

Barriers to the inclusion of underserved groups in research about co-existing dementia and hearing conditions

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Background, Aims and Methods

Introduction:

Dementia and hearing conditions commonly co-occur. It is important that research includes people who experience both dementia and hearing conditions, and people from underserved groups, to address health disparities.

Aims to:

- 1) Identify who is underserved
- 2) Identify what barriers they experience in dementia and hearing research

Methods:

- Semi-structured interviews and focus groups with professionals
- Maximal Diversity Sampling: Approached staff from a variety of relevant professions with experience of working with different underserved groups
- This formed the first part of an experience-based co-design method (Fig1)



Figure 1. Experience based co-design method

Participant characteristics

		N
Gender	Female	21
	Male	2
Ethnicity	White	11
	Asian/ Asian British	8
	Black, Black British, Caribbean or African	2
	Arab / British Arab	1
	Mixed / Multiple ethnic group	1
Profession (note some staff worked across multiple professions)	Research	14
	Primary care	2
	Secondary care	8
	Social care	3
	Voluntary sector / community engagement	2
Direct personal experience of hearing conditions	Tinnitus	3
	Hearing Loss	1
	Deaf Community	1

* We are learning and listening to feedback and will be updating the way we collect and report demographic characteristics

Results: Barriers related to...

Dementia and hearing conditions	Organisational priorities and systems	Researchers, practices and processes
<ul style="list-style-type: none">• Stigma associated with dementia and / or hearing conditions• Misunderstandings and lack of awareness of the conditions• Difficulties with long-term follow-up (when involving people with dementia)• Rigid inclusion of research means that having one condition will often exclude participation in research about the other	<ul style="list-style-type: none">• Mistrust of organisation / health services/ research• Ineffective information sharing and awareness raising of research and health conditions• Differing priorities of institutions/ funders from communities• Poor relationships with 'gate-keepers'• Inflexible ethics and system requirements• Lack of co-ordination between researchers working with underserved groups	<ul style="list-style-type: none">• Communicating in ways that prioritise researchers' budgets and time (e.g. communication in English; digitally)• Not collecting data related to diversity and inclusion• Reliance on participants being linked into a healthcare system (e.g. for recruitment)• Lack of funding for more intensive (inclusive) recruitment methods
<p>“ Some of the blame may cast on ...clinicians and researchers... sometimes it's not clear and sometimes the information [about dementia] is not out there in those communities ... if it's not targeted at those communities, then they are not likely to... have access to it or engage with it since they don't even know about it. ”</p>	<p>“ The big thing is a mistrust toward research ... people will not respond to your e-mail or telephone call as much ...because they don't trust what you're going to be doing ... because these communities have always been ... not only neglected but disenfranchised by research in general. ...there is that idea that you need to protect yourself and your community from research. ”</p>	<p>“ With dementia and older age research I don't think you ask questions about sexual identity ...there's this ... stereotype or assumption that older people are you know, sexless.... but if you don't ask, you don't ... know the kind of population you're involving ... and how can you then translate that into service development or improvement if you don't know what the needs are? ”</p>

Conclusions

Barriers are highly context-specific, and intersectionality is important. However, some common barriers were identified, and whilst some reflect societal and structural problems, others could be immediately addressed by organisations and individual researchers to improve the inclusion and participation of underserved groups in dementia and hearing research.

Further work is needed to develop targeted tools, methods and recommendations to address these issues.

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