

# PROMs in dementia care

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# Dementia

- 750,000 people with dementia in the UK with 200,000 new cases every year
- irreversible decline in global intellectual, social and physical functioning
- impact on behaviour, insight and judgement & neuropsychiatric symptoms such as psychosis, anxiety and depression
- Prime Minister's Challenge 2012-15  
*“One of the greatest challenges of our time... one that steals lives and tears at the hearts of families”*
- emerging consensus of need to measure broad patient-reported outcomes (PROMs) such as health-related quality of life (HRQL)

# The Challenge for PROMs

- assumes respondent can give a reliable report

**BUT**

- memory problems, confabulation, etc.

- reference to a specific time frame

**BUT**

- difficulty in accurately recalling events within a specific time period

- subjective constructs (eg HRQL)

**BUT**

- loss of insight, ability to reflect, etc.



# Early response to the challenge

## Proxy-reported

- Progressive Deterioration Scale (PDS) – DeJong et al 1989
- Alzheimer's Disease Related Quality of Life (ADRQL) - Rabins et al 1999
- Community Dementia Quality of Life Profile (CDQLP) – Salek et al 1999
- The Pleasant Events Schedule –AD – Albert et al 1996

## Self-reported

- DQOL (Brod et al 1999)

## Proxy and Self-reported

- Quality of Life-AD (QOL-AD) – Logsdon et al 1999
- Quality of Life Assessment Schedule (QOLAS) – Selai et al 2000

# Since 2000

- Since 2000, several additional instruments developed
  - Cornell-Brown Scale of QoL in Dementia (CBS) (Ready et al. 2002)
  - QoL in Dementia Scale (QOL-D) (Terada et al. 2002)
  - [DEMQOL & DEMQOL-Proxy \(Smith et al. 2005\)](#)
  - Bath Assessment of QoL in Dementia (BASQID) (Trigg et al. 2007)
  - QUALIDEM (Ettema et al. 2007)
- Only 2 instruments use both self- and proxy-report (QOLAD and DEMQOL)
- As yet no application of “modern” psychometric methods – eg Rasch, IRT



## Classical Psychometric Methods

- Not all scores are measurement
- Only appropriate for group level use
- Most scales are fixed in length
- Content can lack clinical meaning (implications for change scores)

## Rasch Measurement Methods

- Interval rather than ordinal
- Invariance (“fixed ruler”)
- Individual SE, so can be used at the individual level
- Same score can be produced from different combinations of items (or people)
- Ensures items targeted to sample

# DEMQOL and DEMQOL-Proxy

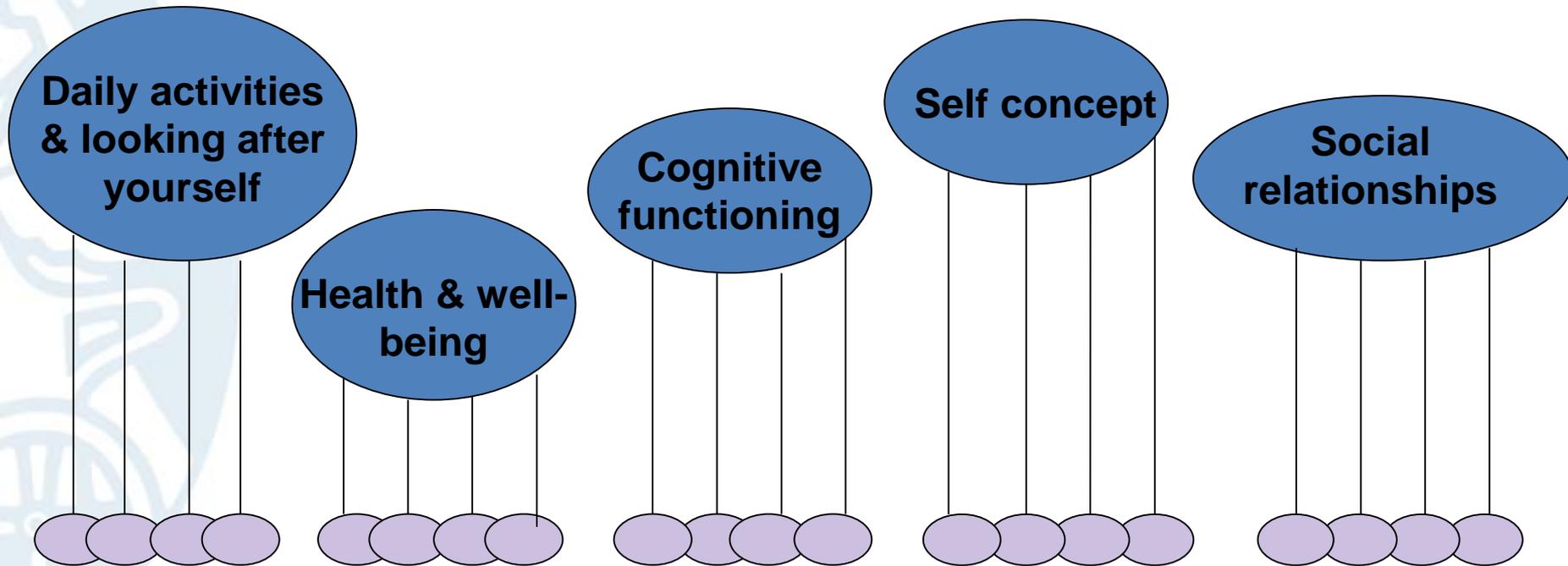
(collaboration: Institute of Psychiatry, LSHTM)

- dementia-specific measure of HRQL within the UK, appropriate for use across the range of severity
- perspective of the person with dementia kept central
- self- and proxy-report versions of the questionnaire
- classical psychometric methods used to establish:
  - DEMQOL – reliable and valid for mild and moderate dementia
  - DEMQOL-Proxy – reliable and valid for mild, moderate and severe\* dementia

\* results for severe sample somewhat limited by a small n

# Conceptual framework: DEMQOL & DEMQOL-PROXY

## Domains



## Items

# DEMQOL-U:

(collaboration: Institute of Psychiatry,  
SCHARR, LSHTM)



- the first condition specific, preference based measures in dementia
- 5-dimension health state classification for DEMQOL (4 response levels)
  - *cognition, negative emotion, positive emotion, social relationships, loneliness*
- 5-dimension classification for DEMQOL-Proxy (4 response levels)
  - *cognition, negative emotion, daily activities, positive emotion, appearance*
- preference based single utility index derived from general population valuations
- additional valuation obtained from people with dementia and their carers

# The challenge in 2014

- many more measures now exist
- people with dementia can tell us about their HRQL
- instruments can be administered to people with dementia and their carers

- BUT**
- what do they measure & how good are the “rulers”?
- BUT**
- what is the relationship between this and proxy reports of HRQL? (and also with HRQL of carers)
- BUT**
- how do we enable HRQL instruments to be appropriately used in practical, applied contexts?

# Using PROMs to Improve Dementia Care



- Large Department of Health (PRP) funded project
- Lead by LSHTM in collaboration with Alzheimer's Society, LSE, KCL and NHS clinicians
- 30 months (began June 2013)
- 3 distinct strands:
  - Evaluation of memory assessment services (MAS)
  - Development of a new method of obtaining HRQL information from people with dementia in residential care
  - Evaluation of feasibility of routine measurement of HRQL in people with dementia

# MAS Evaluation

- Aim is to determine:
  - impact of referral to MAS on HRQL of people with dementia and their carers
- Objectives:
  - identify the key characteristics of MAS and to describe post diagnostic support
  - determine the impact (effectiveness) of MAS on the HRQL of patients and carers
  - investigate association of patient characteristics with impact
  - estimate the cost-utility of MAS
  - determine association between characteristics of MAS and impact
  - determine the cost-effectiveness of different models of MAS.

# Pilot study: Key lessons



- Generally:
  - positive feedback from patients and carers
  - realistic task -- average time 25 mins (pt and carer)
- High number of DNAs and cancellations
  - helped by phoning prior to appointment
  - liaison with admin staff
- DEMQOL-Proxy reliable and valid for *self* administration (rather than interviewer)
- Preliminary version of improved scoring algorithm for DEMQOL (based on modern psychometric methods)

# Measuring HRQL in people with dementia in residential care

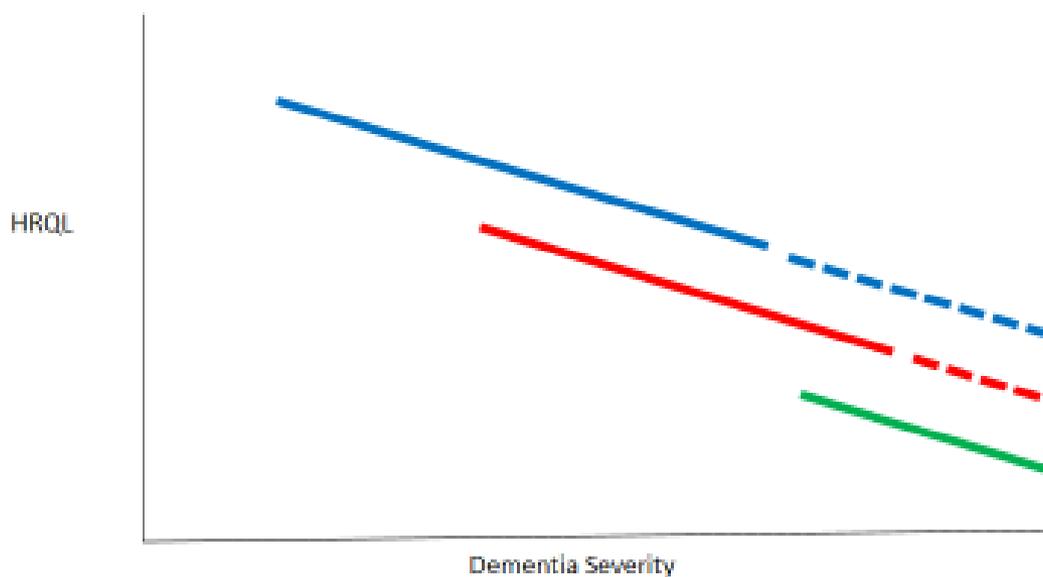


## Aim is to develop:

- a method of using advocates as proxy reporters of the HRQL of people with severe dementia in residential care

## Objectives:

- train advocates as proxies to report DEMQOL-Proxy
- evaluate the psychometric properties of advocate-reported DEMQOL-Proxy
- derive a psychometrically robust algorithm to map the relationship between advocate proxy-reports and family care proxy-reports (which in turn will have already been mapped to self-reports of DEMQOL, thus ensuring that interpretation of all DEMQOL scores are meaningful)



- = Person with dementia self report of HRQL
- = Family carer (proxy) report of HRQL
- = Advocate (proxy) report of HRQL

# Routine use of PROMs in dementia?

- does the PROM have fundamental measurement properties?
- (to what extent) can proxy reports be substituted for self-reports?
- is the measure sensitive to minimally important differences?
- is the use of PROMs acceptable?
- is it cost-effective to use PROMs in dementia?

- what do they measure & how good are the “rulers”? 
- improved scoring algorithm based on modern psychometrics (Rasch);
  - interval level scores
  - individual SE
  - meaningful change
- what is the relationship between this and proxy reports of HRQL? 
- mapping the relationship between self and proxy reports
- are they substitutable?
- how do we enable HRQL instruments to be appropriately used in practical, applied contexts? 
- identify most acceptable ways to implement & use PROMs routinely in dementia