

# Social Media: Bringing People (and Medicine) Closer Together

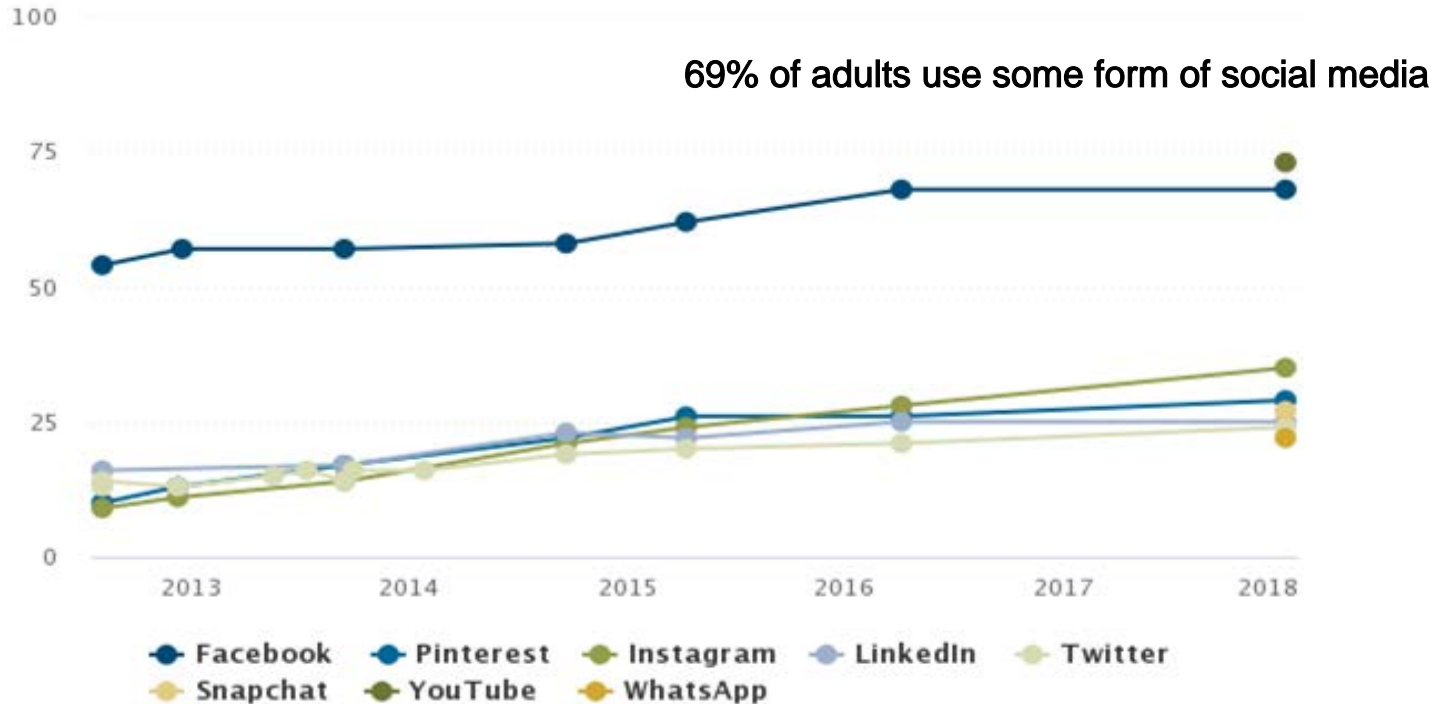
Jen Horonjeff, PhD  
Founder & CEO, Savvy Cooperative  
jen@savvy.coop  
@jhoronjeff

# Disclosures

- Savvy Cooperative works with companies and researchers to connect them with the patient perspective.

# Social Media Use in the US

*% of U.S. adults who use ...*



# Demographics

- **Ages 18 -29 (88%) vs 65+ (37%)**
- **Women (73%) vs men (65%)**
- **College educated (79%) vs HS or less (60%)**
- **Urban (75%) vs suburban (69%) or rural (59%)**
- **High/\$75K+ (77%) vs low/\$30K or less (63%)**
- **Race/ethnicity fairly equal (white, black, hispanic)**

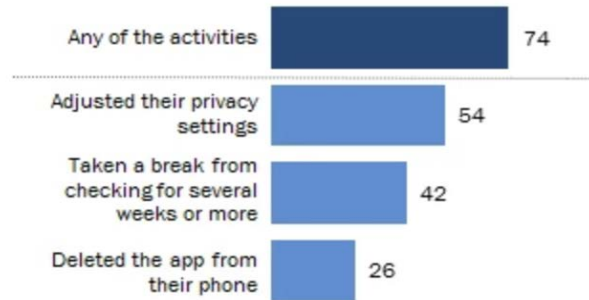
# Social Media and Medicine

- Patient support groups
- Clinical trial recruitment
- Research and product design
- Post market surveillance

# Inclusivity

- Not everyone shares health information
  - Facebook users (230M) vs PatientsLikeMe users (0.6M)
- Compare to clinical trial data sets
- People leaving social for privacy and other reasons

*% of U.S. adults who use Facebook who say they have done the following in the last 12 months ...*



# Privacy Concerns

- Changing privacy policies - for better or worse?
  - Facebook | marketing
    - ◆ RA group | run by marketers
      - BRCA group | Chrome extension for marketers
      - Sexual abuse group | turned erotica group
  - PatientsLikeMe | industry
  - 23andMe | GSK
- De-identified data(?)
- Transparency and consent

# What People Are Saying

- Language barriers
- Linguistic challenges
- Knowledge of diagnosis/symptoms/treatment

Can we trust what patients say?



# Opportunities

- Gives a signal
- PROs
- Patient priorities

**Social listening vs active engagement**

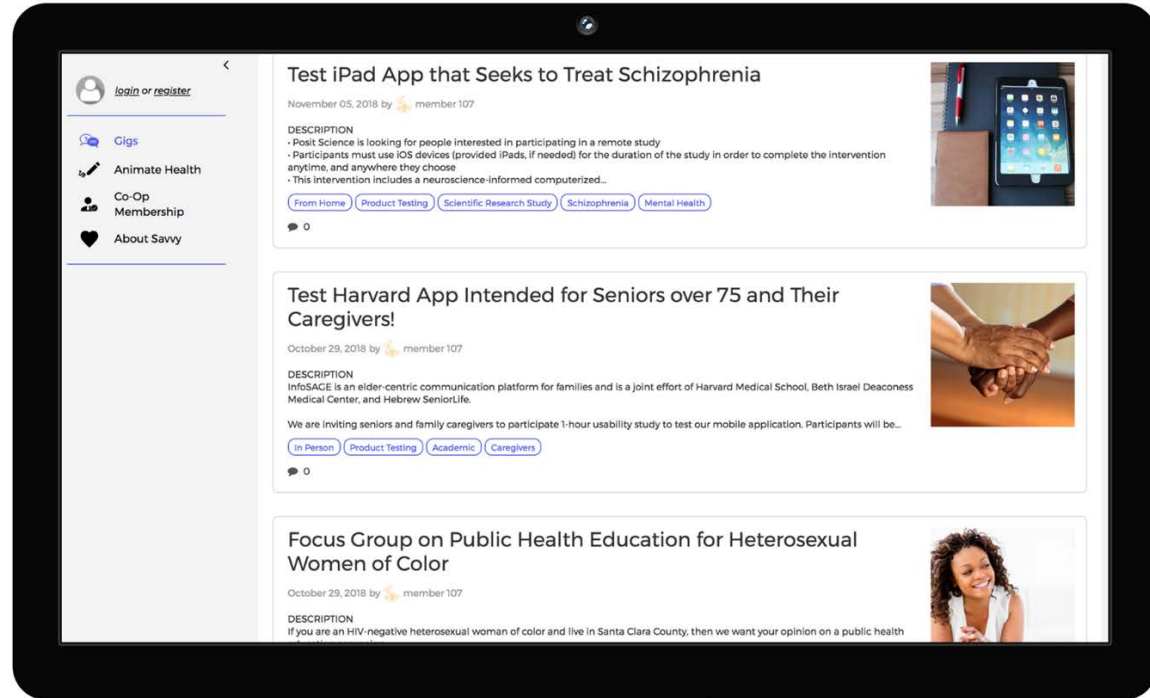
# Savvy Cooperative: patient co-op



# Savvy: Gigs

## Professional Initiated:

- Surveys
- Focus Groups
- Interviews
- User-Testing
- Discussion Boards
- Design Workshops



# Savvy: Animate Health

## Patient/caregiver Initiated:

- Health conditions explained from the patient perspective

### CHRONIC PAIN



**Pain**

by SavvyCoop



**Invisible Illness**

by SavvyCoop



**Fatigue**

by SavvyCoop



**Everyday Activities**

by SavvyCoop



**Sexual Health & Intimacy**

by SavvyCoop



**Stigma Of Opioid Use**

by SavvyCoop



**Hobbies/Leisure Activities**

by SavvyCoop



**Creating A Treatment Plan**

by hobbledchick



**Guilt**

by SavvyCoop



**Work/School Limitations**

by SavvyCoop



**Financial Burden**

by SavvyCoop



**Dating & Relationships**

by SavvyCoop



**Cognitive Impairment**

by SavvyCoop



**Social Isolation & Loneliness**

by SavvyCoop



**Fluctuations In Weight**

by SavvyCoop



**Parenthood**

by SavvyCoop

# Data Without Stories Is Just Math



# Thank you!

Jen Horonjeff, PhD

Founder & CEO, Savvy Cooperative

jen@savvy.coop

@jhoronjeff