



Towards resilience in family caregiving for people with dementia

Family Carer Research Conference

31st August 2017





Project Aim and Objectives

Overall Aim

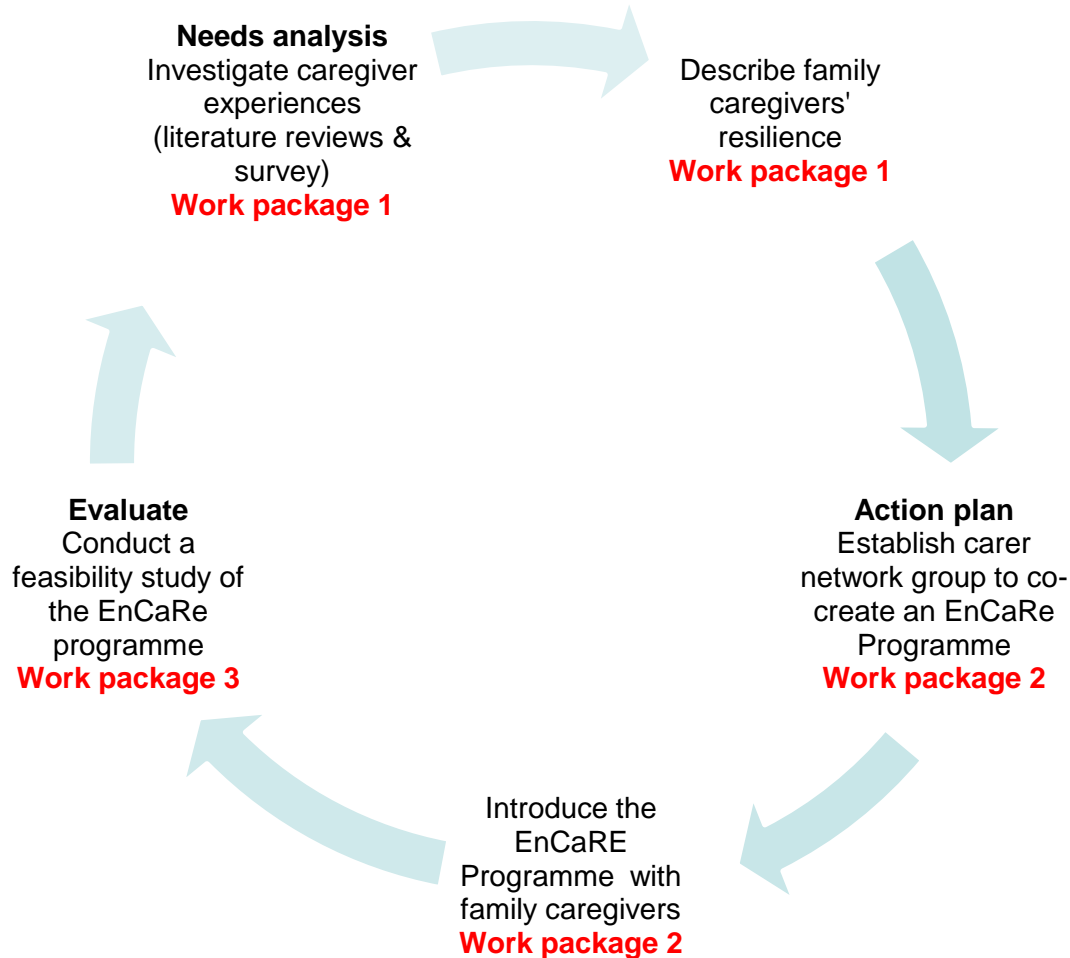
To **promote resilience** in family carers of people with dementia using participatory action research to develop an innovative Enhancing Carers' Resilience (EnCaRe) programme.

Objectives

1. **Synthesise current evidence** of resilience-enhancing and related psychosocial interventions and initiatives aimed at promoting positive outcomes for family carers
2. Measure and **describe family carers' experiences** of caring for a person with dementia and their resilience in caregiving
3. **Establish a network group** comprising family carers of people with dementia and members of the research team and, through the network, develop and **design an Enhancing Carers' Resilience (EnCaRe) Programme**
4. **Conduct a feasibility study** of the EnCaRe Programme through a demonstration project among a cohort of current family carers of people with dementia
5. **Evaluate the EnCaRe Programme** with reference to structure, process and outcome elements

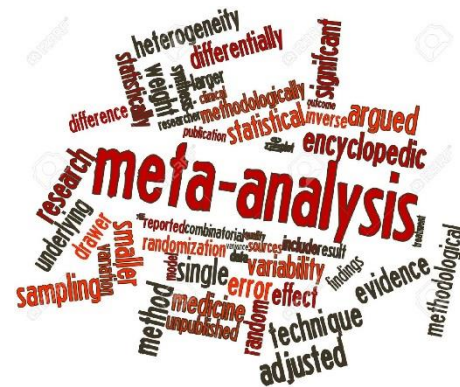


Research Design

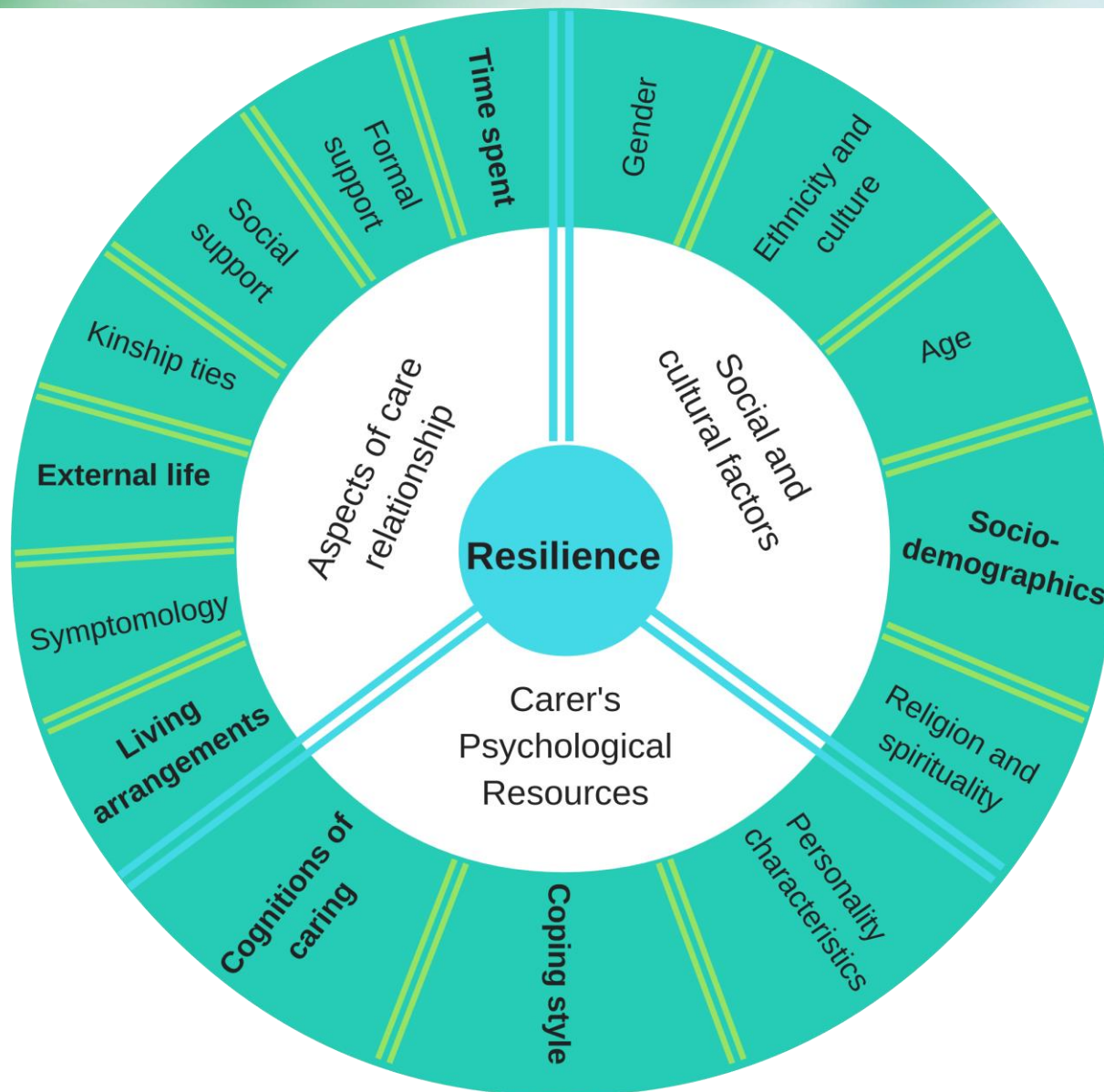


A participatory action research framework based on the principle of collaborative inquiry with the aim of enabling and facilitating carers to develop an Enhancing Carers' Resilience (EnCaRe) Programme for family caregivers of people with dementia.

Work package 1



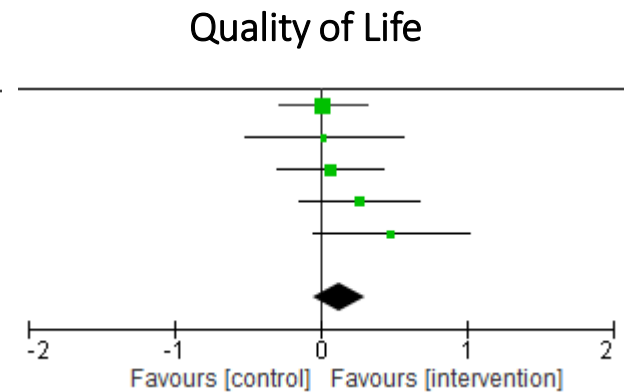
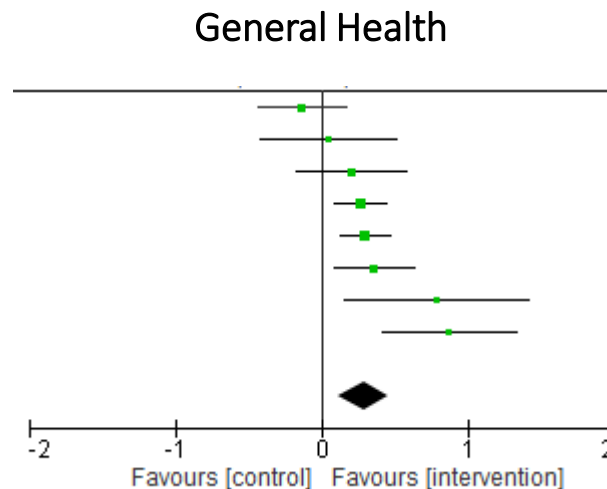
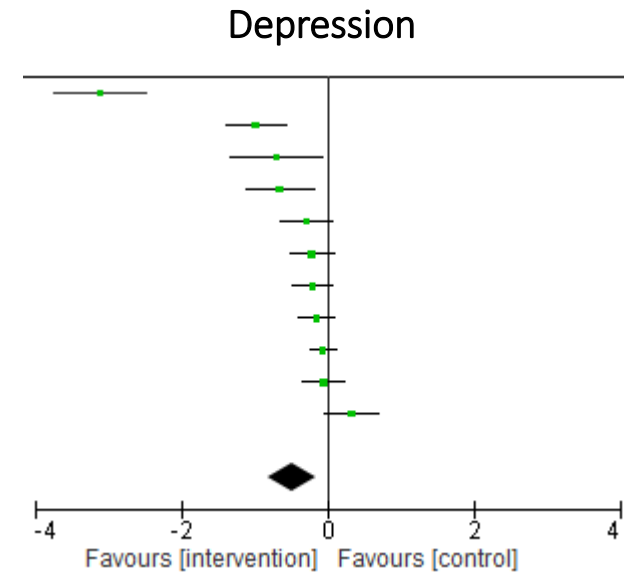
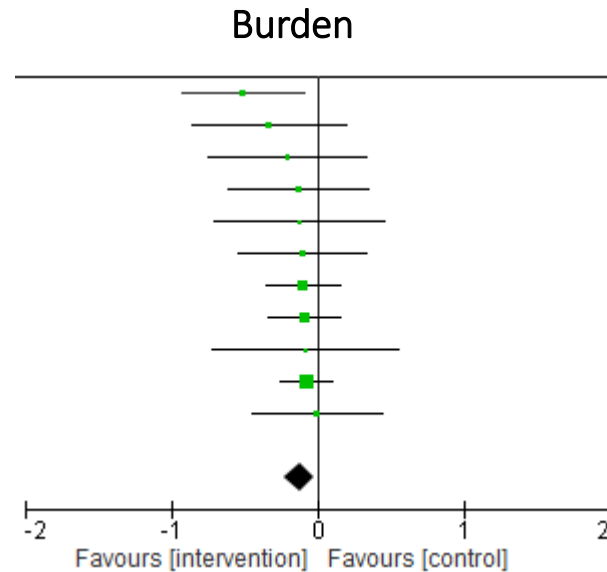
Systematic Review



- Complex psychological construct comprising of many different aspects of carers' lives.
- Outlines different resources, assets and factors shown to affect carer outcomes.
- Similarities with the model outlined by Cherry et al. (2013) but additional factors were identified.

Meta-analysis

- Support interventions had a positive significant impact on caregivers' levels of burden, depression and general health.
- Although non-significant, there was a positive trend toward increased quality of life in family carers post intervention.



Methodology

- 485 respondents indicated that they cared for a person with dementia (aged 65 years and older).



Section 1	Carers' profile
Section 2	Carers' health and wellbeing
Section 3	Caregiving and caregiving activities
Section 4	Caregiving experience
Section 5	Experience of conflict A) Carers' experiences of mistreatment B) Potentially harmful carer behaviour
Section 6	Carers' experiences of support and coping
Section 7	Care recipient profile



Methodology

- An anonymous cross-sectional postal survey of family carers of people with dementia
- Family carers in receipt of a carer's allowance for the care of a person with dementia
- The Department of Social Protection (DSP) facilitated 3 mail-outs.
 - Mail-out 1: Pre-notice letter
 - Mail-out 2: Cover letter, questionnaire & SAE
 - Mail-out 3: Reminder/thank you letter, spare questionnaire & SAE



- 61% response rate
- Response to mail-outs

705 Carers in receipt of a Carer's Allowance for care of a Person with Dementia

519
questionnaires
returned

445
questionnaires
completed

415 eligible
questionnaires



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WP2



22nd June 2017





Work Package 2

AIM:

Establish a network group comprising family carers of people with dementia and members of the research team and, through the network, develop and **design an Enhancing Carers' Resilience (EnCaRe) Programme**



Work package 2

The EnCaRe Network group

- Up to six family carers of people with dementia
- Two research team members
- Meetings every 4-6 weeks
- Using a mix of invited speakers and group discussions to address group aims

EnCaRe Network Group Aims

- Develop a grounded definition of '**resilience**' based on carers' experiences
- A programme designed by carers for carers to enhance resilience of Family Carers of people with dementia (PWD)



Recruitment

Recruitment

Following ethical approval a recruitment strategy was formulated and rolled out

Recruitment Strategy

- Worked with collaborators to recruit family carers of people with dementia
- Strategy targeted:
 - mix of caregiving relationships (18+)
 - male & female carers (18+)
 - current & former carers (18+)
- Used social media and pamphlet to target these groups through existing carer networks



Strategy

 NCPOP

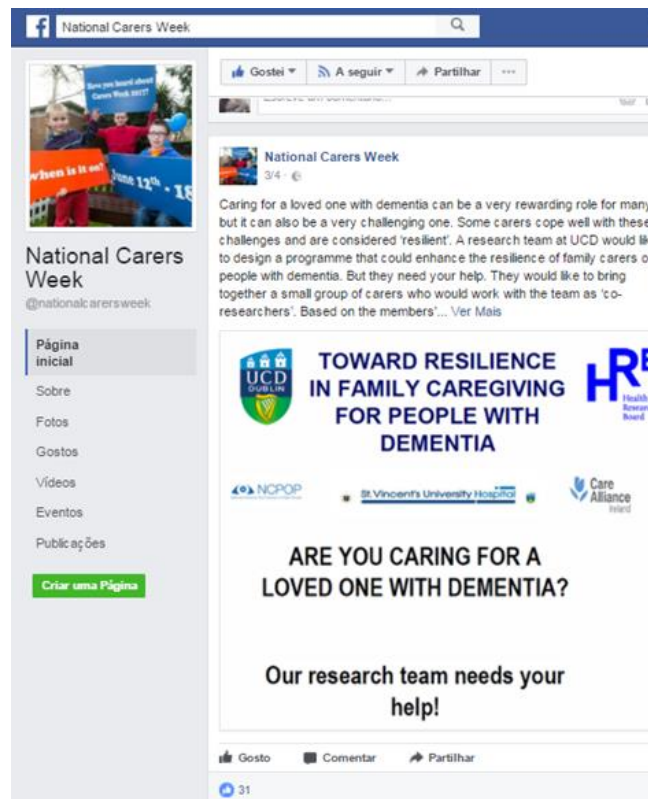
NATIONAL CENTRE FOR THE PROTECTION OF OLDER PEOPLE (NCPOP)



**ARE YOU CARING FOR A
LOVED ONE WITH DEMENTIA?**

**Our research team needs your
help!**

- Caring for a loved one with dementia can be a very rewarding experience, however, it can also be very challenging for many carers. Some carers cope well with these challenges and are considered 'resilient'.
- Our team of researchers would like to develop a programme or tool kit that could help make family carers more resilient when caring for someone with dementia.



**Carers
Programme of
the Mental
Health Services
for Older
Persons (HSOP),
St Ita's Hospital**
This programme
ran for six weeks.



The EnCaRe Network Group



NATIONAL CENTRE FOR THE PROTECTION OF OLDER PEOPLE (NCPOP)

Currently the EnCaRe Network Group comprises:

- 8 members (+2 research staff)
- 4 men and 4 women
- 6 adult-child carers; 2 spousal carers
- Mix of caring experiences





- To date there have been a total of 5 Sessions
- 2-3 hours long
- Have heard from guest speakers on topics of interest to the group
- Earlier sessions focused on concept of resilience as well as policy as it relates to Family Carers of PWD

What does resilience look like?

- Resilience item

Resilience is the ability to:

- 'Switch off'
- 'Accept help'
- 'Find time for yourself'

Resilience Definition?

- Different for everyone
- Academic V real-world





Emerging Themes



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Information

- Lack of information has been highlighted as a key challenge for family carers
- Fragmented; FCI, CAI, ASI, HSE, Genio, Understand Together, GPs, PHNs etc.



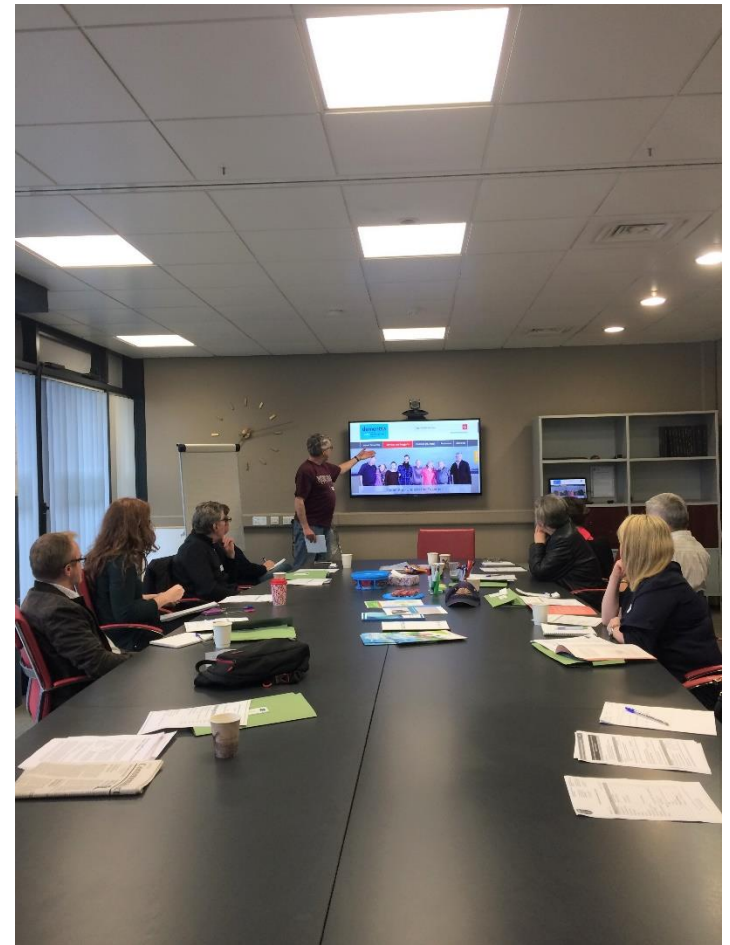
Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive



THE ALZHEIMER
SOCIETY *of* IRELAND

Information

- Family Carers can't find information they need
- Why is this?
- Undermines resilience of Family Carers of people with dementia





Challenges



NCPOP

NATIONAL CENTRE FOR THE PROTECTION OF OLDER PEOPLE (NCPOP)

Public and Patient Involvement (PPI)

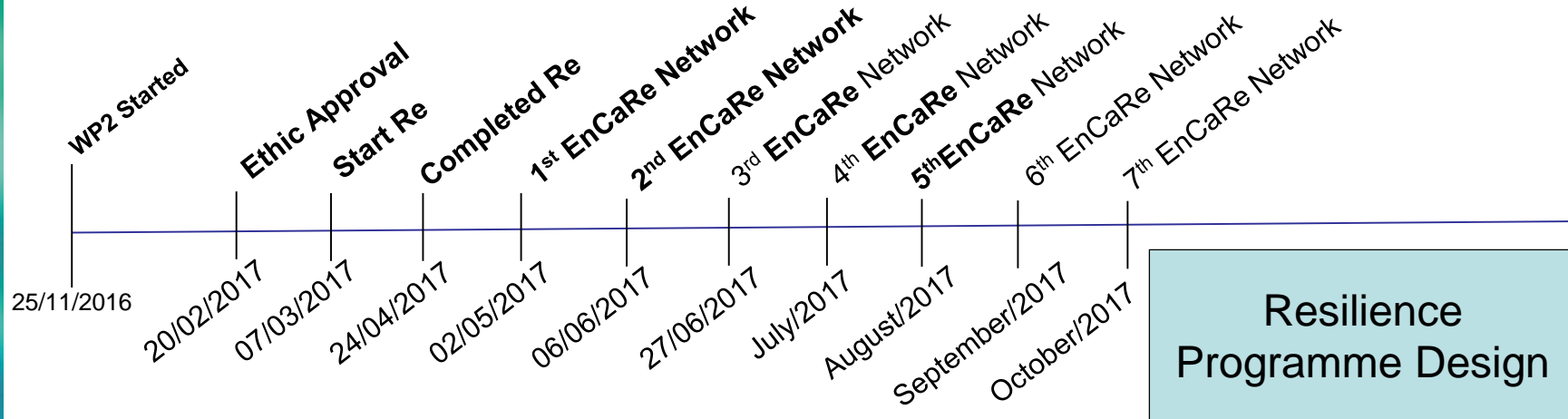
- Ethical Approval
- No 'data collection'
- Role of co-researcher

Recruitment

- Spousal carers
- 2 new members joined in July 2017



Where to next?



- Resilience Definition almost finalised
- Area EnCaRe programme will target has been agreed
- Platform for delivery is in developing stages
- Beginning laying the ground work for WKPG 3 which involves:
 - Pilot
 - Evaluation





Comments & Questions?



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