

“I am not alone in this”:
Co-managing stigmatized chronic
health conditions

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COLLEGE OF
INFORMATION
STUDIES

Motivation

- Common practice of involving others in chronic health management
- Existing work on:
 - Online health support
 - Formal caregiver support
 - Informal elder care
- Gap: **Informal collaboration** within close circles to manage **stigmatized chronic health conditions**



Image Source: <https://www.gograph.com/illustration/helping-the-sick-gg63067065.html>

My previous work

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In previous study on understanding people's lived experiences with Polycystic Ovary Syndrome (Chopra et al., 2021):

- Observed people **managing PCOS with close ones** (e.g., parents, partners, friends)
- Found **stigma** to:
 - Shape people's communication & support-seeking practices
 - Impact people's collaboration decisions

What is “co-management” of health?

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- **Informally share responsibility of health management** with people in close circles.
- Work closely with “co-managers” to **perform concrete health management tasks**
- NOT a formal set-up
- Practices and choices of co-managers influenced by **stigma**

Why is co-management important to study?



Every day I have 32 different doses of medications, vitamins and supplements and stuff like that, I think there's about 32 of them total that I spread out during the day and those help but I'm still in pain all the time.... Which is really, really hard with my 6-year old son. But luckily, my husband is very helpful with that. There's a lot of stuff on a bad day my husband does... everything from helping me walk to the bathroom to helping me get dressed. Some days, I can do it myself but he's been a big part of managing my symptoms and everything.... And the really hard part is it's hard to get anything done to begin with because the medications that I'm on make me so tired...

(P5; Chronic conditions: Crohn's disease, fibromyalgia, chronic migraines, inflammatory neuropathy, rheumatoid arthritis, PCOS, depression, anxiety, bipolar disorder)



Why is co-management important to study?

- **Lifelong nature** of chronic conditions, cannot just stop doing daily activities
- **Constant monitoring** and **management** needed
- Support from close ones on everyday tasks can go a long way

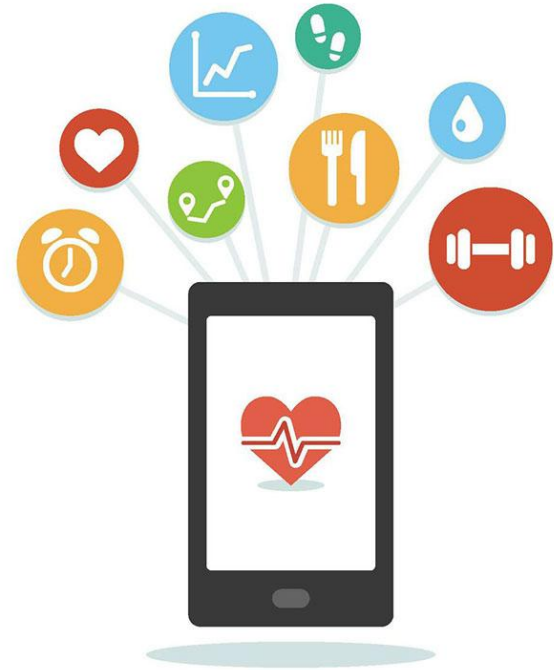


Image Source: <https://www.universityofcalifornia.edu/news/5489/patient-test-thyself>

Why is co-management important to study?



I just turned 29, and I'm using a cane already. I get a lot of people looking at me, like, I'm contagious, or something. A lot of times riding the subway, I go towards the disabled seats and people will just look away like I'm not there.

Most often a friend I'm with will do something. She'll go up and ask for someone to give me a seat. I'm not great at talking to people generally, especially if it's in that kind of a context where they don't want to acknowledge that I'm there.

My friends often will advocate for me when I'm not comfortable doing it myself.

(P12; Chronic conditions: Ehlers-Danlos syndrome, asthma, depression, anxiety)



Why is co-management important to study?

- **Lifelong nature** of chronic conditions, cannot just stop doing daily activities
- **Constant monitoring** and **management** needed
- Support from close ones on everyday tasks can go a long way
- **Stigma** impacts health management & self-view
- Effect of **stigma** on informal collaboration in health is understudied

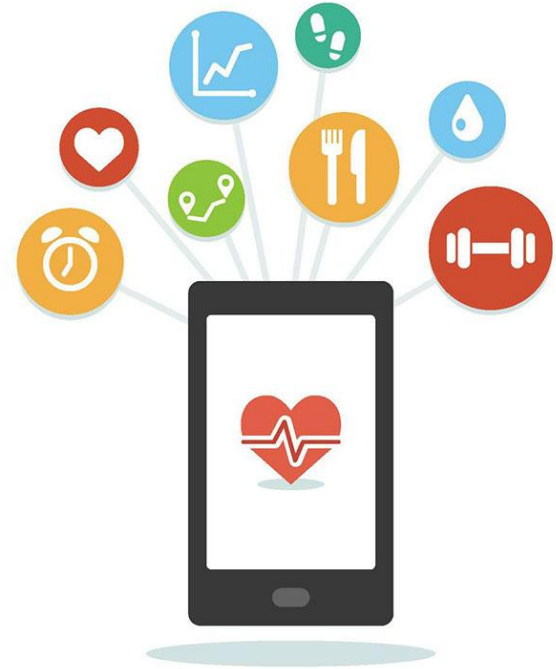


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PAST RESEARCH

Designing for stigmatized health topics

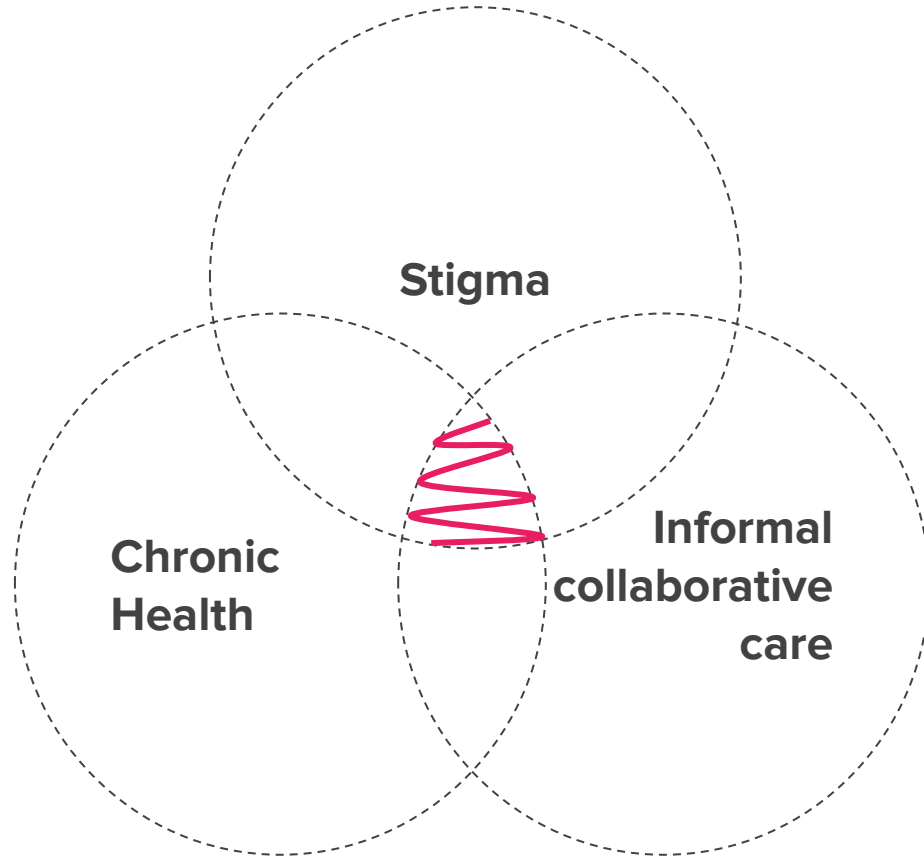
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- Wide range of topics:
 - Menstruation (Tuli 2019, Tuli 2020, Campo Woytuk 2020), Menopause (Lazar 2019, Tutia 2019, Bardzell 2019), HIV (Stutterheim 2017, Sorcar 2017)
 - **Chronic conditions:** PCOS (Chopra 2021), cancer (Marlow 2014, Almeida 2015), mental health conditions (Choudhury 2014, Andalibi 2015, Sharma 2018)
- Navigating stigma to **seek social support** & **access proper health care**
- Potential of technology to overcome barriers to social support from family & friends around stigmatized conditions (e.g., breast cancer (Skeelz 2010))
- I study the impact of stigma on collaboration and co-management

Collaborative Care & Chronic Health Management

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- Sharing health information (Pang 2013, Miller 2016) & care responsibilities (Miller 2016, Berry 2017, Holden 2018)
- Computer-Supported Coordinated Care or CSCC (Consolvo 2004)
 - Design considerations: **emotion, trust & privacy**
- Effect of stigma on informal collaborative care in workplace environments unknown
 - Strategies for disclosure or concealment at the workplace (Ganesh 2021)
- I extend the understanding of coordination & collaborative care to supporting informal collaboration around concrete chronic health co-management tasks in different environments



Research Questions

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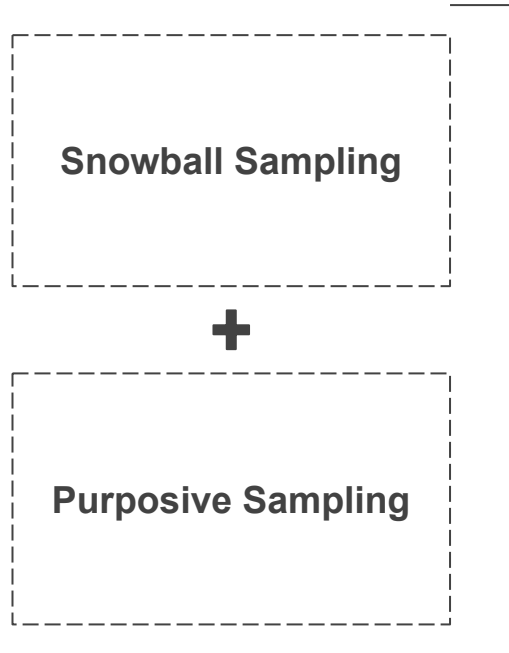
RQ1: How do people living with stigmatized chronic health conditions co-manage their health and daily life activities with people in their close circles?

- How do their experiences with stigma impact their co-management practices, including disclosing, seeking support, and communicating about their health?
- How do their co-management practices vary depending on the space they are in and relationship they share with co-manager(s)?

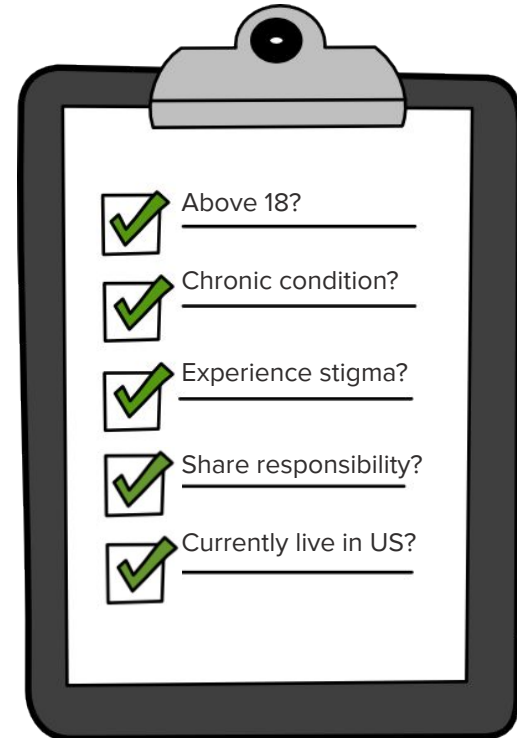
RQ2: How do existing tools and technologies facilitate people's varying co-management needs within different environments (e.g., workplace vs home, virtual vs co-located living)?

METHODOLOGY

Participant Recruitment & Screening



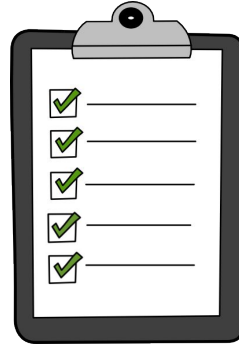
- Electronic means:
 - ◆ Listserv
 - ◆ FB groups
 - ◆ Twitter
 - ◆ Reddit
- Word of mouth



Participant Details



39



17



16

- PCOS
- POTS
- Endometriosis
- Narcolepsy
- Cataplexy
- TMJ disorder
- EDS
- IBS
- Sleep apnea
- Rheumatoid arthritis
- Crohn's disease
- Fibromyalgia
- Chronic migraines
- PTSD
- Bipolar disorder
- Anxiety
- Depression

In-Depth Interviews & Analysis

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- Interviews:
 - One-on-one
 - Duration: 35-60 minutes
- Interview focus:
 - Participants' co-management practices
 - Impact of stigma
- Analysis:
 - Thematic analysis
 - Open + Axial coding

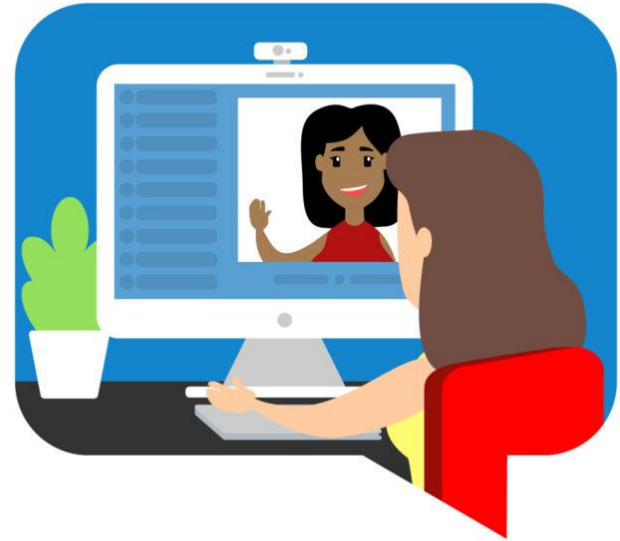


Image Source: <https://blog.editors.ca/?p=6799>

FINDINGS

Findings

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- Disclosure to facilitate co-management in the workplace (RQ1)
- Management and coordination in the living space (RQ1)
- Virtual co-management support (RQ1)
- Co-manager's awareness and engagement (RQ1)
- Technological and physical means to facilitate co-management (RQ2, RQ1)

Findings

- Disclosure to facilitate co-management in the workplace (RQ1)
- Management and coordination in the living space (RQ1)
- Virtual co-management support (RQ1)
- Co-manager's awareness and engagement (RQ1)
- Technological and physical means to facilitate co-management (RQ2, RQ1)

Disclosure to facilitate co-management in the workplace

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- Reasons to disclose:
 - To seek & negotiate reasonable accommodation
 - Co-worker's inquiries
- Reasons to NOT disclose:
 - To stay employed
 - To not be seen as incapable of working
 - Discomfort from past negative experiences
 - Condition felt very personal
 - Didn't feel the need to disclose



Image Source: <https://www.workforcesoftware.com/blog/leave-as-reasonable-accommodation/>

Disclosure to facilitate co-management in the workplace

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More positive impacts:

- Receiving reasonable accommodation (P1, P4, P9, P10)
- Finding understanding workplace co-managers (P1, P7, P9, P10)



I've gotten really sick on the bike path, like travelling to school before and I'll just sort of like send an SOS at people and be like, 'Hello, like, I've kind of collapsed on the bike path. Can someone please come help me?' My colleague actually ended up running out to come get me since he knew where I was.

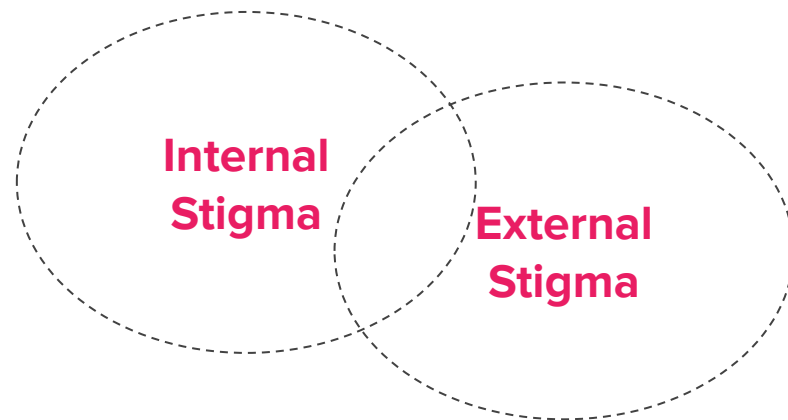
(P1; chronic condition: POTS)



Disclosure to facilitate co-management in the workplace

Address stigma and misunderstandings:

- **External stigma:** Advocate for patient's needs
- **Internal stigma:** Empathize and empower



Surrounding myself with people who get it is definitely helpful and makes me feel less stigmatized, less down, less depressed, makes me feel like I can be more of like, you know, a healthy human being.

(P1; chronic condition: POTS)



Management & coordination in the living space

Physical tasks & active service:

- Bringing medications
- Making food
- Taking for doctor appointments
- Providing physical comfort
- Driving
- Showering

Participant ID	Co-manager(s)	Currently living with at least one co-manager?
P1	Partner, labmates/work colleagues	Yes
P2	Mother, few close friends	No
P3	Mother, work colleagues	No
P4	Parents, sister, best friend	Yes
P5	Husband, grandparents, husband's family	Yes
P6	Close friend	Yes
P7	Mother, partner, work colleague	Yes
P8	Parents	Yes
P9	Wife, children, work colleagues, local friends	Yes
P10	Bible study group	No
P11	Partner, sister, some family members	Yes
P12	Best friend	No
P13	Partner, mother, few close friends	Yes
P14	Best friend, childhood friend	No
P15	Mother, brother	No
P16	Roommate, few close friends	Yes

Management & coordination in the living space

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Emotion support in form of physical actions



I believe that if it wasn't for my partner, I probably wouldn't eat like three square meals a day. Um, I don't do very well on like feeding myself all the time due to the stress and anxiety

(P13; chronic condition: PTSD, OCD, anxiety, depression)



Management & coordination in the living space

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Receiving help without having to ask for it



My dad is great at like being in the background and seeing where holes are, or like seeing where needs aren't being met, and just swoop in and take care of those, even if I don't necessarily realize that I need help with something.

(P8; chronic condition: Endometriosis, PCOS, POTS, GAD, depression)



Management & coordination in the living space

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- Feeling guilty asking for help
- Not ask for help unless absolutely necessary
- Ease burden off co-managers
 - Coordination
 - Keeping them informed

Physical & technological means of co-management

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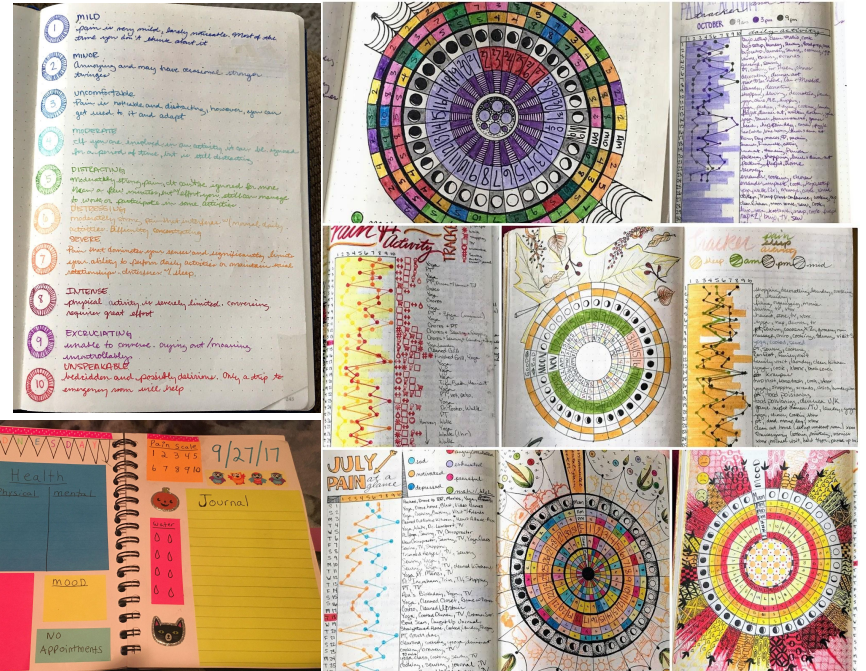
Health tracking and collaborative sense-making

- Very **hands-on** co-management
- Co-manager **observes, tracks & assesses** patient's health
- Tools used:
 - **Physical tools:** paper-based calendar (P2), journal (P5), notepad (P16)
 - **Digital tools:** Excel spreadsheet - Jupyter Notebook combination (P1)

Physical & technological means of co-management

Physical tools

- Advantages:
 - Good for taking detailed notes
 - Easy to provide contextual information
 - Easy to track individually & analyze collaboratively
- Disadvantages:
 - Static data
 - Not easy to compare things
 - Not easy to visualize differently



Physical & technological means of co-management

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Digital tools

- Advantages:
 - Dynamic data & visualizations
 - Easy to compare different parameters
 - Easy to create different visualizations using same data
- Disadvantages:
 - Not used much?



Image Source: Google Images

DISCUSSION

Workplace disclosure & co-management strategies

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- Inviting open discussions to improve awareness among employees & reduce misunderstandings
- Encouraging disclosure during orientation periods
 - **Challenge:** becoming the poster child (e.g., P9 the “Narcoleptic Lawyer”).
- **Selective disclosure** within specific work teams
- Training materials to **educate employees** & devise workplace co-management strategies
- Recognizing chronic health co-managers as **allies** & designing to support allyship

Digital coordination & collaborative health monitoring tools

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- Shared-space digital coordination tools (e.g., digital whiteboard, shared tablet)
 - Both patients & co-managers can contribute
 - Scribble notes, add reminders, create events, etc
 - Reduce planning & coordination burden on co-managers
 - Customized encoding of information
 - Selective visibility, password/biometric-protection
- Collaborative tracking & health monitoring tools
 - Add collaborators & share varying amounts of information
 - Allow co-managers to add notes & observations
 - Hide individually tracked data till ready to collaboratively make sense of it

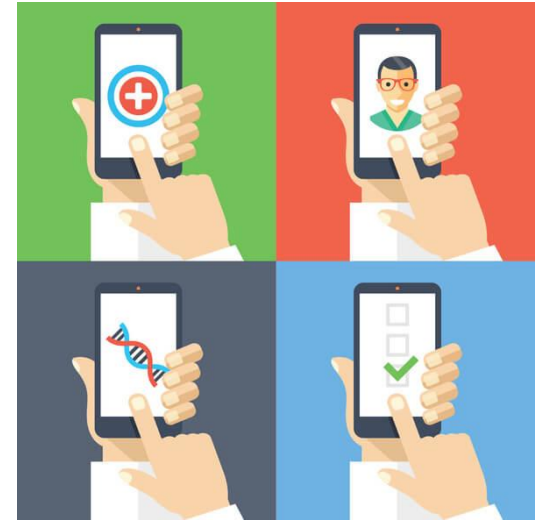


Image Source: Google Images

Main Contributions

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- A detailed account of people's experiences with co-managing their stigmatized health conditions
- Design recommendations & future research opportunities:
 - Workplace disclosure & co-management
 - Shared-space coordination & collaboration
 - Collaborative tracking & health monitoring
- Contextualization of my findings in light of past works, contributing to HCI and CSCW research on designing for stigmatized health topics, chronic health management & collaborative care.

THANK YOU

Any questions?



COLLEGE OF
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STUDIES

