

Performance-Based Outcome Measures

Gary S. Rubin, PhD

Helen Keller Professor

UCL Institute of Ophthalmology and Moorfields Eye Hospital

National Academy of Science- Institute of Medicine

15 November 2014

Examples of PBTs

- Functional Independence Measure (FIM)
- Performance test of Activities of Daily Living (PADL)
- Timed Instrumental Activities of Daily Living (TIADL, Owsley)
- Melbourne Low-Vision ADL Index (MLVAI, Haymes)
- Clinical balance tests – Romberg etc
- Driving (on the road and simulators)
- Mobility
- Face recognition
- Reading

Advantages / Disadvantages

- Theoretical advantages of PBTs
 - Good face validity
 - Better reproducibility than PROs
 - Greater sensitivity to change
 - Influenced less by poor cognitive functioning
 - Influenced less by culture, language, and education
[after Guralnik et al (1989)]
- Potential disadvantages
 - Standardization is difficult
 - Validity
 - Discrepancy with self report
 - Speed / accuracy tradeoff

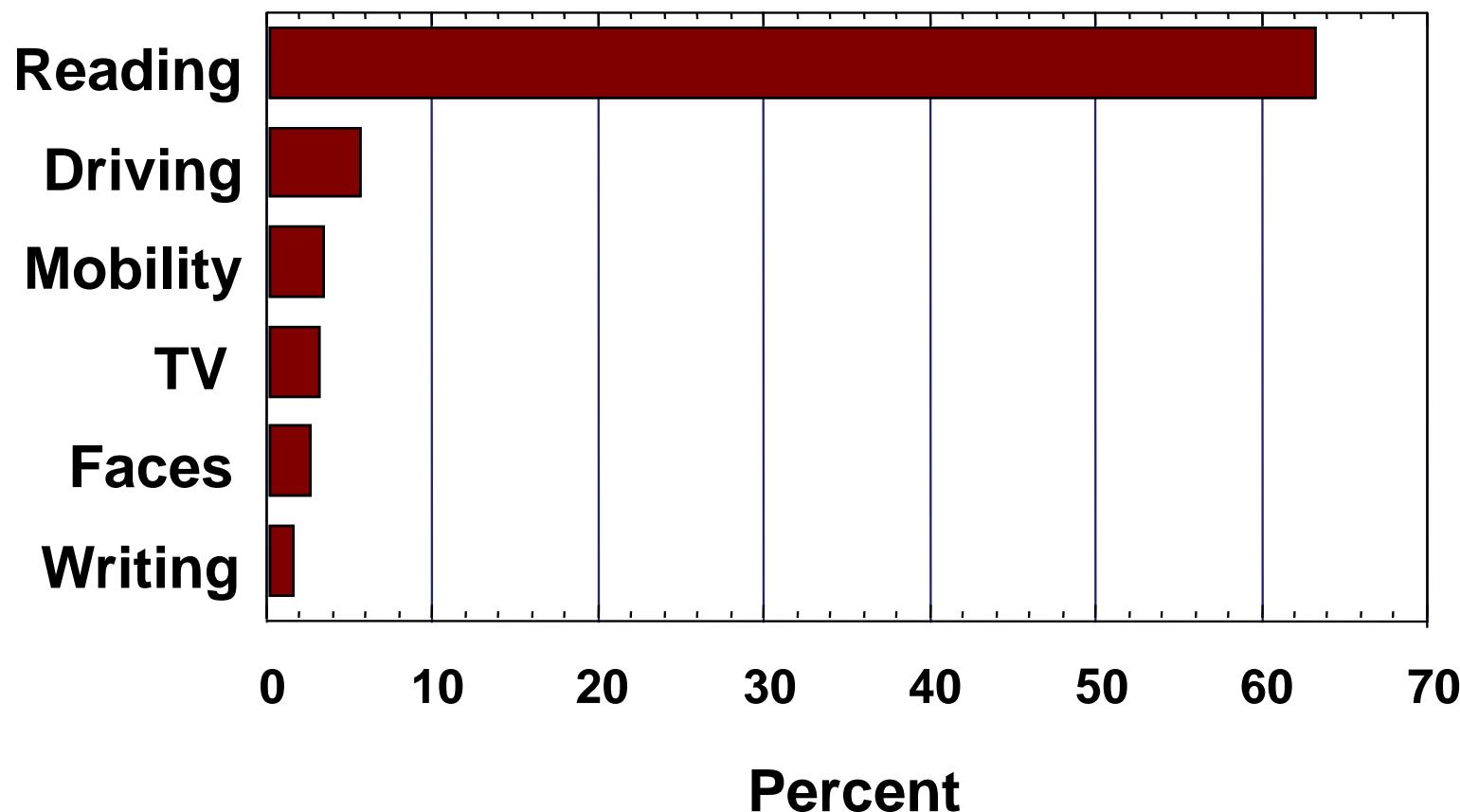
PERFORMANCE-BASED TESTS: READING

Reading Tests Widely Used in Clinical Vision Research

- Used as primary outcome measure for several studies of the effectiveness of low vision rehabilitation (see Binns, *Survey Ophth*, 2012)
- Used as a secondary outcome in clinical trials
 - Laser photocoagulation (safety)
 - Submacular surgery (safety)
 - Photodynamic therapy (efficacy)
 - Anti VEGF (efficacy)
 - Intraocular lens following cataract surgery (efficacy)

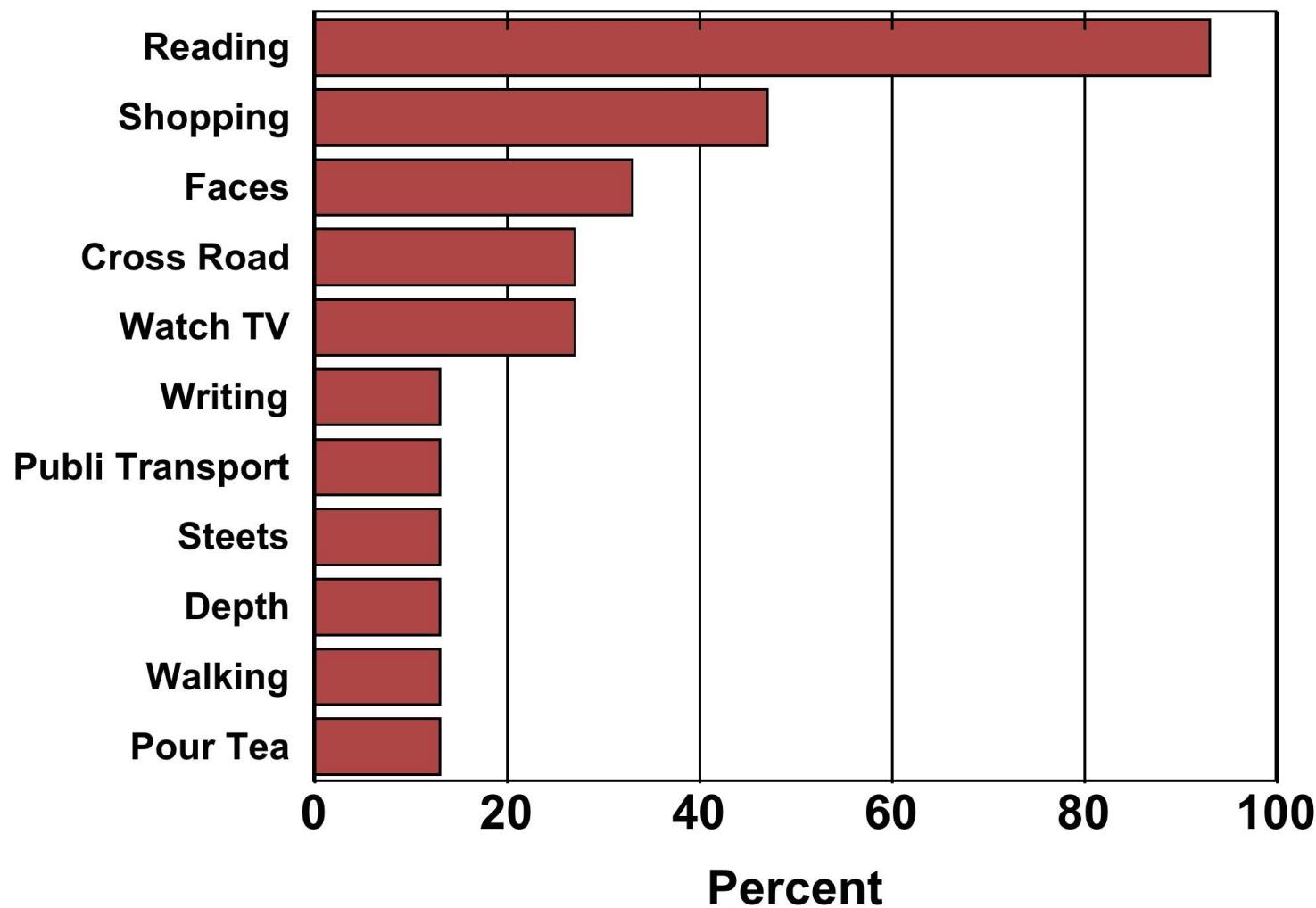
Chief Complaints of Patients Referred for LV

N = 1000; Years 1989 - 1994

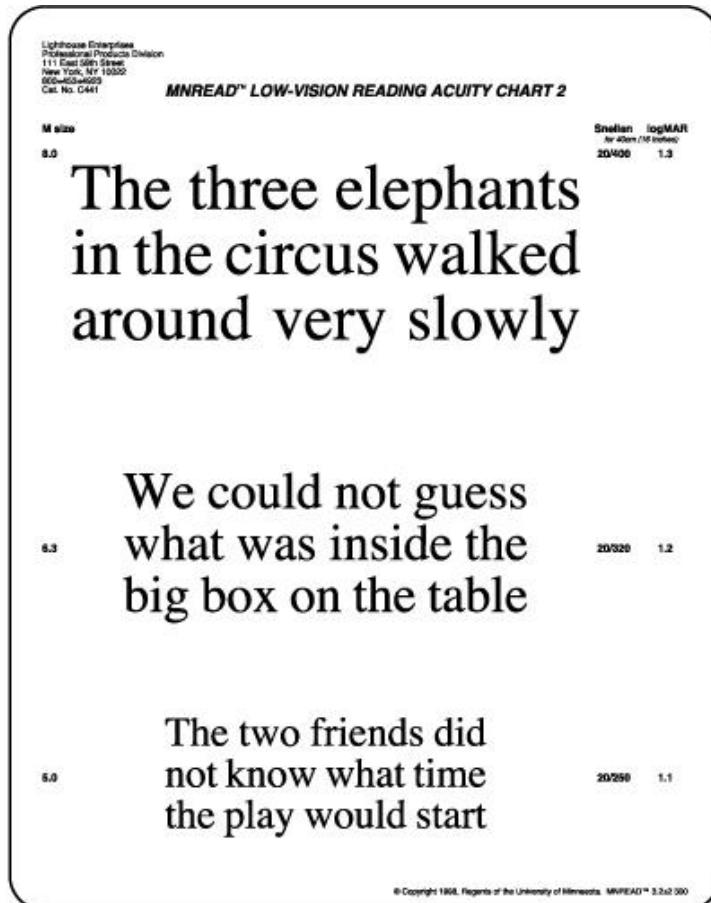


Difficulties and Expectations of LV Patients

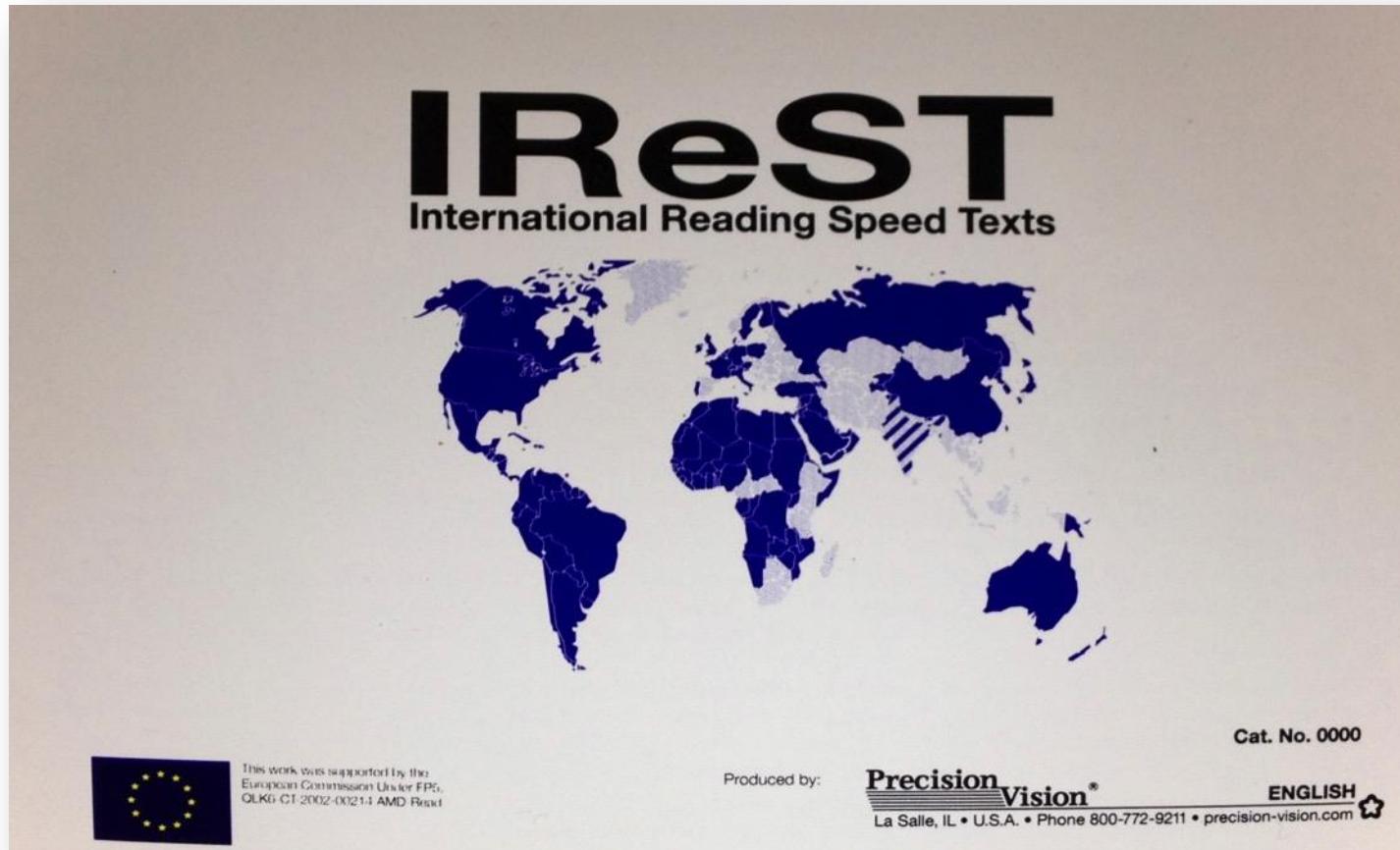
N=25; Year = 2006



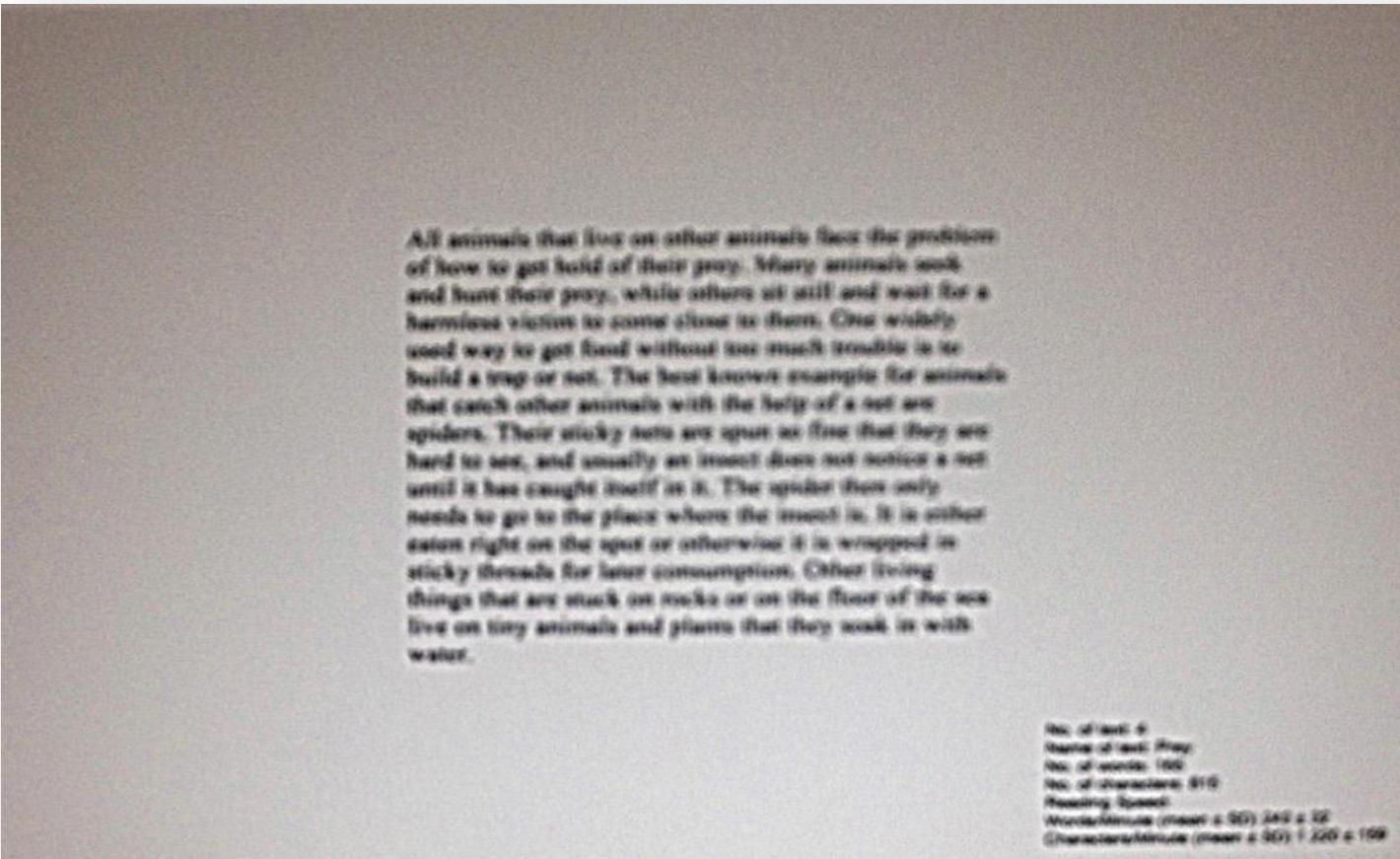
1993: MNREAD Acuity chart



2012: International Reading Speed Texts (IReST)



IReST Available in 17 Languages



All animals that live on other animals face the problem of how to get hold of their prey. Many animals stalk and hunt their prey, while others sit still and wait for a harmless victim to come close to them. One widely used way to get food without too much trouble is to build a trap or net. The best known example for animals that catch other animals with the help of a net are spiders. Their sticky nets are spun so fine that they are hard to see, and usually an insect does not notice a net until it has caught itself in it. The spider then only needs to go to the place where the insect is. It is either eaten right on the spot or otherwise it is wrapped in sticky threads for later consumption. Other living things that are stuck on rocks or on the floor of the sea live on tiny animals and plants that they eat, or with water.

No. of text: 6
Name of text: Prep
No. of words: 100
No. of characters: 810
Reading Speed:
Monosyllabic (mean \pm SD) 249 \pm 12
Character/minute (mean \pm SD) 1,220 \pm 109

DOES READING PERFORMANCE IN THE LAB TELL US ANYTHING ABOUT READING IN EVERYDAY LIFE? (VALIDITY)

Salisbury Eye Evaluation Project (SEE)

- Population-based study of the impact of eye disease and visual impairment on physical disability in the elderly
- 2520 randomly selected residents of Salisbury, Maryland, between the ages of 65-85
- Home interview
- Clinic exam and performance-based tests
- In-home functional assessment for 100 participants

Standardised Lab-based Reading Test

Each spring Adelaide penguins return to a nesting ground that has many small stones. This place is called a rookery. Here each pair of mates builds a nest of stones. The male and female alternate collecting stones because if the nest isn't guarded other penguins will steal the stones.

Our coins are produced at places called mints that are owned and operated by the national government. Coins are made from slender bars of metal called ingots that are purchased by the government from mining companies.

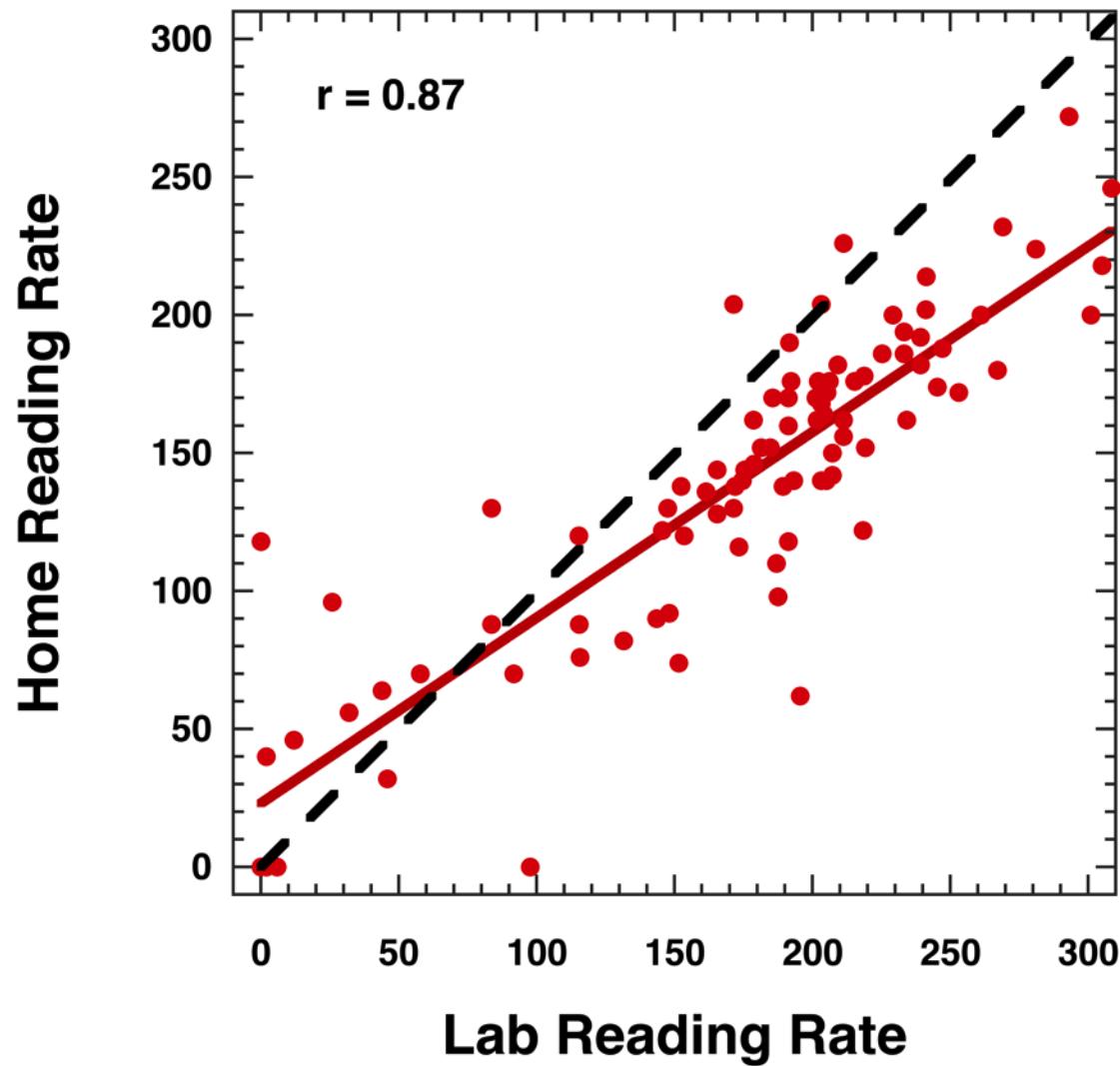
Chief Joseph slumped wearily in his saddle. The moment he had long dreaded was upon him the moment when he must give the order that might take his people forever from the land of

Annie Oakley was a champion sharpshooter. Her childhood in the woods had demanded the toughness of a pioneer.

Home Reading Test



Reading Performance in the Lab vs. Home

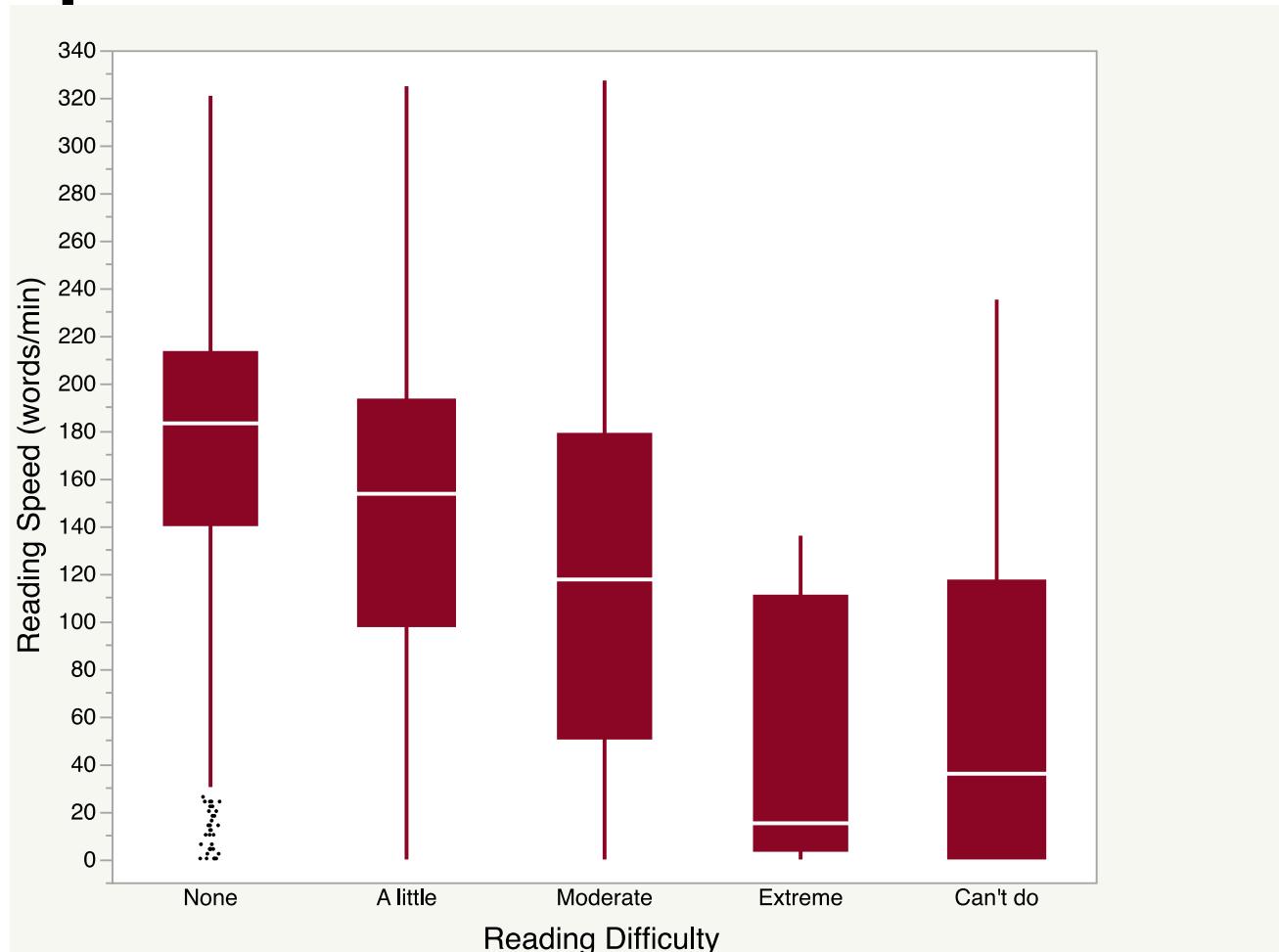


**DO WE NEED TO MEASURE
READING PERFORMANCE? CAN'T
WE JUST ASK?**

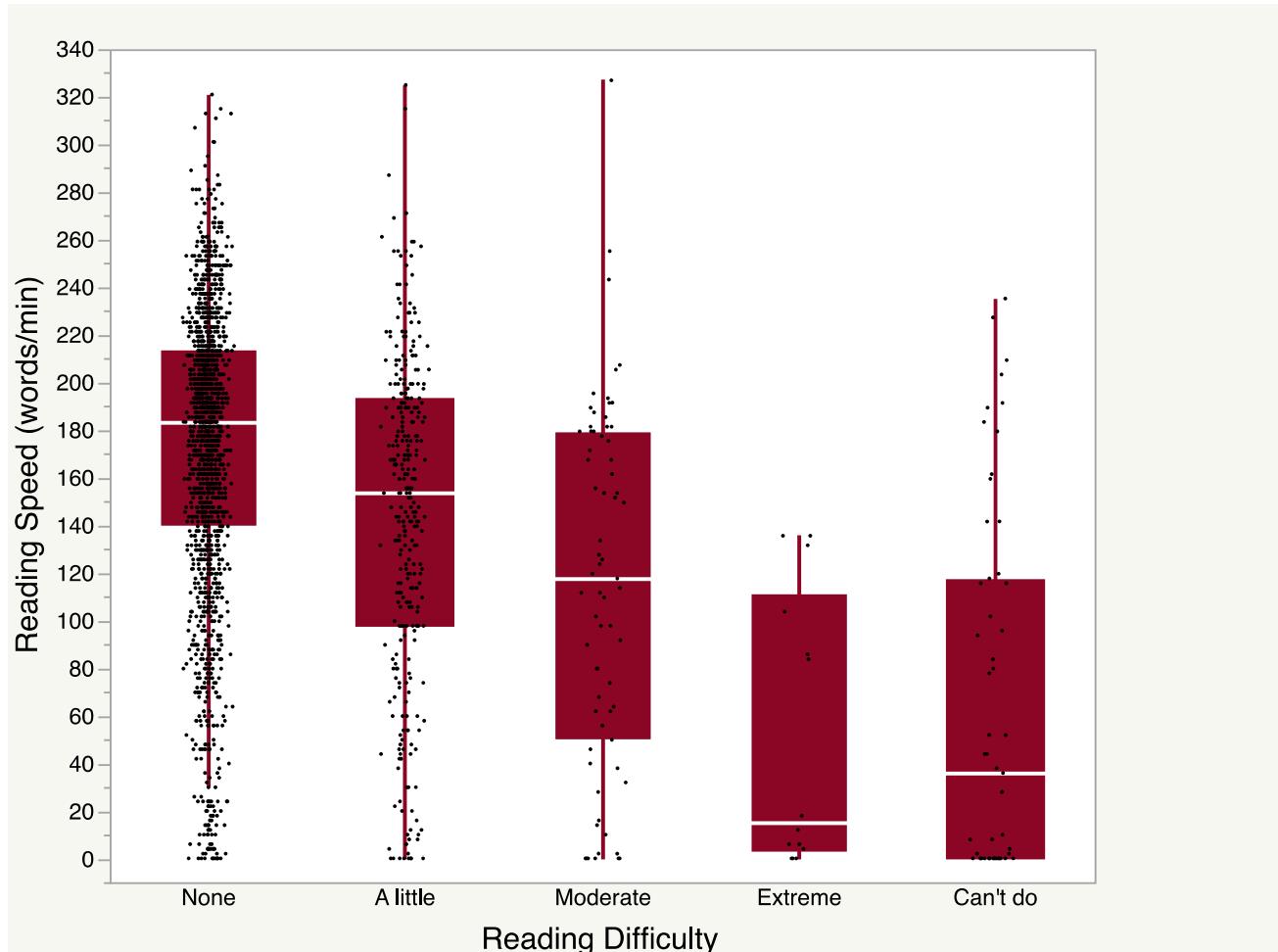
Self-Reported Reading Difficulty in SEE

- From interviewer administered Activities of Daily Vision Scale (Mangione, 1992)
- “Would you say that you read the ordinary print in newspapers with...”
 - No difficulty at all
 - A little difficulty
 - Moderate difficulty
 - Extreme difficulty
 - Unable to do (because of vision)

Measured Reading Speed is Correlated with Self Report



Substantial Discrepancy

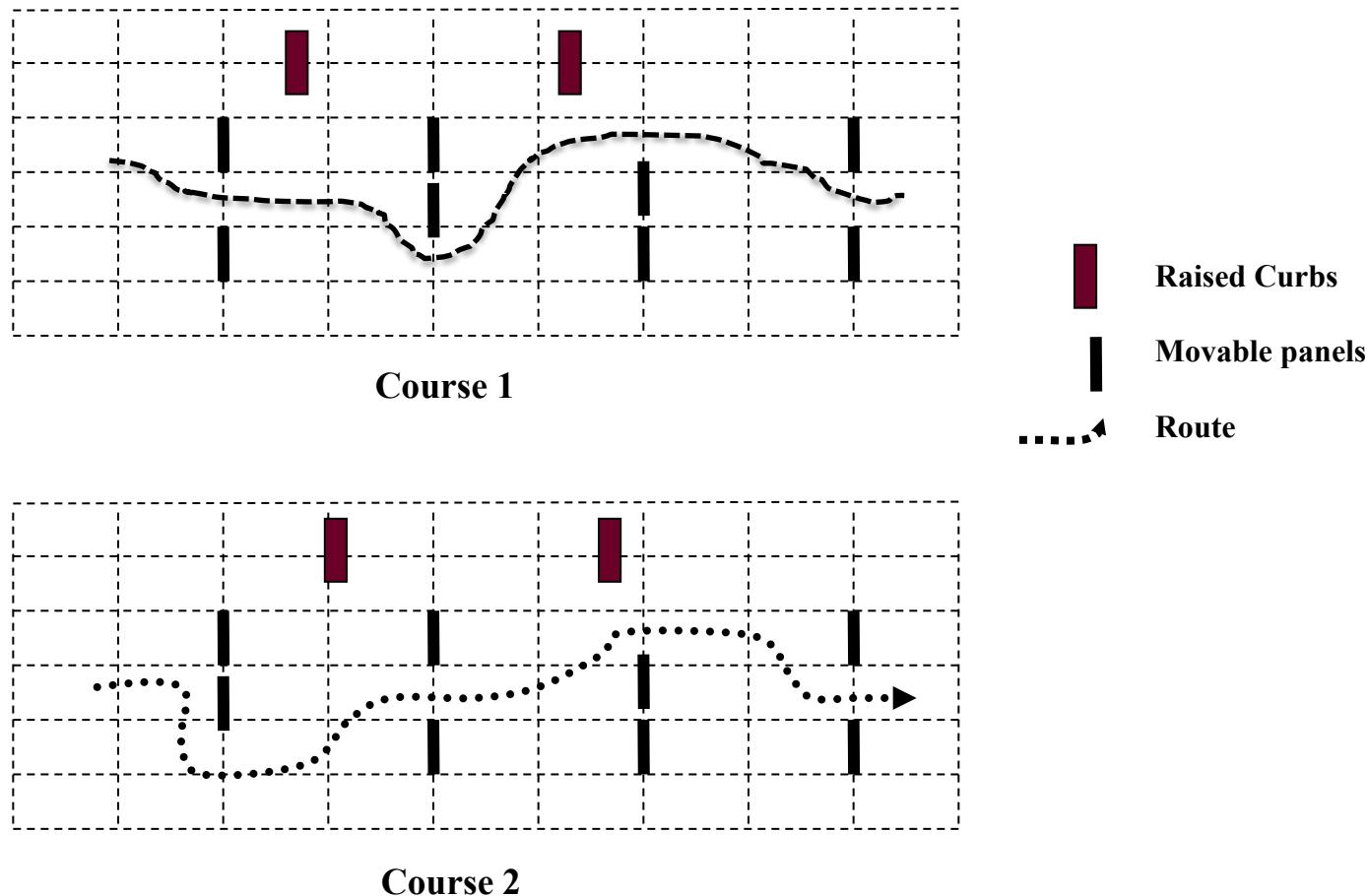


PERFORMANCE-BASED TESTS: MOBILITY

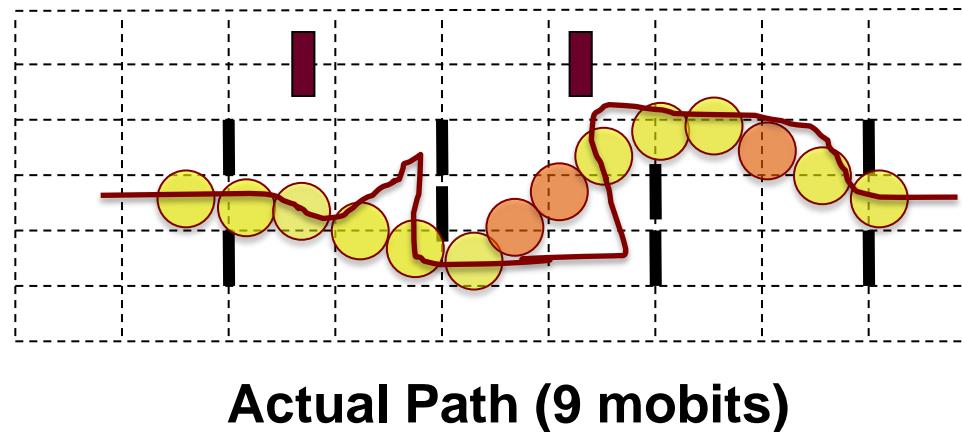
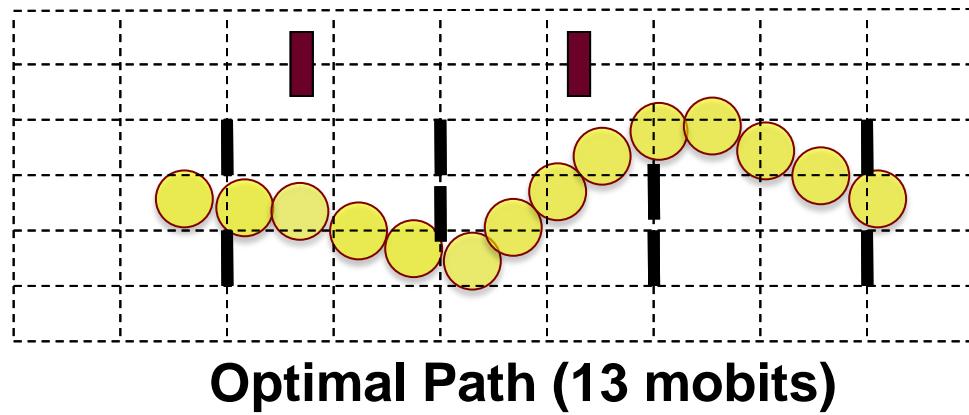
Overhead view of 33m mobility course (PAMELA)



Examples of Mazes Used for Navigation Task



Speed and Accuracy Count (mobits)



Lab Stair Navigation



Lab Stair Navigation

- Custom built flight of 7 steps at a 32° incline
- Lighting standardised
- Allowed to use customary mobility aid
- Separately timed ascent (pause) descent
- No practise trials
- Participant shadowed closely by researcher to prevent falls (none occurred)

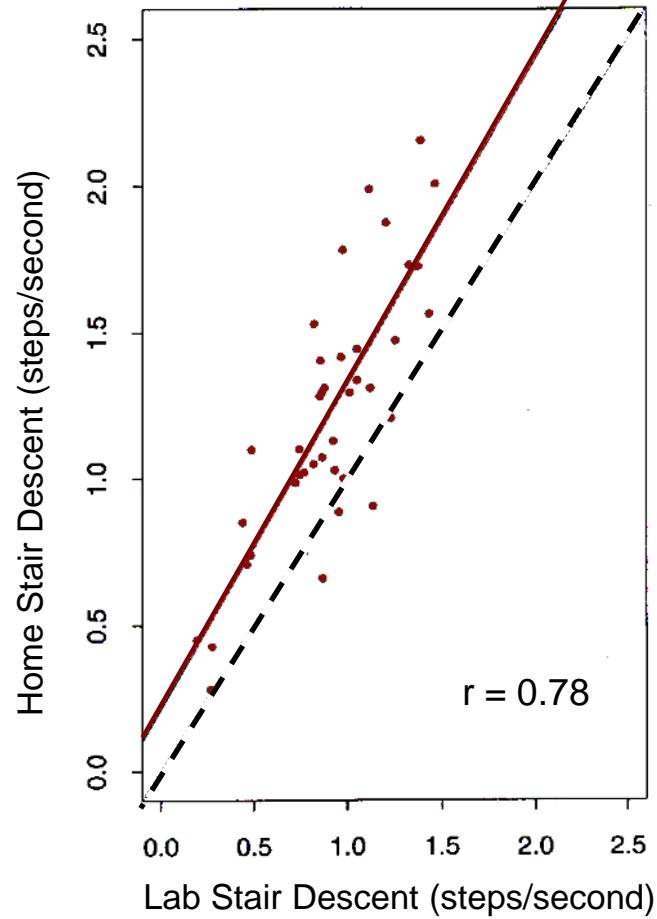
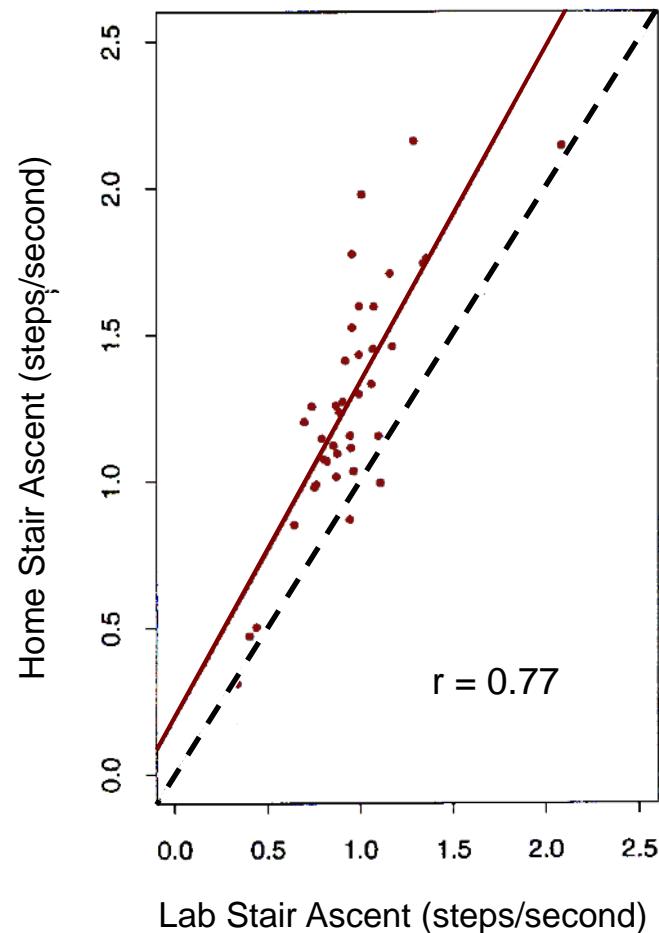
Home Stair Navigation



Home Stair Navigation

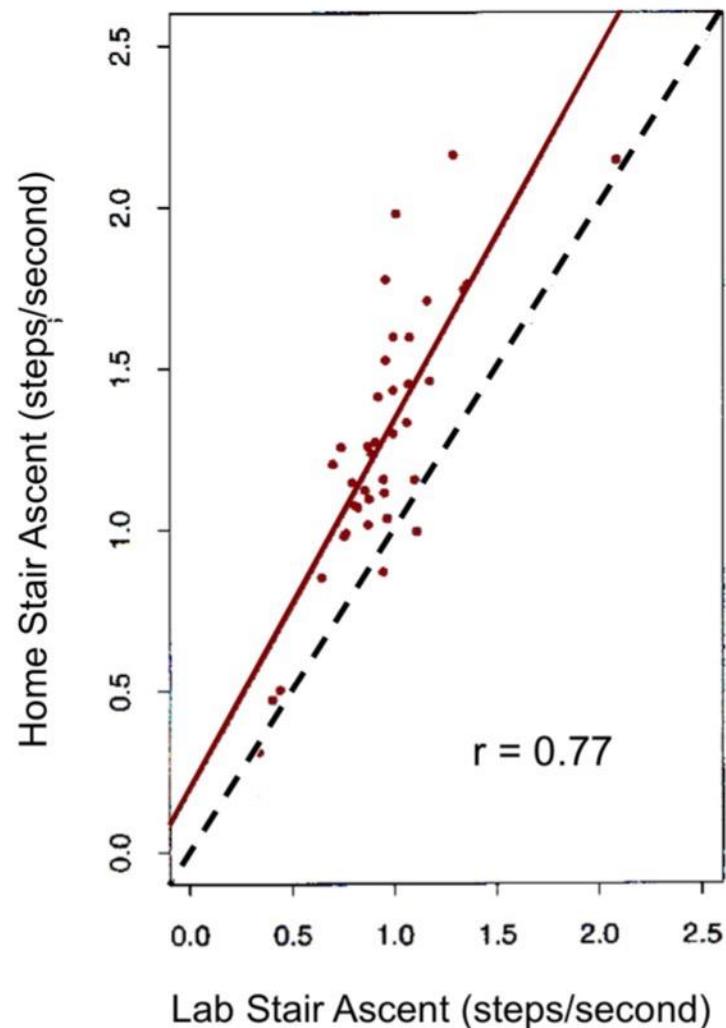
- Data collected for 41 participants who had stairs at home
- Participant ascended and descended one flight of steps to landing (if present)
- Lighting level determined by participant (and measured by experimenter)
- Stair surface and angle of incline recorded
- Participant allowed to use customary mobility aid
- No practice trial

Stair Navigation in the Lab vs. Home



Stair Navigation in the Lab vs. Home

- High correlation between speed at home and speed in clinic ($r = 0.77$)
- Consistent relationship
 - slope of regression line ≈ 1.0
- Constant offset
 - 0.25 steps/second faster at home
- Home stair surface, incline, and lighting had no systematic effect
 - But largest discrepancy where very low illumination at home (5 lux)



Summary

- High correlation between standardised lab tests and 'real world' home tests
- Results suggest that standardised performance-based tests are valid measures of everyday visual performance
- But small discrepancies
 - Those with poor vision perform better at home
 - For some tasks, those with good vision perform better in lab
 - May simply reflect regression to the mean or adaptation / compensation

Interpretation of Discrepancy Data

- 15% of those reporting little or no difficulty actually read slowly
- 20% of those reporting moderate to extreme difficulty actually read fast
- Visual acuity discriminates discrepant from concordant
- Discrepancy may reflect
 - transitional state from no disability to disability
 - use of compensatory strategies

Summary and Conclusions

- Performance-based tests play an important role in patient-centred outcomes assessment.
- Allow standardisation and quantification of visual function while retaining link to everyday life outside the clinic.
- Shown to be valid
 - Highly correlated with direct observation of real tasks
 - Differences between PBT and self-report may be informative about the role of adaption and compensation
- Comparison of PBTs to self report highlights important discrepancies which may reflect
 - Transitional state from no disability to disability
 - Use of compensatory strategies
- Illustrated the use of mobility and reading PBT; there are many others