Living well with dementia

REACH: The Centre for Research in Ageing and Cognitive Health

Dr Catherine Quinn
Senior Research Fellow
REACH: The Centre for Research in Ageing and Cognitive Health
University of Exeter

Advanced Psychological Therapies Conference – 6th May 2016

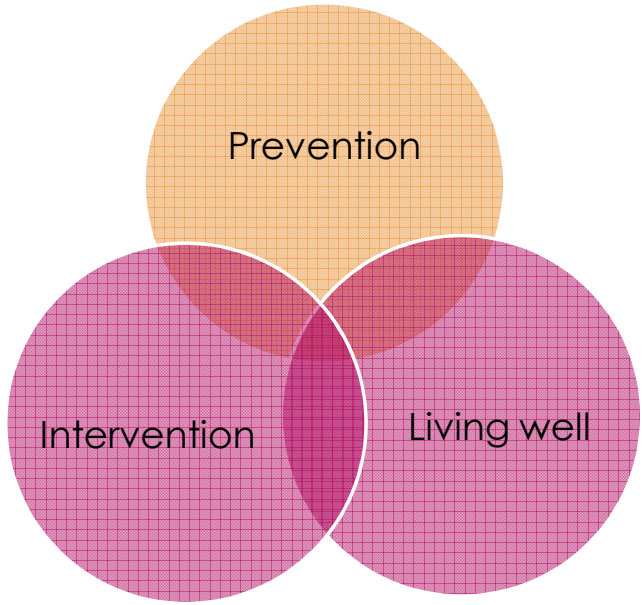
Dementia

- Dementia is typically perceived as affecting memory "short-term memory loss" but has more global impact on cognitive functions, such as language, emotional control and social behaviour.

- Dementia is a global issue, huge challenge for society.

- Whilst there are medications that can temporarily slow down/ improve progression - currently no cure or treatments alter the course of dementia.

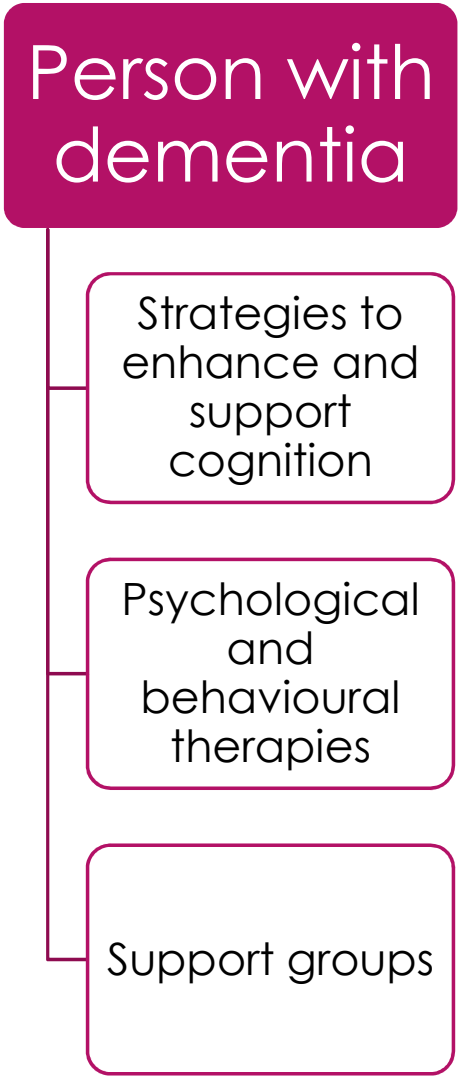
- In research the dominant focus has been on developing a cure or treating symptoms, shifting focus:



Psycho-social interventions

- How can we help people who have dementia
- Nothing we can do?

- 2013 G8 dementia submit emphasised the need for non-pharmacological interventions that are effective and safe and can be used world-wide.
- Focus on developing psycho-social interventions for in the early-stages of dementia.
- Development of effective interventions will have benefits that will help people to **live better** with dementia (Winblad et al., 2016).



The SMART study

REACH: The Centre for Research in Ageing and Cognitive Heath

- Growing emphasis on helping people with chronic conditions to develop self-management skills (Department of Health, 2005). Self-management can be beneficial in a range of long-term health conditions.
- Evidence that people with dementia may find a self-management approach helpful but it would need to be appropriately adapted to take account of the difficulties that people with dementia experience.
- The approach would need to focus on helping people with dementia to practically manage their memory difficulties and to find ways of dealing with changes in their lifestyle.
- Aim: To develop and explore the feasibility of a self-management intervention for people with early-stage dementia.

Quinn, C., Toms, G., Anderson, D., & Clare, L. (2015). A review of self-management interventions for people with dementia and mild cognitive impairment. *Journal of Applied Gerontology, E pub.* doi: 10.1177/0733464814566852

Aim: To identify group-based psychosocial interventions for people with dementia or Mild Cognitive Impairment (MCI) that incorporated significant elements of self-management*.

Results: 15 group interventions were included in the review: three groups were for people with mild cognitive impairment and 12 groups were for people with dementia. We explored what self-management components were included in the groups.

*Common self-management components taken from Mulligan, Steed & Newman (2009)

REACH: The Centre of Research in Ageing and Cognitive Health

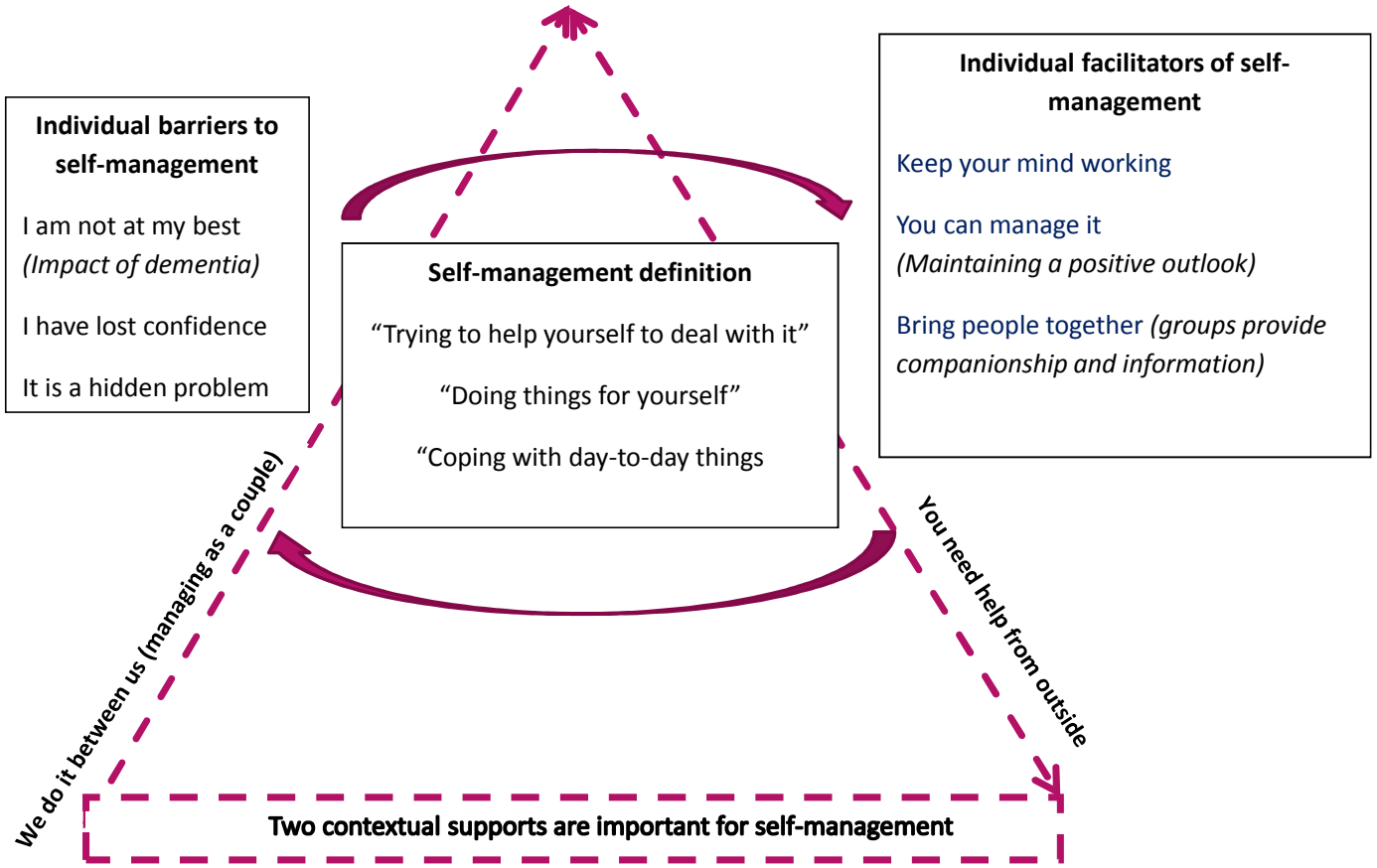
Aim: To explore the views of people with dementia and family caregivers on the use of self-management in dementia.

Results: 13 people with dementia and 11 caregivers took part in semi-structured interviews, which were analysed using thematic analysis.

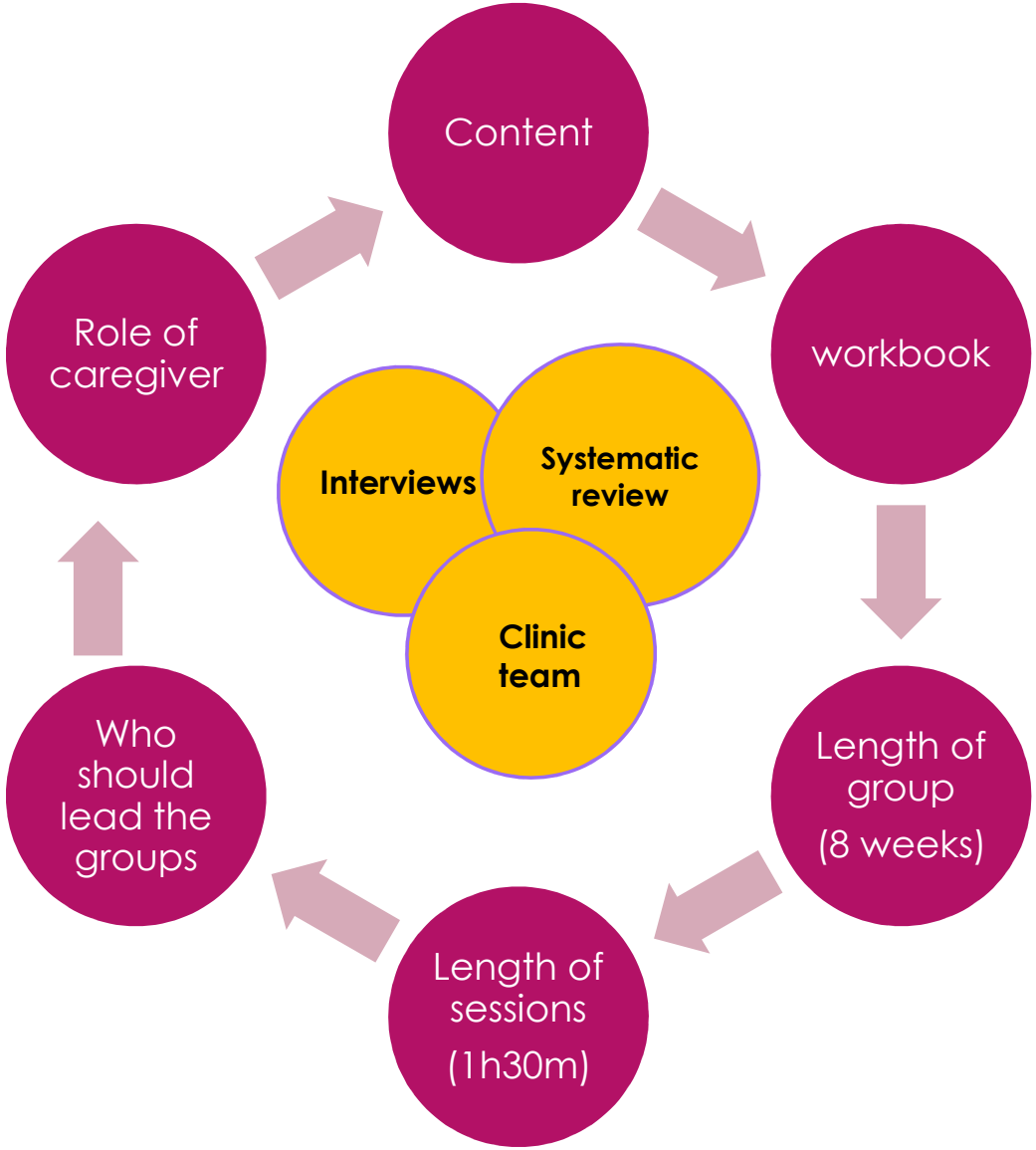
The findings indicate that self-management occurs in the context of peoples' family and social relationships as well as relationships with professional services. Participants spoke of barriers to and facilitators of self-management

REACH: The Centre of Research on Ageing and Cognitive Health

Toms, G. R., Quinn, C., Anderson, D. E., & Clare, L. (2015). Help yourself: Perspectives on self-management from people with dementia and their caregivers. *Qualitative Health Research, 25 (1)*, 87-98. doi: 10.1177/1049732314549604

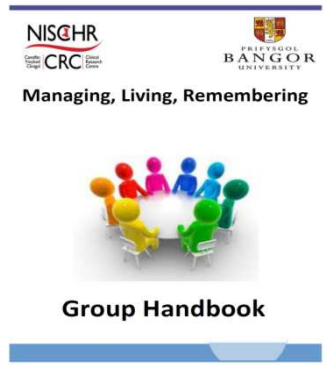


Development of SMART program



REACH:
The Centre of Research on Ageing and Cognitive Health

Contents of the SMART program



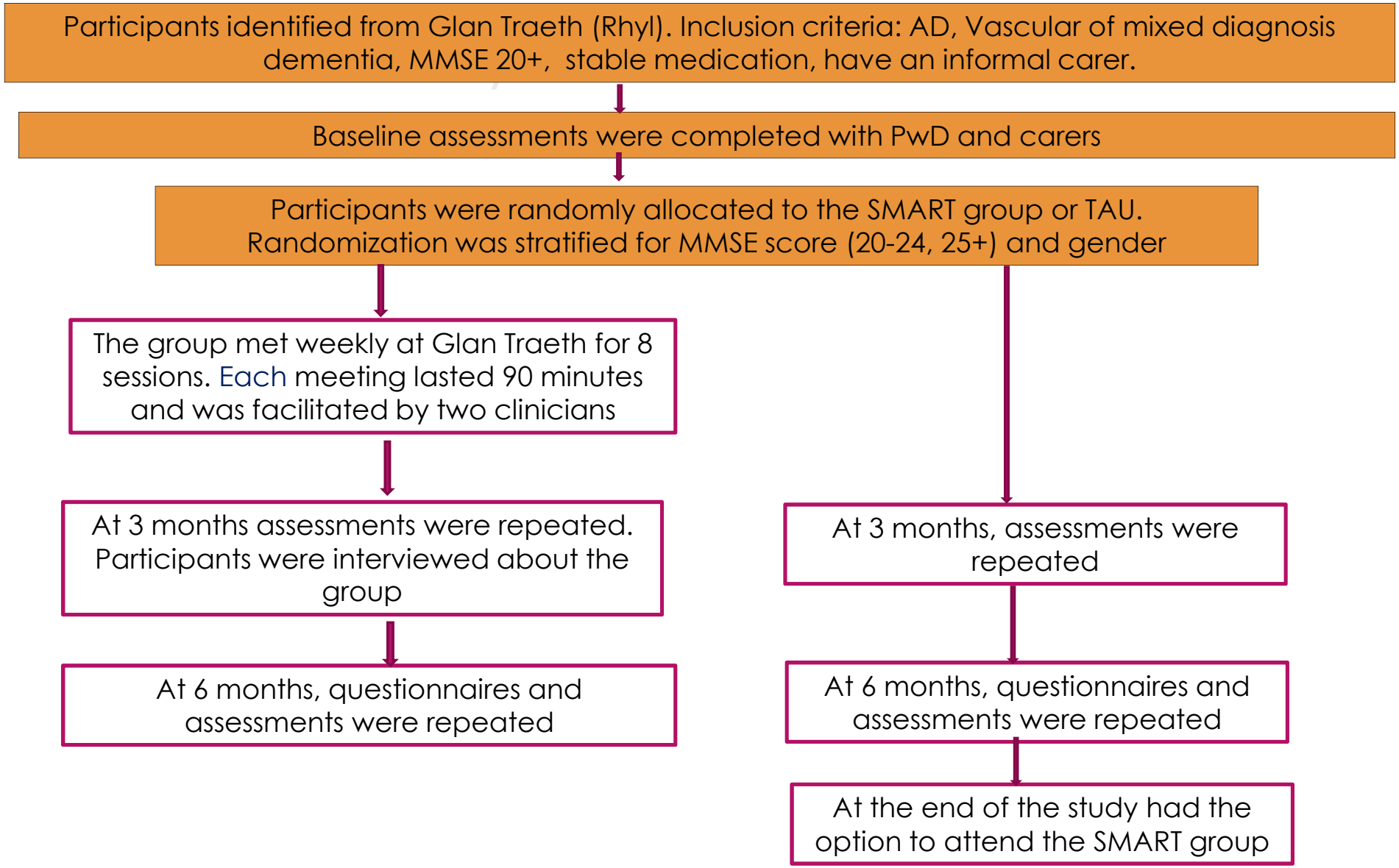
Content influenced by Social Cognitive Theory (SCT) and Self-Regulation Model (SRM)

Facilitation techniques underpinned by SCT and SRM e.g. vicarious learning,

e.g. Used vicarious learning e.g. groups members learning how the other members coped

Session	Title of session	Attendees
1	Information about dementia	Person with dementia and caregiver
2	Enjoying favourite activities and interests	Person with dementia
3	Staying well	Person with dementia
4	Practical ways to manage memory difficulties	Person with dementia
5	Maintaining relationships	Person with dementia
6	Planning for the future	Person with dementia
7	Coping skills	Person with dementia
8	Local Resources	Person with dementia and caregiver

Carers were invited to first and last 5 min of the group to hear a review of what had been discussed



REACH: The Centre of Research on Ageing and Cognitive Health

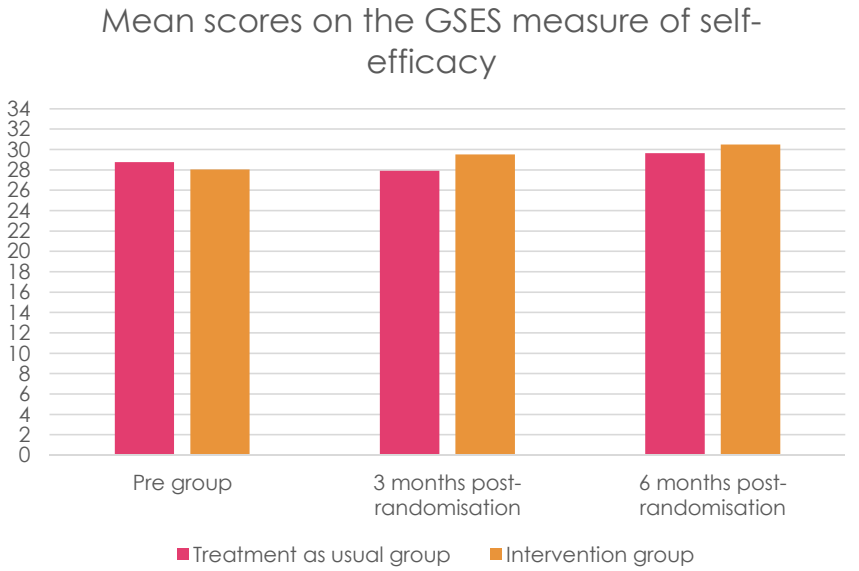
Quinn, C., Toms, G., Jones, C., Brand, A., Tudor-Edwards, R., Sanders, F., & Clare, L. (2016). A pilot randomized controlled trial of a self-management group intervention for people with early-stage dementia (The SMART study). *International Psychogeriatrics*, 28(5), 787-800. doi: 10.1017/S1041610215002094

Aim: To explore the feasibility of a self-management intervention for people with early-stage dementia.

Results: We ran two groups, on the first occasion, the group consisted of six people with dementia and on the second it consisted of seven people with dementia.

Attendance: All participants with dementia attended six sessions or more.

Costs: The annuitized set-up cost was **£8.52** per participant and the cost of providing the intervention was **£70.11** per person with dementia/caregiver (approximately **£9** per dyad per session).



Self-efficacy outcome	Effect Size	Confidence Interval
Generalised Self Efficacy Scale 3 months post-randomisation	0.35	-0.47-1.17
Generalised Self Efficacy Scale 6 months post-randomisation	0.23	-0.6-1.05

Trends for increases in QoL in intervention group and lower depression, but increase in anxiety.

REACH: The Centre of Research on Ageing and Cognitive Health

Feedback from group participants and facilitators

- *Benefits for self-efficacy: "The person's in the group saying concentrate on what you can still do… instead of what you cannot do and he's trying on that" (Carer)*
- *The program fostered independence and reciprocity: "The best really was when everyone was … work working together… to solve problems you know really" (PwD)*
- *The program promoted social support: "It was comforting …to know that there were other people of about my age and very similar backgrounds… all in the same conditions sort of thing" (PwD)*
- *The program provided information and help: "This is, you must be involved in understanding what's going on… about what's available and what… people are doing in the same position as yourself… so you know all of these things are so important… I would recommend it a hundred percent" (PwD)*

Facilitators feedback:

- Participants had been able to discuss topics openly with each other
- Several participants grew in confidence over the course of the program
- Other participants became more amenable to guidance

Recommendations for developing the SMART program

Participants perspective:

- Group was not long enough: *"I could have gone there for the rest of me life to be honest"* (Person with Dementia).
- More pre-program preparation
- The mix of people attending the program is important

Research team reflections:

- More time to allow us to prepare people for the ending of the group.
- Integrate the group into a care pathway which includes other group activities.
- Balancing carer involvement with promoting independence
- Offering a complementary group to the carers
- What is the best way to measure the impact of the group? some of the most meaningful changes occurred 'in the moment' of the session.
- Living well with dementia

Living well

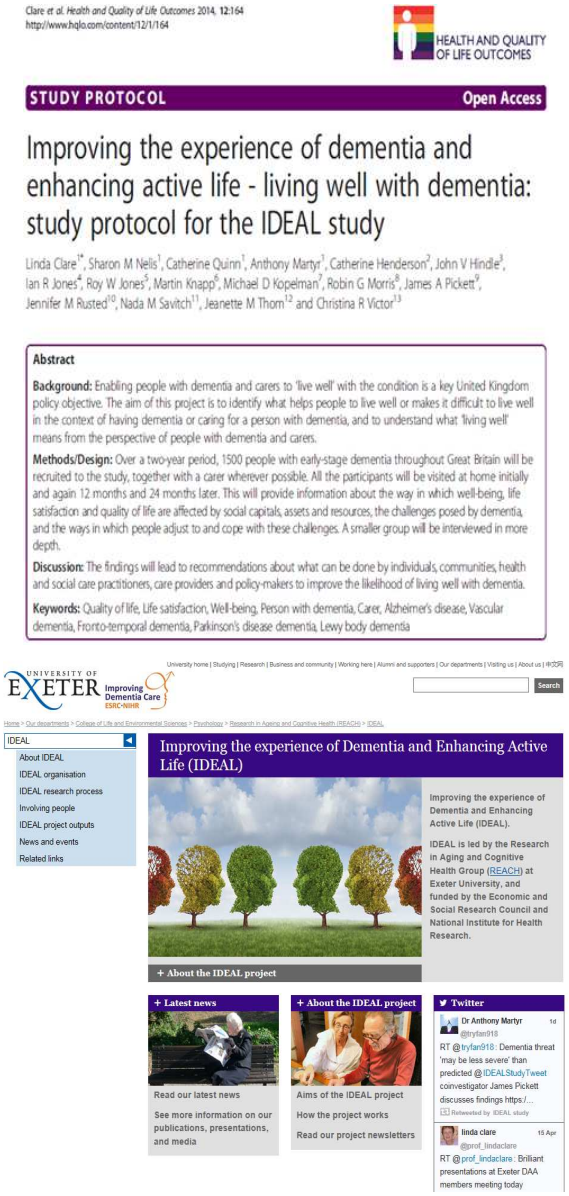
- Target of many interventions is to improve the well-being of people with dementia.
- Enabling people living with dementia to **live well** with dementia is a key UK policy objective, What can help people to live well?

Improving the experience of dementia and enhancing active life: living well with dementia: The IDEAL study.

- In this 5 year large-scale longitudinal study we aim to explore factors that influence the possibility of living well with dementia and to identify changes that could result in improved well-being and quality of life. Focus on:
  - Social capitals, assets and resources (e.g. environment, activity engagement)
  - Resource inputs (e.g. services, supports, medications)
  - Life-events and transitions (e.g. psychological health)
  - Adjustment- changes over time

Who takes part?

- At baseline To be in the study the person must have a diagnosis of dementia (any sub-type) be living in the community, have MMSE above 15 and not have a terminal illness.
- We include people without a carer



REACH: The Centre of Research in Ageing and Cognitive Health

IDEAL study

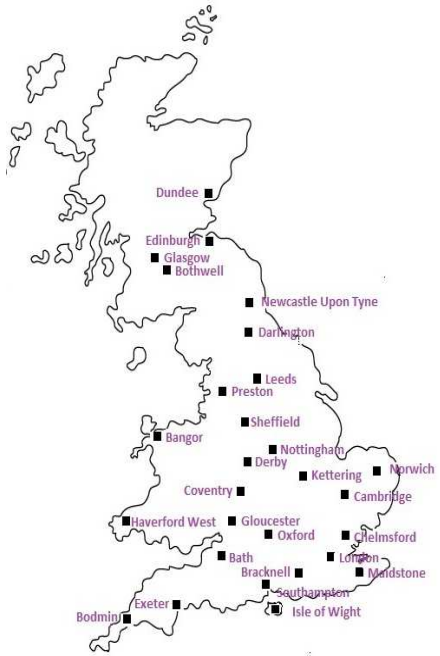
- Participants are being recruited from 29 sites through clinical networks
- **Quantitative** assessments will be conducted:

  Baseline (Time 1: July 2014-June 2016)

  12 months (Time 2: July 2015- June 2017)

  24 months (Time 3: July 2016- June 2018)

- Interviews conducted with a sub-sample



Recruitment March 2016:

- 1348 PwD (89% target), 1146 carers
- 59% men
- 19% living alone
- 56% Alzheimer's disease, 11% Vascular dementia, 19% mixed dementia, 4% Frontal Temporal Dementia, 3% Parkinson's Disease Dementia, 3% Dementia Lewy Bodies, 3% Other

REACH: The Centre of Research in Ageing and Cognitive Health

Conclusion

- Understanding better what helps people to live well with dementia will contribute to the ***development of interventions and practice*** that helps to optimise the information, services and care offered to people with dementia and their carers.
- Increasing development of psycho-social interventions for people with dementia but need a rigorous evidence base.
- Challenges in evaluating the effects the intervention.
- Important to consider the role of the carer in the process: balancing PwD independence with the support carer provides.
- Nothing we can do?

Acknowledgements

REACH: The Centre for Research in Ageing and Cognitive Health

SMART study team
Dr Catherine Quinn (PI)
Prof Linda Clare
Dr Gill Toms
Ms Julie Nixon
Andrew Brand
Dr Carys Jones
Prof Rhiannon Tudor-Edwards
Susan Davies
Maureen Davies
Dr Daniel Anderson
Dr Fiona Sanders

This study was funded by Health and Care Research Wales, Health Award 2012, Grant RFS-12-35.
http://psychology.exeter.ac.uk/reach/

The IDEAL study is funded by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR).

www.idealproject.org.uk

@IDEALStudyTweet

IDEAL study
Prof Linda Clare (CI)
Dr Sharon Nelis (PM)
Dr Catherine Quinn
Dr Anthony Martyr
Dr Yu-Tzu Wu
Dr Cate Henderson
Ruth Lamont
Helen Davey

ALWAYS group Project Advisory Group
Prof Ian Rees Jones
Prof Roy Jones
Prof Martin Knapp
Prof Michael Kopelman
James Pickett
Dr Fiona Mathews
Prof Robin Morris
Prof Jennifer Rusted
Nada Savitch
Dr Jeanette Thom
Prof Christina Victor
Dr Cate Henderson
Helen Collins
Dr John Hindle

I would also like to thank all the people who have taken part in the studies.