

# Kristine Bissenbakker

- **Who Am I?**
- Ph.d. student from Copenhagen University
- **Why am I here?**
- To learn more about the possibilities of wearables in primary health care in the US as research to my project
- **What do I do**
- A study about the use of wearable technology in the danish primary health care



# Patti Brennan, RN, PhD

- Who Am I?
  - Moehlman Bascom  
Professor University of  
Wisconsin-Madison
  - Director-designee,  
National Library of  
Medicine
- Create & evaluate innovative  
computer technologies for  
self-management
- Use VR to figure out how  
home environments shape  
health info management
- Why am I here/What  
do I want to get out of  
the meeting?

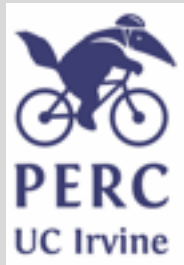
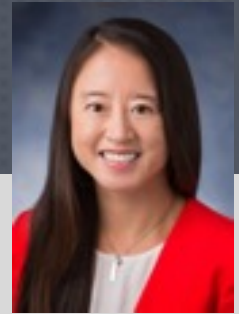


# Clara Caldeira

- Who Am I?
  - UC Irvine
  - PhD student
- Why am I here/What do I want to get out of the meeting?
  - Learn about other research on health data
- What do I do?
  - Research on the health management of older adults
  - Particularly monitoring and self-tracking



# Jen Jen Chen



- Who Am I?
  - Pediatric Pulmonologist
  - Asst Clinical HS Professor at UCI
  - MIDS Candidate UC Berkeley

- Why am I here?

To understand what a  
physicians' role is in data >  
medicine

- What can I do ?

Run exercise tests, do a  
bronchoscopy, and write a  
program in Python that  
answers in pig latin

# Emil Chiauzzi

## Who Am I?

PatientsLikeMe  
Research Director

## Why am I here?

Consider multiple perspectives for encouraging patient health data donation

Consider ways in which patients can increase their participation in the conduct of research

Consider ethical and practical research issues associated with the multiple sources of PHD (genomic, devices, EMR, etc.)

Learn what others have been working on!

## What do I do?

Conduct & supervise research on crowdsourced and other patient-centered data

Design studies that maximize patient participation throughout the research life cycle

Innovate ways in which patients can apply device-based PHD to self-management and behavior change



# Eun Kyoung Choe

- Who Am I?
  - Assistant Professor at Penn State, College of Information Sciences and Technology
- Why am I here?
  - Excited about personal data and personal data visualization for identifying insights and data sharing
  - Hope to find collaborators, especially clinicians and behavioral scientists
- What do I do?
  - HCI, Health Informatics
  - Semi-automated tracking tools for patients
  - Personal data visualization platform
  - Intergenerational collaborative health tracking



Visualized Self



Health Data  
Exploration project

PERSONAL DATA FOR THE PUBLIC GOOD



# Thomas Blomseth Christiansen

- Who am I?
  - Self-tracker & technologist
  - Active self-tracking
  - Co-founder of TOTTI Labs  
(Previously: Co-founder of Mymee)
- What do I want get out of the meeting?
  - Meet people with an interest in data on subjective experience like emotions, sensations, symptoms etc.

- What do I do?
  - Build self-tracking technology for ***observations of subjectively perceived phenomena*** w/Jakob Eg Larsen



# Emme Clark

- Who Am I?
  - Founder and designer of Correlate App for Acne
- What do I want to get out of the meeting?
  - Looking for:
    - researchers in dermatology
    - developers looking for an interesting project
    - data scientists who want to help bridge the gap between patient observations and doctor expertise
  - Have discussions with anyone passionate about the same mission
- What do I do?
  - Help people find which acne treatments works for them
  - Legitimize patient expertise, by helping patients frame their observations in more scientifically sound ways





# Aaron Coleman

- *Who Am I?*
  - Fitabase
  - Founder & CEO
- *Why am I here/What do I want to get out of the meeting?*
  - I'm here mostly to listen. I'd love to connect with anyone interested in how sensors can better be used in research.
- *What do I do?*
  - I lead the Fitabase project. We're helping bridge the gap between consumer wearables and researchers. We provide powerful dashboards, analytics and data tools.

fitabase



# Maggie Crawford

I am a:

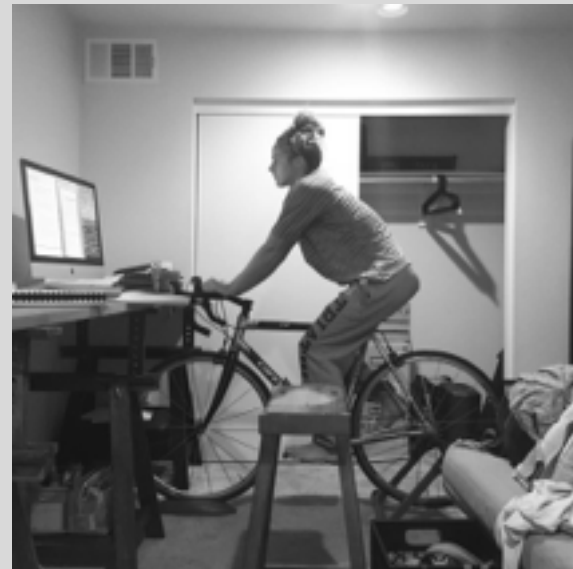
- UCSD PhD student in Public Health, Health Behavior
- Person with Type 1 Diabetes

What do I do?

- Analyze data, surf, climb mountains, analyze data

I am here to learn about:

- Current HDE projects
- New methods for collecting and analyzing personal health data



# F.L. Dammann

- Special Projects Lead
  - NIH's National Institute on Alcohol Abuse and Alcoholism
  - Co-lead on the National Search for a non-Invasive Real Time Blood Alcohol Biosensor Wearable
- I facilitate partnerships, projects, and vision to positive outcomes

HIV – 50,000 new cases each year. Annual cost to the United States \$25,320,700,000.00

Heart Disease – \$108 billion annually.

Diseases directly linked to alcohol use - \$57 billion annually.

We want innovators to innovate means for tracking which will open pathways to cures and treatments.



• **[Fl.Dammann@nih.gov](mailto:Fl.Dammann@nih.gov)**

# Satvinder “Pearly” Dhingra

## Public Good Ventures Limited

Founder & CEO

### What We Do

- **Equip** you to digitize and mobilize your health data making it ever more discoverable, valuable and actionable.
- **Enable** you to create a comprehensive, seamless and integrated health record that is accessible any time, any where on any device.
- **Empower** you with data, information and knowledge to participate in research and take a proactive role in your health and well being.
- **Engage** you with family and friends, peers and professionals to learn, share and care for each other.



Save

### Why I Am Here

I believe health is a human right and knowledge is a public good.  
We offer community intelligence platforms for building a culture of health.



Health Data  
Exploration project

PERSONAL DATA FOR THE PUBLIC GOOD

# Margo Edmunds

- Who Am I?
  - AcademyHealth
  - VP, Evidence Generation and Translation
- What do I do?
  - Information infrastructure
  - Health IT policy
  - Telehealth
  - Consumer informatics
- Why am I here?
  - New people
  - New ideas
  - New partnerships
- I tweet:
- @RedWoofers

# Daniel Epstein

- University of Washington
- PhD Student
- Learn about what others are working on in this space
- Share ideas with researchers and practitioners
- Understand and design personal tracking tools to integrate into people's everyday lives and practices

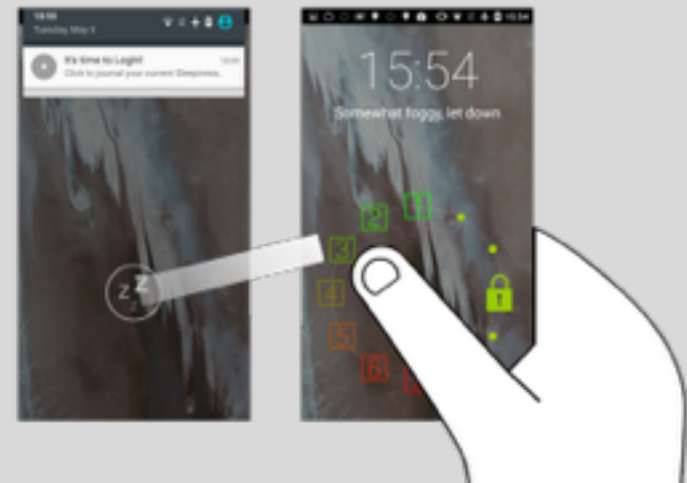
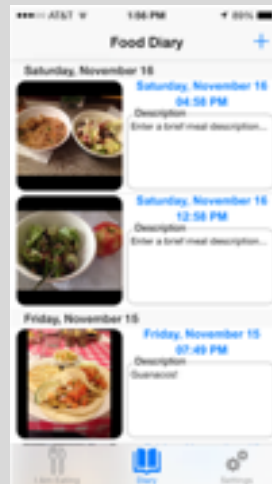




# James Fogarty

Associate Professor  
University of Washington  
Computer Science & Engineering

Self-tracking as everyday  
interaction with personal data



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# Matt Foley

- Hortonworks, Inc.
  - Opensource Big-Data tooling: Apache Hadoop and Apache NiFi software ecosystems
  - Software Engineering Manager and Architect
- What do I do?
  - I log my own health data
  - I have input to Big-Data case studies
  - I want to cure T2D
- Why am I here?
  - to learn
  - to share Opensource Big-Data information
  - to carry the message about PHD for public good



B.-H. Bosnia and Herzegovina  
K. Kosovo  
L. Liechtenstein  
M. Montenegro  
Mac. Macedonia  
S. Slovenia  
S.M. San Marino

Visual & verbal  
thinking &  
communications

Social  
Interaction



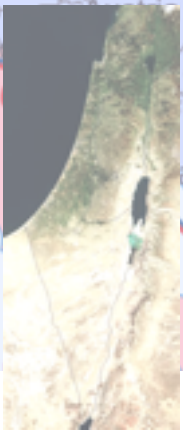
Discovered:  
Humans can't  
live on logic  
alone

**Nahum  
Gershon**  
MITRE  
IEEE

IoT,  
Wearables

Raised as a  
scientist (Johns  
Hopkins, NIH)

Using large  
organizations to  
collect &  
analyze data



**Southeastern  
Europe**

# David Harlow

- Who Am I?
  - THE HARLOW GROUP LLC
  - Digital health lawyer & consultant
- What do I do?
  - Health data privacy, security & more!
  - Digital health strategy
  - Health policy
- Why am I here/ What do I want to get out of the meeting?
  - Learn from smart dreamers & doers
  - Help connect the dots

**HealthBlawg**

@healthblawg



@FlowHealthHQ

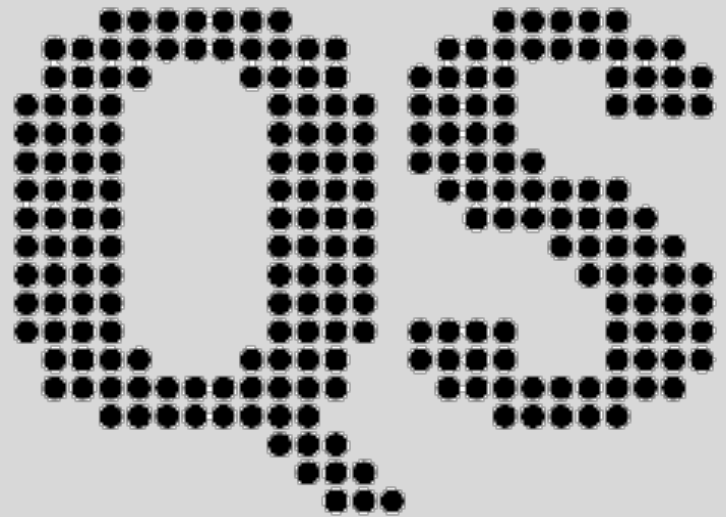
# Jina Huh

- Who Am I?
  - UC San Diego
  - Assistant Professor
- Why am I here/What do I want to get out of the meeting?
  - Learn state of the art QS and personal health data aggregation and analysis
- What do I do?
  - Consumer health informatics
  - Online health communities
  - Socially aggregated knowledge among patients



# Steven Jonas

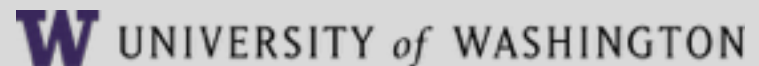
- Who Am I?
  - Quantified Self Labs
  - Senior Editor
- Why am I here/What do I want to get out of the meeting?
  - Get ideas on how to help people use personal data to become smarter about themselves.
- What do I do?
  - Tell stories about people who find meaning from their personal data.





# Matthew Kay

- Who Am I?
  - PhD Candidate at University of Washington
  - Starting Fall 2016: Assistant Professor at University of Michigan School of Information
- What do I do?
  - Human-computer interaction
  - Communicating uncertainty in everyday sensing and prediction (including health sensing)
- Why am I here/What do I want to get out of the meeting?
  - Ideas! Collaborations!



# Julie A. Kientz, Ph.D.

## Who Am I?

- University of Washington
- Human Centered Design & Eng.
- Associate Professor
- HDE Steering Committee

## Why am I here?

- Meet others interested in self-experimentation or family informatics
- Connect with potential partners/ collaborators
- Share research on user burden model and validated measure

## What do I do?

- Understanding and reducing user burden
- Self-experimentation
- Domains: Sleep, food triggers, children's health, families

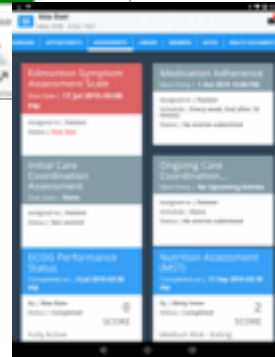
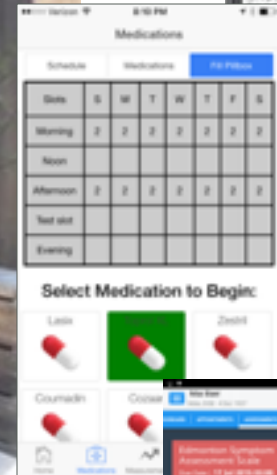


**HCDE** Human  
Centered  
Design &  
Engineering  
University of Washington

**W**  
UNIVERSITY of  
WASHINGTON

**DUB**  
DESIGN USE BUILD

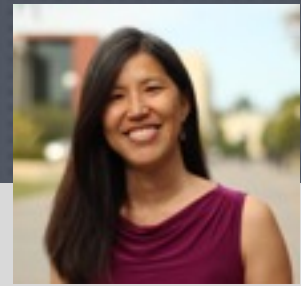
# Katherine Kim



kathykim@ucdavis.edu

UC DAVIS

# Joy Ku



- Dir. of Communication & Engagement, *Mobilize Center, Stanford*
- Goals
  - Learn about efforts related to the sharing of health data, particular wearables
  - Identify potential collaborators
- What do I do?
  - Establish collaborations
  - Building a community to bring physical activity wearables to clinics and research



An NIH Big Data to Knowledge  
Center of Excellence

<http://mobilize.stanford.edu>

# KATE LYDEN, PHD

## Current Positions

### Fossil Group/Misfit Inc.

- Biomedical Research Scientist
  - Design, implement and support research related to physical activity and sleep

### University of Massachusetts, Amherst

- Faculty, Department of Kinesiology



## QS and HDE Network Interests

### “Non-passive” monitoring

- Wearable technology to ENGAGE users in their health and wellness

### Optimizing device functionality for researchers, clinicians and users

- Intersection of Technology and Humanity – A match made in...



# Emily Manoogian, PhD

- Who Am I?

- Salk Institute for Biological Studies
- Postdoctoral Research Fellow working with Dr. Satchin Panda

- Why am I here?

- To learn more about the abilities and limitations of quantified health data.

- What do I do?

- Research from our lab has demonstrated large health benefits of time restricted feeding.
- My research is focused on translating these findings to humans using a smartphone app called MyCircadianClock.



MyCircadianClock is a new type of app that helps you track your body's daily rhythms while contributing to research. This app is part of a research study conducted by Dr. Satchin Panda's lab at the Salk Institute for Biological Research.

Sign up today at  
[www.mycircadianclock.org](http://www.mycircadianclock.org)

salk  
Where cures begin.



# Tracy McMillan, PhD, MPH

Founder & CEO, localeikki

- localeikki helps people be active outside, wherever life takes them

Why am I here?

- To listen, learn, explore, contribute

What do I want?

- To be inspired like last year!



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# Rajiv Mehta, Atlas of Caregiving



- Research & Support Family Caregiving
- Who involved? What activities? What impact?
  - Ethnography + Sensors + Visualization
- Data & Insights — for entrepreneurs, healthcare, policy makers, ...
- Self-empowerment tools — for caregivers



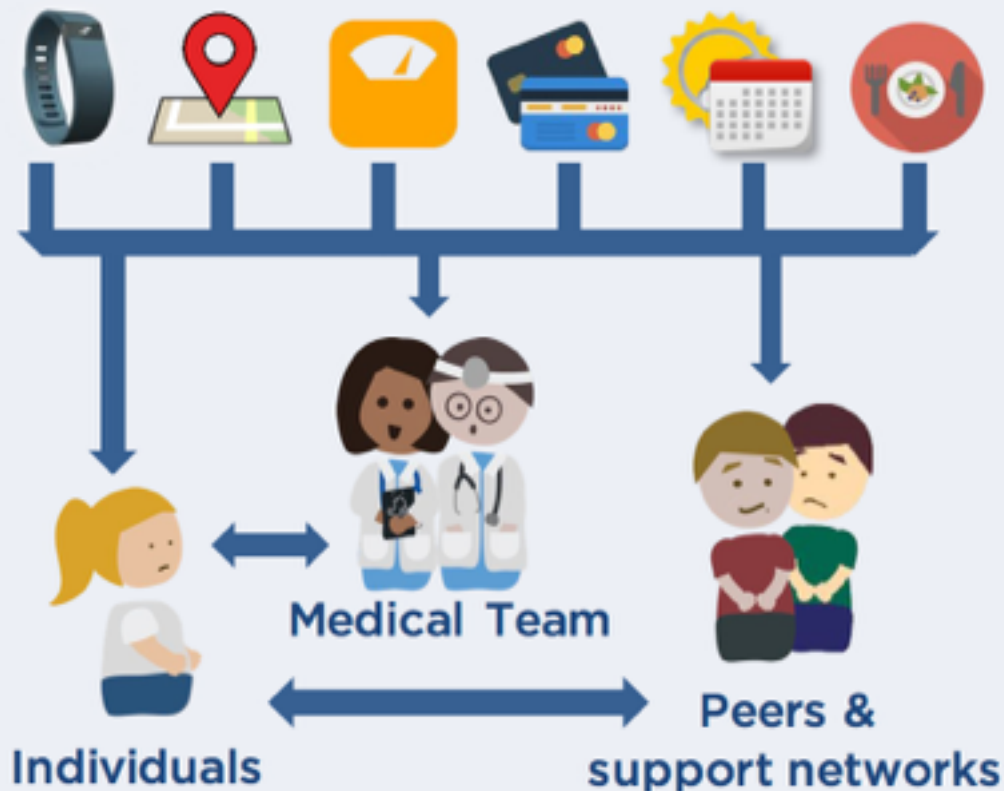
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# David J. Moore, Ph.D.

- Associate Professor
  - Psychiatry
  - UCSD
- Goals
  - Build collaborations
  - Understand new technologies
  - Think about:
    - Behaviors associated with tech
    - How to communicate & change behavior
- HIV Treatment & Prevention Researcher
  - SMS and app interventions to improve medication adherence & other daily behaviors
- Individualized Texting for Adherence Building
  - Believe in engaging content;
  - How do we motivate people to use tech?





Helping people understand and act on their personal data, alone and by collaborating with experts, peers, and their support networks.

# Camille Nebeker



- UC San Diego
- Assistant Professor,  
Principal Investigator

- Here to ...share goals of our CORE (Connected & Open Research Ethics) initiative
- I want...HDE and QSPH stakeholders to value and contribute to the CORE community conversation!

Research methods have never been more sophisticated – or more complicated.

Be part of the solution. Join the CORE.

- Resource Library
- Q&A Forum
- Stakeholder Network

# CORE

Connected and Open Research Ethics

[thecore.ucsd.edu](http://thecore.ucsd.edu)

[thecore@eng.ucsd.edu](mailto:thecore@eng.ucsd.edu)



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# Angela Fidler Pfammatter, PhD

Northwestern University Feinberg  
School of Medicine

Research Assistant Professor  
Clinical Health Psychologist

- Get ideas, learn new things, and meet, chat, and brainstorm with other people with complementary interests!

- I leverage technology (apps, systems, and sensors) to optimize burdensome and inefficient behavioral interventions to prevent chronic disease

[angela@northwestern.edu](mailto:angela@northwestern.edu)

- Twitter: @Apfam



# LAURA R. PINA | Postdoctoral Researcher

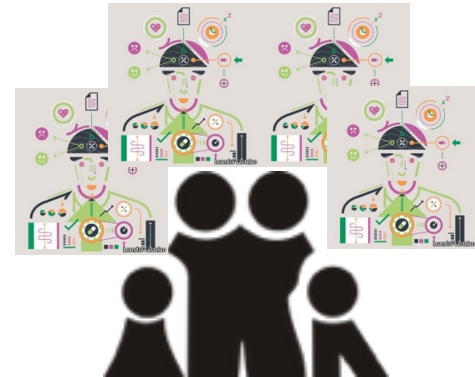
My work: Quantified Family



Self-tracking focuses on the individual



self-care and self-monitoring can go beyond the individual



Designing for families: coordinated and collaborative tracking



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# THE DOG AGING PROJECT: BIG DATA FROM COMPANION DOGS



Daniel Promislow  
Professor,  
Depts. of Pathology and Biology  
University of Washington

- Longitudinal study of aging in 10,000 companion dogs
- Environment
  - air, water, exercise, social interaction, dogs as sentinels
- Genetics
- Multi-omics
  - epigenome, metabolome, microbiome
- Veterinary EMRs
- Sensors, mobile health apps
- Open Science and Citizen Science

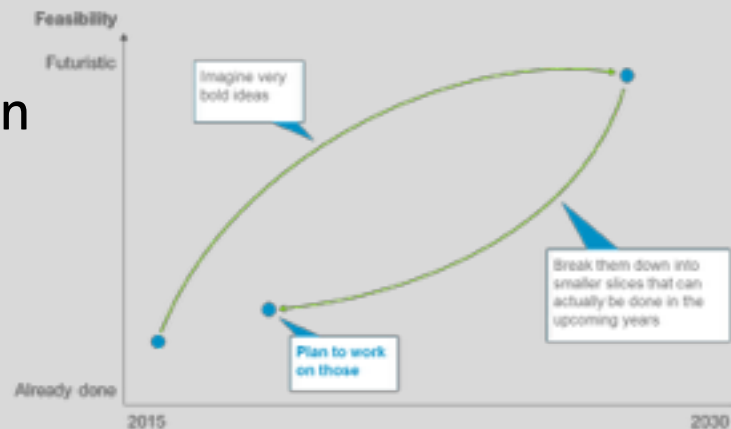
# Jan Samzelius

- CEO, NeuraMetrix
  - Measuring Brain Health through Typing Cadence
- Our continuous measurement of brain health will give CNS disease patients and neurologists feedback on changes in treatment and lifestyle
- Founder
- Inventor
- Sales/Partners



# Dirk Schapeler

- Head of Bayer's LifeScience iHUB in Silicon Valley
- Build on connection with QS community: we did a pain management symposium with QS last year and want to expand that into allergies and cardiovascular disease area
- Connect with innovators to look for the next big thing in lifesciences
- Team works on digital technologies that supports our core business (Pharma, Consumer Health and Croscience)
- Sensors and machine learning are focus
- "beyond the pill" innovation projects



# Tamar Sharon

- Assistant professor, philosophy of technology
  - ❖ Maastricht University, NL
- What do scientists and public health officials think?
- Ethical issues around the use of data generated by mobile devices for health research
  - ❖ Privacy, social justice, new power asymmetries



# Bonnie Spring

- Who Am I?
  - Northwestern University
  - Director, Center for Behavior & Health
- Why am I here/What do I want to get out of the meeting?
  - Learn how to enhance value, reduce burden and maintain greater engagement in mHealth interventions
- What do I do?
  - Develop and evaluate technology-supported health promotion interventions for diet, physical activity, smoking





# Tiffany Woelfel, MPH, MSW

- Researcher, Clinician, Former IRB Reviewer
  - University of Washington
  - 14 years experience
- Processes and training resources on social media & research
- New employment opportunities
- Funding for doctoral research

**Project management**-recruitment and retention of difficult populations

**Administration**-statewide initiatives in interagency data sharing and integration of health services for mental illness, primary care and addiction

**Research**-social media and research ethics

**Practice**-trauma, addiction, HIV/STIs

[innovataresearch.com](http://innovataresearch.com)

[tpw@uw.edu](mailto:tpw@uw.edu)



@tiffpage



[www.linkedin.com/in/tiffanywoelfel](http://www.linkedin.com/in/tiffanywoelfel)

innovata  
RESEARCH CONSULTING



UNIVERSITY of  
WASHINGTON

# Oktawia Wójcik

Program Officer,  
Robert Wood Johnson  
Foundation

- Learn about new projects
- Connect with researchers
- Understand where the field stands
- Research, Evaluation and Learning
  - Examining patient experience using Twitter
  - Systems for Action
- Healthy Communities
  - 500 Cities project
  - Life expectancy at birth
  - NYC housing authority renovation work



Gary Wolf | Quantified Self

Supporting new discoveries about ourselves and our communities that are grounded in accurate observation and enlivened by a spirit of friendship.



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