

# Experiences of Providing Formal Home and Community Dementia Care in Ireland: Advocating for a Holistic Systemic Approach



**Actifcare**

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Access to timely formal care

# The Actifcare Project ([www.actifcare.eu](http://www.actifcare.eu))



ACcess to Timely Formal Care (Actifcare) aims to analyse the pathways to care for people with dementia and their families, to better understand the reasons for inequalities in access to healthcare

This study explored

- Personal experiences
- Perceived barriers and facilitators to service access

From the perspectives of

- People with dementia
- Informal caregivers (variety of ages, relationships)
- **Healthcare professionals (HCPs)**
- **Experts - policy and political decision makers**

# Methodology



- Exploratory qualitative design; purposive sampling
- Expert (decision-maker) interviews ( $n=7$ )
- 3 focus groups with multi-disciplinary HCPs ( $n=18$ )
  - ⇒ Mean years experience = 11.35 ( $SD = 7.2$ )
  - ⇒ Rural (SE), suburban (South Dublin), urban (North Dublin)
- Semi-structured groups/interviews; audio-recorded
- Transcripts analysed using inductive content analysis

Kerpershoek, L.. et al. (2016) Access to timely formal dementia care in Europe: Protocol of the Actifcare (ACcess to Timely Formal Care) Study. *BMC Health Services Research*, 16(1), 423. doi: 10.1186/s12913-016-1672-3

# Themes from the Irish Data



## Individual

- Holistic Needs-focused Care
- Capacity
- Rights

## System

- Service Design
- Service Availability
- Case Management

Education, Awareness, Influence,  
Community Awareness

# Individual

- Holistic Needs-focused Care
- Capacity
- Rights



*"Humans do not just live in the health service." (Ex)*

*"[Capacity] issues take time ... they are difficult." (HCP)*

*"Maximise [their] abilities to participate in society." (Ex)*

*"... start quite light touch .... get more intensive" (Ex)*

*"...multi-disciplinary teams [deal with] your diagnosis, your treatment, your interventions, your care requirements, your psychosocial needs, your home situation, ..." (Ex)*

*"They have a choice and they have the right to decide" (HCP)*

*"...dementia homecare packages that are specifically designed for a person with dementia.... In an integrated way and as comprehensively as possible" (Ex)*

*"We largely understand home-based care as personal care" (Ex)*

# System

- Service Design
- Service Availability
- Case Management



*“And everything is really stretched” (HCP)*

*“Don’t need 24/7 just 50 [hours]” (HCP)*

*“Everyone [working in the HSE] would want individualised services, but it is not there to give” (HCP)*

*“I don’t think we have the political investment” (Ex)*

*“The big danger is that you will end up with relatively privatised homecare services” (Ex)*

*“No one part of the system is going to be able to do this.” (Ex)*

*“[need] statutory basis for home and community based supports” (Ex)*

*“We either have to stop doing something or reconfigure something in some way” (Ex)*

*“There has to be one person that knows everything” (HCP)*

# Case Management – conflicting views



- Many spoke of the need for a Dementia Key Worker role
  - ➔ Dementia Specialist / Dementia Coordinator / Dementia Advisor / Case Manager / Dementia Champion .....
- Conflicting views regarding role definition
  - ➔ A single role or multiple roles?
  - ➔ Must have a clinical background / this is not essential
  - ➔ Definitely in the HSE / Definitely not in the HSE / in the community

*“probably someone outside that system ... outside the HSE network” (Ex)*

*“Not an advisor, a co-ordinator... a clinical person” (Ex)*

*“...necessarily located within a social community... to embed the person within their own local area ” (Ex)*

# Education, Awareness, Influence, Community Awareness



*“Increase our awareness of what’s there and what’s missing” (HCP)*

*“There’s a lot of misconceptions around” (HCP)*

*“A lot more joined up thinking between everyone [and] communities... you don’t know what’s there for people” (HCP)*

*“I think that people’s awareness is that there is no cure.” (Ex)*

*“I’d love to see it go beyond awareness to creating a more activated and engaged community... ‘This is what dementia is AND this is what you can do’” (Ex)*

*“mobilise existing community resources” (Ex)*

*“Work more in partnership with... ASI, carer’s groups ...” (HCP)*

*“We need someone big... like Bono” (Ex)*

*We need more programmes, more features” (Ex)*



# Conclusions



- To a great extent, we know what best-practice is, but few people felt we would be able to implement it
  - ⇒ *“I feel like it’s a bit pie in the sky saying it ...”*
  - ⇒ *“That is should be flexible... that’s a very challenging way to think about delivering a health system”*
  - ⇒ *“I think a lot of us have these great ideas, but making them become realities and changing policies is, it’s like a mountain, isn’t it?”*
- Innovative thinking is constrained by the way we do things now (e.g. current HSE organisation)

# Irish National Dementia Strategy (2014)



**Future Health** (A Strategic Framework for Reform of the Health Service 2012-2015)

*“patient-centred, flexible, community-based service”*

## Individual

- Retain skills, the voice of the PwD
- Need / Escalating need NOT addressed
- Assisted Decision Making (Capacity) Bill

## System

- Integrated, population-based approach to service provision
- Clear descriptions of care pathways
- Timely diagnosis and intervention

- Education, Awareness (better understanding)  
Leadership and clear responsibility

# Irish National Dementia Strategy: Version 2



We need to be thinking about VERSION 2 of the Dementia Strategy

**Holistic, needs-based, person-centred  
multi-disciplinary, community-based, innovative**

*“... a range of services, wrap-around services... that are tailored, and a person could dip in and dip out as was appropriate, and... that there would be a case management approach to people that would kind of, help them... start quite light-touch and as they kind of progress through, that it could be more intensive until you get to the palliative care end” [Ex]*

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## Actifcare Consortium partners



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