

Empowering community members

to promote dementia research participation in high-risk communities: results from a realist review

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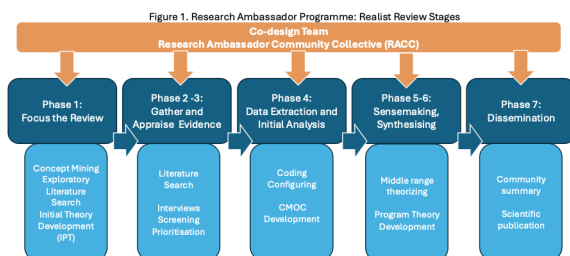
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INTRODUCTION

- Dementia risk is highest for rural, African-American, Hispanic and indigenous communities.
- It is critical to engage these high-risk communities in dementia research - one promising strategy is to leverage the strength and skills of community members.
- The Alzheimer's Clinical Trials Consortium (ACTC) is co-creating a research ambassador platform to empower community members to promote research participation
- We are conducting a realist review to make explicit how programmes that empower volunteers work, who they work for, and the impact context has on expected and unexpected outcomes.

METHODS



CO-CREATED GLOSSARY

TO EMPOWER - the ability to grow, reach out or stand up for what is important to me. *

"Being empowered eliminates fear, it encourages people to go forward with new thoughts and ideas."

TO ADVOCATE - to stand up and speak for someone else in order to bring about change *

"I think of advocacy as a pinch hitter in baseball. You are stepping in to go to bat for a person." *

RESULTS

21 programmes were included and realist interviews were conducted with 17 participants and staff to gather additional explanatory insights.

A co-created glossary of key terms was developed to inform analysis and translation of results to the lived experience of empowerment in dementia.

Figure 2. Our co-created theory of empowerment in dementia



THEORY AREAS

1. Meaningful to the person
2. Co-created and shared expertise
3. Peer support, friendship and joy
4. Customized for community
5. Recognition and Authority
6. Growing and taking action

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CONCLUSIONS

The results reveal aspects of programme mechanisms that would not be discoverable through other research methods.

Our study reveals how the seven theory areas are needed in combination to foster empowerment.

We will translate these learnings to co-create a Research Ambassador Platform

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