



# Developing a Carer Needs Assessment an integrated approach

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**Liam O'Sullivan**, Executive Director, Care Alliance Ireland

# Significance of Family Caring in Ireland

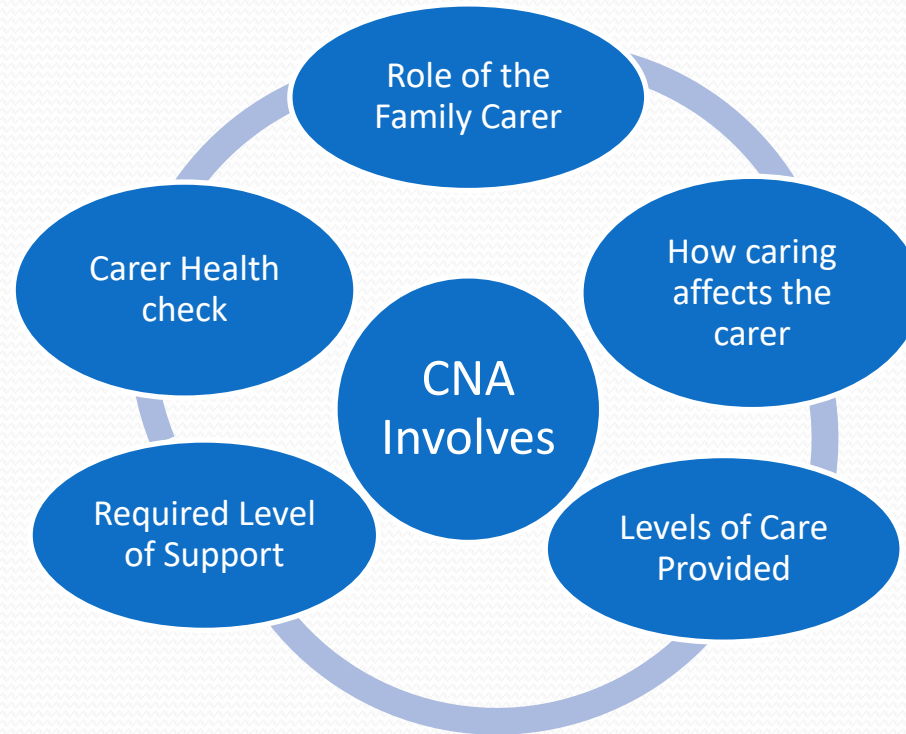
*‘someone (relative/ non-relative) who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty’. (1)*

- Family Carers are the largest provider of care and do so on a ***unpaid*** basis
- NGO’s estimate a €10bn contribution pa in Ireland (v’s €14.6bn public health service budget)<sup>(2,3)</sup>
- 360,000 persons provide care<sup>(4)</sup>. (61%/39% Female/Male)<sup>(5)</sup>
- The average weekly number of hours care provided is 45 <sup>(6)</sup>

References; 1) National Carers Strategy, July 2012; 2) Family Carers Ireland, 2017; 3) Health Services Executive 2017  
4) 2015 Irish Health Survey 2016, Population extrapolation; 5) Census 2011; 6) 2015 Irish Health Survey, 2016

# Carer Needs Assessment for Family Carers

The Carer Needs Assessment (CNA) is designed to identify the needs of Family Carers.



It is a collaborative and integrated approach involving an international consortium of researchers, Irish national health and social care providers, NGO Family Carer organisation and Family Carers.

# Carer Needs Assessments (CNA)

- Allow Family Carers to identify their needs, be given information and advice, explore difficulties they may experience and make contingency plans if they are ill or are unable to continue to provide care.
- Can build carer morale and capacity and are central to care planning. They can provide timely feedback to health and social care professionals and can inform policy and service provision.

# Carer Needs Assessments

## Rationale

- Recognition
- Holistic / Systems Model
- Family as Expert
- Better utilise existing resources

## Use to Date

- UK most extensively
- Some use in the US/Canada / elsewhere
- Local Individuals (Carer Strain Index and other Tools)

## Arguments against Use

- More bureaucracy
- Raise expectations – resulting in disappointment
- Will increase demand on services

# Significance of the Study

The development of a Carer Needs Assessment (CNA) brings many benefits;

## Individual level-

- needs identification using standardised assessments;
- provision of an opportunity to discuss individual needs;
- be referred to local community-based services as appropriate.

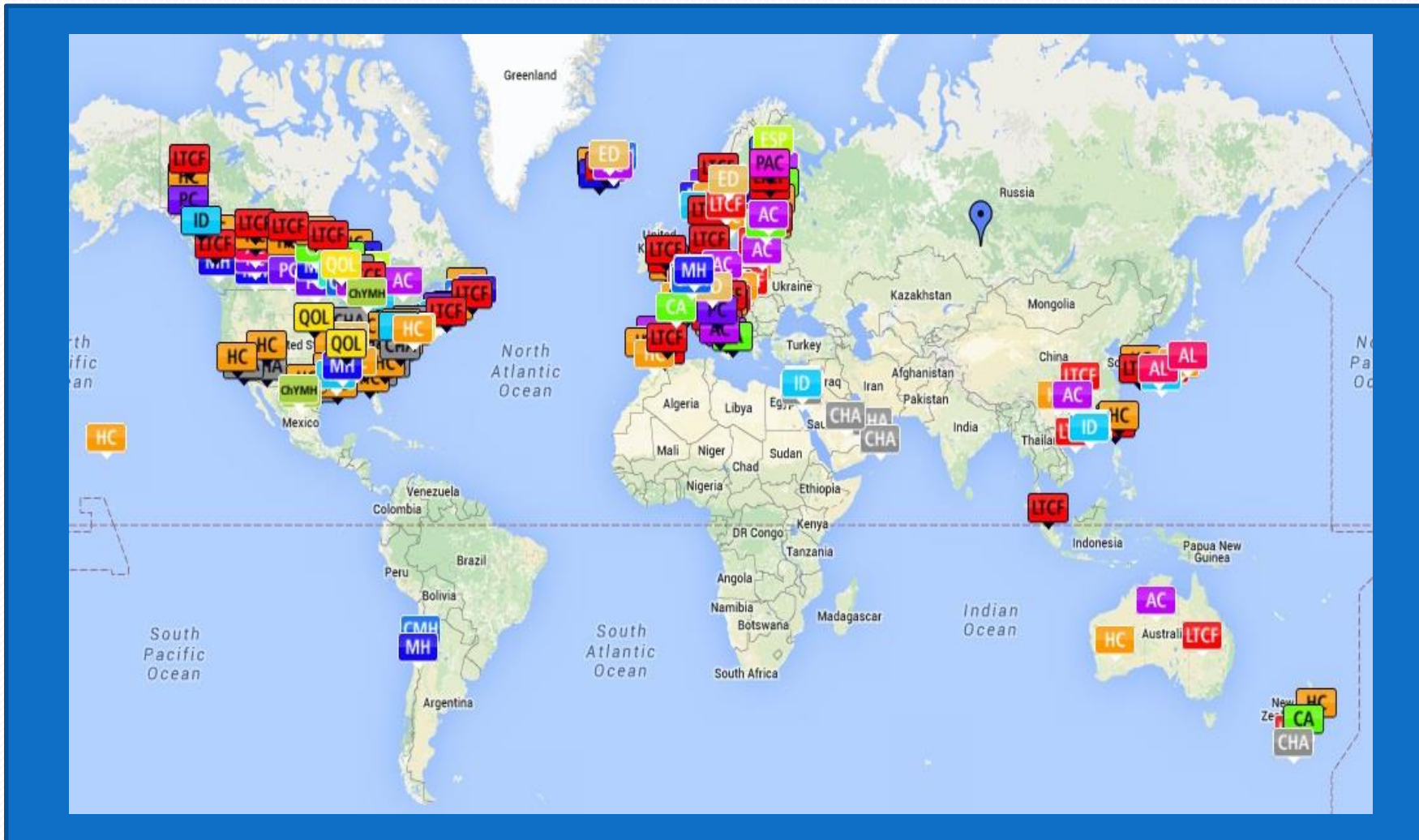
## Aggregated level-

- Ability to quantify family carer's need;
- Track outcomes for both family carers/ their care recipients over time.

# Carer Needs Assessment background

- Carer Needs Assessment Development (CNAD) Working Group as part of the Single Assessment Tool (SAT) project in Health Services Executive (HSE) Services for Older People Care Group in 2013
- SAT project involves the implementation of a comprehensive care needs assessment (interRAI assessment system) by HSE.
- interRAI assessment system used internationally by over 30 countries for a number of different care groups – older people – both home care and long term care, children, people with a disability, palliative care etc.

# interRAI Instruments Used Worldwide



# CNA Working Group membership

1.



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

Led by SAT Project Team –  
Services for Older People \*

2.

Carer NGOs  
Family Carer Reference  
Group



3.



interRAI Consortium  
Instruments & Systems  
Development  
Committee

\* Enabled by Atlantic Philanthropies Funding

*The*  
**ATLANTIC**  
*Philanthropies*

# CNA Methodology 2013-2017

- **Literature Review conducted**
- **Draft Assessment Form and User Manual created**
  - Iterative cycle of Assessment Form design
  - Separate drafts produced (7) /questions reviewed.
  - Sign-off August 2015 (draft for scoping).
- **Scoping Exercise CNA**
  - Ireland / Belgium conducted a scoping exercise with involvement of Family Carers in both countries
  - Feedback on Form sought and received from over 100 Family Carers
  - International meeting May 2016 (Ireland hosted).
  - Final amendments to tools August 2016.
- **CNA International Pilot**
  - International Pilot in 8 countries (Ireland, Belgium, Lebanon, USA, Estonia, Hong Kong, Korea, Netherlands)

# International CNA Pilot

## Pilot Aims:

- Identify problems with the CNA's content/ wording.
- Explore- caring context/ relationships between the care recipient's healthcare support needs, & the impact of these needs on family carers and their caring role.

## Pilot Study

- 8 countries internationally.
- Approximately 50 Family Carers/ 50 Older People (care recipients) per country
- Study approved in Ireland by RCPI Research Ethics Committee.

# Pilot (cont.)

Sites in Ireland (n=4): Cork, Dublin North, Kildare, Roscommon

- Per site-12/13 Adult Family Carers & their 12/13 care recipients (Older People) recruited (Q1 2017) via Family Carer Organisations/ HSE Service Users.

## Data Collection/ Analysis

- Paper-based CNA for Family Carers/ electronic SAT (interRAI HC) assessment for their care recipients
- Post assessment Family Carer Survey
- Clinician Issue log
- Descriptive statistics analysis planned for Ireland
- Aggregated data for International analysis

# CNA – Sections (Draft)

## Family Carer Identification Information

Family Carer: Cognition, Comprehension, Vision

Family Carer: Social Needs

Family Carer: Function/Endurance/Stamina

Family Carer: Self-Reported Mood

Family Carer: Health/Clinical Conditions

Client-Carer Relationship

Family Carer Role

# Examples of Questions in CAN (1)

Which of the following challenges do you face in caring for \_\_\_\_\_?

Challenges	Code
• I have difficulty finding the time to care for _____	
• I sometimes question my ability to help given _____'s problems	
• I sometimes find it difficult to provide care in a timely manner (e.g., I live far away, have a job, go to school)	
• I have other caring responsibilities (e.g., sick child or partner, child rearing, home duties)	
• I have financial difficulties (e.g., have to make trade-offs using funds to cover food, shelter, clothing, or medications)	
• I lack enough support from family and friends	
• I find it difficult to understand and use the healthcare system	
• Caring for _____ is a major source of stress	
• Caring for _____ keeps me from working, making a living, or getting an education	
• I have no time for myself or to enjoy activities I like (e.g., volunteering, visiting friends)	

# Example of Questions (2) : Quality of Life

Code : 0 Never 1 Rarely 2 Sometimes 3 Most of the time 4 Always 5 Don't know/Refuse to Answer

Statement	Code
• I am hopeful about my future	
• I feel good about myself	
• My relationships with family and friends are good	
• Caring for _____ gives me a sense of pride	
• Caring for _____ makes me feel needed, useful, loved	
• Caring for _____ has improved our relationship	
• I feel listened to by healthcare professionals	
• I have people I can count on	
• On the whole, my life is good	
• I play an important role in people's lives	
• If I need help right away, I can get it	
• I manage the stress in my life	
• I can be alone when I wish	
• I can go where I want on the 'on the spur of the moment'	

# Next Steps

Irish Data will be pooled with international data for further analysis by an interRAI statistician- to be concluded Q4 2017.

Conclusion of Pilot

Carer Needs Assessment Form will be added to interRAI international suite of tools and made available for use in over 30 countries

# CNA Outcomes

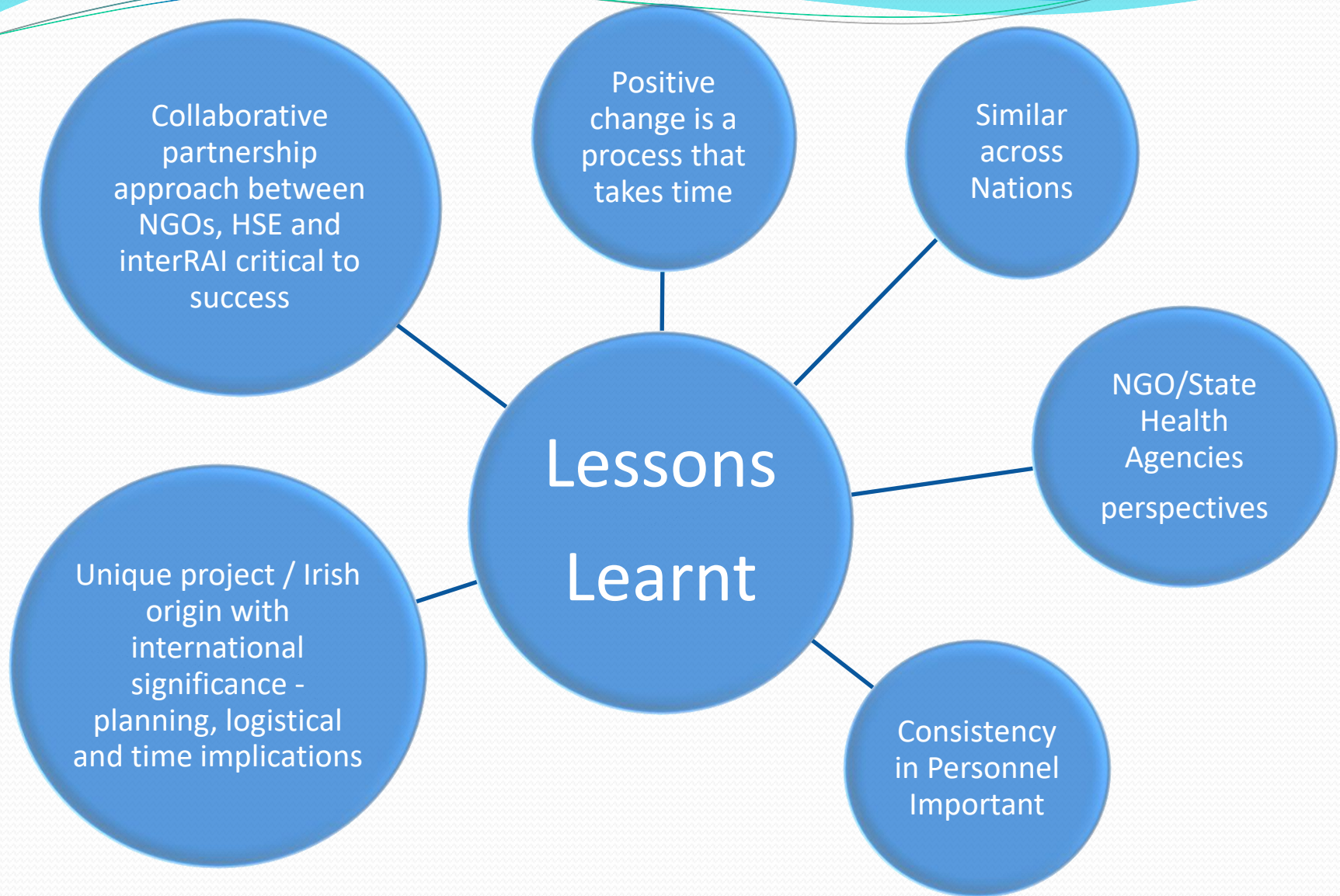
## For Health and Social Care Professionals

- Promotion of integrated model of planning
- Deeper engagement and understanding of Statutory and NGO perspectives and remits.

## For Family Carers

- Recognise carers as partners in care
- Cathartic conversations? just being valued
- More equitable access to supports
- Identification of carers needs and appropriate referral to supports.

*CNA will better measure and identify the health and social care needs of carers.*



# Contact

- Liam O'Sullivan – Care Alliance Ireland

[info@carealliance.ie](mailto:info@carealliance.ie)

[www.carealliance.ie](http://www.carealliance.ie)

@CareAllianceIrl