



Ageing in intellectual disability

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

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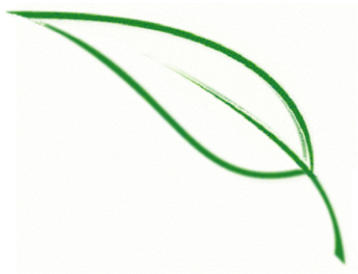
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The SAGE-ID Study

What are the issues?

- Life expectancy of people with ID are increasing world wide
- Increased risk of dementia in ID population
- Mental and physical health declines rapidly compared to non-ID population



Aim of research:

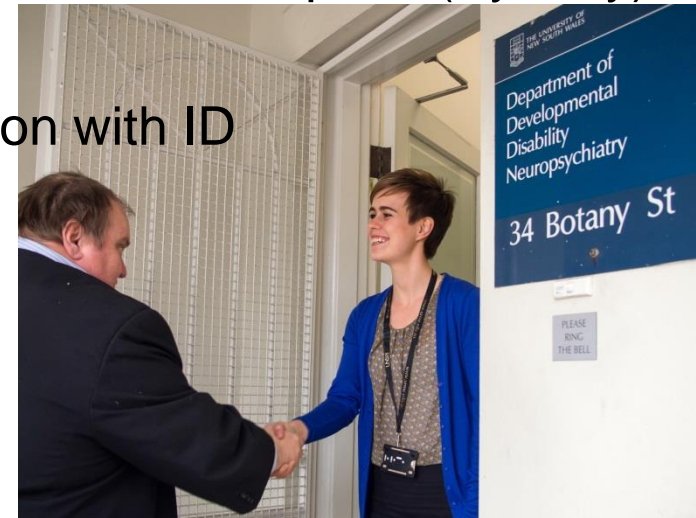
- Conduct a comprehensive investigation of the predictors and correlates of healthy ageing, and of dementia in people with ID.
 - Prevalence of dementia and age specific mental disorders
 - Level of cognitive reserve
 - Service use and carer burden

Our Population:

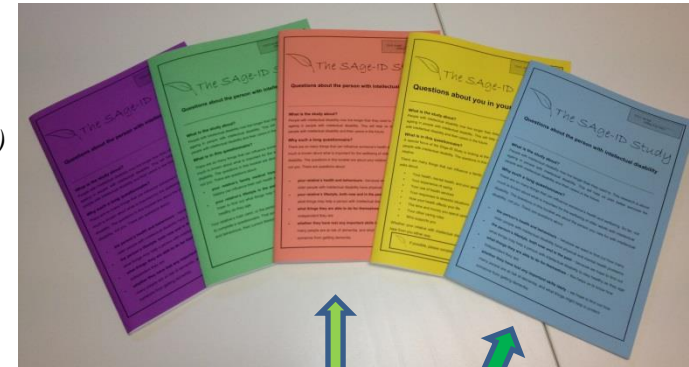
- Men and women aged 40 and over
- Has and intellectual disability of any level
- Lives in either regional (Sydney)/rural (Illawarra) NSW or regional (Melbourne) /rural (Bendigo) Victoria in Australia

Procedures:

- **Person with ID:**
 - **Regional participants;** questionnaire and assessment option (Sydney)
 - Questionnaire – main carer
 - Cognitive & Physical assessment – person with ID
 - **Rural participants;** questionnaire only
- **Family Carers:**
 - **Regional/Rural;** questionnaire only

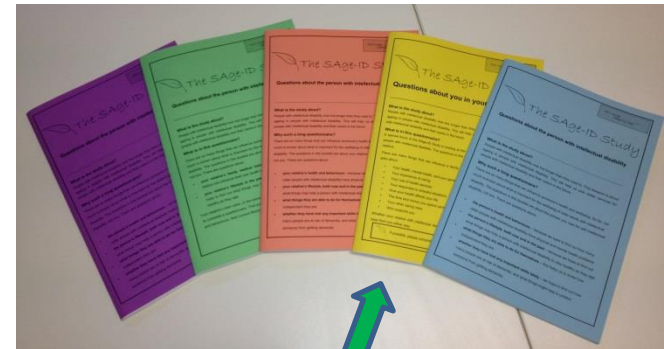


Domain(s) Measured	Instrument Name	Reference
<i>Questionnaire completed by main carer about the person with ID</i>		
Adaptive Behaviour	Scales of Independent Behaviour - Revised (SIB-R)	<i>Bruininks, Woodcock, Weatherman & Hill (1997)</i>
Behaviour problems and psychiatric status	Developmental Behaviour Checklist for Adults (DBC)	<i>Mohr, Tonge, Einfeld, & Gray (2005)</i>
Sleep	Basic Nordic Sleep Questionnaire	<i>Partinen & Gislason (1995) Epworth Adapted</i>
Health and care service use	Client Service Receipt Inventory (CSRI)	<i>Beecham & Knapp (2001)</i>
Significant Life Events	PAS-ADD checklist	<i>Moss et al. (1998)</i>
Dementia screening	Dementia Questionnaire for People with Intellectual Disabilities (DLD)	<i>Evenhuis, Kengen & Eurlings (2006)</i>
	Dementia Screening Questionnaire for Individual with Intellectual Disability (DSQIID)	<i>Deb, Hare, Prior & Bhaumik (2007)</i>
	Adaptive Behaviour Dementia Questionnaire (ABDQ)	<i>Prasher, Farooq & Holder, 2004)</i>
	Cambridge Examination for Mental Disorders of Older People with Down' Syndrome (CAMDEX)	<i>Ball, Holland, Huppert, Treppner & Dodd (2006)</i>



Pink – Family carer
Blue – Paid Carer

Domain(s) Measured	Instrument Name	Reference
<i>Questionnaire completed by family carer regarding themselves</i>		
Objective Carer Burden	National Mental Health and Wellbeing survey	<i>Australian Bureau of Statistics (2007)</i>
Subjective Carer Burden	Zarit Burden Scale	<i>Zarit, Orr & Zarit (1985)</i>
Mental and Physical health of family carer	General health Questionnaire 28 (GHQ)	<i>Goldberg (1978)</i>
	Patient Health Questionnaire 9 (PHQ-9)	<i>Kroenke, Spitzer & Williams (2001)</i>
	Short-Form 12 Health Survey (SF-12)	<i>Ware, Kosinski & Keller (1996)</i>
Quality of Life (health related)	Assessment of Quality of Life survey (AQoL)	<i>Richardson, Atherton Day, Peacock & Iezzi (2004)</i>
Social Supports	Social Support Questionnaire 6 (SSQ6)	<i>Sarason, Sarason, Shearin & Pierce (1987)</i>
Coping responses	Brief COPE	<i>Carver (1997)</i>



Yellow – Family Carer burden

Cognitive Assessment:

Domain(s) Measured	Instrument Name	Reference
Cognitive and functional level of ID	Peabody Picture Vocabulary Test (PPVT)	<i>Dunn & Dunn (2007)</i>
Motor function, language, comprehension, delayed memory, general knowledge and conceptualisation	Test of Severe Impairment (TSI)	<i>Albert & Cohen (1992)</i>
Vocabulary, grammatical morphemes and elaborated phrases and sentences	Test for Auditory Comprehension of language - 3rd Edition (TACL-3)	<i>Carrow-Woolfolk (1999)</i>
Memory encoding, recall and retrieval	Cued Recall Test (CRT)	<i>Buschke (1984), Grober & Buschke (1987)</i>
Executive function - planning and working memory	Scrambled Boxes Test (SBT)	<i>Adapted from Griffith et al. (1999), Ball et al. (2008)</i>
	Tower of London (TOL)	<i>Shallice (1982)</i>
Dementia-related cognitive skills: memory, orientation, language and praxis	Neuropsychiatric Assessment of Dementia in Individuals with ID (NAID)	<i>Crayton & Oliver (1993), Oliver, Crayton, Holland, Hall, & Bradbury (1998)</i>





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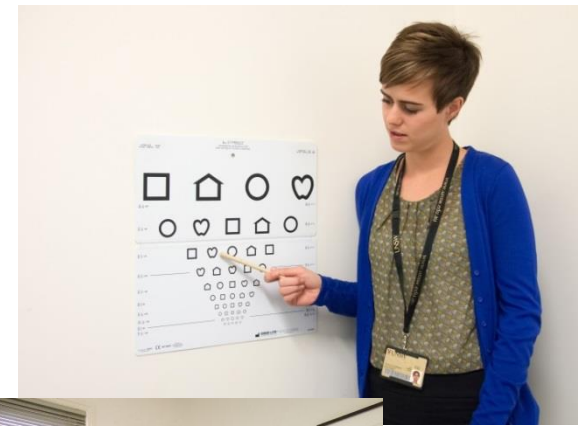
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Physical assessment:

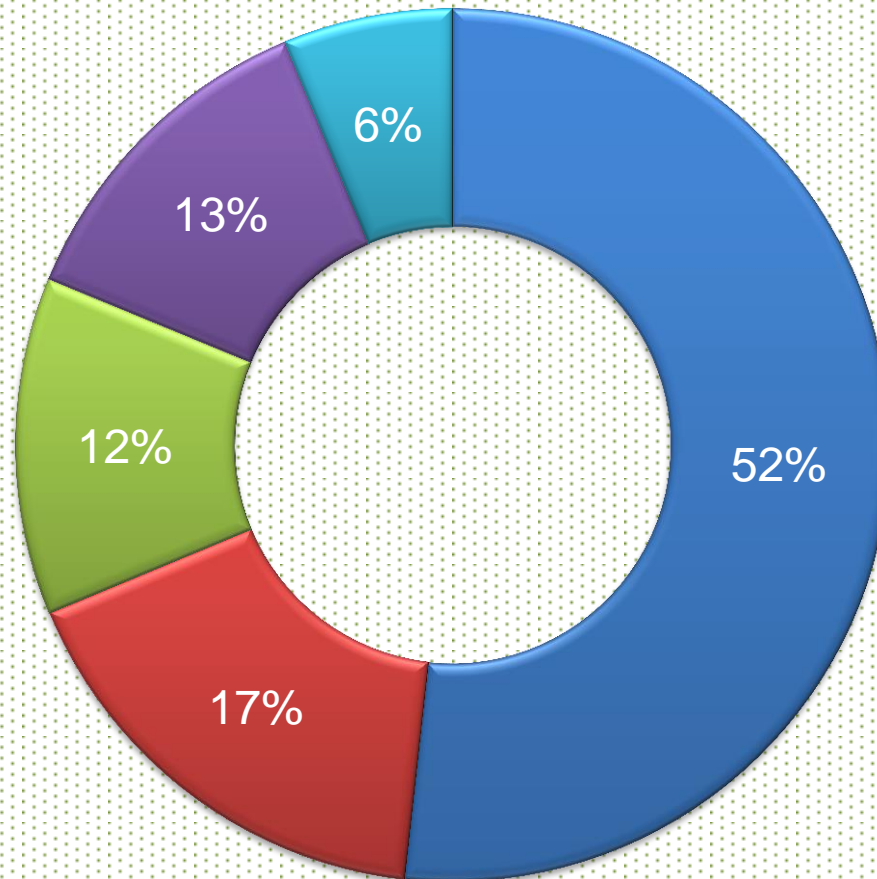


Our questionnaire sample so far..... (n=112)

		Male	Female	Total
Mean Age (yrs)		51.0	51.4	51.2
Marital Status				
	Married	0	2	2
	Single	57	50	107
	Divorced	1	1	2
Location				
	Metro Sydney	26	24	50
	Regional Sydney	20	15	35
	Victoria	12	15	27
Living situation				
	Home w/family	9	6	15
	Small residential	29	23	52
	Large residential	13	12	25
	Independently	6	6	12
	Aged care facility	0	6	6
Currently have a job (paid/voluntary)		17	14	31

Adaptive Behaviour

Broad Adaptive Behaviour (%)



Standard Score

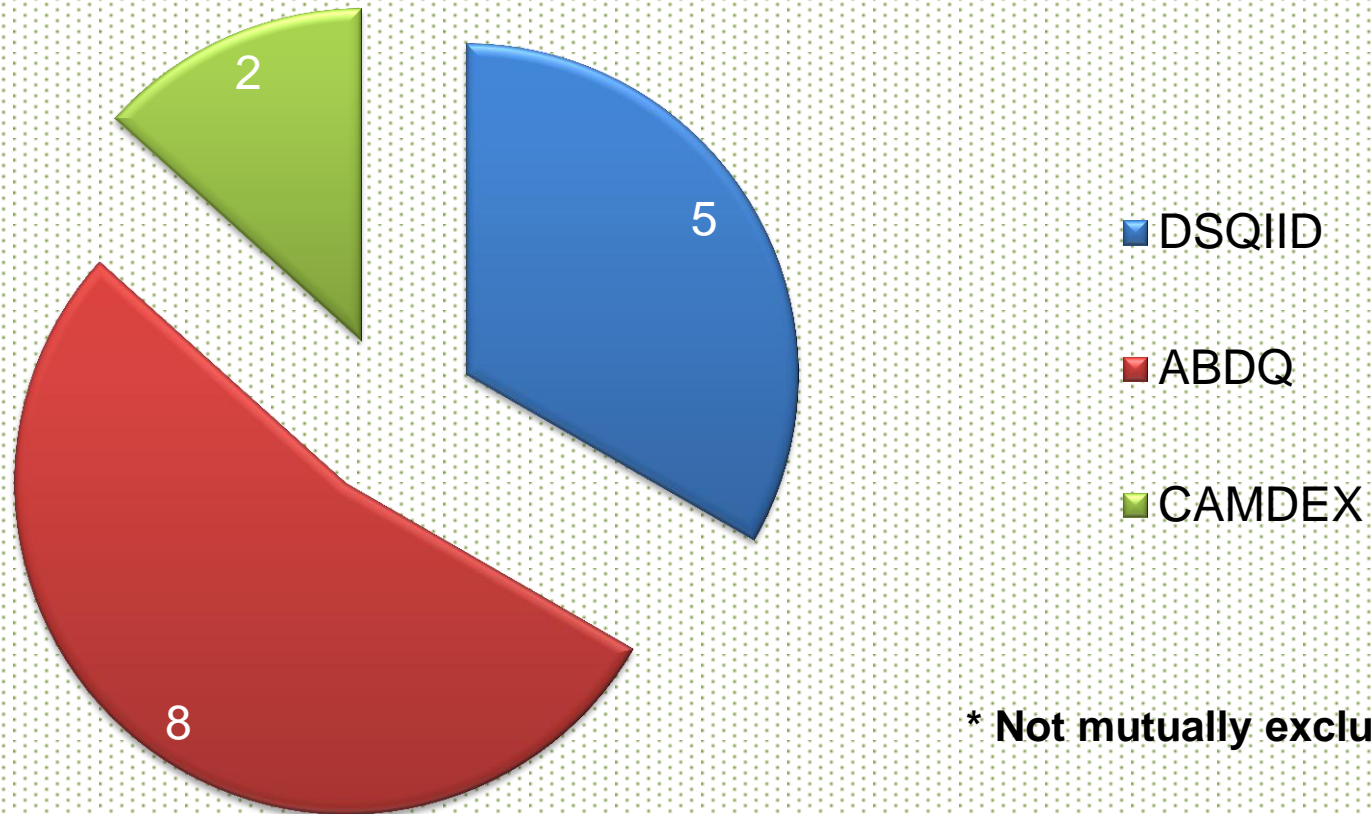
- 0-24
- 25-39
- 40-54
- 55-69
- 70-100

Physical health:

- **BMI** range 17 – 57; **average 29.8 = Obese – Super Obese!**
- Stroke – 5.4% 1 or more
- High blood pressure – 26.7% (only 13.4% meds)
- **Cholesterol – 25.9%** (only 12.5% meds)
- Diabetes – 15.2%
- Thyroid – 12.5% (Underactive 10.7%; Overactive 1.8%)
- **Fits/Epilepsy – 35.7%** (26.8% meds)
- **Consulted a psychiatrist/psychologist – 46.2%**
- Sight problems – 27.7%
- **Physical disability – 33.9%** (11.6% confined to wheelchair)
- Diagnosed with Autism/ASD/Aspergers – 15.2%

Possible Dementia Cases (N=11):

Possible Flagged Dementia Diagnosis from each tool



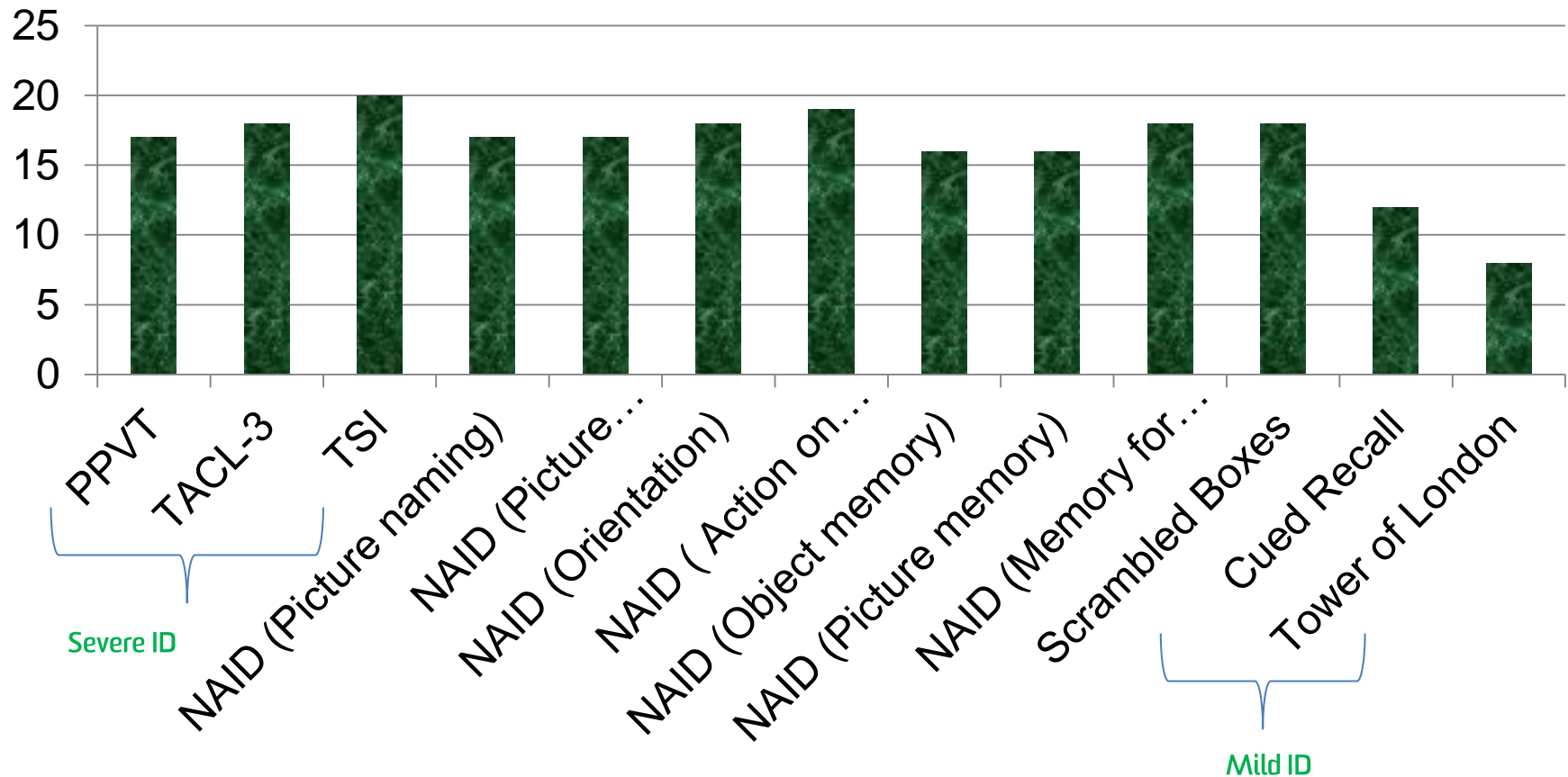
* Not mutually exclusive

Assessment Stats:

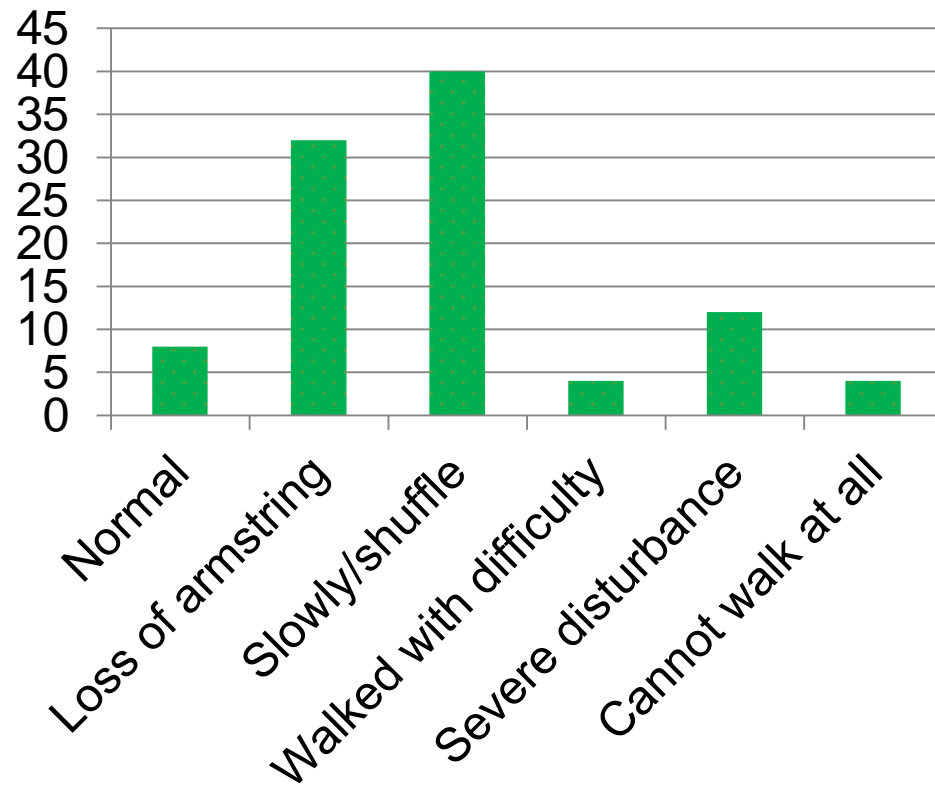
- 27 participants completed assessments
- Nearly all participants were categorised as moderate to severe ID
- Mild – Severe tools: PPVT, TACL-3, TSI
- Mild – Moderate: NAID, Cued Recall, Tower of London

Assessment measures completed

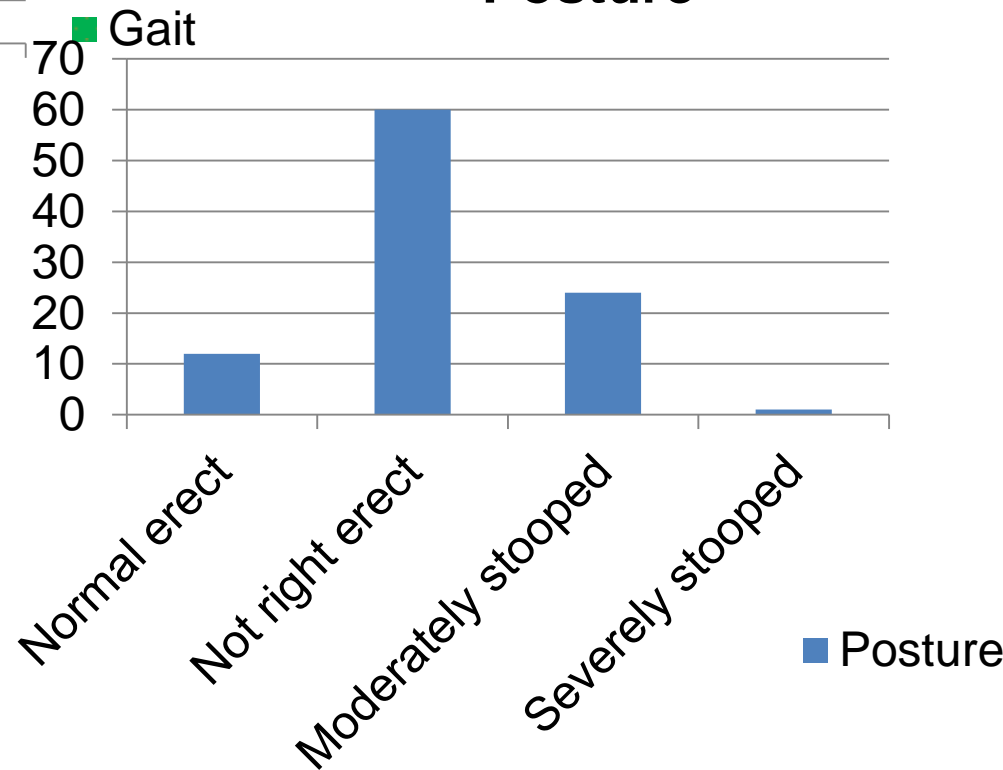
Assessment measures



Gait



Posture



Physical signs of Age related illness

What now....

- Continued recruitment for Time 1
- Time 2 recruitment (30 months) – December onwards
 - Questionnaires
 - Assessments
- Repeated Focus groups; Family carers and health professionals
 - Carer burden and stress
 - Service support and ageing ID population

Any Questions?

