

The Participation Scale

Measuring a key concept in public health

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Participation

- **Participation** is involvement in a life situation
 - e.g. marriage, being employed, taking part in religious ceremonies and social events
- **Participation restrictions** are problems an individual may experience in involvement in life situations

International Classification of Functioning, Disability and Health (WHO, 2001)



Participation domains in ICF (WHO, 2001)

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life



Aim of the research project

To develop an interview-based scale to measure (social) participation restrictions



Phases of scale development

- Phase 1
 - Item collection
 - Development of draft questionnaire
 - Pilot testing
- Phase 2
 - Item reduction
- Phase 3
 - Psychometric testing of draft scale
- Phase 4
 - Development of (training) manual
 - Beta-testing.



Example question

Do you have the same respect in the community as your **peers**?

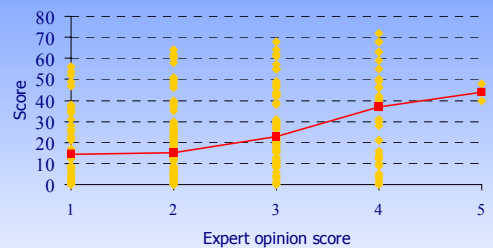
- Yes
- Sometimes (not always)
- No
- Next question . . .
- How big a problem is that for you?
 - No problem
 - Small problem
 - Medium problem
 - Large problem



P-scale interviews Phase 2

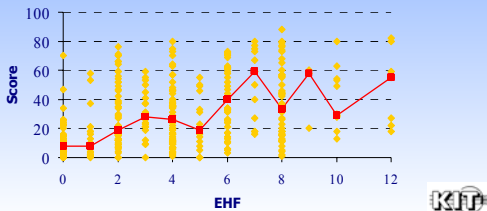
| Country | Total | Leprosy | Disability | Control | Expert |
|----------|-------|---------|------------|---------|--------|
| Nepal | 65 | 48 | 10 | 7 | 50 |
| Brazil | 150 | 73 | 54 | 23 | 150 |
| Naini | 90 | 60 | 20 | 10 | 34 |
| Calcutta | 92 | 82 | | 10 | 51 |
| Salur | 100 | 80 | 11 | 9 | 40 |
| TN | 194 | 141 | 42 | 11 | 59 |
| Total | 691 | 484 | 137 | 70 | 384 |

Expert assessment

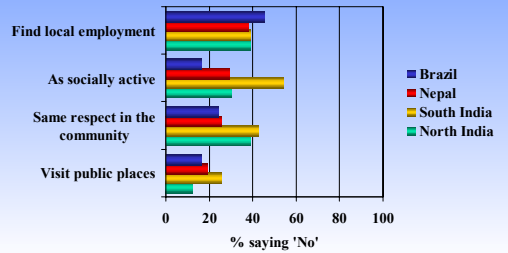


Impairment status

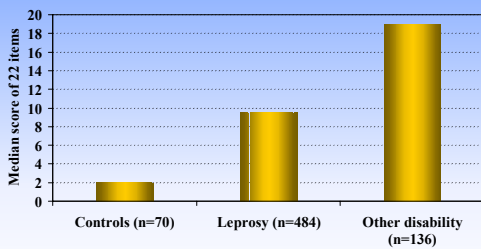
- Used EHF as a measure of impairment
- Association is significant $p < 0.001$



A few sample results



Median participation scores



Phase 3 psychometric testing

- Validity against expert score
- Inter-interviewer reliability
- Stability
- Discrimination between clients and controls
- Responsiveness to change.

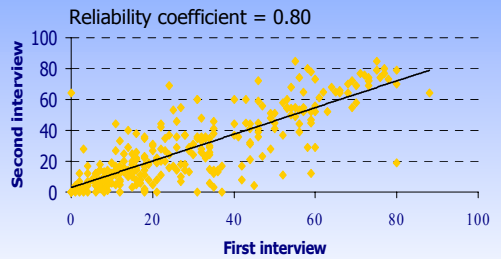


P-scale interviews Phase 3

| Country | Total | Leprosy | Disability | Control | Expert |
|----------|-------|---------|------------|---------|--------|
| Nepal | 110 | 83 | 15 | 12 | 51 |
| Brazil | 140 | 83 | 23 | 34 | |
| Naini | 227 | 159 | 42 | 26 | 35 |
| Calcutta | 176 | 130 | 16 | 30 | 53 |
| Salur | 188 | 76 | 49 | 63 | 29 |
| TN | 338 | 193 | 95 | 50 | 23 |
| Total | 1179 | 724 | 240 | 215 | 229 |



Reliability

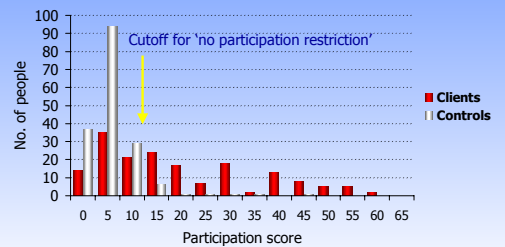


Phase 3: main results

- 18-item scale (in 7 major languages)
- Median duration < 20 minutes
- 'Vital' statistics
 - Scale use: 100%
 - Cronbach's alpha 0.92
 - Factor analysis: first factor 80+%
 - Reliability coefficient (ICC): 0.80
 - Stability coefficient (ICC): 0.83



Discrimination



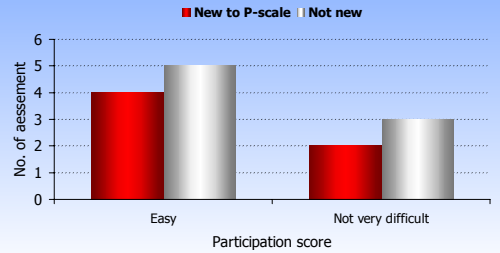
Participation Scale layout

Participation Scale

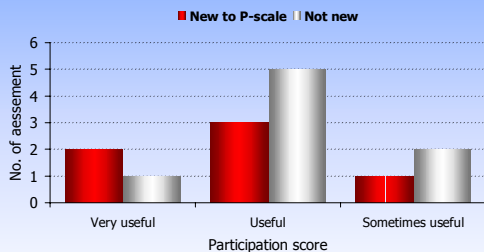
Name:
 Age: Gender:
 Diagnosis/medical issue:
 Occupation:

| | Not assessed by you | Not assessed by others | How easy is it for you to take part in P-scale with problems | | | | None | Medium | Large | BIGGER |
|---|---------------------------|------------------------------|--|---|---|---|------|--------|-------|--------|
| | | | 1 | 2 | 3 | 4 | | | | |
| 1 Do you have equal opportunity as your peers to find work? <i>(If Sensitive, No or Inadequate: How big a problem is it to you?)</i> | 0 | | | 1 | 2 | 3 | 4 | | | |
| 2 Do you work as hard as your peers do? <i>(Learned from, sign of work, etc.)</i> | 0 | | | 1 | 2 | 3 | 4 | | | |
| 3 Do you contribute to the household economically in a similar way to your peers? <i>(If Sensitive, No or Inadequate: How big a problem is it to you?)</i> | 0 | | | 1 | 2 | 3 | 4 | | | |
| 4 Do you make extra travel outside your village as much as your peers do? <i>(Travel for treatment, e.g. to school, visits, family village)</i> | 0 | | | 1 | 2 | 3 | 4 | | | |
| 5 Do you make extra travel outside your village as much as your peers do? <i>(If Sensitive, No or Inadequate: How big a problem is it to you?)</i> | | | | 1 | 2 | 3 | 4 | | | |

Overall ease of using the P-scale



Overall utility of the P-scale



Uses of a participation scale

- Needs assessment
- Monitoring
- Evaluation
- Research
- Advocacy
- Risk assessment (disease control)



Conclusions

the Participation Scale is

- a valid and reliable generic instrument to measure client-perceived participation
- a measure for comparison between clients, interventions and programmes
- for use in institutions and at the peripheral level
- suitable to collect information for programme planning and advocacy work.



Acknowledgements

- Clients and interviewees
- Participation Scale Development Team
- Participation Scale Advisory Group
- The Leprosy Mission International
- American Leprosy Missions
- GLRA
- Beta-testing centres



Comments on the Manual

| | Count |
|---|-------|
| No | 5 |
| Okay | 2 |
| Clear | 1 |
| Good enough | 1 |
| Sufficient and good | 1 |
| Systematic and useful | 1 |
| Excellent | 1 |
| Examples should also be on the form? | 1 |
| If possible, language may be simplified | 1 |
| Grand Total | 14 |

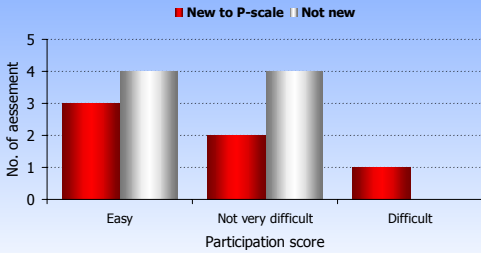


Type of programme where the P-scale was beta-tested

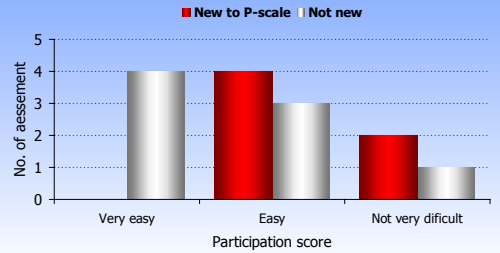
| | Count |
|---|-------|
| CBR | 6 |
| Hospital inpatients | 6 |
| Hospital-based rehabilitation programme | 5 |
| Occupational therapy department | 3 |
| Physiotherapy department | 2 |
| Social work department | 2 |
| Other | 4 |
| Grand Total | 28 |



Ease of using the response scales



Ease of calculating the sum score



Ease of asking the questions

