

# Mapping a road to driving retirement with the driver who has a diagnosis of dementia:

## Enhancing acceptance of the difficult decisions.



**Catherine Andrew**  
Occupational Therapist,  
University of Wollongong

**Associate Professor Victoria Traynor**  
School of Nursing, Midwifery and Indigenous Health

**Pro-Vice-Chancellor (Health) Professor Don Iverson**  
Vice Chancellor's Unit  
University of Wollongong

**Dr John Carmody**  
Staff Specialist Neurologist, Wollongong Hospital

# Overview of presentation

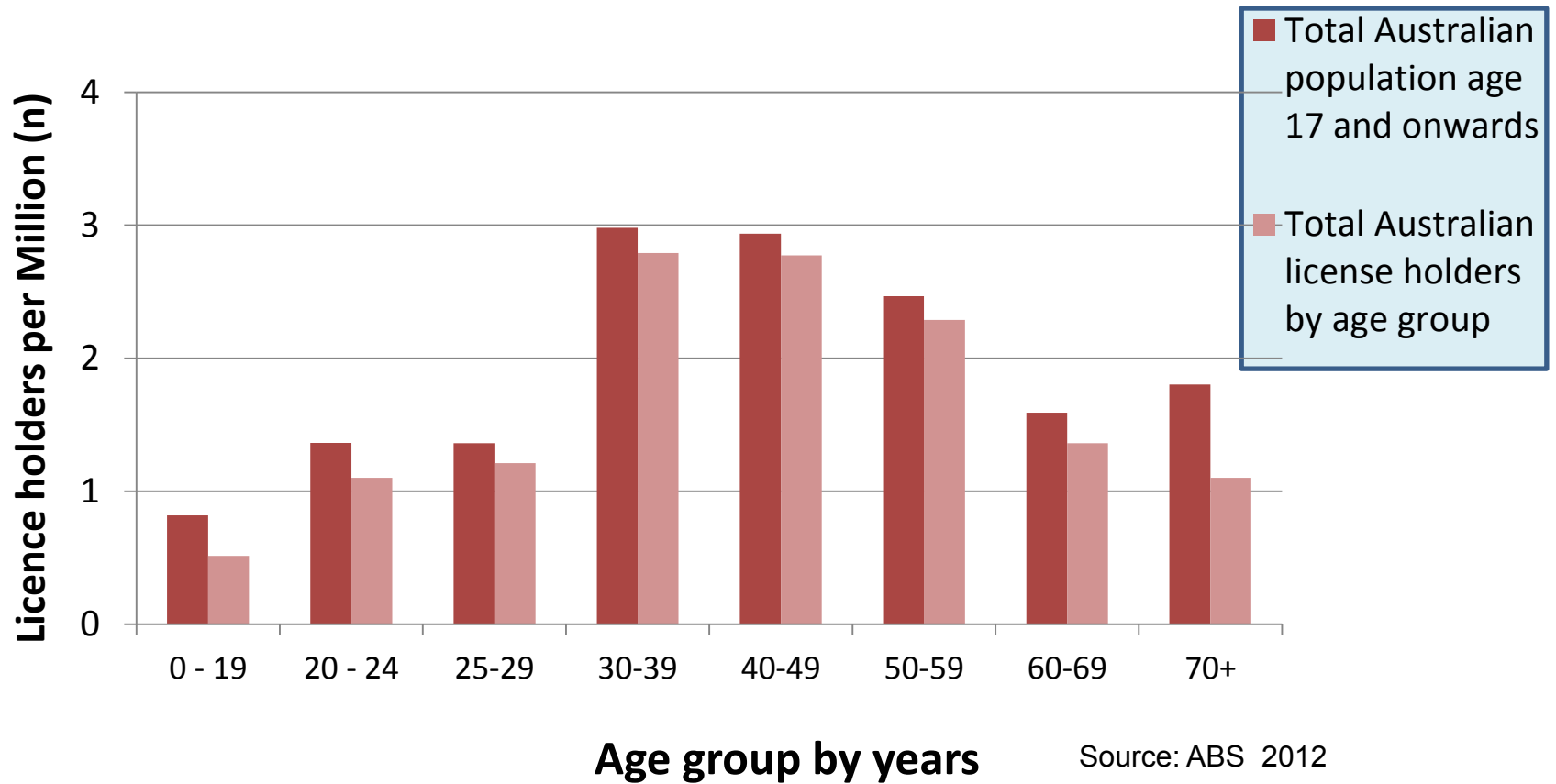
- Key issues about driving and dementia
- Evidence
- Research
- Implications for practitioners: How can they better provide support for individuals living with a dementia on the topic of driving and dementia
- Where to from here? Testing a Driving Dementia Decision Aid (DDDA)

# Dementia is a National Health Priority in Australian

- Dementia is one of the major issues facing Australia's rapidly ageing population
- There are currently 170,000 people living with dementia
- By 2041 this figure can be expected to rise to 500,000.
- Focus should be on:
  - i) Increased funding for research in dementia : biological causes; prevention and treatment; provision of clinical and community services
  - ii) Carer support services
  - iii) Better training and education for Health professionals

<http://www.anzsgm.org/documents/AGEDCARESHEETS-4.pdf>

# Distribution of Australian Population and License Holders by Age (per million)



**When is the  
right time to  
retire from  
driving ?**



# The Driver Assessment process: NSW



- Concerns regarding driver safety initiate need to seek medical advice



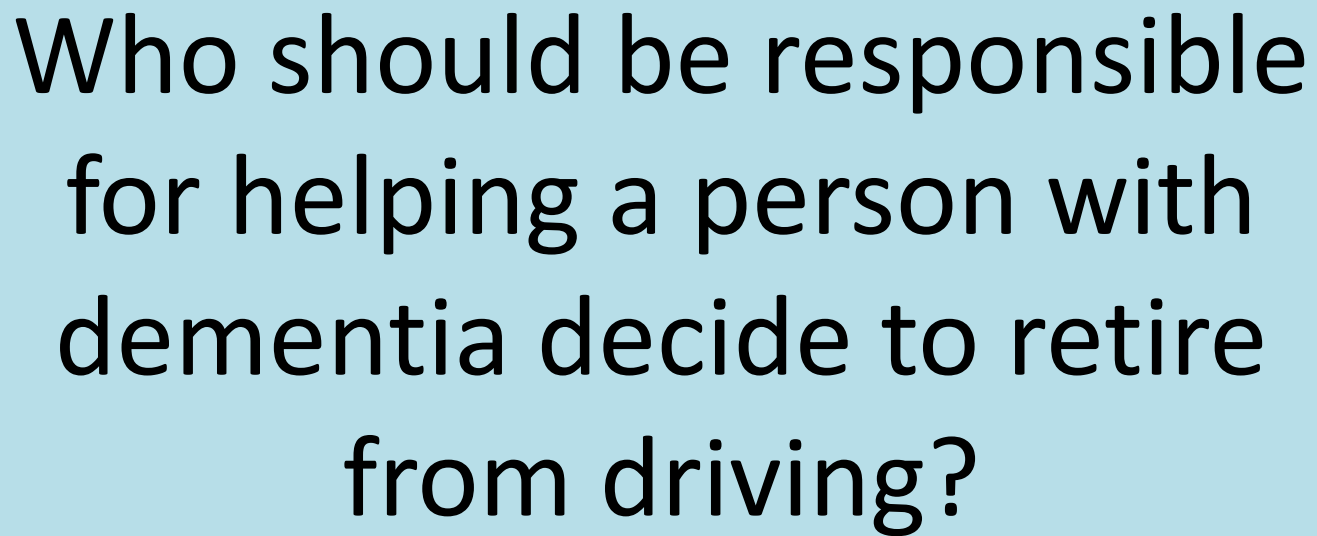
- Medical practitioner initiates referral for assessment of fitness to drive



- Assessment is conducted to
  - (i) determine fitness to drive;
  - (ii) quantify any restrictions; or
  - (iii) recommend licence cancellation

# The Evidence:

- A diagnosis alone is insufficient evidence to recommend driving retirement because severity and impact of dementia varies between individuals (Perkinson et al., 2005)
- Drivers with dementia who continue to drive may be at higher risk of road accidents compared to their peers (Wheilian et al., 2005)



Who should be responsible  
for helping a person with  
dementia decide to retire  
from driving?



# Independence versus safety

- Can drivers with dementia be involved in making decisions?
- If you were a driver and diagnosed with dementia what issues would concern you?

# Research Aim

To identify decisional support needs for enhancing acceptance of driving retirement for drivers with dementia.



# Literature Review

Driving is a complex task that can be compromised by dementia

Onset and severity of dementia are difficult to define

Dementia is progressive and impacts on driving skills

Assessment of fitness to drive remains subjective

Some drivers with dementia are reluctant to accept negative assessment outcomes

The search continues for most effective means of preparing drivers with dementia for accepting driver retirement

# Method

## Setting and sample

- Cross-state community study current drivers over 55 years who self-identified as :
- (i) having a dementia (n=2) ; or
- (ii) having no known cognitive impairment (n=13).

## Data collection

- Qualitative study - Unstructured interviews (one to one and group)

## Data analysis

- Thematic analysis

# Results

- Whose opinion will I accept as trustworthy?
- Real on road experiences are most convincing.
- Let's discuss this before my judgement is compromised.
- Would knowing my alternatives influence my decision?
- Informative resources that include checklists are useful.

# 1. Whose opinion will I accept as trustworthy?

*The relationship is a very important factor*



2. Real on road experiences are most convincing.

*I think the clues might be when you're driving...*



### 3. Let's discuss this before my judgement is compromised

*If you see the signs ...say to me, 'You're not safe to drive'....*





4. Would knowing my alternatives influence my decision ?



*....it would be more of a psychological loss than a real loss of ability to go places...*

Would knowing my alternatives increase acceptance ?

Yes

Perceived barriers are explicit and can be resolved with practical solutions

No

Perceived barriers are less tangible and potential solutions are not considered acceptable

I have always been a good driver....  
I love to drive....  
I don't like buses....  
I need to be independent..

## 5 Informative resources that include checklists are useful.

- Availability of tools
- Sensitivity to the complexity of the decision- making process
- Relevancy for dementia of generic over-55 tools
- Interactive functions in tools
- Format of the tools

# What we now know:

Combining views of trusted sources, early discussions about driving, feedback from real on road experiences, and identifying suitable alternatives can enhance driving retirement decision making for people with dementia.

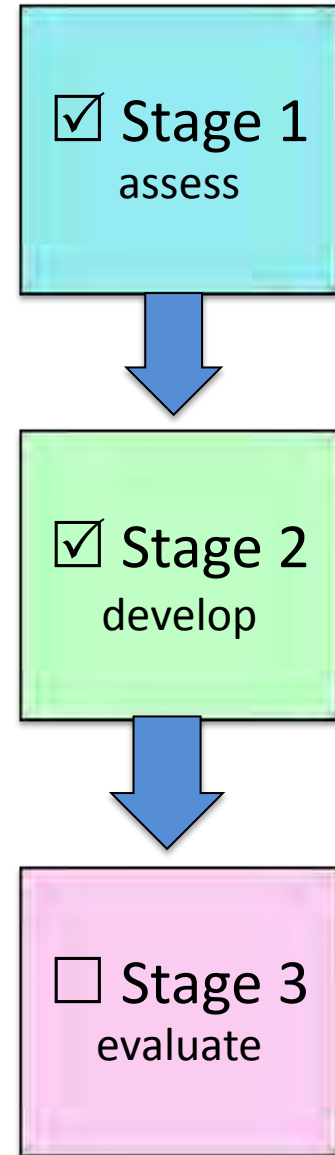
# Implications for Carers and Practitioners

- Risks identified
- Early discussion
- Objective evidence
- Choose to be assessed or retire
- Accept Cancellation or Challenge the decision
- Retirement or cancellation



# Where to is our research headed from here?

- ✓ Further quantitative research has been in progress to develop the tool (Carmody et al., 2012)
- ✓ next stage is the evaluation of the usefulness of the new tool by asking for feedback from consumers (Andrew et al., 2013)



# Conclusion

Retirement from driving can be enhanced for people with dementia by including:

- ✓ views of trusted sources
- ✓ feedback from real on road experiences
- ✓ early discussion
- ✓ identification of suitable alternatives
- ✓ relevant, concise and informative resources

# References

- Carmody, J, Traynor, V & Iverson, D 2012, 'Dementia and driving: An approach for general practice', *Australian Family Physician*, vol. 41, no.4, pp. 230-3.
- O'Conner AM & Jacobsen MJ 2007, '*Decisional conflict: supporting people experiencing uncertainty about options affecting their health*', Ottawa Health Research Institute, Ottawa (available at <http://decisionaid.ohri.ca/odsf.htm>, accessed August 2008)
- Australian Bureau of Statistics 2012