

INTENSIVE HOMECARE PACKAGES (IHCPs): EXPERIENCES & OUTCOMES FOR FAMILY CARERS

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Transforming
Social Services

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Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

National Dementia Office in the HSE - Programme Implementers and Co-Funders of the Evaluation



Co-Funders of the Programme and Evaluation



Supporting Dr Fiona Keogh to continue with Genio as Principal Investigator of this evaluation

OVERVIEW

- Background and context
- Mixed-methods evaluation
- Preliminary findings
- Concluding remarks

DEMOGRAPHIC BACKGROUND



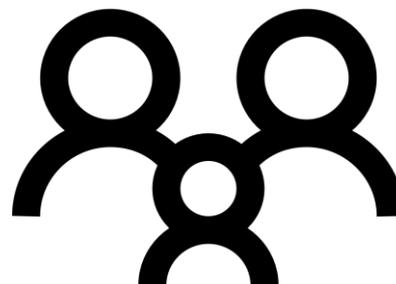
55,000

people with
dementia



35,000

living at
home



60,000

informal
carers –
mostly family



Increase

in people with
dementia &
carers

POLICY CONTEXT

- The Irish National Dementia Strategy (DoH, 2014)
- The National Carer's Strategy (DoH, 2012)

IHCPS FOR PEOPLE WITH DEMENTIA

Since 2014	Complex needs	Person- centred	Flexible
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€500 - € 1500 per week

EVALUATION

IMPLEMENTATION & IMPACT

- Realist Evaluation Framework: *what works, for whom, in what circumstances?*
- User satisfaction
- Quality of life
- Caregiver burden
- Costs and cost-effectiveness

METHODS

MIXED METHODS RESEARCH STUDY

A COMMON
EVOLVING
ANONYMISED
HSE DATASET

INTERVIEWS
WITH HSE STAFF

IN-DEPTH STUDY OF FAMILY UNITS

Qualitative interviews with
family carers and person

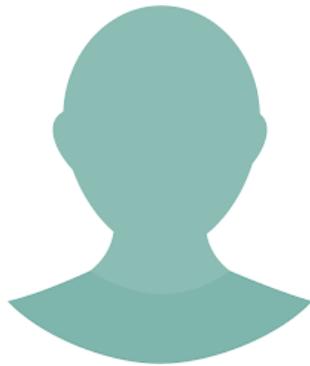
Family carer measures:

- Health-related QOL
- Caregiver stress
- Resource utilisation
- Caregiving time

DATASET & QUESTIONNAIRES

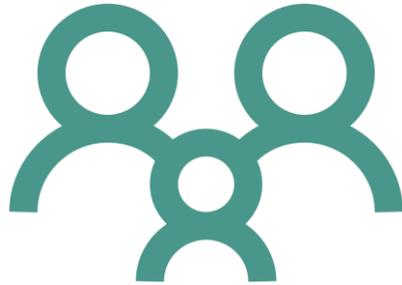
PRELIMINARY FINDINGS

PROFILE OF PEOPLE WITH DEMENTIA

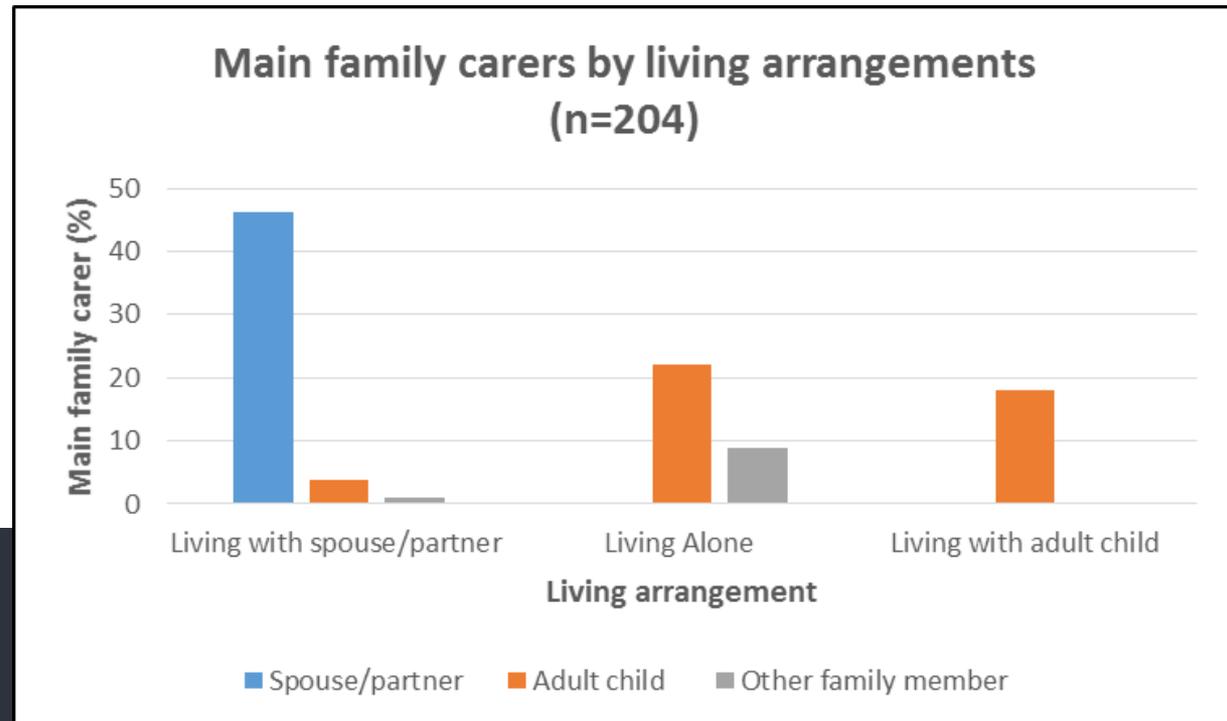


- **242** receiving IHCP
- **81** average age (51-101)
- **80%** High or Max Dependency
- **92%** have family carers
- **53%** married, **34%** widowed, **8%** single
- **51%** living with spouse/partner, **29%** alone, **15%** with adult child

PROFILE OF FAMILY CARERS



- 228 main family carers
- **40%** spouse/partner
- **45%** adult child (mostly daughters)



IHCPS

Average 33 care worker hours p/w (23 - 47)

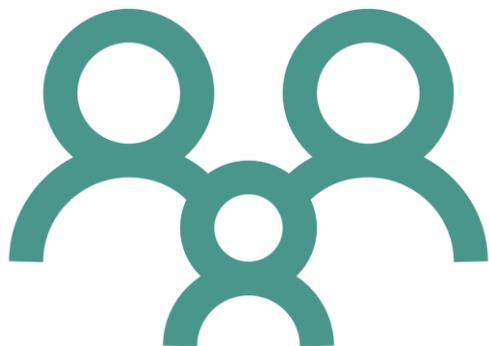
Average weekly cost €941 (€388 - €1,828)

IN-DEPTH STUDY

PRELIMINARY FINDINGS

PROFILE OF FAMILY CARERS

TO DATE 27 FAMILY CARERS IN SAMPLE



- Daughters **10**, wives **9**, husbands **5**, sons **3**
- **Two-thirds** women
- **62** average age (*42 to 81*)
- Almost **80%** living with person with dementia
- **5** not co-residing: *caring from abroad (2), between two homes (2), formal live-in carers (1)*

“*[To keep husband at home]* is, without a shadow of a doubt our aim, and it is not a preference, it is a very sincere commitment, it is much more than a preference”

Wife of man with
advanced dementia

“Putting someone in a nursing home, that is the final straw. I know a lot of families reach that, I would hate it to happen to myself and none of us want it to happen to mum.”

Daughter of woman with
severe dementia

Woman
with
dementia:

“I thought I wanted to stay there [*nursing home*] sometimes but I don't think I would like it at all now, I think it would be a big mistake to just go ahead with things.”

Daughter:

“Why would it be a mistake to move there?”

Woman
with
dementia:

“Because I would end up with no house or no nothing, just my few bits in a bag.”

Woman with mild dementia in
conversation with her daughter

FAMILY CARER HEALTH AND STRESS

- **57%** self-rated general health as very good or excellent
- **33%** experienced moderate to severe caregiver burden
- **52%** experienced mild to moderate caregiver burden
- **15%** with little or no caregiver burden



OUTCOMES FOR FAMILY CARERS (N=10)

- **Moderate to severe** caregiver burden:
So far little change in ZBI score with IHCP
- **Mild to moderate** caregiver burden:
So far improvements seen with IHCP,
but only for some.
- **Little or no** caregiver burden:
So far remained unchanged with IHCP

FACTORS CONTRIBUTING TO STRESS

- Emotional impact
- Competing demands (*e.g. demands of providing care, full-time work, young children, living between two houses*)
- Caring from a distance / another country



“It is a superb massive improvement, it is absolutely so much better ... It is the difference between night and day ... Oh my God, it means I can go outside with [name of son]. He is only 3 and he doesn't understand why he has to be stuck inside on a nice day, so I can go outside with him.”

Daughter of woman with
severe dementia

HOW ARE IHCPs SUPPORTING FAMILY CARERS?

- ‘**peace of mind**’
- **personal care** tasks
- **breaks** from demands of full-time/intense caring
- combine **work** and caring
- spend **quality time** with their own family
- supporting families **financially**



CONCLUDING REMARKS

- **242** people with dementia benefitted from IHCPs to end June 2017
- IHCP focus is very much on **care worker hours**
- **Families** are providing bulk of care
- **IHCPs supplementing family carers** & enabling them to continue to care for relatives at home
- **IHCPs have enabled people with dementia to remain at home**, in many cases for a significant period of time