Healthforce Center at UCSF

Transforming Care by Engaging Patients as Palliative Care Advocates

California Health Care Foundation

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Problem Statement

Default care at end of life leads to:

- Re-hospitalizations
- Burdensome and expensive treatments
- Regrets for patients, families and providers

Initial Discovery

Initial Hypothesis was Provider-Focused: **Data = Action**

- **Systemic Barriers** create insurmountable competing priorities with little likelihood for significant change.

Pivoted to Consumer-Focus: Demand = Action

- Engaging palliative patients as consumer advocates harnesses the passion of those most urgently committed to enhancing EOL care.

Revised Hypothesis: ***Increasing consumer awareness of palliative care principles will drive demand for transformation in EOL care.***

- Recruited seriously ill e-Patients (patients actively engaged in social media) to annual Palliative Care Summit to test feasibility.

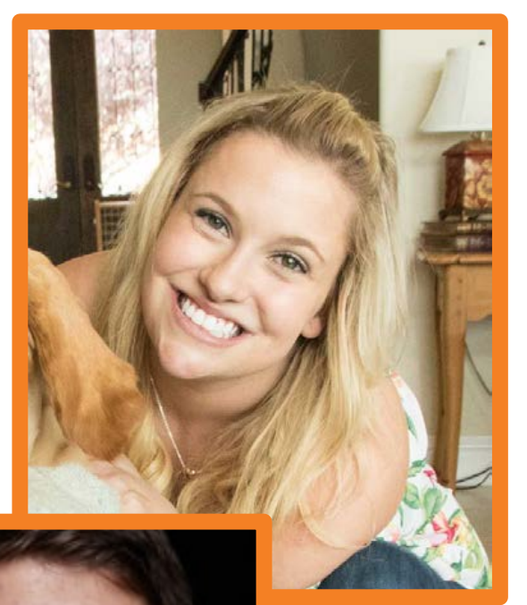
Discovery

Integrated e-Patients (N=15) in Palliative Care Summit

- Pre-conference Design-Thinking Workshop
- Office Hours
- Networked with Providers
- Art Work Display
- Young Adult Plenary Panel
- Interviews and Articles on Social Media

Society for Participatory Medicine
BMJ
New York nymag.com
SCIENCE OF US
CaliforniaHealth REPORT
REAL SIMPLE life made easier every day
npr

Professional participants (N=346) reported benefits of e-Patient Integration in Summit



- *My absolute favorite part of the conference. Extraordinarily articulate young people with so much valuable feedback we need to hear.*
- *Wonderful opportunity to see into the patients' world.*
- *Highlight of the conference - inspiring, courageous and heartbreaking.*

Mission Model Canvas

Key Partners

- Consumers
- Patients
- Caregivers
- Organizational Partners
- Granting Agencies

jwH JOHN & WAUNA HARMAN FOUNDATION
pcori PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Key Activities

- Partner with patient advocacy organizations
- Disseminate palliative care principles through social media
- Increase consumer awareness and demand

Key Resources

- e-Patients
- Family Caregivers
- Passionate Professionals
- Advocacy Organizations
- Funders

Value Propositions

Increased consumer awareness of key palliative principles will drive transformation in EOL care.

Palliative Care Principles:

- Contextualized Care
- Collaborative Team Approach
- Clear Communication
- Exquisite Symptom Management

Buy-in & Support

- e-Patient advocates
- Organizational partners

National Brain Tumor Society
WomenHeart The National Coalition for Women with Heart Disease
MDA Muscular Dystrophy Association Fighting Muscle Disease
American Cancer Society

Deployment

Social media platforms

- Patient blogs
- Facebook
- Twitter
- Instagram
- Organizational newsletters and marketing outlets

Beneficiaries

- Patients
- Caregivers
- Communities
- Providers
- Healthcare organizations
- Society

Mission Budget/Cost

- Subsidized e-Patient palliative care educational meetings
- Support for organizational partners
- Administrative support to coordinate advocacy activities and disseminate findings

Mission Achievement/Impact Factors

- Improved Quality of Care
- Lowered Cost of Care
- Increased Patient, Family, and Provider Satisfaction
- Less Regret

Lessons Learned

Key takeaways:

- Feasible to recruit seriously ill e-Patients
- Feasible to integrate e-Patients into professional conference
- Feasible to raise consumer awareness of palliative care through social media
- Parallels with the "Birthing Movement" resonated (e-Patients eager to "take back" the medicalization of EOL care, just as consumers revolutionized the way childbirth now occurs)
- e-Patient's demonstrated commitment to the "cause" by continuing to actively advocate post-Summit
- Shared humanity recognized ("we're all mortal")
- "Whole-person care" requires "whole-provider care"
- Initially "Palliative Care" = ☹
- But Palliative Care *Principles* = ☺
- Funders are supportive
- Organizations are receptive
- Minimal investment = strong return
- Demonstrated proof of concept

Next Steps

Expand efforts to engage patients and their families as palliative care advocates.

- Recruit e-Patients to develop and disseminate palliative care and advance care planning information in conjunction with advocacy organizations.

Both "top-down" and "bottom-up" strategies are needed to increase consumer demand if we are to transform the culture of care and make the "default" truly person-centered and goal-concordant.

COALITION FOR COMPASSIONATE CARE OF CALIFORNIA

CHILDREN'S HOSPICE & PALLIATIVE CARE COALITION