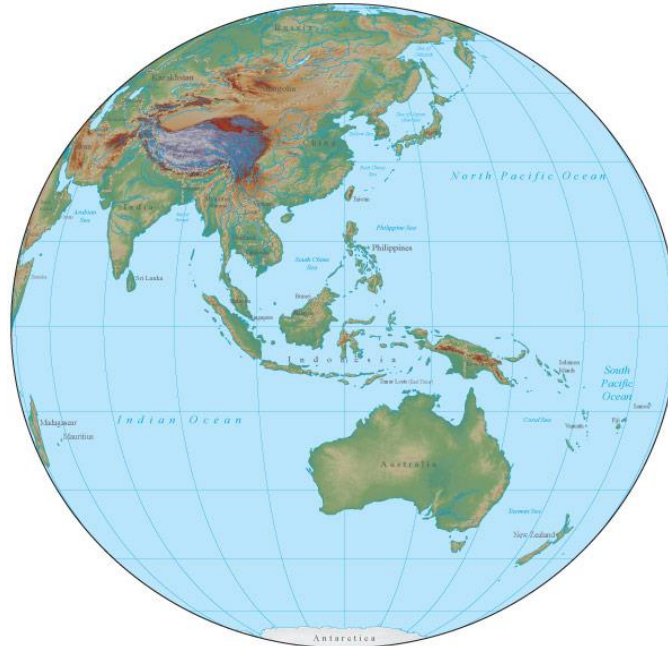


Australia's Dementia Research Initiative: The Contribution of Nursing Science



Elizabeth Beattie, PhD, RN, FGSA

*Professor Aged and Dementia Care, School of Nursing,
Queensland University of Technology, Director,
Dementia Collaborative Research Centre: Carers and
Consumers and Qld Dementia Training Study Centre*

Today:

- The pressing issue- Dementia as a global and local issue.
- Current organization of, and major changes in, Australian dementia research funding.
- Nurse-led dementia research in Australia: *The National Quality of Life in RACF study (AusQoL)* as an example.
- Challenges for dementia nurse scientists.



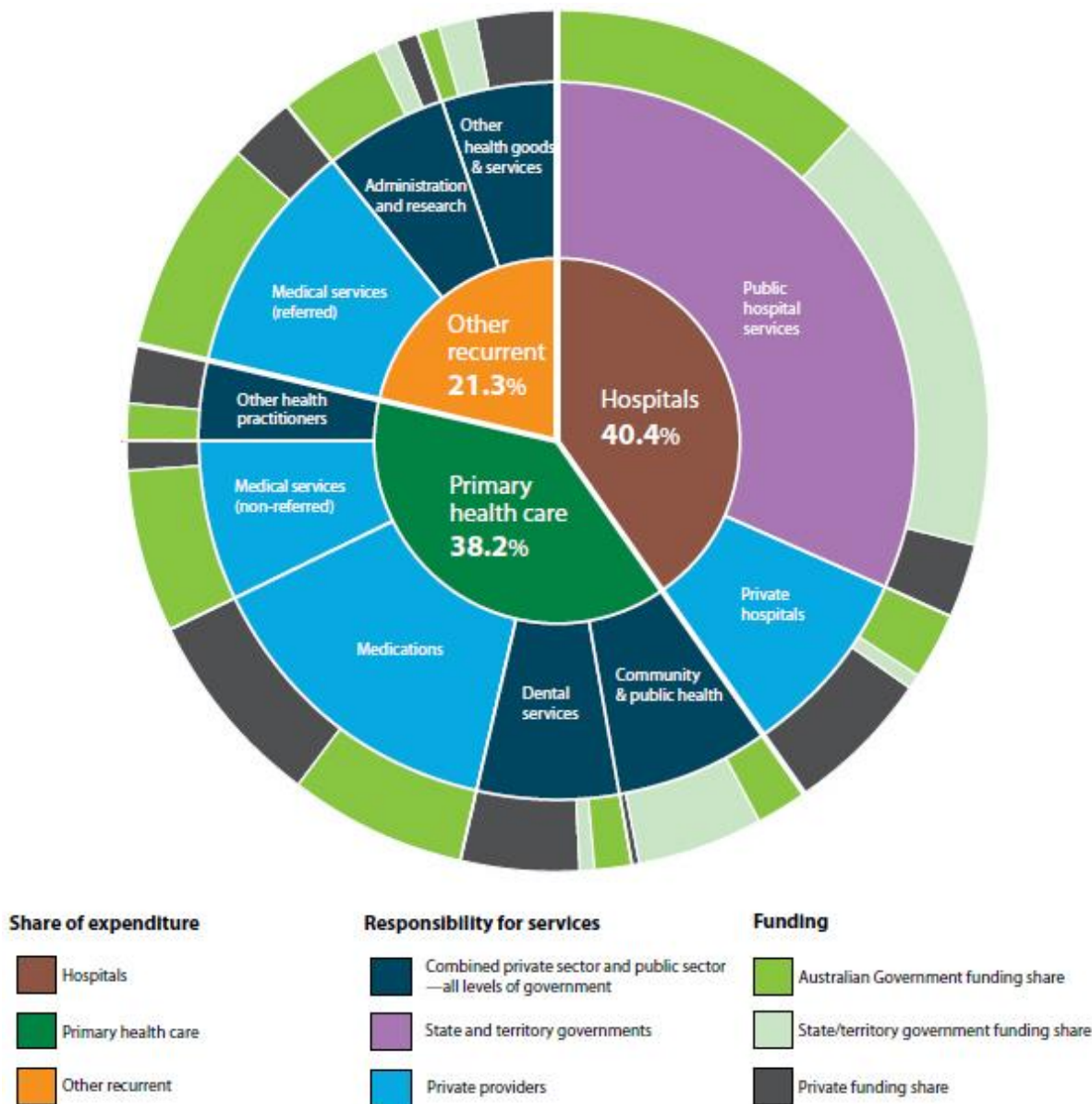
- Universal health insurance + private health coverage
- A multi-faceted web of public and private providers, settings, participants and supporting mechanisms.
- Health providers include medical practitioners, nurses, allied and other health professionals, hospitals, clinics and government and non-government agencies.
- Providers deliver a plethora of services across many levels, e.g. community public health and preventive services, primary health care, emergency health services, hospital-based treatment, and rehabilitation and palliative care.
- \$142 Billion in 2011-2012 and rising.

23,820,300 people (July 5, 2015)

A Federation of 6 states and two territories

A Parliamentary democracy

A Commonwealth



Note: Inner segments shows relative size of expenditure in each of the 3 main sectors of the health system ('hospitals', 'primary health care', and 'other recurrent').

Middle ring shows the relative expenditure on each service in the sector (shown by the size of each segment) and who is responsible for delivering the service (shown by the colour code).

Outer ring shows the relative size of the funding (by size of each segment) and the funding source for the difference services (by the colour code).

http://www.aihw.gov.au/australias-health/2014/health-system/#figure_2_1

Recent International Developments in the Fight Against Dementia

The World Dementia Council

<https://dementiachallenge.dh.gov.uk/category/wdc/>

WHO Global Action Against Dementia

http://www.who.int/mental_health/neurology/dementia/en/

The Global CEO Initiative:

<http://www.ceoalzheimersinitiative.org/mission-and-vision>

**47million
and
growing**



Dementia in the USA



It's the only cause of death in the top 10 in America that **CANNOT BE PREVENTED, CURED OR SLOWED.**



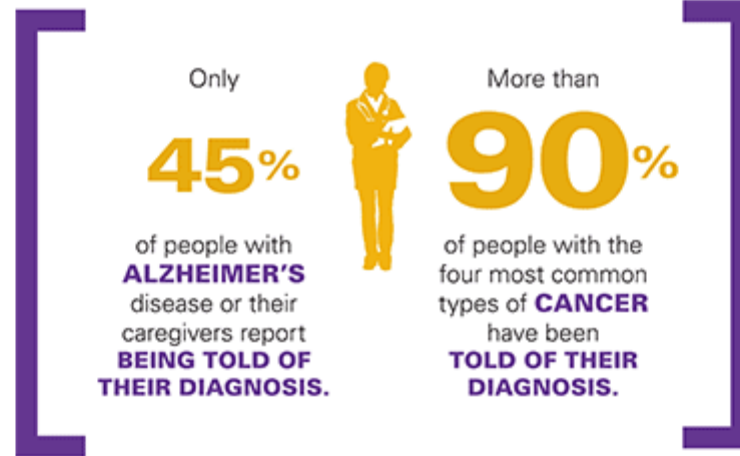
ALMOST TWO THIRDS of Americans with Alzheimer's disease are women.



SENIORS dies with Alzheimer's or another dementia.



Alzheimer's disease is the **6TH LEADING CAUSE OF DEATH IN THE UNITED STATES.**



By 2050, these costs could rise as high as **\$1.1 TRILLION.**



In 2015, Alzheimer's and other dementias will cost the nation **\$226 BILLION.**

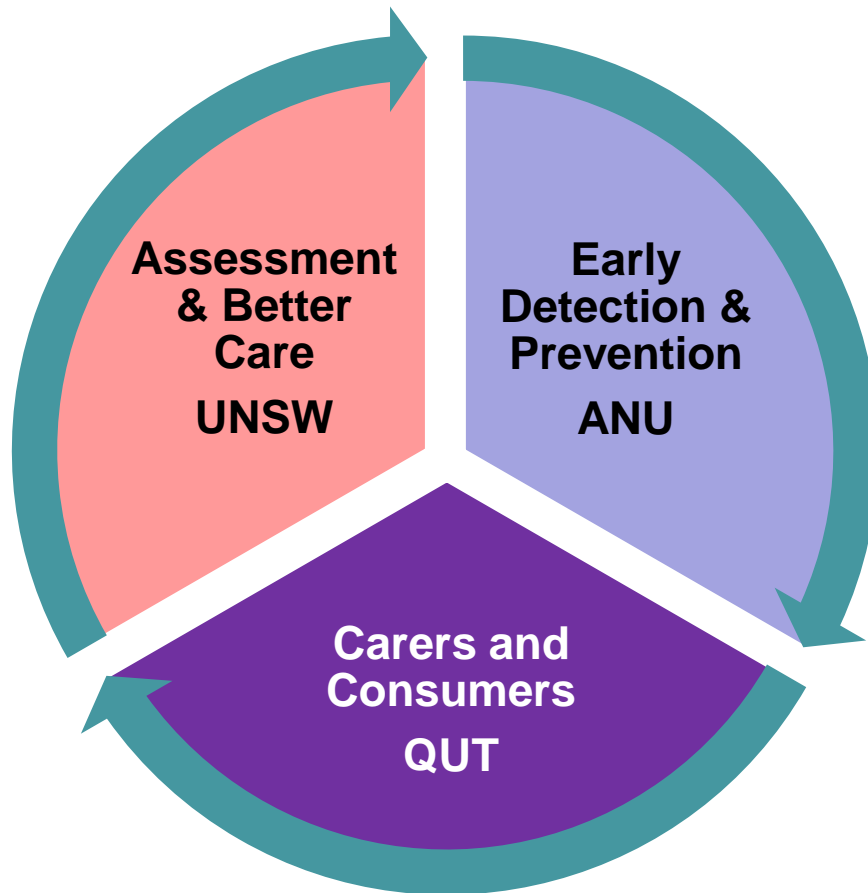
<http://www.alz.org/facts/overview.asp>

Dementia in Australia

- 342,800 + Australians living with dementia
- Expected to increase by 1/3 400,000 in less than ten years
- Without a medical breakthrough, almost 900,000 by 2050
- 1,700 new cases of dementia/week in Australia: approx. one person every 6 minutes. This is expected to grow to 7,400 new cases each week by 2050
- 24,700 people with Younger Onset Dementia
- Three in ten people over the age of 85 have dementia
- An estimated 1.2 million Australians are caring for someone with dementia
- Dementia is the second leading cause of death (the second leading cause in women) in Australia
- On average symptoms of dementia are noticed by families three years before a firm diagnosis is made.



<https://fightdementia.org.au/about-dementia-and-memory-loss/statistics>



- Established 2007 by competitive Dpt. Health & Ageing funding 2007-2010
- Refunded 2010-2013. Moved under National Health & Medical Research Council in late 2012.
- Reviewed by NHMRC 2013.
- Since funded on an annual basis approx. \$1.4M/centre
- Currently funded until June 30, 2015 with refunding expected to December 2017.

<http://www.dementiaresearch.org.au/>

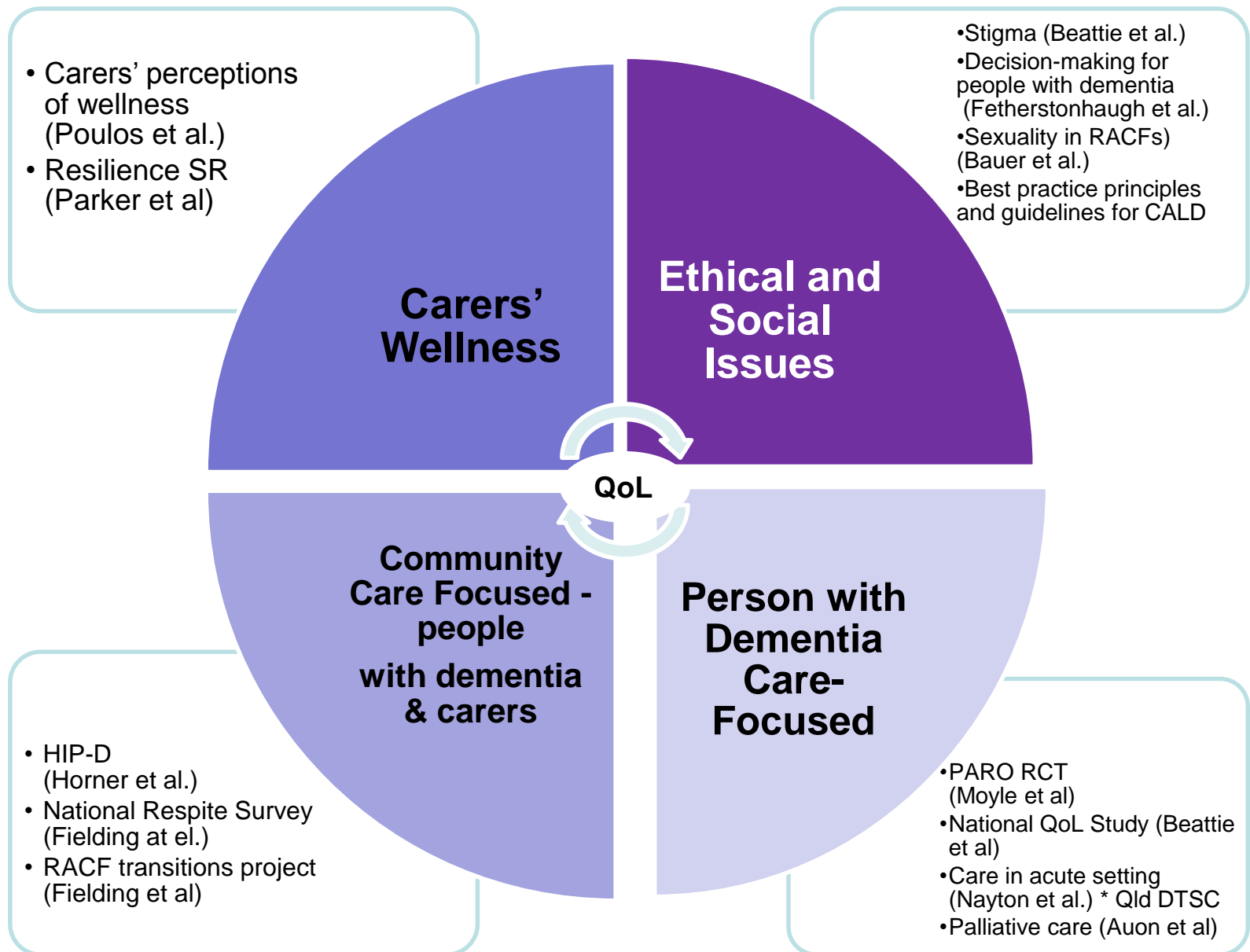


DCRC: Carers and Consumers

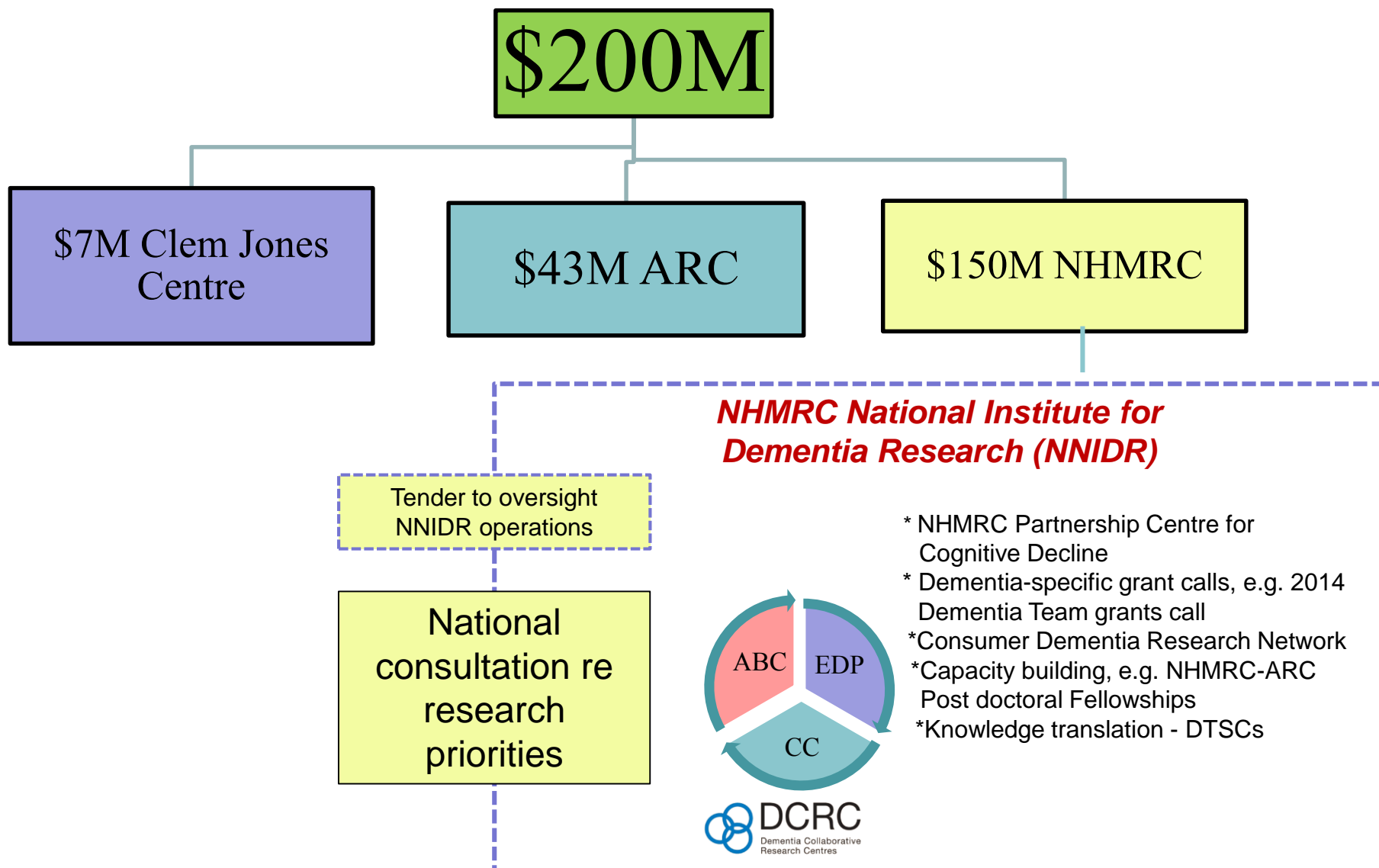
- A collaborative partnership model



DCRC: CC CORE FOCI



The \$200M Commitment for Dementia Research



The NHMRC Dementia Research Priorities and Draft Clinical Guidelines

The top dementia research and translation priorities identified through the survey and interviews were:

- For professional care providers, senior investigators, researchers and medical practitioners: to identify effective interventions to reduce the risk of and prevent the incidence of dementia.
- For people with dementia: timely, accurate and supported diagnosis with prevention their second priority, a reminder of the importance of accurate and sensitive diagnosis and support for people and their families
- For personal carers: to develop effective interventions to support their opportunity and capacity to care which are quite patchy currently; prevention as their second priority
- Draft clinical guidelines developed by an expert panel and led by the NHMRC Partnership Centre in Cognitive Decline will be published in July, 2015 following the completion of public consultation and revision.

<https://www.nhmrc.gov.au/research/boosting-dementia-research-initiative/nhmrc-consultation-dementia-research-priorities>

Dpt. of Social Services developments related to dementia

- Review of all Govt. dementia programs designed to support people living with dementia and their carers.

<https://www.dss.gov.au/ageing-and-aged-care/news/2015/analysis-of-dementia-programmes>

- Establishment of the Severe Behaviour Response Teams (SBRTs) The SBRTs will work closely with the existing Dementia Behaviour Management Advisory Services (DBMAS) in each state and territory. Integrated in 2016-17

<http://mitchfield.dss.gov.au/media-releases/more-support-for-people-with-severe-symptoms-of-dementia-in-aged-care>

- Piloting of the national quality indicators in RACFs.

<https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/aged-care-reform/quality-indicators-for-aged-care/quality-indicator-programme-frequently-asked-questions>

- Continuation of the Healthy Ageing grants round

<http://mitchfield.dss.gov.au/media-releases/innovative-aged-care-projects-receive-34-million-boost>

Nurse-led Dementia Research in Australia

- Very small cadre of PhD-prepared RNs in gerontology and psychogeriatrics qualified to undertake dementia research.
- No dedicated research institute focused on nursing science.
- Limited appreciation of the extent of basic research needed about multiple aspects of dementia care.
- An imperative to collaborate.
- Growing body of published nurse-led research and knowledge translation projects.
- Developing appreciation of the contribution of nurse scientists and our disciplinary lens to solving complex health problems.

Challenges to Improving Dementia Care Across the Disease Trajectory and in Multiple Contexts



- The cure-prevention-care triad
- Workforce characteristics
- Workforce education and training
- Effective translation of knowledge into practice – sustaining change
- Stigma and language
- Dignity, respect and advocacy for people living with dementia
- Carer support

The AusQoL Group

- Prof Elizabeth Beattie* (QUT)
- Prof Wendy Moyle* (Griffith University)
- Assoc. Prof Barbara Horner* (Curtin University)
- Dr Deirdre Fetherstonhaugh* (La Trobe University)
- Prof Lynn Chenoweth* (University of Technology Sydney)
- Prof Andrew Robinson* (University of Tasmania)
- Dr Maria O'Reilly (QUT)
- Dr Elaine Fielding (QUT)





Elizabeth Beattie*



Wendy Moyle*



Elaine Fielding



Deirdre Fetherstonhaugh*



Barbara Horner *



Maria O'Reilly



Andrew Robinson*



Lynn Chenoweth*

DCRC: CC AusQoL GROUP

Translating dementia research into practice

Keeping Up with What's New in Dementia



- DTSC free lectures and seminars at QUT

<http://dtsc.com.au/qld/>



<http://journalofdementiacare.com/>

Quality of Life in Dementia: Reality or Rhetoric?



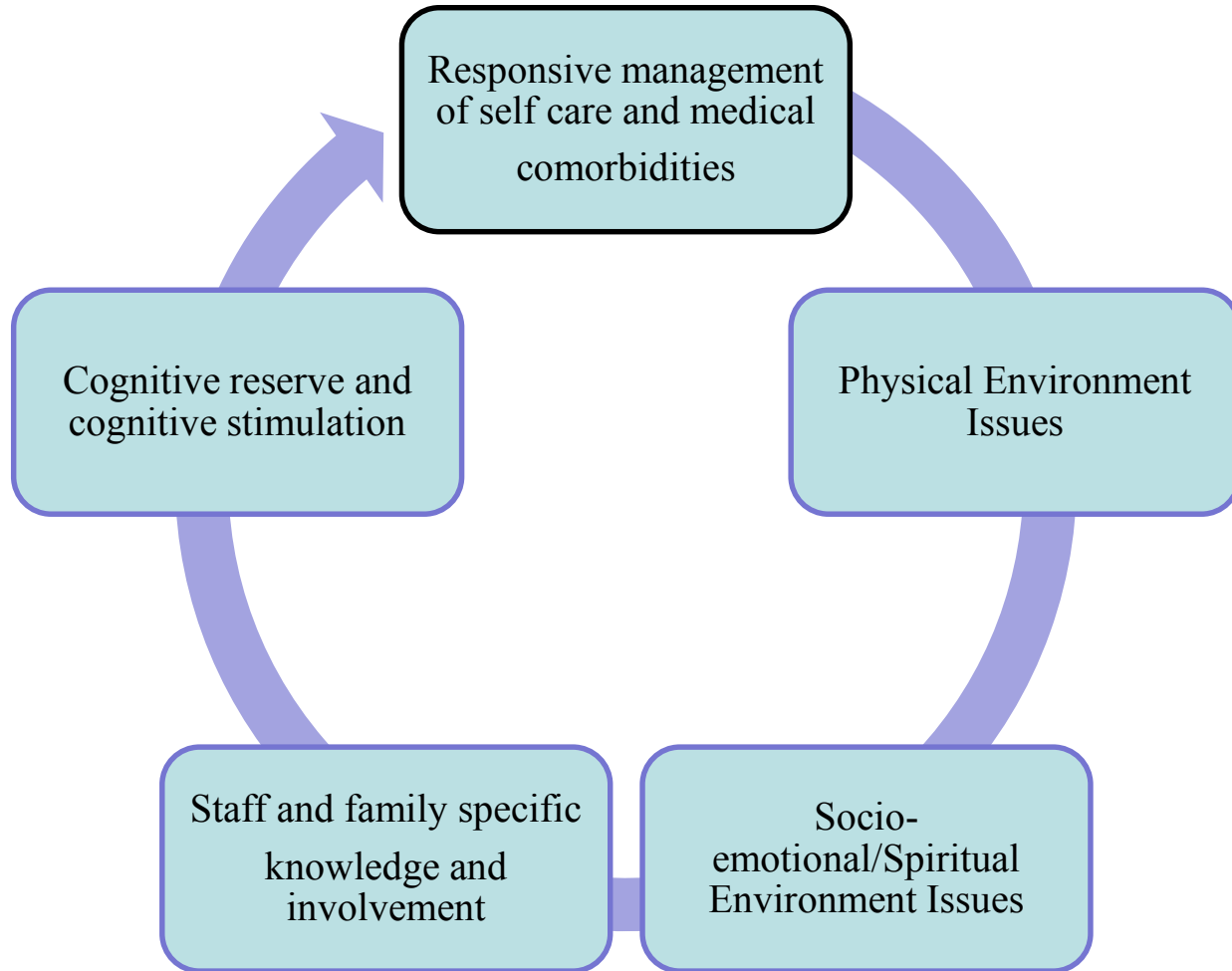
QoL in Dementia

No Cure/s —→ **Focus
on QoL**

Determined by, e.g.

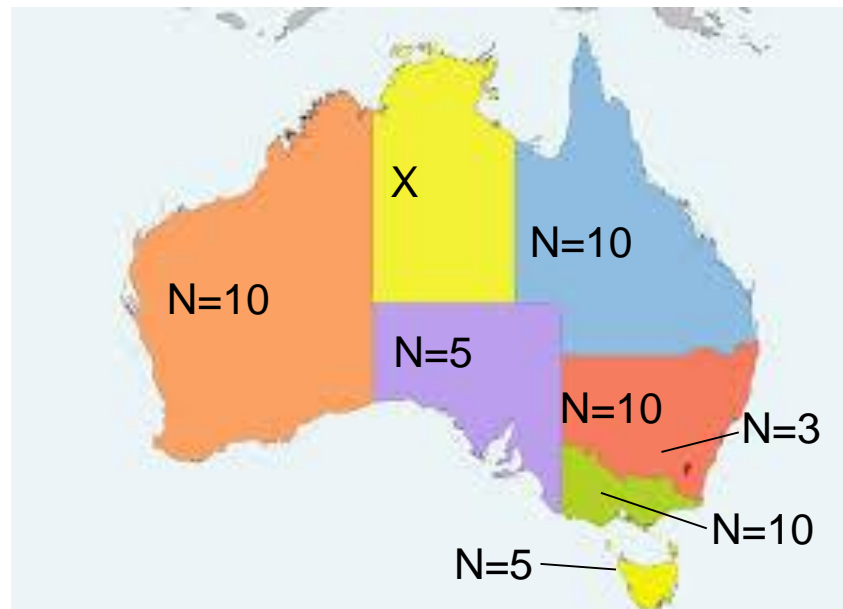
- Overall Health
- Leisure Activities
- Ability for self care
- Environment
- Relationships
- Mood/Depression
- Ability for self-determination
- System factors

Aspects of QoL with research evidence.



The AusQoL Project

- DCRC: CC first nationally representative descriptive, exploratory study of QoL of RACF residents with dementia, conducted 2012-2014.
- Data drawn from a stratified random sample of residents with dementia in Australian RACFs
- 53 RACFs, 440 residents, 435 staff and 404 family members



Beattie et al., 2015
*International
Psychogeriatrics*

The AusQoL project:

- **Aims**

- Investigate quality of life for people with dementia in Australian residential aged care facilities from **multiple perspectives**
- Explore the **relationship between resident, staff, care, and facility characteristics and QoL** for people with dementia in Australian RACFs

Methods: Sampling Design



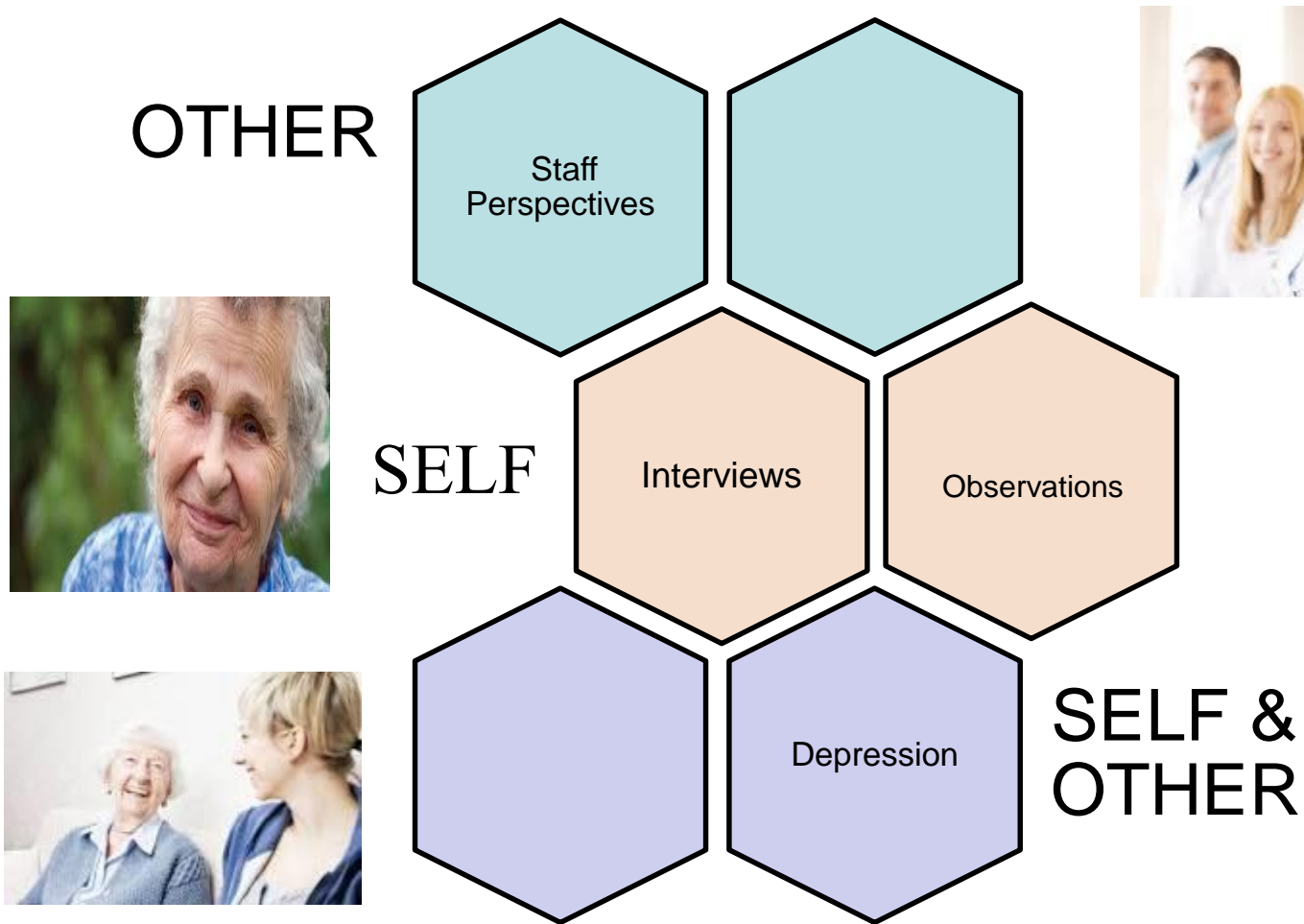
- Goal: recruit all staff members having care-related activities in a **nationally generalisable** sample of Australian RACFs.
- Starting from a list of all Australian RACFs, very small (< 25 bed) and remote facilities (N=250) were eliminated for **practical** reasons.
- A **stratified random sample** of all other facilities (N=2,524) ensured representation by **geographic area** (major city, inner regional, outer regional) and **organisational type** (charitable/religious, private, public).

The Lens Matters: Person with Dementia vs Carer vs Staff Views



- Multiple measures in multiple domains
- The cognitive limits of self report in dementia- have we tried hard enough?
- Proxy carer and family reports – who do you choose and why?
- Staff proxy reports – who and why?
- One data point vs longitudinal?

Three Lens



Quality of Life and Depression for Aged Care Facility Residents with Dementia: Proxy or Self Report?



Elizabeth Beattie (QUT/DCRC)

Wendy Moyle (Griffith University/DCRC)

Maria O'Reilly (QUT/DCRC)

Deirdre Fetherstonhaugh (La Trobe University/DCRC)

Elaine Fielding (QUT/DCRC)

AusQoL Group

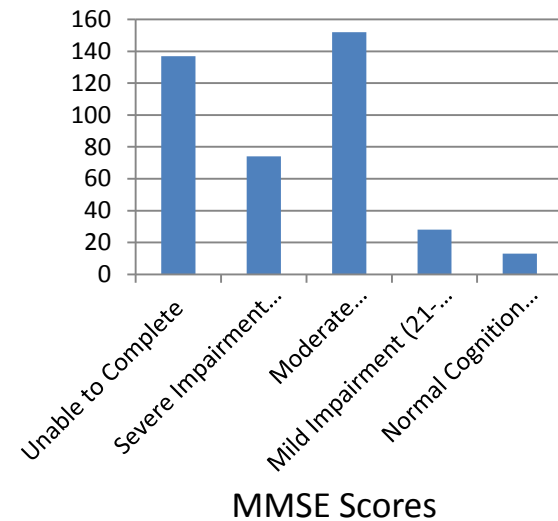


Self Report vs. Proxy Report

- Generally, self report is considered **the most effective and direct** means of administering any measure.
- **Questions of validity** raised within a group who may be unable to provide their own consent, manage their own affairs and make other important life choices.
- The **highly subjective** nature of QoL means that, even in the presence of cognitive deficits, people with dementia are arguably the most important source of information about their QoL.
- Proxy reports while secondary, do come from **a source without memory or other cognitive deficits** (by self report only).
- Both self report and proxy reports provide **different pieces of the same puzzle** because they come from different LENS.

Sample Characteristics

- Residents (n=440) had a mean age of 86.0 (6.8) years with a confirmed diagnosis of dementia (MMSE M=13.7, SD=7.0).
- Staff (n=435) were participants familiar with the residents. Staff were primarily PCAs (37.4%) AINs (25.5%) or RNs (10.7%).
- Family (n=404) participants were mainly adult children(75.4%) and partners (11.7%).
- All three groups provided information on QoL and depression of the residents.



Measures

The measures used were:

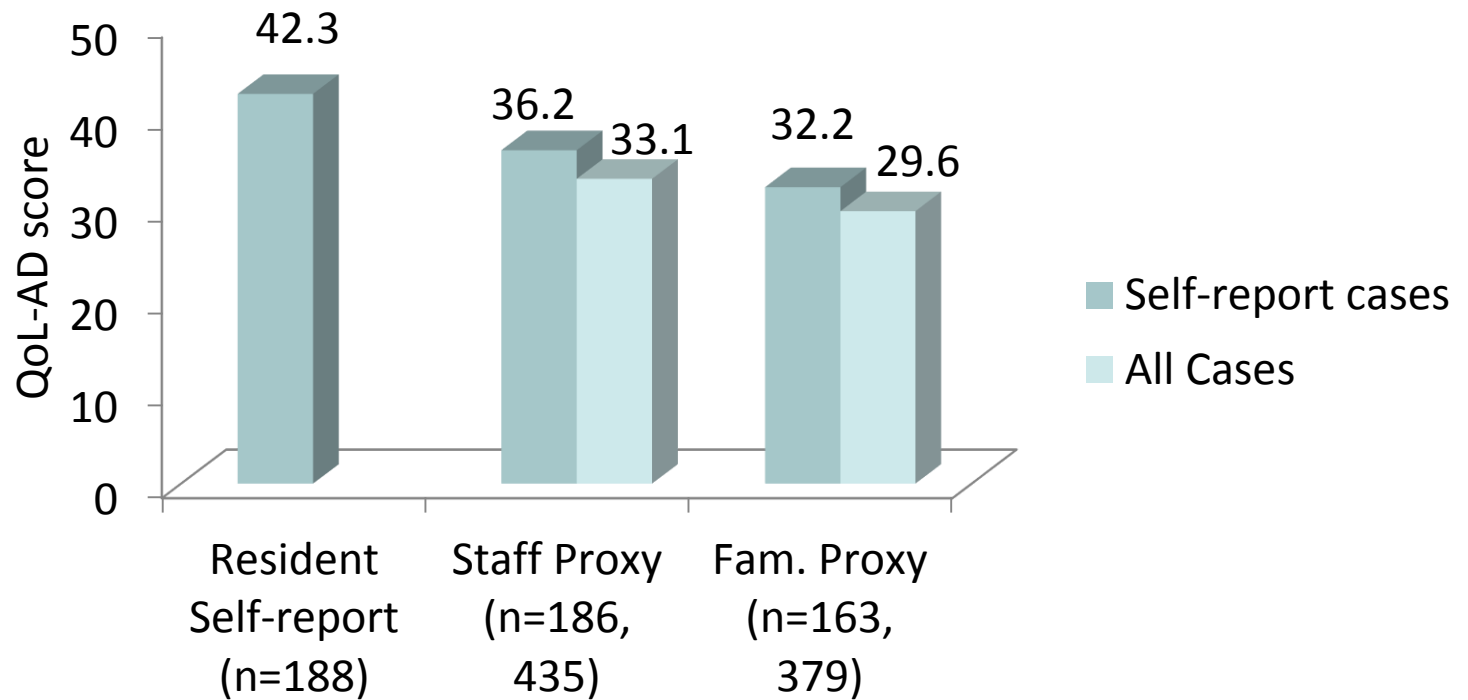
- **Quality of Life in Alzheimer's Disease (QOLAD)** is a 15-item measure of QoL covering areas such as physical health, relationships with family and friends, ability to do things for fun and life overall. Aspects of QoL are assessed on a 4-point Likert scale (poor- excellent) giving a total possible score range of 15-60.
- **Geriatric Depression Scale (GDS)** is a 12-item yes/no measure of depression symptoms in RACF residents. The GDS includes items on life satisfaction, activities and interests, happiness and helplessness.
Scoring: 0-4: No depression; 5-10: Mild Depression; 11-12: Severe Depression

The extent of self-report

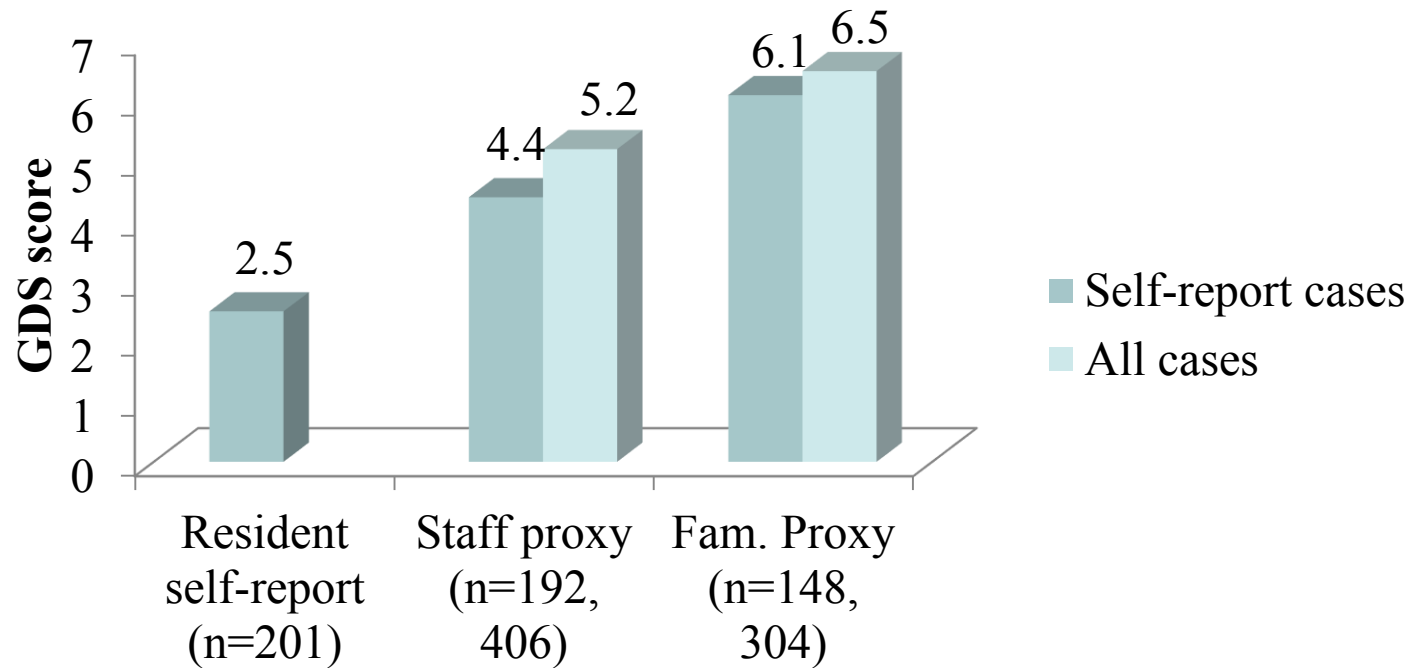
- About $190/440 = 43\%$
- Approached LAR for permission to approach resident.
- High proportion of LARs agreed (98%)
- AFTER we gained informed consent for study participation of resident.



Results: QoL-AD scores from three perspectives

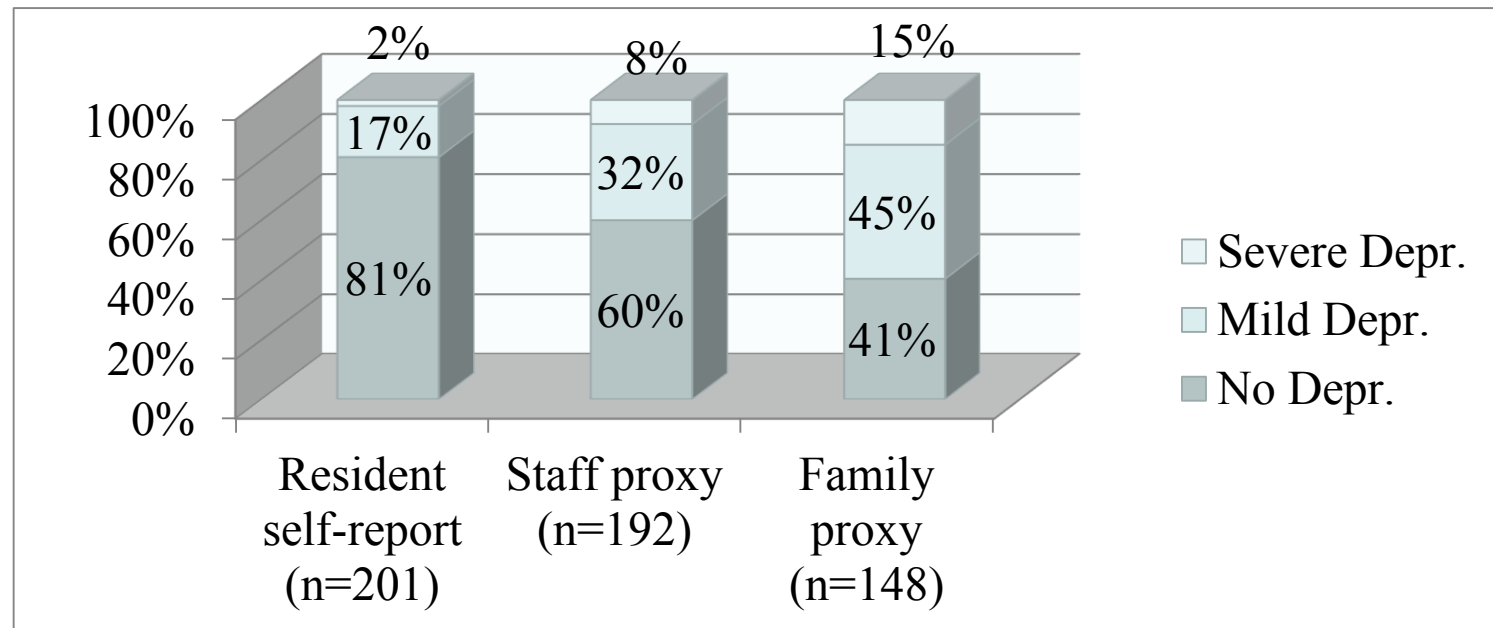


Results: GDS scores from three perspectives



Results: GDS severity from three perspectives

(No=0-4, Mild=5-10, Severe=11,12)



Correlation results

- The QoL-AD and GDS variables were significantly correlated as might be expected (e.g. QoL-AD and GDS were negatively correlated) with the following exceptions:
 - Although significant, **Resident self-report QoL-AD** showed only low (< 0.3) correlations with Staff and Family proxy QoL-AD.
 - **Resident self-report GDS** was only significantly correlated with Resident QoL-AD and Staff proxy GDS and not with Family GDS or either proxy QoL-AD.
 - **Staff proxy GDS and Family proxy GDS** showed only a low, but significant correlation (0.19).

Conclusions

- As in other studies, RACF staff and family members of residents often rate QoL lower and depression higher than the residents themselves.
- All three groups reported different levels of depression and QoL for the residents, yet, despite this, within each group depression was negatively correlated with the group's QOLAD assessment.
- Several possible explanations may explain these findings:
 - Differences in expectations based on stage of life
 - Differences in importance of factors
 - Resident deficits in the capacity for insight

Importance of Findings

- The exact differences underlying proxy and resident QoL are as yet unexplained.
- Findings suggest that differences in perspectives and outlook (different LENS) result in different QoL ratings → consistent with international findings.
- If the resident's QoL is the most important aspect of care in the absence of an effective treatment or cure then the resident's self reported QoL is arguably the most valid metric, regardless of cognitive impairment.

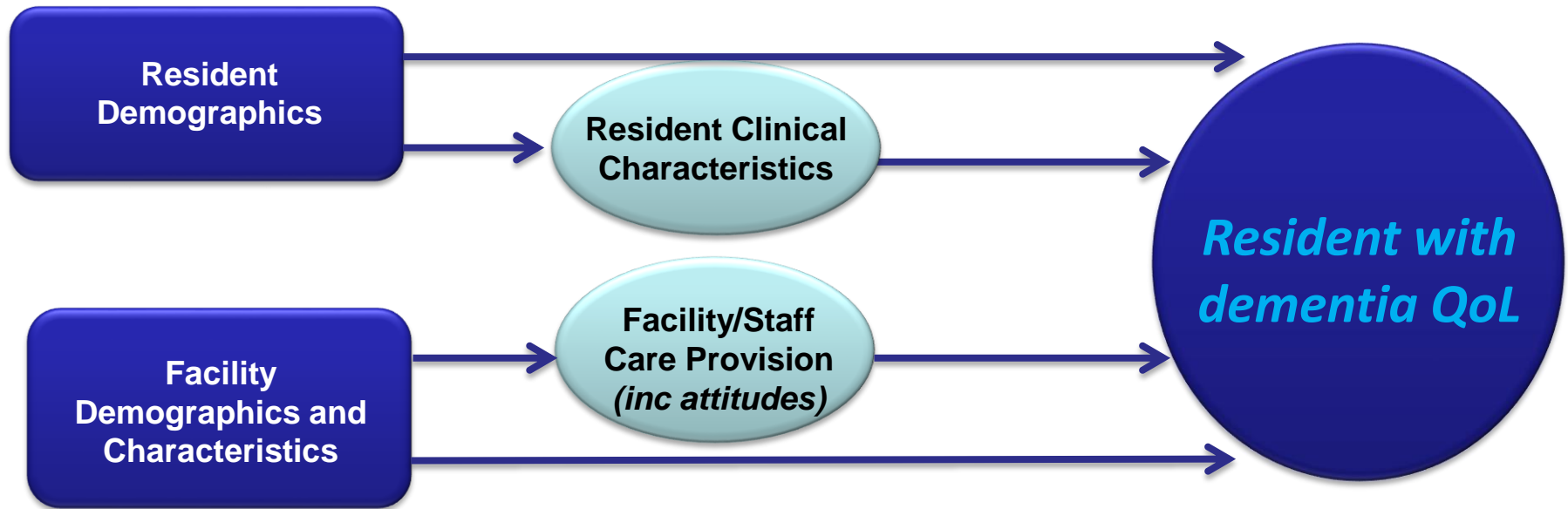
Staff Attitudes toward Care of People with Dementia in Australian Residential Aged Care Facilities



Lynn Chenoweth (UTS)
Elaine Fielding (QUT)
Elizabeth Beattie (QUT)
Maria O'Reilly (QUT)
Wendy Moyle (GU)
Andrew Robinson (UTAS)
& *The AusQoL Group*



Factors underlying resident quality of life for which data were collected



- **Focus on** the **attitudes** of residential aged care **staff** as one of the elements contributing to the QoL of people with dementia.

Staff attitudes

- Quality care for people with dementia relies on staff experience and attitudes – **more favourable attitudes are related to better care.**
- Positive attitudes among staff are **beneficial also to the facility** (lower staff turnover) **and the individual** (higher job satisfaction and enhanced self-efficacy).



This analysis

- Offer insight into staff attitudes towards people with dementia within Australian residential aged care facilities (RACFs).
- Explore the relationships between staff demographic, experience and educational characteristics and attitudes.



Methods: Survey Measures

- **Paper cross-sectional survey** administered to staff
- **Measures** related to staff experience:
 - **Demographics** (e.g. Gender, age, highest level of education, working hours, dementia-specific education etc.)
 - **Strains in Dementia Care Scale (SDCS)**
 - **Staff Experience Working with Demented Residents (SEWDR)**
 - Approaches to Dementia Questionnaire (ADQ)

Approaches to Dementia Questionnaire (ADQ)

- Developed by **Lintern & Woods (1996)**
- ***Subscale 1 – Hope (8 items)***
 - Level of **hope for people with dementia and their life** (higher scores indicating higher levels of hope)
- ***Subscale 2 – Recognition of Personhood (11 items)***
 - Recognition that people with dementia are **sentient human beings** (where higher scores indicate greater recognition of personhood)
- Each item scored as follows on 5-point Likert scale from *Strongly Agree* (1) to *Strongly Disagree* (5)
- We present **mean score within subscale** for ease of understanding

Examples of ADQ Items

- **Subscale 1 - *Hope*:**
“There is no hope for people with dementia”
- **Subscale 2 – *Recognition of Personhood*:** *“People with dementia need to feel respected, just like anybody else”*



Results



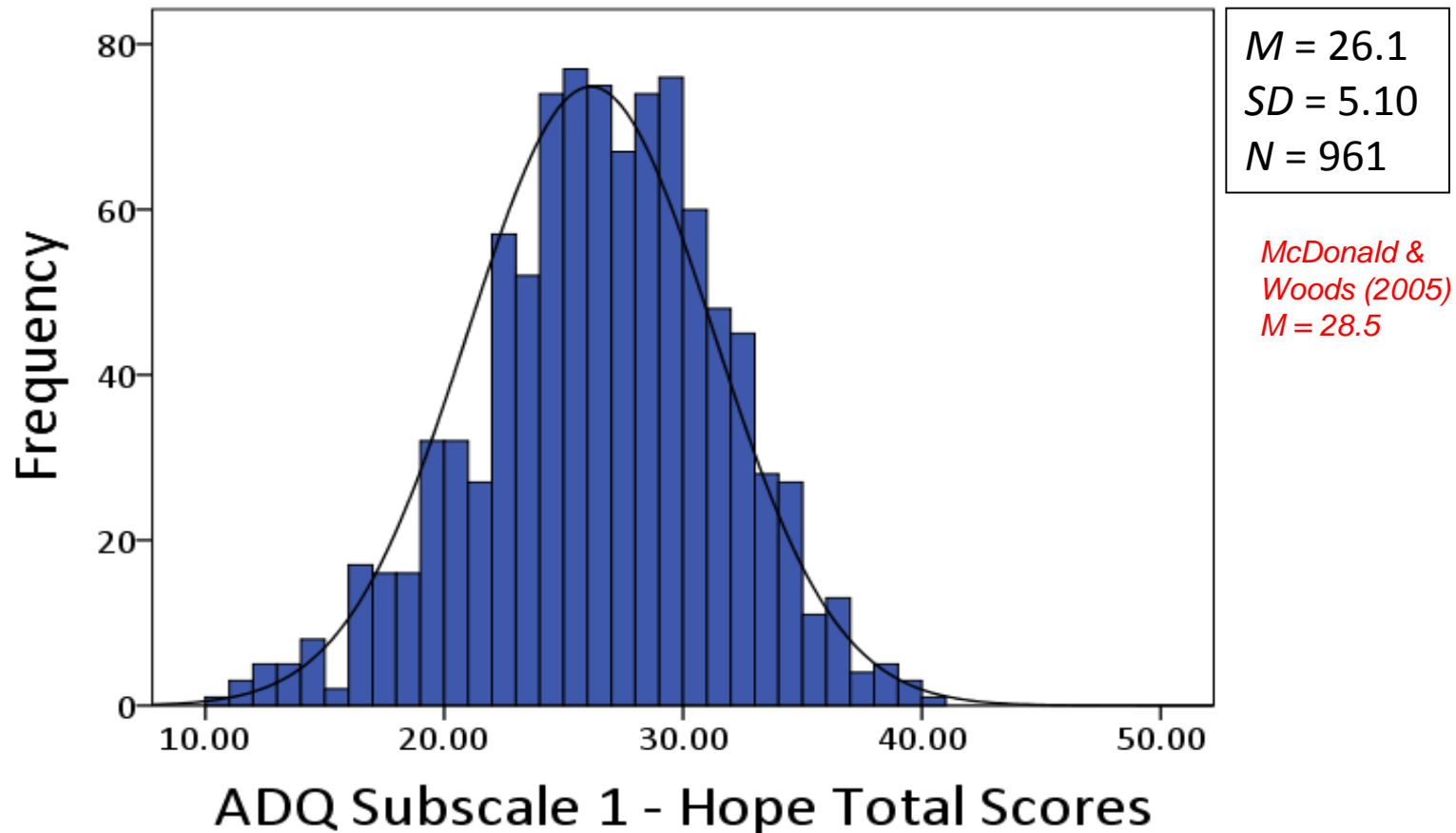
- From a sample of **53 facilities**, a total of **nearly 1000 staff** (n=978) were surveyed

- Majority **female** (n = 851, 90.5%)
- More than half **aged 41-60 years** (n = 545, 55%)
- Most common level of education was **TAFE or other diploma**
- Most common professions:
 - **Personal Care Assistant** (38%)
 - **Assistant in Nursing** (26%)
 - **Registered Nurse** (11%)

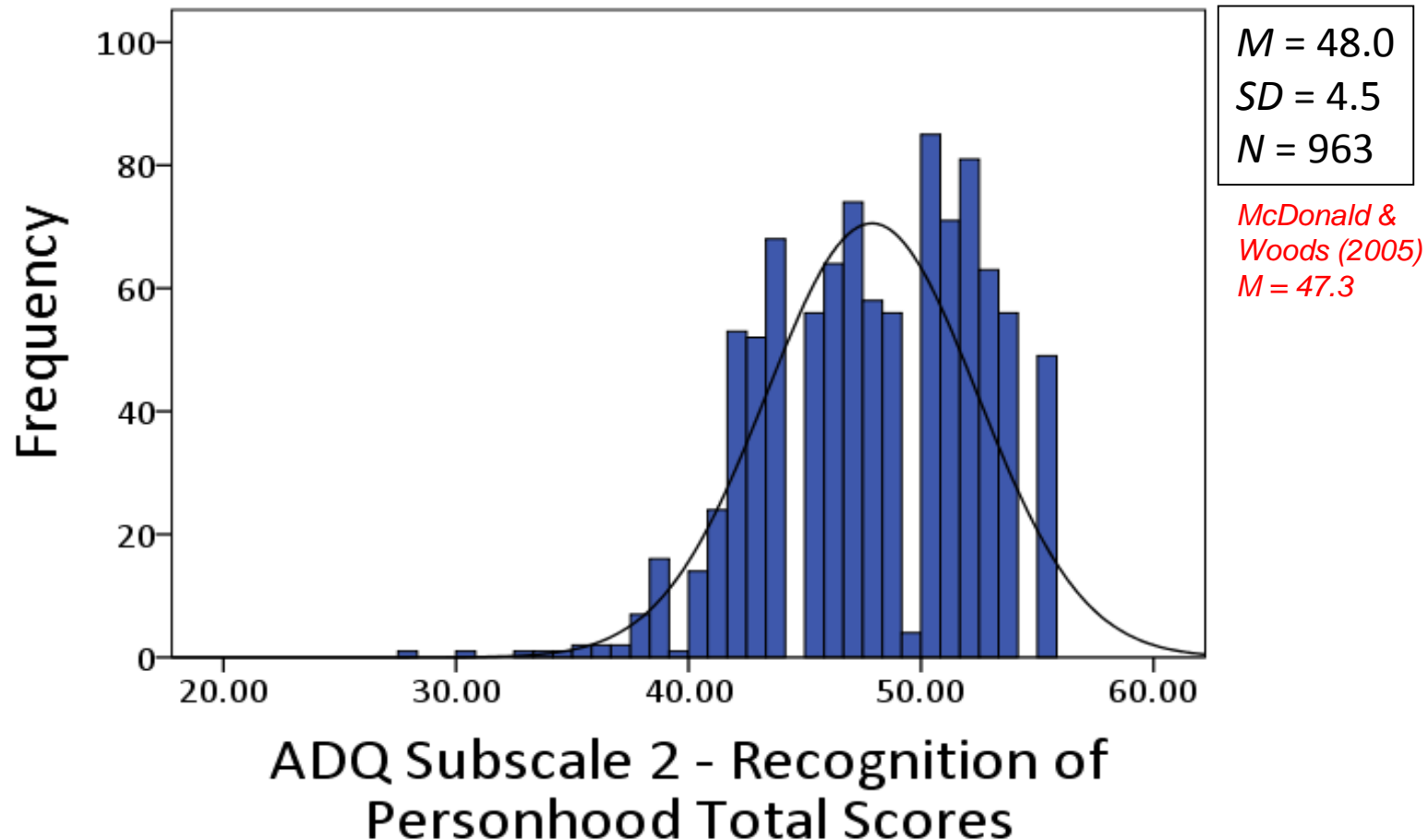
Employment Characteristics

- Most staff reported that their **role always involved communicating with people with dementia** (66%)
- Majority worked **permanent part-time hours** (over 70%)
- Almost half had **worked in aged care between 3-10 years** (46%)
- Majority (87%) had **some dementia-specific training**, mainly (multiple possible):
 - Facility in-service course
 - Self-directed learning
 - Dementia specific conferences

ADQ-Hope Mean Scores



ADQ-Personhood Mean Scores



Predicting ADQ

- In a regression model, the following staff characteristics showed a significant relationship with the **Hope** subscale:
 - **Professional group** (see later table)
 - Length of **time in aged care** work (**more time working → higher hope**)
 - **Frequency of communication** with people with dementia in daily job (**more communication → higher hope**)
 - **Night duty** (**Day staff → higher hope**)

ADQ Subscales

Mean Scores by Profession Group

Profession Group	Hope mean (s.d.)	Personhood mean (s.d.)
Care (PCA, AIN) (n=607)	25.2 (5.15)	47.4 (4.65)
Enrolled Nurse (n=113)	27.0 (4.20)	48.0 (4.13)
Registered Nurse (n=127)	27.9 (4.36)	48.5 (4.20)
Allied Health (n=94)	28.2 (5.00)	49.5 (4.06)
Management (n=11)	30.7 (7.32)	51.3 (3.66)
Total (n=952)	26.2 (5.11)	47.9 (4.53)

Dementia-Specific Education

Type of dementia education	Hope Means (s.d.)		Personhood Means (s.d.)	
	No	Yes	No	Yes
Any	25.0 (4.15)	26.4 (5.18)*	46.8 (4.78)	48.1 (4.48)*
Self-directed	25.8 (5.14)	26.6 (5.06)*	47.5 (4.57)	48.4 (4.48)*
Facility inservice	25.7 (5.11)	26.5 (5.10)*	47.7 (4.83)	48.0 (4.36)
Online course	26.0 (5.15)	27.5 (4.63)*	47.9 (4.52)	48.2 (4.79)
Dementia conference	25.5 (4.95)	27.5 (5.20)*	47.6 (4.58)	48.6 (4.42)*
Undergraduate course	26.1 (5.17)	26.7 (4.84)	47.8 (4.56)	48.5 (4.44)
Postgraduate course	26.1 (5.09)	27.9 (5.77)	47.9 (4.55)	48.3 (4.67)

**No/Yes Difference is statistically significant*

Keeping Up with What's New in Dementia Research and Practice in Australia and across the globe



<http://journalofdementiacare.com/>

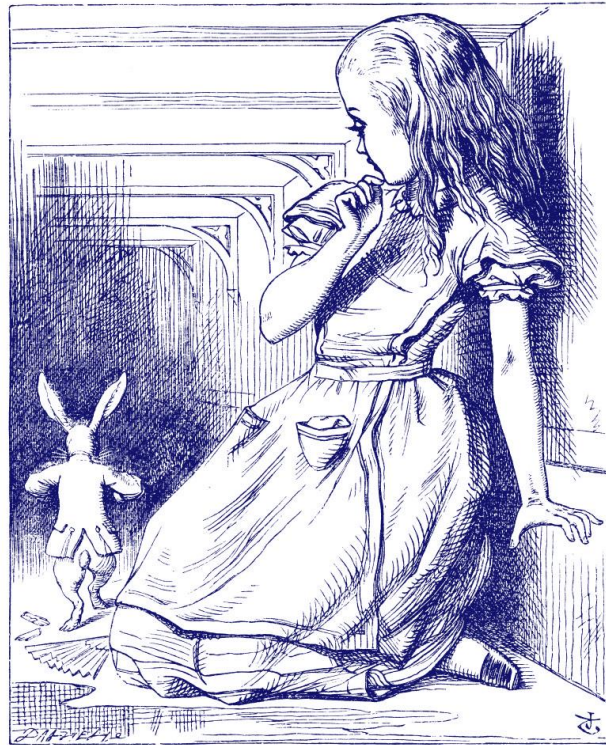
- DTSC free lectures and seminars at QUT
<http://dtsc.com.au/qld/>



Acknowledgements



- *Thank you to all the facilities, their staff, residents and families for their participation in the project.*
- *Thank you to **Dr Elaine Fielding** for leading data analysis, & **Lina Karlsson, Mitch McMaster** for their work alongside her.*
- ***Dr Sheryl Zimmerman** (UNC Chapel Hill) and the expert panel members for their support and insight.*
- ***Mark Brandon** for additional research support.*



AusQoL Study: Beattie, E., O'Reilly, M., Moyle, W., Chenoweth, L., Fetherstonhaugh, D., Horner, Robinson A., & Fielding E. (2015). Multiple perspectives on quality of life for residents with dementia in long term care facilities: protocol for a comprehensive Australian study. *International Psychogeriatrics*, April 22nd, 1-9.