

Grand Rounds

Shaping Dementia Research Together: Engaging People Living With Dementia and Care Partners

Presenters



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IMPACT Community Review Panel



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Housekeeping

- All participants will be muted upon entry
- Enter **all questions** in the Zoom **Q&A/chat box** and send to Everyone
- Moderator will review questions from chat box and ask them at the end
- Visit impactcollaboratory.org
- Follow us on LinkedIn



NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE



ENGAGING
PARTNERS TEAM

Shaping Dementia Research Together: Engaging People Living with Dementia and Care Partners

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Why Does it Matter?

Engaging people living with dementia and care partners is essential to ensure interventions are **acceptable** and **aligned** with community priorities, and that the results of embedded Pragmatic Clinical Trials (ePCTs) will have a positive **impact**.

Engagement Across the Research Cycle



Engagement Across the Research Cycle

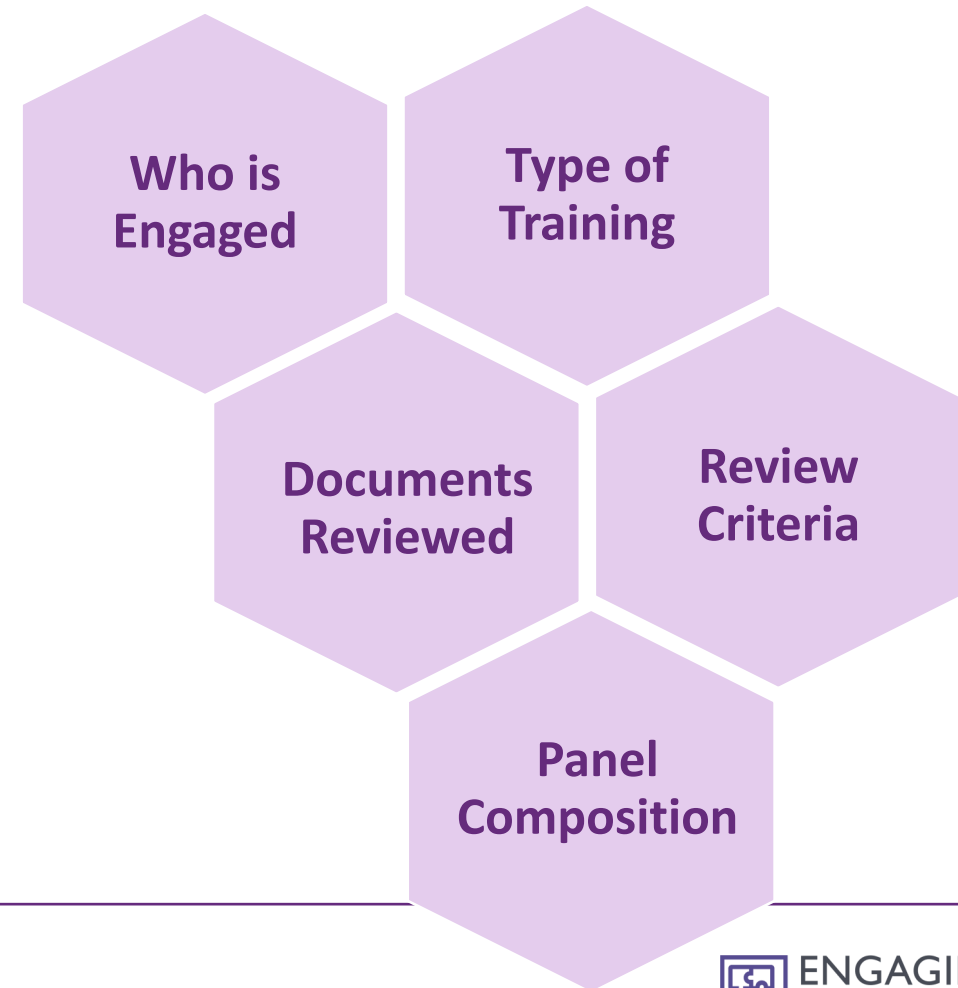


Engagement in Proposal Review

Organizations that involve members of the public in proposal review

- Patient Centered Outcomes Research Institute (PCORI)
- Clinical and Translational Science Award Recipients (CTSAs)
- National Institute for Health and Care Research (NIHR)

Approaches Vary



IMPACT Community Review Panel

- Established to engage people with lived experience in reviewing applications for IMPACT research funding
- 8 to 12-member panel including individuals living with cognitive symptoms and care partners

Pilot Grant

Designed to test the feasibility and inform the design of future full-scale, Stage IV effectiveness ePCT to evaluate non-pharmacological interventions.

Demonstration Project

Designed as full-scale, Stage IV effectiveness ePCTs to evaluate the effectiveness of non-pharmacological interventions.

Engaging People Living with Cognitive Symptoms

Capacity

Heterogeneity

Approaches

Care Partners

Engaging People Living with Cognitive Symptoms

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- Clear roles
- Fit with capacity, strengths, and preferences
- Progression of symptoms over time

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- Range in disease severity
- Diversity in race and ethnicity, gender, etc.

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- Accessible written materials
- Sufficient time to review materials in advance
- Frequent check-ins and individual support

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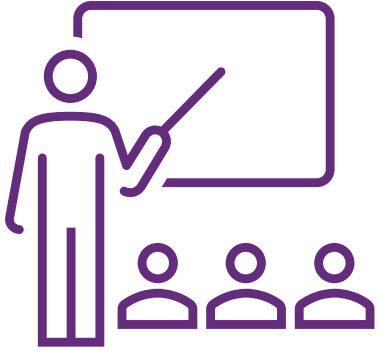
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Care Partners

- Level of burden
- Own perspective or responding as proxy

Orientation and Training



- One-on-one call with new panel members
- Welcome packet describing IMPACT and the review process
- Optional orientation meeting before each review meeting

General Audience Summary

Required for all Pilot and Demonstration Project Applications

1

Please describe your study in 5-7 sentences. What are you proposing to do? Think of this description as your elevator pitch.

2

Why are you proposing this study? What problem(s) does your intervention solve for people living with dementia and care partners? How do you know?

3

What makes you think that the intervention will work? Has the intervention been tested before? What is the background for this intervention?

General Audience Summary

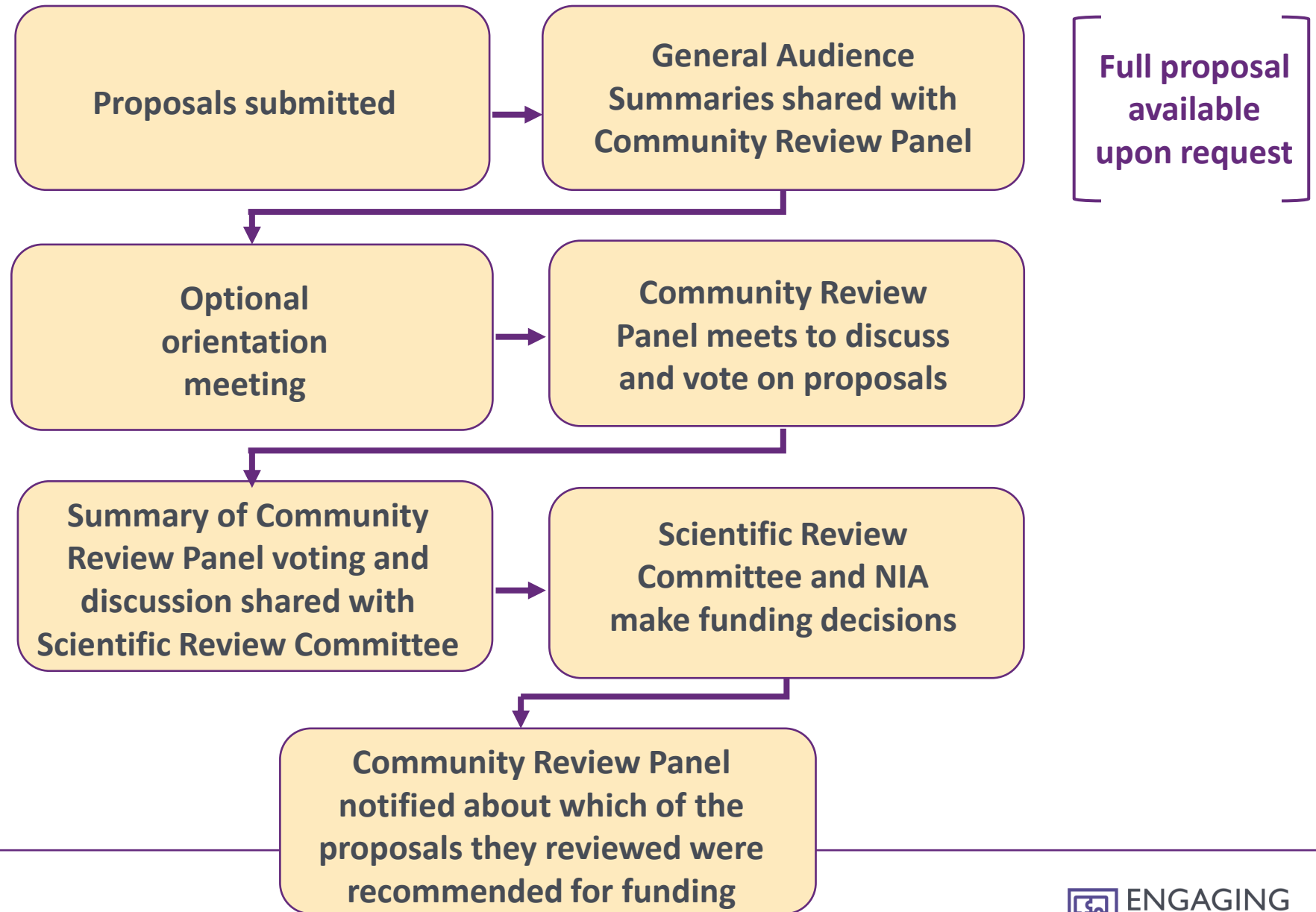
4

Will people living with dementia and care partners be recruited to participate in your study? If no, please describe the targeted population (i.e., health care providers). If yes, please describe the recruitment process. *Include specific examples of the consumer-friendly language, including ways you have ensured the readability of materials, that you will use to pitch your study and recruit people living with dementia and care partners. Please describe any efforts to address health equity.*

5

What are your outcomes? How will they be measured? Why are these outcomes important to people living with dementia and care partners? How do you know?

Review Process



Review Criteria and Voting

1. Is this research important?
2. Does this research address an unmet need for people living with dementia and care partners?
3. Will this research make a difference in the real world for people living with dementia, care partners, and health care systems?

Yes: This proposal should be recommended for funding

No: This proposal should NOT be recommended for funding



Questions?

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