

# Scientists as Patients and Patients as Scientists

Noémie Elhadad

noemie.elhadad@columbia.edu  
@noemieelhadad

**Columbia University**  
Biomedical Informatics  
Data Science Institute

# Disclosure

I have no conflict of interest to report.

Hi, I'm Noémie

I like computers and medicine.

# Hi, I'm Noémie



@endowhat

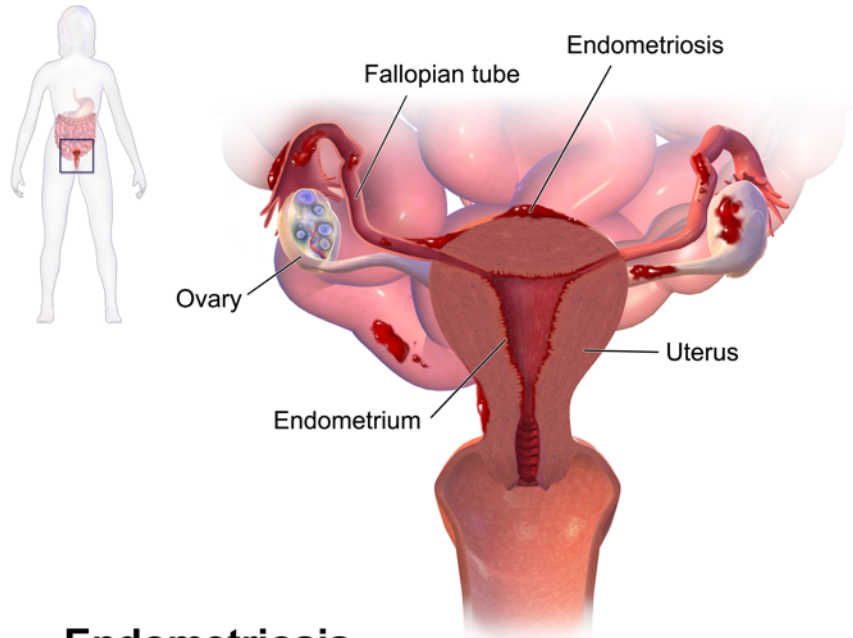
**Reddit AMA:**  
**Menstrual Health and Endometriosis**

Hosted by r/TwoXChromosomes  
Thursday, February 28, 11am EST

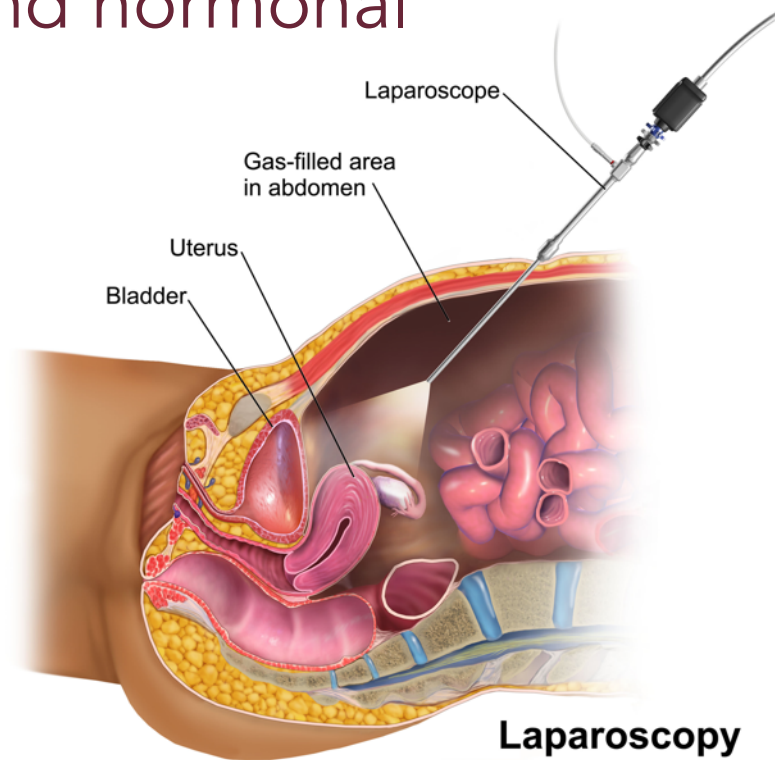
Women Discuss The Invisible Pain Of Endometriosis

# Endometriosis – Ask a gynecologist

- Endometrial-like **cells outside** the uterus
- Diagnosis is done through surgery
- **Symptoms** include dysmenorrhea and infertility
- **Treatments** are surgical and hormonal



**Endometriosis**



**Laparoscopy**

# Endometriosis – Ask an epidemiologist

- 1 in 10 women in reproductive age
- Delayed diagnosis of 4-17 years
- No established risk factors
- Increased risk for ovarian cancer, heart disease
- High morbidity, with loss of productivity
  - Average 10 hours / week

# Endometriosis – Ask a clinical researcher

- 4 surgical disease stages/ 3 histological phenotypes established
- No known biomarkers to diagnose or monitor progression
- No understanding of which treatment will work for whom
- No cure
- SNPs identified through GWAS but with low explanatory power

“a riddle wrapped in a mystery inside an enigma”

-Emory Wilson, MD

## Endometriosis: an enigmatic disease with many faces

Dipak J. Limbachiya, Grishma P. Agrawal\*

Department of Obstetrics and Gynecology, EVA Endoscopy Training Institute, Ahmedabad, Gujarat, India

Received: 21 December 2016

Accepted: 13 December 2016

**\*Correspondence:**

Dr. Grishma P. Agrawal,

E-mail: grishma.agrawal29@gmail.com

**Copyright:** © the author(s), publisher and licensee Medip Academy. This is an open-access article distributed under the terms of the Creative Commons Attribution Non-Commercial License, which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

### ABSTRACT

Endometriosis is a benign disease defined by the presence of the endometrial glands and stroma outside of the uterus, both at pelvic and extra pelvic sites. We are reporting 4 unusual cases of endometriosis that are unique on their own due to site of endometriosis, presenting symptoms, complications and treatment. Endometriosis was present at post caesarean scar site in one case, at vault site in another case, in bladder in third case and in the last case it caused frozen pelvis with hydroureter, hydronephrosis and possibly infertility. All four patients have been treated

### Endometriosis: where are we and where are we going?

Alexis D Greene<sup>1,\*</sup>, Stephanie A Lang<sup>2,\*</sup>, Jessica A Kendzioriski<sup>2</sup>, Julie M Sroga-Rios<sup>1</sup>, Thomas J Herzog<sup>1,3</sup> and Katherine A Burns<sup>2</sup>

<sup>1</sup>Department of Obstetrics and Gynecology, University of Cincinnati Center for Reproductive Health, Cincinnati, Ohio, USA, <sup>2</sup>Department of Environmental Health, University of Cincinnati College of Medicine, Cincinnati, Ohio, USA, and <sup>3</sup>University of Cincinnati Cancer Institute, University of Cincinnati College of Medicine, Cincinnati, Ohio, USA

Correspondence should be addressed to K A Burns; Email: [Katherine.Burns@uc.edu](mailto:Katherine.Burns@uc.edu)

\*A D Greene and S A Lang contributed equally to this work

### Abstract

Endometriosis currently affects ~5.5 million reproductive-aged women in the U.S. with symptoms such as painful periods (dysmenorrhea), chronic pelvic pain, pain with intercourse (dyspareunia), and infertility. It is defined as the presence of endometrial tissue outside the uterine cavity and is found predominately attached to sites within the peritoneal cavity. Diagnosis for endometriosis is solely made through surgery as no consistent biomarkers for disease diagnosis exist. There is no cure for endometriosis and treatments only target symptoms and not the underlying mechanism(s) of disease. The nature of individual predisposing factors or inherent defects in the endometrium, immune system, and/or peritoneal cavity of women with endometriosis remains unclear. The literature over the last 5 years (2010–2015) has advanced our critical knowledge related to hormones, hormone receptors, immune dysregulation, hormonal treatments, and the transformation of endometriosis to ovarian cancer. In this review, we cover the aforementioned topics with the goal of providing the reader an overview and related references for further study to highlight the progress made in endometriosis research, while concluding with critical areas of endometriosis research that are urgently needed.

Reproduction (2016) 152 R63–R78



## American Journal of Obstetrics and Gynecology

Available online 6 January 2019

In Press, Accepted Manuscript

Call to Action

### Clinical diagnosis of endometriosis: a call to action

Sanjay K. Agarwal MD<sup>1</sup>, Charles Chapron MD<sup>2</sup>, Linda C. Giudice MD, PHD<sup>3</sup>, Marc R. Laufer MD<sup>4</sup>, Nicholas Leyland MD<sup>5</sup>, Stacey A. Missmer ScD<sup>6</sup>, Sukhbir S. Singh MD<sup>7</sup>, Hugh S. Taylor MD<sup>8</sup>  

 Show more

<https://doi.org/10.1016/j.ajog.2018.12.039>

Get rights and content

Under a Creative Commons license

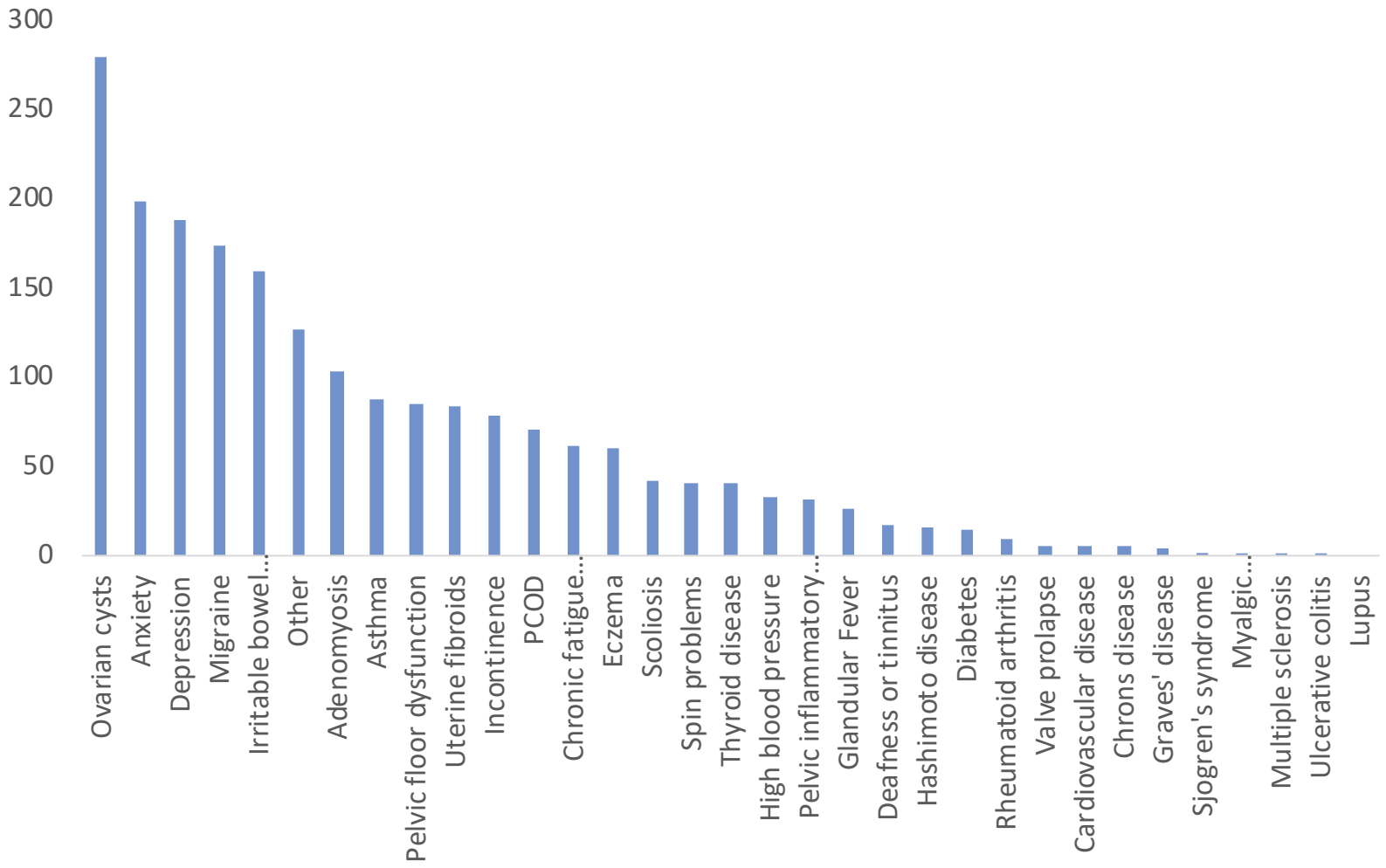
open access



# Endometriosis – Ask me

- Symptomatic for 30 years
- Hormonal treatments for 20 years, pain killers
- 7 endo-related surgeries + 1 complication follow-up surgery
  - Endometriosis lesions found on 8 organs (left alone, resected, or removed)
- Misdiagnosed with 3 cancers, IBD, 2 auto-immune diseases

# Endometriosis – Ask the patients





# Endometriosis – Ask the patients

*“It has ruled (and ruined) my life since I was 13. I’m 30 now and feel like I’ve had no life.”*

*“At 32, I have exhausted the treatments available. Endo has taken my social life, sex life, and I have to struggle to work. Now it has taken my ability to have children... I feel like endo has taken my identity. I grieve for the woman I would have been without synthetic hormones and medication, would I have been a different person without endo? Unfortunately I’ll never get to know who the ‘real me’ ever was. That is my biggest loss.”*

Sacrum  
Shoulders

300

150

Graves' disease  
Sjogren's syndrome  
Myalgic...  
Multiple sclerosis  
Ulcerative colitis  
Lupus

Pe

Ca

# Endometriosis – Ask the patients

300

*“It has ruled (and ruined) my life since I was 13. I’m 30 now and feel like I’ve had no life.”*

*“At 32, I have been suffering since I was about 18 and I am going to be 48. I often wonder what I could have accomplished if I not had this monster disease. I have no sex life, and I have to struggle to work. Now it has taken my ability to have children... I feel like endo has taken my identity. I grieve for the woman I would have been without synthetic hormones and medication, would I have been a different person without endo? Unfortunately I’ll never get to know who the ‘real me’ ever was. That is my biggest loss.”*

Graves' disease  
Sjogren's syndrome  
Myalgic...  
Multiple sclerosis  
Ulcerative colitis  
Lupus

Pe

Ca

# Endometriosis – Ask the patients

300

*“It’s left my body broken.”*

*“It has ruled (and ruined) my life since I was 13. I’m 30 now and feel like I’ve had no life.”*

*“At 32, I have been suffering since I was about 18 and I am going to be 48. I often wonder what I could have accomplished if I not had this monster disease. I have no sex life, and I have to struggle to work. Now it has taken my ability to have children... I feel like endo has taken my identity. I grieve for the woman I would have been without synthetic hormones and medication, would I have been a different person without endo? Unfortunately I’ll never get to know who the ‘real me’ ever was. That is my biggest loss.”*

Graves' disease  
Sjogren's syndrome  
Myalgic...  
Multiple sclerosis  
Ulcerative colitis  
Lupus

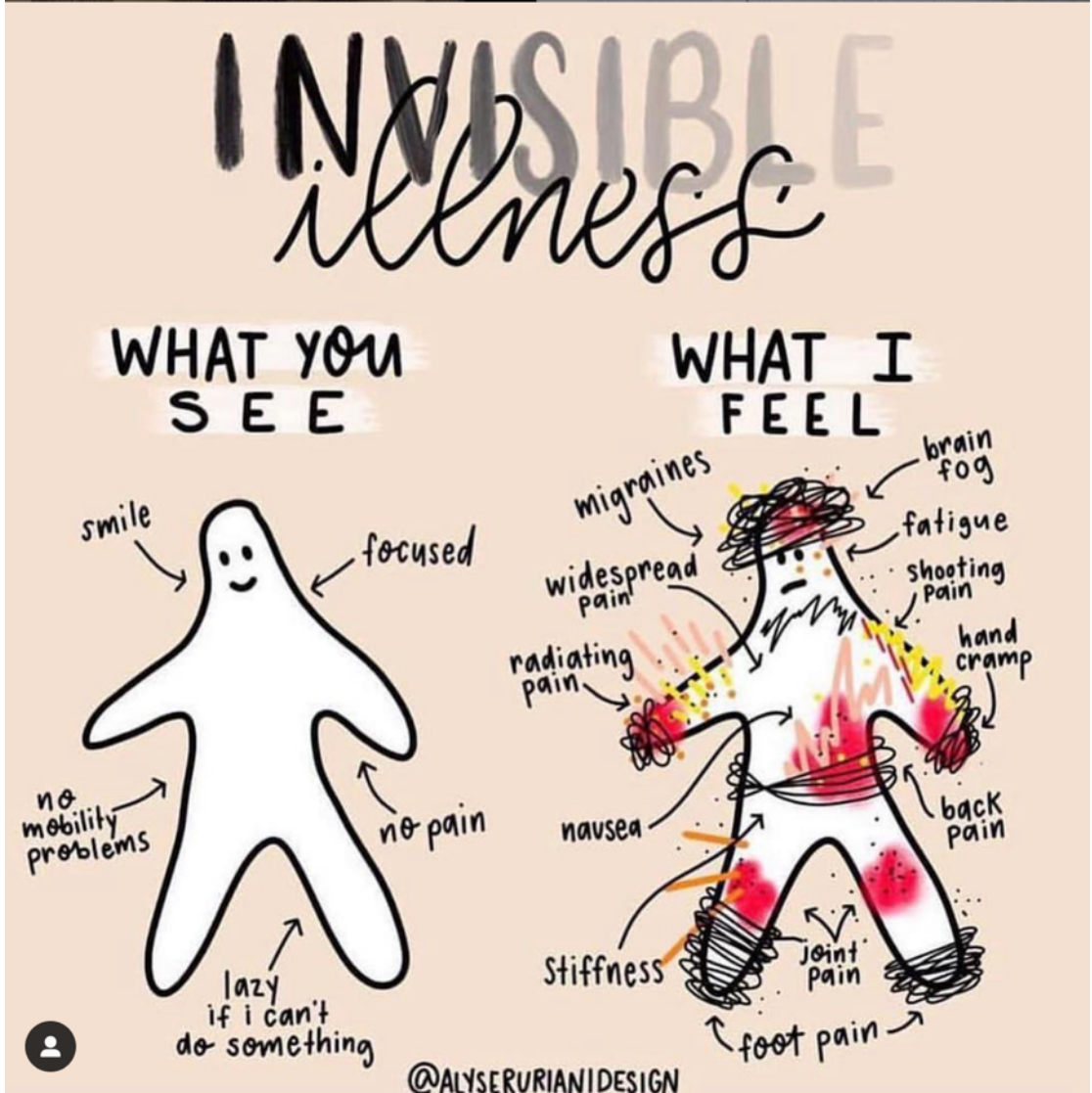
Pe

Ca

# Endometriosis – Ask the patients



[@georgiewileman](https://twitter.com/georgiewileman)



# The problem

- There is a disconnect between the way patients experience the disease and its current scientific characterization
  - Proposed phenotypes do not correlate with symptoms and their severity
  - Current characterization ignores many of the symptoms and their temporal trajectories
- Impacts detection, monitoring, and research
- Frustrating to patients
  - Loss of trust in doctors and scientists



- How do I get better?
    - How do I stay functional? Active member of my family, community?
    - How do I do it without quitting my job and breaking the bank?
  - Is my daughter at risk? → is that endo?
  - What will happen to me?
  - How will I know if something *\*really\** bad happens to me?
- 
- Detection / Phenotyping
  - Decision making
  - Trajectory prediction

# (Patient | Scientist) → Patient Scientist

- I am
  - Keeping my endo as private as possible (stigma of invisible illness)
  - Keeping my personal and professional life compartmentalized
- I should use my data-science skills to contribute endo research
  - The data I have access to (EHRs, claims) agrees with the gyne and epi views
  - There are patient narratives online, but is this enough to advance knowledge of disease?
  - Are the questions I asked myself as a patient any relevant to current scientific questions?
- I want to do research in endometriosis
  - "Why? Do you have endo?"
  - "You might be too emotionally invested to do good research"
  - "Join the club"

- maybe don't track it if it will make you a hypochondriac / doctors won't understand  
 why track?  
 - to help remember  
 - research  
 - trends  
 - give symptoms to doctor  
 - communicate w/ close friends & family  
 - Sheathe  
 - Answer questions about myself  
 - Communicate w/ doctors?  
 - find what works  
 - communicate w/ close friends & family

What track?  
 Pain  
 Irritability  
 PMDD  
 bleeding?  
 Birth control  
 Food? - sugar, dairy, temperature  
 time in bed  
 Endo belly  
 Alcohol  
 Smell  
 Digestion  
 Urinary issues  
 Sleep  
 Mental stress  
 Muscu  
 Throwing up  
 Certain exercises  
 Family members w/ endo  
 Sex?  
 Relationship Problems?  
 uterus, cervical

Questions  
 How does it come about?  
 Better diagnosis, way to communicate doctors  
 How tracked?  
 Mentally  
 Calendar  
 My fitness pal  
 Period trackers  
 didn't like

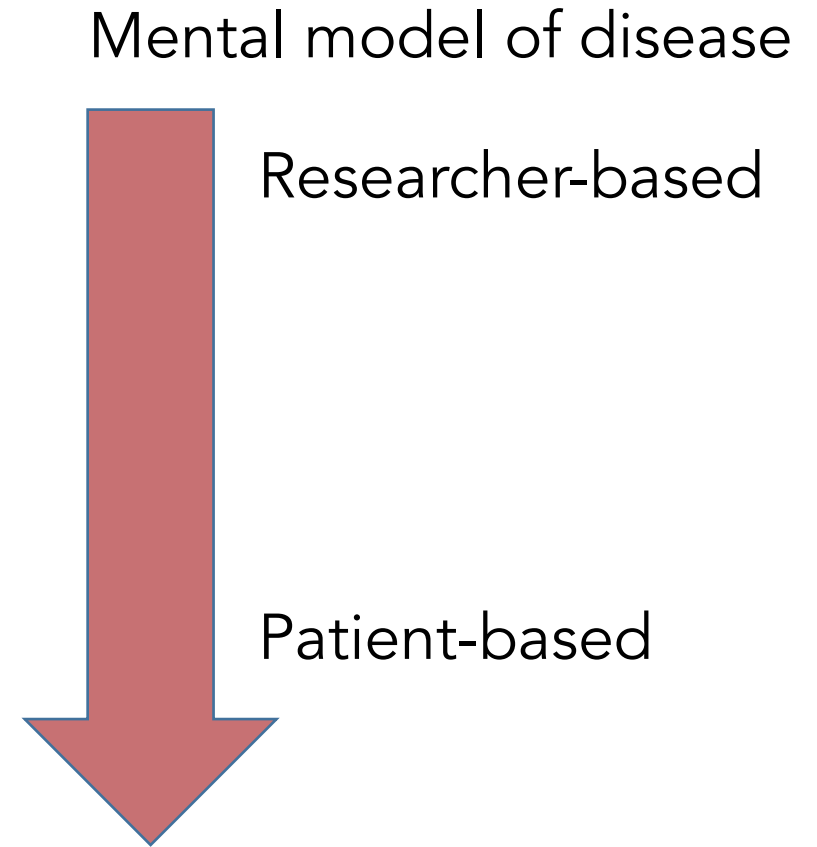
Symptoms/features  
 leg pain, numbness  
 Nauseas, headaches  
 Cramps  
 temporal data  
 fever  
 Cold  
 digestion problems, IBS symptoms  
 length  
 emotions  
 diet  
 bloating  
 Night Sweats  
 breast tenderness  
 Flow  
 Tools  
 Paper app  
 Keeping it in your hand  
 Obstacles  
 time  
 Can be depressing  
 Can get busy  
 Can be overwhelming  
 treatment  
 Yoga  
 Stretching / rollers  
 Medications  
 Why track  
 predict  
 plan  
 how you feel  
 Communicate with doctor  
 Patterns  
 Urination frequency  
 fatigue  
 skin

What to track  
 - food triggers (and alcohol)  
 - track a trigger (eg sex)  
 - menstrual cycle  
 - exercise (type)  
 - stress  
 - GI  
 - fertility vs age groups is  
 - location  
 - scale  
 - time  
 - trigger  
 Why not track?  
 - depressing to see pain every day  
 - predictable patterns  
 - too depressed to track  
 - hard to tell what is useful to track when no diagnosis  
 - when not diagnosed, normalization of symptoms  
 How track  
 - Notes app  
 - App  
 - Google Docs  
 - Journaling  
 other types of pts  
 - migraine  
 - endo belly  
 - urinary  
 - fatigue  
 - medical procedure test  
 - drs  
 - infections or comorbidities  
 - treatments or all

Features  
 Education  
 Advice, opinions  
 Reminders  
 coping tips  
 how to manage  
 health app  
 How to track  
 Vital's  
 doctor reviews  
 which doctors I've seen  
 Glow  
 fit bit  
 PTSD app  
 Calones, diet  
 My endo team  
 head  
 google sheet / calendar  
 apps?  
 no ads  
 no pictures  
 no sound rules  
 treating me as a whole  
 difficult w/ tracking  
 amonging burdens  
 privacy balance  
 What to track?  
 leaky gut  
 comorbidities  
 secondary symptoms (thyroid)  
 Sleep  
 mood  
 condition  
 reflect history  
 what I like  
 more specific on what to track  
 list of symptoms  
 less work inputting data  
 tracking symptoms  
 reduce burden of managing doctors that understand (not many!)  
 be clear with how into things used?

What to track  
 diet  
 work stress (change in general)  
 Pain  
 treatments  
 exercise  
 fatigue  
 Sex  
 digestion?  
 Urination?  
 Sleep  
 Everyone is different!  
 track symptoms regularly  
 Symptom Tracking  
 use mlt calendar  
 period tracker apps  
 Google, Excel spreadsheets  
 track irregular bleeding  
 pain  
 endo belly  
 bloating  
 digestive symptoms, urinary symptoms  
 apps I use  
 Fitness app  
 my fitness pal, map my run  
 iphone health app  
 medications  
 Google fit  
 close

- Interviews (n=3)
- Focus groups (n=27)
- Online surveys (n=741)
- Content analysis of online endometriosis community (1,500 posts)



## Exploring Self-Tracking as a Participatory Research Activity Among Women with Endometriosis

By [Mollie McKillop](#), [Natalie Voigt](#), [Rebecca Schnall](#) and [Noémie Elhadad](#)

CHI 2018 Paper

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

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

**Mollie McKillop, MPH, MA**  
Columbia University  
New York City, USA  
[mm4234@cumc.columbia.edu](mailto:mm4234@cumc.columbia.edu)

**Lena Mamykina, PhD**  
Columbia University  
New York City, USA  
[om2196@cumc.columbia.edu](mailto:om2196@cumc.columbia.edu)

**Noémie Elhadad, PhD**  
Columbia University  
New York City, USA  
[noemie.elhadad@columbia.edu](mailto:noemie.elhadad@columbia.edu)

#### 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

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].

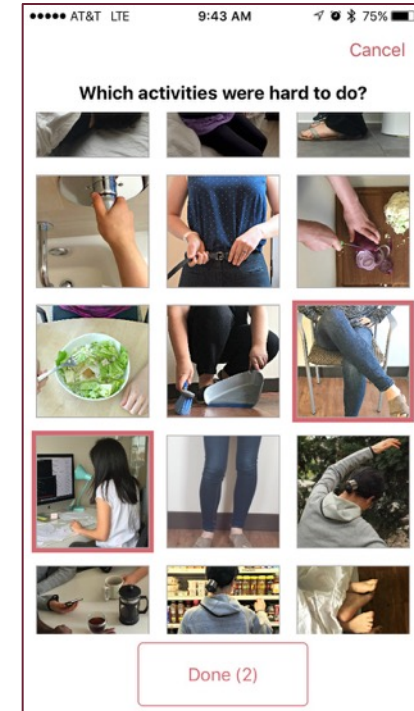
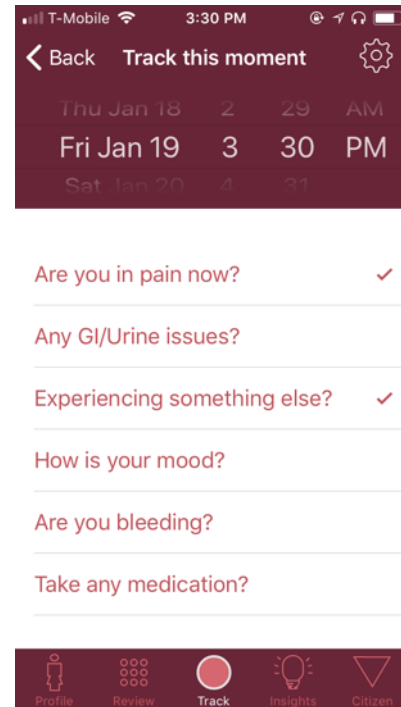
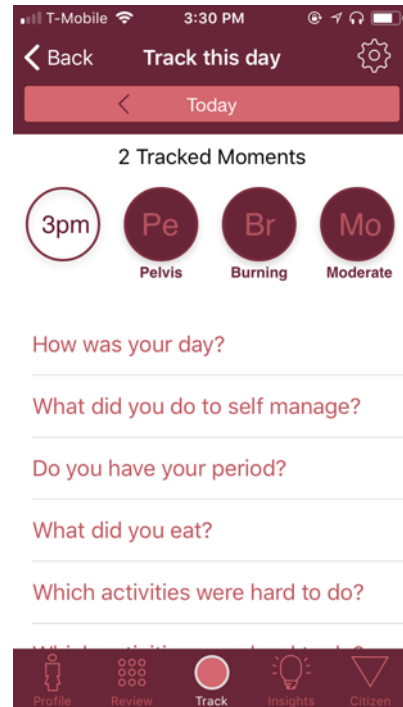
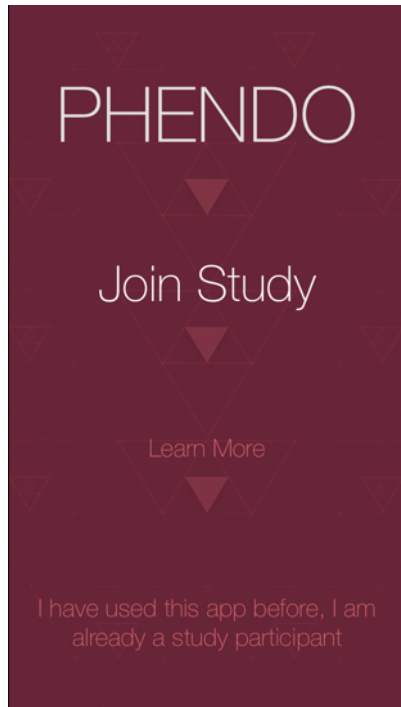
# Citizen Endo (citizenendo.org)

- Community
- Meetups, “challenges”
- Email > Instagram > Facebook & Twitter
- Patient advocacy

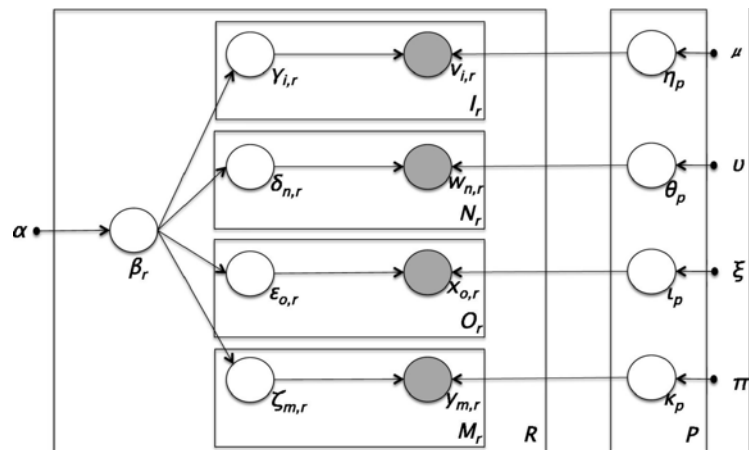
# Citizen Endo



- A research self-tracking app



# Learning from self-tracked data



Proceedings of Machine Learning for Health Care 1–22, 2018

Machine Learning for Health Care 2018

## Phenotyping Endometriosis through Mixed Membership Models of Self-Tracking Data

**Iñigo Urteaga**

*Department of Applied Mathematics  
Columbia University, New York, NY, USA*

INIGO.URTEAGA@COLUMBIA.EDU

**Mollie McKillop**

*Department of Biomedical Informatics  
Columbia University, New York, NY, USA*

MM4234@CUMC.COLUMBIA.EDU

**Sharon Lipsky-Gorman**

*Department of Biomedical Informatics  
Columbia University, New York, NY, USA*

SRG2128@CUMC.COLUMBIA.EDU

**Noémie Elhadad**

*Department of Biomedical Informatics  
Columbia University, New York, NY, USA*

NOEMIE.ELHADAD@COLUMBIA.EDU

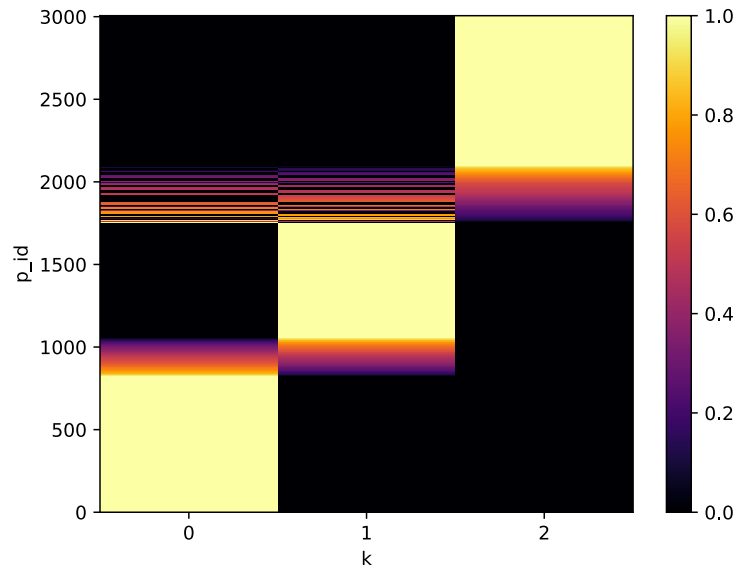


### Abstract

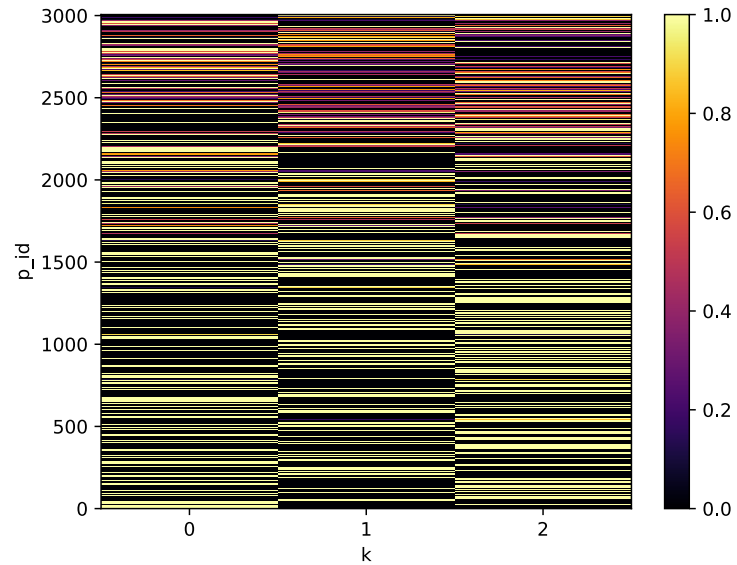
We investigate the use of self-tracking data and unsupervised mixed-membership models to phenotype endometriosis. Endometriosis is a systemic, chronic condition of women in reproductive age and, at the same time, a highly enigmatic condition with no known biomarkers to monitor its progression and no established staging. We leverage data collected through a self-tracking app in an observational research study of over 2,800 women with endometriosis tracking their condition over a year and a half (456,900 observations overall). We extend a classical mixed-membership model to accommodate the idiosyncrasies of the data at hand (i.e., the multimodality of the tracked variables). Our experiments show that our approach identifies potential subtypes that are robust in terms of biases of self-tracked data (e.g.,



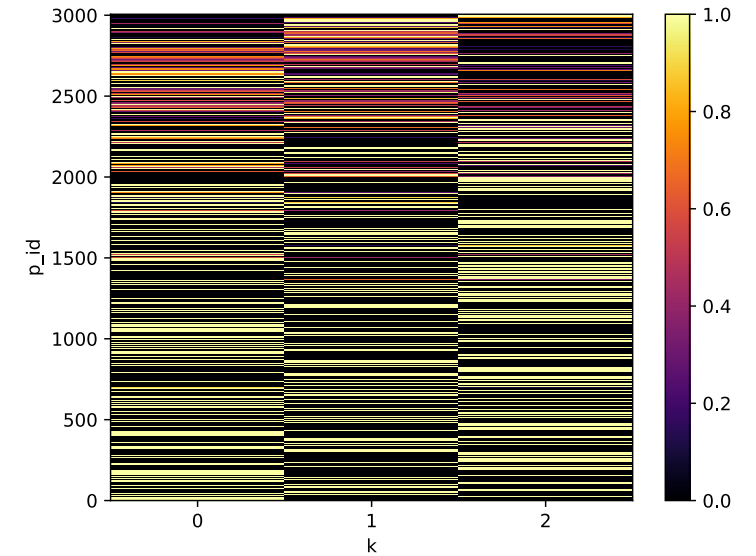
# Learning from self-tracked data



Participants ordered by phenotype assignments



Participants ordered by number of days tracked



Participants ordered by number of observations tracked

# Patient questions beyond phenotyping

- Role of menstruation and hormones?
- Role of environment?
- Is there a connection between endo and X?
- How do I know whether I am getting sicker?
- How do I help my care team take care of me?

*“I cannot tell what’s possible scientifically, so it’s hard for me to tell whether my questions make sense, but I have so many”*

## Narrative Medicine

### A Model for Empathy, Reflection, Profession, and Trust

Rita Charon, MD, PhD

**M**S LAMBERT (NOT HER REAL name) is a 33-year-old woman with Charcot-Marie-Tooth disease. Her grandmother, mother, 2 aunts, and 3 of her 4 siblings have the disabling disease as well. Her 2 nieces showed signs of the disease by the age of 2 years. Despite being wheelchair bound with declining use of her arms and hands, the patient lives a life filled with passion and responsibility.

"How's Phillip?" the physician asks on a routine medical follow-up visit. At the age of 7 years, Ms Lambert's son is vivacious, smart, and the center—and source of meaning—of the patient's world. The patient answers, Phillip has developed weakness in both feet and legs, causing his feet to flop when he runs. The patient knows what this signifies, even before neurologic tests confirm the diagnosis. Her vigil tinged with fear, she had been watching her son every day for 7 years, daring to believe that her child had escaped her family's fate. Now she is engulfed by sadness for her little boy. "It's harder having been healthy for 7 years," she says. "How's he going to take it?"

The physician, too, is engulfed by sadness as she listens to her patient, measuring the magnitude of her loss. She, too, had dared to hope for health for Phillip. The physician grieves along with the patient, aware anew of how disease changes everything, what it means, what it claims, how random is its unfairness, and how much courage it takes to look it full in the face.

Sick people need physicians who can understand their diseases, treat their

The effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others. Medicine practiced with narrative competence, called *narrative medicine*, is proposed as a model for humane and effective medical practice. Adopting methods such as close reading of literature and reflective writing allows narrative medicine to examine and illuminate 4 of medicine's central narrative situations: physician and patient, physician and self, physician and colleagues, and physicians and society. With narrative competence, physicians can reach and join their patients in illness, recognize their own personal journeys through medicine, acknowledge kinship with and duties toward other health care professionals, and inaugurate consequential discourse with the public about health care. By bridging the divides that separate physicians from patients, themselves, colleagues, and society, narrative medicine offers fresh opportunities for respectful, empathic, and nourishing medical care.

JAMA. 2001;286:1897-1902

www.jama.com

medical problems, and accompany them through their illnesses. Despite medicine's recent dazzling technological progress in diagnosing and treating illnesses, physicians sometimes lack the capacities to recognize the plights of their patients, to extend empathy toward those who suffer, and to join honestly and courageously with patients in their illnesses.<sup>1,2</sup> A scientifically competent medicine alone cannot help a patient grapple with the loss of health or find meaning in suffering. Along with scientific ability, physicians need the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf. This is narrative competence, that is, the competence that human beings use to absorb, interpret, and respond to stories. This essay describes narrative competence and suggests that it enables the physician to practice medicine with empathy, re-

flection, professionalism, and trustworthiness.<sup>3</sup> Such a medicine can be called *narrative medicine*.

As a model for medical practice, narrative medicine proposes an ideal of care and provides the conceptual and practical means to strive toward that ideal. Informed by such models as biopsychosocial medicine and patient-centered medicine to look broadly at the patient and the illness, narrative medicine provides the means to understand the personal connections between patient and physician, the meaning of medical practice for the individual physician, physicians' collective profession of their

**Author Affiliation:** Division of General Medicine, College of Physicians and Surgeons of Columbia University, New York, NY.

**Corresponding Author and Reprints:** Rita Charon, MD, PhD, Division of General Medicine, College of Physicians and Surgeons of Columbia University, P4-9-East, Room 105, 630 W 168th St, New York, NY 10032 (e-mail: rac5@columbia.edu).

**The Patient-Physician Relationship Section Editor:** Richard M. Glass, MD, Deputy Editor.



## EDITORIALS

### Better together: patient partnership in medical journals

The BMJ's experience can be a springboard for others

Tessa Richards *senior editor, patient partnership*, Sara Schroter *senior researcher*, Amy Price *patient editor*, Fiona Godlee *editor in chief*

The BMJ, London, UK

The BMJ has had patient editors for over 20 years, and they have brought a new dimension to our work and thinking. None more so than the peerless Rosamund Snow.<sup>1</sup> But her predecessors left their mark too, including Peter Lapsley, who 10 years ago underlined that "patients have more to contribute to the BMJ than simply [recounting] their experience of illness and treatment."<sup>2</sup> He died before we launched our revolutionary patient partnership strategy,<sup>3</sup> but he would have welcomed the changes it has brought to our editorial processes and the movement, supported by patients,<sup>4</sup> now spreading to other journals.

Our strategy was co-produced with an international patient advisory panel and continues to be co-steered by them. The lively exchanges with and between panel members and *The BMJ* staff, moderated by the journal's patient editors, raises editorial awareness of patient led initiatives and issues that matter to patients and carers and informs commissioning decisions across the journal. Panel members are often among the first to comment on articles, and many patients and their linked communities follow and respond to our Twitter feeds and debates.

The database we have built to embed patient review of submissions alongside peer review has grown steadily. We refer to people who help us in this way as "patient and public reviewers." This acknowledges that although most reviewers have long term conditions, some are carers, parents, those who access services only intermittently and don't think of themselves as patients, and members of health related charitable and voluntary organisations. Similarly, our patient panel includes health professionals and policy experts who champion patient empowerment and shared decision making. Accordingly, our strategy has been renamed a "patient and public partnership" strategy, a terminology now in common use among other organisations.

The requirement introduced four years ago that authors of research in *The BMJ* must report if and how they involved patients and the public in their studies<sup>5</sup> supports growing advocacy to embed partnership in the global research enterprise. Other journals now requiring a "PPI" (patient and public involvement) statement include *BMJ Open*, *BJOG*, *Research*

*Involvement and Engagement*, and several leading titles in BMJ's portfolio of specialist journals. We recently pledged to advance debate on establishing new tenets to govern patients' roles and rights in research.<sup>6</sup>

Content written and co-written by patients—including BMJ Opinion, the What Your Patient is Thinking series,<sup>7</sup> commentaries, and editorials—provides valuable insights, not least into the reality of care at the sharp end and ideas on how to improve it. Podcasts about organisations advancing partnership and the Partnership in Practice series<sup>8</sup> aim to fulfil our pledge to illuminate the "science and art" of partnership in clinical practice, policy, and medical education.

Although we set internal targets for co-production of content, we recognise that chasing numbers is not enough. It is the quality and timeliness of the input that matters most. For our educational content we have clarified our guidance on co-production of articles to support authors.<sup>9</sup> Co-production and review of educational articles by patients and carers provide a wider understanding of living with illness and its biopsychosocial impact, which is often unrecognised or poorly understood by health professionals. We are now spreading the principles of co-production across BMJ's learning and clinical decision support resources.

The campaign to include patients in medical meetings, initiated by Lucien Engelen in 2013, has been a notable success. Organisers of conferences now regularly self accredit as #PatientsIncluded. *The BMJ* has made strides here, notably in the International Quality and Safety in Healthcare forums, and is committed to identifying best practice and avoiding tokenism.<sup>10</sup> Having patients on organising committees is crucial. Patients and patient advocates also routinely sit on the judging panels for the BMJ Awards.

Evaluation of a strategy that is as much about changing hearts and minds as practice and policy is not easy, but we are making progress. A comparison of PPI reported in research papers published in *The BMJ* before and one year after the introduction of our PPI reporting policy showed an increase, albeit a small one.<sup>11</sup> Peer review by patients and the public has been shown to be feasible, and editors think it adds value.<sup>12</sup> A survey of reviewers<sup>13</sup> showed that they welcome being part of the editorial

Correspondence to: T Richards trichards@bmj.com @tessa@richards

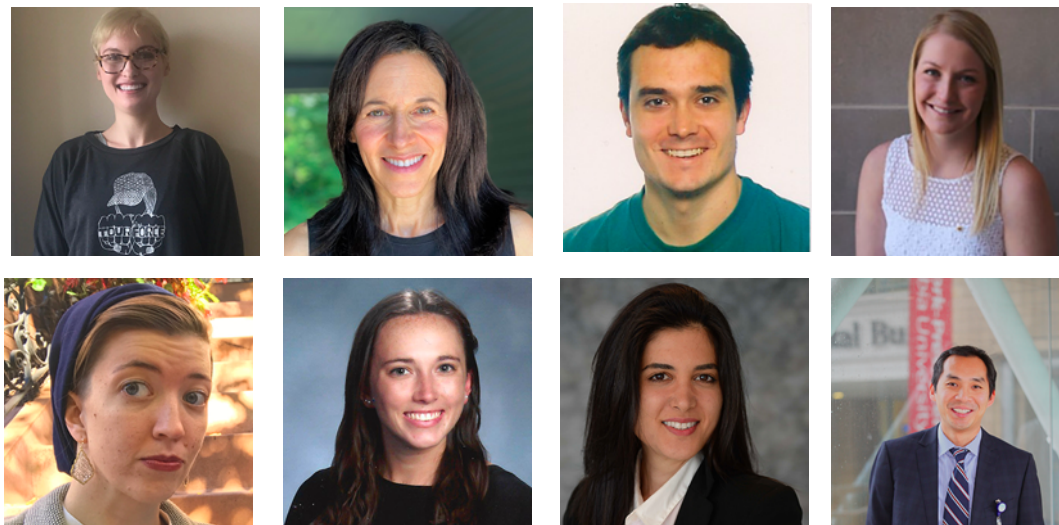
For personal use only. See rights and reprints <http://www.bmj.com/permissions>

Subscribe: <http://www.bmj.com/subscribe>

Participatory Medicine  
Citizen science  
Human Centered Computing  
Patient entrepreneurs

- Patients and scientists each contribute to advancing medicine in complementary ways
- Go beyond existing datasets and convenient questions that can be answered just because of availability of current datasets
- Partner with patients
  - Observe them, learn from their experiences, but also their questions and ideas
  - Develop a common language
  - Feed your results back to patients
  - Iterate

# Thank you!



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