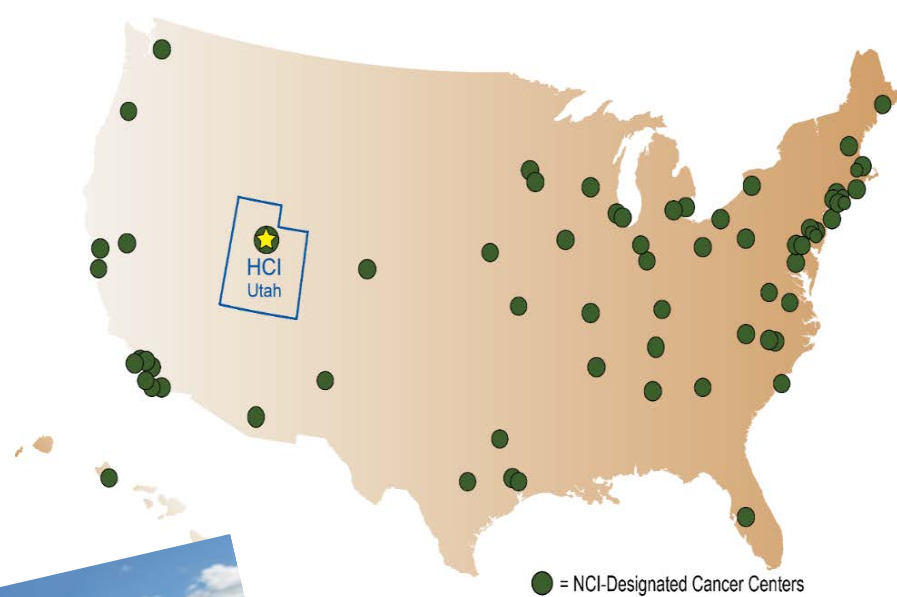# Using Technology for Recruitment, Retention, Data Collection and Intervention Delivery

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= NCI-Designated Cancer Centers

The Huntsman Cancer Institute Catchment Area

- Includes 5 Intermountain West states covering 17% of the US continental landmass

- 30% of patients being treated at the Huntsman Cancer Institute live in rural/frontier communities

- Sparse population densities:
  - Utah = 35.5 people/mi^2
  - Nevada = 26.3 people/mi^2
  - Idaho = 20.0 people/mi^2
  - Montana = 7.1 people/mi^2
  - Wyoming = 6.0 people/mi^2

- Utah population- 3 million people
- Utah encompasses nearly 85,000 mi^2
- 96% of Utah is rural (<100 persons/mi^2)
- 70% of Utah is frontier (<7 persons/mi^2)
- Utah is home to 7 Native American tribes/nations

Recruitment

- Connecting to the target population- trust
- Marketing the opportunity
- Engaging the target population
- Social media
  - Methods of recruitment
  - Examples: Army of Women Susan Love Foundation; Apple/Stanford Heart Study
- Patient-facing portal of the electronic health record
- Video/Video sharing
  - Example: ORIEN Total Cancer Care Cohort
- Combine person-based and technology-based methods

- Social media use issues
  - Network and venue bias
  - Snowball sampling bias
  - Accuracy of reported data
  - Abuse of incentives

Retention

- Automated reminders; encouragement from influentials
- Updates, boosters, newsletters
- Just enough- not too much
- Use of technology to track accrual and retention
  - Research management systems

Technology delivery modes:

- Mobile phone text
- Automated telephone message- smart or not
- Email
- Patient-facing portals of the electronic health record
- Social media
- Telecommunication

Data Collection

- Electronic capture of patient-reported data-
  - Multiple platforms- phone, internet, app, research management systems
  - Ecological Momentary Assessment (EMA)
  - Computer Adaptive Testing (CAT)
  - Electronically Activated Recorder (EAR)
- Automated monitoring- wearable, home, community sensor data
- Telecommunication

- Advantage to collect many data points very quickly

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Intervention Delivery

- Multiple platforms
- Treatment fidelity
- Easily adapted
- Scalability

- Use of adaptive designs to test a variety of interventions
- Can combine data collection with intervention delivery

An example of technology-assisted retention, data collection, and intervention delivery

Symptom Care at Home (SCH)- a remote symptom monitoring and automated self-management coaching platform with alerts to clinicians for poorly controlled cancer symptoms

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Extending Care beyond the Cancer Center Walls

Symptom Care at Home

Telephone based- automated voice response system (IVR)- soon to include web and app platforms

1. Daily automated monitoring of common symptoms (presence, severity (1-10), drill-down for rapid triage) of patient and caregiver

2. Automated algorithm-based patient or caregiver coaching based on reported symptoms and intensity. Short-term and long-term behavioral change coaching

3. Automated alerting of clinicians for poorly controlled symptoms- symptom graphs for patterns and guideline-based decision support system for intensifying symptom management

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Significant Benefit for Patients

Calls 5 min. avg. length
90% daily call adherence

Calls 11 min. avg. length
73% daily call adherence

For Chemotherapy (n=358)

- **Significantly less symptom severity** than usual care; p <.001
  - **67% less <u>severe</u> symptom days** than UC (8-10 severity, (0-10 scale); p<.001
  - **40% less <u>moderate</u> symptom days** than UC (4-7 severity); p<.001
  - **60% more <u>mild</u> days** than UC (1-3 severity); p=.006
  - **25% more <u>asymptomatic</u> days** than UC;(0- not present) p=.006

- **Benefit extended across geography and race**

For Hospice/End of Life (n=298)

- **Significantly less symptom severity for patients** as reported by the family caregiver than usual hospice care; p=.03

- **Rapid onset** of patient benefit compared to usual hospice care; p<.02

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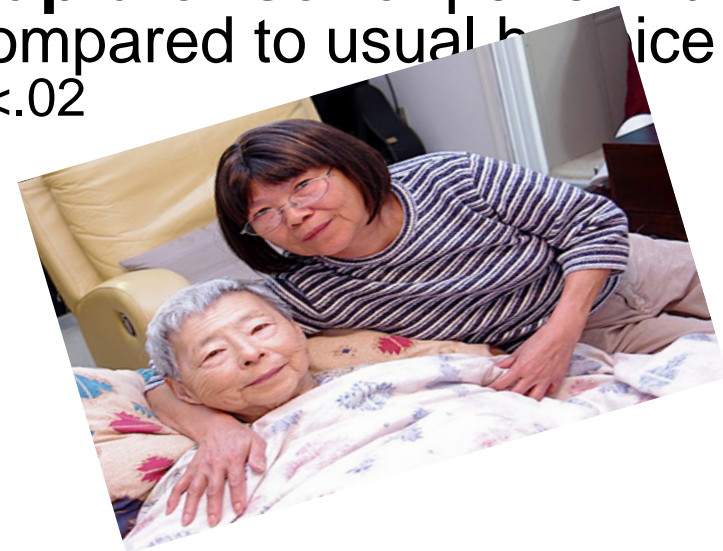
Large Mental Health Benefit for Men
# Potential value of technology over face to face

- Men gain a significant mental health advantage from automated monitoring and support for emotional concerns during treatment (SF36 mental health subscale)
- Gender x benefit interaction favoring men (p=.016)
- SCH men gained 5.2 scale points per month (p=.003), 21 scale points overall (4 months)
- 21 scale points overall (0-100)= 11.7 gain in normed T-score where 3.0 is the minimally important difference (MID)

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Family Caregiver vitality maintained during caregiving

Lower fatigue, better sleep, and less activity disruption (p<.001)

- 51% reduction in the number of daily moderate-to-severe symptoms for family caregivers (p<.001)
- In SCH (but not UC), caregiver symptom reduction mediated a reduction in patient symptoms, p=.027
- Supporting caregiver's health translates to improved patient symptom outcomes; both are benefited
- 6 months after death of spouse, SCH spouses showed better bereavement outcomes than UC spouses (p=.01)

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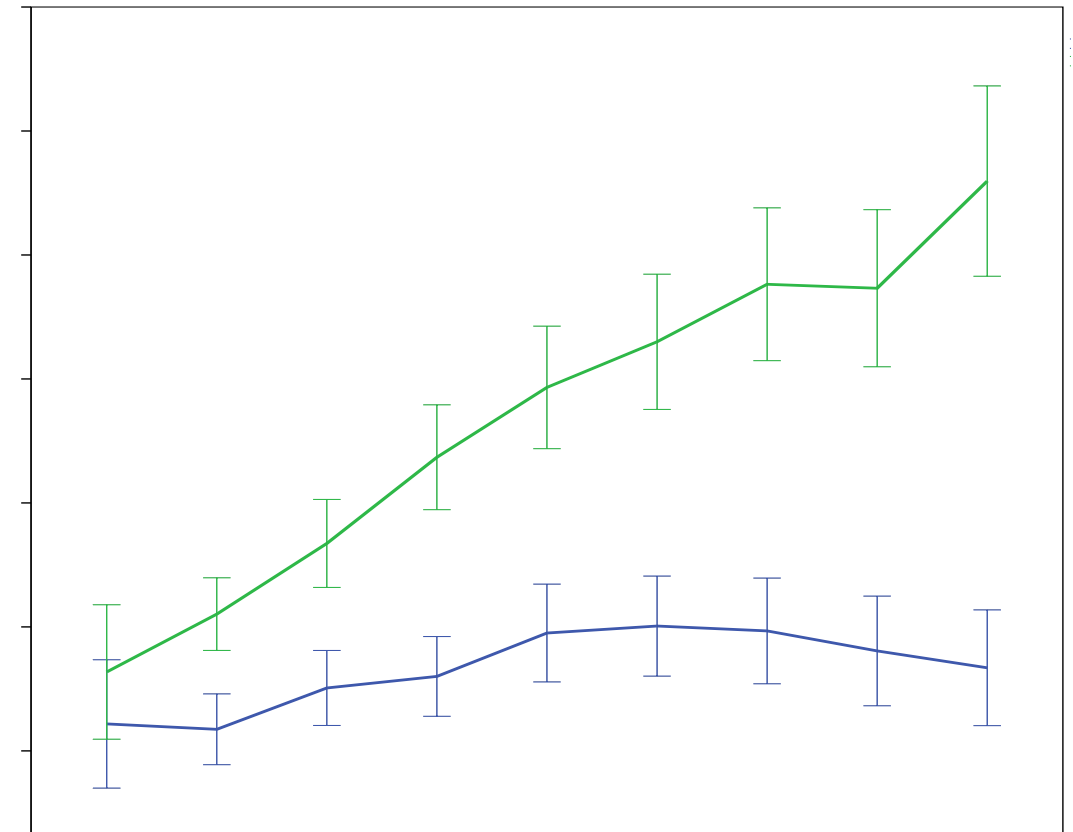
People will engage and benefit from technology

Hospice Family Caregiver post-intervention interviews:

- I did my calls at the end of the day and it was a release of sorts for me…the time I spent alone at night to reflect on mom's day and how she did.

- Good outlet/input for me-pointing out I wasn't alone and she was not really unusual.

- It gave me a sense of confidence that what I was seeing and feeling was 'normal'.

- It helped calm me when I was having a bad day.

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- Being able to anonymously tell someone what is going on made it easier to be helped.
- It felt like someone else was listening to what I had to say. Another person on the team.
- It made me realize I was forgetting who he had been. I was just seeing him as a sick person- that was so helpful so I could change.
- It got me through the hardest time in my life.

Technology can assist in improving health research in small, hidden, and hard to reach populations

- Technology has been used successfully in each and across research phases
- Use technology that is familiar to the target population
- Health technology is a growth industry, we need equivalent advances in health research use
- Engage participants/communities in how to improve the technology
- If it didn't work, don't assume it was the technology- technology is the vehicle not the content or intervention
- There is a need for further research examining best practices in technology use for recruitment, retention, data collection and intervention delivery