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# *Dementia: who cares?*

*A comparison of community needs and primary care services  
in Mackay, North Queensland, Australia*

*NZAG and Aged Concern conference 8/10/2009*

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GP pilot trial supported by an RACGP Informatics Scholarship  
Continuing GP workshops funded by an Eli Lilly research grant*

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# Key messages

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- Patients with dementia and their carers need help from primary care health services
  - Many primary care workers do not know how to help people with dementia
  - People dealing with dementia in the community may find their best help comes from family and friends
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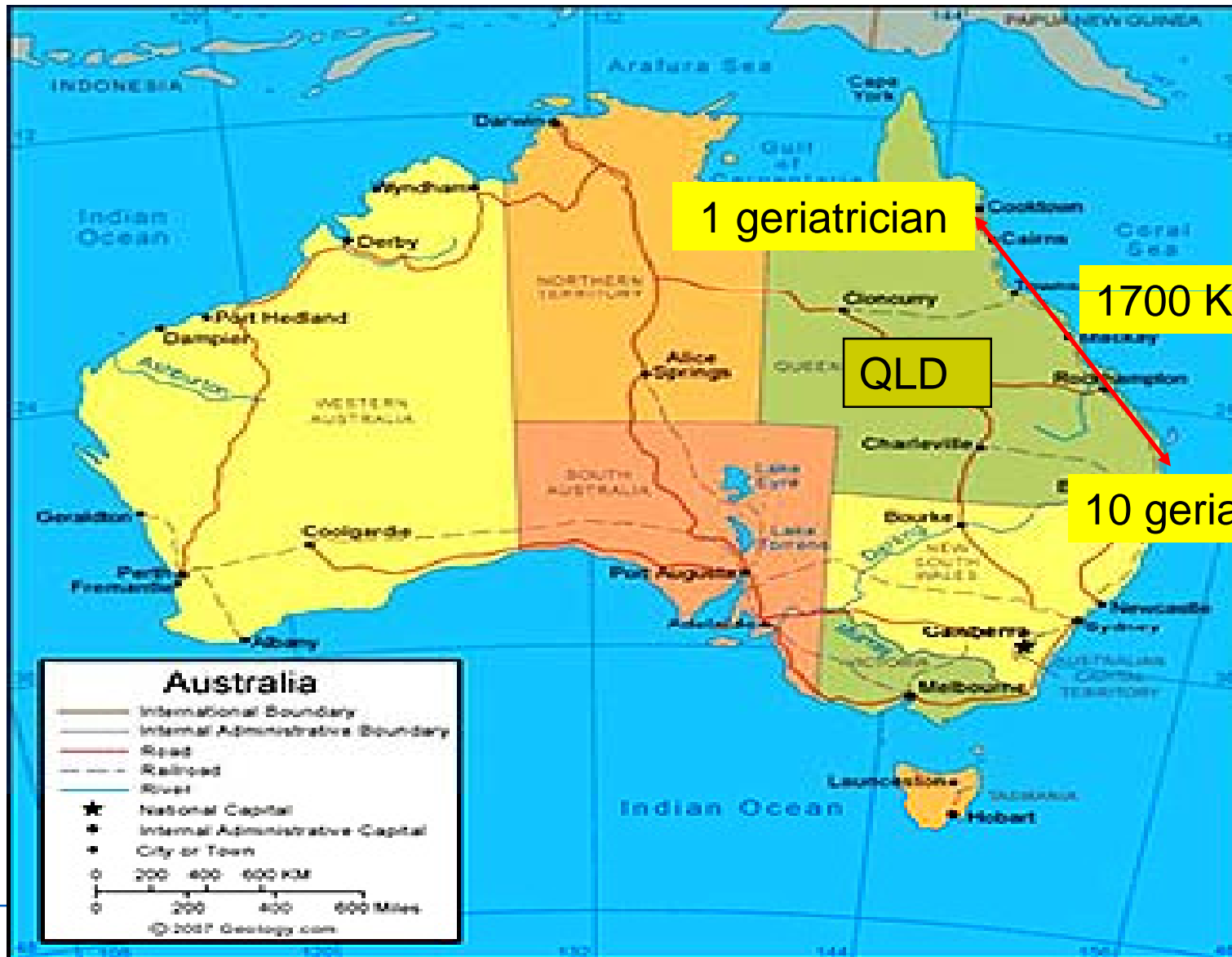
# Challenges for dementia services

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- A dementia diagnosis can lead to support that improves quality of life for patient and carer
  - Many patients hide their symptoms
  - Many doctors do not investigate obvious symptoms
  - A diagnosis is usually made when symptoms become a problem
  - There is no one test that will always confirm a dementia diagnosis
  - Many primary care workers feel inadequately trained to diagnose or manage dementia cases
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# Challenges for regional Queensland, Australia

population 4,320,000 (NZ=4,270,000)  
Size 1,727,000sq km (6.5 x the size of NZ)



# Our research



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- The consumer experience
    - 20 non-directed interviews with groups of people dealing with dementia, discussing their experiences
    - A dementia survey for GP patients aged over 30 years, testing the impact of Alzheimer's Australia 'Mind Your Mind' dementia risk reduction summary
  - The health professional's perspective
    - 2 surveys of primary care health professionals, asking about their knowledge and perceived role in dementia care
    - Results of an educational intervention to improve GP detection of dementia
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# Methods

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- Interviews x 20
    - Twenty family groups who are currently caring or have previously cared for a person with dementia, including the patient where appropriate.
  - Surveys x 3 (one page)
    - Postal to GPs and practice nurses (survey 1)
    - Attendees at dementia forums (survey 1)
    - GPs and practice nurses in education trial (survey 2)
    - Patients >30 yrs in GP waiting rooms (survey 3)
  - Trials x 2 using interventions of:
    - Education and audit feedback for GPs
    - Dementia risk reduction information for consumers
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## The consumer experience

Interviews, survey and trial of  
dementia risk reduction  
information

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# Our interview participants

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- The patients
    - aged from 70-99 years
    - 16 females, 4 males
    - 8 living at home, 12 in care
    - Interviews included all patients living at home
  - The interview groups
    - patients, spouse, children, niece, children and children in law
  - Interview group size
    - ranged from 1 to 5
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# Interview results

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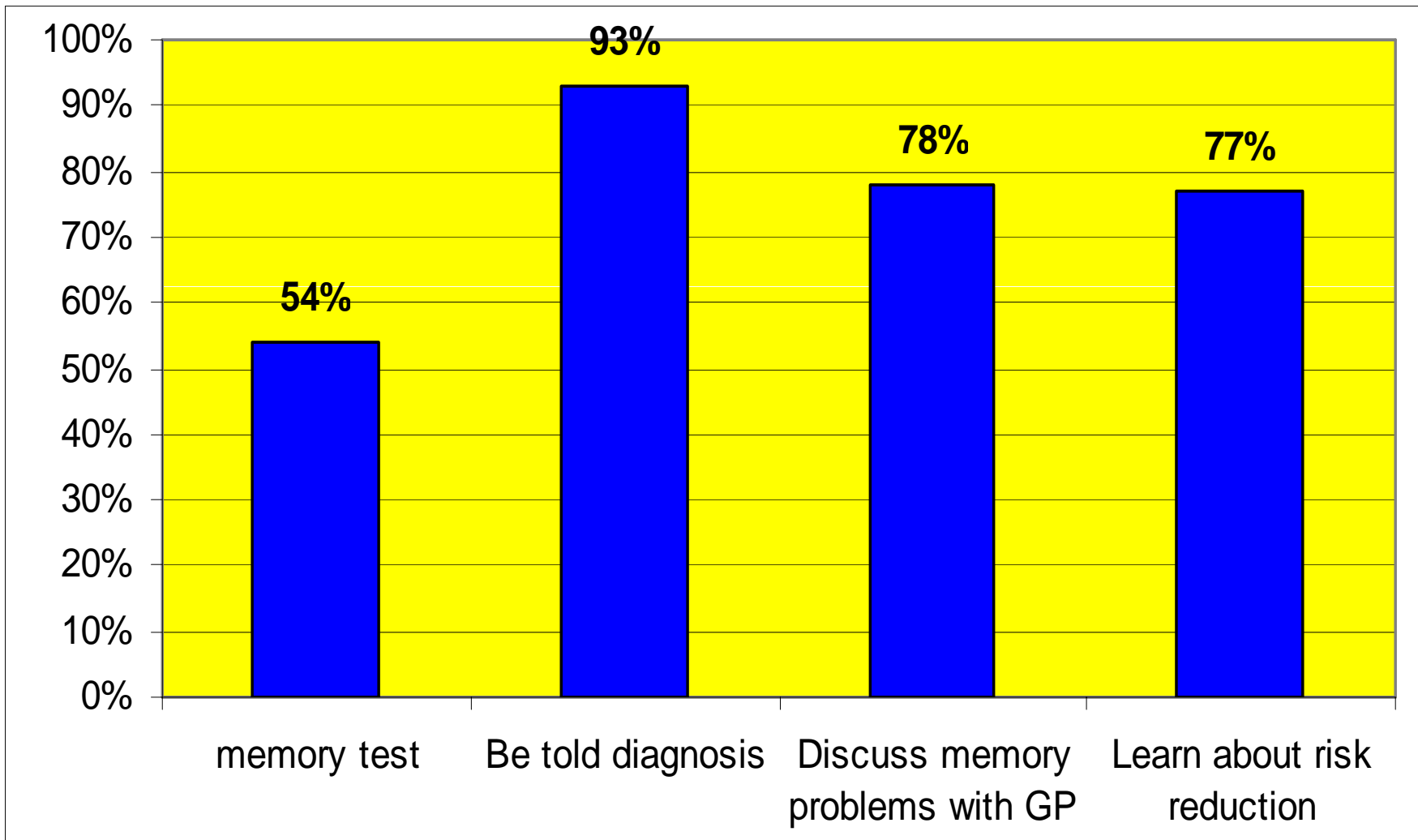
- **Appreciation of**
    - Timely diagnosis 13/20
    - Adequate support 6/20
    - Investigation and management of symptoms 13/20
  - **Frustration from**
    - Ignored symptoms 15/20
    - Inadequate management 7/20
    - Absent referral for support 3/20
    - Delayed diagnosis (1-8 year) 15/20
    - Wrong diagnosis 2/20
    - Denied access to ‘memory’ medication 2/20
    - Medication side effects, compliance issues 9/20
    - Inadequate support for self caring patient 13/20
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# Our Consumer survey results (over 30 years of age)

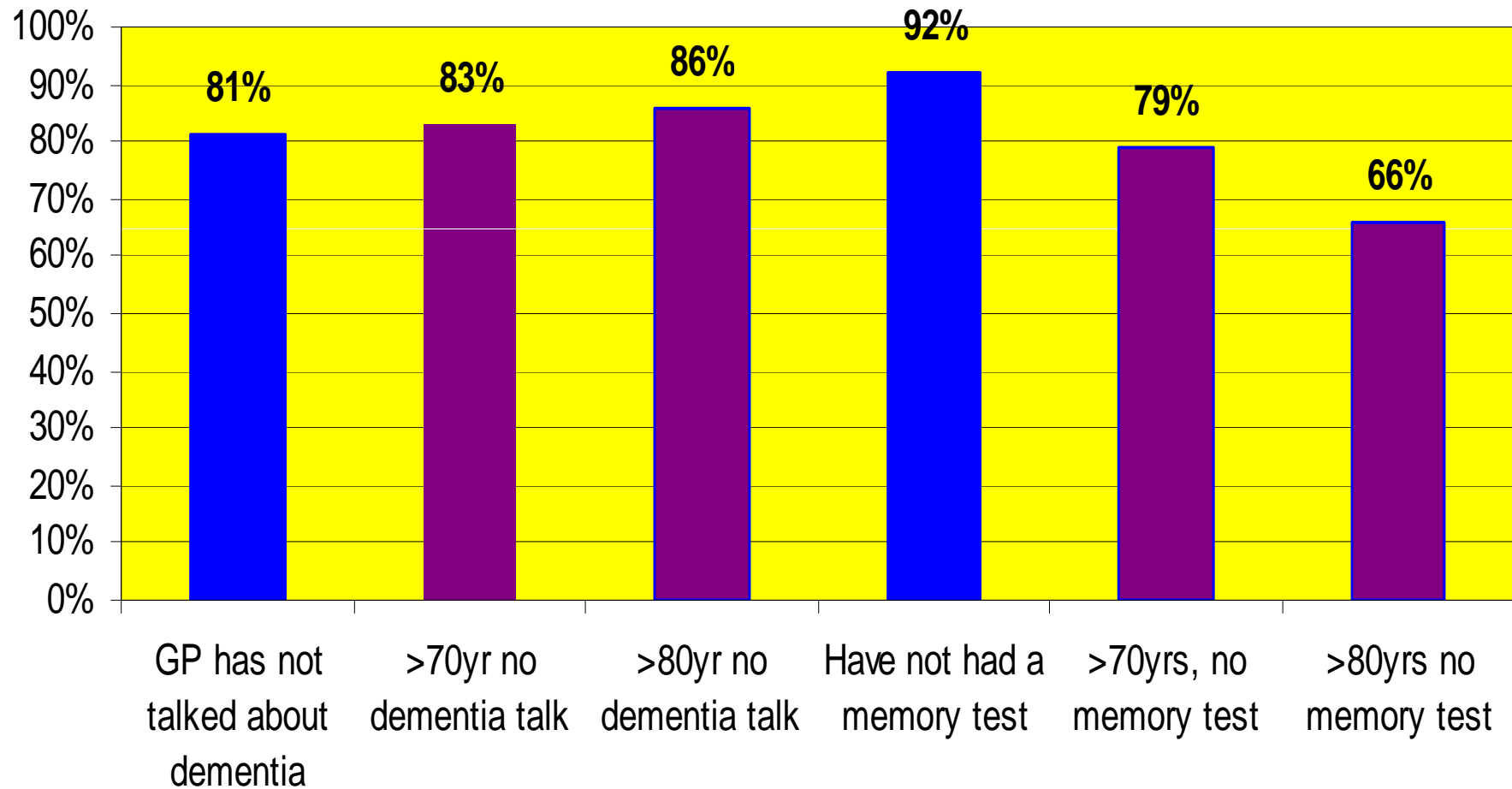
N=500

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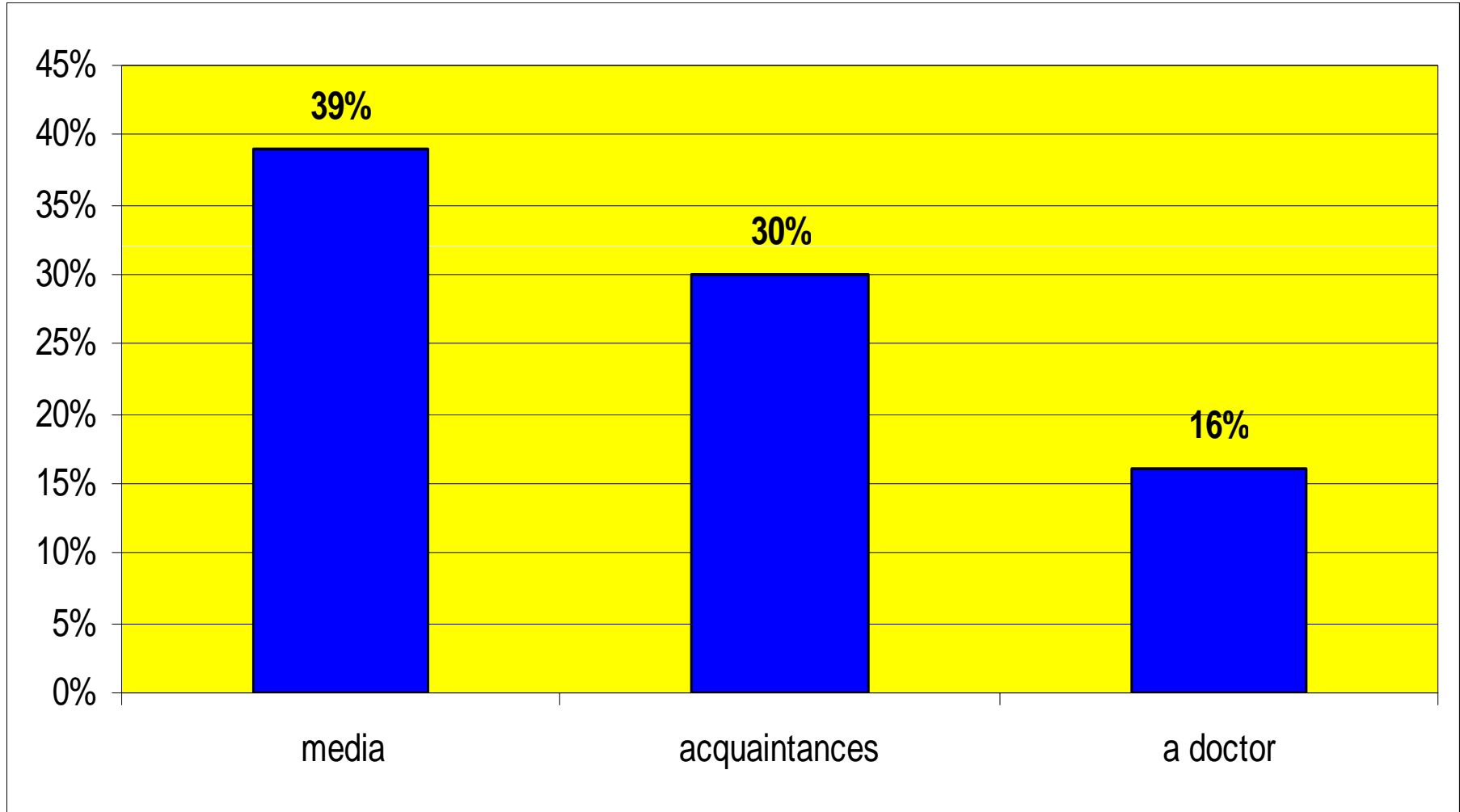
# What consumers want



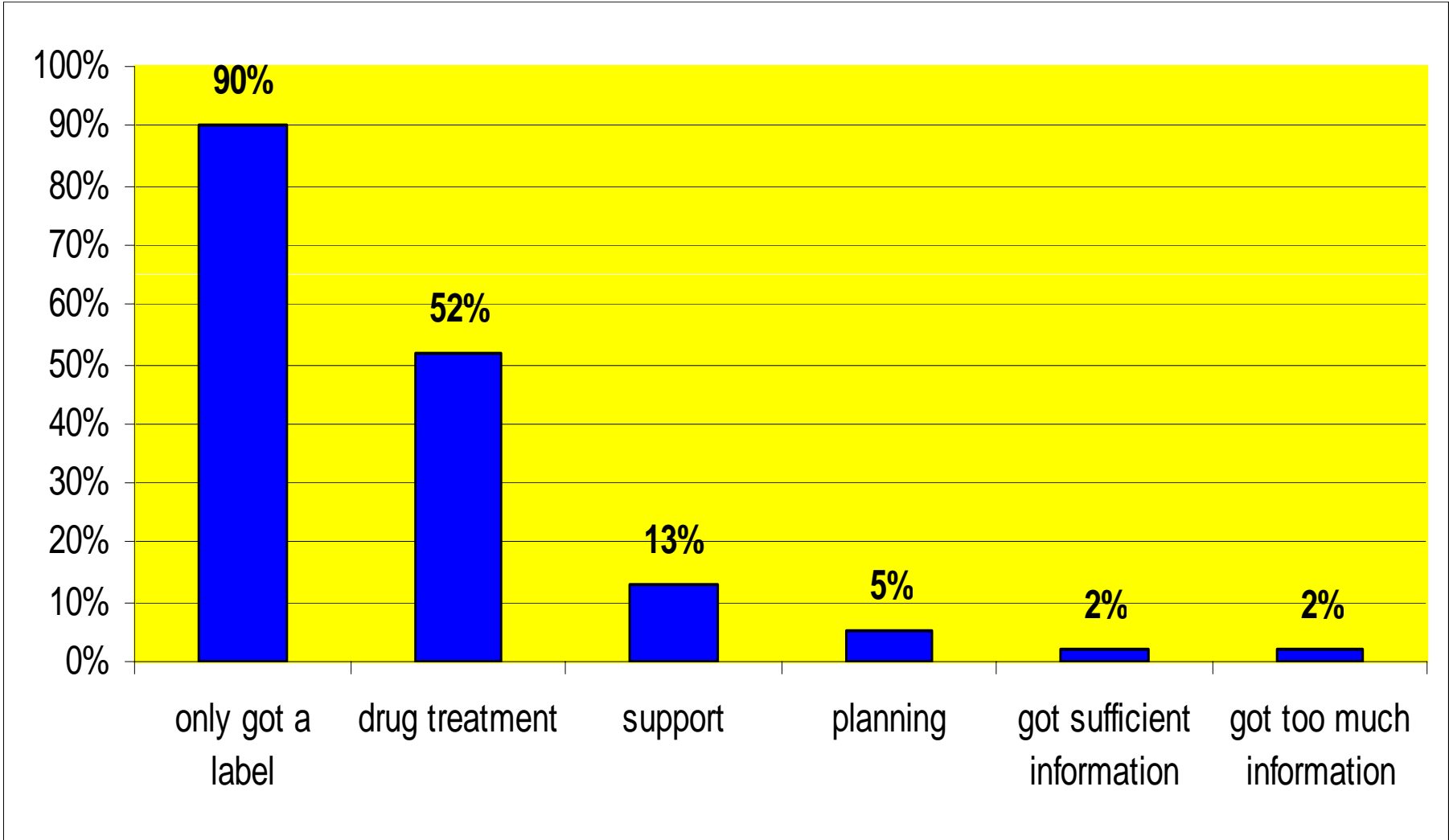
# What consumers miss out on



# Where consumers learn about dementia



# Results of other research outcomes for people with dementia (Jean Georges IAGG2009)



# Consumer ‘Mind Your Mind’ dementia risk reduction trial

Patients aged >30 years  
N=500

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## Mind your Mind to keep your brain healthy

We now have good evidence from research that shows adopting a 'brain healthy' lifestyle may reduce the risk of developing dementia. Alzheimer's Australia's Mind your Mind® program involves seven signposts to help keep your brain healthy and reduce your risk of developing dementia.

For more information on Alzheimer's Australia's Mind your Mind program contact us.

[www.alzheimers.org.au](http://www.alzheimers.org.au)

National Dementia Helpline 1800 100 500  
An Australian Government initiative

There are a number of factors that increase your risk of developing dementia, including age and genes. Following the Mind your Mind signposts, can't guarantee that you won't get dementia, but it may help reduce your risk or delay the onset of dementia.

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## Mind your Mind® signposts



### Mind your Brain

Challenge your brain every day with new things

- ◆ Play crosswords, number and word puzzles or board games
- ◆ Learn a language, a musical instrument or enrol in a course
- ◆ Experience new activities like going to plays, concerts, museums and galleries



### Mind your Diet

Enjoy healthy eating by choosing:

- ◆ A wide variety of foods
- ◆ Vegetables, fruits, legumes (dried peas, beans, chickpeas and lentils), wholegrain breads and cereals
- ◆ Lean meats, chicken, fish and reduced-fat dairy products
- ◆ Oils such as olive, sunflower, safflower, soy, canola and flaxseed



### Mind your Body

Be active every day in ways you find enjoyable

- ◆ Walk or cycle to work or around your neighbourhood
- ◆ Go dancing, jogging or swimming
- ◆ Join a gym, yoga, tai chi or pilates group
- ◆ Do some gardening
- ◆ Play sport socially or competitively



### Mind your Health Checks

Know your blood pressure, blood cholesterol, blood sugar and weight

- ◆ These can all increase your risk of developing dementia if they are too high. Ask your doctor to check these and help you manage any problems.



### Mind your Social Life

Participate in social activities, stay socially connected

- ◆ Catch up with family and friends
- ◆ Join a club or group
- ◆ Participate in community events or become a volunteer



### Mind your Habits

Avoid 'bad habits'

- ◆ Don't smoke
- ◆ If you drink alcohol, drink in moderation



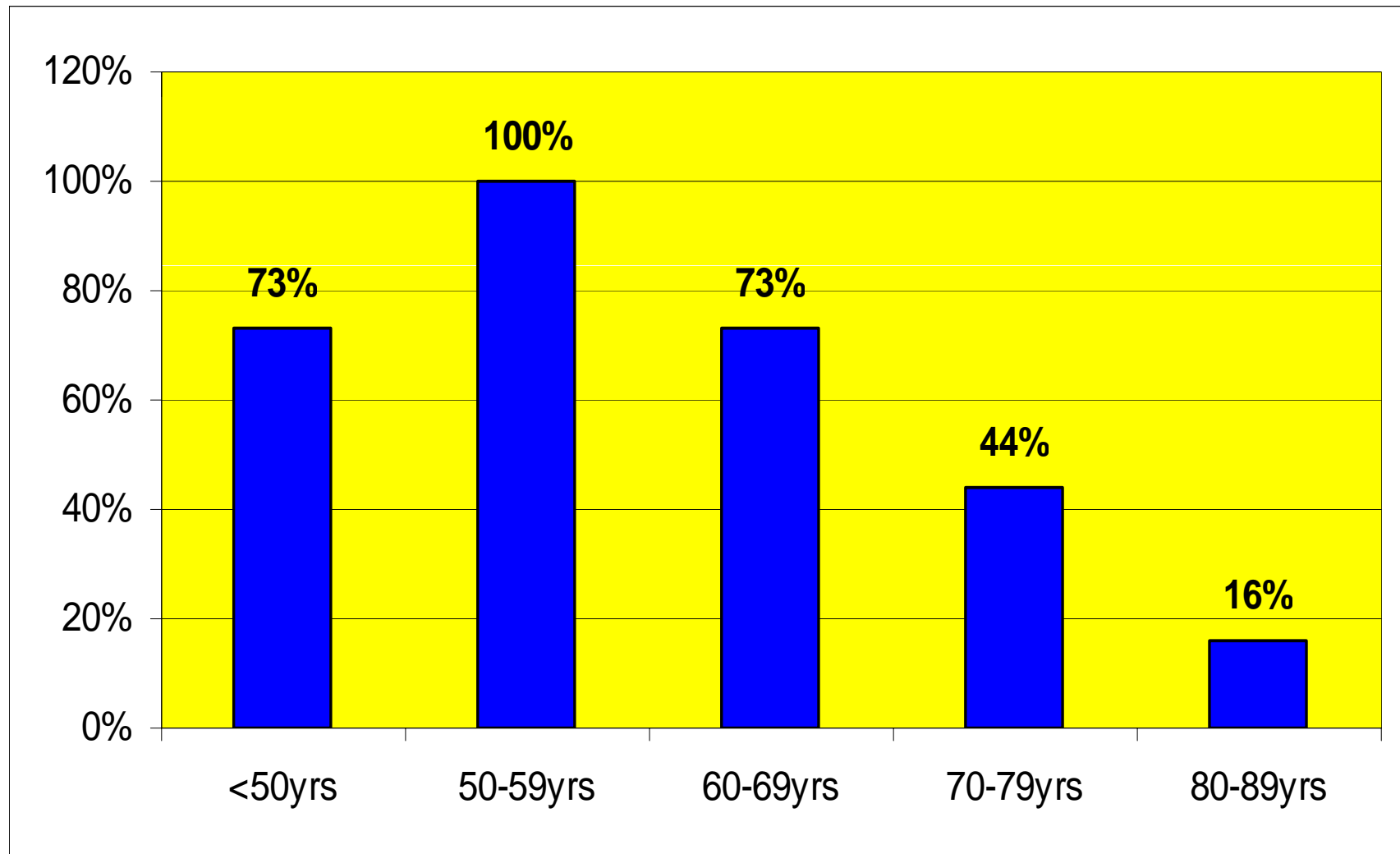
### Mind your Head

Protect your head from serious injury

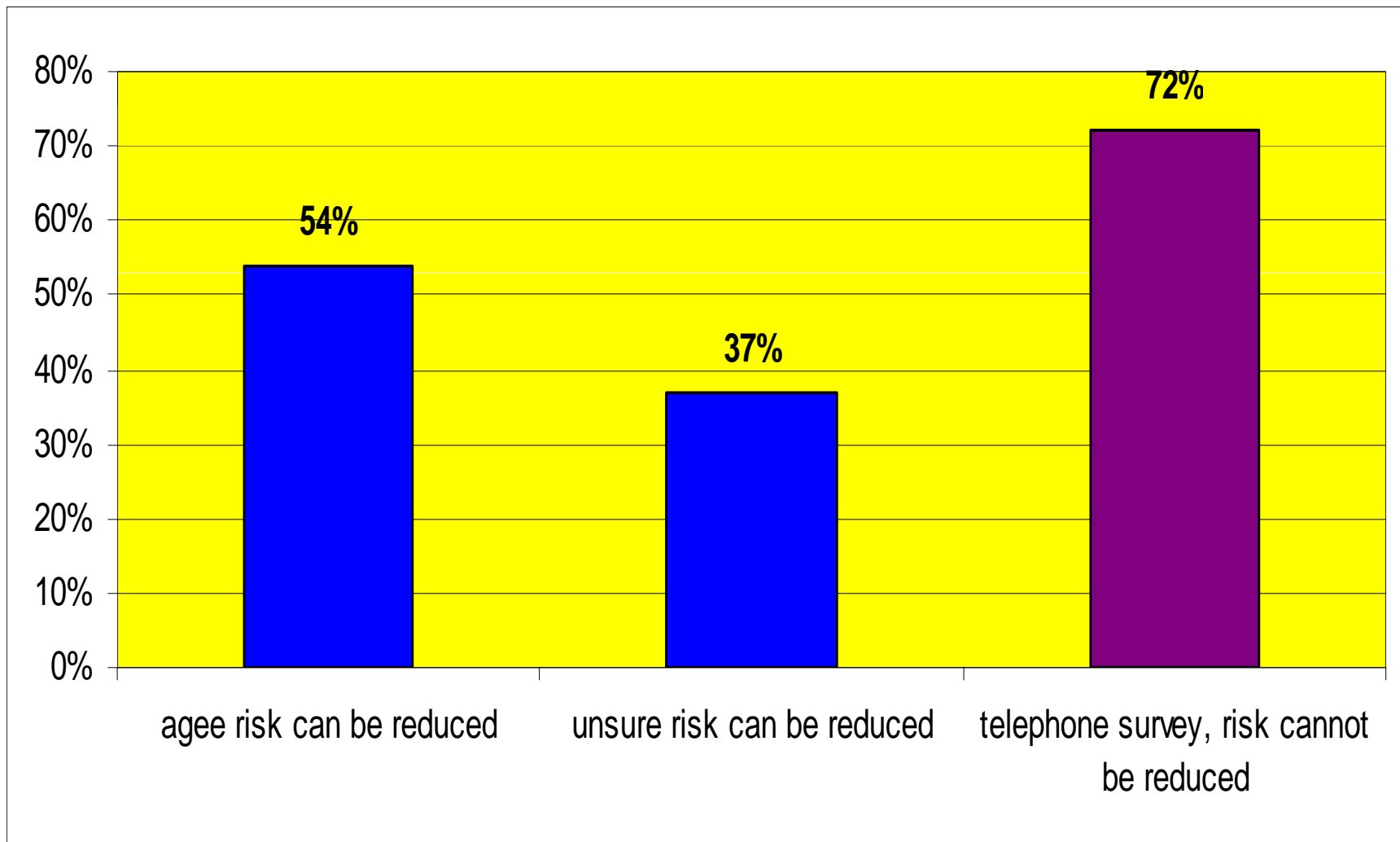
- ◆ Take care as a pedestrian and always wear a seatbelt
- ◆ Use protective headgear when riding, skating and playing sport



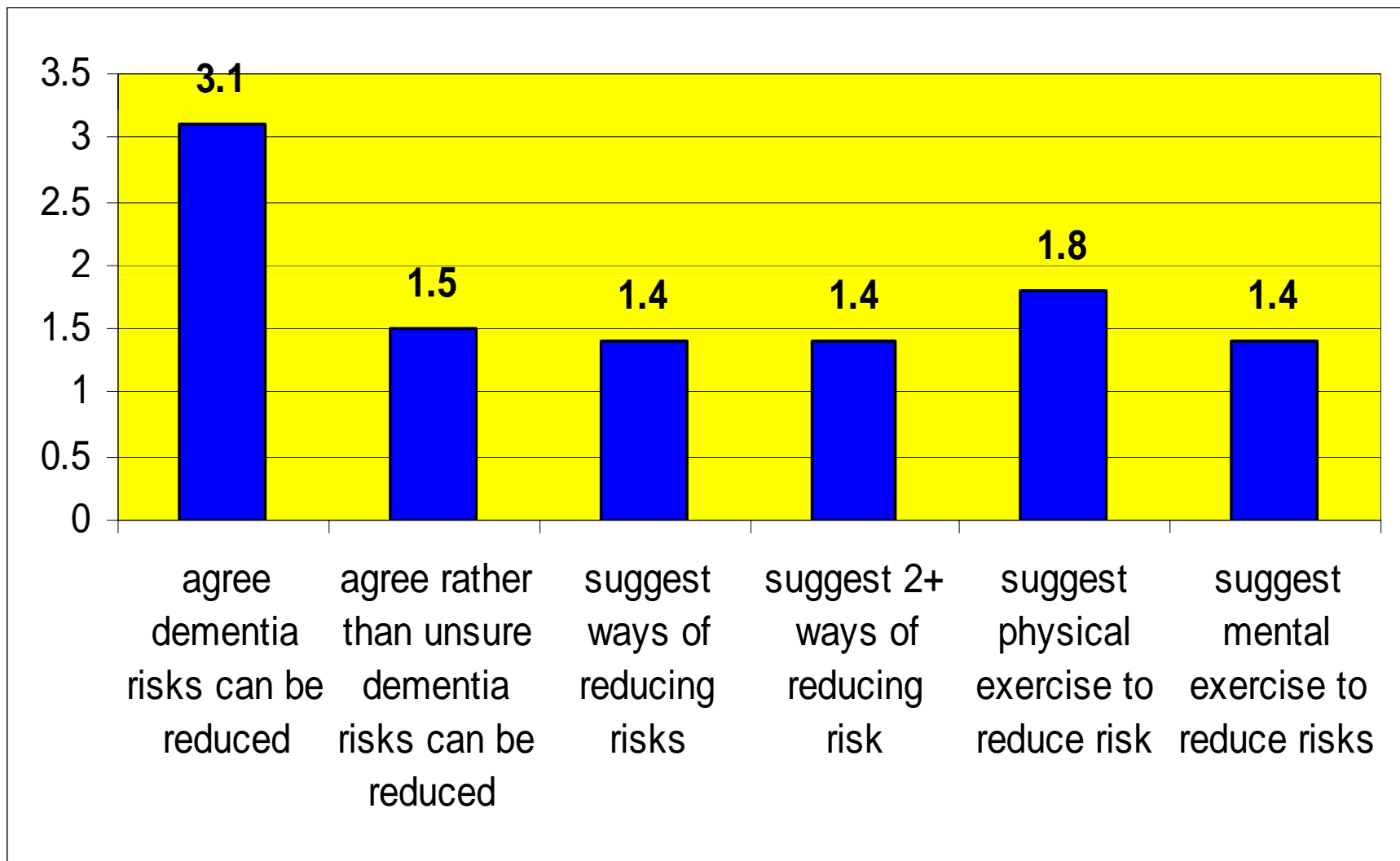
# Would like to learn about risk reduction by age group



# Understanding of dementia risk factors



# Likelihood (RR) of knowing about risk reduction tasks when given 'MYM' intervention ( $p < .004$ )



## The health professional perspective

Surveys and education trial (pilot)

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# Survey of health professionals

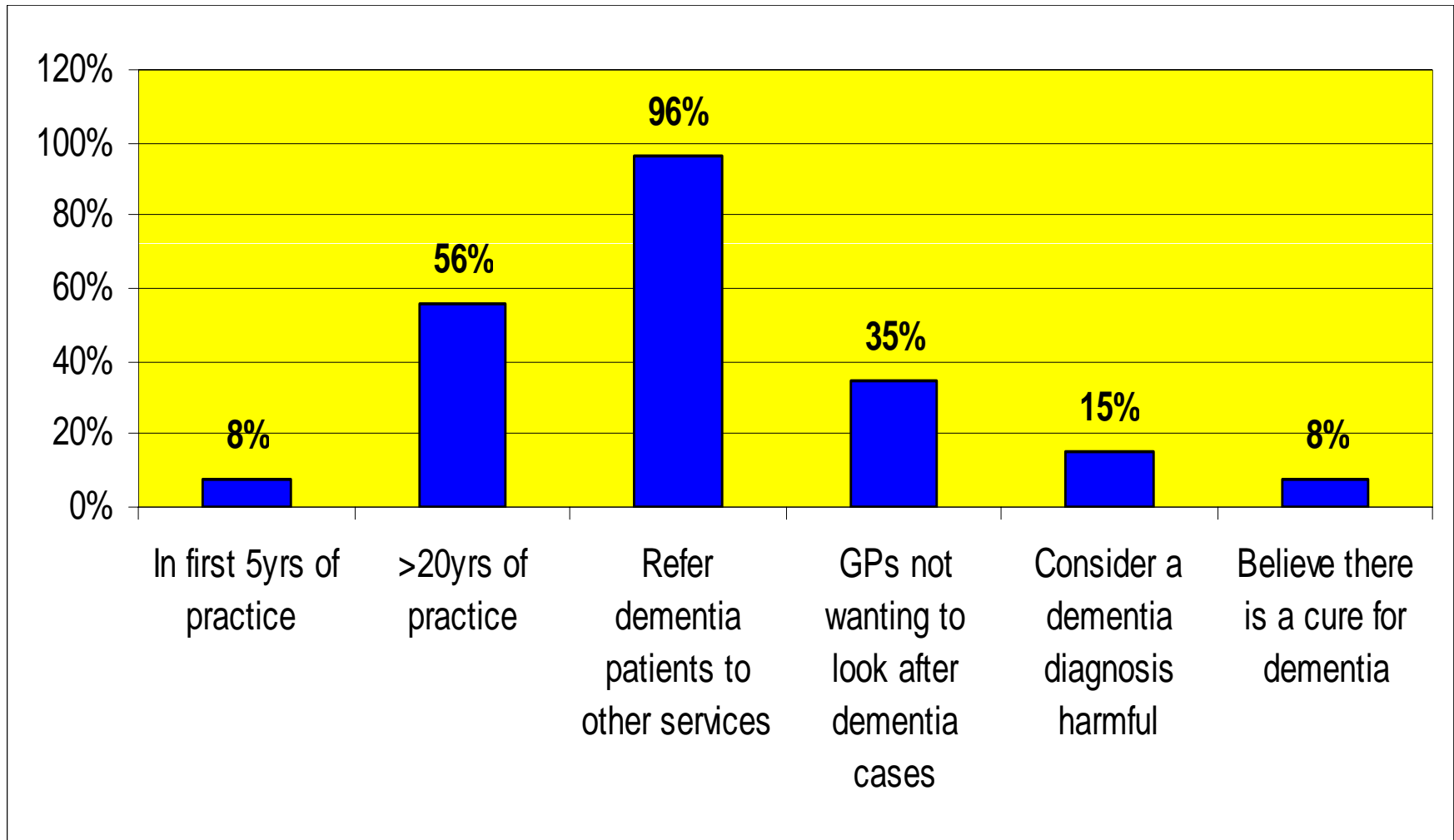
## Participants

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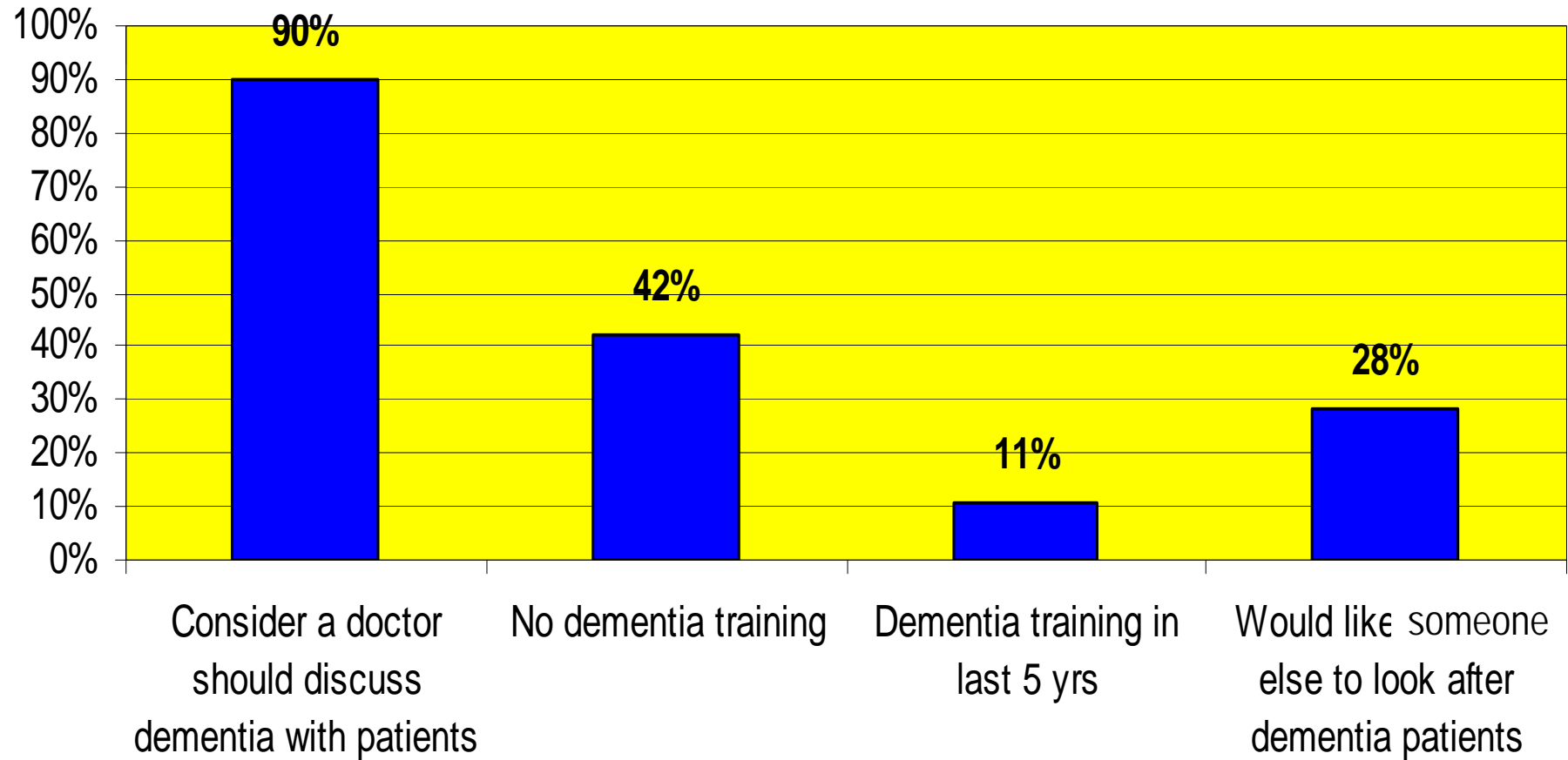


- Health professionals (total) n=114
    - 53% GPs
    - 33% nurse
    - 13% allied health
    - 1 specialist
  - Attendees at dementia forums n=59(52%)
  - GP postal survey n=55(48%)
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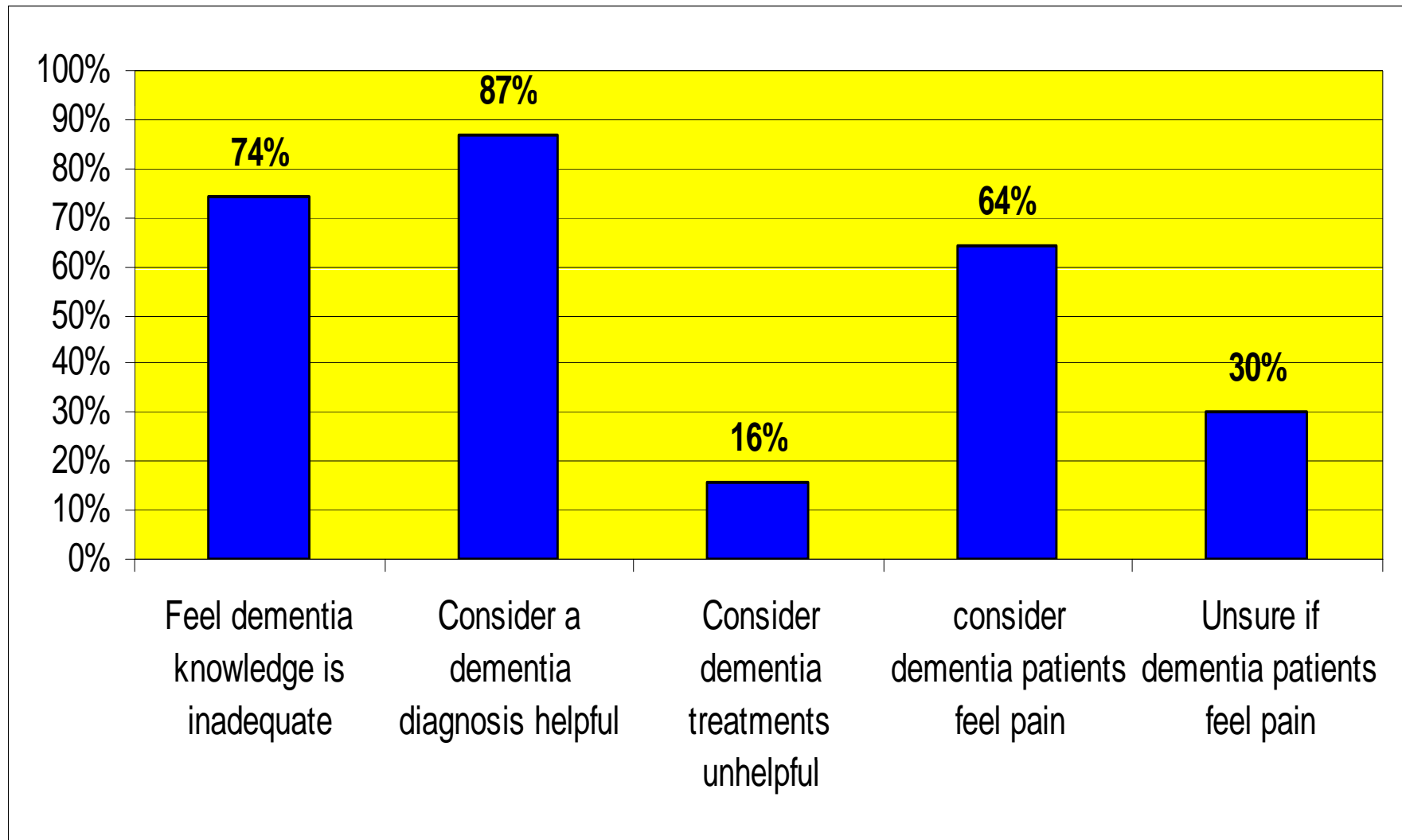
# Health professional survey



# GP/nurse survey-role in dementia care



# GP/Nurse survey-dementia knowledge



# Trial to improve GP detection of dementia

Pilot results N=18

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# Trial 2 (GP education and audit)

## Method

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- 2 interventions
    - Educational workshop on GP guidelines for patients with dementia and their carers GPs assigned to one of 3 groups
    - Audit feed back of the number of dementia cases documented in their computer records, and the number they should have
      - (5% patients over 65 years)
  - 3 GP groups
    - Control
    - Education
    - Education and audit feedback
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# Analysis of results of GP trial

## Wilcoxon test

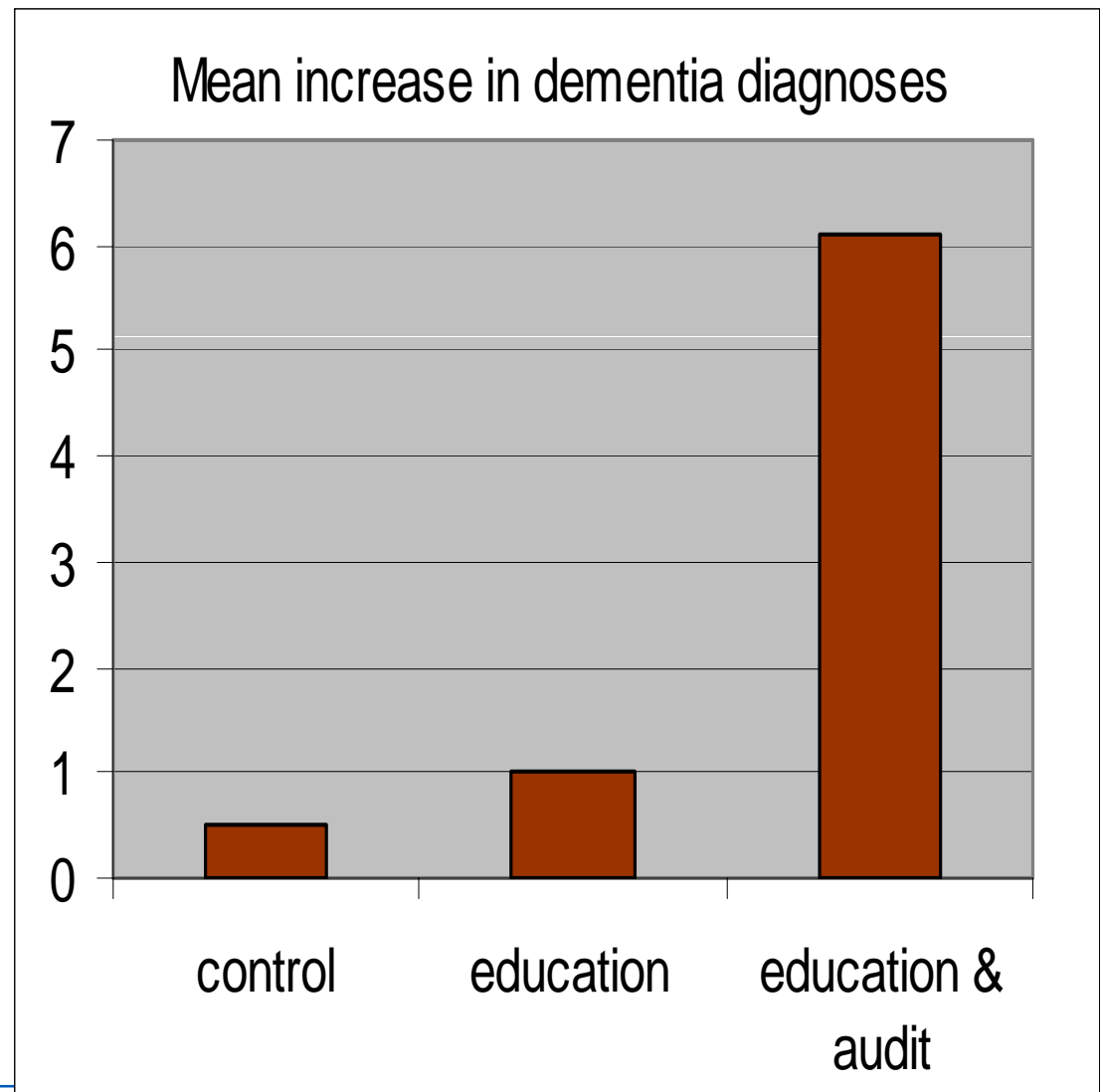
(for non-parametric  
paired data  
significant if  $p < .05$ )

Testing each group for  
significant changes in  
diagnoses.

**Ed & audit**  $p = .018$

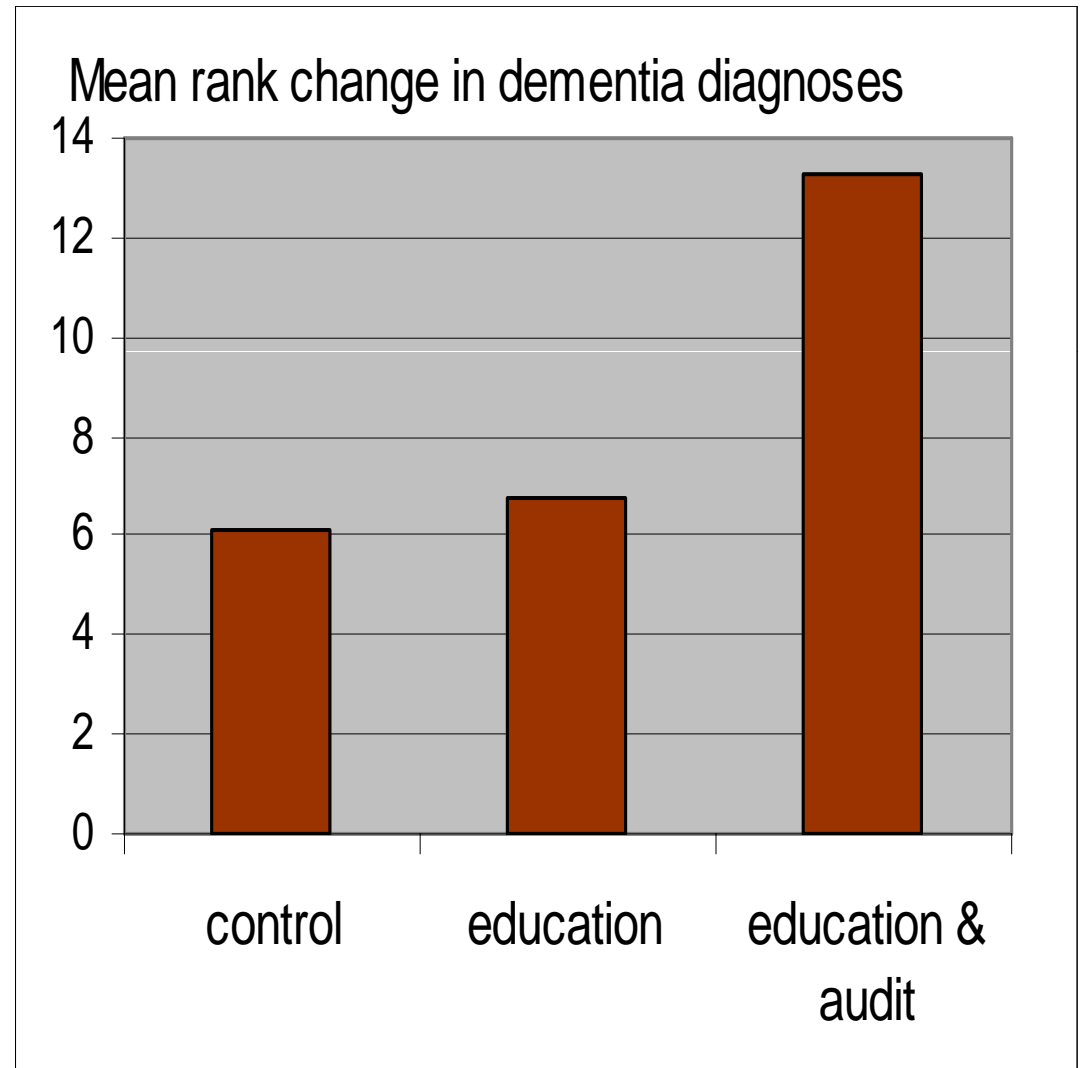
Ed alone  $p = .180$

Control  $p = .180$



# Analysis of results of GP trial

**Kruskal-Wallis test** to compare the mean rank change in dementia diagnoses for the 3 groups.  
**p = .020**  
**significant**



# Summary –the consumer

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- Consumers want to know if they have dementia
  - Consumers want an explanation for dementia symptoms
  - Consumers want assistance negotiating pathways to care
  - Consumers want to know about dementia risk reduction
  - A one page 'MYM' information sheet can improve consumer knowledge of modifiable dementia risks
  - Consumers dealing with dementia may consult with health professionals who consider their dementia training inadequate
  - Consumers dealing with dementia may find their best help comes from others dealing with dementia
  - Consumers dealing with dementia may need to ask their health professional for the services they need.
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# Summary-health professionals

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- Many health professionals lack training and/or interest in managing dementia cases
  - Health professionals should refer dementia cases to appropriate agencies, especially if they do not wish to manage dementia cases
  - Health professionals should respond to consumer requests for investigations for dementia symptoms and provide or arrange appropriate support
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# Key messages

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- Patients with dementia and their carers need help from primary care health services
  - Many primary care workers do not know how to help people with dementia
  - People dealing with dementia in the community often find their best help comes from family and friends
  - Health professionals need to work together to bridge knowledge and skill gaps
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*Thank you for your  
attention*

**Questions**

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