Using Rasch Measurement Theory in the Development of a Quality of Life Instrument for Dementia Carers

Mike Horton[1], Molly Megson[1], Paul Kind[1], Jan Oyebode[2], Linda Claire[3], Hareth Al-Janabi[4], Carol Brayne[5], Alan Tennant[6], Zoe Hoare[7], Penny Wright[1]

1 = University of Leeds, 2 = University of Bradford, 3 = University of Exeter
4 = University of Birmingham, 5 = University of Cambridge, 6 = Swiss Paraplegic Research, 7 = Bangor University
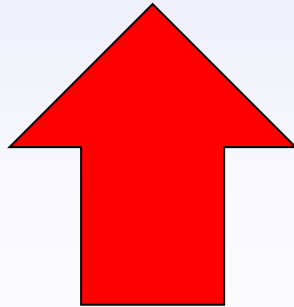
Background

- The number of people living in the United Kingdom (UK) with dementia is rising

- People with dementia, society, and health/social care agencies are reliant upon informal carers, such as friends and family, to provide care and support

- In 2015 the number of UK primary informal carers for people with dementia was estimated at more than 670,000

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Background

- **Without informal carers**, people with dementia would be dependent upon health and social care services and government costs would be increased greatly

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Background

- Having a caring role can have a large impact on:
    - **Well-being**
    - **Quality of life**
    - **Finances**

- It is therefore important that the quality of life of carers is **accurately measured** so that appropriate support can be provided at the right time

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Background

- The instruments that are currently used for this purpose have been questioned in terms of their:

  - **Focus**
  - **Length**
  - **Reliability**
  - **Sensitivity**
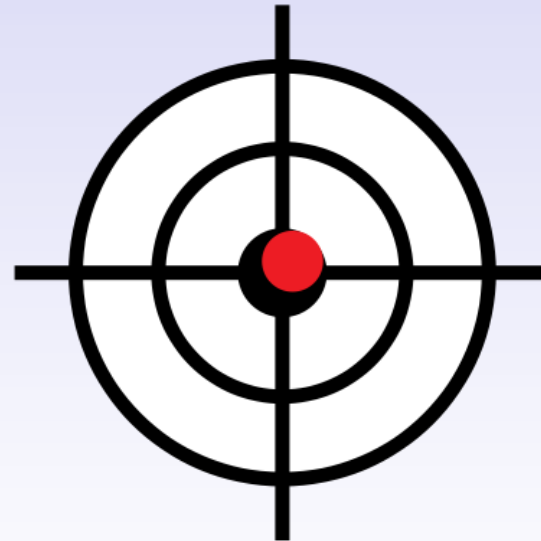
DECIDE Study Aim

To develop a new instrument to measure the quality of life of people caring for someone living with dementia

- Psychometrically sound
- Short enough to be used in research and routine supportive care practice
- Economic evaluation??

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Approach

- Needs-led model of quality of life

- Focuses on the satisfaction of individual needs in order to improve quality of life

- Conceptually unidimensional

Item development

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Item development

- Semi-structured carer interviews carried out in order to generate statements relating to their quality of life
  - 42 carers
  - Purposively diverse sample

- This resulted in an initial item set of 70 dichotomous (agree/disagree) items

Data collection

- Questionnaire contained:
  - DECIDE 70-item pool
  - EQ-5D 3L
  - Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS)
  - Socio-demographic questions

Data collection

- Completed by community-dwelling carers of someone with dementia (n=570)

    - 22 locations across England and Wales

    - Across a range of services and settings

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS
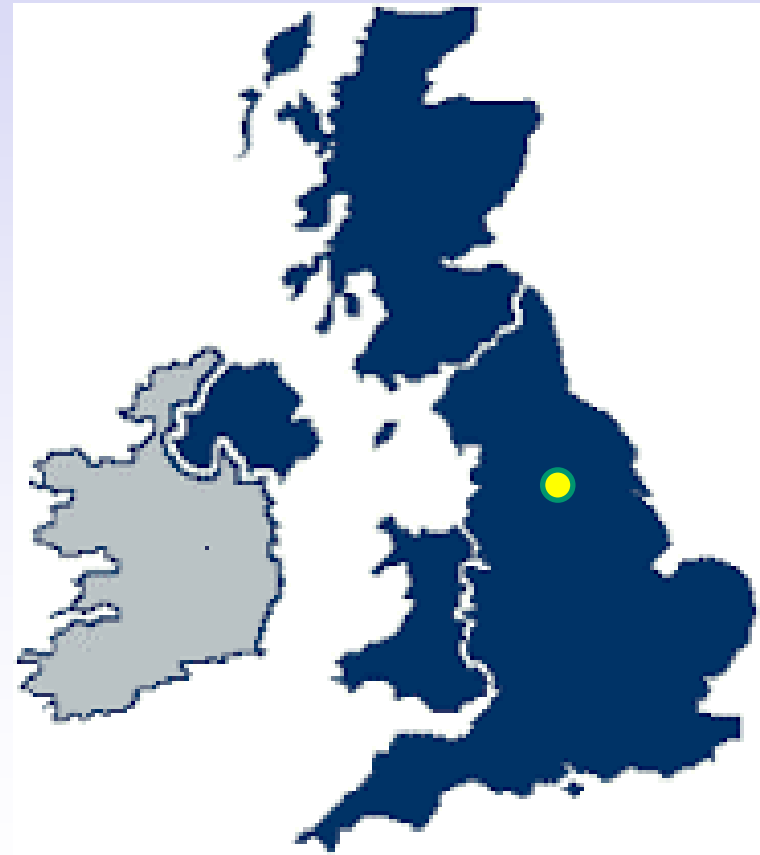
Rasch Measurement Theory

Purpose:

- **To test validity of total score**

- **To reveal anomalies in measurement structure**

Offers **unified framework** to investigate:

- Misfit Patterns
- Dependency
- Targeting
- Differential Item Functioning (DIF)

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Initial analysis

- All data was read into **RUMM2030** for item analysis, with the intention of removing anomalies and reducing the item set down to a bank of items that represent a single useable construct

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Initial analysis

- Do the 70-items form a useable unidimensional construct?

- In short…   **No**

	Item Fit Residual		Person Fit Residual		Overall Chi-Square Interaction				
Analysis	**Mean**	**SD**	**Mean**	**SD**	**Value**	**df**	**p**	**PSI**	**Alpha**
Initial 70	-0.16	2.64	-0.15	0.92	1229.8	560	<0.0001	0.92	0.92
target values	0	<1.4	0	<1.4	non-significant			>0.7	>0.7

- Unidimensionality T-test series = **29.2%**
  (Lower CI: 27.4%)

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Initial analysis

- Do the 70-items form a useable unidimensional construct?

- In short… **No**

Analysis	Item Fit Residual		Person Fit Residual		Overall Chi-Square Interaction				
	Mean	SD	Mean	SD	Value	df	p	PSI	Alpha
Initial 70	-0.16	2.64	-0.15	0.92	1229.8	560	<0.0001	0.92	0.92
target values	0	<1.4	0	<1.4	non-significant			>0.7	>0.7

- Unidimensionality T-test series = **29.2%**

    (Lower CI: 27.4%)

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

What next?

EFA

- A preliminary exploratory factor analysis (EFA) was carried out to inform on potential domain structures

- Carried out using Mplus software, under a tetrachoric correlation matrix

- This identified 4 potential factors
  - RMSEA = 0.021
  - CFI   = 0.966
  - TLI   = 0.962

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

EFA

- Separated into four domains which aligned with four understandable concepts:

1. Issues affecting the carer themselves
2. Issues affecting the person being cared for
3. Support and information
4. Emotional interaction between carer and person being cared for

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Focus on main factor

- All items loading onto the first factor were considered as candidate items to take forward into the secondary Rasch analysis

- Select all items that load at 0.3 or higher on the first factor

- Cross-loading items included

- Resulted in reduced item set of 37 items

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

First factor

- Do the 37-items form a useable unidimensional construct?

- In short… **Not really**

| Analysis | Item Fit Residual | | Person Fit Residual | | Overall Chi-Square Interaction | | | | |
	Mean	SD	Mean	SD	Value	df	p	PSI	Alpha
Initial 70	-0.40	2.13	-0.17	0.92	558.8	296	<0.0001	0.90	0.91
target values	0	<1.4	0	<1.4	non-significant			>0.7	>0.7

- Unidimensionality T-test series = **12.0%**
  (Lower CI: 10.2%)

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

First factor

- Do the 37-items form a useable unidimensional construct?

- In short…   **Not really**

Analysis	Item Fit Residual		Person Fit Residual		Overall Chi-Square Interaction				
	Mean	SD	Mean	SD	Value	df	p	PSI	Alpha
Initial 70	-0.40	2.13	-0.17	0.92	558.8	296	<0.0001	0.90	0.91
target values	0	<1.4	0	<1.4	non-significant			>0.7	>0.7

- Unidimensionality T-test series = **12.0%**
  (Lower CI: 10.2%)

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Range of issues to address, but…

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Rasch analysis item-fit criteria

- Individual item misfit anomalies

  - Non-significant at Bonferroni-adjusted chi-square p-value Standardised Fit-Residuals within ±2.5

- Response dependency

  - Q3 criterion cut point = 0.2 above average residual correlation

- DIF assessment by

  - Age

  - Gender

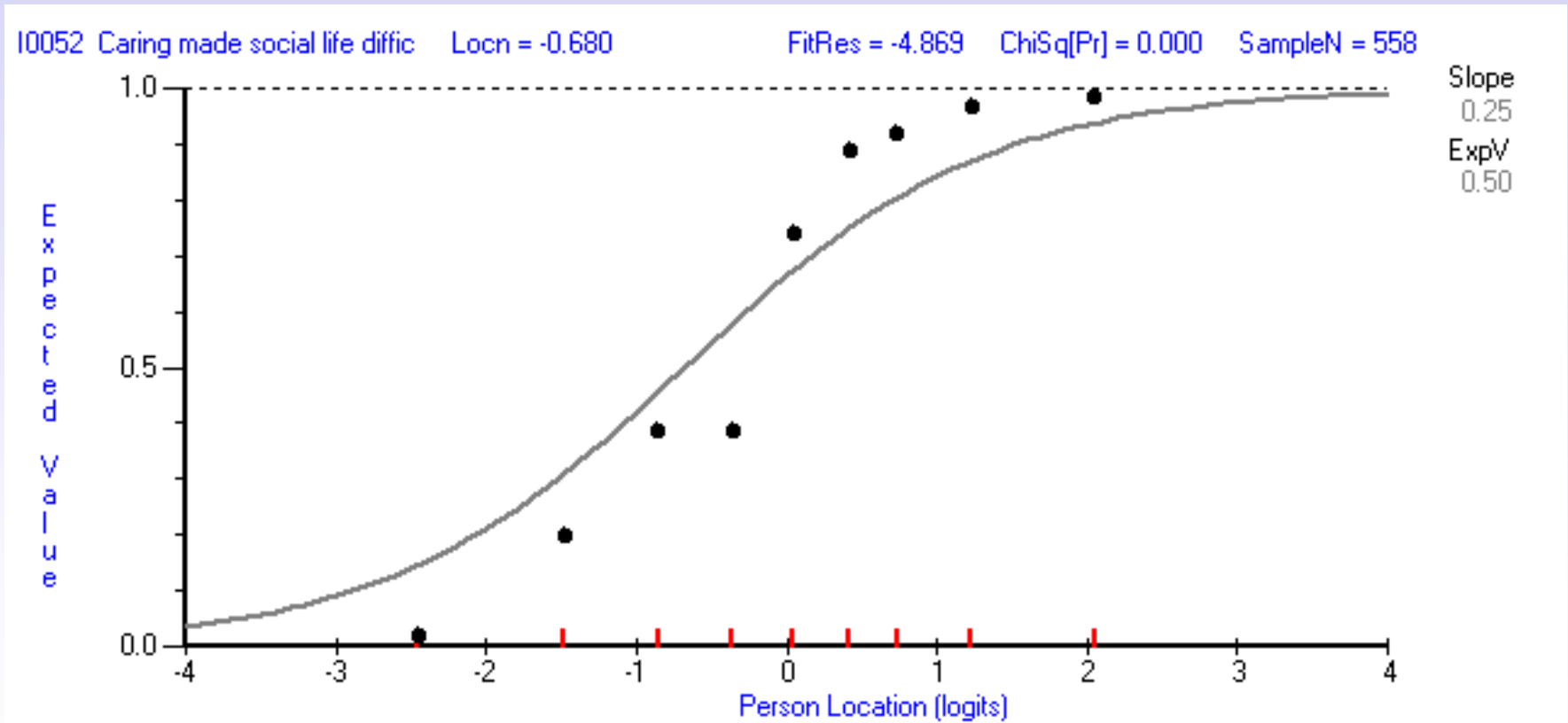 - Carer relationship to person being cared for (spouse/non-spouse)

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Individual Item Issues

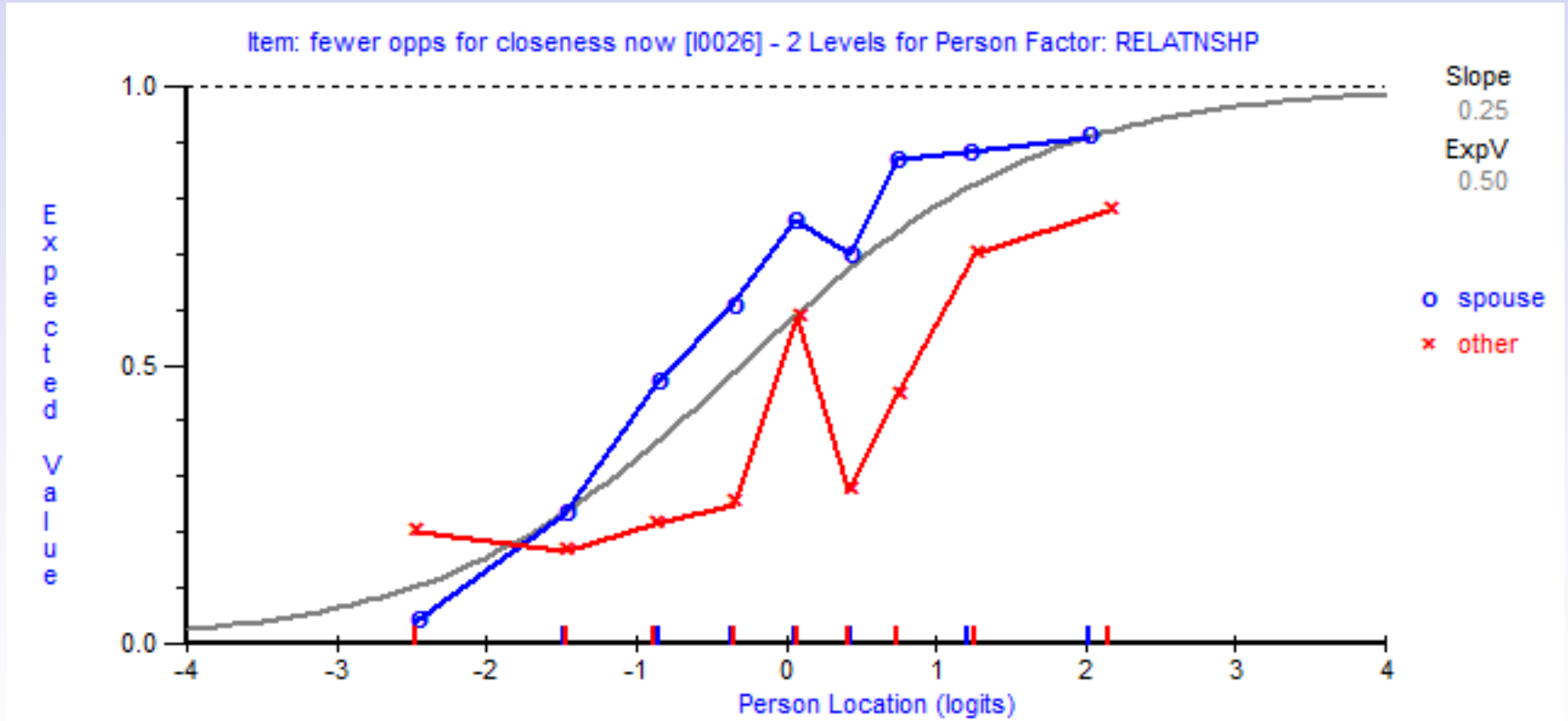- Under-discrimination
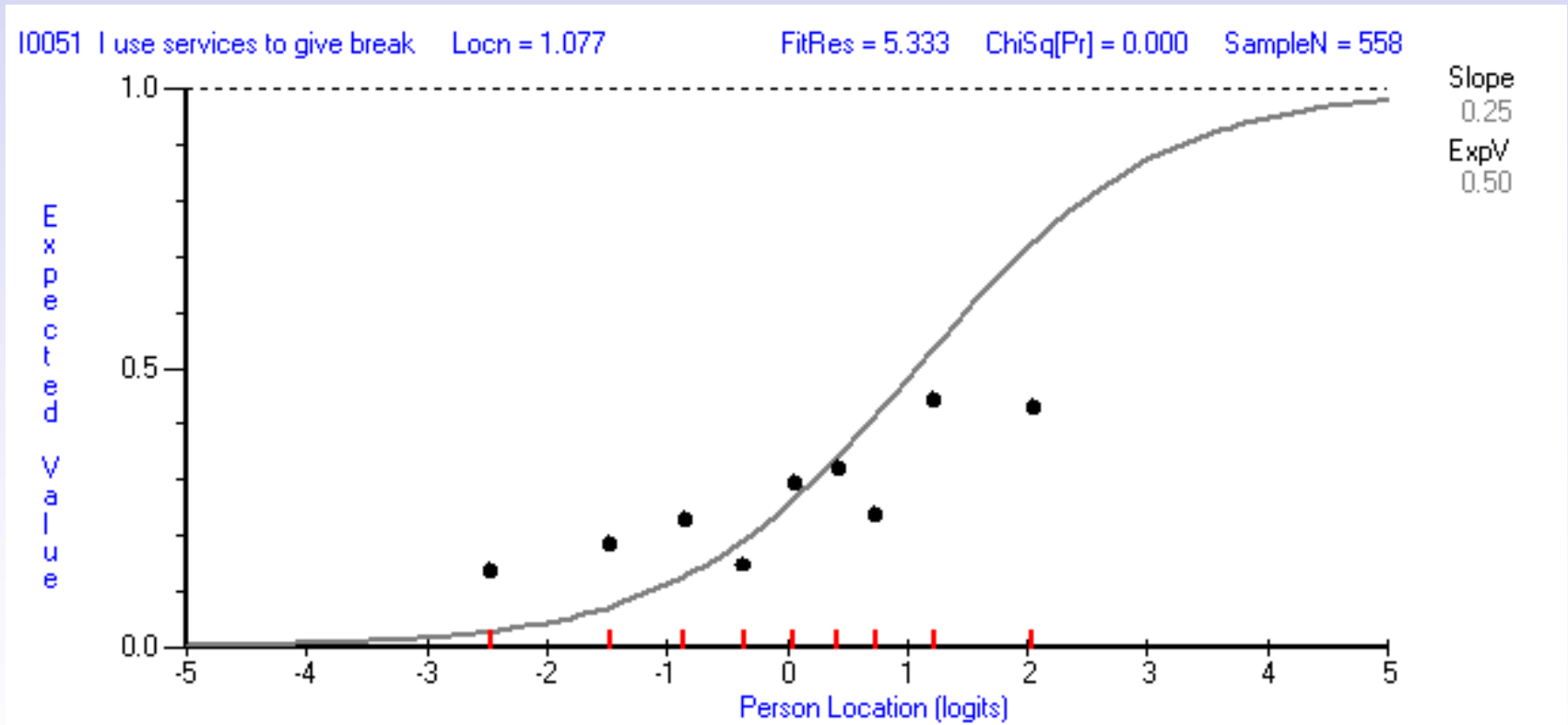
Individual Item Issues

- Over-discrimination

Individual Item Issues

- DIF (by carer relationship)

Individual Item Issues

- Response Dependency

- Example of pairwise item dependency:

"I have to overcome a lot 'red tape' when sorting things out for the person I care for"

"I spend a lot of time trying to sort out services"

"I ignore my own health needs"

"I don't take very good care of myself"

Items iteratively removed (n=19)

n items removed	Reason for Removal			
	Misfit	Dependency	DIF	Practical Reasons
5	🟥			
5		🟥		
3			🟥	
1	🟥	🟥		
4	🟥		🟥	
1				🟥

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Final Item Set

- Does the final (18) item set form a useable unidimensional construct?

- In short…   **Yes!**

Analysis	Item Fit Residual		Person Fit Residual		Overall Chi-Square Interaction				
	Mean	SD	Mean	SD	Value	df	p	PSI	Alpha
Final 18	**-0.32**	**1.13**	**-0.20**	**0.72**	**184.1**	**162**	**0.113**	**0.81**	**0.83**
target values	0	<1.4	0	<1.4	non-significant			>0.7	>0.7

- Unidimensionality T-test series = **4.0%**

    (Lower CI: 2.2%)

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Final Item Set
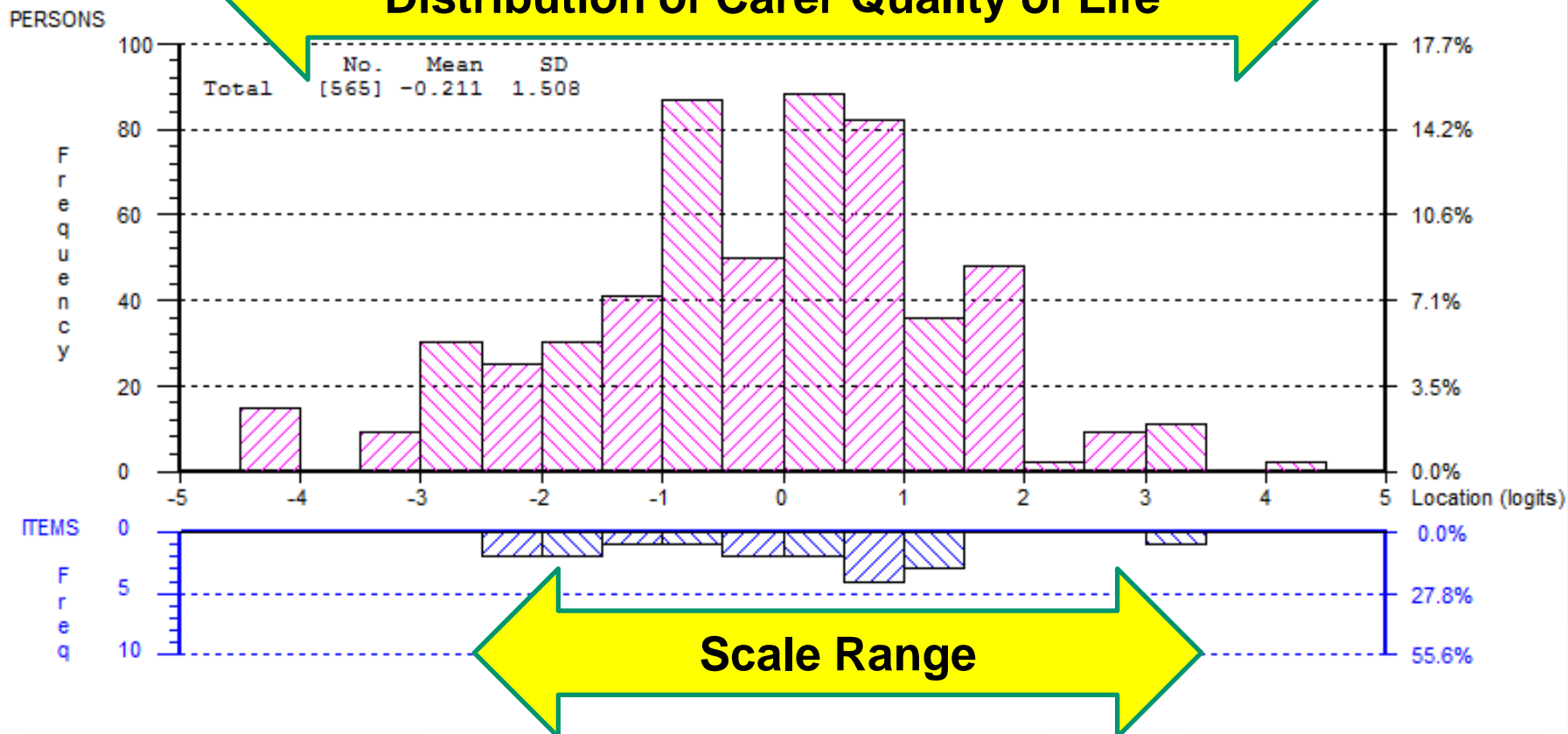
- Does the final (18) item set form a useable unidimensional construct?

- In short…   **Yes!**

| Analysis | Item Fit Residual | | Person Fit Residual | | Overall Chi-Square Interaction | | | | |
	Mean	SD	Mean	SD	Value	df	p	PSI	Alpha
Final 18	-0.32	1.13	-0.20	0.72	184.1	162	0.113	0.81	0.83
target values	0	<1.4	0	<1.4	non-significant			>0.7	>0.7

- Unidimensionality T-test series = **4.0%**
  (Lower CI: 2.2%)

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Targeting

Distribution of Carer Quality of Life

PERSONS

Total [565] No. Mean SD
-0.211 1.508

Scale Range

Floor:
N= 16/565 = 2.83%

Spearman Correlations:
SWEMWBS = -0.58
EQ-5D VAS = -0.36

Ceiling:
N= 2/565 = 0.35%

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Additionally…

- Each of the items that had been removed was individually added back into the final item set, in order to test for whether the source of misfit (and reason for removal) remained

- The original source of misfit remained for all of the 19 removed items

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Final Item Set

Scale Properties:

- **Derived directly from carers** ✓
- **Valid** ✓
- **Reliable** ✓
- **Unidimensional** ✓
- **Free from DIF** ✓
- **Free from local dependency** ✓
- **Well-targeted to population** ✓
- **Raw-score is sufficient statistic** ✓
- **Interval transformation** ✓

Issues

- Question direction

- Confounded factors?

- Practical issues Vs psychometric value

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Still to do…

- Test-retest reliability

- Sensitivity to change

- Evaluation of economic utility (DECIDE Workstream 2)

- Assessment of further (remaining 3) domains

Conclusion

Aim: To develop a new instrument to measure the quality of life of people caring for someone living with dementia

- Psychometrically sound
- Short enough to be used in research and routine supportive care practice
- Economic evaluation??

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Conclusion

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Information

- This work was supported by the Medical Research Council (MRC) and the National Institute for Health Research (NIHR).

- Grant title: HQLC Dementia Carers Instrument Development: DECIDE (MR/M025179/1).

- Chief Investigator: Dr Penny Wright

- Contact: m.c.horton@leeds.ac.uk

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS

Shameless Plug

- Dates for Leeds Rasch Courses (using RUMM2030)

  - **May 2018**: Introductory
  - **September 2018**: Introductory

    Intermediate

    Advanced (led by Prof. Svend Kreiner and Dr Karl Bang Christensen)

  - **November 2018**: Introductory

- Google 'psylab leeds'

- Contact: m.c.horton@leeds.ac.uk

DECIDE
Dementia Carers Instrument Development

UNIVERSITY OF LEEDS