This presentation reports independent research commissioned and funded by the Department of Health Policy Research Programme (Using Patient Reported Outcome Measures to Assess Quality of Life in Dementia, 0700071). The views expressed in this publication are those of the author(s) and not necessarily those of the Department of Health.
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 (e.g., 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

- Daily activities & looking after yourself
- Health & well-being
- Cognitive functioning
- Self concept
- Social relationships

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
• **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)
[Image description: A graph showing the relationship between Dementia Severity and HRQL (Health-Related Quality of Life). The x-axis represents Dementia Severity, and the y-axis represents HRQL. Three lines are plotted: a solid blue line for the person with dementia self-report of HRQL, a solid red line for the family carer (proxy) report of HRQL, and a dotted red line for the advocate (proxy) report of HRQL. The lines show a negative correlation, indicating that as Dementia Severity increases, HRQL decreases.]
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”?  
• what is the relationship between this and proxy reports of HRQL?  
• how do we enable HRQL instruments to be appropriately used in practical, applied contexts?  

• improved scoring algorithm based on modern psychometrics (Rasch);  
  • interval level scores  
  • individual SE  
  • meaningful change  
• mapping the relationship between self and proxy reports  
• are they substitutable?  
• identify most acceptable ways to implement & use PROMs routinely in dementia