

# Hearing the Older Adults and Caregivers Voice in Medication Optimization Initiatives

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## 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 for addressing the medication-related needs of caring for older adults. Engaging older adults, caregivers, and family is necessary to produce relevant and meaningful evidence and tools.

## Objectives

**Elder Care Medicine Network (ECMN) :** Develop a co-designed medication-related research agenda through engagement of caregivers/families, healthcare providers and researchers.

**PRIME (PReparing people living with dementia and their carers to initiate deprescribing conversations about MEdications):** Develop a co-designed consumer-centric, educational tool to empower people living with dementia and their caregivers.

## Methods

**Elder Care Medicine Network (ECMN)**

**3 regional partners:** (1) Hawai'i Islands; (2) Midwest (Illinois, Minnesota) & (3) MidAtlantic (West Virginia, Pennsylvania, Delaware, Maryland, Washington DC, Virginia) consisting of 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.



### Network Development and Growth

- Elder Care Medicine Network has engaged over 120 older adults, caregivers, pharmacists and researchers.

### PRIME

- Formed a diverse, international stakeholder steering group (SG) comprised of 6 consumers (3 people living with dementia; 3 caregivers) and HCPs (2 geriatricians, a general medicine clinician, a nurse practitioner, and a social worker)
- Conducted six one-hour SG meetings to select key elements, plan interviews with consumers and revise the draft of the tool
- Conducted 35 one-to-one semi-structured interviews and a focus group session (26 with consumers; 9 with HCPs to assess readability.

## Results

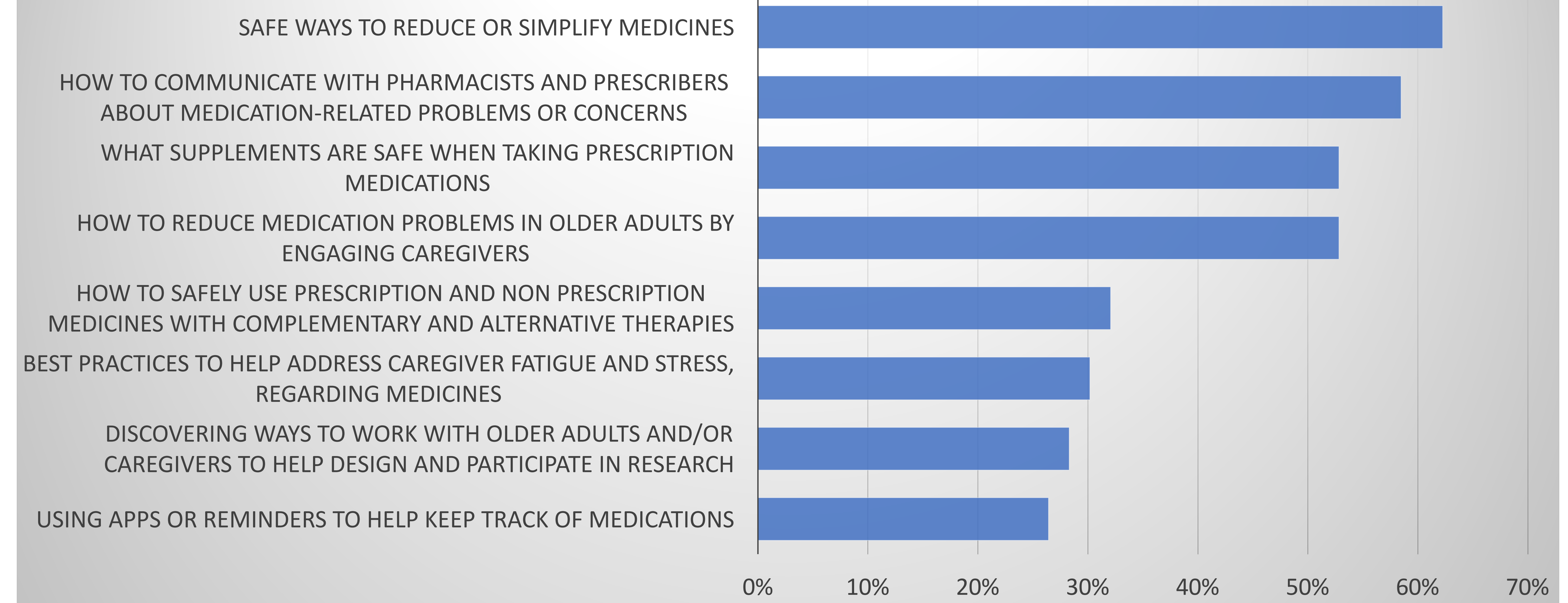
### ECMN Results

#### Medication Related Research Agenda

- Total of 53 completed survey respondents out of 110 network members (48% response rate).

Demographic	N	%
<b>Gender</b>		
Male	13	24.53%
Female	40	75.47%
<b>Race/Ethnicity</b>		
Asian	4	7.55%
Black or African American	19	35.85%
Hispanic or Latino/a	0	0.0%
Native Hawaiian/Pacific Islander	1	1.89%
Middle Eastern/North African	1	1.89%
White	27	50.94%
Prefer not to say	1	1.89%
<b>Age In Years</b>		
≤ 44 years	11	20.75%
45-64 years	14	26.42%
65-74 years	9	16.98%
75-84 years	16	30.19%
≥85 years	2	3.77%
Prefer not to say	1	1.89%
<b>Stakeholder Group(s)</b>		
Older Person	29	54.72%
Caregiver/Family of older adult	11	20.75%
Clinician	17	32.08%
Researcher	9	16.98%
<b>Education</b>		
Grade or Elementary	0	0.0%
High school graduate or GED	3	5.66%
Post HS training (vocational)	0	0.0%
Some College	3	5.66%
College Graduate	11	20.75%
Postgraduate	36	67.92%

### Topics Recommended for Future Research Efforts



## Conclusions

- These 2 different initiatives complement each other in that the prioritized area identified primarily by older adults focused on safe ways to reduce or simplify medicines.
- The PRIME tool provides people living with dementia and their carers a way to initiate deprescribing conversations with their healthcare team.

## Support

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

**PRIME:** Funding: National Institute of Aging (US Deprescribing Research Network) 1R24AG064025



## Results: Co-designed the PRIME tool

**The purpose of this tool is to:**

- Empower you to start a conversation with your health professional (e.g., pharmacist, doctor, nurse) about how your medicines may impact your day-to-day activities
- Make you aware that some medicines may cause side effects

**Get familiar with the medicines you or the person you care for takes.**

These medicines may be from your doctor and any other medicines you buy from the pharmacy or supermarket

**Do not change your medicine(s) without speaking with a health professional**

**How to start a conversation about your medicines**

This is a tool to help people living with dementia or memory problems and their carers start a conversation about reviewing their medicines with their health professional

You may choose to bring this to your next medical visit

**BACKGROUND**

The benefits and harms of medicines can change over time

Reviewing your medicine list can help you consider:

- Your goals of care
- The trade-off between the benefits and risks of your medicines

**Talk to your health professional about your medicines if:**

- You are experiencing side effects from the medicine(s) such as:
  - Increased confusion
  - Falls
  - Drowsiness or sleepiness
- Your health has changed or worsened
- You want to take less medicines
- Your medicines are no longer working or making you feel better

**SELF REFLECTION**

Please circle your answer

- Do you know what medicines you take? Yes Maybe No
- Do you think you take too many medicines? Yes Maybe No
- Do you think that you are taking any medicines that you don't need anymore? Yes Maybe No
- Do you get stressed if changes are made to your medicines? Yes Maybe No
- Have you had a bad experience in the past when a medicine was stopped? Yes Maybe No
- If your doctor said it was possible, would you stop one of your medicines? Yes Maybe No
- Overall, are you satisfied with your medicines? Yes Maybe No

**CALL TO ACTION**

Which medicines would you like to talk to your health professional about?

To start a conversation with your health professional about your medicines, you could say:

I don't like taking \_\_\_\_\_ (write name of medicine). I'm worried it's giving me side effects, or I don't think it is working. Could you please review it? or

I'm not sure why I take \_\_\_\_\_ (write name of medicine). Could we talk about this? or

I would like you to please review if I still need this medicine. Could I possibly stop taking this medicine?

**CONTACT US**

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The PRIME tool was co-designed with people living with dementia, their carers, health professionals and researchers from:

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