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# The use and value of health status & HRQOL measurement

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# The use and value of health status & HRQOL measurement

**Abstract**

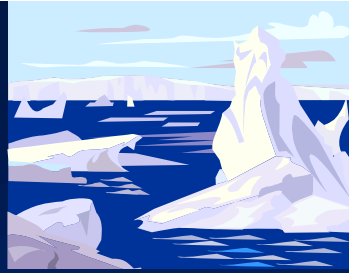
Powerpoint presentation presented at Managing and Measuring Health Outcomes, Menzies School of Health Research, Darwin

**Keywords**

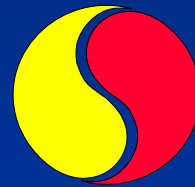
health, hrqol, measurement, value, status

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# The Use and Value of Health Status & HRQOL Measurement



Jan Sansoni

Australian Health Outcomes Collaboration

University of Wollongong

## Health Outcomes (Australia)

EBM

CQA

CPI

CQI

HRQOL

ACE

PopH

HO more encompassing term in Australia - health practice improvement and better patient outcomes are the common threads

**Health Outcomes –focus on use of HRQOL and health status measurement for**

- ✦ population health surveys
- ✦ to evaluate the effects of health interventions and to monitor patient outcomes at the clinical level and
- ✦ for pharmaceutical registration and reimbursement (PBS)

# National Health Survey

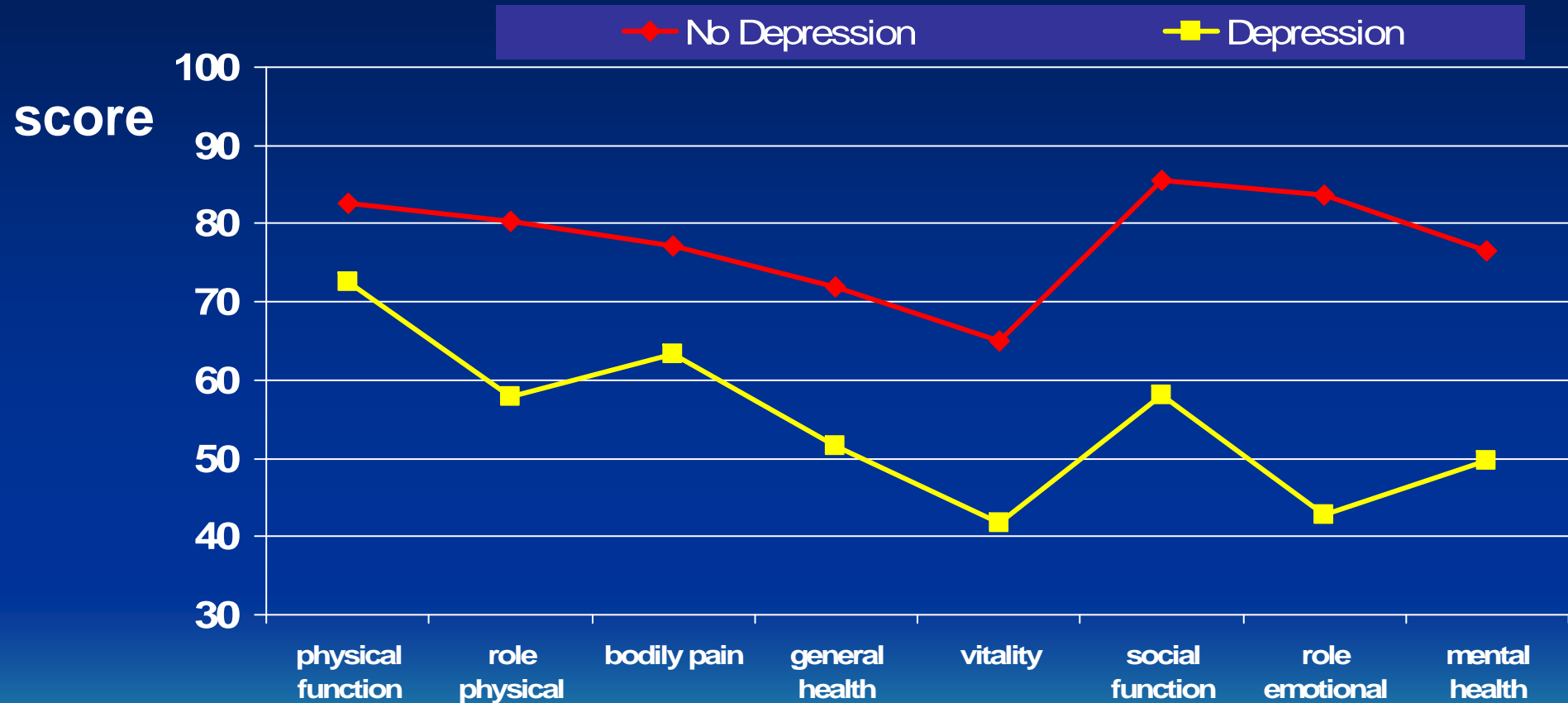
- First inclusion of patient rated health status measure other than a global item – SF-36 (1995); SF-12 (1997) Kessler 10 mental health screener (2001, 2004, 2008)
- Surveys also contain items on health conditions, service use, health behaviours, socio-demographic aspects
- Value seen in identifying disease profiles for self reported health conditions, and for across disease comparisons. Provides useful normative data
- Not much analysis of health related actions/service use in relation to SF-36 in 1995
- Other later, related, projects confirmed previous associations of SF-36 with survival, future health, health utilization/expenditures etc.

# Instruments Used: Major Health Surveys

- SF-36V1 (*PSM 1995, NHS 95, WHA, CCHOP, State Surveys*)
- SF-12, GHQ12, Kessler 10, CIDI (*NMHWBS 1997*)
- EQ-5D (*NSW 1998 – note recent UK developments*)
- Kessler -10 (*NSW 1998, NHS 2001,2004, 2008; 45 and up*)
- SF-36V2 (*SAHOS 2004*)
- A major value has been the provision of normative data supporting clinical research and the use of surveys to trial some instruments for proposed HO research and monitoring initiatives

# SF-36 Subscale Scores by Depression

(NHS '95)



# Women's Health Australia

- ★ 20-year longitudinal cohort study of the health and well-being of Australian women, Newcastle & Queensland Unis
- ★ Commenced 1996 and continuing
- ★ Funded by Commonwealth Dept. of Health & Ageing
- ★ Postal surveys and linkage to Medicare database
- ★ Social view of health:
  - physical health and symptoms, emotional well-being
  - health service use, access and satisfaction, demographics
  - health behaviours, time use, life events

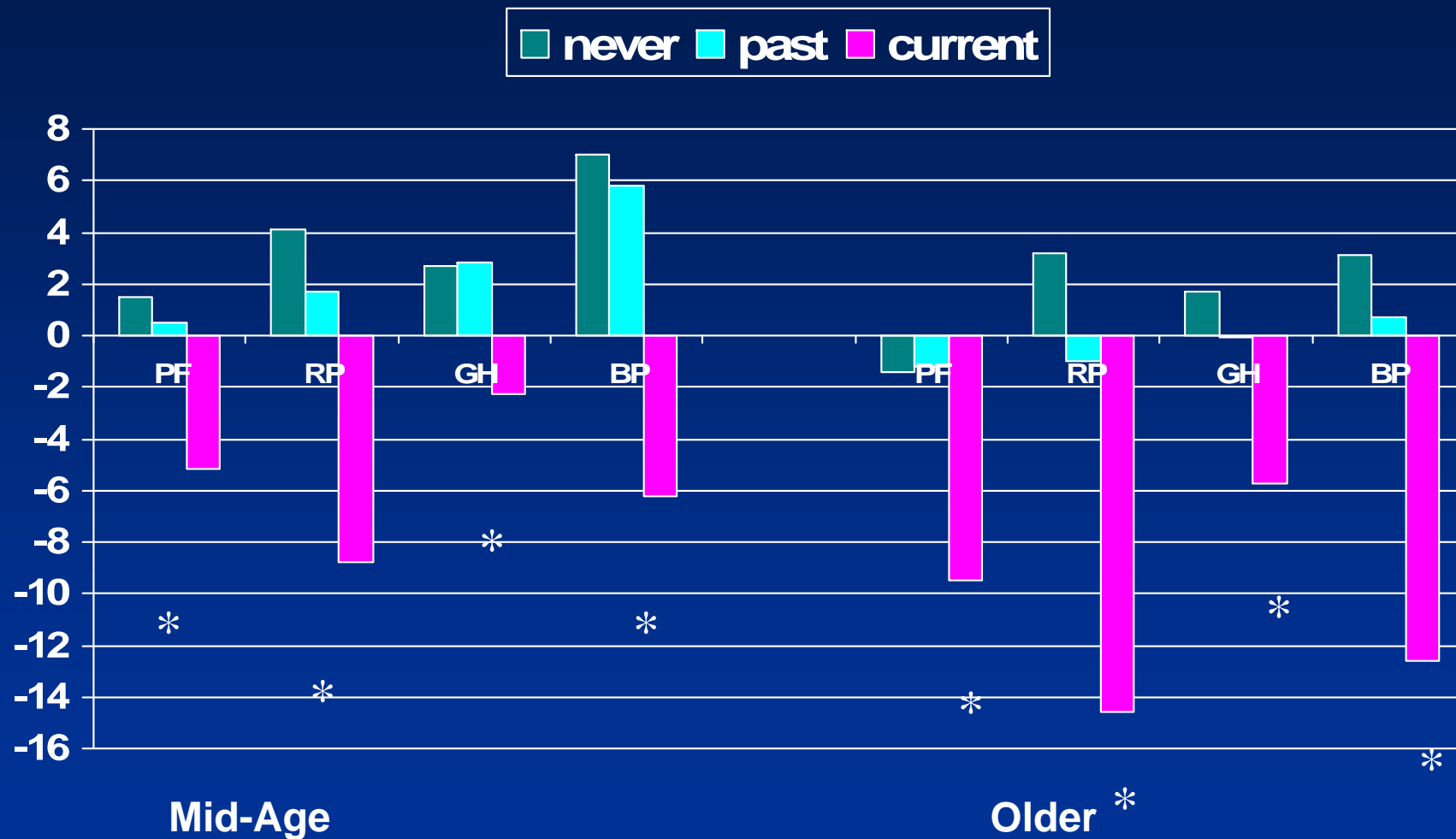
★ Web site is at [www.newcastle.edu.au/centre/wha](http://www.newcastle.edu.au/centre/wha)



# Goal

- ★ to determine social, psychological, physical and environmental factors which determine health among in women throughout adult life
- ★ to contribute to the development of policy and practice in key areas for women's health
  - ★ National Health Priority Areas - diabetes, asthma ...
  - ★ Health Targets e.g. Ageing Well, Continence, Quality Use of Medicines, National Tobacco Strategy, Watching Australia's Weight, Active Australia ...
- ❖ Cohorts = Young (18-25) Mid (45-50) Older (70-75) at commencement (1996). Cohorts 12,500 – 14,000 with high retention rates, follow up 3 - 5 years....longitudinal 'snapshots'

# Stiff or Painful Joints and Change in SF-36 Physical Health: Mid and Older Women



NB: change scores are adjusted for Survey 1 scores

# Health Service Delivery: Coordinated Care Trials

- **Trials which examined ‘fund pooling’ models to provide coordinated care for elderly with chronic conditions vs. usual GP care**
- **Hypothesized to improve outcomes... or maintain / slow rate of decline – given nature of trial population?**
- **SF-36 used to monitor outcomes of all comparison/control groups; disease specific measures and patient satisfaction were unique to each particular trial**
- **Few SF-36 differences detected – no surprise given subtle nature of intervention - access to services ? and timeframe ??**
- **Conclusions reflect poor understanding of HRQOL assessment?**

# Clinical Monitoring: Mental Health

- Review of consumer outcome measures – Andrews et al, 1994
- Small trial of potential consumer measures (BASIS, MHI, SF-36) and provider measures (HoNOS, LSP, RFS)
- Development of MH Classification and Service Costs Project MH-CASC (HoNOS, LSP, RUGS-ADL).
- Routine Implementation – HoNOS, LSP for all inpatients plus chosen consumer measure (K-10, BASIS, MHI) - latter also used for outpatients

# Clinical Monitoring

- Benchmarking of service comparisons – outcomes results adjusted for patient mix - Casemix Adjusted Relative Mean Improvement (CARMI).....but some issues
- ? HoNOS - assumed predictor of cost also a good predictor of outcome
- Is a clinician severity rating measure a good measure for monitoring patient outcomes over time?
- **Australian Rehabilitation Outcomes Centre (AROC) - Similar benchmarking initiatives in rehabilitation (FIM)**  
→ **web enabling**
- **Issues of real time feedback are critical for clinical use, static databases are not the answer**

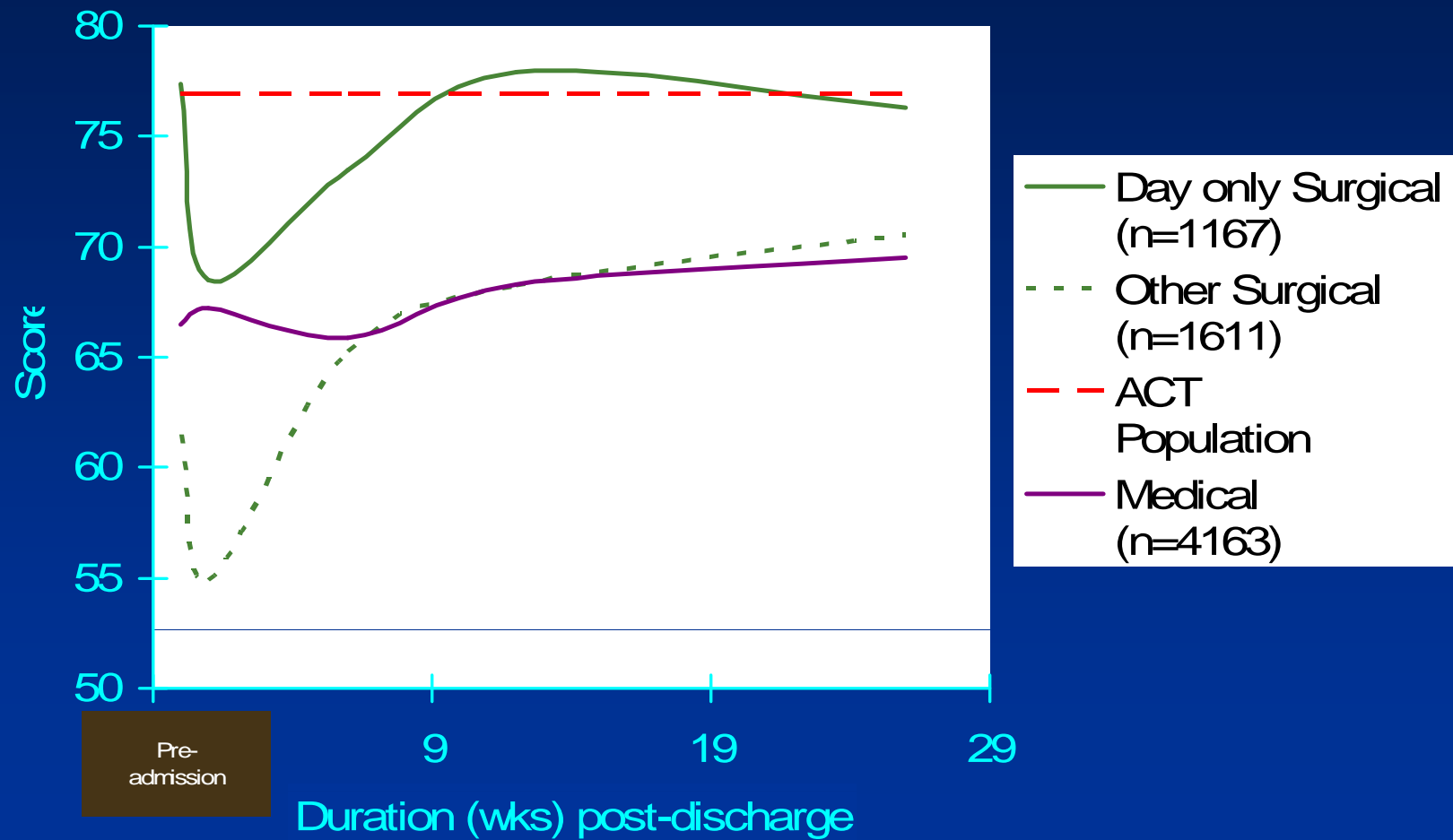
# The Continuum of Care and Health Outcomes Project

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- A longitudinal study of 7154 inpatients including both retrospective and prospective data (1995-96)
- Develop profiles on health outcomes, care, service use and financial costs
- Compare various patient and population groups in their service use and health outcomes
- Use the findings to help clinicians and administrators improve their decision making - implement and develop outcomes management model

# Mean Pain Scores (SF-36) for Surgical and Medical Patients



# CCHOP to DiscoverQuick

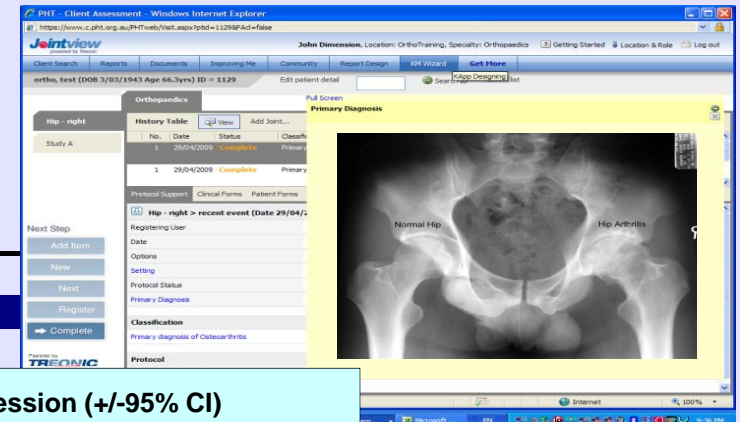
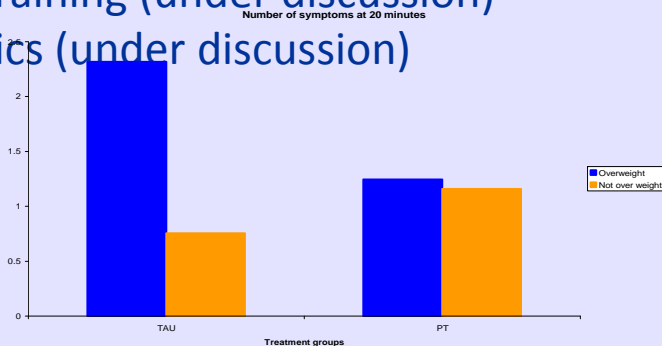
- Need to streamline system for use in routine care and research settings
- DiscoverQuick is a web enabled intelligent knowledge management system for **outcomes management** - providing **real time** feedback to clinicians
- Allows recruitment to RCTs and HSR studies while providing support for patient care
- Integrates EBM knowledge bases, guidelines, in developing decision support algorithms
- Includes **HRQOL** data with settings which can be linked to instrument review repositories and provide feedback to these



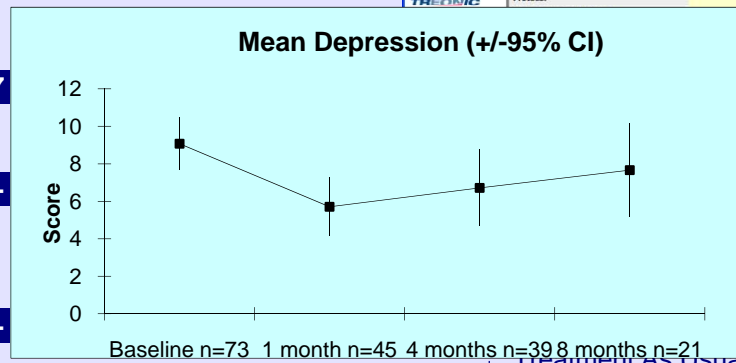
# DiscoverQuick

Overwhelmingly enthusiastic response

- Neonatology
- Pain management
- Gastroenterology
- Orthopaedics/Cardiology
- Diabetes Educators Association
- CLP Project
- Arthritis ACT, SA, Qld, Tas
- Academic medicine unit
- Endometriosis (gynaecology)
- Respiratory and Sleep Medicine
- Mental health (working towards a start)
- Rheumatology (under discussion)
- Registrar training (under discussion)
- Anaesthetics (under discussion)



## Minimisation Group < 7 years old & Not Overweight



...	2
...	17
...	14
...	7
...	6
<b>Grand Total</b>	<b>52</b>

# HRQOL: Needs Assessment

- Community and Primary Care -Initial Needs Assessment, Ongoing Needs Assessment, Health and Community Care Screening, Aged Care Assessment, Provision of Appliances for Disabled Persons
- Tiered approaches, screening and follow up assessment **to determine needs and assign services**
- Use of ADL and IADL functional skills profiles (Modified Barthel, FIM, Lawton's IADL)
- Mainly needs assessment but also for outcomes monitoring in some projects

# Aged Care Assessment

- Desire to standardise aged care assessments nationally – great goals - given the diversity of these assessments
- Screening and follow up assessments
- Ensure all clients receive a cognitive assessment
- Desire for valid and reliable assessment.....but do committee choices really reflect this aspect?

# Summary of Ratings for Cognitive Assessment Instruments

Criteria	Weight	MMSE (3MS)	SMMSE	RUDAS <sup>a</sup>	KICA- COG	KICA- CARER	IQCODE
Theoretical/empirical basis	3	3	3	3	3	3	3
Availability of comparison data	3	3	2	2	2	2	2
Length/feasibility of instrument for inclusion in battery	2	2	3	2	2	3	2
Complexity of administration/ cognitive burden	2	2	2	2	3	3	3
Cultural Appropriateness	1	2	2	3	3	3	2
Ease of obtaining score	2	2.5	2.5	3	3	3	3
Sensitivity	3	3	2.5	2	2	2	2.5
Reliability evidence	3	3	3	3	2.5 <sup>b</sup>	2 <sup>b</sup>	3
Validity evidence	3	3	3	2.5 <sup>b</sup>	2.5 <sup>b</sup>	2 <sup>b</sup>	3
Cost of the instrument	2	3	2 <sup>c</sup>	2	3	3	3
Cost of instrument administration	2	2	2	2	2	2	2
<b>Weighted Total</b>		<b>70</b>	<b>65.5</b>	<b>62.5</b>	<b>65</b>	<b>64</b>	<b>68.5</b>

Based on the DOMs review in 2008 – this review needs to be updated

b. Scored as 2 or 2.5 because of there being limited evidence/publications or independent publications but what there is indicates good sensitivity, validity and/or reliability.

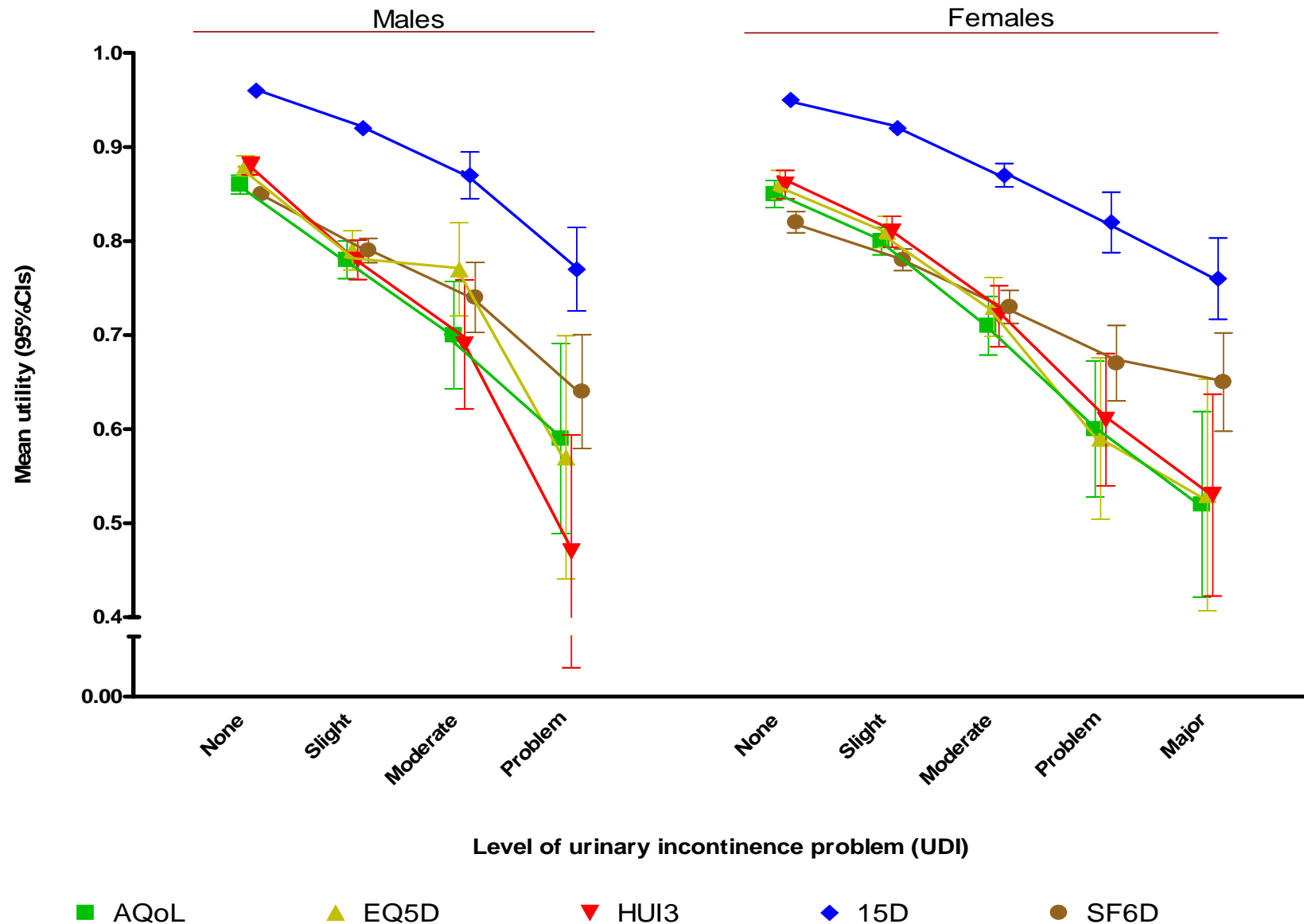
c. Rated as 2 vs.1 as the costs are minimal and estimated at 12 cents per use

From Sansoni J et al.(2010) Selecting Tools for ACAT Assessment: A Report for the Aged Care Assessment Program (ACAP) Expert Clinical Reference Group. CHSD, University of Wollongong. Report for the Aged Care Assessment Program, Australian Government Department of Health and Ageing, Canberra

# SAHOS: User Pays Survey

- ★ 3000 sample community survey used by researchers and government
- ★ 2004 survey compared utility measures EQ5D, AQOL, HUI3, SF-6DV2, 15D in relation to incontinence items and also deriving interim norms for SF-36V2
- ★ Also reflects earlier government interest in developing outcome measurement suites (e.g. dementia, continence)...standardizing use of measures/items...for clinical applications

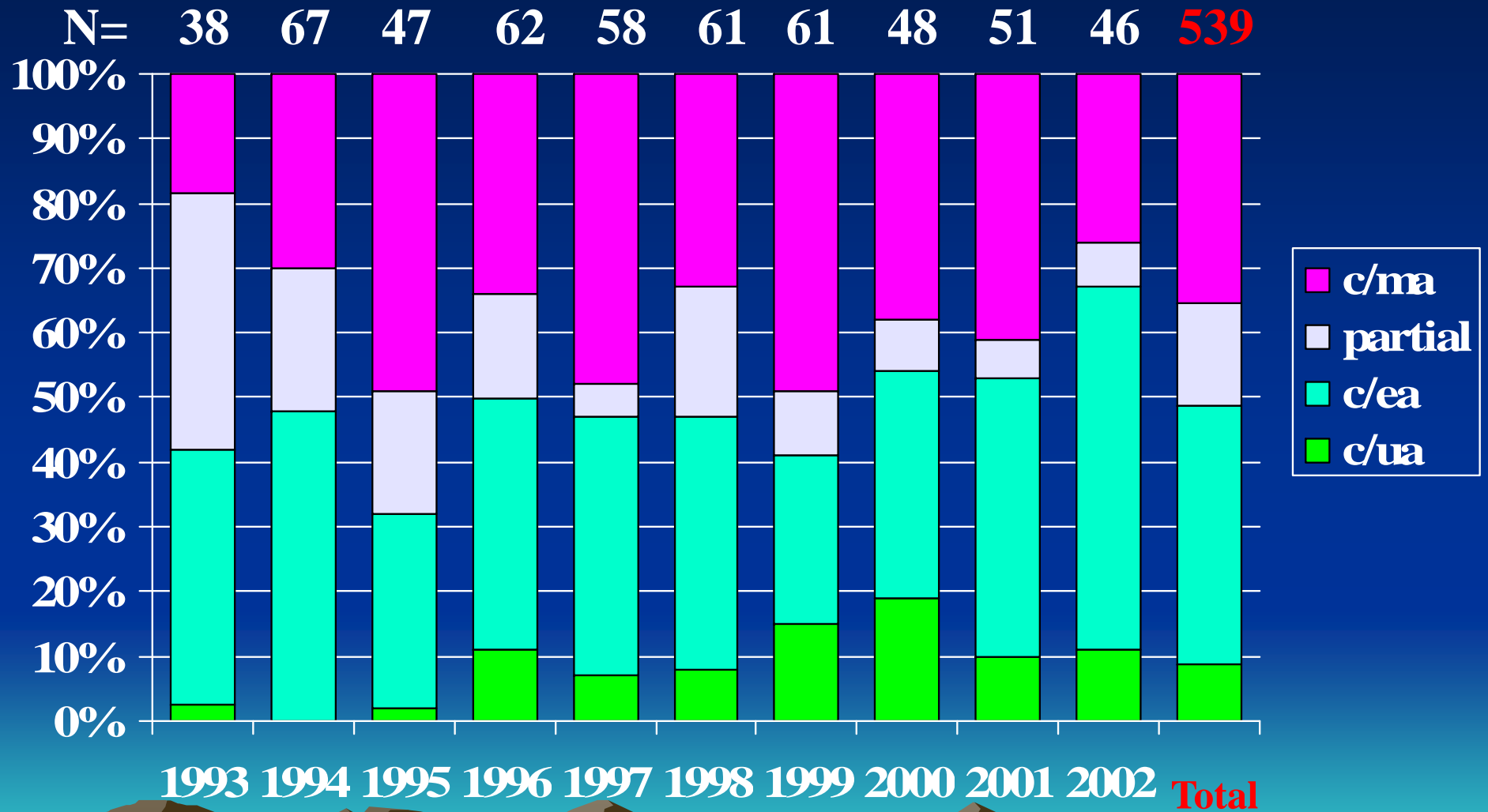
# Effect of urinary incontinence on HRQoL by gender



# Regulatory Aspects: PBS

- **Pharmaceutical Benefit Scheme (PBS) 1992 – required to conduct economic evaluation (with a focus on outcomes including HRQOL) for drug registration to attract government subsidy**
- **Subsidised medicine prices capped with a patient co-payment @ \$5.60 healthcare card, others \$34.20**
- **Reference Pricing ... a ‘me too’ drug price will be set at the price of the lowest comparable drug (CMA). To gain a higher price for a new drug one must show relative benefit per \$ over existing drugs...CEA, CUA analyses**
- **HRQOL data particularly relevant for submissions for chronic conditions and need to justify psychometric properties of selected instruments (PBAC Guidelines)**

# Types of Economic Evaluation





# Pharmaceutical Benefits Scheme

- Quality of economic evaluations - 67% had some methodological flaw (Hill et al, 2000 ... analysis, interpretation, est. comparative clinical efficacy, modeling)
- More recent revisions of PBAC guidelines... but need for greater expertise and greater 'genuine' transparency?
- Despite these issues – a very effective scheme for pricing
- See [www.health.gov.au/pbs](http://www.health.gov.au/pbs)

# Some Issues

- Plenty of **use** but sometimes not gaining as much **value** – reflects lack of familiarity with assessment and interpretation of HRQOL data (e.g. reliability and validity rhetoric vs. reality)
- Instrument selection issues ... need to relate to purpose of assessment, develop more wisdom concerning the use of measures
- Convenient/routine follow up assessment points may not always be the most informative
- Easier to collect data than to use it to inform practice
- HRQOL assessment issues may need more thought and the development of greater expertise

# Future Directions

- Becoming more sophisticated – and an increasing recognition of HRQOL measurement issues
- A number of national (large scale) initiatives (e.g. 45 and up study, WHA) and increasing implementation in clinical practice
- A focus on improving technology to facilitate outcomes monitoring and service comparisons for practice improvement





# CLINICAL ASSESSMENT

Hospital Device, DOB : 1/1/1945

Assessed By: Dr. Bruce Shadbolt

## Risk Assessments and Diagnoses

Breast Cancer

## Severity

Early unilateral single primary invas. BC

## Setting

In Patient

## Status

Follow up phase

Add New Diagnosis  Add New Assessment

### A. Tumour size (invasive)

21-50 mm

### B. Tumour margin

0 mm

### C. Nipple involvement

Yes

### D. Widespread disease

No

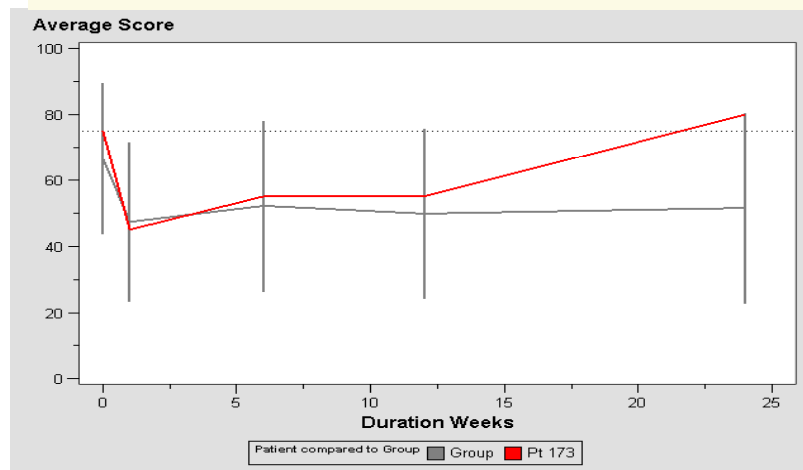
### E. Nodal categories

No regional lymph node metastasis

## Patient progress

Vitality by time

Average Vitality Levels (+/- SD) over time comparing Patient against Group



# Distribution of HRQoL utility scores by instrument

