

Eugene Washington PCORI Engagement Award Program

Engagement Awardee Lunch and Learn:
Virtual Engagement

June 24, 2020

Agenda

- Introduction
- Engagement Awardee Presentations
 - Bruce Leff and Orla Sheehan
 - Johns Hopkins University School of Medicine
 - Joanne Nicholson and Shannon Hennig
 - Brandeis University
 - Mandi Pratt-Chapman
 - George Washington University
 - Emily Godfrey and Molly Pam
 - University of Washington
- Q&A
- Wrap-Up

Housekeeping

- This webinar is available to the public and is being recorded
- The slides and webinar recording will be made available on PCORI's website following the webinar
- Attendees are in listen-only mode
- To learn more about the awardees presenting in this webinar and their Eugene Washington PCORI Engagement Award projects, click here:
<https://www.pcori.org/events/2020/engagement-awardee-lunch-and-learn-virtual-engagement>

Welcome



Eugene Washington PCORI Engagement Award Program Background

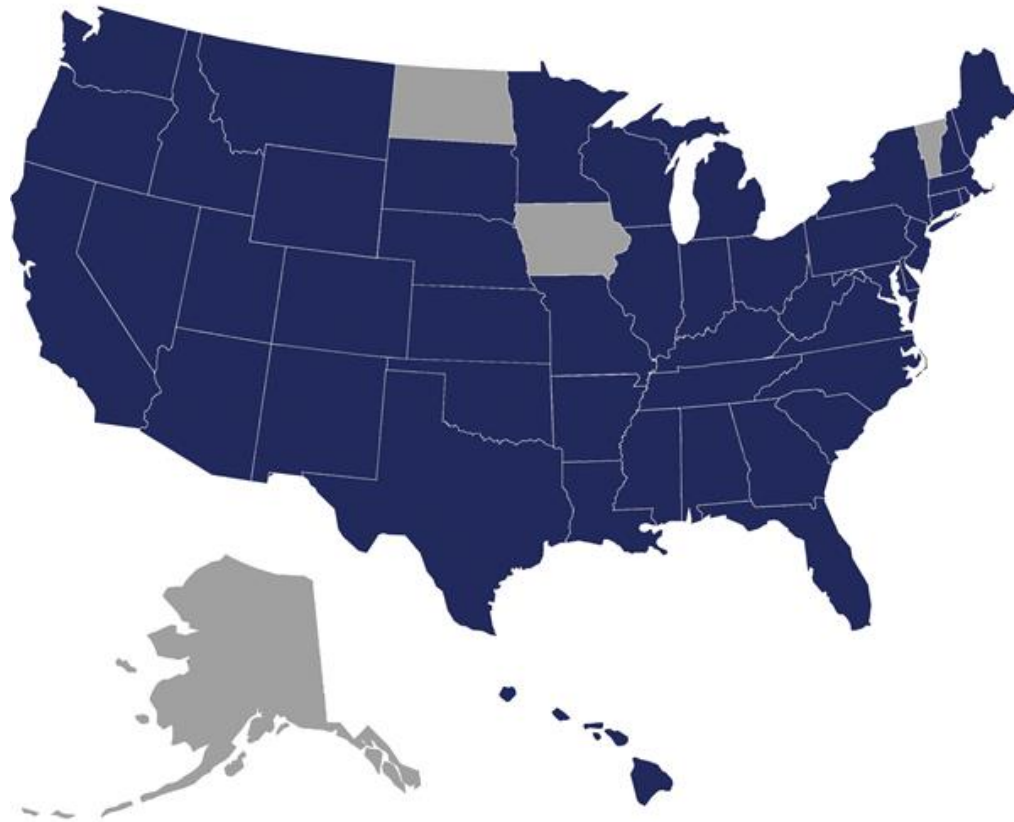


- Support projects to build a community of patients and other stakeholders equipped to participate as partners in clinical comparative effectiveness research (CER), as well as serve as channels to disseminate PCORI-funded study results
- Funding for projects and conferences, NOT research



Building a National Network for PCOR

- ~\$96.4 million awarded since 2014, creating an expansive network of individuals, communities and organizations interested in and able to participate in PCOR



Evolving Stakeholder Needs: Virtual Engagement

- An increase in the use of various technology and virtual platforms in engagement
 - Cost-effective
 - Wide reach of audience
 - Ideal in times of social distancing
- As the COVID-19 pandemic has evolved, so have opportunities to build and scale virtual engagement platforms that have proven to be critical during this time



Engaging the Invisible Homebound and their Caregivers in the Development of Home-Based Medical Care Research

Bruce Leff, MD, Project Lead

Orla Sheehan, MD, PhD, Co-Investigator

Christine Ritchie, MD, MSPH, Co-Project Lead

Johns Hopkins University School of Medicine
Harvard Medical School



Acknowledgment and Disclaimer

- This work was funded through a Patient-Centered Outcomes Research Institute® (PCORI ®) Eugene Washington PCORI Engagement Award (7258-JHU).
- The views presented in this presentation are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI ®), its Board of Governors or Methodology Committee.

There are Lots of Homebound Older Adults in the US!

- National Health and Aging Trends Study
 - Completely homebound: 400K
 - Mostly homebound: 1.6 million
 - Semi-homebound: 5.3 million
- **Total 7.3 million**

JAMA Intern Med. 2015;175:1180-6

The Problem

Homebound older adults are an invisible and vulnerable population who have not had a voice in shaping research relevant to their needs



Project Aims

- **Aim 1:** Qualitative research to **develop strategies and tactics to optimally and continuously recruit, train, and engage stakeholder homebound patients and their caregivers** as partners in PCOR and CER
- **Aim 2:** **Recruit and train bi-coastal Homebound Stakeholder Advisory Groups** comprised of homebound patients and their caregivers in PCOR and CER
- **Aim 3:** Engage and **partner with the Homebound Stakeholder Advisory Groups to develop and prioritize a research agenda**
- **Aim 4:** **Disseminate** the research agenda to researchers in the field by partnering with key national organizations
- **Long Term Goal:** Develop a sustainable approach to incorporating the voice of homebound older adults and their caregivers to inform the work of researchers in this field

Qualitative Research: Recruitment, Engagement & Retention Strategy for Homebound

- Semi-structured interviews
 - Experiences and perceptions of being homebound or a caregiver
 - Engaging stakeholders in the research process
 - Strategies to involve stakeholders as research partners, advisors
- 30 interviews (San Francisco and Baltimore):
 - 13 homebound older adults, 17 caregivers
 - 38% Medicaid
 - 73% Women
 - 57% Non-white

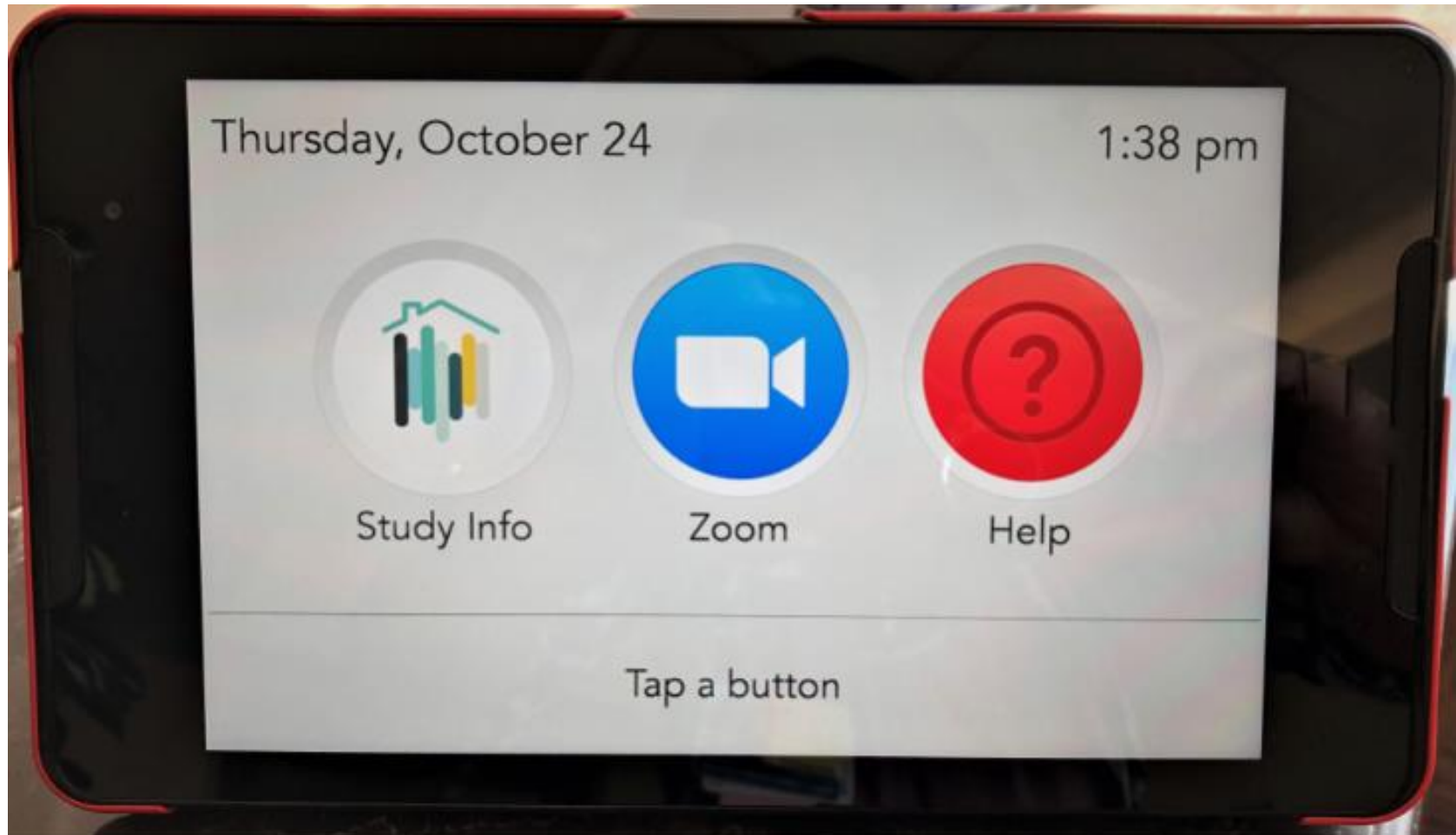
- **Attitudes**: Most viewed research as important and an opportunity to learn and share knowledge
 - *"We need these opportunities...you know, to learn from and to teach others"*
- **Relevance**: Many felt research could impact people like them
 - *"They might not fix me, but they can fix someone else...I would love to hear that someone else got healed"*
- **Roles**: Most reported interest in advising researchers; some expressed fears over having the ability to contribute
 - *"If I could be of any help, I wouldn't mind"*
 - *"If I could get out"*
 - *"I am no expert"*
- **How to Engage**
 - Phone preferred, limited openness to trying other methods

Choosing a Device on Which to Conduct Virtual Meetings?

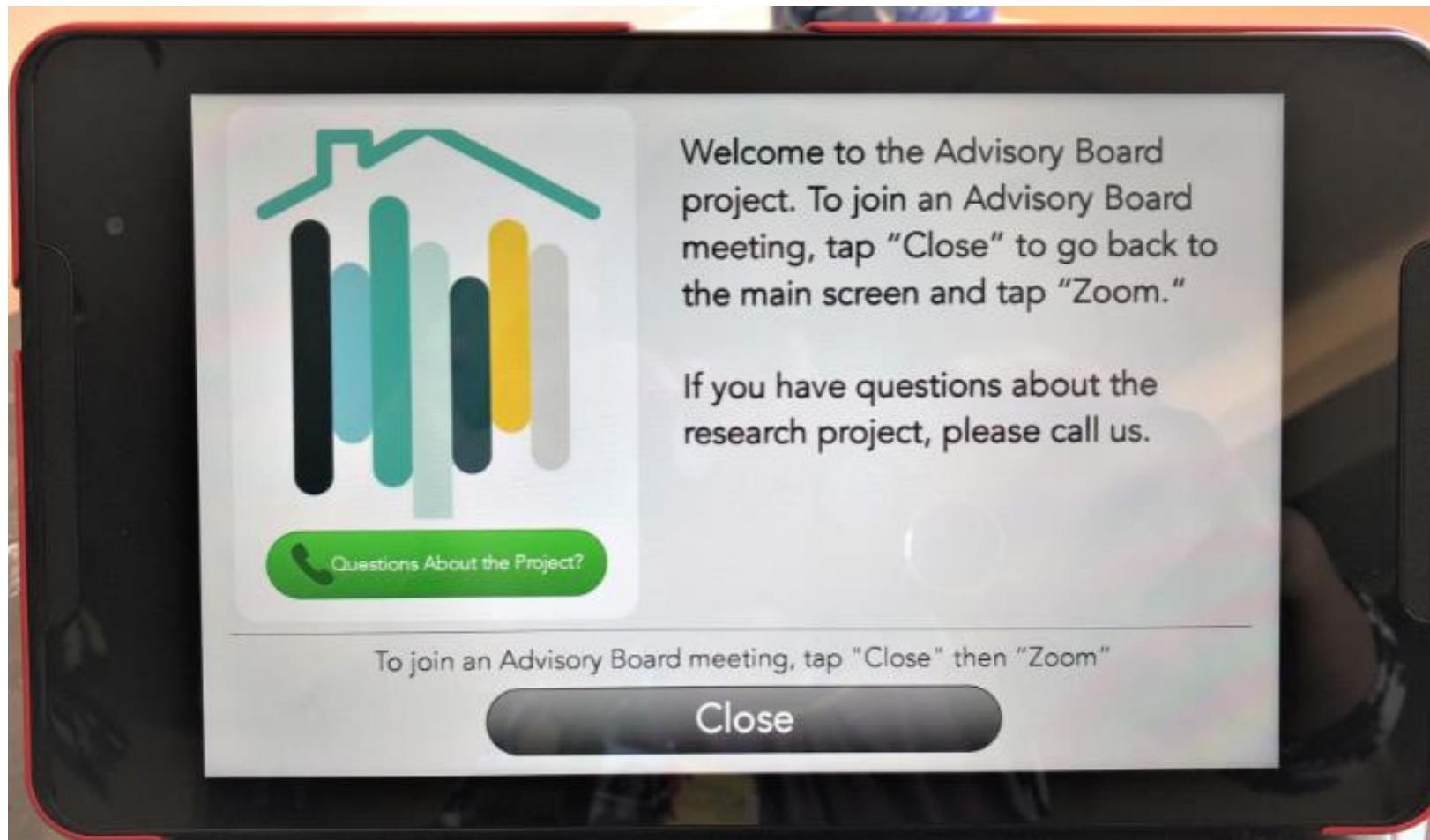
- Ipad / Samsung tablets
 - Cost
 - Data plan
 - IRB reluctant
- Grandpad: Alternate tablet
 - Programmable
 - In-built data plan
 - Rental option
 - Designer for older adults – large button, clear instructions, excellent support



The Grandpad



Grandpad Interface



Strategic Advisory Board Meetings

SAB Meeting Content and Tasks	SAB Meeting Number							
	1	2	3	4	5	6	7	8
Welcome and introductions / Ice-breaker question / review purpose and goals of project								
SAB administration – review of meeting ground rules, development of group charter, group naming								
Training of SAB members in patient-centered outcomes research								
Generate list of research domains								
Generate research questions								
Prioritization of research domains								
Open discussion of all SAB members from Baltimore and San Francisco								

Zoom Virtual Meeting on the Grandpad



Research Domains Identified by SAB Members

Domain (Number of Research Questions Generated)

Out-of-pocket costs of caregiving (10)

Access to home-based care and related policy issues (19)

Relationship with doctors (15)

Getting to know patients and caregivers as individuals (7)

Understanding patient and caregiver needs and well-being (13)

Specialist care in the home (8)

Challenges of receiving care outside the home (6)

Communication (5)

Issues regarding paid caregivers (9)

Home as a therapeutic place (4)

Quality of nursing homes (14)

Technology in the home (6)

Dementia (7)

Delivery services (4)

Sample Research Questions

Domains	Sample Research Questions
Out-of-pocket costs of caregiving	<p>What are the effects on caregivers who are burdened by out-of-pocket costs?</p> <p>What are the best processes or practices for caregivers to learn about resources that are available to assist with out-of-pocket costs of caregiving?</p>
Access to home-based care and related policy issues	<p>What are the changes needed in the system to get more social services or assistance covered under medical or health insurance?</p> <p>What are the policies that make life most difficult for homebound people and their families?</p>

Challenges

- Translating and maintaining the patient / CG voice
- Recruitment/retention issues: Advisors frail, get sick, die
- Our participants struggled mightily with PCORI language
- Even “easy” tech isn’t foolproof (Grandpads, US mail)
- Translating personal experience to broader issues
- How and when to stop

- Materials on PCORI site
- Publications
- Action
 - Collaborations with professional societies and technical assistance entities to bring the patient voice to home-based medical care
 - Research Hub

Unanticipated Benefit of PCORI



Research Letter

Unanticipated Therapeutic Value of the
Patient-Centered Outcomes Research
Institute (PCORI) Stakeholder
Engagement Project for Homebound
Older Adults

J Am Med Dir Assoc. 2020 May 3:S1525-8610(20)30258-9

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www.improvehousecalls.org

Creating a Community with Mothers with Mental Illness Using Opioids

Shannon Hennig, MA
Joanne Nicholson, PhD

Maternal Mental Health
Research Collaborative &
Brandeis University

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Objectives

- Create opportunities to connect mothers with mental health & opioid use with researchers.
- Engage mothers & researchers in virtual community development (*research4moms.com*).
- Implement a tailored, in-person community engagement studio model.

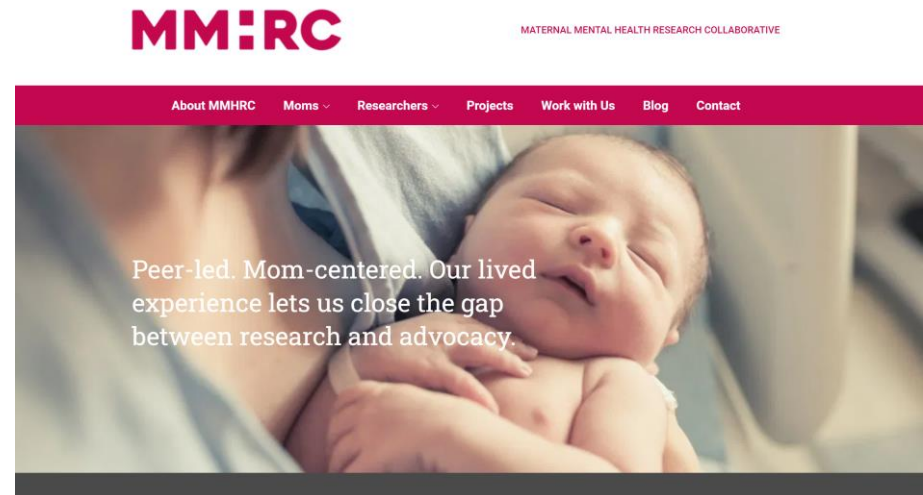


Photo credit: Unsplash.com

What was Done

Creating the MMHRC Community

- Leveraging social media & online tools & resources – ***research4moms.com***, **Facebook**, **Twitter**, **Instagram**, **LinkedIn**.
- Engaging with stakeholders through iterative processes and rapid idea generation.



How it was Done

Building relationships & trust

- Posting relevant content on a consistent, predictable basis.
- Using best practices from business & management.
- Adopting digital marketing strategies.
- Generating feedback (polls, surveys).

Post Details


Maternal Mental Health Research Collaborative - MMHRC is sharing a COVID-19 Update.

Published by Shannon Hennig · May 11 at 2:10 PM

You know how much harder COVID-19 has made getting the social and peer support you need right now. Everyone's experience is going to be different and we want to know more about how you've given and received support from other moms since COVID-19 started.

We have three quick questions that ask about your experience. These questions will take about five minutes of your time and will help develop new research priorities to take forward to funders.

https://brandeis.qualtrics.com/jfe/form/SV_40De5JozHMgAONv



Maternal Mental Health Research Collaborative - MMHRC
Health & Wellness Website

[Learn More](#)

Performance for Your Post

7,466 People Reached		
392 Reactions, Comments & Shares		
332 Like	329 On Post	3 On Shares
29 Love	29 On Post	0 On Shares
5 Comments	4 On Post	1 On Shares
27 Shares	26 On Post	1 On Shares
249 Post Clicks		
38 Photo Views	30 Link Clicks	181 Other Clicks

NEGATIVE FEEDBACK

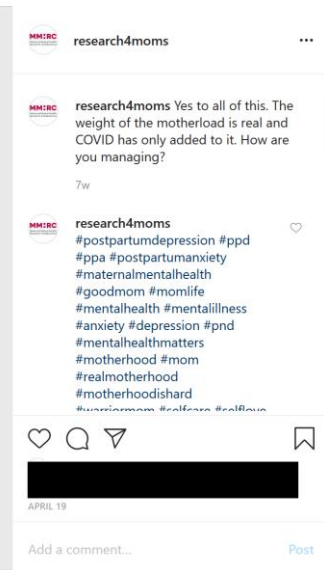
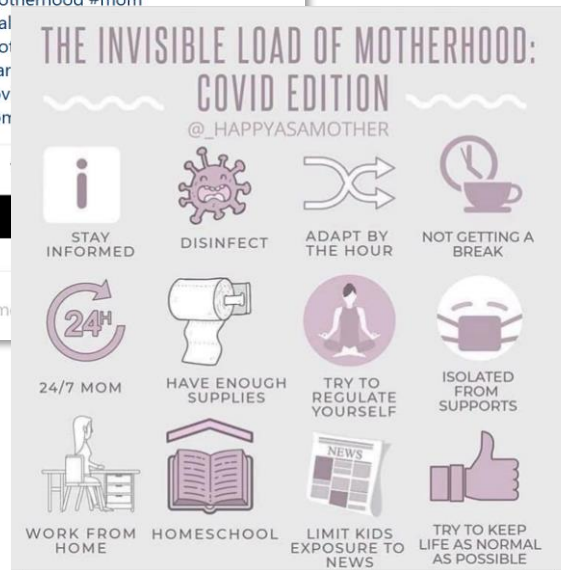
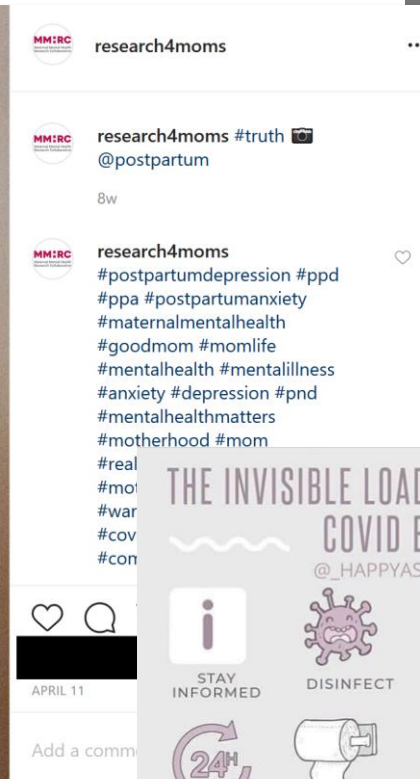
0 Hide Post	0 Hide All Posts
0 Report as Spam	0 Unlike Page

Insights activity is reported in the Pacific time zone. Ads activity is reported in the time zone of your ad account.

Example of survey opportunity

How it Worked

Examples of social media content



How it Worked

Opioid specific content

Maternal Mental Health Research Collaborative - MMHRC
Published by Hootsuite [?] · September 24 at 3:01 PM ·

"Stigma is a common barrier to care for pregnant drug users. Many people at the needle exchange said doctors treat them poorly, they're brusque or don't give enough local anesthetic, for example when they realize they are injection-drug users." <http://ow.ly/YZdl30IEopV>



THEATLANTIC.COM
Pregnant and Addicted to Heroin
In Fresno County, drug use is about two times the state average. Pregnant...

1,251 people reached

Boost Post

You get what you deserve if you can't stop drugs for your baby or get on birth control to prevent getting pregnant while you're using you don't deserve sympathy

Like · Reply · Message · 1d

Maternal Mental Health Research Collaborative - MMHRC This comment isn't helpful or necessary and is EXACTLY why mothers who use drugs have issues accessing care.

Like · Reply · Commented on by MMHRC [?] · 23h

Maternal Mental Health Research Collaborative - MMHRC then remove it if you don't like it. I stand by it. I don't believe in coddling people. Addiction is a crutch and making it seem like it's not in their power to change it is a disservice to people who actually struggle with addiction like me and like me, those who have overcome it and carry on with productive lives and become great parents. The only enemy is yourself the only one you can blame for your addiction is yourself, no matter what you went through or why you use it's your fault entirely, you chose poor coping mechanism, chose to use and not get healthy and not seek treatment for mental health issues rather than using. If you feel guilty and ashamed that is on you and you probably should because you know what you're doing isn't right. If you find people judging you maybe it's not them it's you and your choices, taking responsibility is what needs to happen not a pat on the back and a good job. Sometimes the best thing that can happen to an addict is losing everything and especially those who enable the behavior by not setting ultimatums, the best thing that can happen is having people refuse to be around you and support your addiction. Sometimes it's a kick in the gut but the truth isn't pretty and reality is harsh and a good dose of reality is what people need when it comes to addiction.

Like · Reply · Message · 22h

Example of opioid content

How it Worked

Research questions

THE MENTAL LOAD OF TAKING BABY TO THE DR DURING A PANDEMIC

How can I avoid
all the germs?

This is making me anxious.
Is anyone else worried?

Do I need to
sanitize my car
seat now?

How can I keep
baby safe?

Should I cover baby?

What should I
bring with me?



@MommysBundle



research4moms



3w 3 likes Reply

View replies (1)



I took my son for his...
4 month well check today. It was
actually the least stress I've had
for a pediatric doctor's visit. They
checked our temp at the door,
then took us straight back to the
exam room, so there was no
waiting in the waiting room. The
waiting room is what usually
makes me nervous because that's
where all the other kids who may
be sick are.

3w Reply

View replies (1)



MAY 15

Add a comment...

Post

Example of comments generating potential research questions

What was Done

Research 101 & Mothers 101

- Crowd sourced questions about research from moms
- Asked moms about their participation in research



[Mothers 101 video series](#)
[Click here to watch](#)



[Research 101 video series](#)
[Click here to watch](#)

What was Done

Implementing the CES Model

- Mothers provide input into researchers' questions & procedures.
- Not a focus group.
- Designed to facilitate dialogue between researchers and stakeholders.



Photo credit: Pexels.com

What was Done

Community Engagement Studio



Photo credit: Unsplash.com

- Brief training and survey before session.
- Short presentation from researcher.
- Facilitator to guide conversation.
- Feedback from all participants gathered at end.

COVID-19

Virtual engagement

- Well positioned for virtual engagement to continue.
- Moved in-person CEs to Zoom sessions.
- Challenges with children present, confidentiality, etc.
- Assumed that stakeholders could participate remotely.
- Learned re: barriers to treatment during pandemic.



Photo credit: Unsplash.com

Lessons Learned

Online engagement, CES & more

- Understand needs & preferences of the stakeholder.
- Develop a brand presence & build trust. This takes time – lots of time.
- Regular, consistent posting of a variety of content include images & video.
- Paid advertising to promote page & content is essential.
- Ensure project team & participants are equipped & can be trained to use technology effectively.
- Attend to nuances of virtual CES sessions & adapt accordingly.

Contact Information

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MMHRC website – www.research4moms.com

Facebook – www.facebook.com/research4moms

Instagram – www.Instagram.com/research4moms

Twitter – www.twitter.com/research4mom

LinkedIn – www.linkedin.com/company/research4moms

Disseminating Patient-Driven Standards for Quality Cancer Survivorship Care

EADI-12744

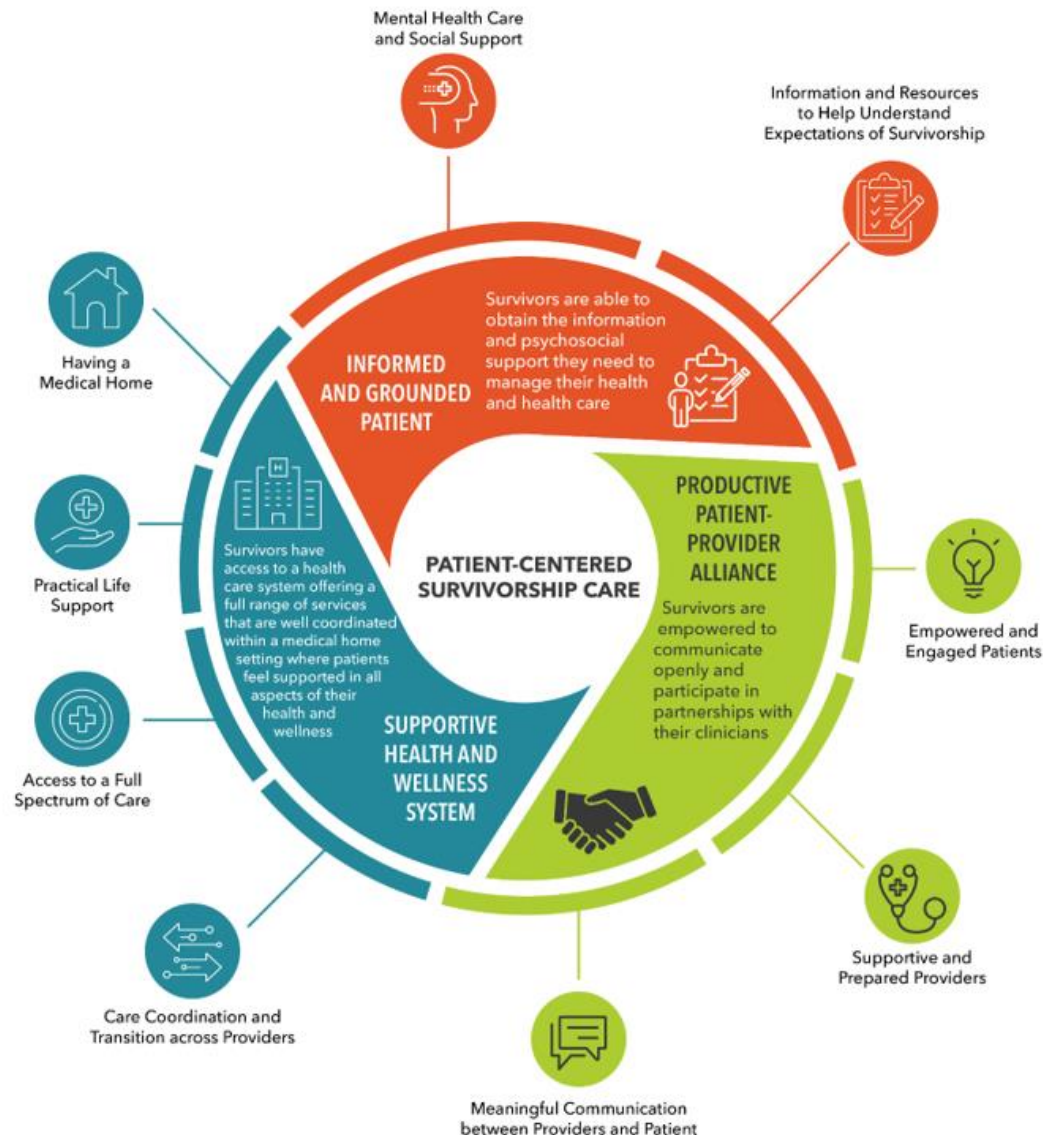
Mandi L. Pratt-Chapman, PhD

GW Cancer Center

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Patient Centered Quality Survivorship Care Framework



Project Objectives

- Increase the reach of evidence of quality survivorship care through the creation and dissemination of
 - One toolkit with tip sheets to optimize patient-provider interactions and resources to support care improvements
 - A CE-accredited module for the Cancer Survivorship E-Learning Series showcasing the toolkit and how it can help improve care
- Increase ability of clinicians and organizations to improve survivorship care by facilitating four workshops
- Increase motivation to apply evidence by facilitating peer-to-peer learning through an online forum

Successes: Online Toolkit

You may not see your cancer treatment team as often now that you have finished treatment. But, talking with your doctor about your health needs is important. Take 10 minutes to fill out this worksheet before your next doctor's visit. Bring it with you and share with your doctor.

In the last three months, how often have you worried about your:

	Never	Rarely	Sometimes	Often	Always
HEALTH General health					
Side effects from cancer					
Sexual relationships					
QUALITY OF LIFE Ability to do things you enjoy					
Cancer coming back					
Emotions (such as being sad, angry or anxious)					
Outlook on life					
Relationship with spouse/partner					
Relationships with family and friends					
PRACTICAL Health care team not addressing concerns					
Insurance					
Paying for medical care (such as doctor's visits, drugs, counseling)					
Follow-up care (getting tests, referrals to other doctors for help)					
Job					
Finances					

Other things I am worried about:

Use this checklist to help inform your clinical encounters with people who have a history of cancer and are not in active treatment. Encourage your patients to use the patient worksheet before they come to their next visit. The patient worksheet and provider checklist are designed to be used together to support patient-provider communication.



SCREENING & SURVEILLANCE

- ☐ Ask the patient what kinds of cancer screenings and surveillance they receive. Obtain records of screenings from providers.
- ☐ Use cancer survivorship guidelines to recommend cancer screening and surveillance and connect patients with appropriate clinicians.



PHYSICAL/PSYCHOSOCIAL EFFECTS AND HEALTH PROMOTION

- ☐ Ask the patient about what physical and/or psychosocial challenges they are facing.
- ☐ Ask the patient what healthy lifestyle behaviors they take part in (e.g. diet, exercise, smoking cessation).
- ☐ Ask the patient what they would like to change to improve health, and provide relevant resources on healthy nutrition, physical activity and smoking cessation.
- ☐ Use cancer survivorship guidelines to inform referrals and care recommendations.



ACCESS TO CARE

- ☐ Ask the patient what problems or barriers they may have to getting care (e.g. transportation, time off from job, childcare, finances, insurance).
- ☐ Provide patients with local, state and/or national resources to address issues as needed.



COMMUNICATION

- ☐ Use simple, plain and clear language without medical jargon.
- ☐ Ask the patient what language they are most comfortable using. Obtain interpretation services for every appointment.
- ☐ Use the teach-back method. For example: "I want to make sure I am being clear...Can you tell me what you heard me say?"
- ☐ Ask the patient what questions they have.
- ☐ Include the patient in all decisions about their cancer-related follow-up care.
- ☐ Engage the patient in problem-solving their issues with you.



CARE COORDINATION

- ☐ If you are part of treatment team, provide a survivorship care plan to the patient and all of the patient's providers. If you are the patient's primary care doctor or another specialist, ask treatment team for a survivorship care plan.
- ☐ Provide the patient with tools and resources to help them understand their follow-up care.
- ☐ Use cancer survivorship guidelines to inform referrals to medical, rehabilitation, mental health and/or behavioral specialists to address concerns.
- ☐ Refer patients to appropriate support groups and/or community-based resources as needed.
- ☐ Ask the patient who is currently involved in their care (partner, family, friends, children, etc.) and if there is anyone else they would like to be involved in their care.

Bit.ly/Advancing
CancerSurvivorshipCareToolkit2019

6,900+ downloads in 7
months

Successes: E-Learning Module



CANCER SURVIVORSHIP E-LEARNING SERIES FOR PRIMARY CARE PROVIDERS

**150+ participants in
Mini-Module**

OVERVIEW

FACULTY

ACCREDITATION

REGISTER/TAKE COURSE

Primary care providers play a critical role in providing follow-up care for cancer survivors, including dealing with many of the physical, psychological, practical, informational and spiritual challenges after the completion of cancer treatment.

Clinicians can learn about caring for survivors of adult-onset cancers through a series of ten enduring online educational modules:

- Module 1: The Current State of Survivorship Care and the Role of Primary Care Providers

COURSE SUMMARY

Course opens:	04/15/2020
Course expires:	12/31/2025
Cost:	\$0.00
Rating:	★★★★★

Challenges due to COVID-19

- Delayed in-person workshops
- No activity on online forum



- Forum was supposed to foster interaction after training
- May not be a fit for audience

Opportunities due to COVID-19



Cancer Center

TIPS FOR COPING WITH COVID-19

A Resource for Cancer Survivors and Caregivers

The COVID-19 pandemic continues to challenge us to find new ways to interact as a society and within our communities. As someone affected by cancer—in treatment, after treatment, or as a caregiver—you may have questions or concerns about how to keep yourself and your loved ones as healthy as possible during this unprecedented time. While the GW Cancer Center does not endorse any particular product or services, below are resources that may help you and those you love while practicing Social Distancing and Sheltering in Place.

Recommendation

Resources



Support your general health through physical activity and healthful eating.

Remember to MOVE! The American Cancer Society provides [guidance](#) on exercises you can do at home and ideas for healthy meals.

Join the [Joyful Movement App](#), practice [yoga at home](#) or learn basic yoga skills with the [Down Dog App](#) (free through May 1, 2020).

Get groceries delivered to you. [Instacart](#) offers home delivery, as does Whole Foods through Amazon.com and [Peapod by Giant](#). Food delivery from local restaurants is also available through [Door Dash](#) and [GrubHub](#).



If possible, use tele-health rather than in-clinic visits until the pandemic is over.

Ask your doctor about tele-health options for visits that may not need to be in-person. The American Cancer Society (ACS) has [suggested questions](#) to ask your doctor about follow-up appointments, going to work and other concerns.

More than 700 downloads since April 2020

Enhancement Award

- Survey of cancer survivors: needs, health care utilization, perceived quality of survivorship care during pandemic
- Survey of cancer survivorship providers: Explore short-and long-term consequences of adjustments to the pandemic
- Incorporate findings to adjust live workshops
- Disseminate findings via webinar and manuscripts



Next Steps

- Surveys
- Zoom platform for virtual meetings
 - Registration
 - Breakout session capability
 - Document attachments
- Possibly live workshops
- Reassess Forumbee



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[Bit.ly/Advancing CancerSurvivorshipCareToolkit2019](https://bit.ly/AdvancingCancerSurvivorshipCareToolkit2019)

Sign-up for the GW Cancer Center's Patient Navigation and Survivorship E-Newsletter: bit.ly/PNSurvEnews

Sign-up for the GW Cancer Center's Cancer Control Technical Assistance E-Newsletter: bit.ly/TAPenews

Best Practices for Online Engagement

Building Research Partnerships to Improve Sexual and Reproductive Health for Women with CF

Emily Godfrey, MD, MPH, Project Lead
Molly Pam, Patient Partner

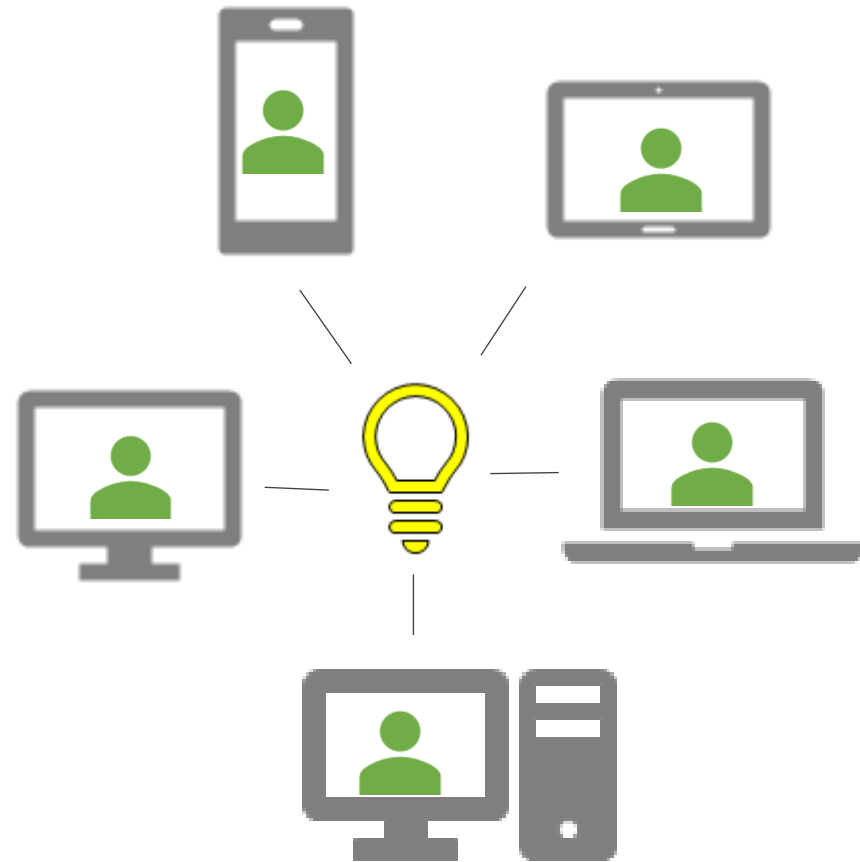
Department of Family Medicine,
University of Washington

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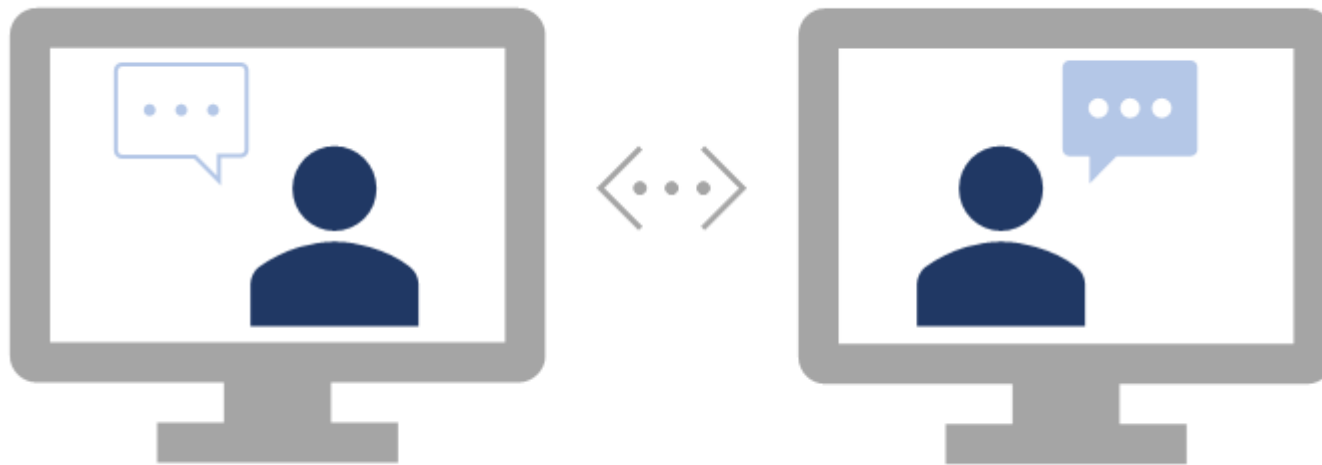
Cystic Fibrosis (CF)

- A progressive, genetic disease that causes persistent lung infections, pancreatic insufficiency and affects other organs in the body
- There is a high risk of cross-infection when people with CF are in close contact with one another
- Our PCORI engagement team has been engaging virtually since the start of our project



What We Proposed

- “User Guide” for PCOR teams that engage solely online



What Was Done

- Semi-structured interviews using Zoom conferencing software
- Key informants:
 - CF community members
 - Non-profit stakeholders
 - Researchers
- Audio recorded, transcribed, and uploaded into dedoose for analysis



What We Found



Online Platforms Enhanced Collaboration

Using video enhanced collaboration by

- Developing connection
- Increasing focus and accountability

Other online platforms helped

- Improve efficiency
- Overcome distance



Multiple Platforms Are Needed

Document sharing

Dropbox, Google Docs.

Communication tools

E-mail, Slack, WhatsApp.

Project management software

Asana, Trello

Scheduling

Doodle, Calendly

Workflow Automation

Zapier, Microsoft Flow, Monday

Video Conferencing software

Zoom, Bluejeans, WebEx, Skype, GoTo Meeting, Google Hangouts, Facetime, WhatsApp

Values for Tool Selection

What to consider when selecting a tool

- Access
- Cost
- Integration
- User-friendliness
- Synchronicity
- Security + Privacy

Challenges of working remotely and using communication technology

- Technology inconsistency
 - Faultiness
 - Resource disparities
 - Inconsistency in tool adoption/use
- Establishment of norms
- Communication challenges
- Buy-in (institutional and individual levels)
- Personal connectedness



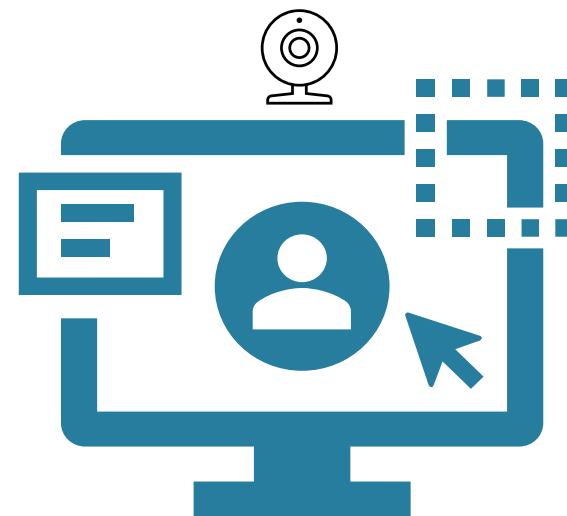
Suggestions for Successful Virtual Engagement

- Be willing to change (establish buy-in)
- Provide a specific purpose for using the new platform
- Create norms to develop community so that team members feel sense of shared purpose



What to think about before choosing a platform

- Know the technology needs before starting video conferencing
 - Camera
 - Internet
 - Headphones
- Know your team's online user literacy
- Consider language and disability barriers



Contact Information

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Q&A and Wrap-Up

- Feel free to ask questions by typing into the Questions pane on the Control Panel.
- Recording and slides will be posted on the event page after the webinar.

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Visit: <https://www.pcori.org/engagement/eugene-washington-pcori-engagement-awards>

Thank You!

