

A Roadmap for AI-Powered Women's Health

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Hi, I'm Noémie

I have no conflict of interest to disclose

Research Funding:



Data partners:



Data, AI, and technology can help

- elucidate the roles of sex and gender in health
- identify new knowledge about women's health
- create new solutions to support women

But they also add a layer of complexity

Team science



At Columbia



Roadmap for AI-powered women's health

- AI techniques that account for biases about women's health encoded in the data
- Human-centered AI approaches to ensure that the solutions created are aligned with needs and values of individuals and populations
- Team science

- Menstrual health, oral contraception, PCOS, menopause
- Endometriosis
 - Under studied condition → **characterization** (new data and tools, existing data)
 - Lag to diagnosis → **early detection**
 - Complex self-management → **individualized recommendations**

TL;DR

New data and tools → new insights

- **Human-centered insights**
 - People with stigmatized/dismissed conditions want to contribute to science under specific conditions
- **AI and tech insights**
 - Mobile health is a powerful way to engage day to day (rather than once in a while through surveys)
 - AI methods that check for potential artifacts of data and tools to collect data
 - AI methods that identify patterns through data with complex, non-linear patterns
- **Endometriosis insights**
 - Systemic condition
 - Highly heterogeneous
 - High temporal variations

Citizen Endo (citizenendo.org)



- Mission: partner with patients to (1) build datasets that reflect the lived experiences of endometriosis and that advance scientific knowledge of the condition; and (2) build tools to support patients in managing their disease
- Community of (to date) 19,000+ patients (~9K in the US)

Partnership with patients

- Citizen science principles, participatory design, community-based participatory design
- Partnership between researchers and patients in
 - Determining the research questions
 - Deciding what data gets collected and how
- Education, advocacy, and engagement with the public



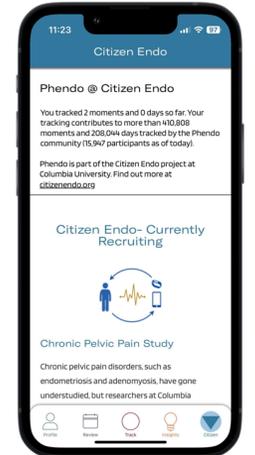
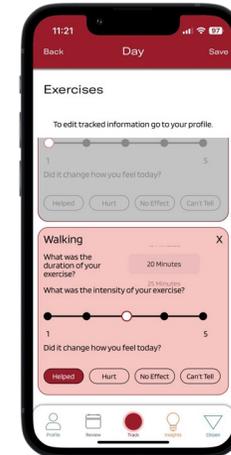
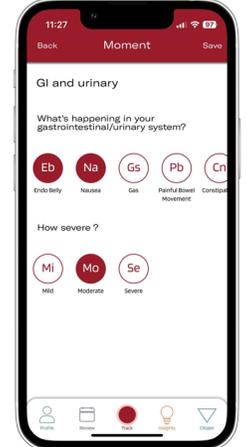
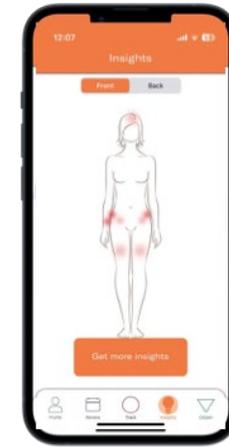
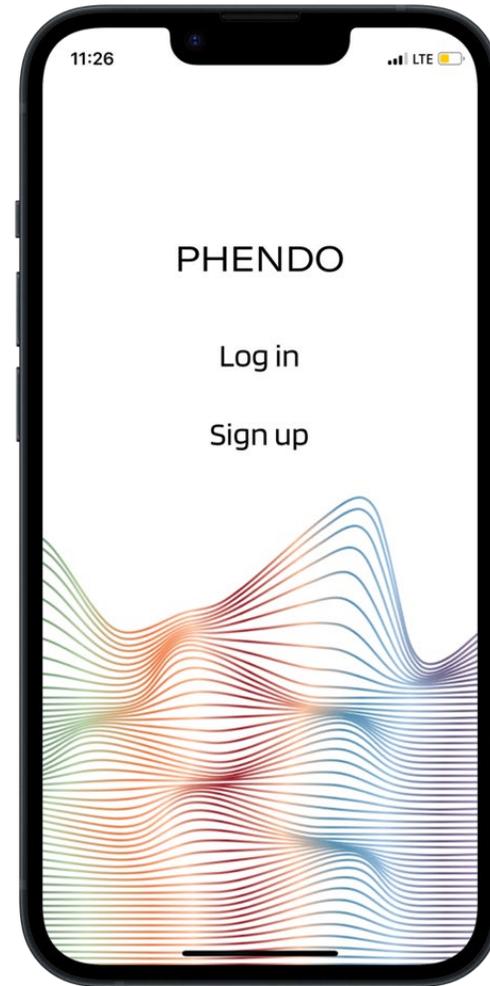
@endowhat



Phendo: a research-based app to track endometriosis



- Approved by Columbia IRB
- Informed consent as part of the app, with electronic signature and parental assent for >13 years old
- Data stored on HIPAA-certified servers



citizenendo.org/phendo

CHI 2018 Paper

CHI 2018, April 21–26, 2018, Montréal, QC, Canada

Designing in the Dark: Eliciting Self-Tracking Dimensions for Understanding Enigmatic Disease

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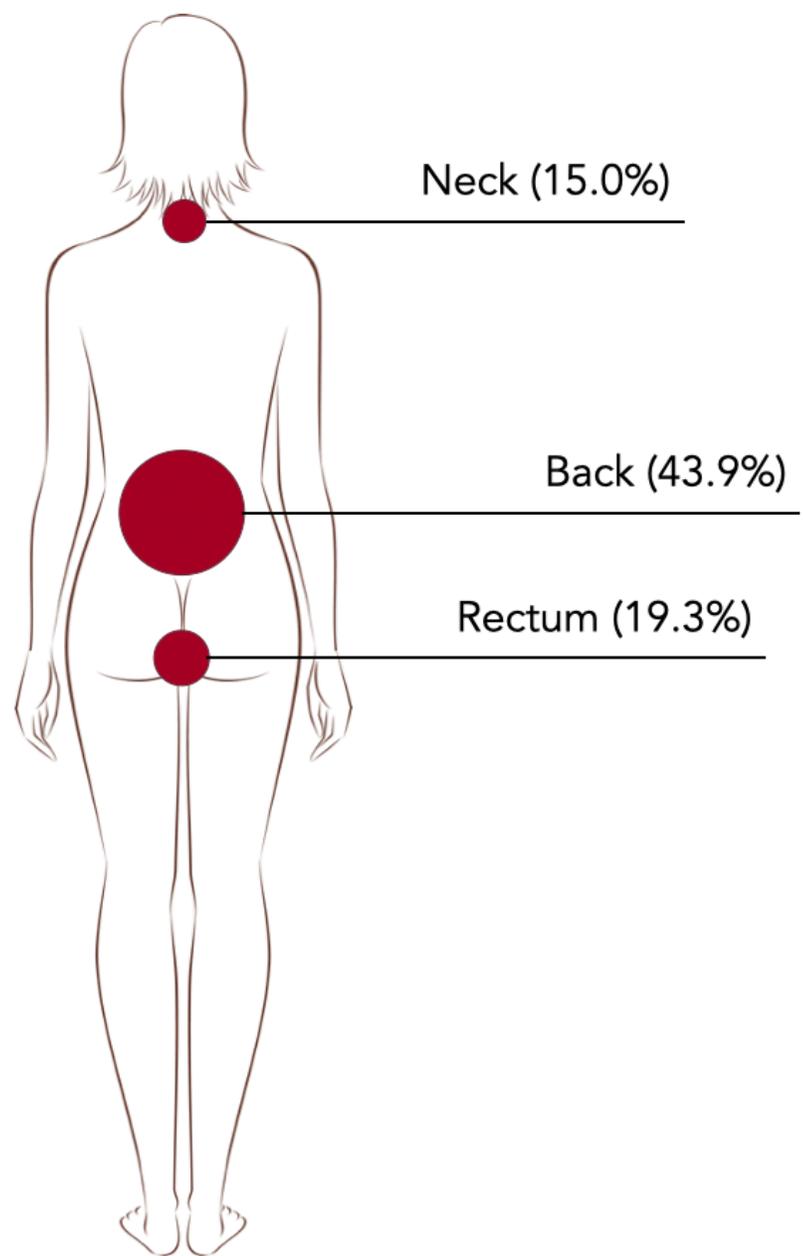
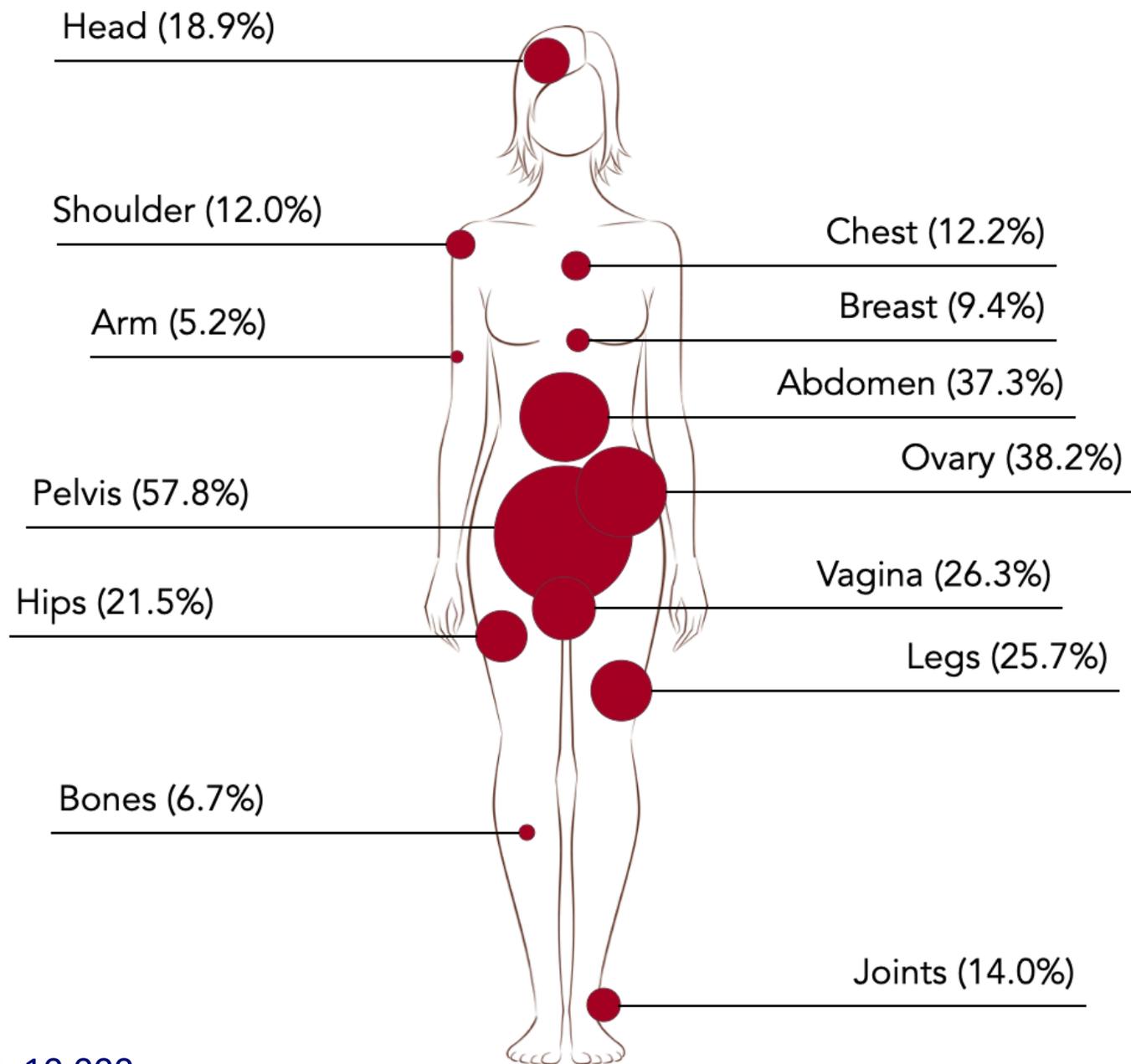
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ABSTRACT

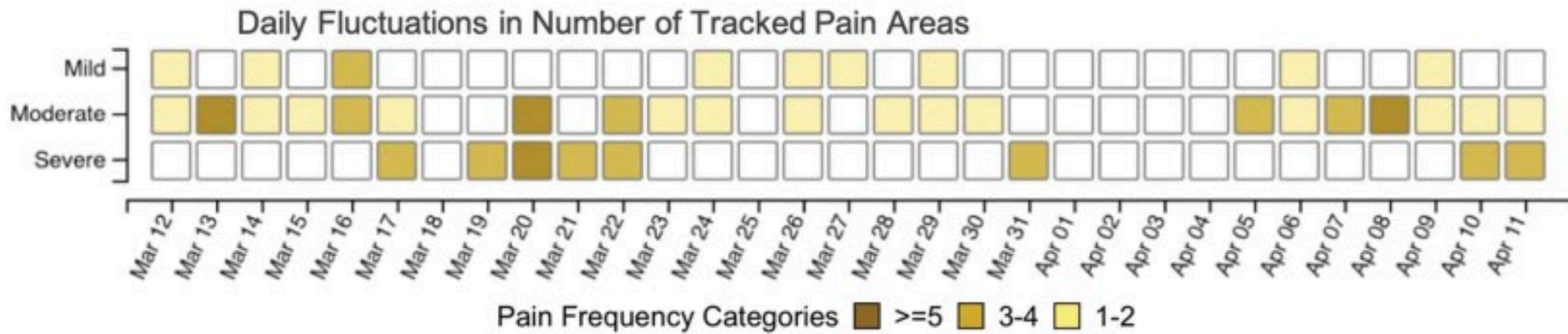
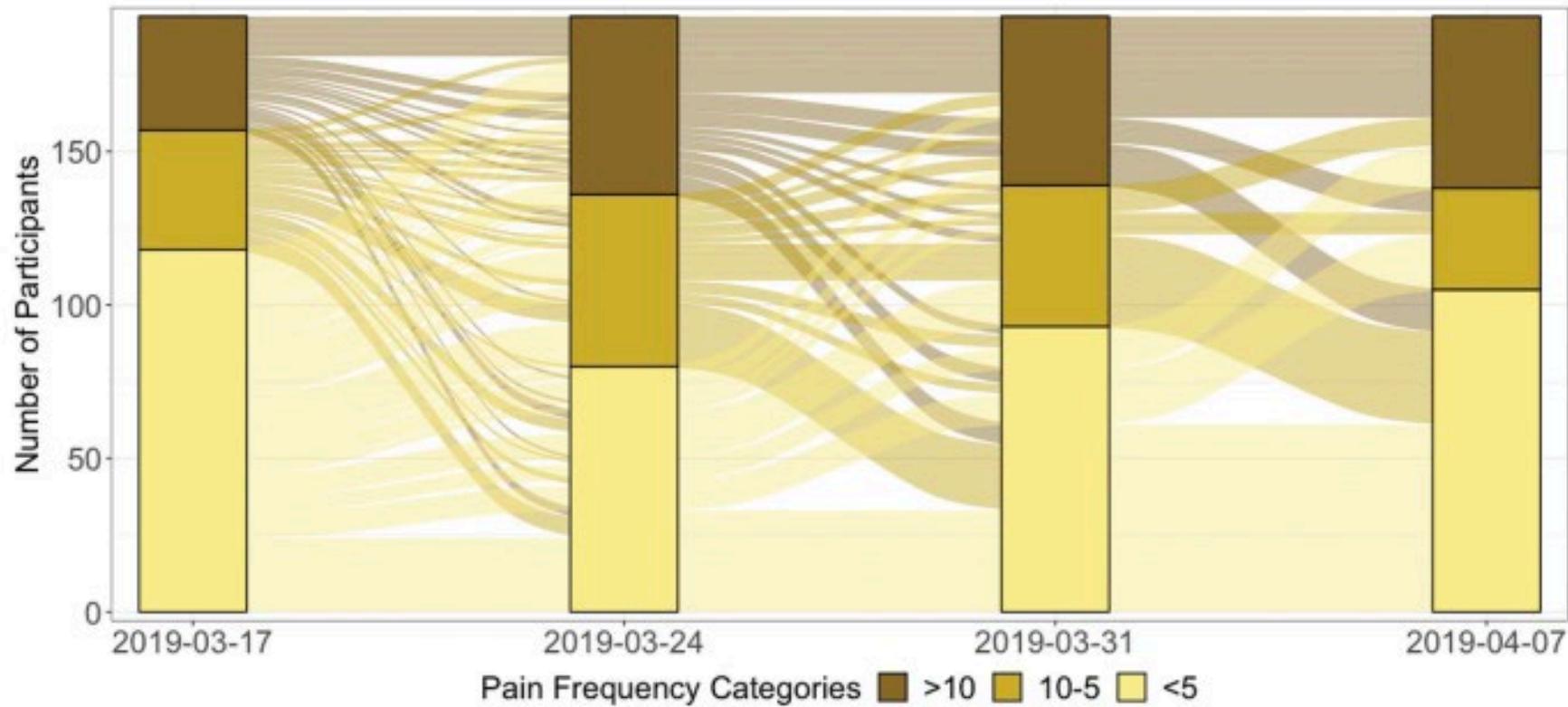
The design of personal health informatics tools has traditionally been explored in self-monitoring and behavior change. There is an unmet opportunity to leverage self-tracking of individuals and study diseases and health conditions to learn patterns across groups. An open research question, however, is how to design engaging self-tracking tools that also facilitate learning at scale. Furthermore, for conditions that are not well understood, a critical question is how to design such tools when it is unclear which data

People with chronic conditions, who are often faced with a complex set of decisions and environments to navigate, have additional incentives to understand and manage their condition, and thus engage in self-tracking.

Self-tracking systems that “help people collect personally relevant information for the purpose of self-reflection and gaining self-knowledge” are part of personal informatics, as defined by Li and colleagues [59]. Within the health domain, personal informatics tools have traditionally



N=10,000



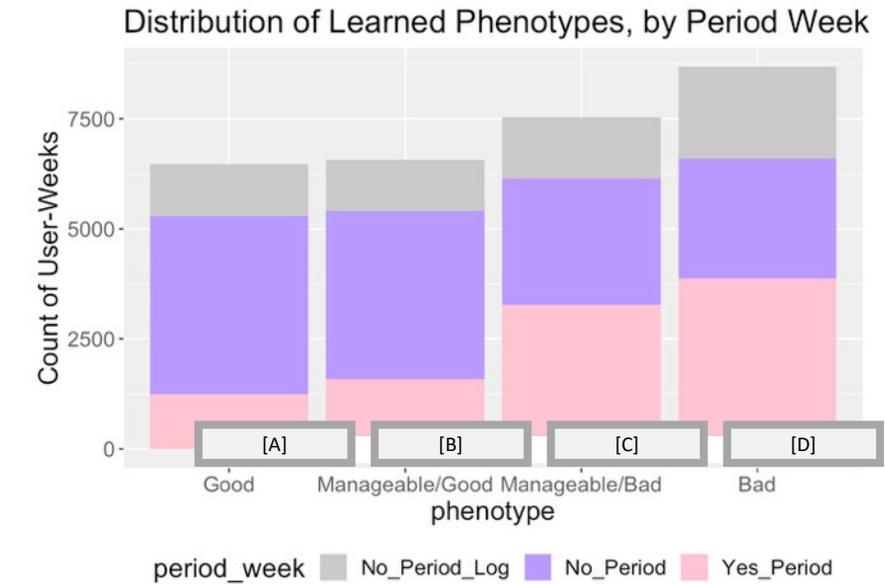
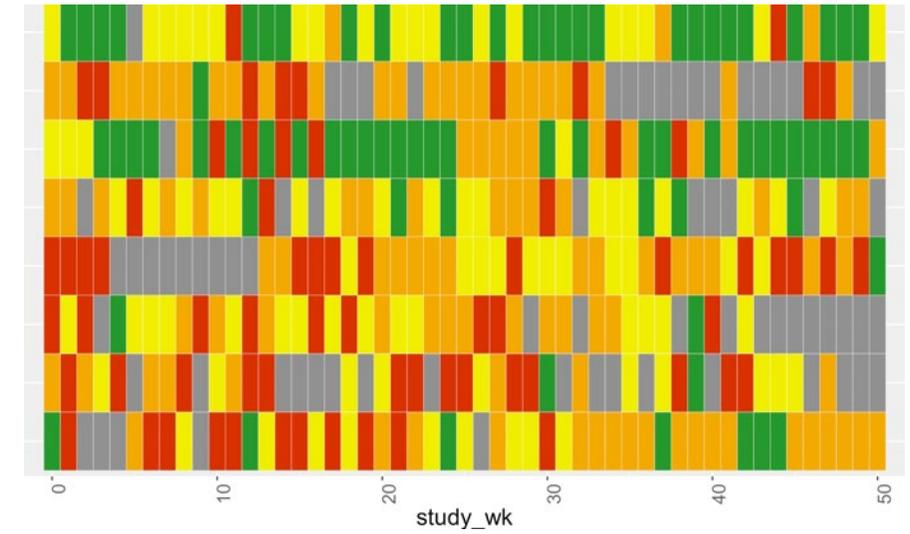
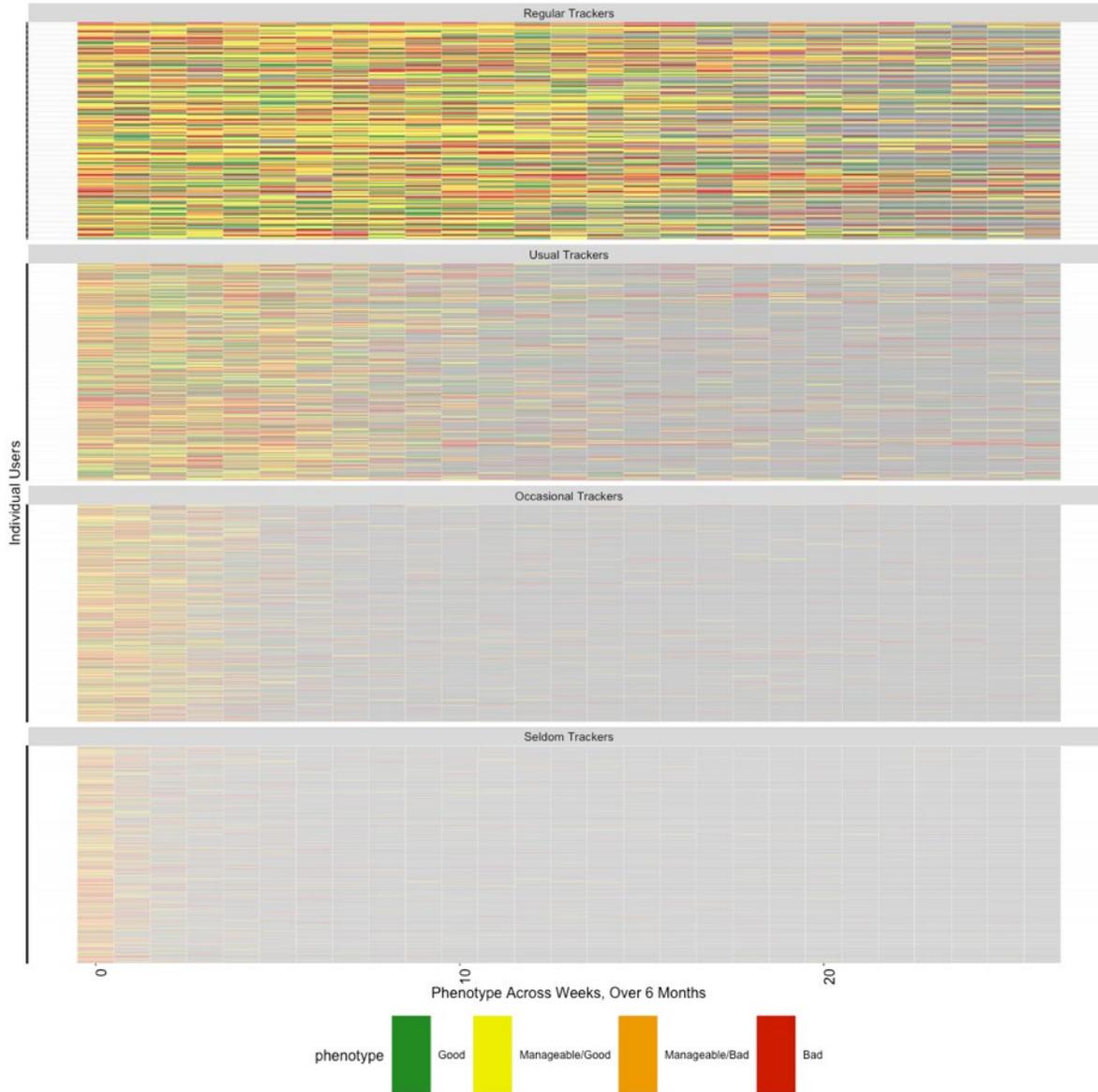
Learning endometriosis phenotypes from patient-generated data

Iñigo Urteaga ^{1,2}, Mollie McKillop³ and Noémie Elhadad ^{2,3}✉

Endometriosis is a systemic and chronic condition in women of childbearing age, yet a highly enigmatic disease with unresolved questions: there are no known biomarkers, nor established clinical stages. We here investigate the use of patient-generated health data and data-driven phenotyping to characterize endometriosis patient subtypes, based on their reported signs and symptoms. We aim at unsupervised learning of endometriosis phenotypes using self-tracking data from personal smartphones. We leverage data from an observational research study of over 4000 women with endometriosis that track their condition over more than 2 years. We extend a classical mixed-membership model to accommodate the idiosyncrasies of the data at hand, i.e., the multimodality and uncertainty of the self-tracked variables. The proposed method, by jointly modeling a wide range of observations (i.e., participant symptoms, quality of life, treatments), identifies clinically relevant endometriosis subtypes. Experiments show that our method is robust to different hyperparameter choices and the biases of self-tracking data (e.g., the wide variations in tracking frequency among participants). With this work, we show the promise of unsupervised learning of endometriosis subtypes from self-tracked data, as learned phenotypes align well with what is already known about the disease, but also suggest new clinically actionable findings. More generally, we argue that a continued research effort on unsupervised phenotyping methods with patient-generated health data via new mobile and digital technologies will have significant impact on the study of enigmatic diseases in particular, and health in general.

npj Digital Medicine (2020)3:88; <https://doi.org/10.1038/s41746-020-0292-9>

Individual Health Status Trajectories



TL;DR

Existing data and new questions → new insights

- **Human-centered insights**
 - How we define a disease changes who gets diagnosed and studied
- **AI and tech insights**
 - Large data networks are critical to identify patterns and validate robustness of signals
 - Despite individual clinicians' inability to diagnose endometriosis, documented symptoms, treatments, care shows a strong signal – the dots are there to connect
- **Endometriosis insights**
 - Systemic condition
 - Wide range of treatments that tackle symptoms only
 - Highly comorbid condition

Who has endometriosis?

- Endometriosis phenotype definitions:
 - Traditional endometriosis phenotype definition: laparoscopic surgery with pathology confirmation
 - ESHRE 2022 guidelines are symptoms based
- 500,000 patients across 4 databases
- Each cohort strong positive predictive value (0.84–0.96)
- Different patients depending on phenotype definition (ages, symptoms, access to care)

The Impact of Evolving Endometriosis Guidelines on Diagnosis and Observational Health Studies

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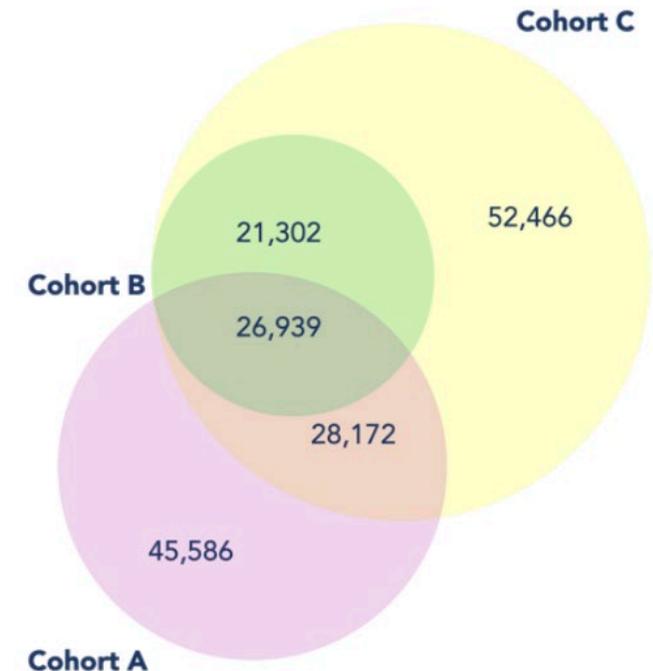
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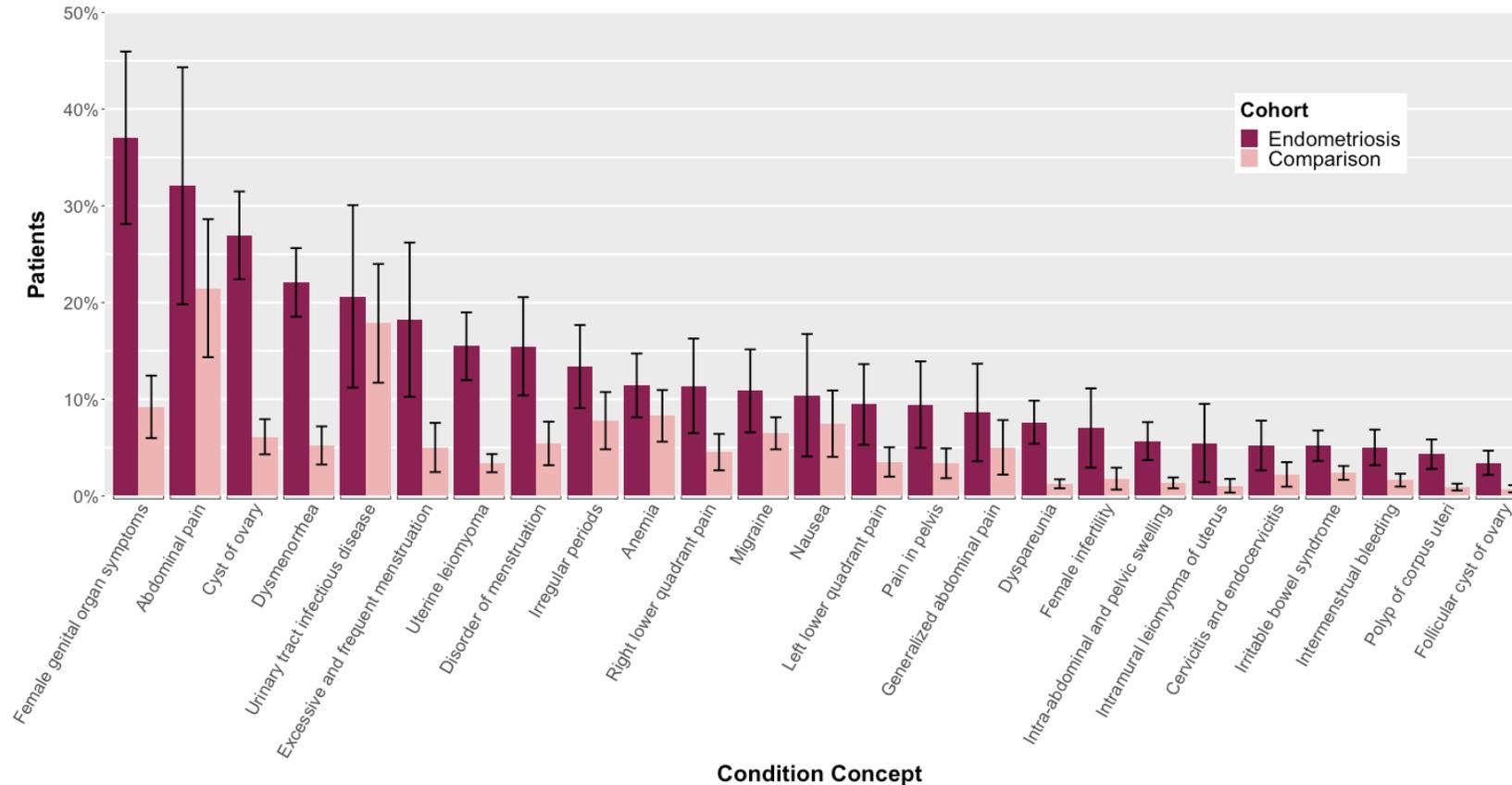
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Characterization from EHR/claims

- 1.88 million reproductive-age women across nine databases
- 2.11 million endometriosis patients were identified

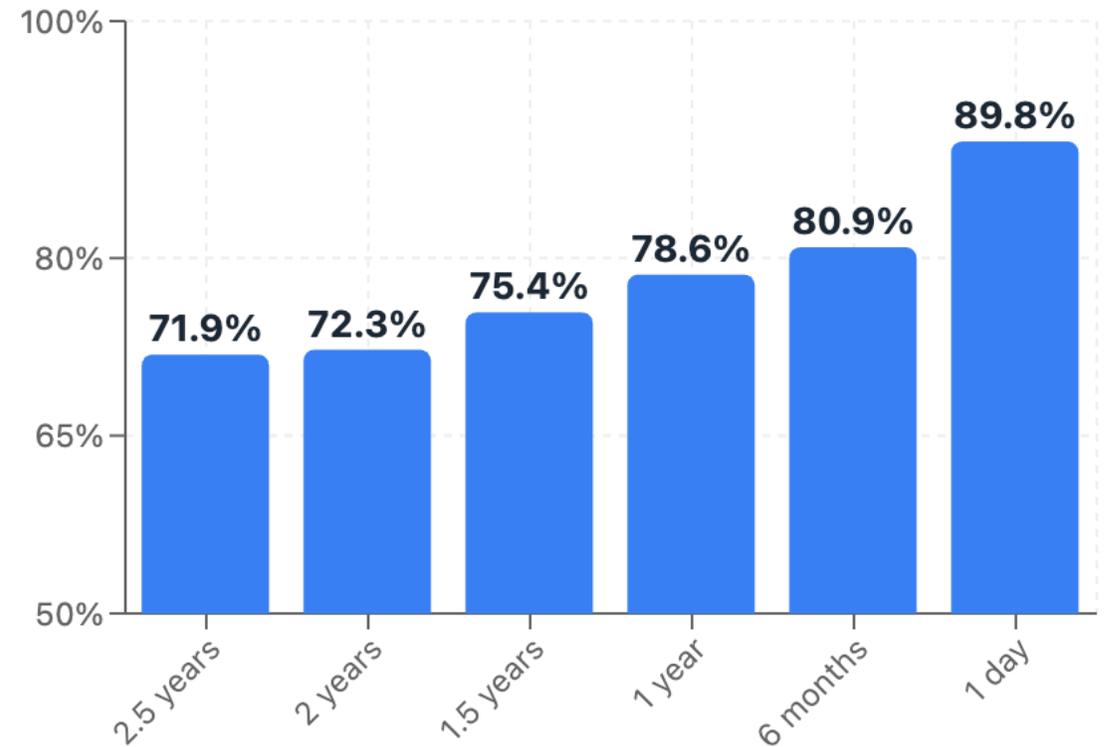


Endometriosis

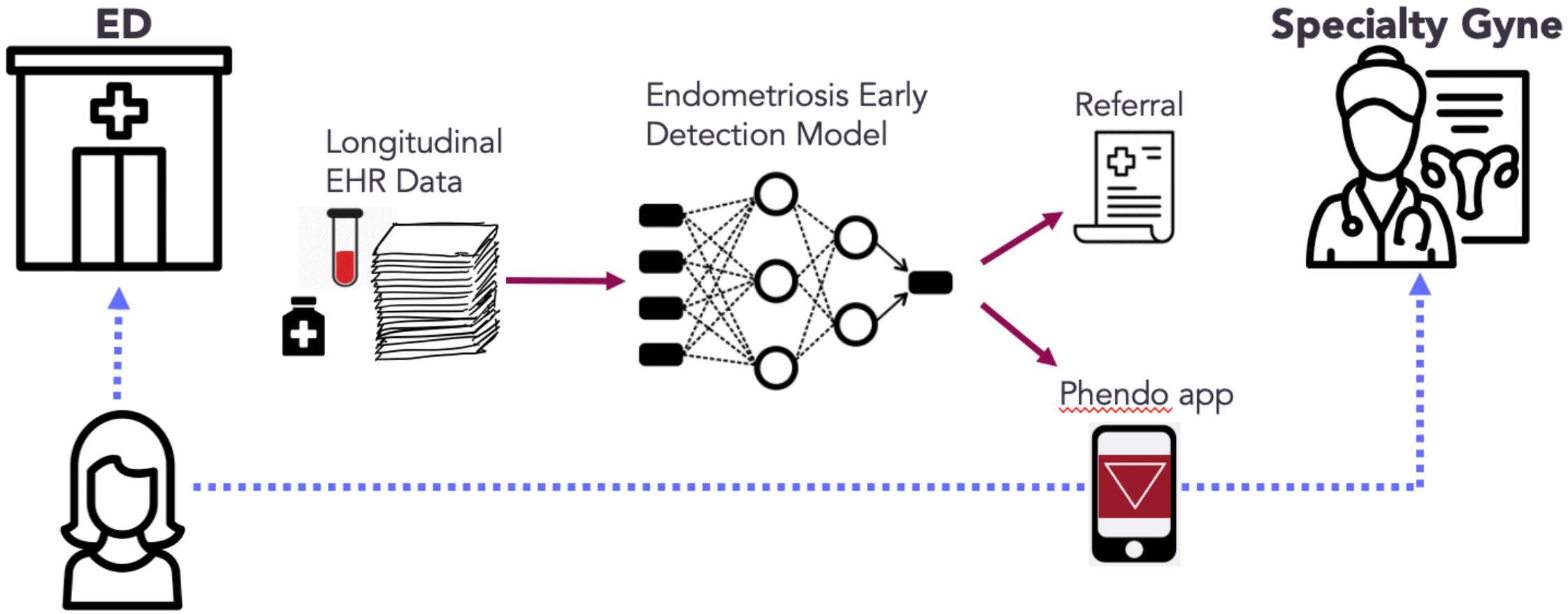
- Under studied condition → characterization
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- Complex self-management → support

Early detection

- Early detection through time
- Trained on 341,400 patients (10% endometriosis, 90% controls)
- Tested on 48,900 endometriosis patients and 77,600 controls



Early detection



Endometriosis

- Under studied condition → characterization
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Co-design AI solutions with patients and providers

- Patients need individualized support and look positively to AI
“AI can hear me better than my doctor” “showing my data gives me a voice”
- **Human control** – from algorithmic-centric suggestions to interactive systems that let patients decide and explore recommendations
- **Privacy** – patients are highly aware of risks of giving their data
- **Trust** – trust in algorithms and in who designs the algorithms are both concerns for patients
- **Safety** – patients assume common sense in AI (and they shouldn't)

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

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KAYLA SC
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NOÉMIE E

The Voice of Endo: Leveraging Speech for an Intelligent System That Can Forecast Illness Flare-ups

ADRIENNE PICHON, Columbia University, Department of Biomedical Informatics, USA

Informing the Design of Individualized Self-management Regimens from the Human, Data, and Machine Learning Perspectives

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Intelligent systems for self-management can help patients and improve quality of life. However, designing AI-based systems is challenging because designers need to account not only for user needs, but also for capabilities and practical constraints of underlying algorithms. We propose a novel approach – Multi-Perspective Directed Analysis – to align human and technological requirements and constraints that can guide the design of an intelligent system for personal health. We use concepts from a machine learning technique, Reinforcement Learning (RL), to elicit user needs, through directed content analysis of user interviews, and uncover practical data constraints, through analysis of user engagement logs. We gather and triangulate human-machine-data requirements for a self-management tool for individuals with endometriosis – a poorly understood, complex chronic condition with no reliable treatment. We present design implications for developing a system that will meet user needs and is feasible from human user, data, and machine learning perspectives.

CCS Concepts: • **Human-centered computing** → *User studies*; • **Computing methodologies** → **Reinforcement learning**; • **Applied computing** → **Health informatics**.

Additional Key Words and Phrases: reinforcement learning, self-management, chronic illness

ACM Reference Format:

Adrienne Pichon, Iñigo Urteaga, Lena Mamykina, and Noémie Elhadad. 2023. Informing the Design of Individualized Self-management Regimens from the Human, Data, and Machine Learning Perspectives. 1, 1 (September 2023), 44 pages. <https://doi.org/10.1145/>

Roadmap for AI-powered women's health

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Thank you!



Source: The Faces of Endo. <http://endoforever.blogspot.com/>

