Human-Centered AI Approaches to Endometriosis Detection and Management

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Hi, I'm Noémie

I have no conflict of interest to disclose

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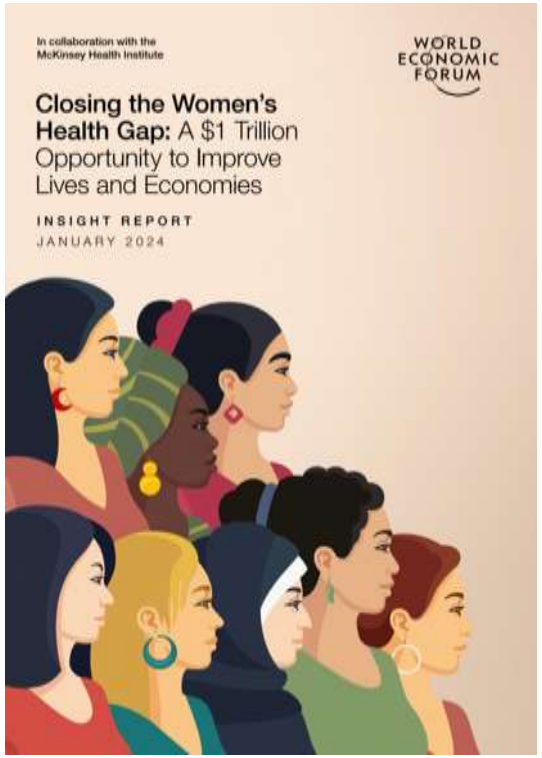
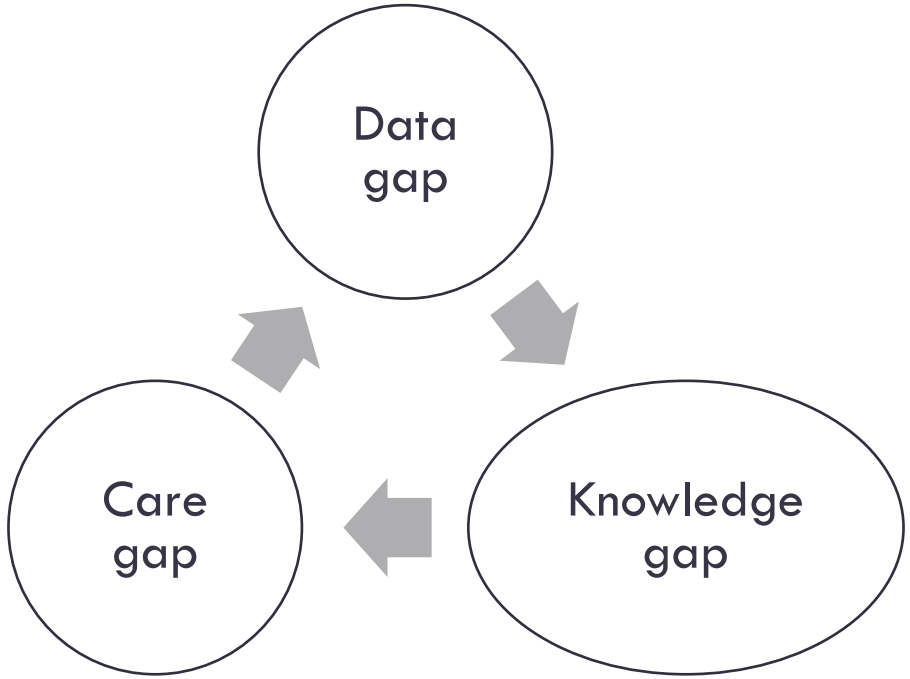
Data partners:

There are multiple, interrelated phenomena at the intersection of sex, gender, and medicine





Clinical Review & Education

JAMA Internal Medicine | Review

Clinical Advances in Sex- and Gender-Informed Medicine to Improve the Health of All
A Review

Deborah Bartz, MD, MPH; Tanuja Chitnis, MD; Ursula B. Kaiser, MD; Janet W. Rich-Edwards, ScD, MPH; Kathryn M. Rexrode, MD, MPH; Page B. Pennell, MD; Jill M. Goldstein, PhD; Mary Angela O'Neal, MD; Meryl LeBoff, MD; Maya Behn, BA; Ellen W. Seely, MD; Hadine Joffe, MD, MSc; JoAnn E. Manson, MD, DrPH

IMPORTANCE Biological sex and sociocultural gender
among patients, and recent research has shown the
health. A growing body of literature describes wides
with cells, organs, and the manner in which individua
systems. Sex- and gender-informed medicine is a yo
medical research founded on this literature that cons
with each element of the disease process from risk, t

OBSERVATIONS Characteristics that underlie sex and
exogenous factors that change throughout the life c
examples with broad applicability that highlight sex
domains of genetics, epigenomic modifiers, hormon
neurocognitive aging process, vascular health, respo
with health care systems. These domains interact wi
associations, contributing to the diversity of the sex
identified differences of clinical relevance with the p

CONCLUSIONS AND RELEVANCE Clinicians should cons
in their decision-making to practice precision medici
components of patient individuality. Recognizing the
that affect the disease course is imperative to optimizing care for each patient. Research highlights the myriad ways sex and gender play a role in health and disease. However, these clinically relevant insights have yet to be systematically incorporated into care. The framework described in this review serves as a guide to help clinicians consider sex and gender as they practice precision medicine.

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Medicine has been traditionally practiced using pattern recognition, seeking resemblance to the familiar to make a broadly generalizable diagnosis. This approach has

mosomes functioning in all cells, not just those c
reproduction.[3] Furthermore, autosomal gene exp
ously assumed to be wholly similar between se

Review

Sex and gender: modifiers of health, disease, and medicine

Franck Mauvais-Jarvis, Noel Bairey Merz, Peter J Barnes, Roberta D Brinton, Juan-Jesus Carrero, Dawn L DeMeo, Geert J De Vries, C Neill Epperson, Ramaswamy Govindan, Sabra L Klein, Amedeo Lonardo, Pauline M Maki, Louise D McCullough, Vera Regitz-Zagrosek, Judith G Regensteiner, Joshua B Rubin, Kathryn Sandberg, Ayako Suzuki

Clinicians can encounter sex and gender disparities in diagnostic and therapeutic responses. These disparities are
and response to treatment. This
he major causes of death and
logical sex influence physiology
munity, clinicians, and patients
and researchers to consider sex
necessary and fundamental step

Lancet 2020; 396: 565–82

This online publication has been corrected. The corrected version first appeared at thelancet.com on September 3, 2020

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mental modifiers of chronic
a necessary and fundamental
edicine that will benefit women

fier of biology and disease
prevalence, manifestation, and
rooted in the genetic differences
. Genetic sex differences start at
vum fuses with a sperm cell
nosome, resulting in an embryo
Y chromosomes. This funda-
nosome complement (eg, genes
mining *SRY* gene) generates

follow this mandate, and many of those who did include women did not analyse the results by sex,[2,3] minimising the effectiveness of this policy. Preclinical research and drug development studies have also predominantly used male animal models and cells.[4–6] It is not surprising that a 2001 US Government Accountability Office report found that eight of the ten prescription drugs withdrawn from the market between 1997 and 2000 "posed greater health risks for women than for men".[7] Most funding agencies from Europe and North America have implemented policies to support and mandate researchers to consider sex and gender at all levels of medical research.[8] Still, the field of sex-based biology and medicine is often viewed as a specialised area of interest, rather than a

ubiquitous sex differences in the molecular makeup of all male and female cells.[9] First, the Y chromosome carries genes that exhibit subtle functional differences from their X-linked homologues (eg, *ZFY vs ZFX* and *UTY vs UTX*), and also carries genes with no homologue at all (eg, *SRY*). In addition, in men, the X chromosome carries only maternal imprints—ie, epigenetic modifications made by the parent in generating the sex cells—which alter the expression of genes in the offspring. As women have X chromosomes from both parents, they carry maternal and paternal imprints, which target a different set of genes. Random inactivation of one of the X chromosomes in female cells, which prevents sex differences in X chromosome gene dosage, causes another degree of

"*Research highlights the myriad ways sex and gender play a role in health and disease. However, these clinically relevant insights have yet to be systematically incorporated into care.*"

(Bartz et al. JAMA Intern Med. 2020)

Comment

A two way view of gender bias in medicine

M Teresa Ruiz, Lois M Verbrugge

"It isn't true, couldn't be; there must be other variables not taken into account that confound the results." This was the remark of a psychiatrist colleague to the s there is reasoned evidence of health care based on patient g action aligns with that of health and researchers' longing for sim comes and also with a contem data analysis. It is not unusual ments like his when criticisms ar health services for women comp

This editorial comment consid care contributes to the health i sociated with gender, a questio many since the WHO Europe 1990.[1–6] There are two ways in service delivery and research can bias – firstly, by assuming that men's health situations and ris when in fact they are not, and assuming differences where the similarities. Actions and resear either approach may influence w outcomes in negative ways. An in ber of scientific papers on gend past five years has intensified t cause results often confirm the presence of inequity. Yet there remain some conceptual, methodological, and empirical limitations that keep the picture hazy.

The first view: assumed equality of women and men

Scientists have often assumed that disease risks and expressions are similar or the same in men and women. The many clinical trials that have been conducted only among men carry the assumption that the results can automatically be applied to women, as if women had been studied too.[7–9] The persistent exclusion of pregnant women from trials (which, of course, is very often important for reasons of safety) may serve to reinforce the assumption of no gender differences, without proof. As a consequence,

tained from studies in men, but it is readily applied to women.[10] Similarly, risk factors and

pression of complaints, how their milieux of social support affect health and health behaviour, and their behavioural strategies for treating and adjusting to health problems.

A statistical reflection of the "sexes-are-equal" assumption appears in multivariate analyses of health data. Sex is an included variable, but it serves as a potential confounder rather than a predictive or prognostic variable. No particular substantive interest is given to it.[14] Its effects are statistically controlled and ignored.[4]

The second view: assumed differences of women and men

A contrasting view occurs in those situations where women and men are viewed as fundamentally different in respect of health, and

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M T Ruiz

Institute of

"The first view: assumed equality of women and men […]
The second view: assumed differences of women and men"

(Ruiz and Verbrugge J Epidemiol Community Health. 1997)

(2)

The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain

rding why treatment differences might exist, looking to e sociologic and feminist literature for a framework to xplain these assumptions.

We conclude, from the research reviewed, that men and omen appear to experience and respond to pain differently, t that determining whether this difference is due to bio-gical versus psychosocial origins is difficult due to the com-ex, multicausal nature of the pain experience. Women are ore likely to seek treatment for chronic pain, but are also ore likely to be inadequately treated by health-care provid-s, who, at least initially, discount women's verbal pain eports and attribute more import to biological pain con-ibutors than emotional or psychological pain contributors. e suggest ways in which the health-care system and health-are providers might better respond to both women and men who experience persistent pain.

to be given pain medication.[2] Speculation as to why this difference might exist has included the following: Women complain more than men; women are not accurate reporters of their pain; men are more stoic so that when they do complain of pain, "it's real"; and women are better able to tolerate pain or have better coping skills than men.

In this article, we report on the biological studies that have looked at differences in how men and women report and experience pain to determine if there is sufficient evidence to show that gender[3] differences in pain perception have biological origins. We then explore the influence of cognition and emotions on pain perception and how socialized gender differences may influence the way men and women perceive pain. Next, we review the literature on how men and women are diagnosed and treated for their

Do Men and Women Experience Pain Differently?

The question of whether men and women experience pain differently is a relatively recent one. Until about a decade ago, many clinical research studies excluded women, resulting in a lack of information about gender differences in disease prevalence, progression, and response to treatment.[4] Research on sex-based and gender-based differences in pain response has mounted over the past several years, partially motivated by 1993 legislation mandating the inclusion of women in research sponsored by the National Institutes of Health.[5]

Three review articles summarized the research findings

Menstruation: science and society

Hilary O. D. Critchley, MD; Elnur Babayev, MD; Serdar E. Bulun, MD; Sa
Peter K. Gregersen, MD; Aoife Kilcoyne, MBBCh, BAO; Ji-Yong Julie Kim
Erica E. Marsh, MD, MSCI; Kristen A. Matteson, MD, MPH; Jacqueline A
Inmaculada Moreno, PhD; Kami Silk, PhD; Marni Sommer, DrPH, MSN;
Ridhi Tariyal, MBA, SM; Hugh S. Taylor, MD; Günter P. Wagner, PhD; L

Women's health concerns are generally und
hampered by a lack of understanding of bas
between menarche and menopause, most w
often catastrophically disrupts their physic
involved in menstruation, abnormal uterine
care. Furthermore, a deeper mechanistic u
yield insights into a myriad of other disease
women now delay pregnancy and that there
Health and Disease Branch of the *Eunice*
meeting, "Menstruation: Science and Soc
awareness of the need for more research in
biology (including omic analysis of the end
abnormal uterine bleeding and fibroids) and
disorders including abnormal uterine bleedi
literacy and dissemination frameworks acr
incorporating the patient voice at the launch of the meeting. Here, we provide an enh
submission) context, capturing the spectrum from how the basic processes of mens
drawal, through the role of tissue-resident and circulating stem and progenitor cells in
on how dysregulation leads to abnormal uterine bleeding and other menstruation-relat
fibroids—to the clinical challenges in diagnostics, treatment, and patient and societa
global agenda concerning menstruation, and specifically menstrual health and hygi
investment in addressing menstruation-related barriers facing girls in schools in
"menstrual equity" and "period poverty" movements spreading across high-income

Key words: abnormal uterine bleeding, adenomyosis, endometrium, fibroids, me
effluent, period poverty, stem cells, tissue engineering, uterus

Clinical diagnosis of endometriosis: a call to action

Sanjay K. Agarwal, MD; Charles Chapron, MD; Linda C. Giudice, MD, PhD; Marc R. Laufer, MD; Nicholas Leyland, MD; Stacey A. Missmer, ScD; Sukhbir S. Singh, MD; Hugh S. Taylor, MD

THE PROBLEM: Endometriosis is undiagnosed in a large proportion of affected women, resulting in ongoing and progressive symptoms with associated negative impacts on health
ards, which rely primarily on laparoscopy for a
apy, frequently result in prolonged delay between
ent treatment.

agnostic techniques may reduce the delay in time
id relief to affected patients, limit disease pro-

Endometriosis has such wide-ranging and pervasive sequelae that it has been described as "nothing

"Women's health concerns are generally underrepresented […] but reproductive health in particular has been hampered by a lack of understanding of basic uterine and menstrual physiology."

(Critchley et al. AJOG. 2020)

infertility are usually of greatest concern, as they are 2 of the disease's more common symptoms. However, the real toll is even greater: women with endometriosis experience diminished quality of life, increased incidence of depression, adverse effects on intimate relationships, with greater risk of obstetric and neonatal complications.[9–12]

The challenge of diagnosing endometriosis

There are no pathognomonic features or biomarkers necessary and sufficient to define endometriosis. Rather, key symptoms that currently prompt surgical evaluation, such as pain and infertility, can have multiple causes. Endometriosis is typically defined by its histology: extrauterine lesions consisting of endometrial glands, endometrial stroma, and/or hemosiderin-laden macrophages. Based on location and depth, lesions are further described as superficial peritoneal lesions, ovarian endometrioma, or deep endometriosis. However, the presence of lesions does not preclude other etiologies for the

From the Center for Endometriosis Research and Treatment (Dr Agarwal), University of California San Diego, La Jolla, CA; Université Paris Descartes (Dr Chapron), Sorbonne Paris Cité, Faculté de Médecine, Assistance Publique–Hôpitaux de Paris (AP-HP), Hôpital Universitaire Paris Centre (HUPC), Centre Hospitalier Universitaire (CHU) Cochin, Department of Gynecology Obstetrics II and Reproductive Medicine, Paris, France; Department of Obstetrics, Gynecology and Reproductive Sciences (Dr Giudice), University of California, San Francisco, CA; Boston Center for Endometriosis, Boston Children's Hospital and Brigham and Women's Hospital; Department of Obstetrics, Gynecology, and Reproductive Biology (Dr Laufer), Brigham and

There are multiple, interrelated phenomena at the intersection of sex, gender, and medicine

Data (new and existing), AI, and technology can help

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

But they also add a layer of complexity

Human-centered approaches are critical

Endometriosis

“Endometriosis is a condition where tissue similar to the lining of the uterus (endometrium) grows outside the uterus, often in the pelvic area. This tissue can attach to various organs, including the ovaries, fallopian tubes, ligaments, and even the bowel and bladder. ”

Endometriosis

- Under-funded
- Under-studied
- Under-understood

- Estimated 6-10% of women in reproductive age
- Debilitating symptoms, sub-fertility, systemic
- No cure, no biomarker
- 6-7 years delay in diagnosis / multiple doctors

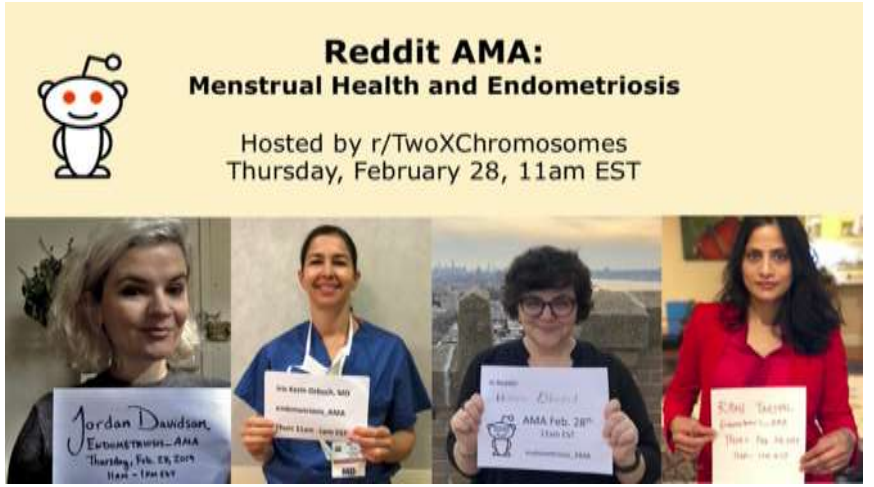
Endometriosis

- Under studied condition → characterization
- Lag to diagnosis → early detection
- Complex self-management → support

Citizen Endo

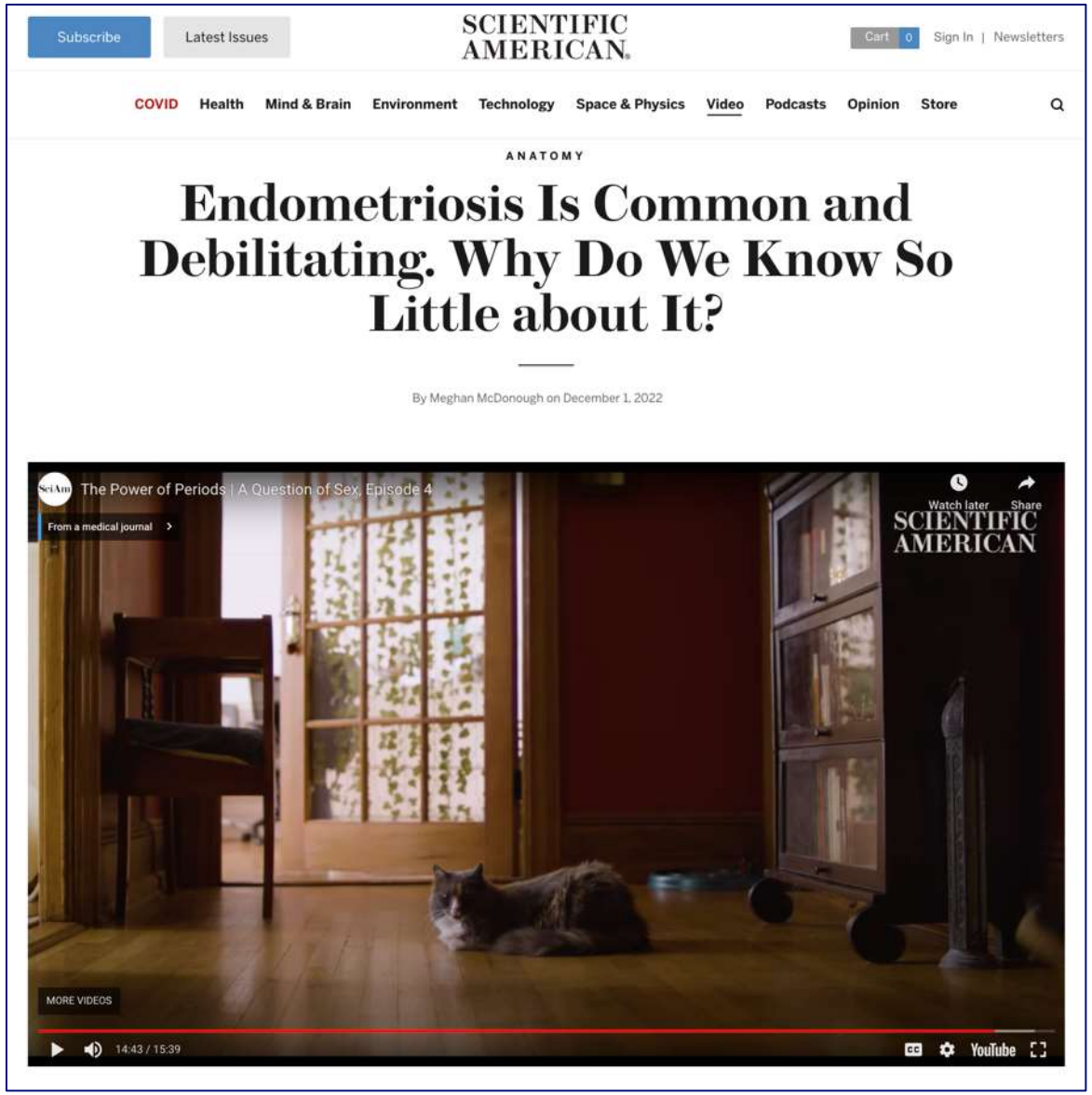
- Community of (to date) 19,000 patients
- Citizen science (return of results, partnership in identifying questions)
- Tools for data collection and analysis that reflect the lived experiences of endometriosis
- Advocacy

@endowhat



Citizen Endo

- Patient scientist as a framework for advancing research in enigmatic conditions



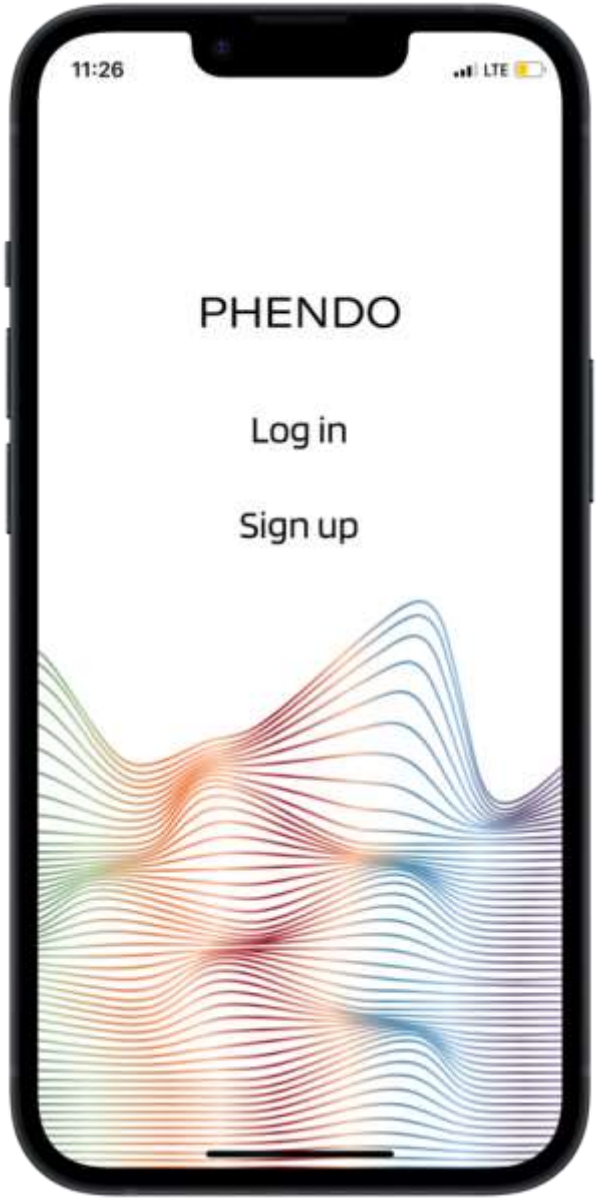
Phendo: a research-based app to track endometriosis

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

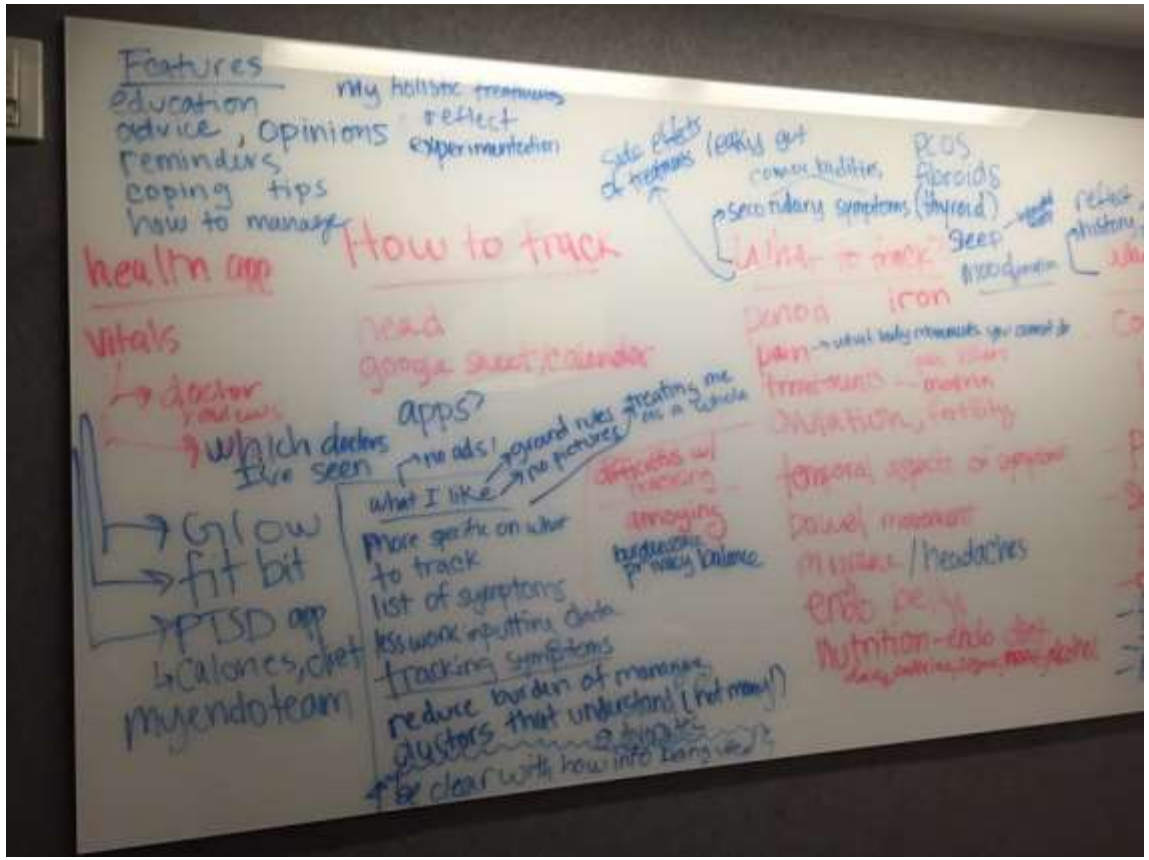
citizenendo.org/phendo

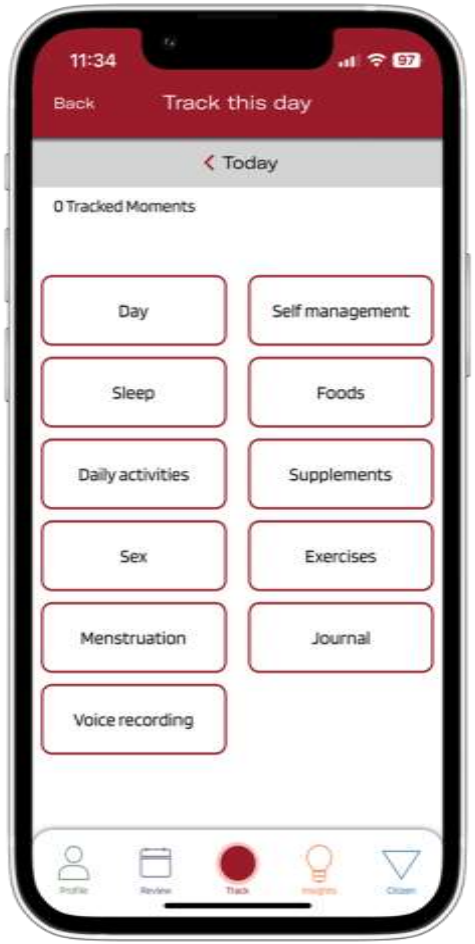
Download on the App Store

GET IT ON Google Play



Phendo: a research-based app to track endometriosis

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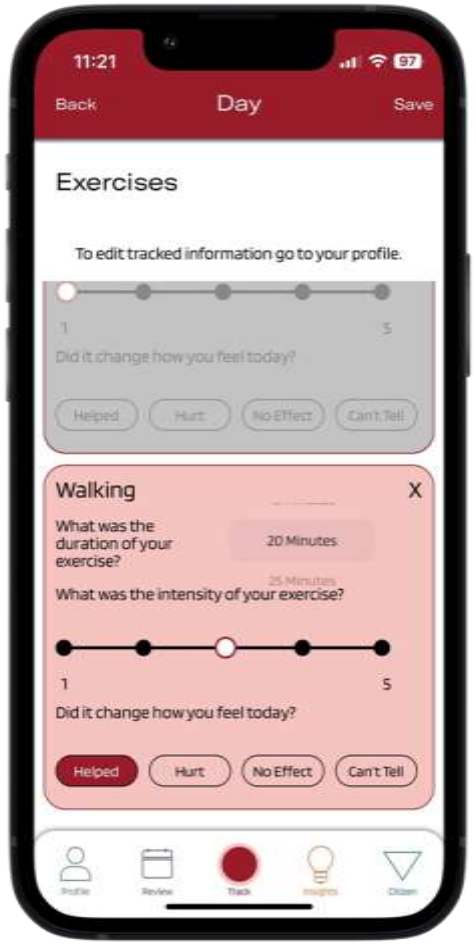
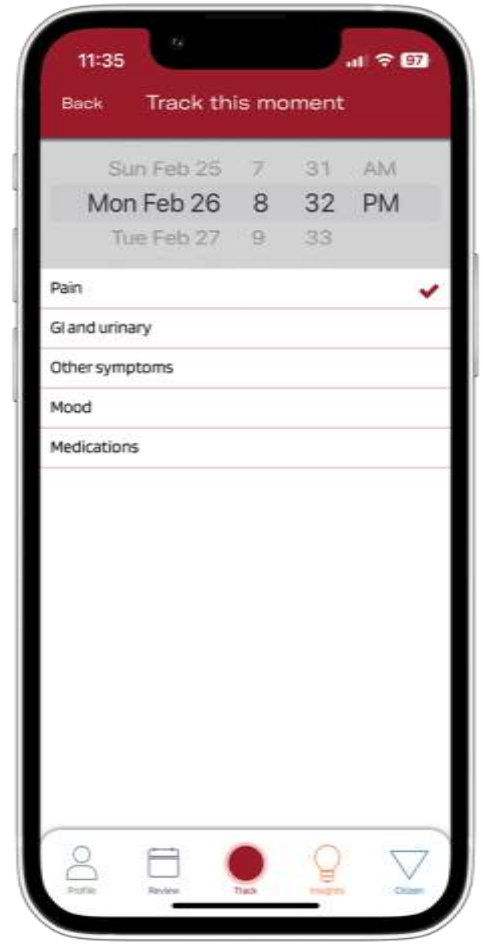
Track this day
Today
0 Tracked Moments
Day
Self management
Sleep
Foods
Daily activities
Supplements
Sex
Exercises
Menstruation
Journal
Voice recording


11:21
Back
Day
Save
Exercises
To edit tracked information go to your profile.
Did it change how you feel today?
Helped
Hurt
No Effect
Can't Tell
Walking
X
What was the duration of your exercise?
20 Minutes
What was the intensity of your exercise?
1
5
Did it change how you feel today?
Helped
Hurt
No Effect
Can't Tell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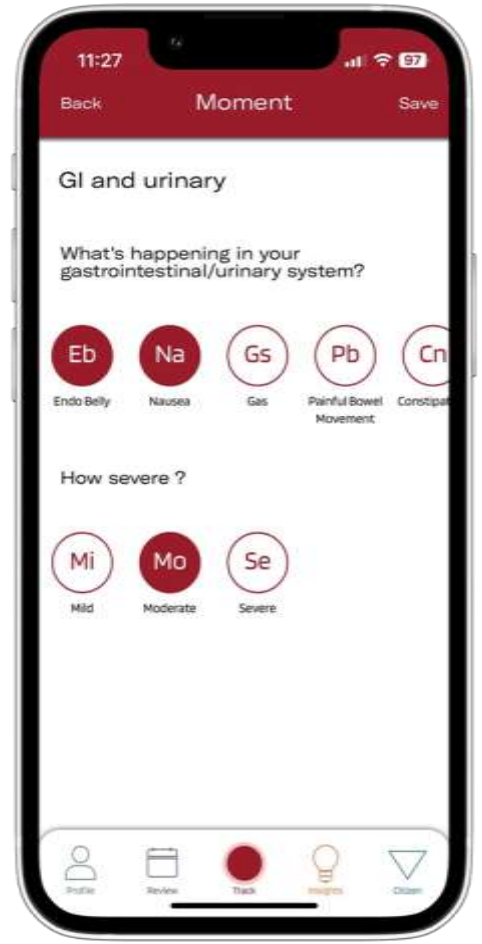
Track this moment
Sun Feb 25 7 31 AM
Mon Feb 26 8 32 PM
Tue Feb 27 9 33
Pain
GI and urinary
Other symptoms
Mood
Medications


11:27
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Moment
Save
GI and urinary
What's happening in your gastrointestinal/urinary system?
Eb
Endo Belly
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Nausea
Gs
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Painful Bowel Movement
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How severe ?
Mi
Mild
Mo
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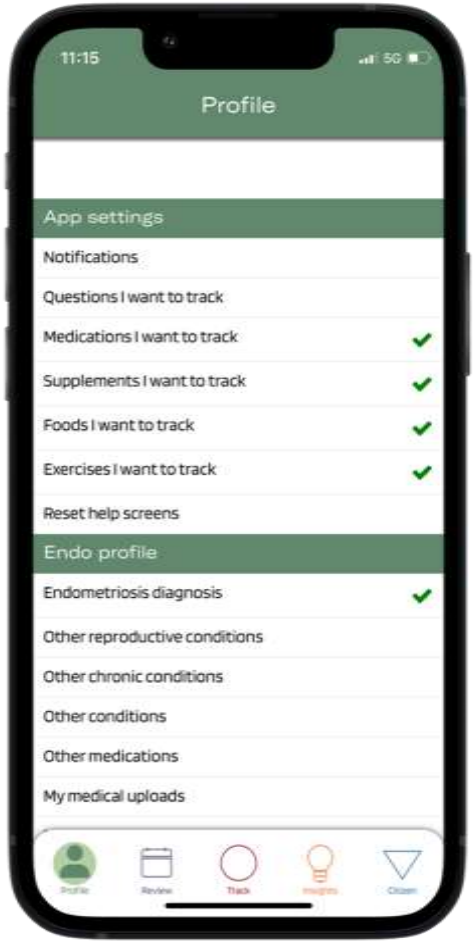
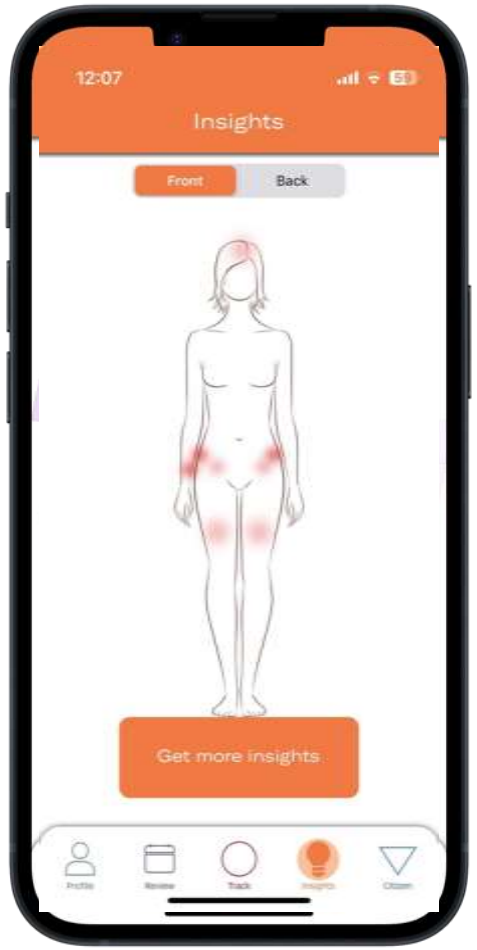
Se
Severe


11:15
Profile
App settings
Notifications
Questions I want to track
Medications I want to track
Supplements I want to track
Foods I want to track
Exercises I want to track
Reset help screens
Endo profile
Endometriosis diagnosis
Other reproductive conditions
Other chronic conditions
Other conditions
Other medications
My medical uploads


11:20
Review
February 2024
Sun Mon Tue Wed Thu Fri Sat


12:07
Insights
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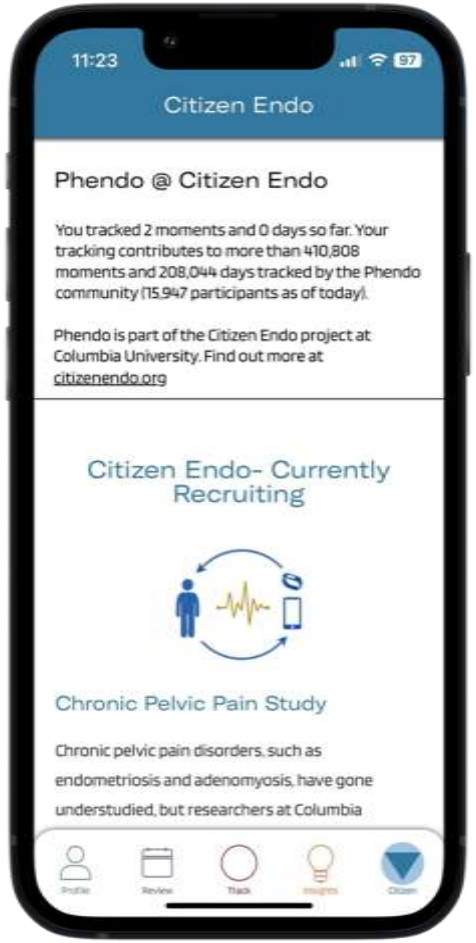
Back
Get more insights


11:23
Citizen Endo
Phendo @ Citizen Endo
You tracked 2 moments and 0 days so far. Your tracking contributes to more than 410,808 moments and 208,044 days tracked by the Phendo community (15,947 participants as of today).
Phendo is part of the Citizen Endo project at Columbia University. Find out more at citizenendo.org
Citizen Endo- Currently Recruiting
Chronic Pelvic Pain Study
Chronic pelvic pain disorders, such as endometriosis and adenomyosis, have gone understudied, but researchers at Columbia

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

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

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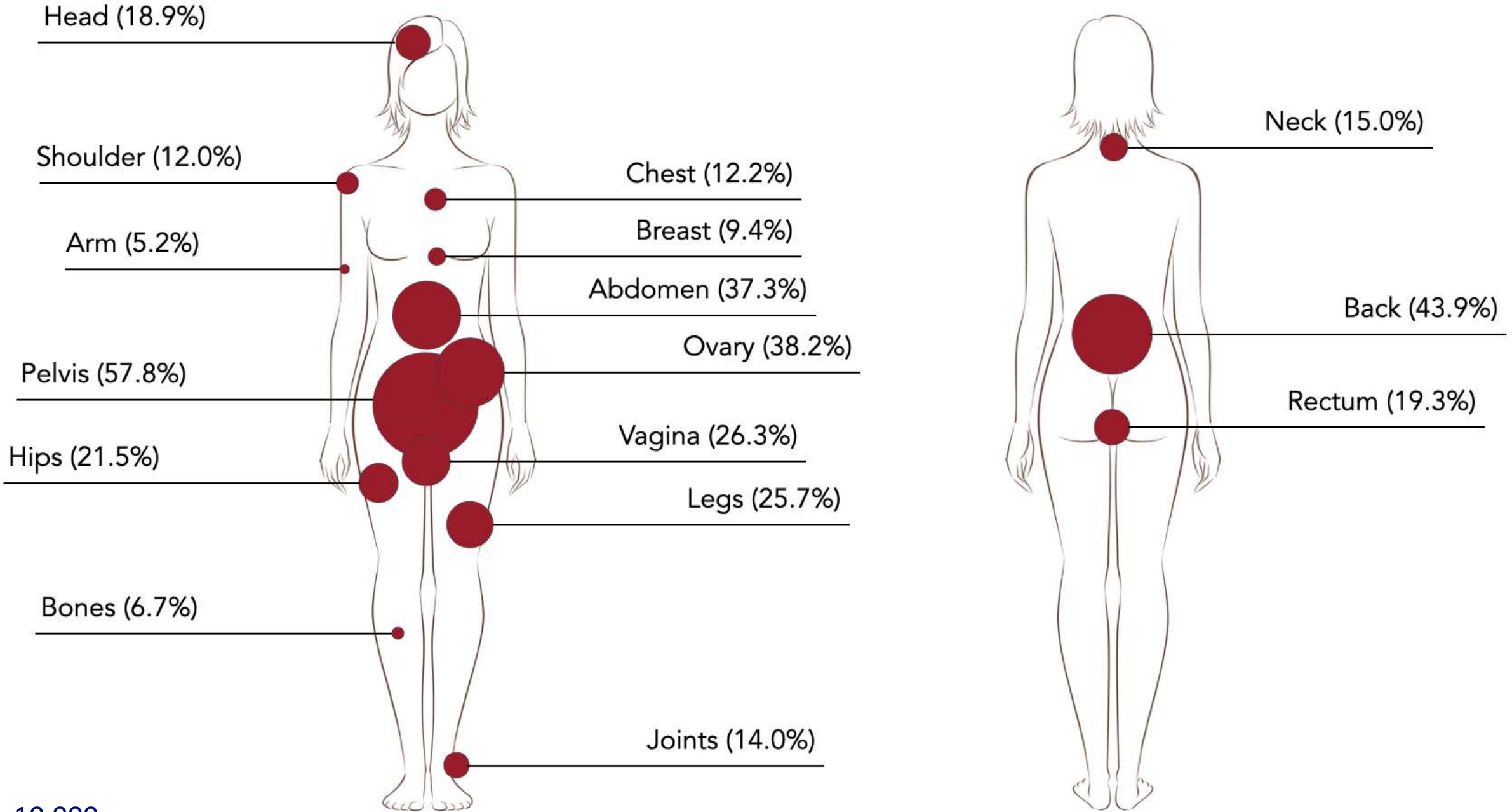
ABSTRACT
The design of personal health informatics tools has traditionally been explored in self-monitoring and behavior change. There is an unmet opportunity to leverage self-tracking of individuals and study diseases and health conditions to learn patterns across groups. An open research question, 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 types are relevant to the disease. We outline the process of identifying design requirements for self-tracking endometriosis, a highly enigmatic and prevalent disease, through interviews (N=3), focus groups (N=27), surveys (N=741), and content analysis of an online endometriosis community (1500 posts, N=153 posters) and show value in triangulating across these methods. Finally, we discuss tensions inherent in designing self-tracking tools for individual use and population analysis, making suggestions for overcoming these tensions.

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 focused on self-monitoring for individuals to gain health-related self-knowledge or achieve a health-related goal [26,54]. In fact, designs of such tools have been proposed and evaluated for many chronic diseases, including diabetes [5,41,69,80,91], COPD [12,102], cardiovascular diseases [4,96], and Parkinson's [11,72,77].

In the context of a chronic disease, there are a large number of data points that may be self-tracked. They fall into a set of well-known data types, or dimensions, which include signs and symptoms of the disease, biomarkers and behavioral markers like physical activity, treatments, self-

Users with at least 1 week of usage
Engagement over first 12 weeks


Head (18.9%)
Shoulder (12.0%)
Arm (5.2%)
Pelvis (57.8%)
Hips (21.5%)
Bones (6.7%)
Chest (12.2%)
Breast (9.4%)
Abdomen (37.3%)
Ovary (38.2%)
Vagina (26.3%)
Legs (25.7%)
Joints (14.0%)
Neck (15.0%)
Back (43.9%)
Rectum (19.3%)

N=10,000

ARTICLE OPEN

Check for updates

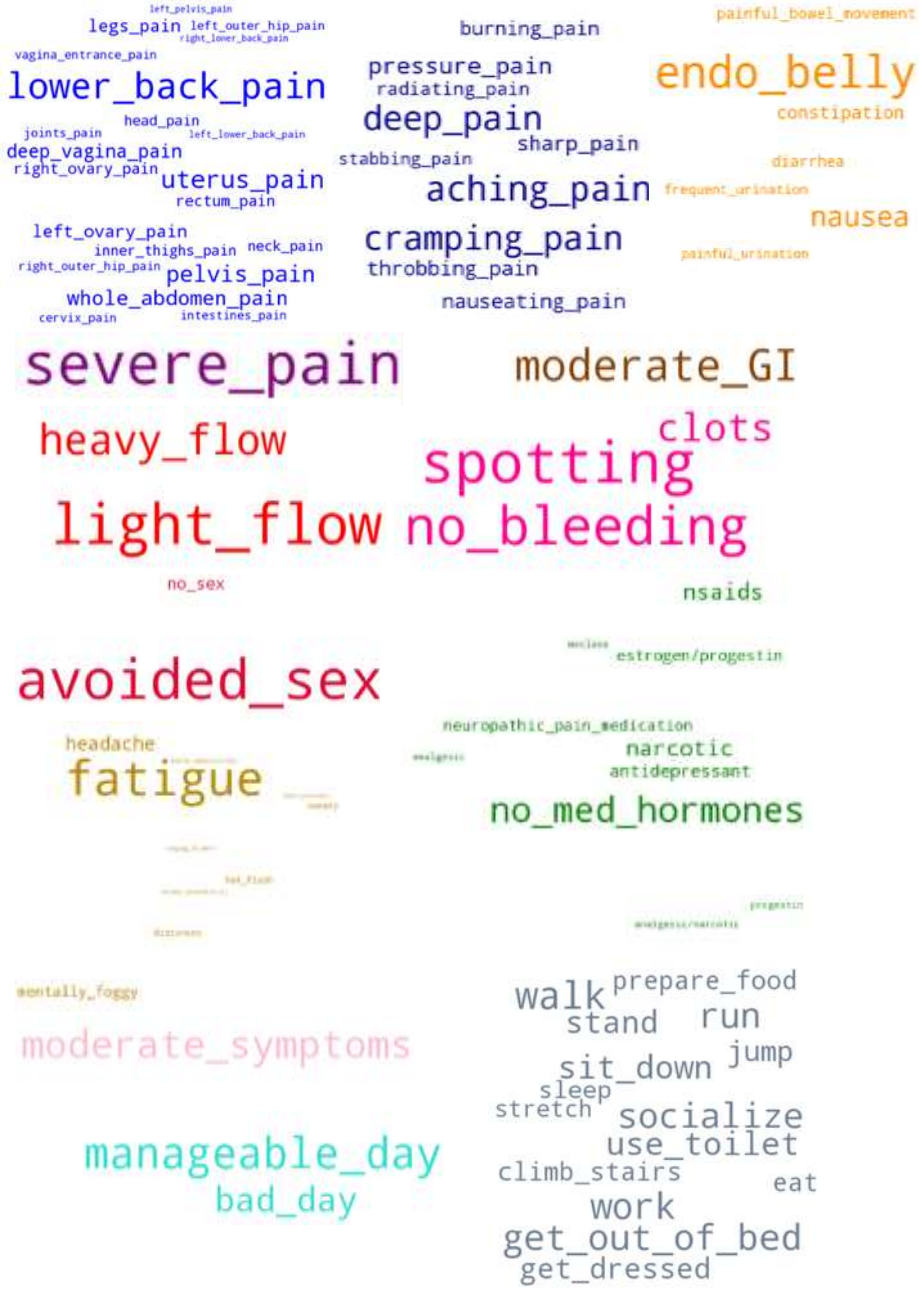
Learning endometriosis phenotypes from patient-generated data

Iñigo Urteaga[1,2], Mollie McKillop[3] 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.

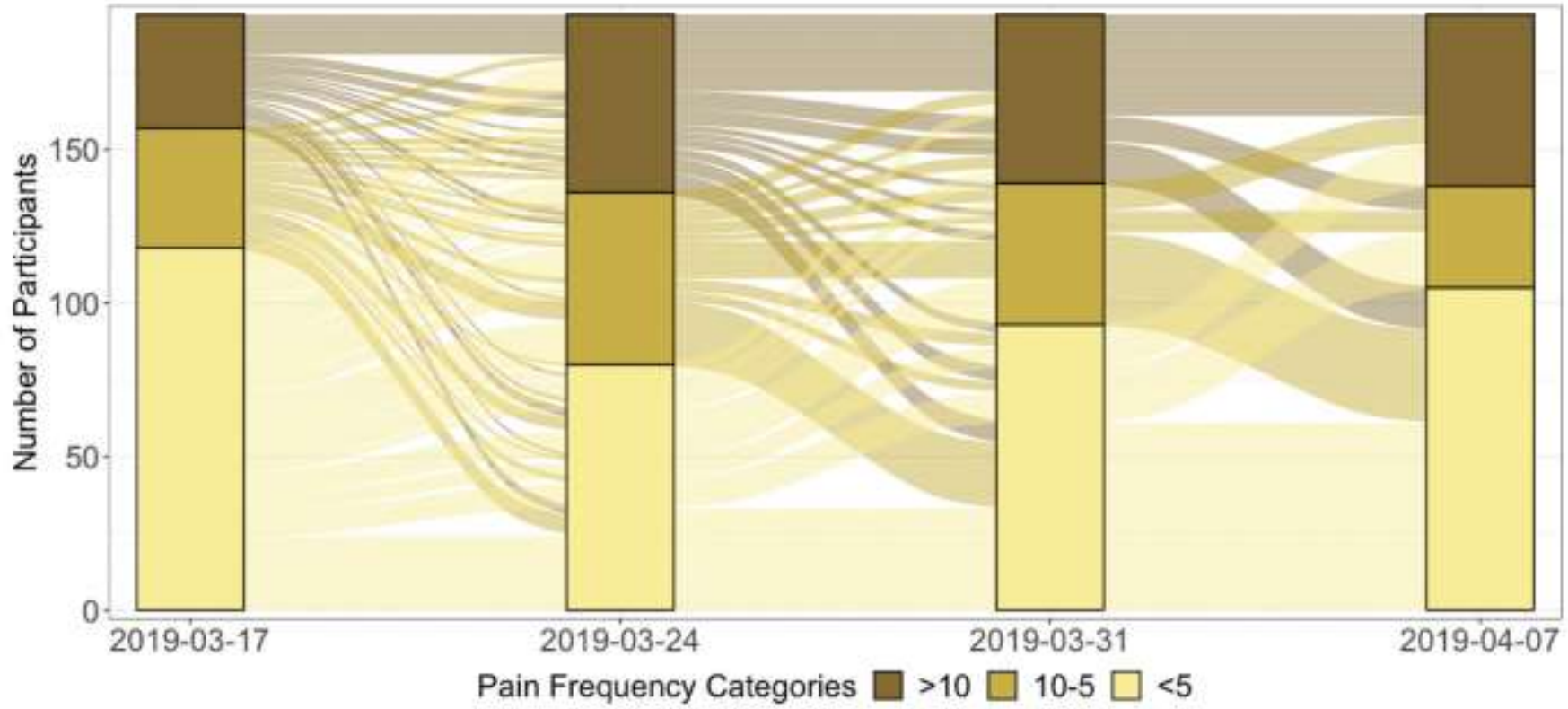
npj Digital Medicine (2020)3:88 ; https://doi.org/10.1038/s41746-020-0292-9

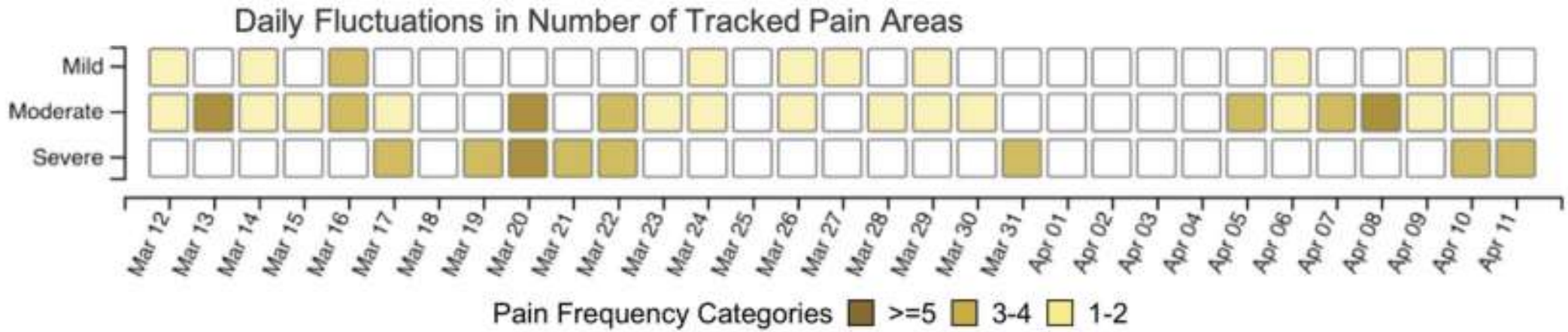
Bad



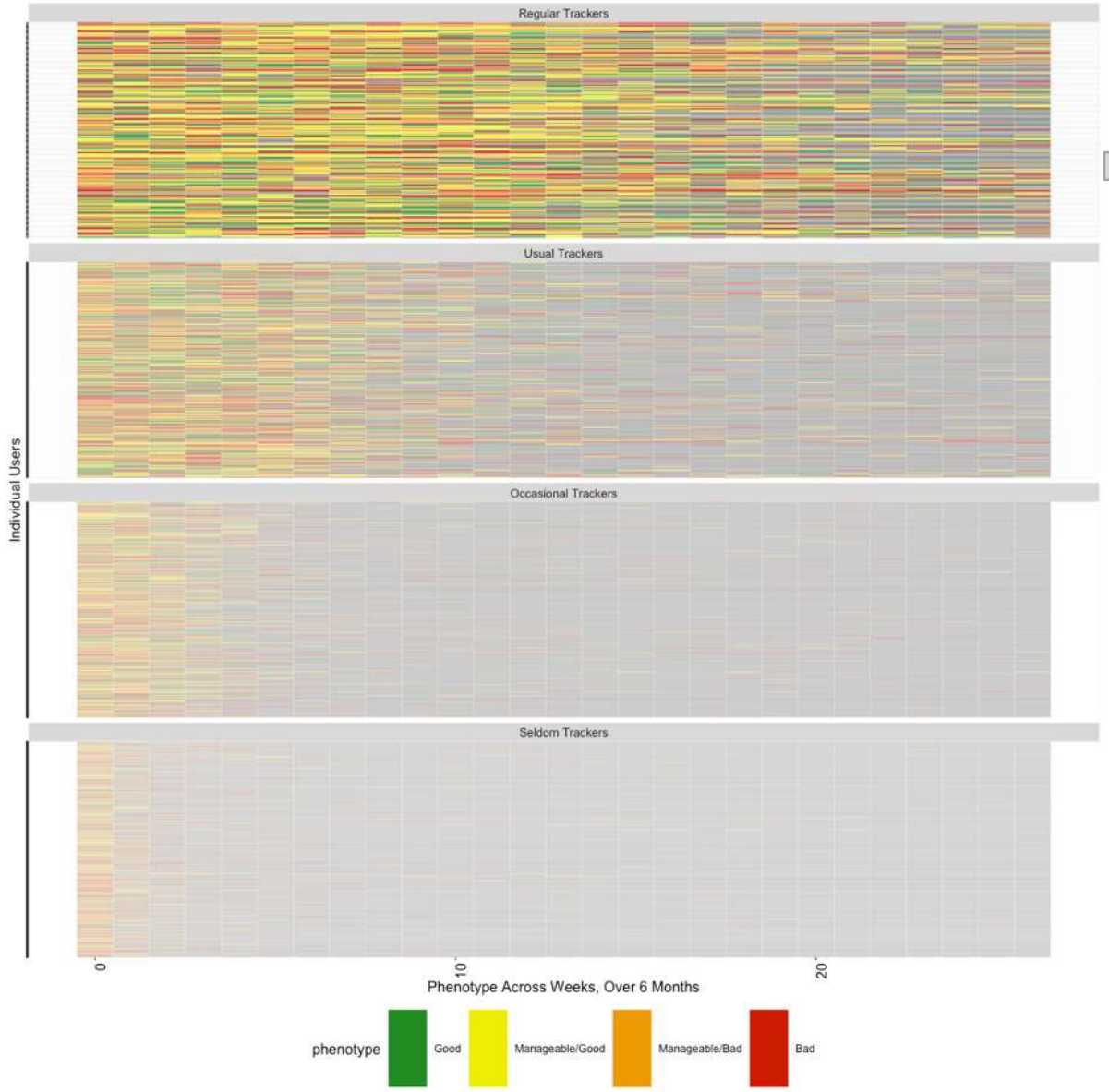
Manageable

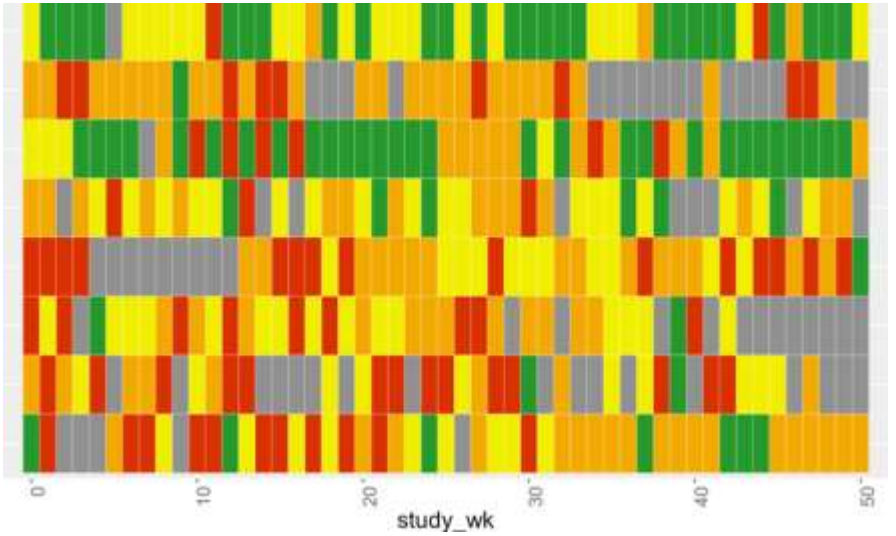
Good

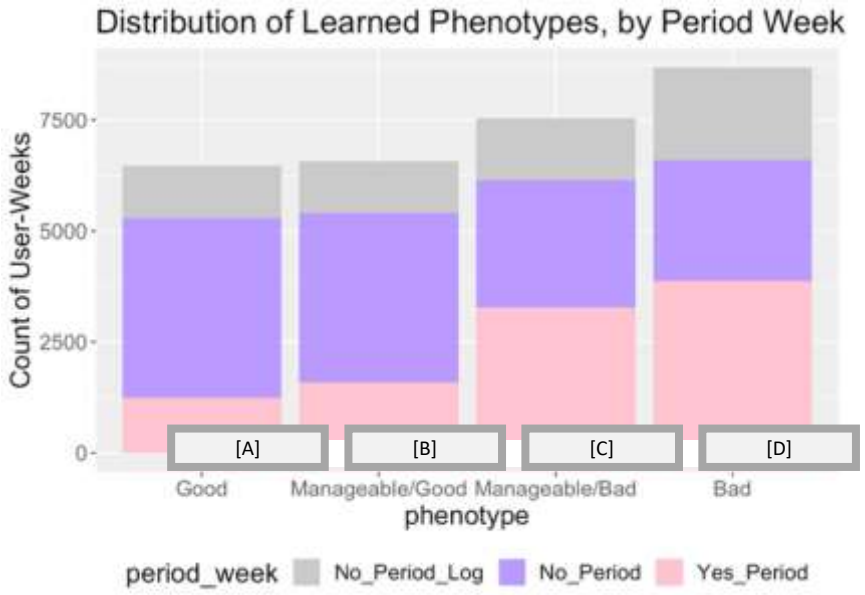

Number of Participants
150
100
50
0
2019-03-17
2019-03-24
2019-03-31
2019-04-07
Pain Frequency Categories >10 10-5 <5


Daily Fluctuations in Number of Tracked Pain Areas
Mild
Moderate
Severe
Mar 12
Mar 13
Mar 14
Mar 15
Mar 16
Mar 17
Mar 18
Mar 19
Mar 20
Mar 21
Mar 22
Mar 23
Mar 24
Mar 25
Mar 26
Mar 27
Mar 28
Mar 29
Mar 30
Mar 31
Apr 01
Apr 02
Apr 03
Apr 04
Apr 05
Apr 06
Apr 07
Apr 08
Apr 09
Apr 10
Apr 11
Pain Frequency Categories >=5 3-4 1-2

Individual Health Status Trajectories







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

Characterization from existing data

- Electronic health records and claims datasets
- They are not The Truth, but they are still very insightful
- 188 million reproductive-age women across nine databases
- 2.11 million endometriosis patients were identified
  - How did we identify them? More on that in a minute

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

How to identify endometriosis patients in an EHR/claims dataset?

- Traditional endometriosis phenotype definition: laparoscopic surgery with pathology confirmation
- ESHRE 2022 guidelines are symptoms based
- What is the impact of shift of diagnosis guidelines on the design of observational studies?

Who has endometriosis?

- 500,000 patients across 4 databases
- Each cohort strong positive predictive value (0.84–0.96)
- Different patients depending of which definition
  - Different ages
  - Different symptoms documented
  - Access to care

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

Harry Reyes Nieva, MPhil, MAS, MA,[1,2] Aparajita Kashyap, MA,[1] Erica A. Voss, PhD, MPH,[3] Anna Ostropolets, MD, PhD,[1,3] Adit Anand,[1] Mert Ketenci, MS,[4] Frank J. DeFalco,[3] Young Sang Choi, MS, MA,[1] Yanwei Li,[1] Monica N. Allen, MD,[5] Stephanie A. Guang, MD,[5] Karthik Natarajan, PhD,[1] Patrick Ryan, PhD,[1,3] Noémie Elhadad, PhD[1,4]

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[2] *Department of Medicine, Harvard Medical School, Boston, MA, USA*
[3] *Global Epidemiology, Janssen Research & Development, LLC, Raritan, NJ, USA*
[4] *Department of Computer Science, Columbia University, New York, NY, USA*
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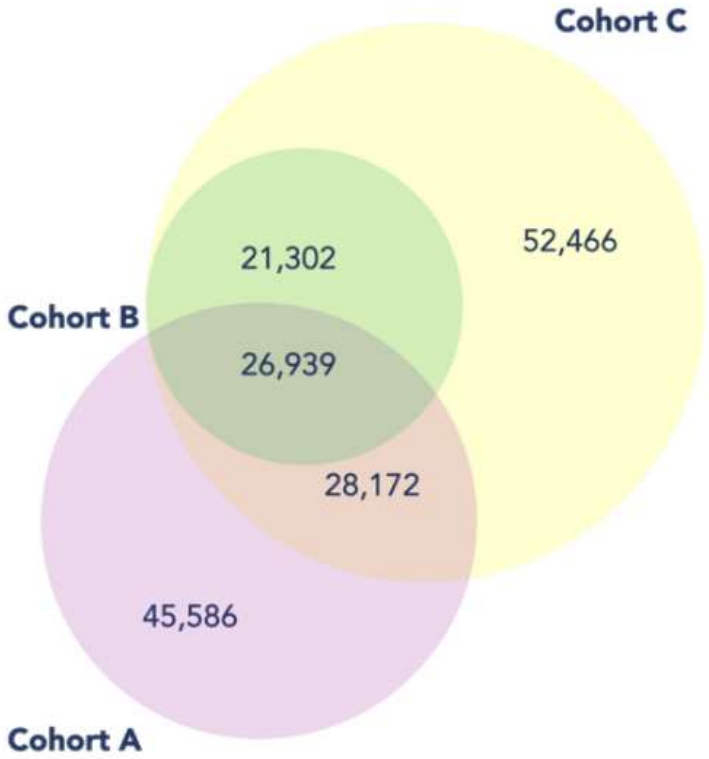
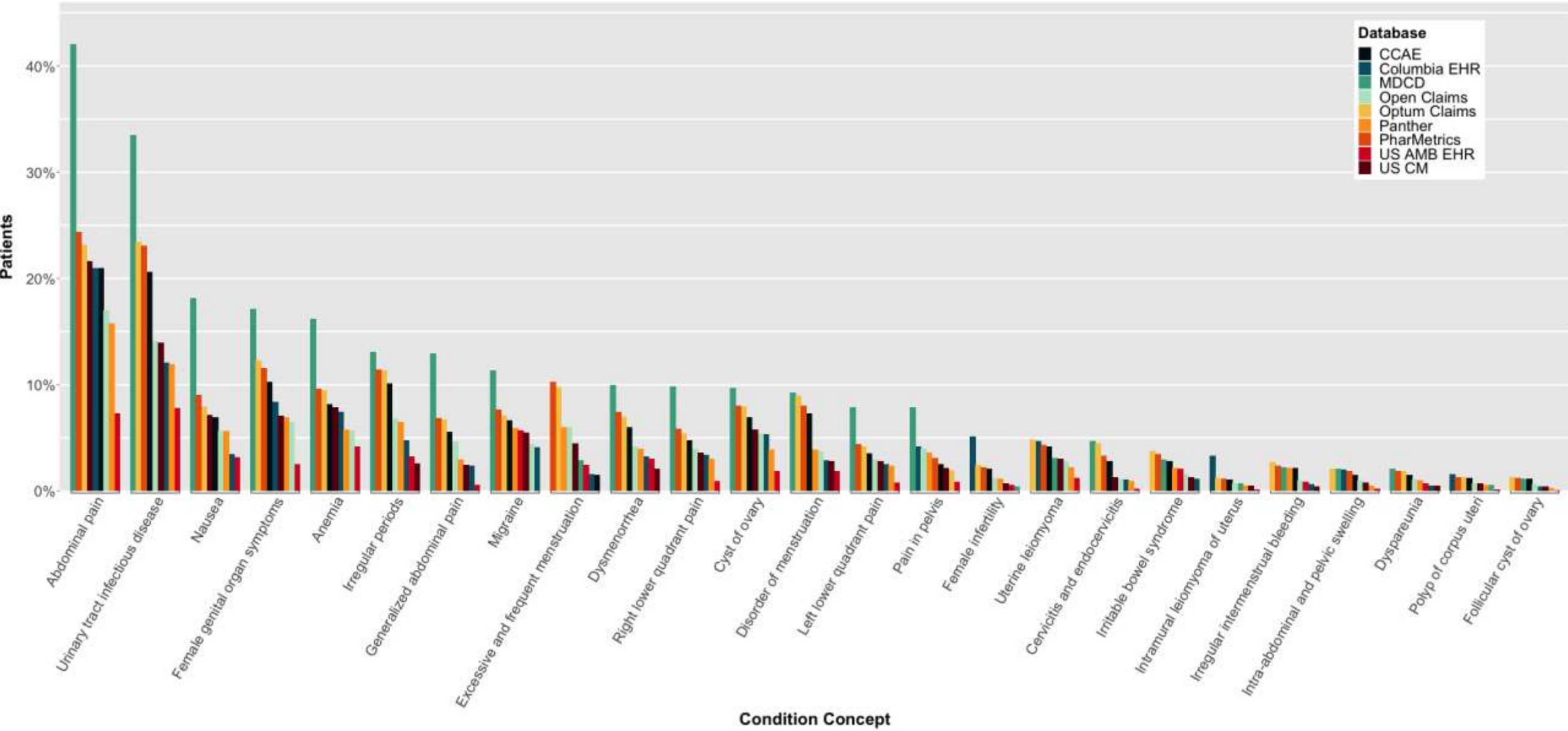
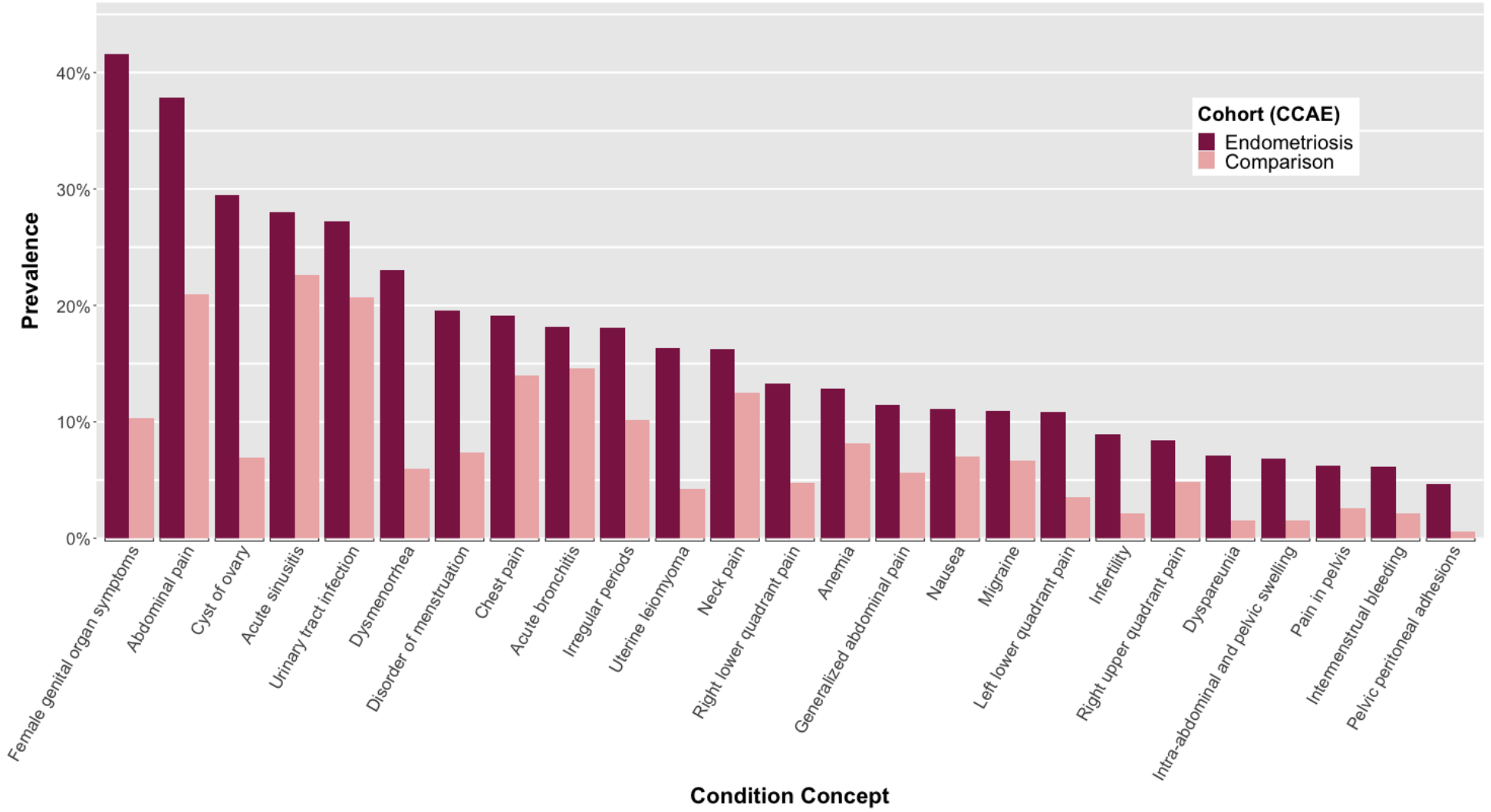


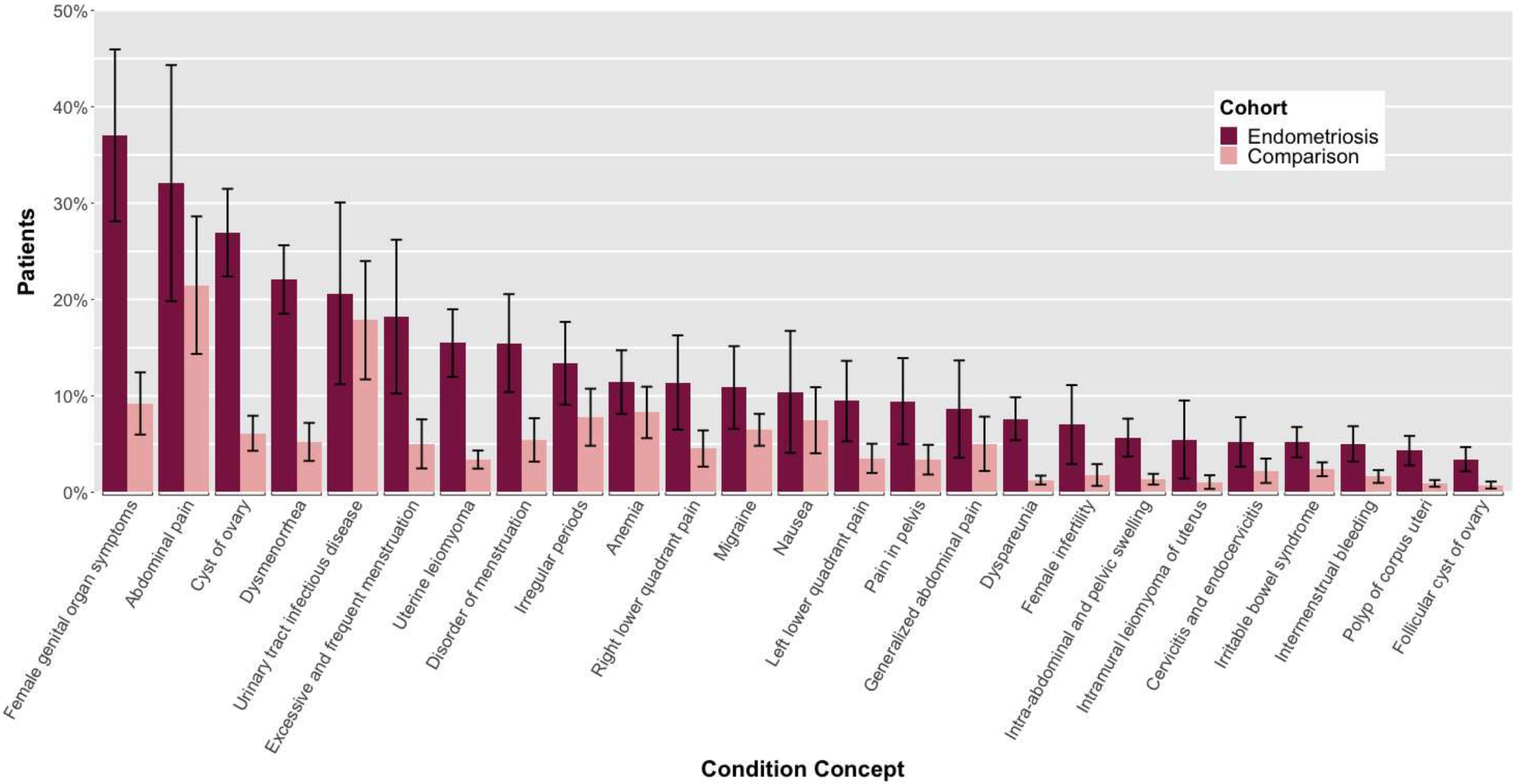
Characterization from EHR/claims



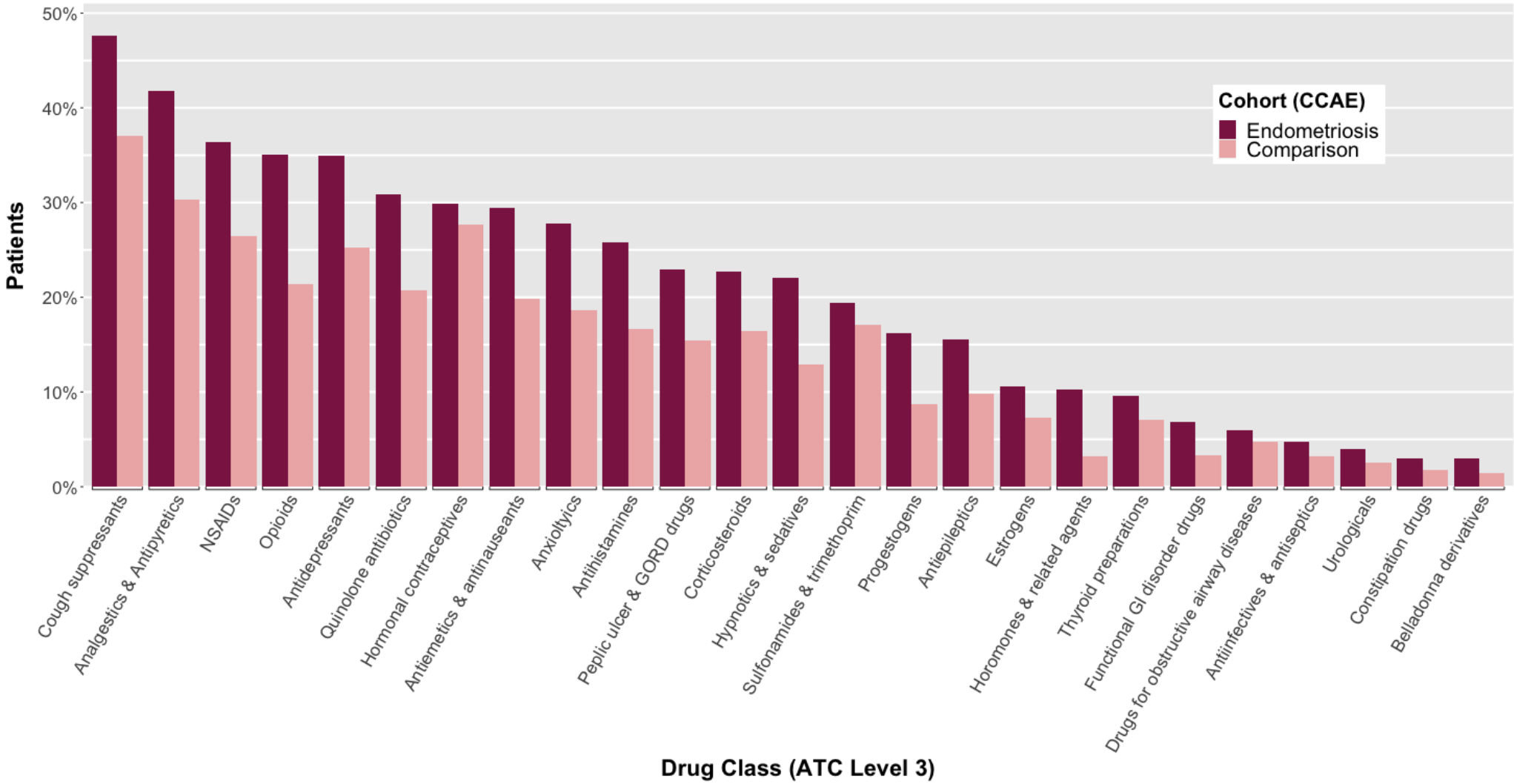
Characterization from EHR/claims



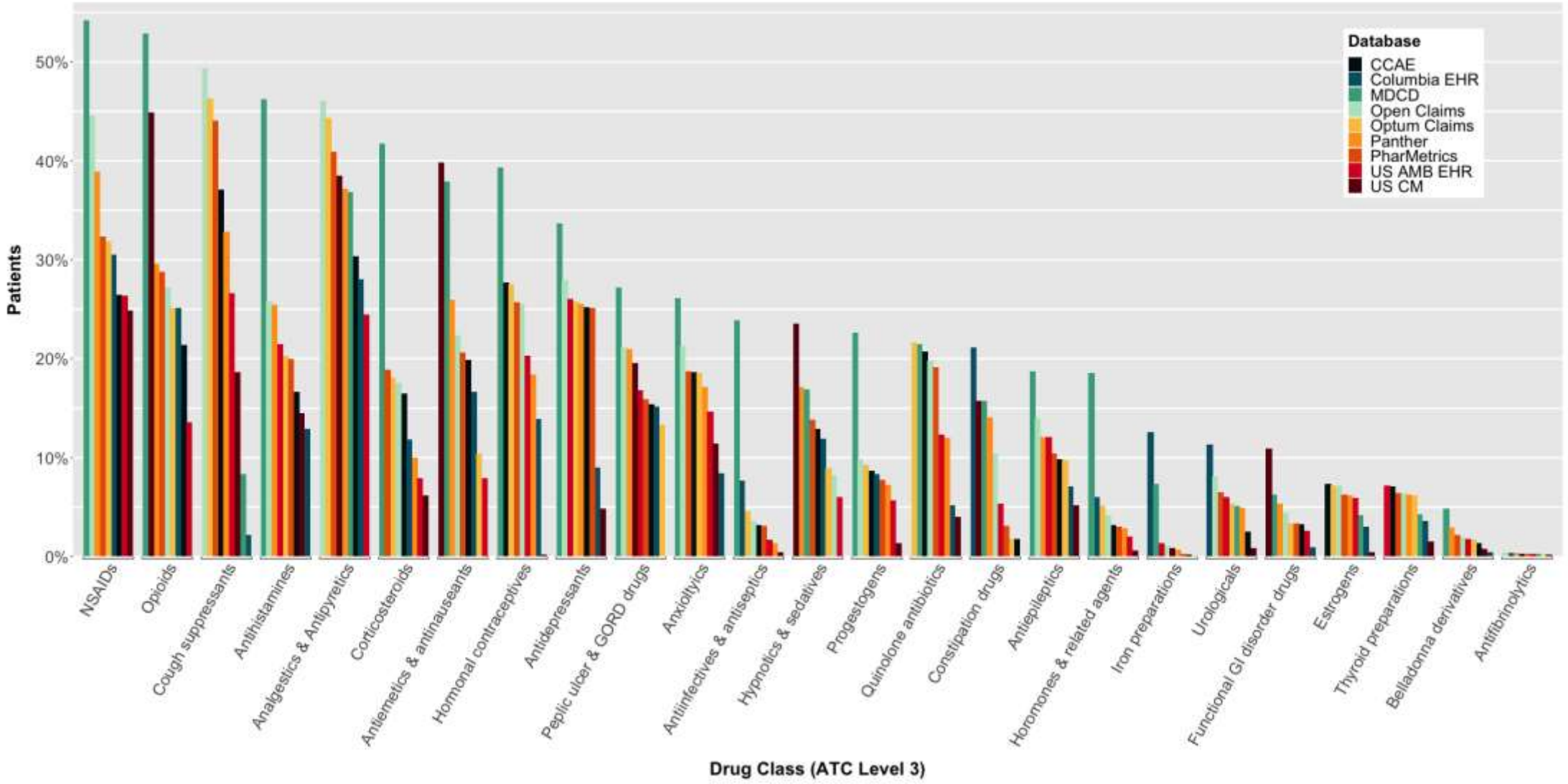
Characterization from EHR/claims



Characterization from EHR/claims



Characterization from EHR/claims



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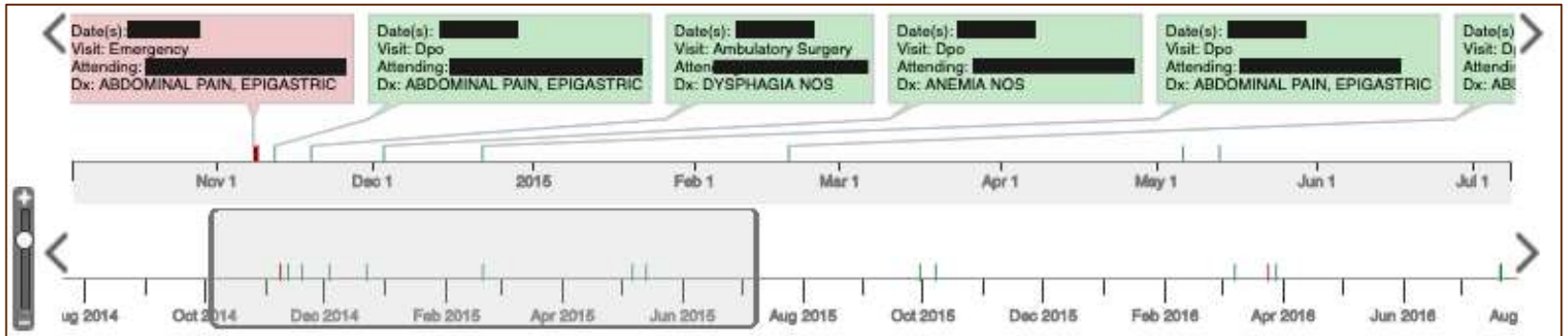
Endometriosis

- Under studied condition → characterization
- Lag to diagnosis → early detection
- Complex self-management → support



epigastric pain fistula poor sleep biliary colic GERD nausea urticaria allergy cramping vomiting pain peptic ulcer ...

More

All notes [redacted]

PACU Admission Note	[redacted]
PACU Discharge/Transfer Note	[redacted]
PACU Admission Note	[redacted]
Ambulatory Surgery Patient Discharge Instruction	[redacted]
Brief Op Note	[redacted]
Anesthesia Post Op Note	[redacted]
Order Reconciliation	[redacted]
Ambulatory Surgery and Same Day Surgery Adult Admission note	[redacted]
ED Patient Discharge Form	[redacted]
ED Disposition Note	[redacted]
ED Attending Brief Note	[redacted]
ED Nursing Assessment Note	[redacted]
ED Pre-Assessment Note (Allen)	[redacted]

ED Attending Brief Note
Prescription
Writer

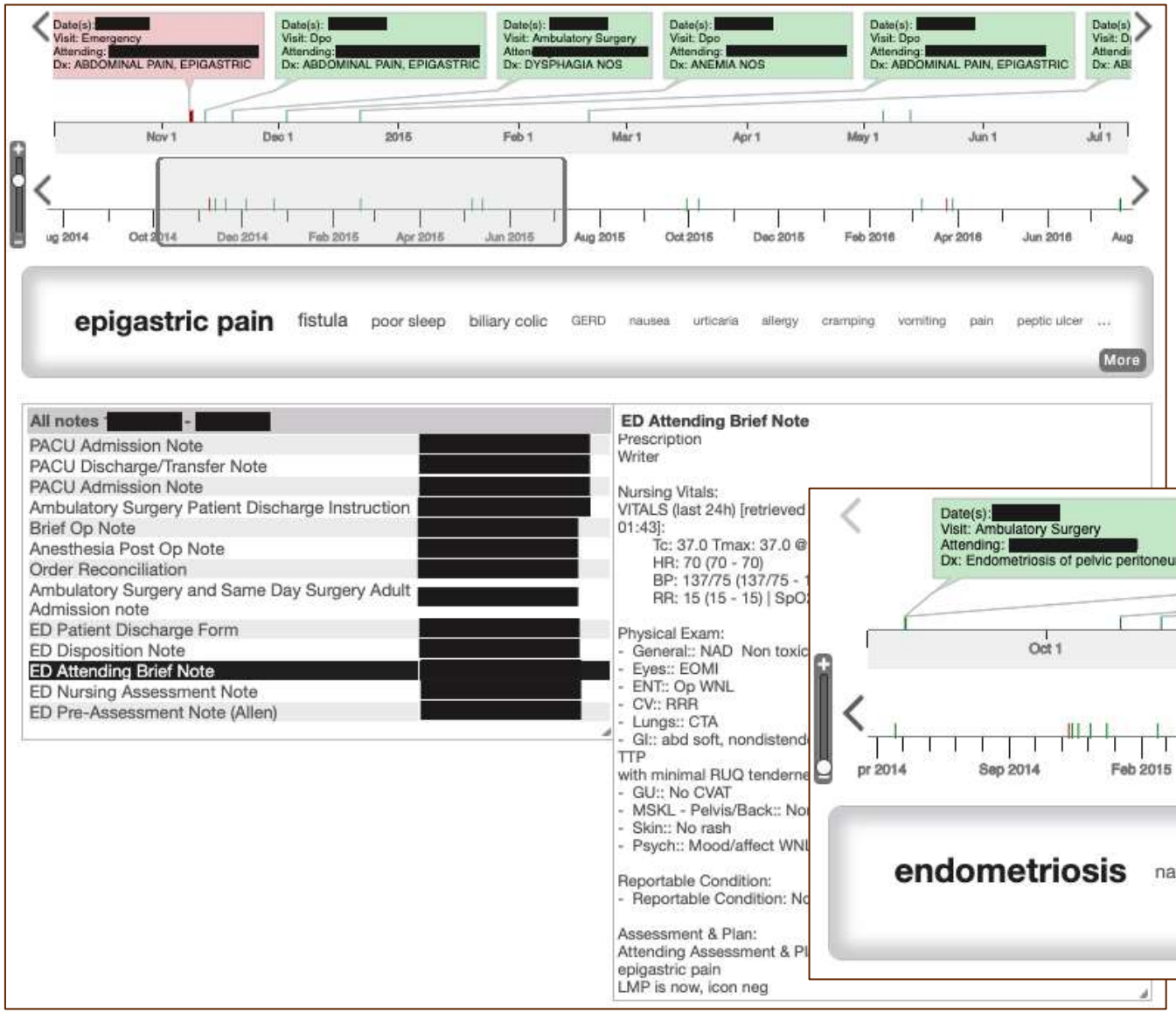
Nursing Vitals:
VITALS (last 24h) [retrieved for [redacted] at [redacted] 01:43]:
Tc: 37.0 Tmax: 37.0 @ [redacted]
HR: 70 (70 - 70)
BP: 137/75 (137/75 - 137/75)
RR: 15 (15 - 15) | SpO2: 97% (97% - 97%).

Physical Exam:
- General:: NAD Non toxic Well hydrated
- Eyes:: EOMI
- ENT:: Op WNL
- CV:: RRR
- Lungs:: CTA
- GI:: abd soft, nondistended, no rebound or guarding, some epigastric TTP
with minimal RUQ tenderness and neg murphy's
- GU:: No CVAT
- MSKL - Pelvis/Back:: Non-tender back
- Skin:: No rash
- Psych:: Mood/affect WNL Oriented X3

Reportable Condition:
- Reportable Condition: No

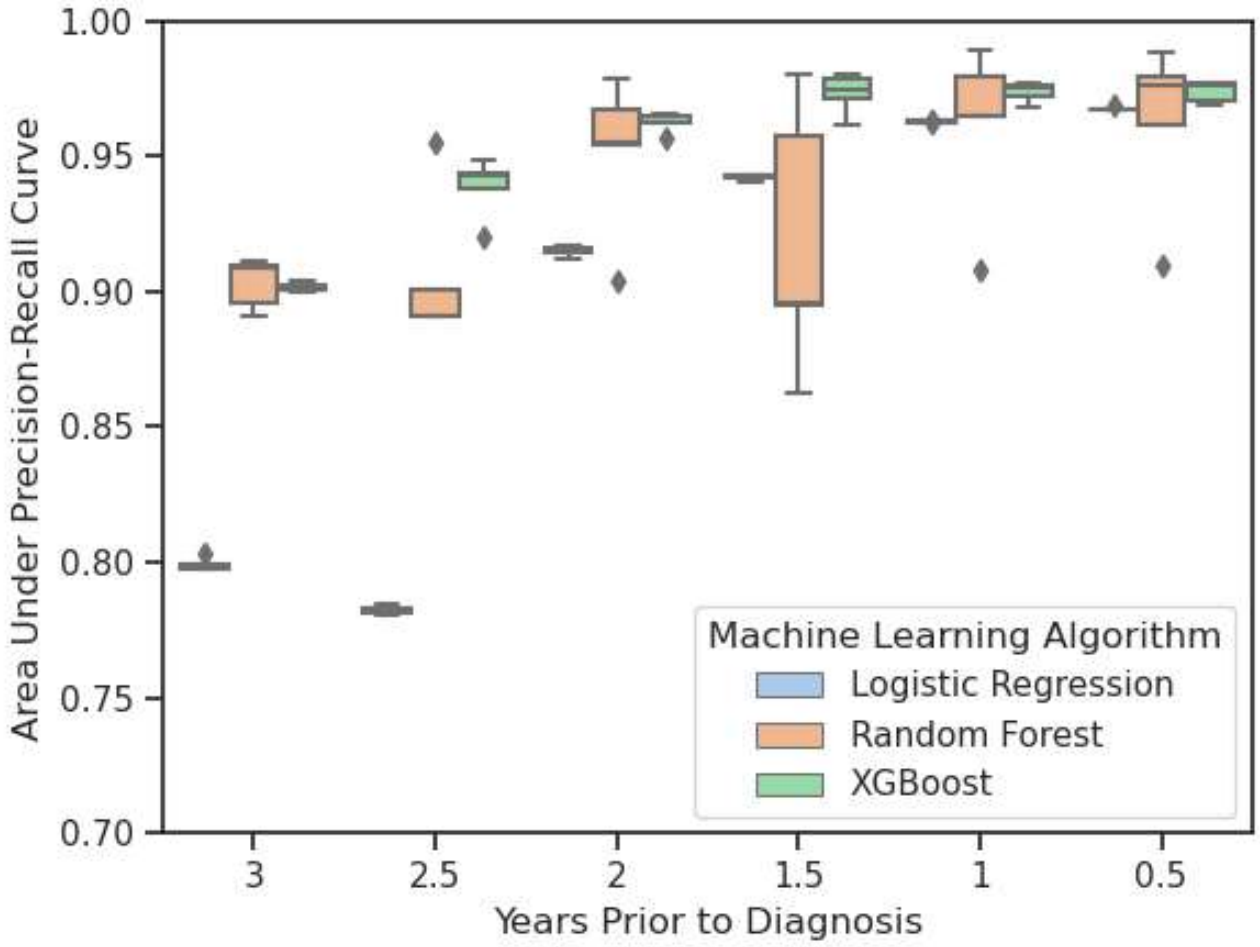
Assessment & Plan:
Attending Assessment & Plan 34 year-old female as above with 1-2 days of epigastric pain
LMP is now, icon neg

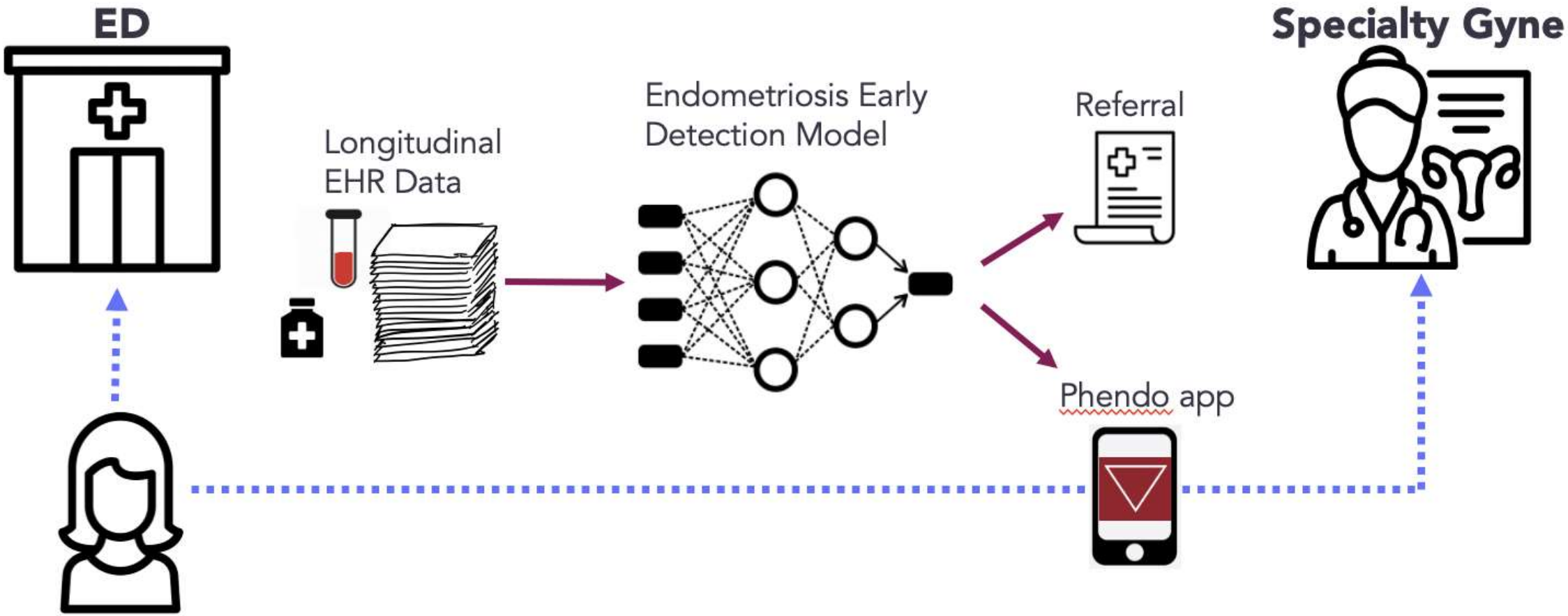
Early detection



Early detection

	Endometriosis N = 53,866	Controls N = 223,117
	Mean (SD)	
Age, years	47 (8)	47 (15)
Hospitalizations	0.50 (1.16)	0.44 (1.22)
Outpatient Visits	62 (51)	53 (56)





Foundation for Women's Health

NewYork-Presbyterian

Endometriosis

- Under studied condition → characterization
- Lag to diagnosis → early detection
- Complex self-management → support

Self management

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

No established
management guidelines

Obstacles to communication

Monitoring is difficult

Treatment is difficult

Partnership & understanding
are difficult for both
patients & providers

Difficulty of care & management is compounded for complex chronic illness

Ask the humans

- Patients and providers have multiple misalignments
- Temporality + disease complexity
  - Patients and providers have difficulty assessing health status through time
- Lack of scientific knowledge
  - Patients and providers have difficulty identify management plans and monitoring their impact
- Disease complexity
  - Cannot identify triggers for flare-ups

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

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KAYLA SCHIFFER, Columbia University, Barnard College, USA
EMMA HORAN, Columbia University, Department of Biomedical Informatics, USA
BRIA MASSEY, Columbia University, Department of Biomedical Informatics, USA
SUZANNE BAKKEN, Columbia University, Department of Biomedical Informatics and School of Nursing, USA
LENA MAMYKINA, Columbia University, Department of Biomedical Informatics, USA
NOÉMIE ELHADAD, Columbia University, Department of Biomedical Informatics, USA

In chronic conditions, patients and providers need support in understanding and managing illness over time. Focusing on endometriosis, an enigmatic chronic condition, we conducted interviews with specialists and focus groups with patients to elicit their work in care specifically pertaining to dealing with an enigmatic disease, both independently and in partnership, and how technology could support these efforts. We found that the work to care for the illness, including reflecting on the illness experience and planning for care, is significantly compounded by the complex nature of the disease: enigmatic condition means uncertainty and frustration in care and management; the multi-factorial and systemic features of endometriosis without any guidance to interpret them overwhelm patients and providers; the different temporal resolutions of this chronic condition confuse both patients and providers; and patients and providers negotiate medical knowledge and expertise in an attempt to align their perspectives. We note how this added complexity demands that patients and providers work together to find common ground and align perspectives, and propose three design opportunities (considerations to construct a holistic picture of the patient, design features to reflect and make sense of the illness, and opportunities and mechanisms to correct misalignments and plan for care) and implications to support patients and providers in their care work. Specifically, the enigmatic nature of endometriosis necessitates complementary approaches from human-centered computing and artificial intelligence, and thus opens a number of future research avenues.

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

Additional Key Words and Phrases: illness work; patient-provider partnership; enigmatic disease

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2573-0142/2020/12-ART261
https://doi.org/10.1145/3434170

Ask the humans to create AI solutions

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

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JESSICA R. BLUMBERG, University of Delaware, USA
LENA MAMYKINA, Columbia University, Department of Biomedical Informatics, USA
NOÉMIE ELHADAD, Columbia University, Department of Biomedical Informatics, USA

Managing complex chronic illness is challenging due to its unpredictability. This paper explores the potential of voice for automated flare-up forecasts. We conducted a six-week speculative design study with individuals with endometriosis, tasking participants to submit daily voice recordings and symptom logs. Through focus groups, we elicited their experiences with voice capture and perceptions of its usefulness in forecasting flare-ups. Participants were enthusiastic and intrigued at the potential of flare-up forecasts through the analysis of their voice. They highlighted imagined benefits from the experience of recording in supporting emotional aspects of illness and validating both day-to-day and overall illness experiences. Participants reported that their recordings revolved around their endometriosis, suggesting that the recordings' content could further inform forecasting. We discuss potential opportunities and challenges in leveraging the voice as a data modality in human-centered AI tools that support individuals with complex chronic conditions.

CCS Concepts: • **Human-centered computing** → **Interactive systems and tools**; **Smartphones**; • **Applied computing** → **Health informatics**.

Additional Key Words and Phrases: chronic illness, forecasting, voice analysis

ACM Reference Format:
Adrienne Pichon, Jessica R. Blumberg, Lena Mamykina, and Noémie Elhadad. 2025. The Voice of Endo: Leveraging Speech for an Intelligent System That Can Forecast Illness Flare-ups. In *CHI Conference on Human Factors in Computing Systems (CHI '25), April 26-May 1, 2025, Yokohama, Japan.* ACM, New York, NY, USA, 23 pages. https://doi.org/10.1145/3706598.3714040

1 INTRODUCTION

Chronic illnesses are challenging for care systems and individuals to manage. These conditions are often heterogeneous in their symptoms and presentation, which means that individuals need personalized support. In some chronic conditions, management is further complicated by unpredictability of flare-ups and uncertainty in how to alleviate them. Endometriosis, a systemic, painful condition with a debilitating impact, is an example of such complex illnesses [4, 83, 110].

Evidence shows that people living with endometriosis want to monitor their illness day-to-day to ascertain their

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

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IÑIGO URTEAGA, Basque Center for Applied Mathematics & Basque Foundation for Science (IKERBASQUE), Spain
LENA MAMYKINA, Columbia University, Department of Biomedical Informatics, USA
NOÉMIE ELHADAD, Columbia University, Department of Biomedical Informatics, USA

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/XXXXXXX

1 INTRODUCTION

Care for chronic conditions is a major health priority globally [87]. Self-management – the day-to-day activities individuals undertake outside of the clinic to cope with their chronic illness – plays a critical role in managing and preventing the progression of disease [18, 19, 31, 32, 64, 132]. However, establishing a self-management care regimen

Human-centered AI

- Patients need individualized support and like the idea of 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)

Endometriosis

- Under studied condition → characterization
- Lag to diagnosis → early detection
- Complex self-management → support

- Beyond endometriosis and other women-specific conditions: menstruation, contraception, menopause

There are multiple, interrelated phenomena at the intersection of sex, gender, and medicine

Data, AI, and technology can help

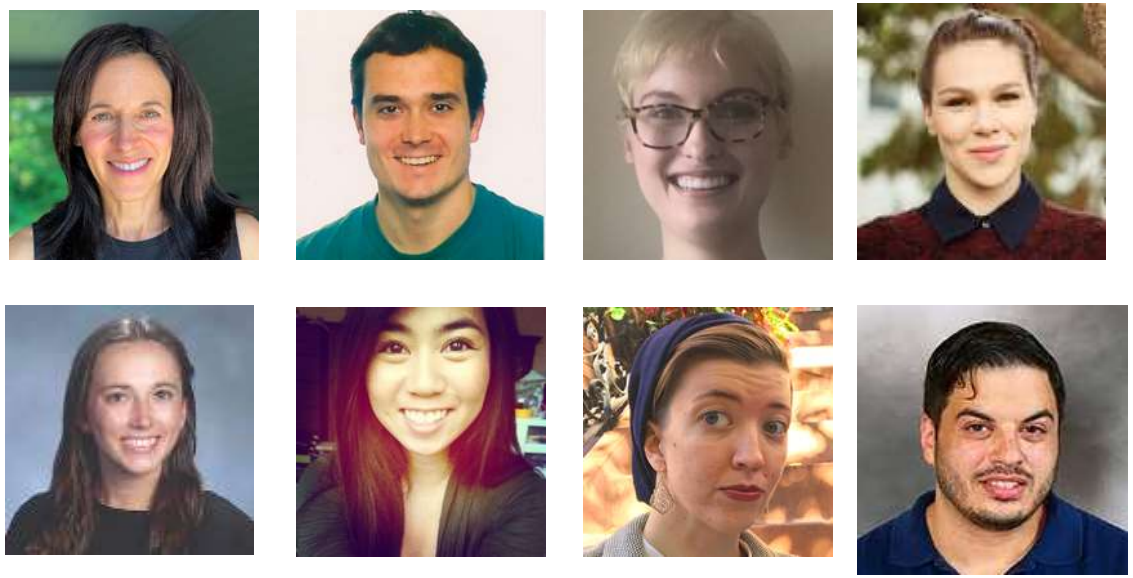
- elucidate the roles of sex and gender in health
- identify new knowledge
- create new solutions

But they also add a layer of complexity

Human-centered approaches are critical

Thank you!

Source: The Faces of Endo. http://endendoforever.blogspot.com/



Menstrual Health and Gender Justice Working Group