

National Survey of Alzheimer Cafés in Ireland

Presenter: Áine Teahan
Centre for Economic and Social Research on Dementia, NUI Galway



@aine_teahan

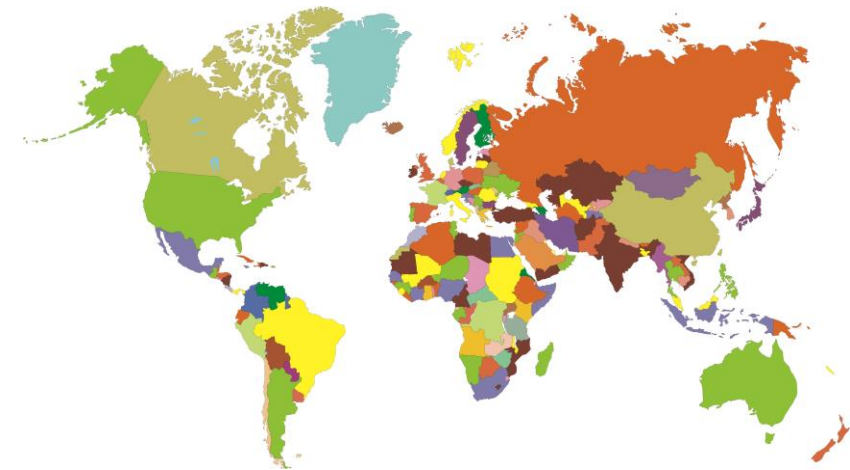
email: a.teahan1@nuigalway.ie



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Background

- Originally set-up by Beré Miesen in 1997
- Addressing psychosocial aspects of dementia
 - Social network development (Greenwood et al., 2017; Dow et al., 2011; Capus et al., 2005)
 - Reduce Isolation (Dow et al., 2011)
 - Information source (Dow et al., 2011; Capus et al., 2005)
 - A sense of place and social inclusion (Akhtar 2017)
 - Normalising dementia (Greenwood et al., 2017)
 - Improved wellbeing, vitality, and emotional burden (Merlo, 2017)
- Education and support intervention
- International uptake: Europe, Australia, America, South America, Canada etc.



The Changing Café

European Model

- Themed and medical discussions
- Access and consultation with healthcare professionals
- Venue is flexible once it is accessible
- Safe space to discuss dementia

American Model

- Primarily a social gathering
- Located in a community business like a coffee shop or restaurant
- Dementia is 'not in the room'
- Primary aim to reduce isolation

Australian Model

- Social and informational focus
- Flexible location
- Informal 'counsellors'
- Guest speaker or an entertainer
- External contact encouraged

Our Research: Irish Model?

Map existing Alzheimer Café provision across the country

Explore the key characteristics; establishment, structure, program, facilitation, attendance, governance, funding

Survey Methodology

Identification

- Alzheimer Society of Ireland website, google searches, local newsletters, facebook pages

Confirmation

- Closure, contact details had changed, change of co-ordinator
- Phonecalls, e-mails, word of mouth, referrals

Survey

- Online survey informed by earlier qualitative data
- Project Advisory Groups

Follow-up

- Two follow-up points of contact to maximise response rate

Findings

1. Mapping

2. Activities

3. Governance

4. Attendance

5. Funding

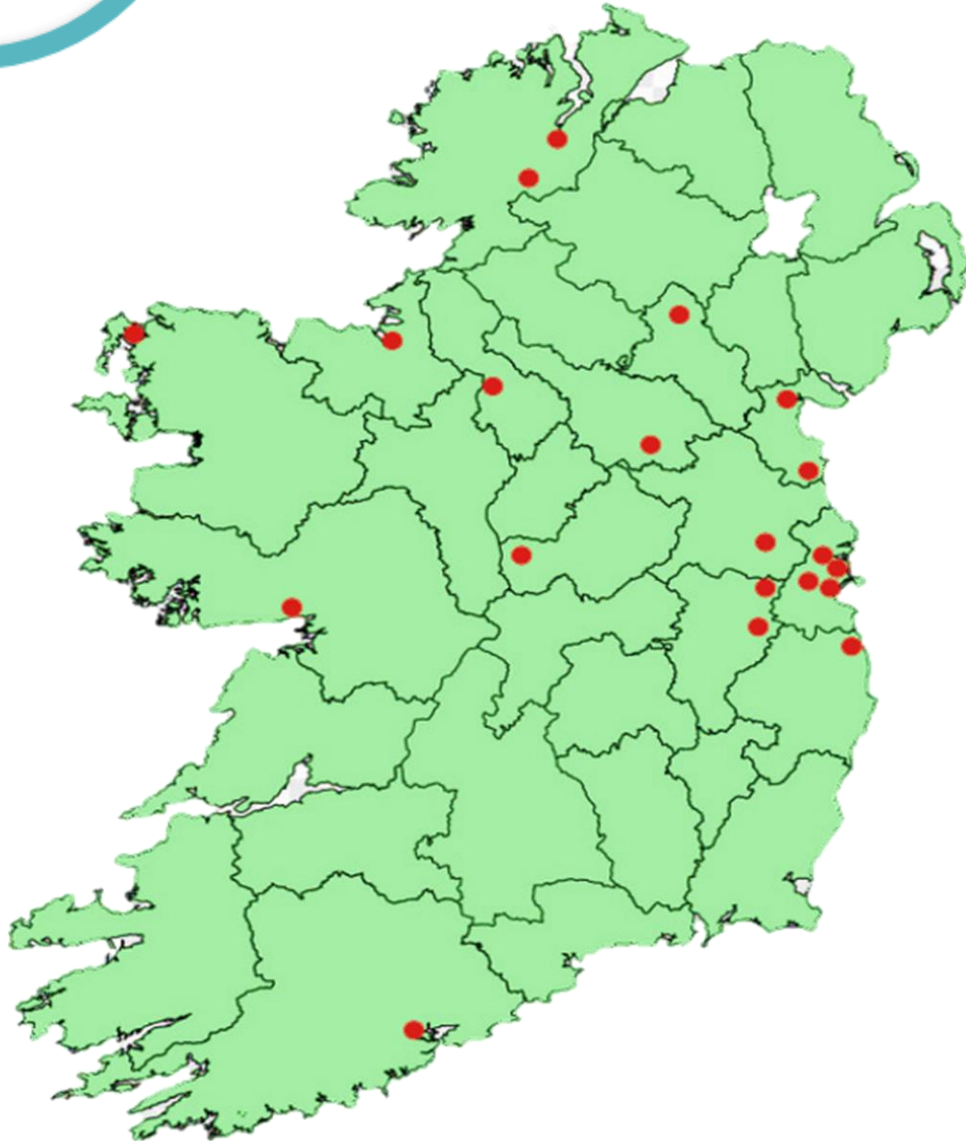
6. Challenges

1. Mapping

- First Alzheimer Café established in 2011
- 26 Alzheimer's Cafés have been set up across Ireland
- 20 Alzheimer Cafés are currently running (100% response rate)
- Developed inconsistently across the country



1. Mapping



CHO 1 Cavan, Donegal, Leitrim, Monaghan and Sligo	6
CHO 2 Galway, Roscommon, Mayo	2
CHO 3 Clare, Limerick, North Tipperary/East Limerick	0
CHO 4 Kerry, North Cork, North Lee, South Lee, West Cork	1
CHO 5 South Tipperary, Carlow/Kilkenny, Waterford, Wexford	0
CHO 6 Wicklow, Dun Laoghaire, Dublin South East	1
CHO 7 Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West	4
CHO 8 Laois/Offaly, Longford/Westmeath, Louth/Meath	4
CHO 9 Dublin North, Dublin North Central, Dublin North West	2

2. Activities

Once a month (90%)
Two hour duration (75%)

Most
common

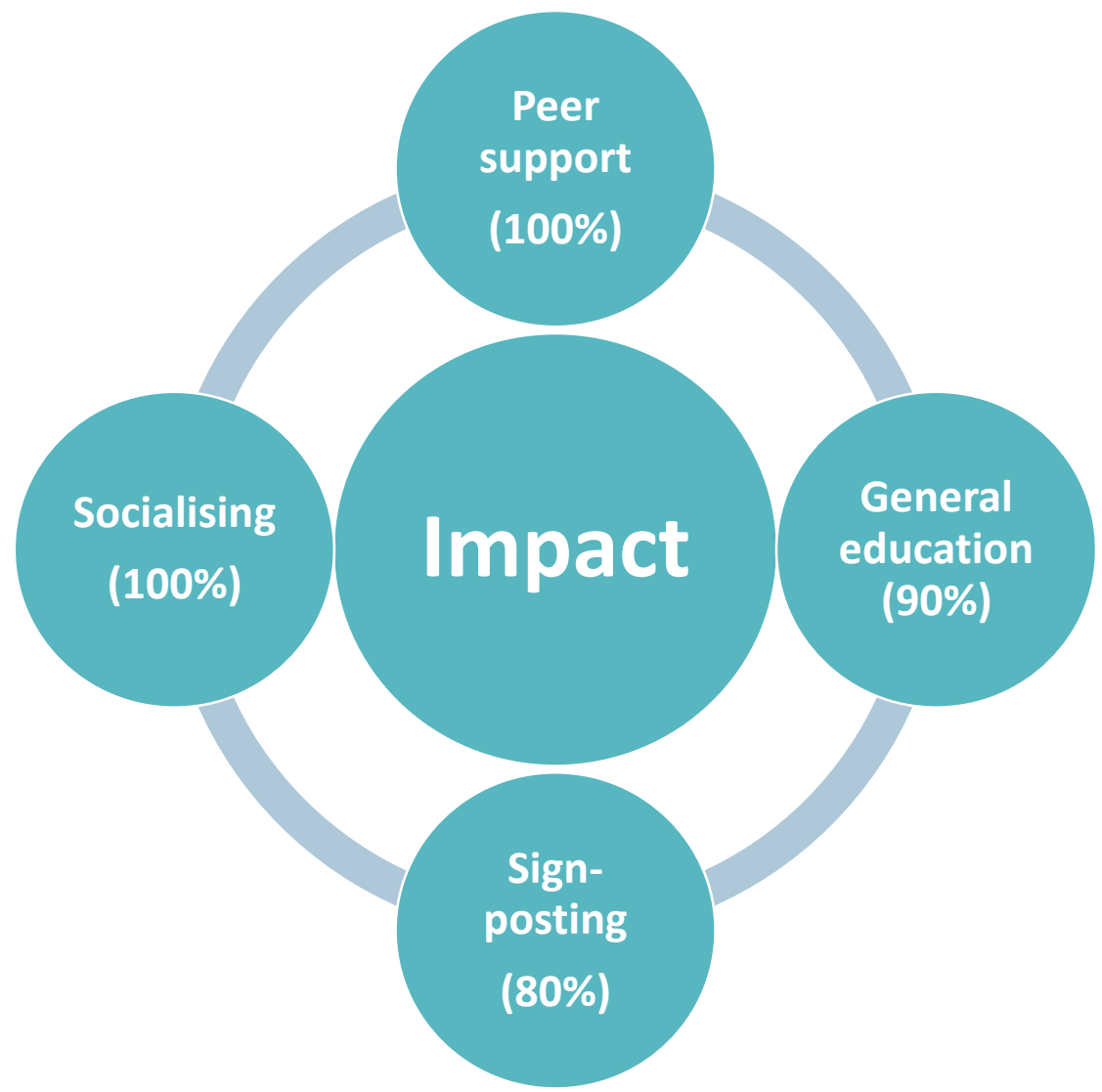
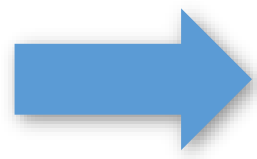
Less
common

Attendees arrive and are greeted
Informal chatting
Consulting with volunteers/healthcare professionals
Open discussion on dementia
Guest speaker (90%)

Separate activities (10%)
Different venue every Café (5%)
Music and dance (50%)

2. Activities: Impact

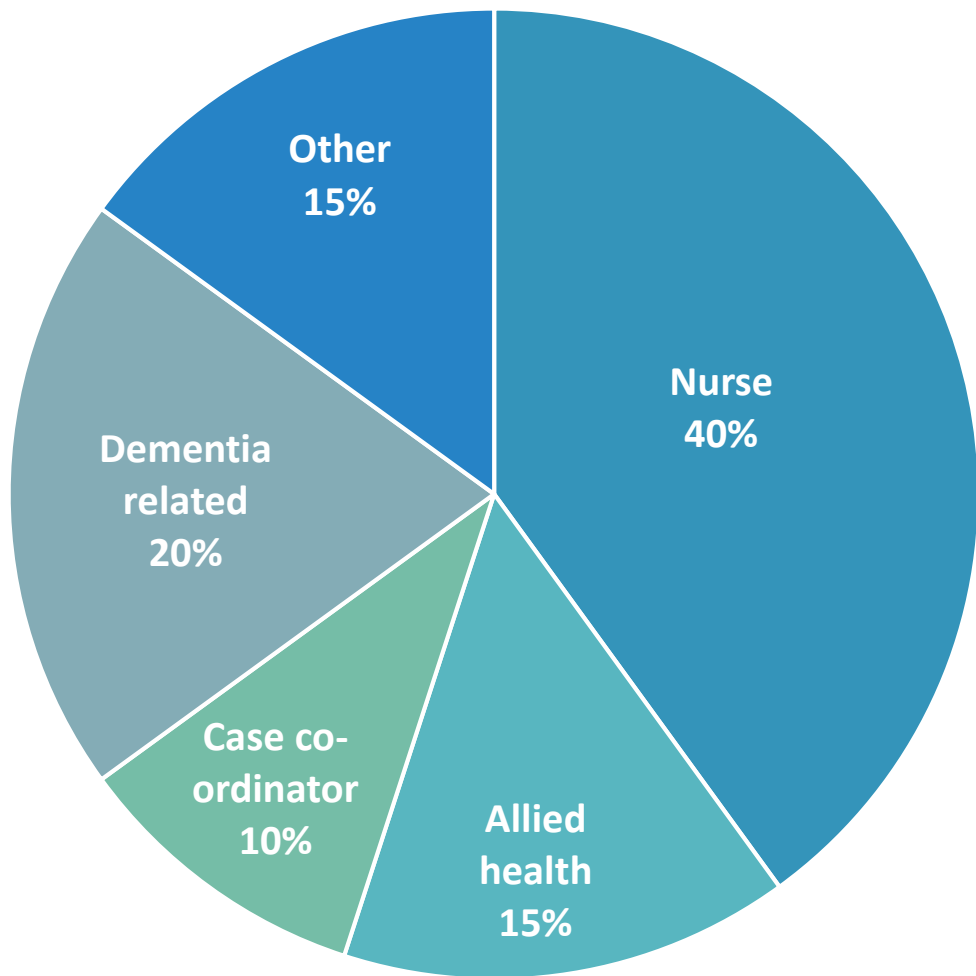
Activities



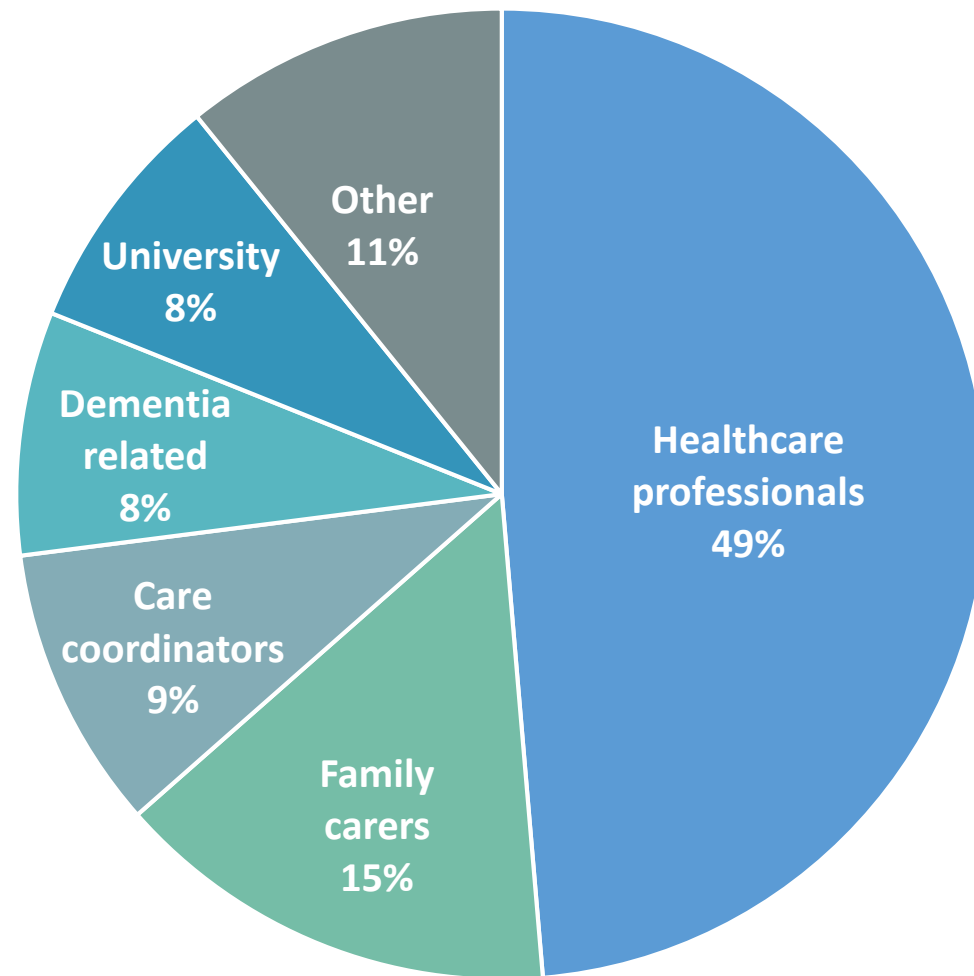
3. Governance

Co-ordinator	Volunteers	Steering Group
<p>60% attended Alzheimer Café training</p> <p>70% have contacted other Cafés</p> <p>74% spend 0-5 hours organising the Café, 21% spend 0-15 hours, 5% spend 15+ hours</p>	<p>106 volunteers involved in Alzheimer Cafés across Ireland</p>	<p>60% of Alzheimer Café have a steering group</p> <p>75 individuals act as steering group members nationwide</p> <p>Majority of steering groups meet 2-4 times a year</p>


Co-ordinator



Steering group

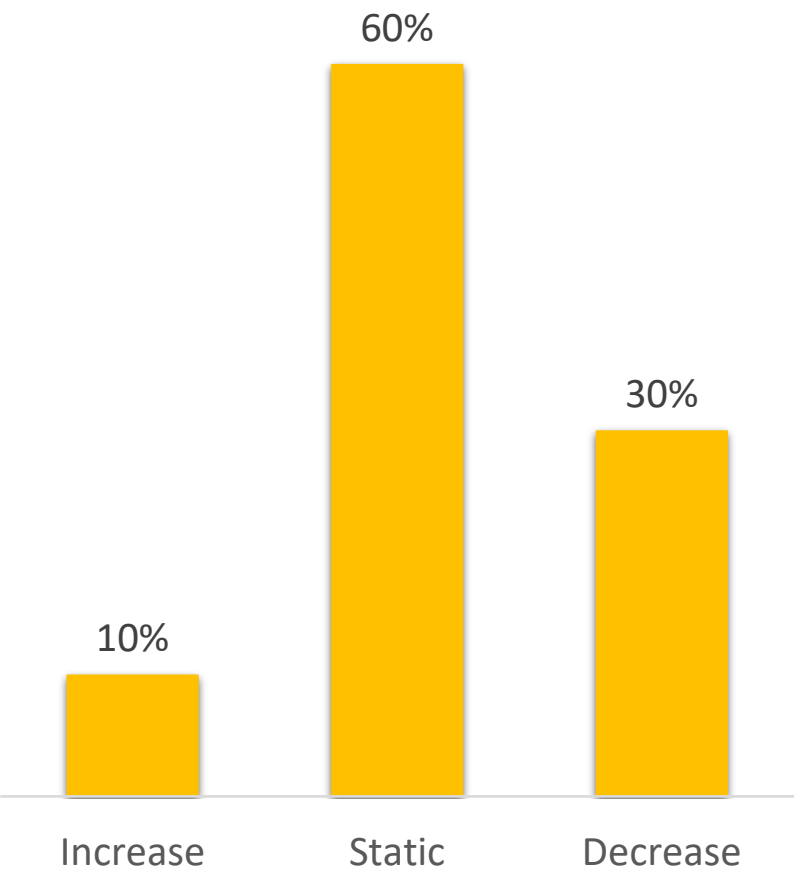


4. Attendance

Overall attendance	People with dementia	Family carers	Other
<p>479 people with dementia and family carers</p> <p style="text-align: center;"></p> <p>Majority are return attendees</p>	<p>Mild dementia (40%), Moderate dementia (49%) and Advanced dementia (10%)</p>	<p>Caring in community (76%), Caring in long term care (19%) and former carers (5%)</p>	<p>Healthcare professionals</p> <p>Non-healthcare professionals</p>

4. Attendance

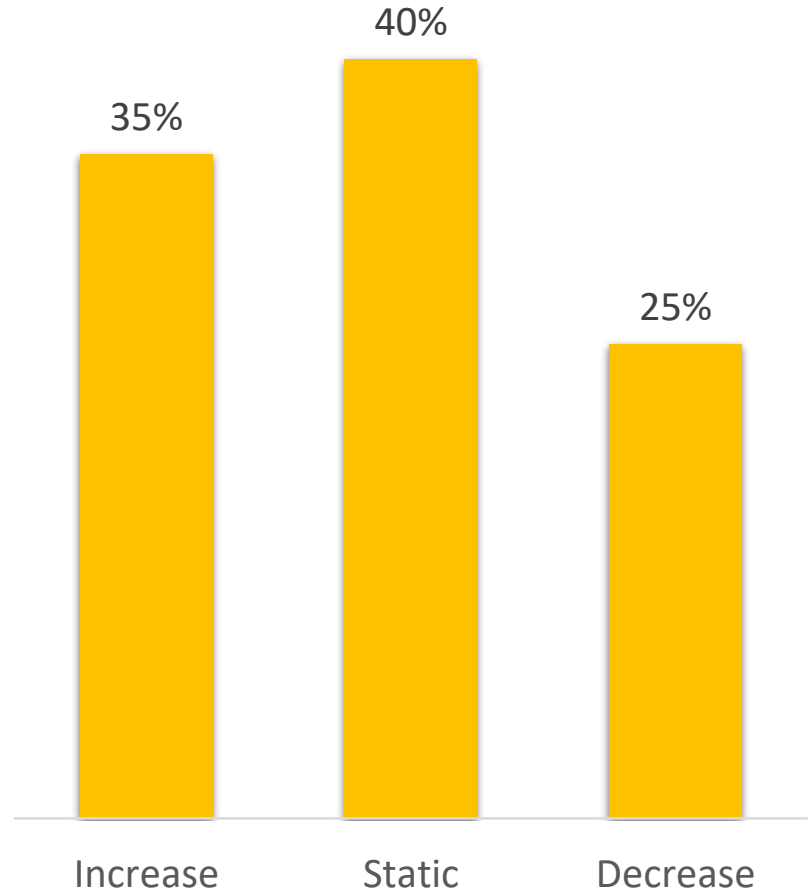
Attendance trend since 2017:
People with dementia



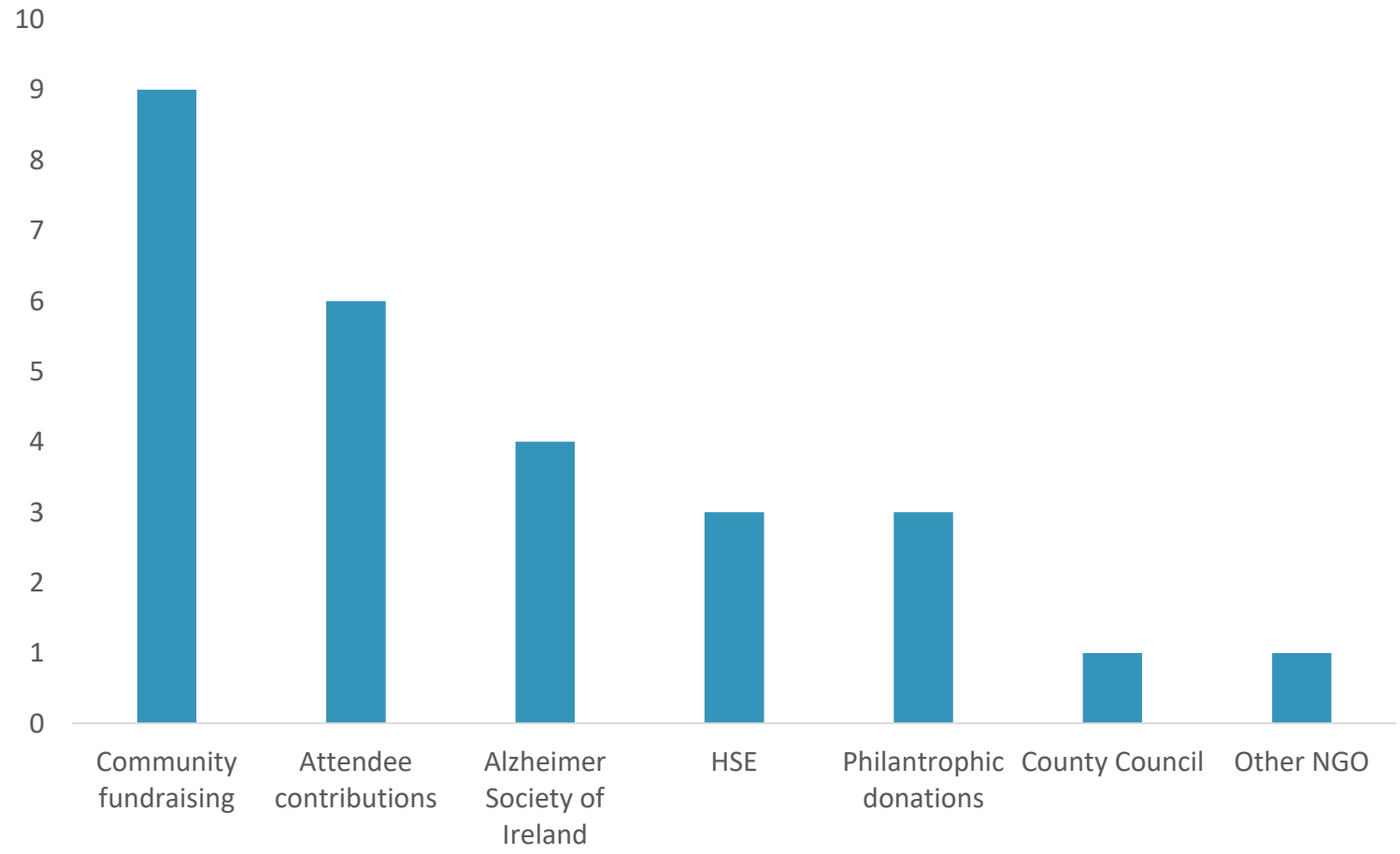
Referrals from:
 Word of mouth
 Parish newsletter
 Community healthcare

Less frequently used:
 Social media
 Hospital healthcare

Attendance trend since 2017:
Family carers



5. Funding



- Average annual cost: €1235
- Majority (85%) do not request contributions from attendees

6. Challenges

- Lack of clear evidence on impact
- Time constraints
- Additional workload
- Maintaining attendance
- Formality
- Identifying speaker
- Progression of dementia



Discussion

- Developing an expert support structure around the co-ordinator
- People with dementia and family carers as active organisers
- Becoming more linked in with the local community
- Advertisement, promotion and dissemination
- Developing a set of outcome indicators
- Support the growth of new Alzheimer Cafés
- Provide support and guidance to existing Alzheimer Cafés



Acknowledgements

Research Team

- Áine Teahan, PhD researcher, CESRD
- Christine Fitzgerald, Post doctoral researcher CESRD
- Eamon O'Shea, Director CESRD

Project Advisory Group Members

- Aisling Harmon, Family Carer
- Sineád Grennan, CEO Engage Dementia
- Maureen Mannion, ASI Dementia Advisor
- Emer Begley, National Dementia Office

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