



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

CREATE CHANGE



COGNITIVE
DECLINE
PARTNERSHIP
CENTRE

Valuing quality of life for people with dementia: the AD-5D project (activity 33)

Project team: Tracy Comans, Kim-Huong Nguyen, Alyssa Welch, Brendan Mulhern, Julie Ratcliffe, Megan Corlis, Wendy Moyle, Sanj Kularatna, Tara Quirke, Elaine Todd

Utility instruments used in dementia literature

Instrument	Domains	Number of health states	Number of studies
EQ-5D	Mobility, self-care, usual activities, pain/discomfort, and anxiety/depression	243/3,125	45
HUI 2/3	Vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain	24,000/975,000	15
QWB	Mobility, physical activity, and social activity	1,170	4
15D	Mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality, and sexual activity	31 billion	3
AQoL	Illness, independent living, social relationships, physical senses, and psychological well-being	16.8 billion	2
Demqol-U, Demqol-proxy-U	Positive emotion, memory, relationships, negative emotion and loneliness/positive emotion, memory, appearance, and negative emotion	1,024/256	2

SYSTEMATIC REVIEWS

Utility-Based Instruments for People with Dementia: A Systematic Review and Meta-Regression Analysis

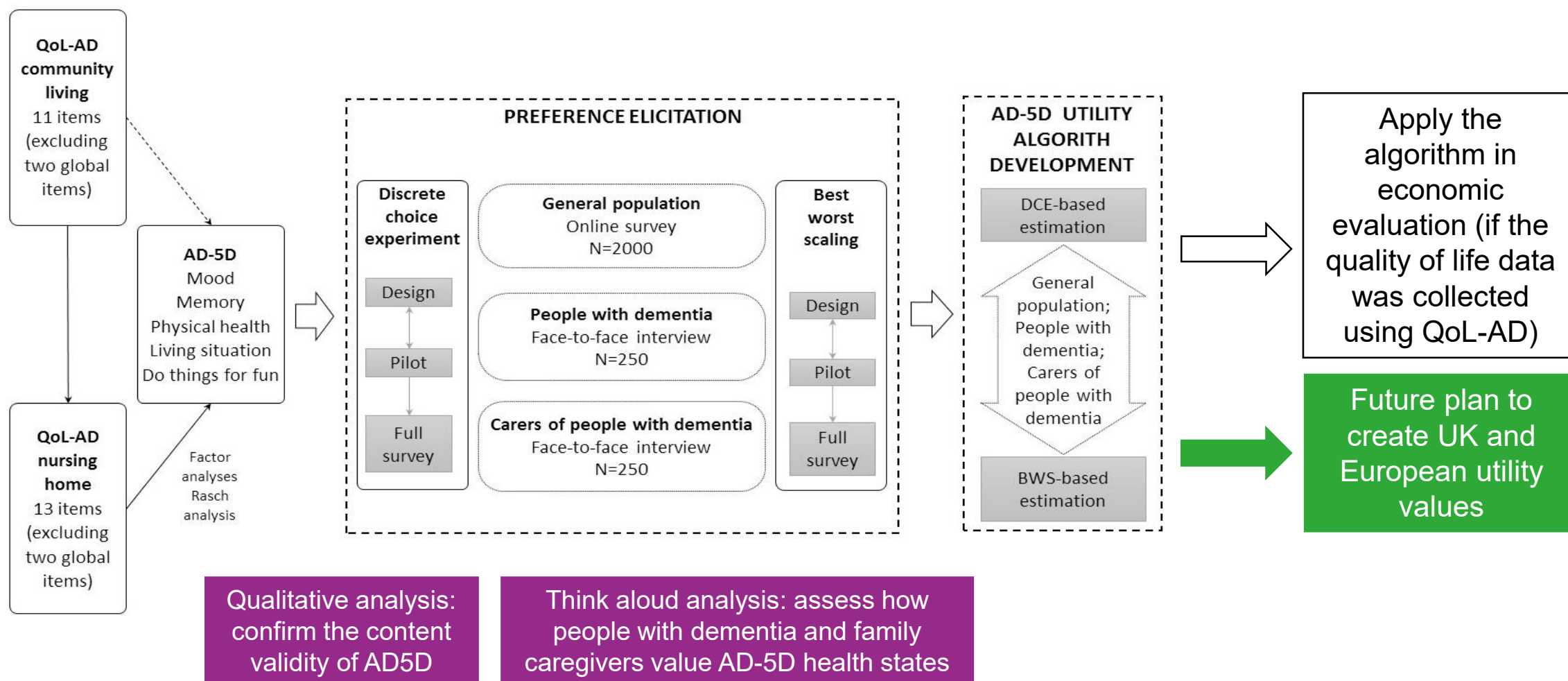
Li Li, MHEcon(Adv), BPharm^{1,*}, Kim-Huong Nguyen, PhD^{1,2}, Tracy Comans, PhD^{1,2,3}, Paul Scuffham, PhD¹

¹Centre for Applied Health Economics, Menzies Health Institute Queensland, School of Medicine, Griffith University, Nathan, Queensland, Australia; ²The NHMRC Cognitive Decline Partnership Centre, Sydney, New South Wales, Australia; ³Metro North Hospital and Health Service District, Brisbane, Queensland, Australia

Psychometric properties

Criteria		EQ-5D	HUI2/3	QWB	DEMQOL-U/ Proxy-U	AQoL	15D
Feasibility	Average patient-rated completion time (min)	4.5	16.3	18.7	29.4	NA	NA
	Average proxy-rated completion time (min)	2.3	7.7	11.3	22.5	NA	NA
	Average missing items	1%	19%	24%	15% / 2.8%	NA	NA
Precision	Shows ceiling effect	Yes	No	No	Yes	No	NA
	Shows floor effect	No	Yes	No	No (Yes proxy)	No	NA
Reliability	Test-retest reliability	Moderate	Moderate	Strong	Weak	Weak	Weak
	Inter-rater agreement	Weak	Weak	Weak	Weak	Weak	Weak
Validity	Number of relevant attributes included	10	11	25	NA	NA	NA
	Convergence validity	Strong	Inconclusive	Moderate	Weak	Moderate	Weak
	Known-group validity according to MMSE	Moderate	Inconclusive	NA	Weak	Moderate	NA
Responsiveness	Responsiveness	Medium	Low	Low	Low	Low	NA

Activity 33: AD-5D project flow



AD-5D classification system

Table 5 Proposed health state classification system for the new preference-based instrument AD-5D

Dimension	Descriptions
Memory	You have excellent memory You have good memory You have fair memory You have poor memory
Mood	You have excellent mood You have good mood You have fair mood You have poor mood
Physical health	You have excellent physical health You have good physical health You have fair physical health You have poor physical health
Living situation	You have excellent living situation You have good living situation You have fair living situation You have poor living situation
Do fun things	You have excellent ability to do fun things You have good ability to do fun things You have fair ability to do fun things You have poor ability to do fun things

- Memory and Mood are two single items that represent their own domains.
- “Physical health” represent the physical health domains (containing energy and physical health)
- “Living situation” represent six items that can be loosely grouped as “interpersonal environment” domain (family, staff, friend, make choice, living situation, live with others)
- “Do things for fun” represent self-functioning domain (take care of self, keep busy and do things for fun)



Confirming the content validity of the AD-5D classification system domains using qualitative analytical approaches

Methodology

1 Baker R, Thompson C, Mannion R. Q methodology in health economics. Journal of Health Services Research & Policy. 2006;11(1):38-45.

- 3 focus groups (the P set)
 - Group 1: people living with dementia (n=2) and a caregiver (n=1)
 - Group 2: caregivers and former caregivers for people with dementia (n=8) and one person living with dementia (n=1)
 - Group 3: former caregivers and relatives of LTC residents (n=10)
- Q methodology¹
 - Designed to consider qualitative and quantitative factors for health economics

Q set

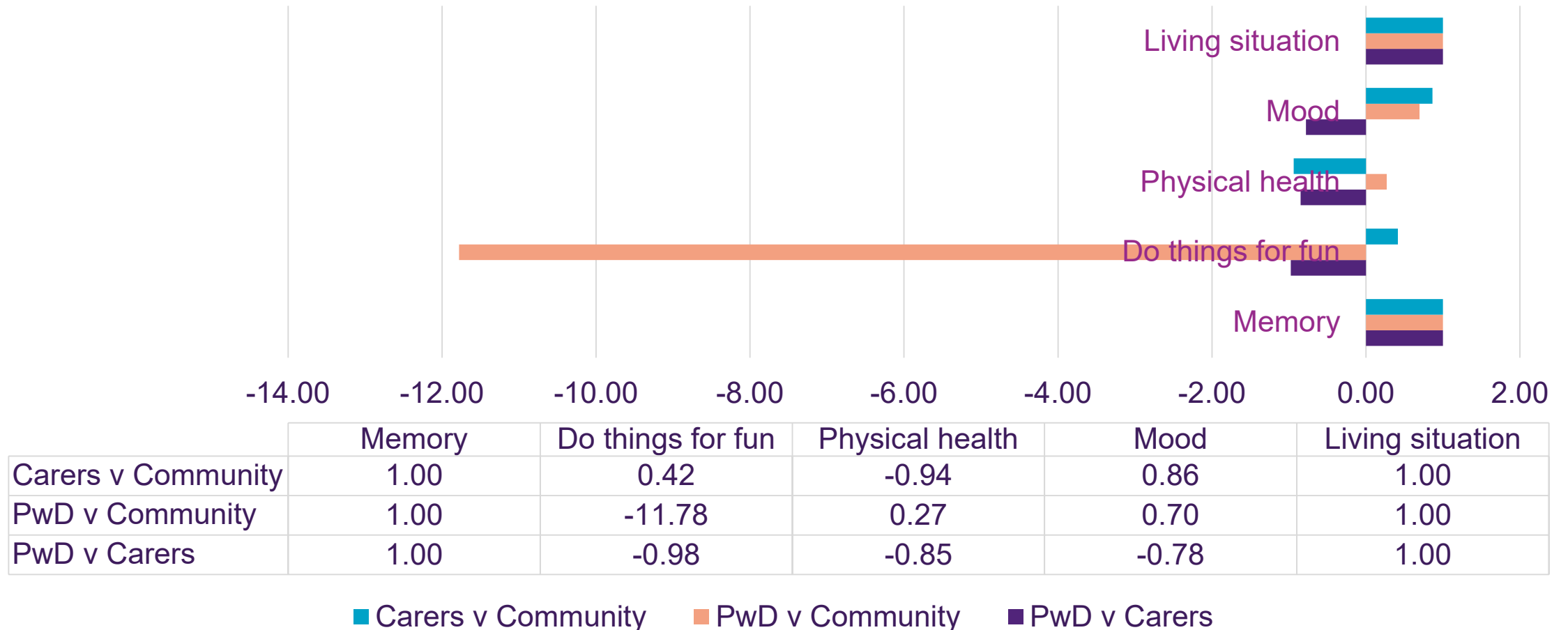
- Established using structured and unstructured methods
- **Question:** What are the everyday things and activities that contribute to or take away from your quality of life?
- Top two answers shared until all responses exhausted
- Answers written onto adhesive notes → Mapped to the AD-5D domains, duplication permitted.

Results

- Cognitive stimulation, family relationships, emotional support, physical and financial independence identified by all groups
- Inter-relationship between domains identified:
 - Social interaction allocated to three domains
 - **Sleep** allocated to all five domains
- **All activities** could be mapped to at least one of the AD-5D domains



Factor analysis: agreement between groups



Perspectives: people living with dementia

- Contributing factors to quality of life
 - Relationships, social engagement and support
 - Having a sense of purpose and identity
 - Maintaining wellbeing for continued enjoyment of life
 - Maintaining a sense of humour, optimism and positive attitude
- The main detractor from quality of life was the **stigma** dementia participants believed was expressed in the community



Perspectives: carers / care partners

- Contributing factors to quality of life
 - Identity and sense of self
 - Independence and space
 - The joy of caring for a loved one
- Detractors from quality of life included
 - A sense of loss and sacrifice
 - Changes to family and personal relationships

Perspectives: community members

- Most comments were prefaced with
 - “I would miss ...” or
 - “I really enjoy doing ...”
- Emphasis was placed on the value of activities in their own daily lives right now
- Contributors to quality of life were primarily those that increased comfort and the ability to do the things they love, such as health and strength.
- Participants generally expressed a reluctance towards a future with reduced capacity or a need to live in a nursing home, with one noting “once you’re locked up, you’re locked up.”



AD5D utility algorithm: how different did the general population value dementia quality of life health state vs. dementia dyads?

Health preference elicitation method

- Discrete choice experiment with duration (DCE_{TTO}): we ask respondents to choose between two “hypothetical” health scenarios

Health Description A	Health Description B
You have poor physical health	You have excellent physical health
You have good mood	You have fair mood
You have fair memory	You have fair memory
You have good living situation	You have fair living situation
You have good ability to do things for fun	You have good ability to do things for fun
You live in this state for 4 years and then you die.	You live in this state for 7 years and then you die.
<input checked="" type="checkbox"/>	<input type="checkbox"/>

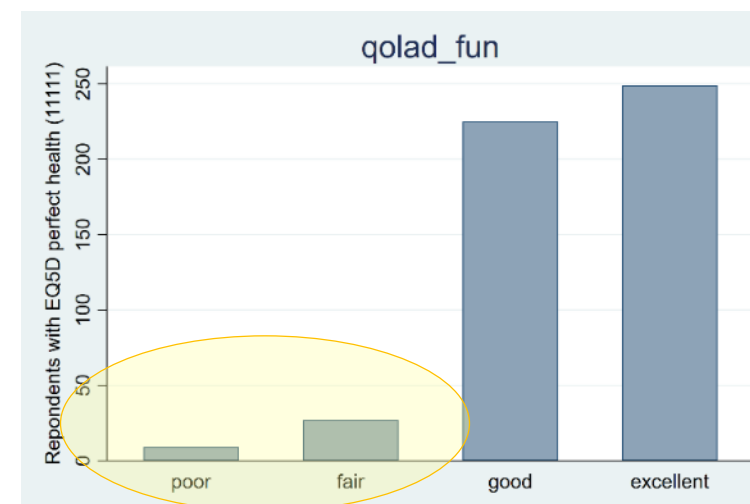
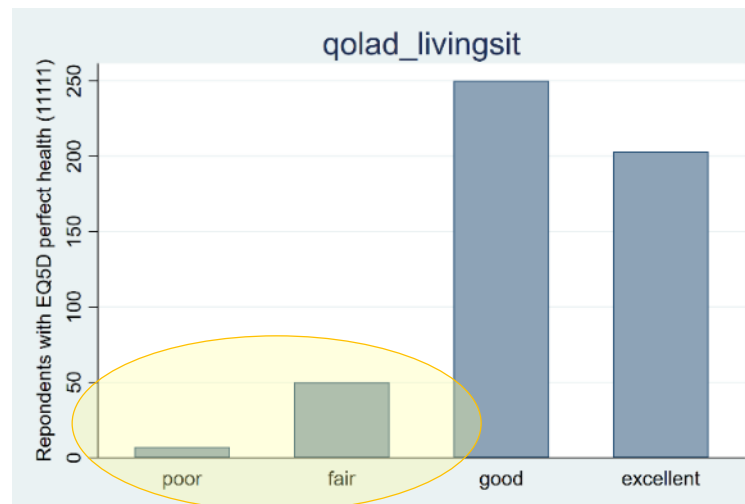
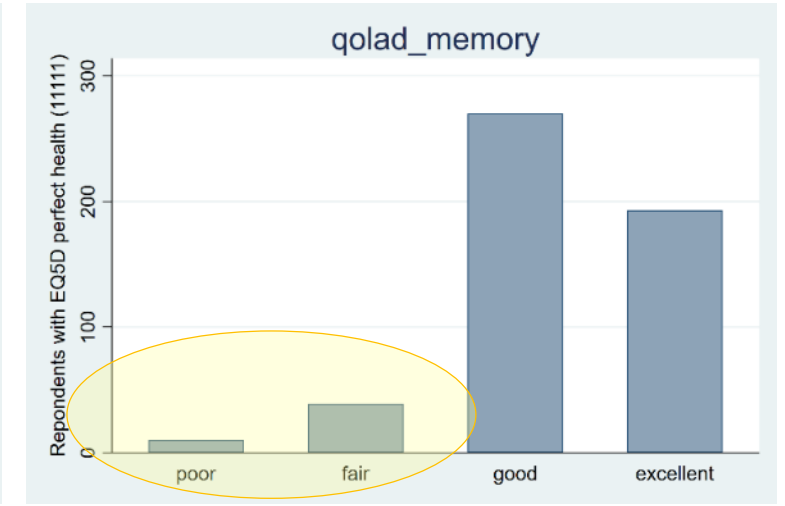
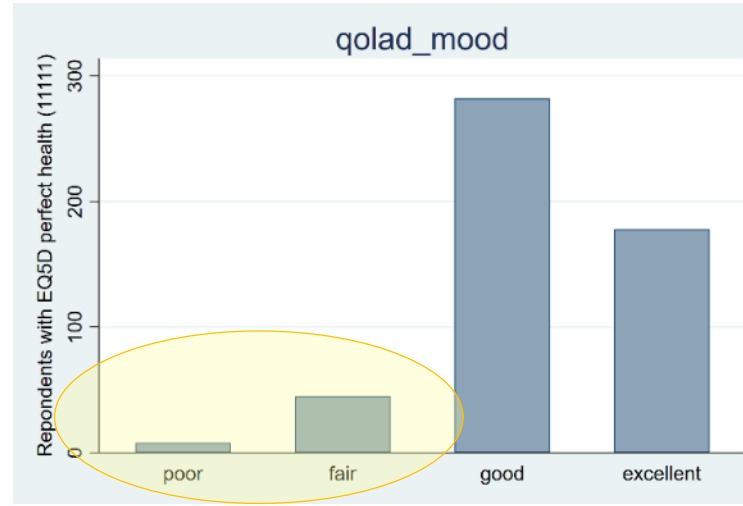
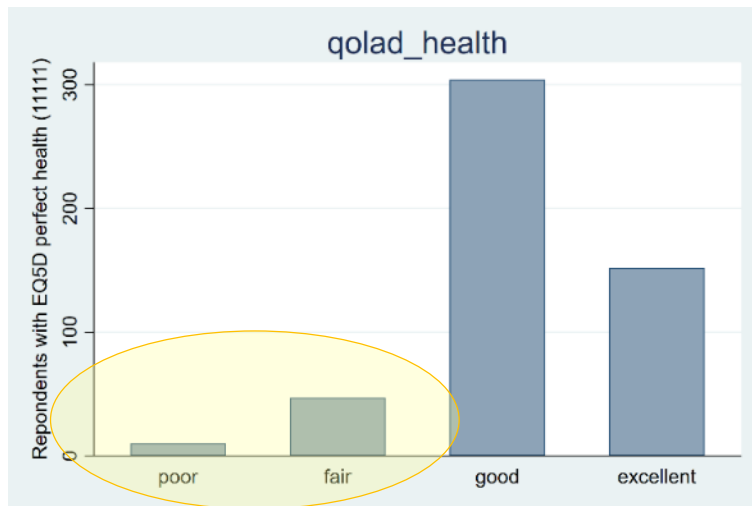
Design: discrete choice experiment (DCE) with duration

- D-efficient design (using Ngene):
 - No label: we did not describe the survey is about “quality of life with dementia”, only “quality of life” in general.
 - For a statistical model with 16 covariates (duration + duration*15 attribute-levels – excluding 1 level as the base); duration treated as a continuous variable
- Survey settings:
 - General population and carer: 20 blocks of 10 choice sets each = 200 choice sets; each choice set has two health scenarios
 - Person with dementia: 40 blocks of 5 choice sets each = 200 choice sets; each choice set has two health scenarios

Data collection

- An online sample of 2,000 members of the Australian general public (Pureprofile)
 - Demographic information + EQ-5D-5L + QoL-AD (self-rating)
 - Complete the health preference elicitation task (e.g. DCE)
 - Feedbacks
- Interviews with dementia dyads (*on going*)
 - So far we have interview data for 98 dyads
 - *Preliminary analysis presented here*

Perfect health by EQ-5D-5L vs. QoL-AD



Which model is the best to produce an utility algorithm?

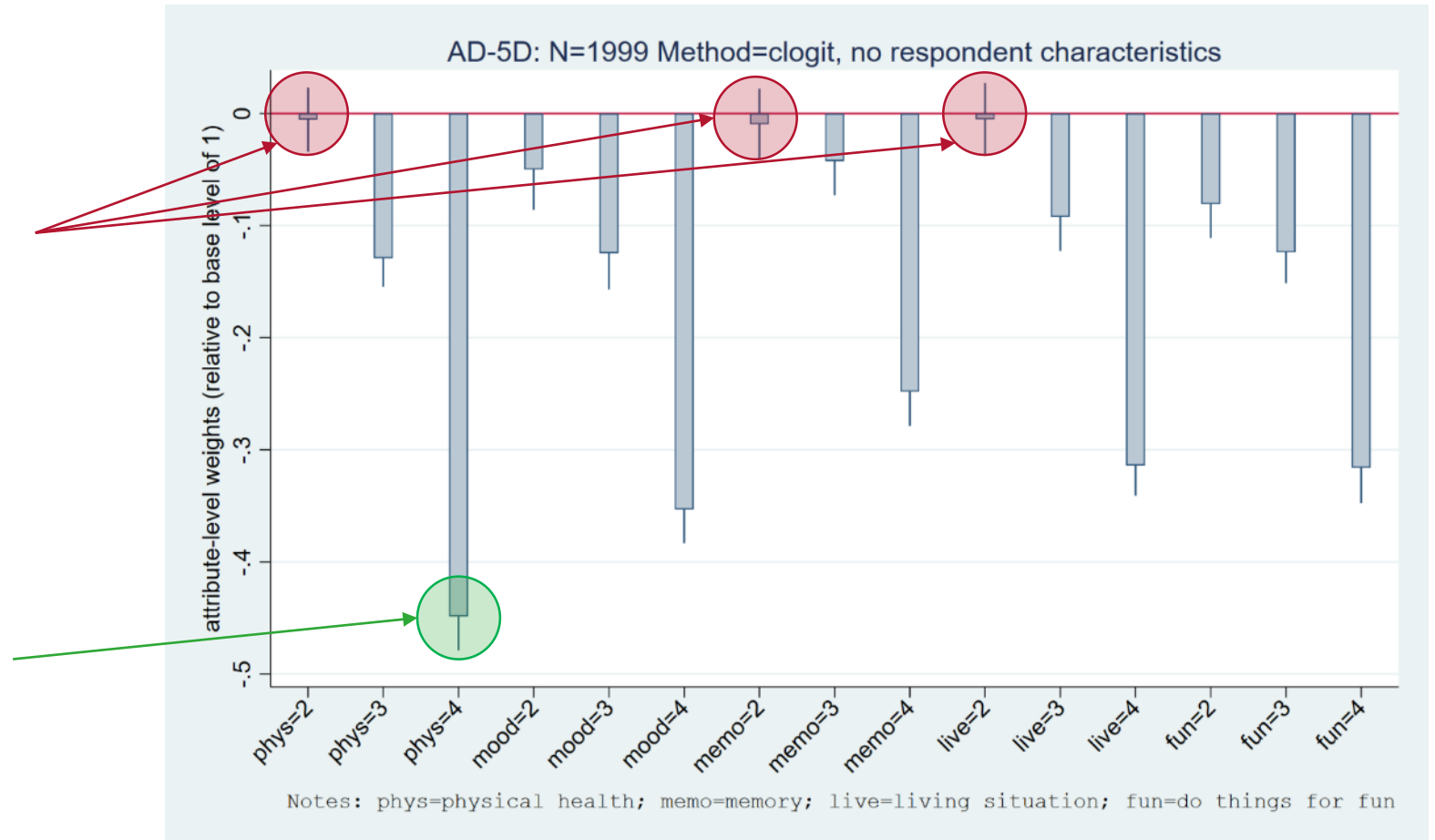
Decision criteria: Logical / sensible / as expected / best fit

- The sign of duration coefficient should be positive: utility “should” increase with the time spent living in full health
- The levels in each attribute should be negative (base=excellent) and have a logical ordering:
 - Severe levels should have larger decrements from the base=excellent
- Most (if not all) coefficients should be statistically significant

Conditional logit: general public

Coefficients with correct sign (negative) but not statistically significant

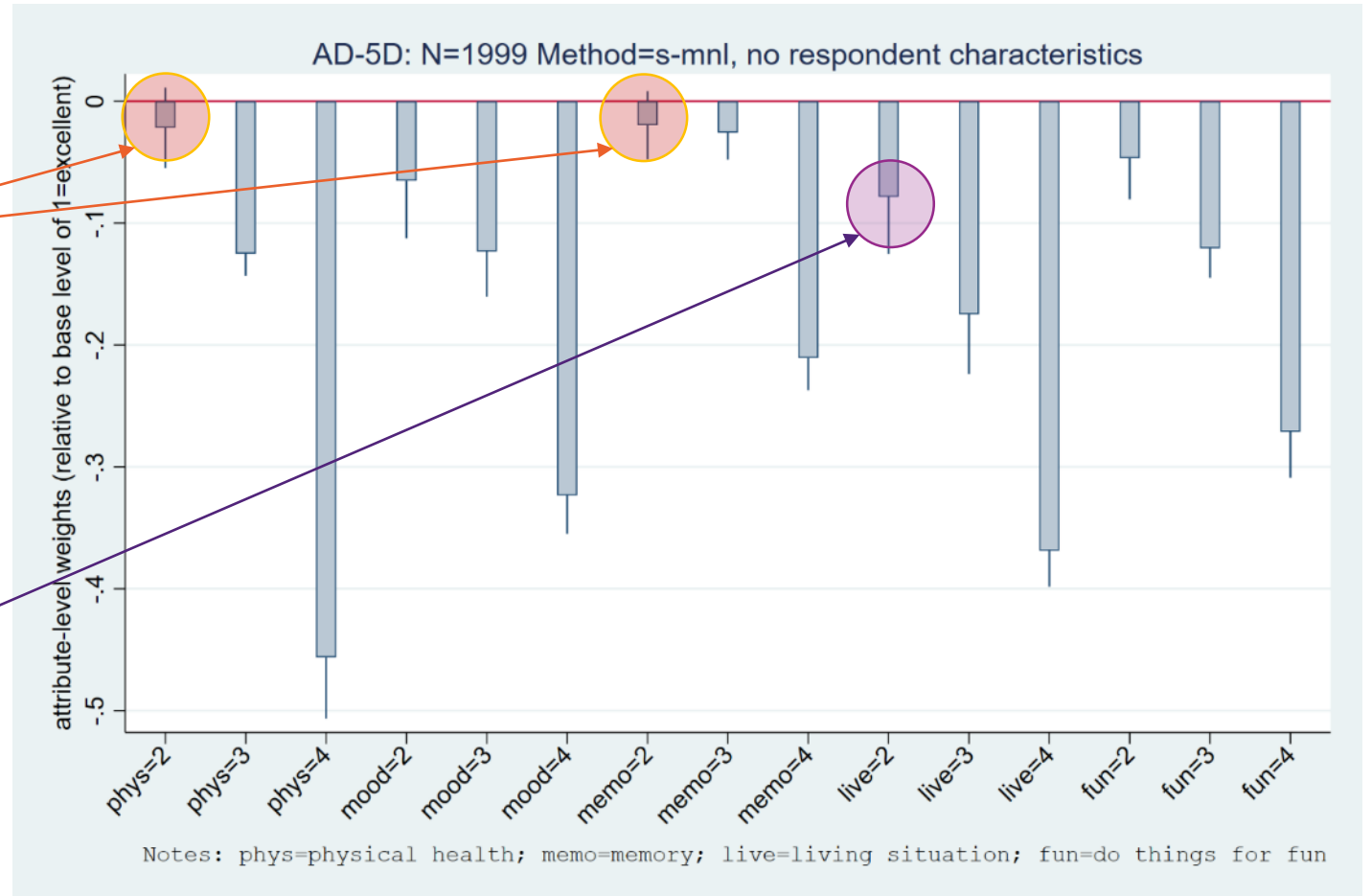
Poor physical health has the highest disutility



Scale multinomial logit: general public

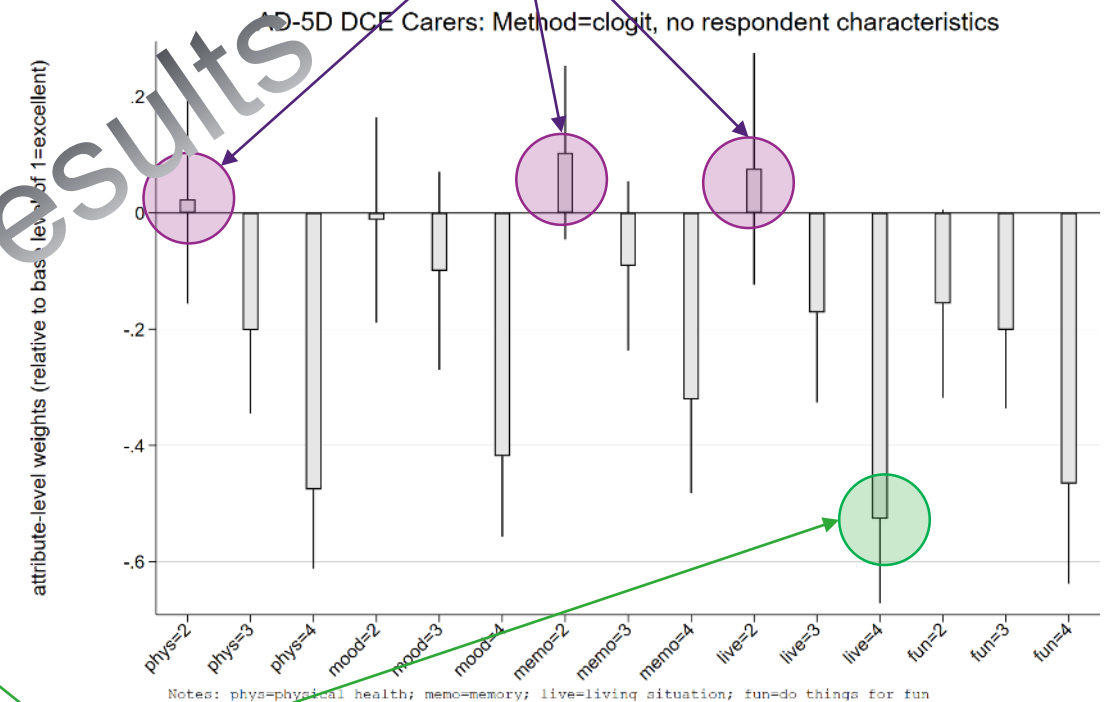
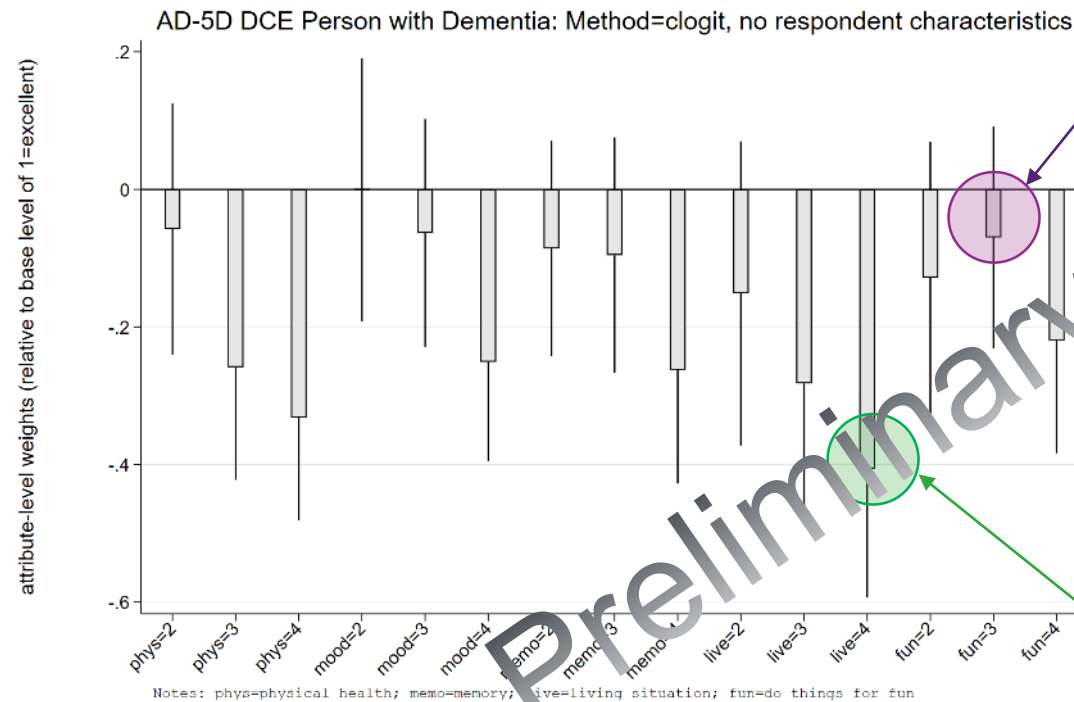
Coefficients not statistically significant; all in logical order and reasonable size

Good living situation becomes significant with a sizable coefficient



Conditional logit: dementia dyad

Disordering in some coefficients



Poor living situation has the highest disutility

Preference differences?

People living with dementia			Caregivers		General population	
Order	Focus group	DCE	Focus group	DCE	Focus group	DCE
1	Fun things	Living situation	Living situation	Living situation	Living situation	Physical
2	Mood	Physical	Fun things	Physical	Fun things	Mood
3	Physical	Memory	Physical	Fun things	Physical	Fun things
4	Living situation	Mood	Mood	Mood	Mood	Living situation
5	Memory	Fun things	Memory	Memory	Memory	Memory

Future plan

- Publish algorithms for scoring
- Set up web page for these resources
- Apply the algorithms to current CDPC projects underway (Simpler, EP)
- Whose preferences should be used for public funding?



Outputs to date

Publications

Published

1. Nguyen et al, 2017 Developing a dementia-specific health state classification system for a new preference-based instrument AD-5D: HQLO 15:1 p21
2. Comans et al, 2018 Developing a dementia-specific preference-based quality of life measure (AD-5D) in Australia: a valuation study protocol

Under review

1. Welch et al, Confirmatory analysis of a health state classification system for people living with dementia: a mixed methods approach, J Health Ser Res & Policy
2. Ratcliffe et al, How do people with dementia and family carers value dementia specific quality of life states? An explorative 'Think Aloud' study, Aust J Ageing CDPC special issue

Presentations / seminars / workshops this year:

1. UQ Geriatric medicine seminar series
2. UQ-Exeter Initiator Grant Seminar
3. University of Sheffield 2018 Seminar
4. ISPOR, 2018: 3 presentations (WS: dementia progression and economic evaluation)
5. AHES, 2018: 4 presentations (organised session on AD5D project)
6. IAHPR 2018: 1 presentation



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

CREATE CHANGE

Thank you

A/Prof Tracy Comans | Boosting Dementia Research Leadership Fellow
Centre for Health Services Research
t.comans@uq.edu.au
0401 021 091



@UQ_HERMU



www.linkedin.com/in/tracy-comans-709b6a19

