

# Elder Care Medicine Network: Engagement of Older Adults and Caregivers as Partners in Medication Optimization Patient Centered Outcomes Research



Jodi-Ann Haynes, BS, PharmD Candidate, Sabrina Wang, BS, PharmD Candidate, Viviane Tang, BA, PharmD Candidate, Merton Lee, PharmD, Drew Genuit, BE, Brian Isetts, PhD, Catherine E. Cooke, PharmD, MS, BCPS, PAHM, Nicole Brandt, PharmD, MBA

**Community Council:** Jennie Jarrett, Les Krenk, Rudolf Lamy, Pat Merryweather-Arges, Judy Mikami, Karen Pellegrin, Del Price, Avra Thomas, Dayna Wong-Otis; Todd Selma, Jeanette Averett



## Background

The cumulative effects of health determinants are more prevalent as individuals age and endure multiple chronic conditions needing multiple medications. To meet this growing concern, additional evidence is needed to improve approaches to addressing medication-related needs care for older adults. Engaging older adults, caregivers and family is necessary to produce relevant and meaningful evidence. Patient-centered-outcomes research (PCOR) engages these individuals as research partners.

## Objective

This project describes efforts to increase capacity of local communities – older adults, their caregivers, healthcare providers and researchers – to participate in medication related PCOR.

## Partnership



### 3 regional partners:

- Hawai'i Islands
- Midwest (Illinois, Minnesota)
- MidAtlantic (West Virginia, Pennsylvania, Delaware, Maryland, Washington DC, Virginia)



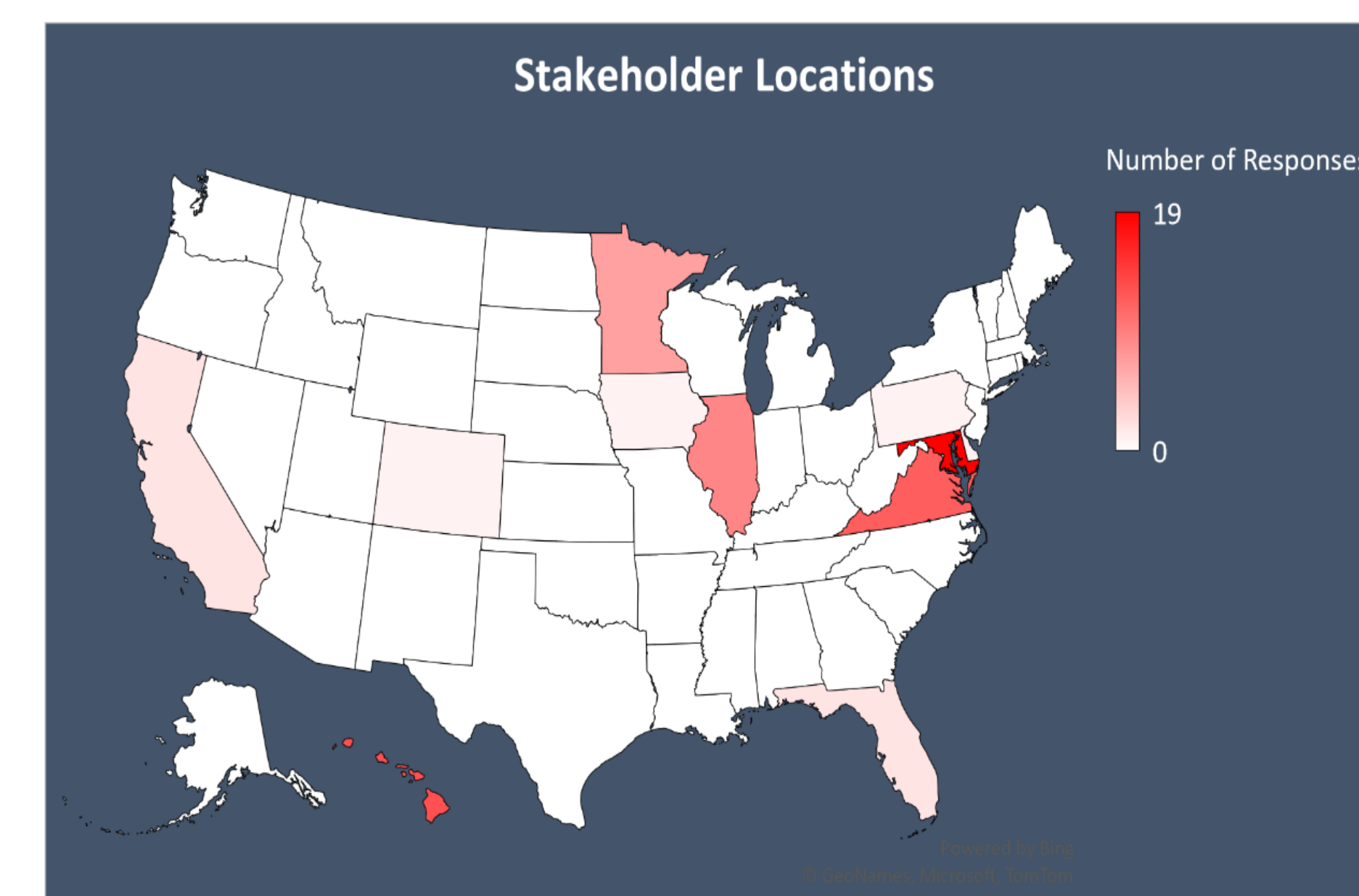
## Community Council

A Community Council of 12 members (4 from each region) was formed with 6 older adults/caregivers and 6 pharmacists/researchers to guide the project. The Council created the network name, the Elder Care Medicine Network (ECMN), including logo and website (publicly available), along with a 'one-pager' to educate about the project in plain language.

## Accomplishments

### Network Development and Growth

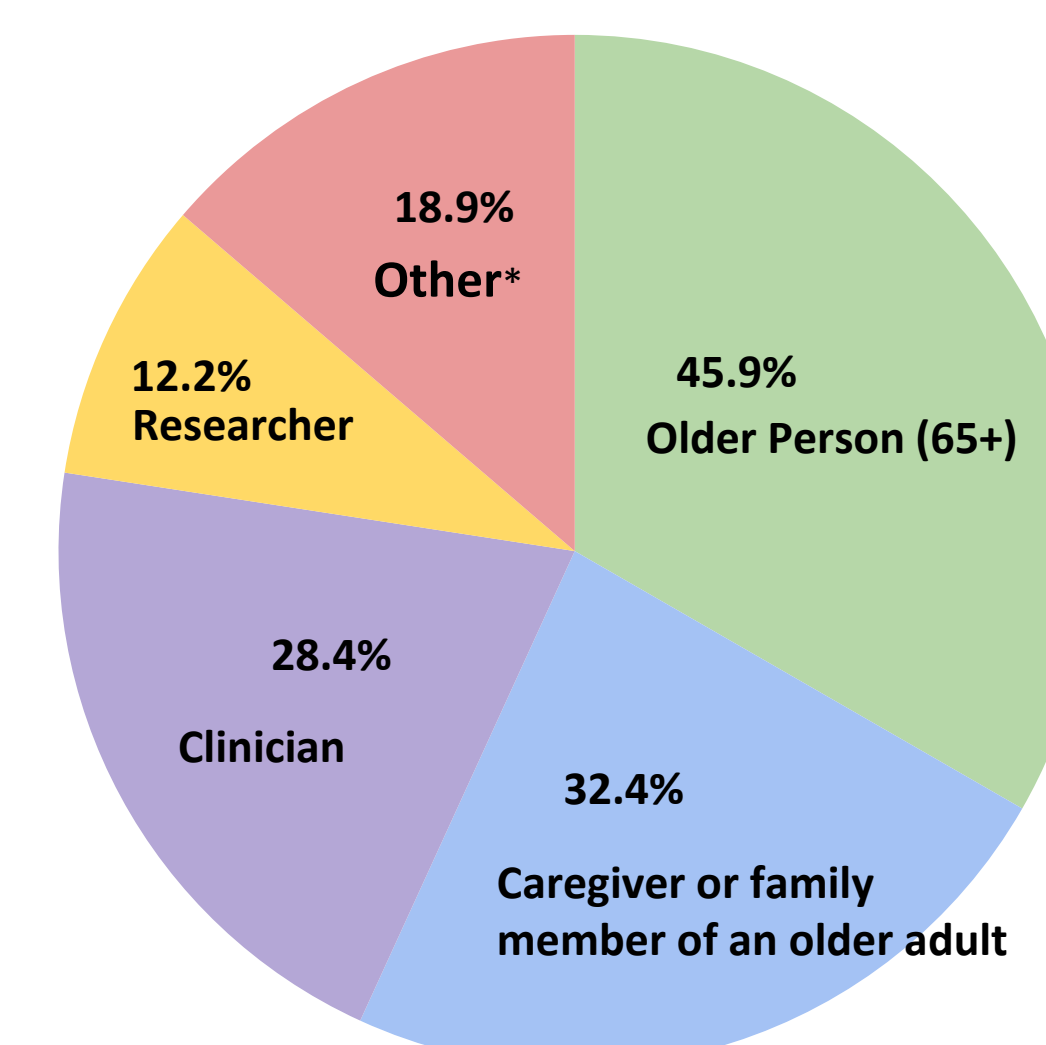
- Elder Care Medicine Network has engaged over 100 older adults, caregivers, pharmacists and researchers
- Network expansion beyond original 3 regions (see Figure)



### Assessing the needs of stakeholders to learn about PCOR

- Survey sent to network registrants

Stakeholder Groups (n = 74)



Important Topics for PCOR Discussion	%
Explain patient-centered outcomes research and PCOR	71.6
Share examples of how community members can participate on a research team	73
Hear from community members on how they felt the first time they participated on a research team	47.3
Talk about developing trust with the research team	55.4
Discuss how the community member can work with the research team to explain which questions people might be reluctant to share	73
Learn about common terms that the research team uses	67.6
Discuss how to help the people in my community understand what the research results mean to them	74.3
Other*	12.2

### Discussion Sessions about PCOR with ECMN

- Based on results of needs assessment, a facilitator's guide was developed to guide discussions sessions with stakeholders about PCOR
- During the discussions, medication-related needs were identified

#### Identifying Priority Themes for our Network

How best to work with a pharmacist about your medicines
Communicating with pharmacists about medication related problems or concerns (e.g., dosing, side effects, quantity of medications taken)
Safe ways to reduce or deprescribe medications.
How to safely use traditional medicine with complementary and alternative.
What supplements are safe when using other medications
Using apps or reminders to help keep track of medications.
How to reduce medication problems in older adults and as caregivers
Best ways to work with older adults and/or caregivers to co-design and participate in research (Help researchers ask questions)
Best practices to help address caregiver fatigue and stress regarding medicines

#### Developing PCOR Agenda

- Surveying ECMN to determine medication-related research agenda

## Engagement

- Deciding the network name and logo brought greater investment and fostered community among our 3 regions
- Community Council ensured plain language terms were used.
- Building the ECMN website allowed centralized access point and sharing of our work beyond the ECMN
- PCOR Medication related video interviews were produced and uploaded to the ECMN website
- Newsletters featuring regional activities were shared with the ECMN every other month
- Book club on reducing medication was held
- Presentations at Pharmacy Quality Alliance and the American Society of Consultant Pharmacists meetings

## Conclusions

- Working together facilitated accomplishments
- Future efforts will focus on conducting PCOR with network members to address their medication-related needs.
- Sharing of the co-designed research agenda will help further medication related PCOR that matters to older adults.

## Reference

- Heckert A, Forsythe LP, Carman KL, et al. Researchers, patients, and other stakeholders' perspectives on challenges to and strategies for engagement. Res Involv Engagem. 2020;6:60. doi:10.1186/s40900-020-00227-0

## Support

This project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award #21121-UMD.

