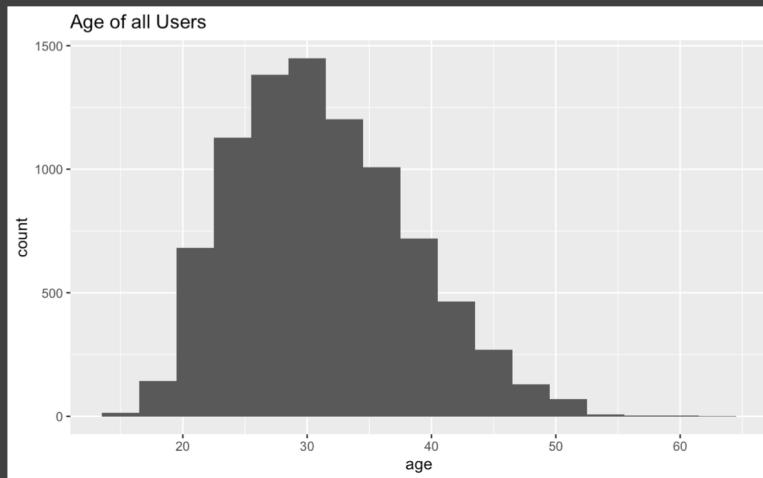
- I am using a warehoused version of the data from March 2019, where **n= 8838** (but app has 12k+ users)



← Join Dates

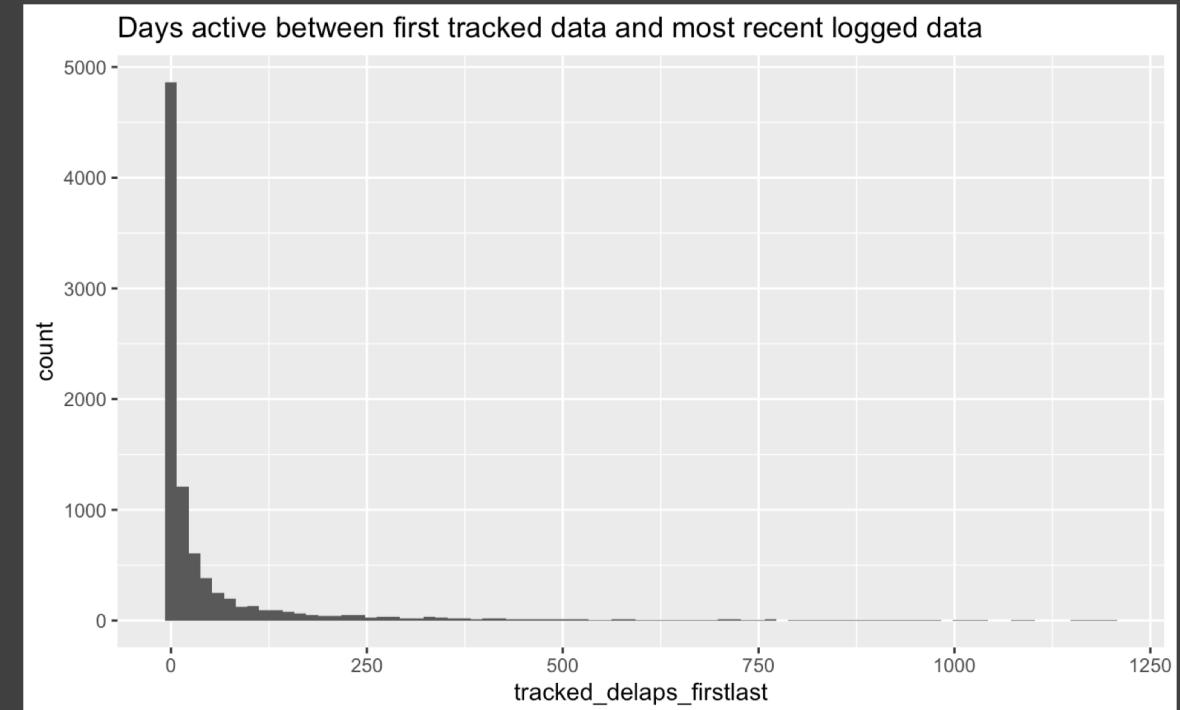
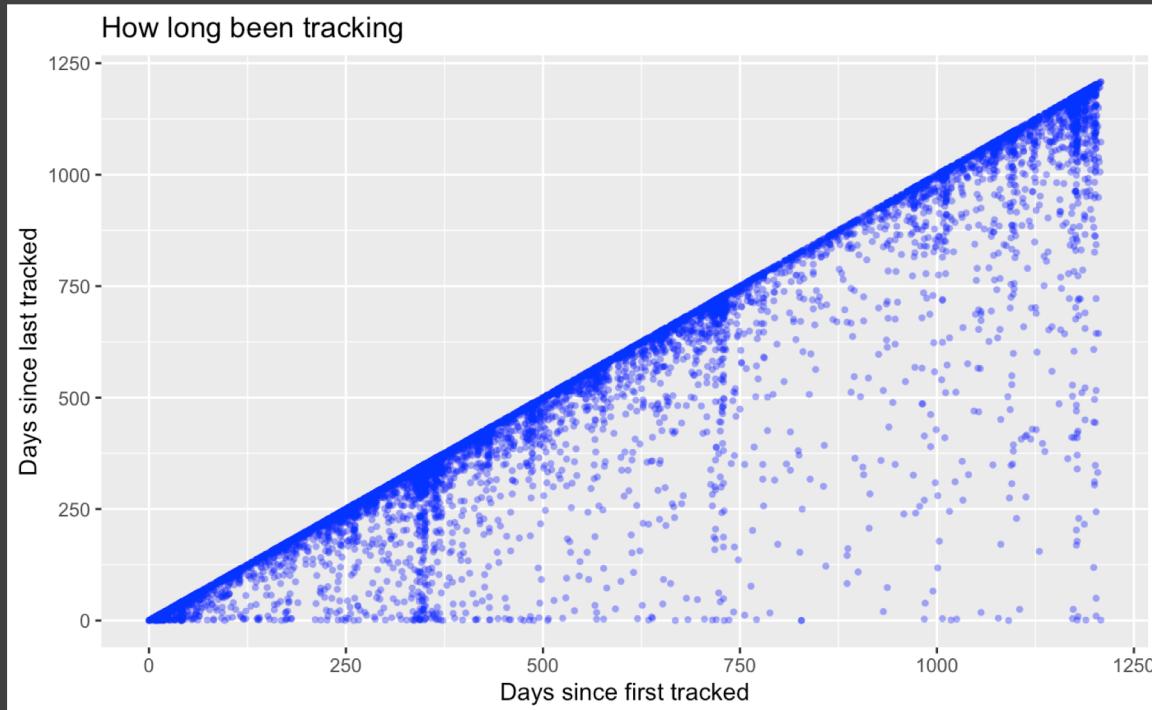
Users age ranges btwn 14-63, with median = 31

- If you look at those who were diagnosed via surgery, they are older than those who have a presumed diagnosis (by self or doc)... this lines up with the known delay in time-to-diagnosis

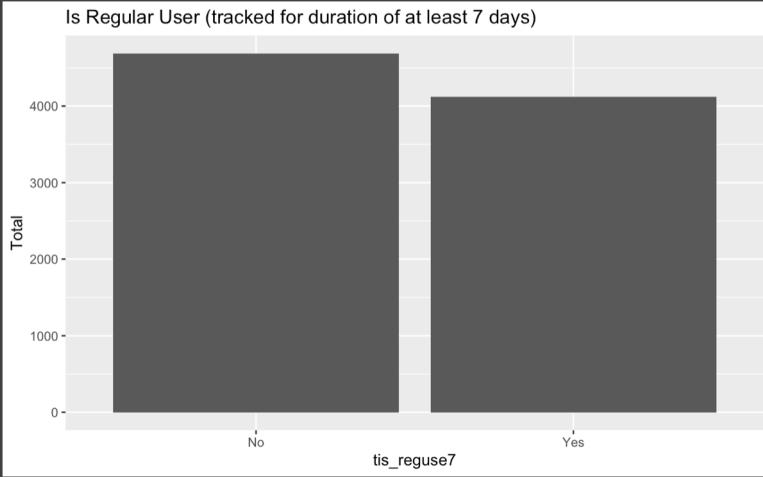


Tracking Patterns

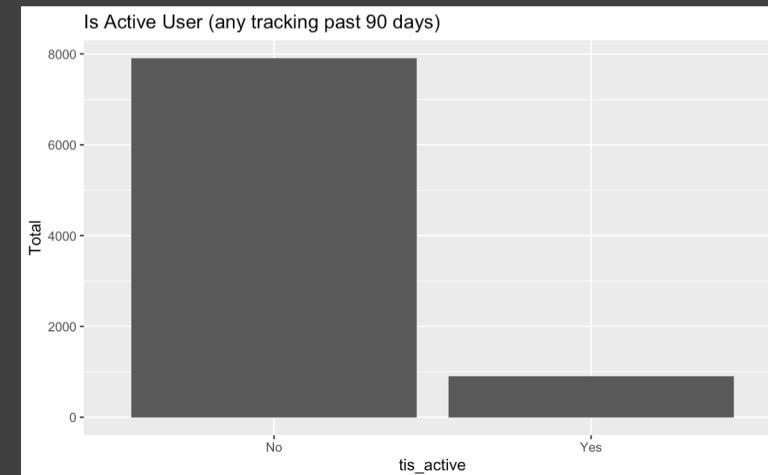
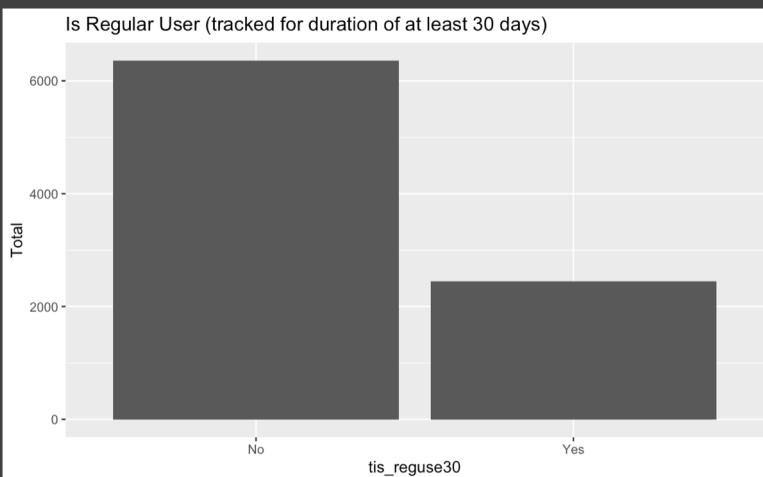
People don't use the app forever... some never use it, others use it for a short while, some use it for a longer period, and only a handful use it >6 months



Tracking Patterns



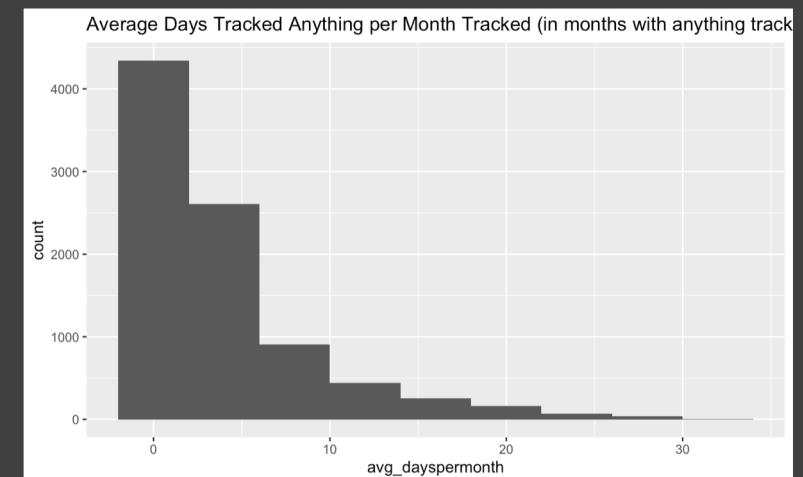
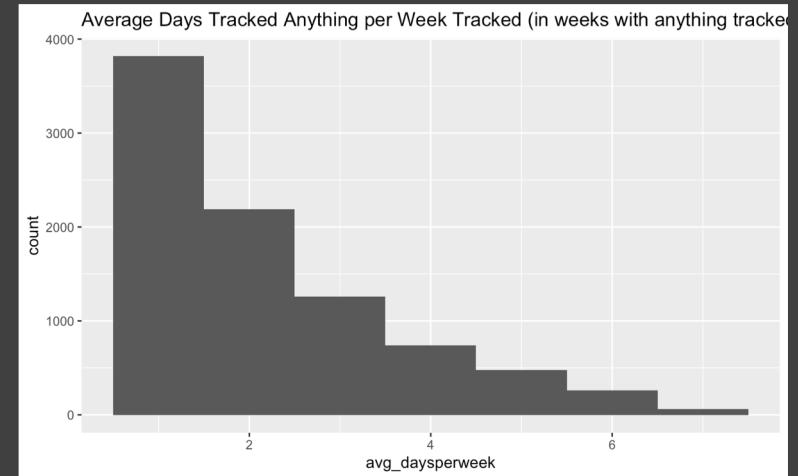
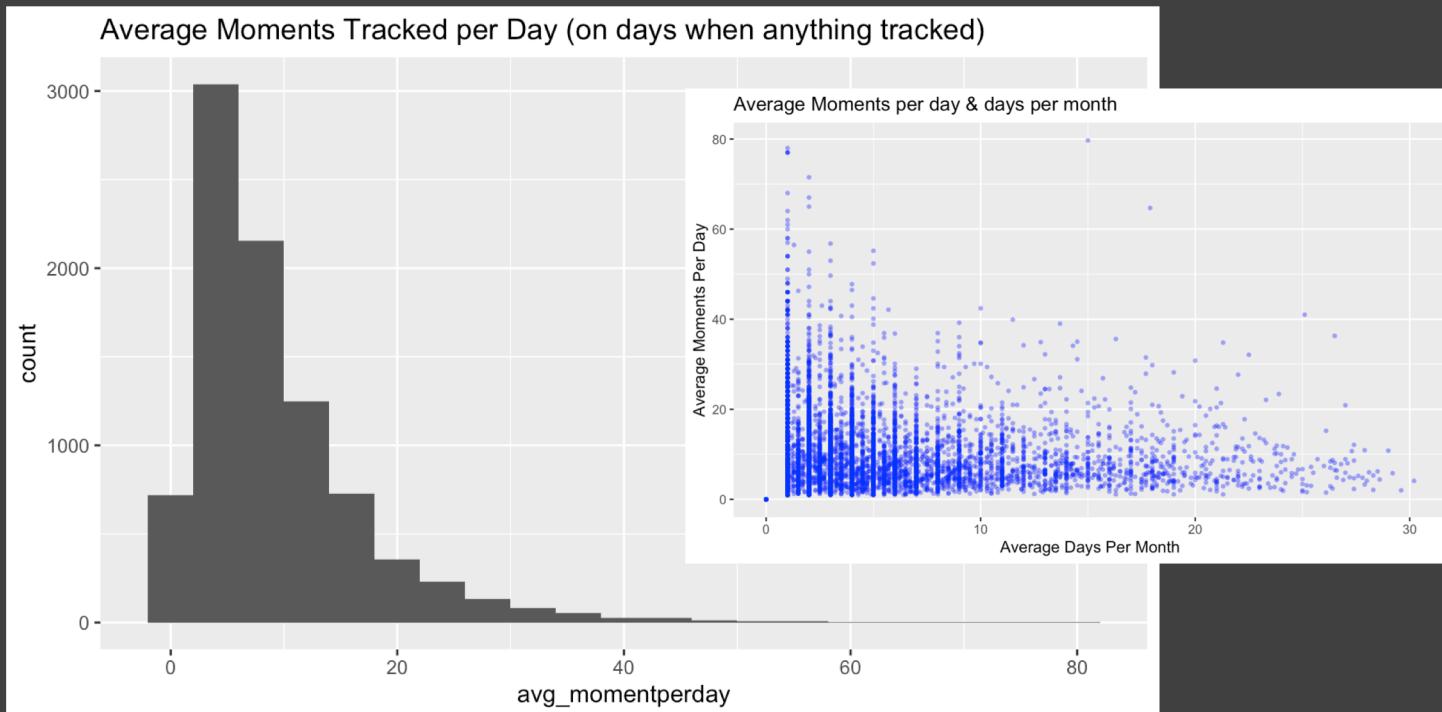
47% of users track for at least 7 days,
28% of users track for at least 30 days,
10% of users were active in the last 90 days



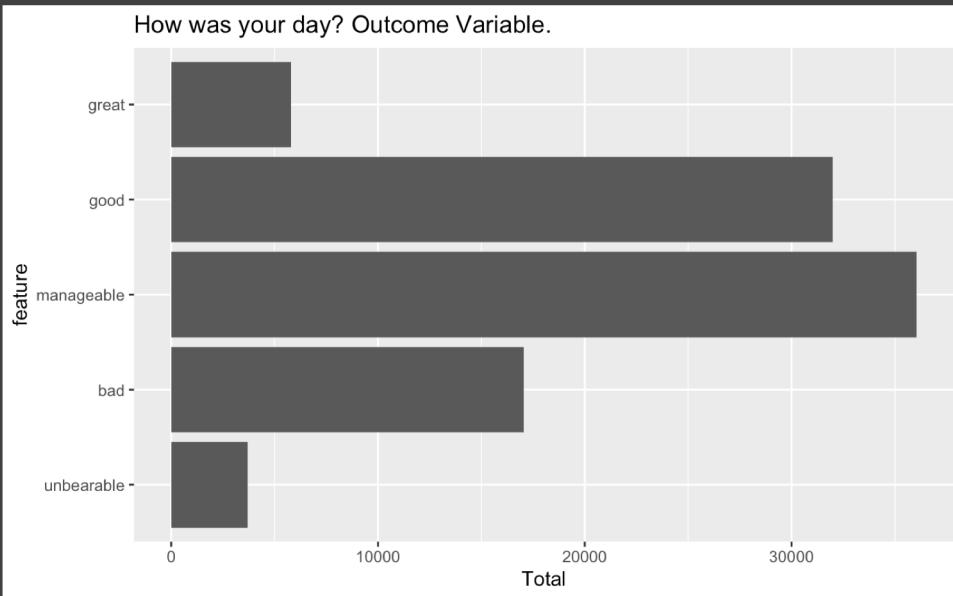
Tracking Patterns

Users generally log several moments (individual data points) per day when they track (median of 7)

Users don't generally log data every day, but lots track multiple days per week or month

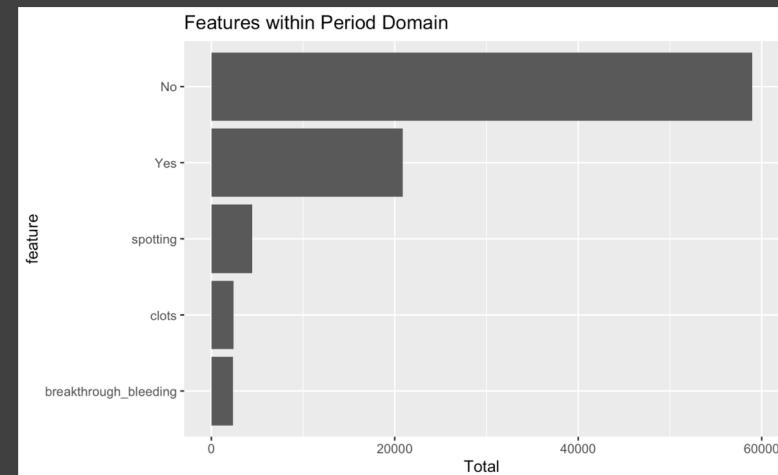
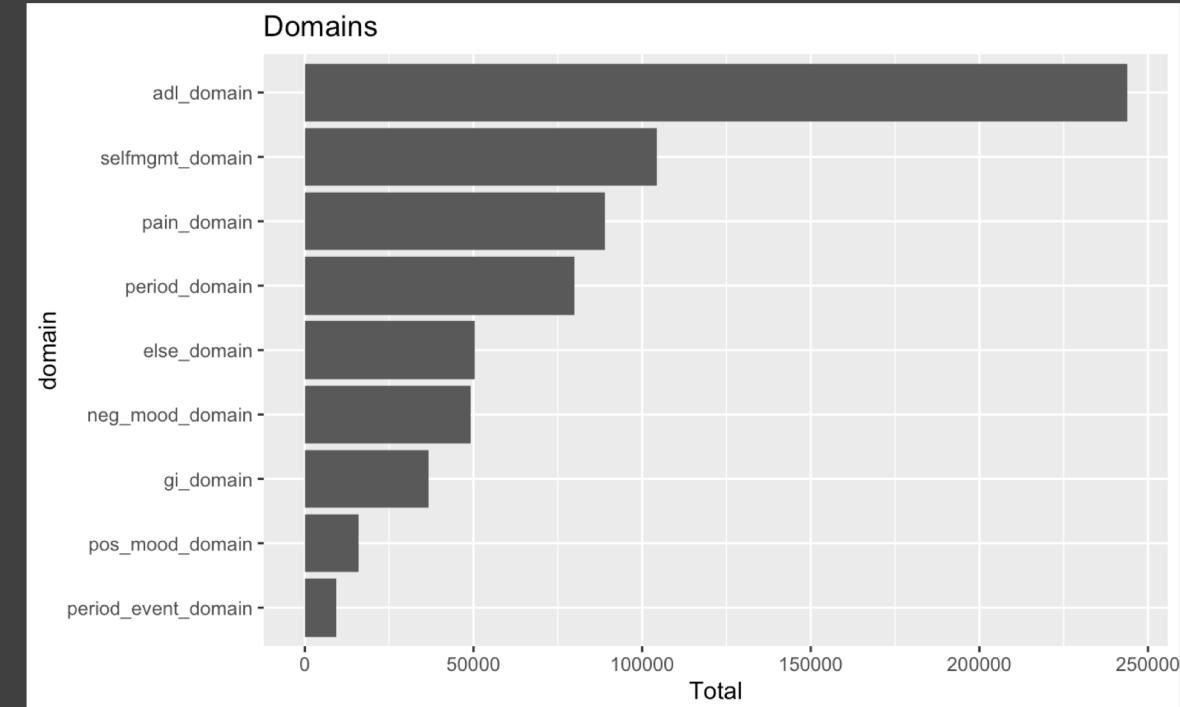


Aggregated Data

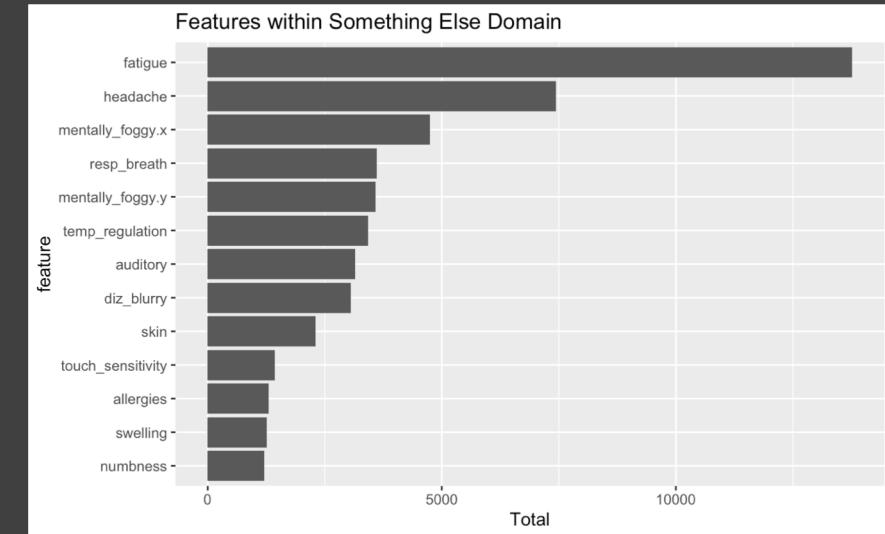
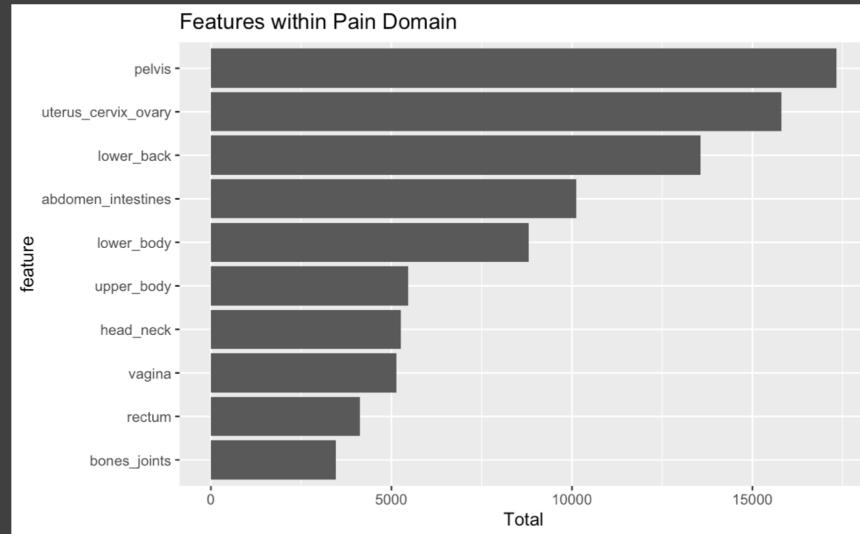


^ This **daily self-assessment** is the main and most-tracked outcome

Period is frequently tracked →
(light/mod/heavy also logged but not included here)

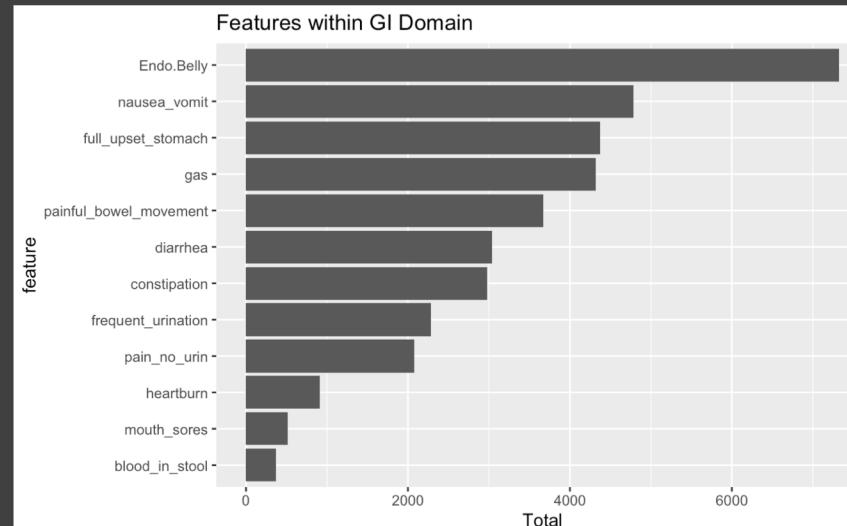


Aggregated Data – Symptom Domains

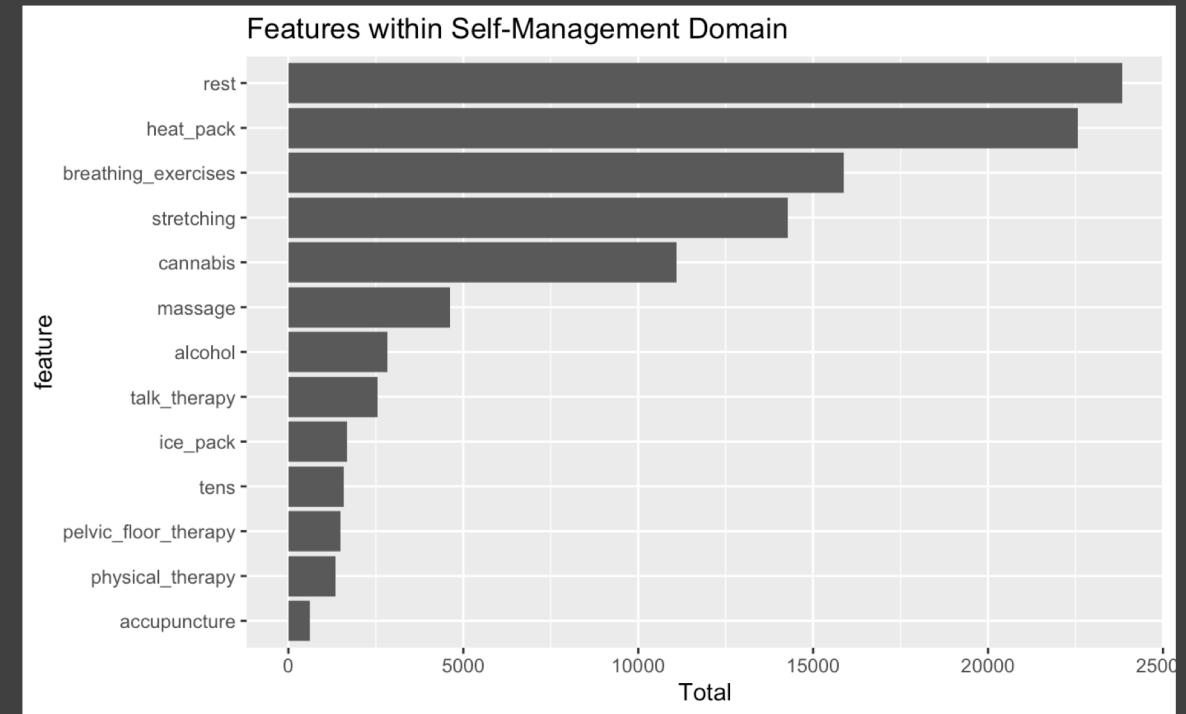
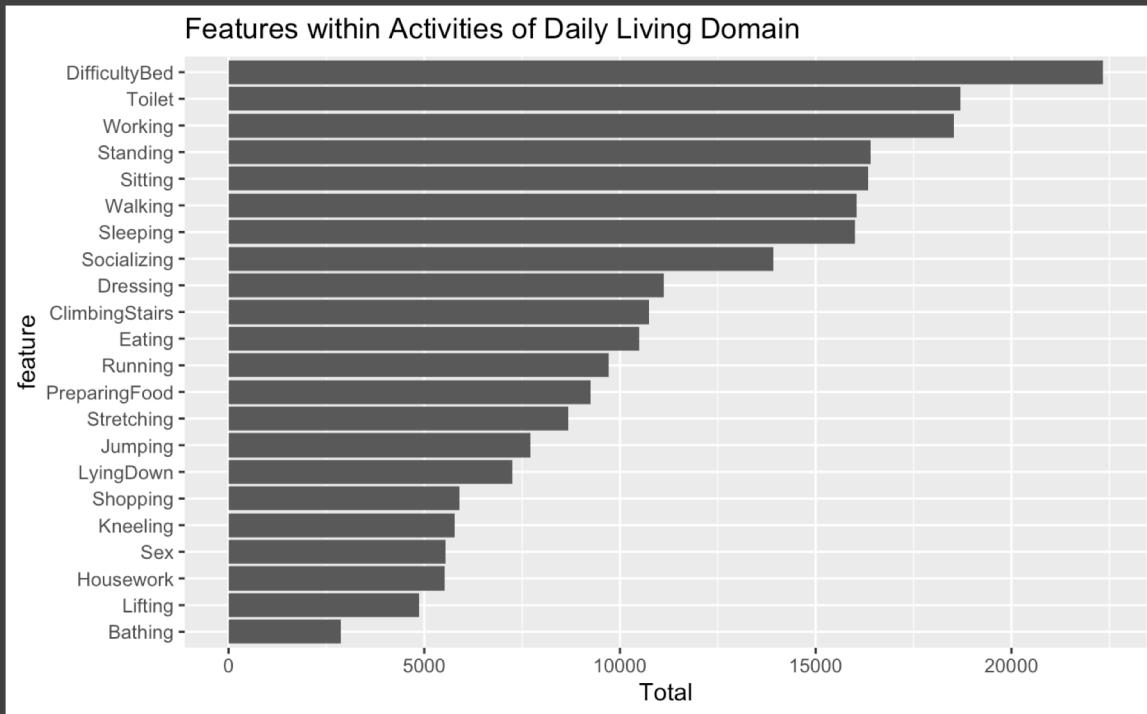


Not all domains shown. Others include positive/negative mood, sex.

Modifiers not shown.

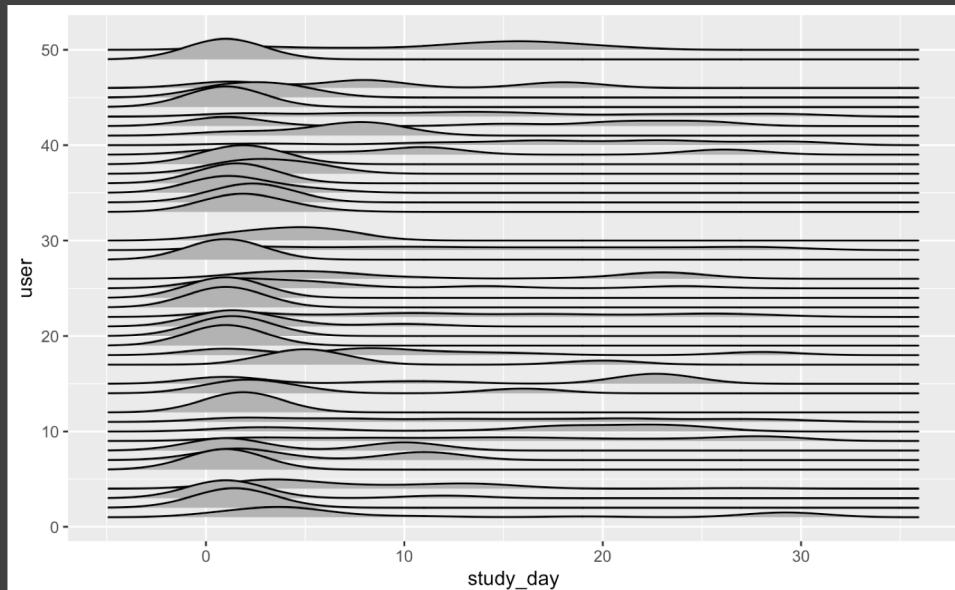


Aggregated Data – Activities of Daily Living & Self-management

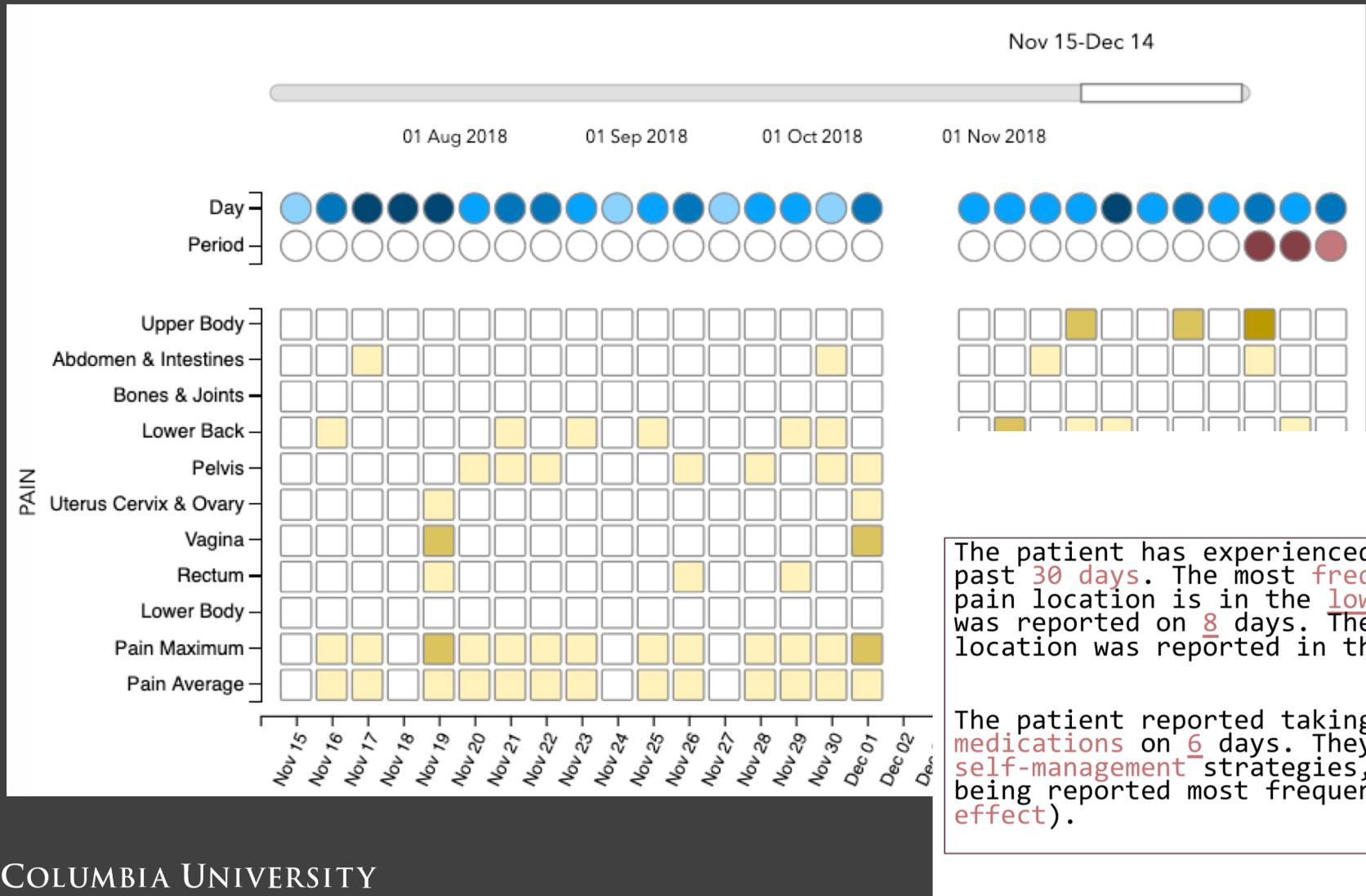


Not all domains shown. User-defined medications, supplements, exercise, and foods all collected. If self-management strategies are helpful/hurtful is also collected.

... the aggregated data give us a good idea → vast & rich data → for visualization & discovery, **but we want to design for individuals** (+ across time, at different granularities)...



Snapshot of initial mock-up using Phendo data

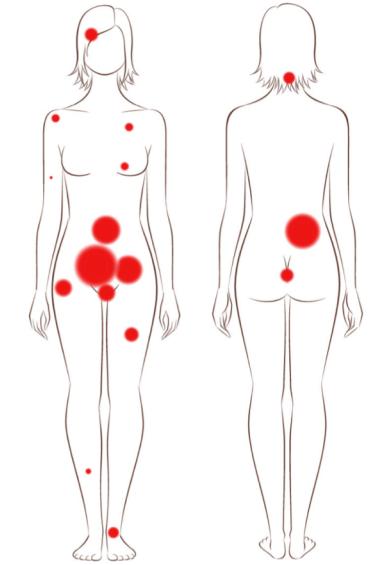


Here's our first attempt – before the qualitative research (we showed this viz to users).

All domains will be shown, and collapsed into an aggregate row (eg, max/average)

The patient has experienced pain 10 of the past 30 days. The most frequently reported pain location is in the lower back, which was reported on 8 days. The most severe pain location was reported in the pelvis.

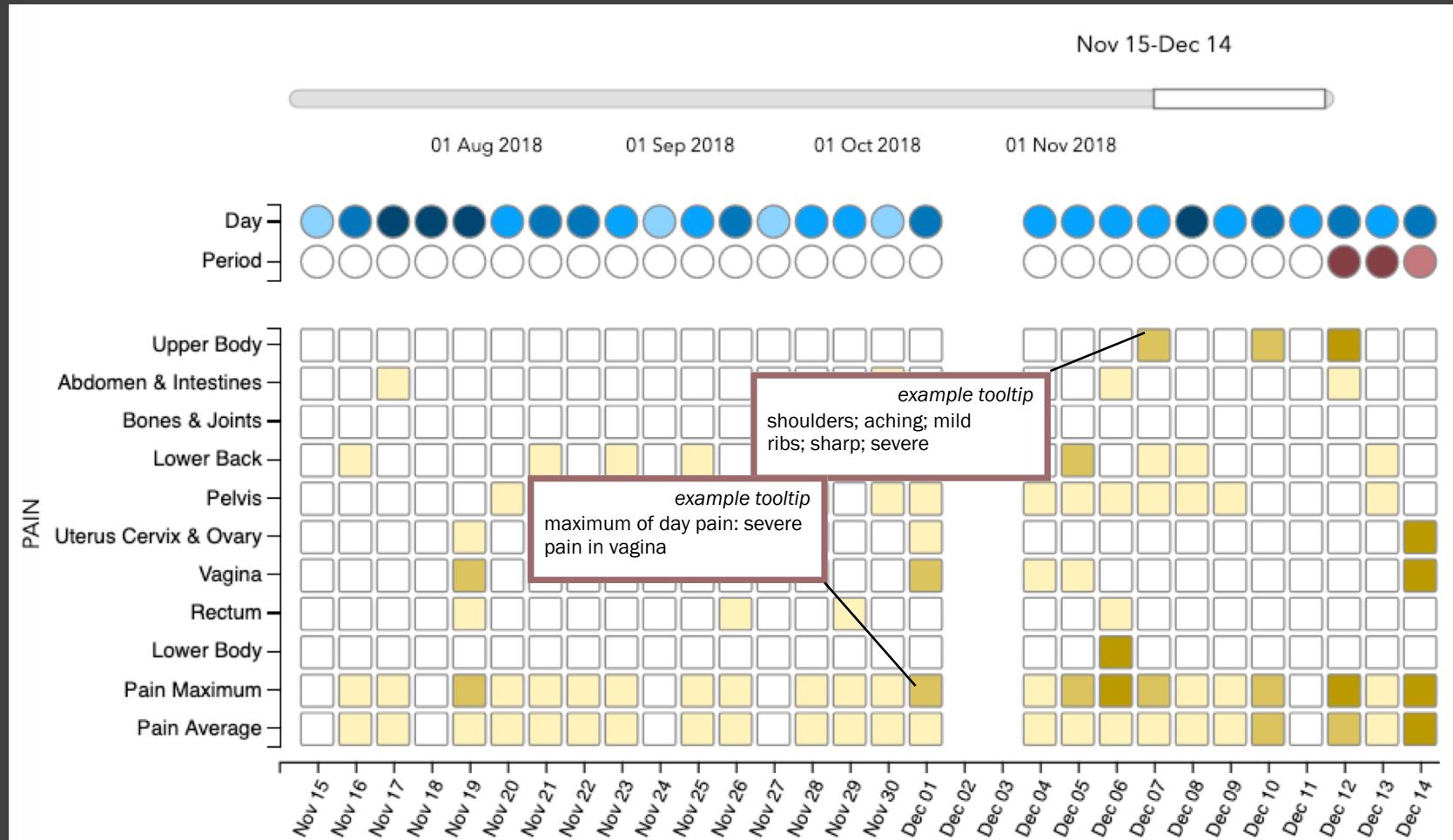
The patient reported taking opioid medications on 6 days. They also utilized self-management strategies, with heating pad being reported most frequently (with no effect).



What the data looks like & connecting to viz

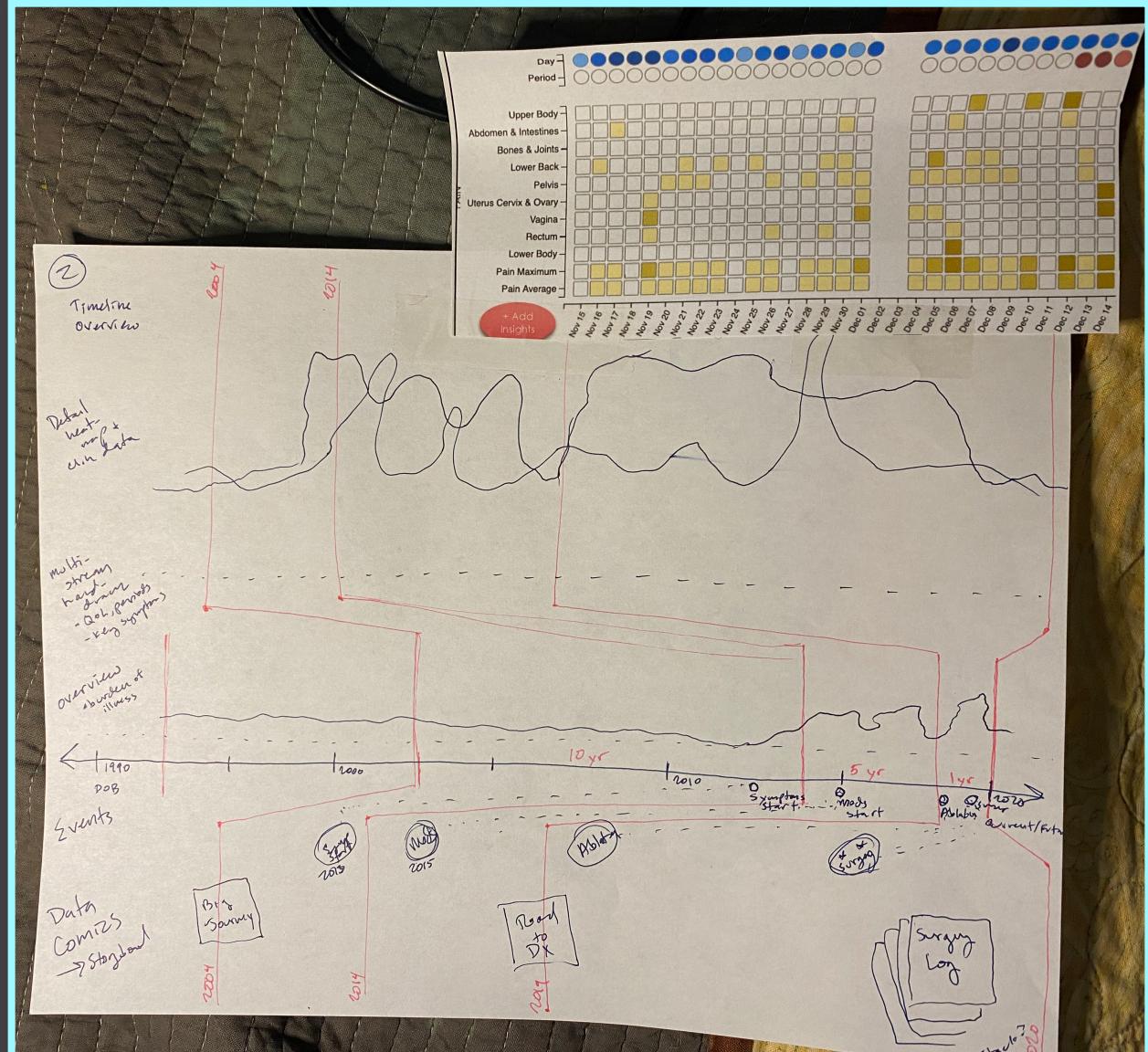
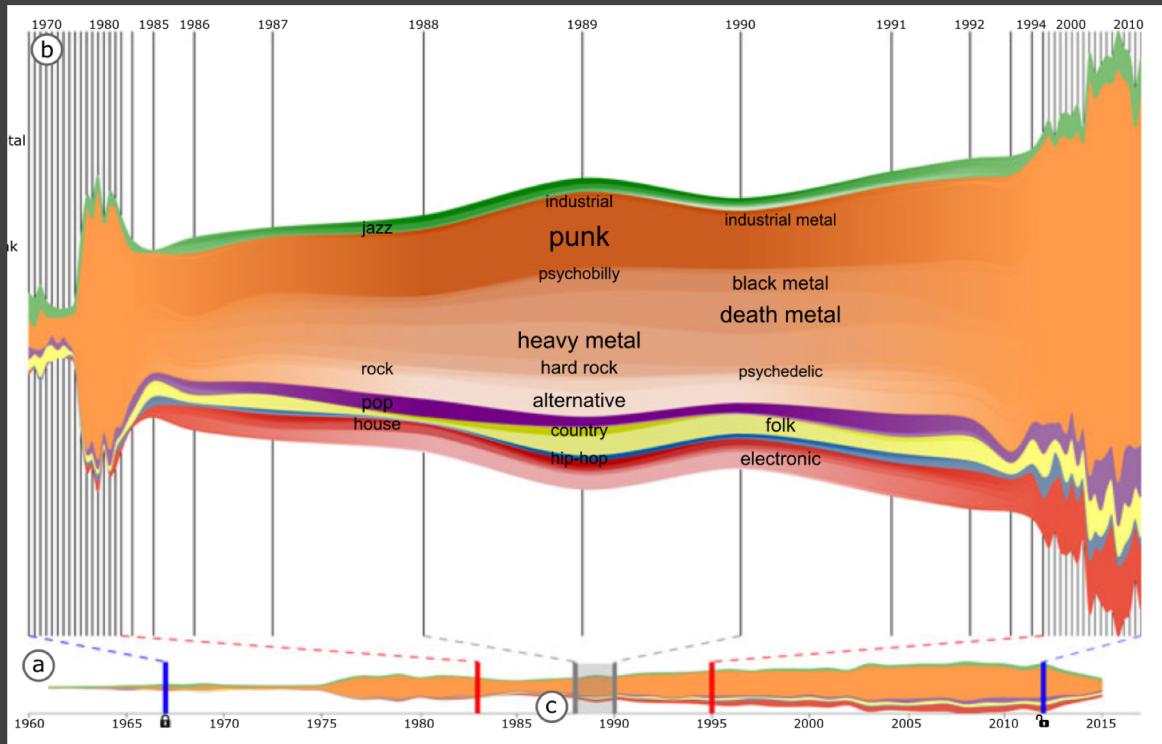
user_id | study_day | features {how was day | period } {domain | feature | severity | description}

- Can collapse features into domain, show 1 line summary
- Can summarize by week/month, but how to aggregate?
- Can use tooltips for modifiers
- Rethink missing data columns
- Add legend, day labels
- Pin period/day at the top when domains scroll down
- Ways other than a heatmap to show this data??



Multi-resolution Annotated Timeline

Example, from Cuenca 2018



VIZ Brainstorming

How to design for multi-resolution, multi-granularity?

How can we best aggregate domains?

How can we deal with missing data? Sparsity?

THANK YOU ALL for listening, and for your help brainstorming the tool. Email me with any more notes, thoughts, ideas, questions, or for a copy of the paper.



Project website:
CitizenEndo.org

Thank you! Reach out –
✉ ab3886@cumc.columbia.edu
🐦 @citizen_endo
🐦 @AdriennePichon1

Grant support from NLM (T15 LM007079 & R01 LM013043),
and from the Endometriosis Foundation of America

Icons: The Noun Project

Conversation

Q/As for me or for the group!!

- Research?
- Masters or Doctoral programs?
- Jobs?
- Viz in the real world?

Keep in touch-

✉ ab3886@cumc.columbia.edu

🐦 @citizen_endo

🐦 @AdriennePichon1