

Evaluation of Engagement with a Diverse Stakeholder Advisory Council for Research in Dementia Care

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BACKGROUND

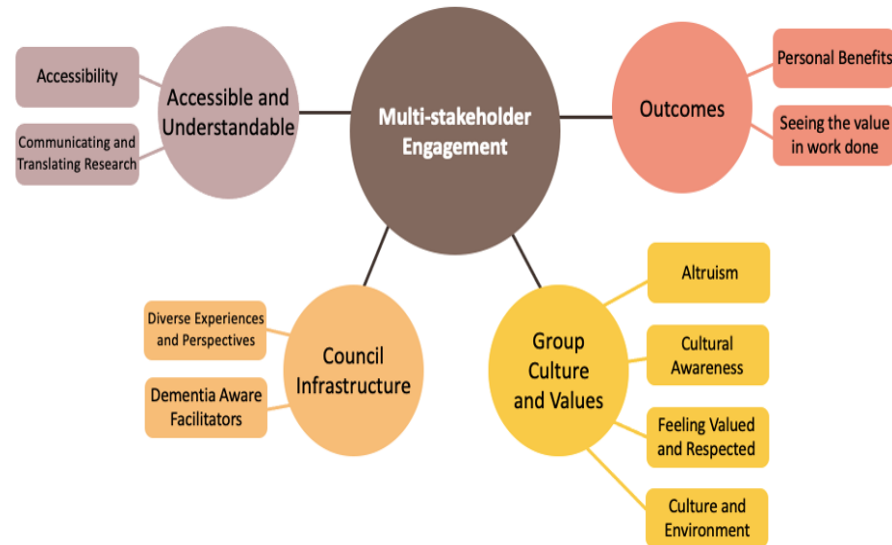
- The **purpose** of this preliminary research was to evaluate the SAC's engagement in setting research priorities.
- Stakeholder Advisory Councils (SACs) incorporate multi-stakeholder perspectives and provide a useful mechanism to generate translational research
- Person(s) living with dementia (PLWD), care partners, health and social care professionals, and researchers from the San Antonio community were brought together to establish a SAC in order to identify priorities in dementia care research
- The input from PLWD and their care partners, along with the other members in the SAC, was critical and provided valuable insight into many of the gaps present in dementia care.

METHODS

- Semi-structured individual interviews were conducted with members of the SAC (n=11)
- Core Principles for Involving People with Dementia in Research* (SDWGR, 2014) was used as a sensitizing framework
- Two researchers then independently reviewed, analyzed, and coded transcripts from each interview.
- A **thematic analysis** was used to evaluate and discover common themes related to SAC member engagement

RESULTS

- Ten unique themes emerged from the data and were grouped under four domains: Group Culture and Values, Council Infrastructure, Outcomes, and Accessible and Understandable.
1. Feeling valued and respected
 2. Diverse experiences and perspectives
 3. Culture and environment
 4. Cultural awareness
 5. Dementia aware facilitators
 6. Communicating and translating research
 7. Accessibility (planning and logistics)
 8. Personal benefits to participating
 9. Altruism
 10. Seeing the value in the work done



"Personally, I thought it's one of the best things that could come up....it works out very well. It's been real good for me." – Person Living With Dementia

"She (facilitator) was very cognizant that not everybody in the room had a large or small research background. We started everything at the beginning..." –Care Partner

"Everyone has an opportunity to say something that can change the dynamic of the research, to impact the people." –Social Care Professional

"...my lived experiences, I feel like, have been listened to and respected, and have been maybe an asset to where we're trying to go." –Care Partner

"I love the fact that we have so much diversity. That's really, really important. ...They don't have to look like you. They don't have to have the same background. They don't have to have the same language by any means but you function well together, that's a beautiful thing. That's called harmony." –Social Care Professional

Conclusion

- Findings suggest that there are many important considerations for establishing diverse SACs
- PLWD are not often engaged in the SAC model for research, though their perspectives are critical for research that is translatable and relevant
- When collaborating for research with multi-stakeholder groups, accommodating the needs of PLWD can facilitate meaningful engagement for all members

References
Scottish Dementia Working Group Research Sub-Group (SDWGR), UK (2014). *Core principles for involving people with dementia in research: innovative practice*. Dementia (London, England), 13(5), 680–685.

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