

Research for Societal Impact - Some experiences of an NGO

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The Lived Experience

- ▶ Reflective of a shift away from the hegemony of ‘academic or expert knows best’
- ▶ Public Patient Involvement (PPI) See <https://www.carealliance.ie/PPI-Ignite>
- ▶ Co-creation (See <https://personaloutcomescollaboration.org/carers/>)
- ▶ Documenting the process and experience of the lay participants (see <https://www.carealliance.ie/Past-projects>)

Publications as Currency



- ▶ Under- use of Grey Literature
- ▶ Open Access Movement (Lenus)- un-stopable.

Some Approaches we have Taken

- ▶ Develop our own research/publications (Briefing papers/ Discussion Documents) - Desk based - Positive Feedback - Awards
- ▶ Focus on Public Patient Involvement - and Collaborative Research/Applied Projects (with Universities, NGO's, State Bodies)
 - ▶ - Valuing others time
- ▶ Groups; Family Carer Research group (Ireland based); Student group via Slack (International for Post Graduate students)
- ▶ Care Alliance Ireland Research & Policy online resource
<https://wakelet.com/@careallianceireland>
- ▶ Extensive use of Twitter to share others research and build relationships

Some of our Recent Research

- ▶ Discussion Paper Series (10 published to date)
 - ▶ Less discussed topics
 - ▶ Awkward/ sensitive topics
 - ▶ Desk-based (literature review & some secondary data analysis - Census etc.)
 - ▶ Conclude with “Suggested responses” at practice, policy and individual levels
 - ▶ 2018: Difficult Relationships & Family Care; Family Care & Minority Populations; Rural Family Caring
- ▶ Briefing Papers/Overview Reports/Response Documents (c15 published to date)
 - ▶ Mix of literature review & secondary data analysis
 - ▶ Topical - eg Home Care provision in Ireland, Carer Statistics, Response to Health Service Plans
 - ▶ Use of Freedom of Information requests etc. to access data for example needs assessment practice amongst health and social care practitioners.



- ▶ Trust
- ▶ Time



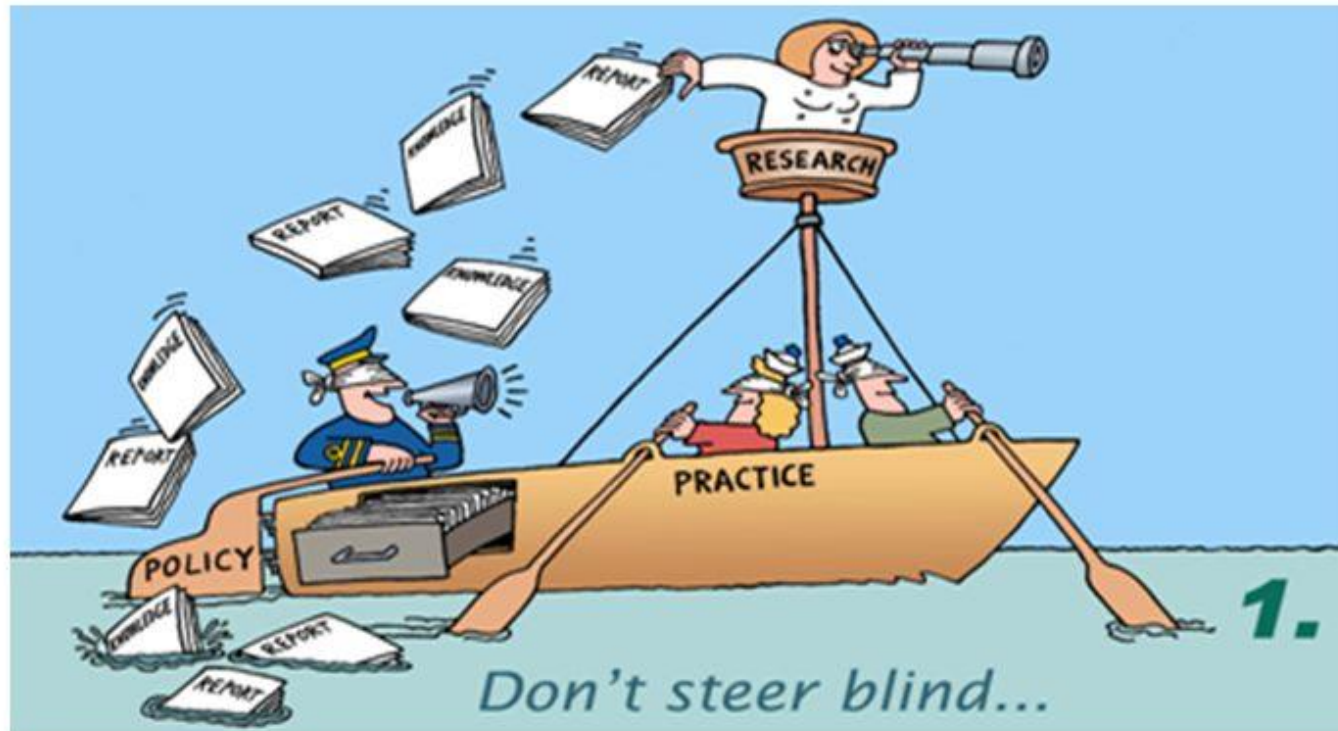
Co-Production/Co-creation



Open Access Research

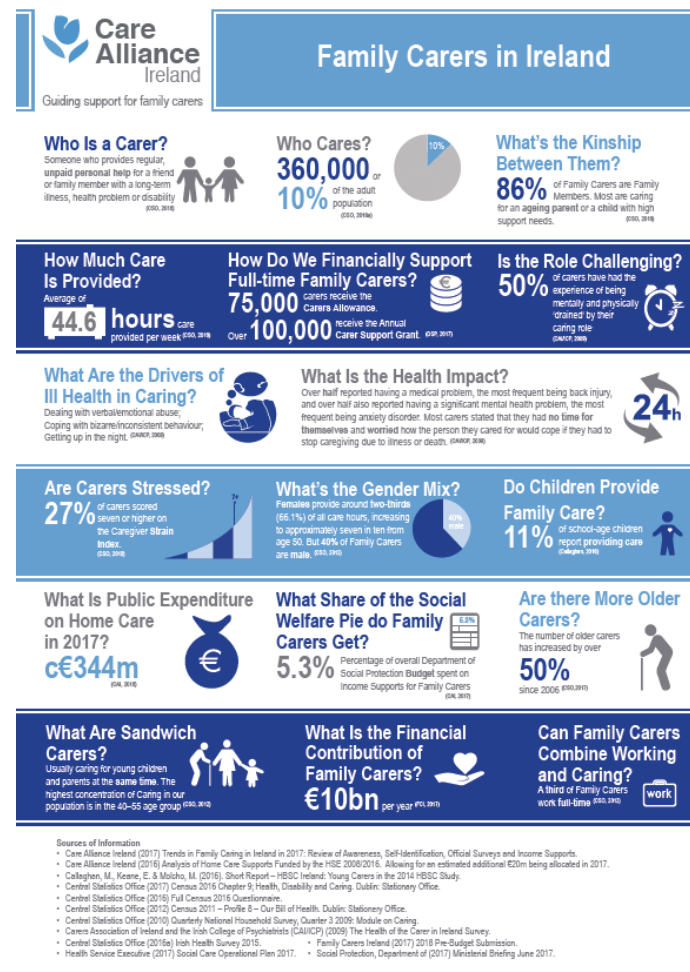


Research → Policy → Practice



Presenting Research

- Chasing headlines or making an impact?
- Media Like Stats
- (Most) People Like Stats
- Officials more circumspect!
- Combine with personal stories
- No big bang usually - incremental changes more likely



Can Family Carers Combine Working and Caring?

A third of Family Carers work **full-time** (CSO, 2012)



Are there More Older Carers?

The number of older carers has increased by over

50%

since 2006 (CSO, 2017)



What Is the Financial Contribution of Family Carers?

€10bn per year (FCL, 2017)



Are Carers Stressed?

27% of carers scored seven or higher on the Caregiver **Strain Index**.

(CSO, 2010)



Is the Role Challenging?

50% of carers have had the experience of being mentally and physically 'drained' by their caring role

(CAI/ICP, 2009)



What Are Sandwich Carers?

Usually caring for young children and parents at the **same time**. The highest concentration of Caring in our population is in the 40–55 age group (CSO, 2012)



AWARD - CONTRIBUTION TO SOCIAL WORK PRACTICE



Challenges

- ▶ **GDPR** - Data Protection - Rights of family carers?
- ▶ **Replicating Interventions** - bringing them to 'practice'
- ▶ **Funding** - health and social care providers focussed on 'services to clients' not 'research about family carers'
- ▶ **Responding** to Third level Undergraduate/Post Graduate enquiries

Innovate ways of Doing Research

- ▶ **‘Soft’ Research** - Carers Week Survey - June 2019 - “Family carers use of Online Supports.” See http://www.carealliance.ie/publications_researchreportsphp
- ▶ **Freedom of Information Requests** - re service delivery, assessment approaches,
- ▶ **Social Media** - Facebook page - 20,000 Followers - <https://www.facebook.com/nationalcarersweek>
 - ▶ Using the Facebook page to promote others research
 - ▶ Participant recruitment to undertake surveys of family carers
- ▶ **Pushing Traditional Boundaries** - Principal Investigator Power/Money - Hypothesis V Story Telling eg Journal article <https://bit.ly/2k0dWxZ>
- ▶ **Trust Funds** - Executive Director connections - €400k x 3 Universities/Psychology body

Closing Messages - To All

- ▶ Make the case to funders to value Research Functions within organisations
- ▶ Collaborate not Control
- ▶ Share the knowledge - accessibly
- ▶ Keep at it - build the relationships
- ▶ Use the data consistently - credibility matters

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Thank You