



# Measuring outcomes of long-term care

Ann Netten

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# Need for a measure of outcome

- Help identify best use of resources
- Health quality adjusted life year (QALY)
  - Comparison across health interventions
  - Cost per QALY threshold
- Does not reflect impact of long term care
- Need measures that
  - Have strengths of health QALY
  - Reflect impact of long term care

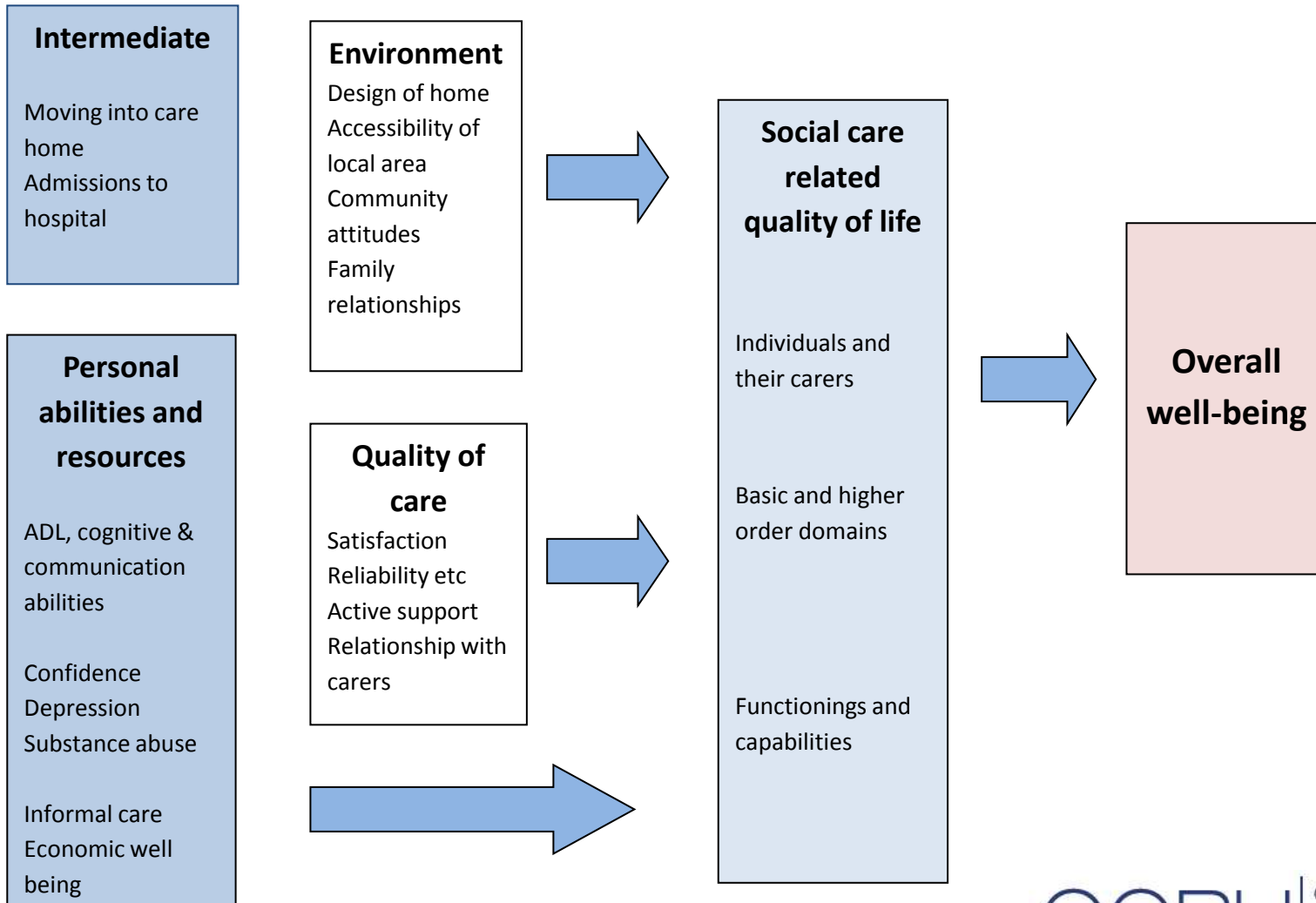
# What is long-term care?

- For people with long-term conditions
  - ....often deteriorating over time
  - ....often multiple
  - ....which result in impairment in activities of daily living
- Most provision by informal carers
- Services:
  - Substitute for what individual would have done
    - home care/personal assistance, care homes/assisted living etc
  - Improve individual's productivity
    - assistive technology
  - Prevent avoidable deterioration/ health problems
    - Through meeting needs (e.g. reducing isolation)

# Health and social care

- Health
  - Treatment and mitigation of impairment
  - Health related quality of life (HRQoL)
    - *Ability* to undertake activities, pain etc
  - Prevention
- Social care
  - Compensation for impairment
  - Social care related quality of life (SCRQoL)
    - Personally clean, fed, socially engaged etc
  - Prevention
- LTC primarily *social* care

# 'Types' of social care outcome



# Social care related quality of life (SCRQoL)

- Personal cleanliness and comfort
- Food and drink
- Safety
- Clean and comfortable accommodation
- Social participation and involvement
- Control over daily living
- Occupation
- Dignity

# What does social care do?

- Ensures needs are met
  - Very basic aspects of peoples lives – fed and washed
- Latterly policy emphasis on..
  - Personalisation
  - Giving people control
- Need to reflect relevant aspects of quality of life
- Also objectives within these aspects:
  - Functionings: states of being e.g. clean, well-fed, safe
  - Capabilities: the *freedom to be able* to do something that is valued

# Response options

- Needs as functioning i.e. don't do (enough) X
  - Some needs (no health implications)
  - High needs (health implications)
    - For some domains ultimately 'being dead'
- Absence of need as capabilities i.e. able to do X
  - No needs (musn't grumble, not as much as want)
  - Preferred situation (aspirations, as much as want)



# Occupation

## Which of the following statements best describes how you spend your time?

- I'm able to spend my time as I want, doing things I value or enjoy
- I'm able to do enough of the things I value or enjoy with my time
- I do some of the things I value or enjoy with my time but not enough
- I don't do anything I value or enjoy with my time

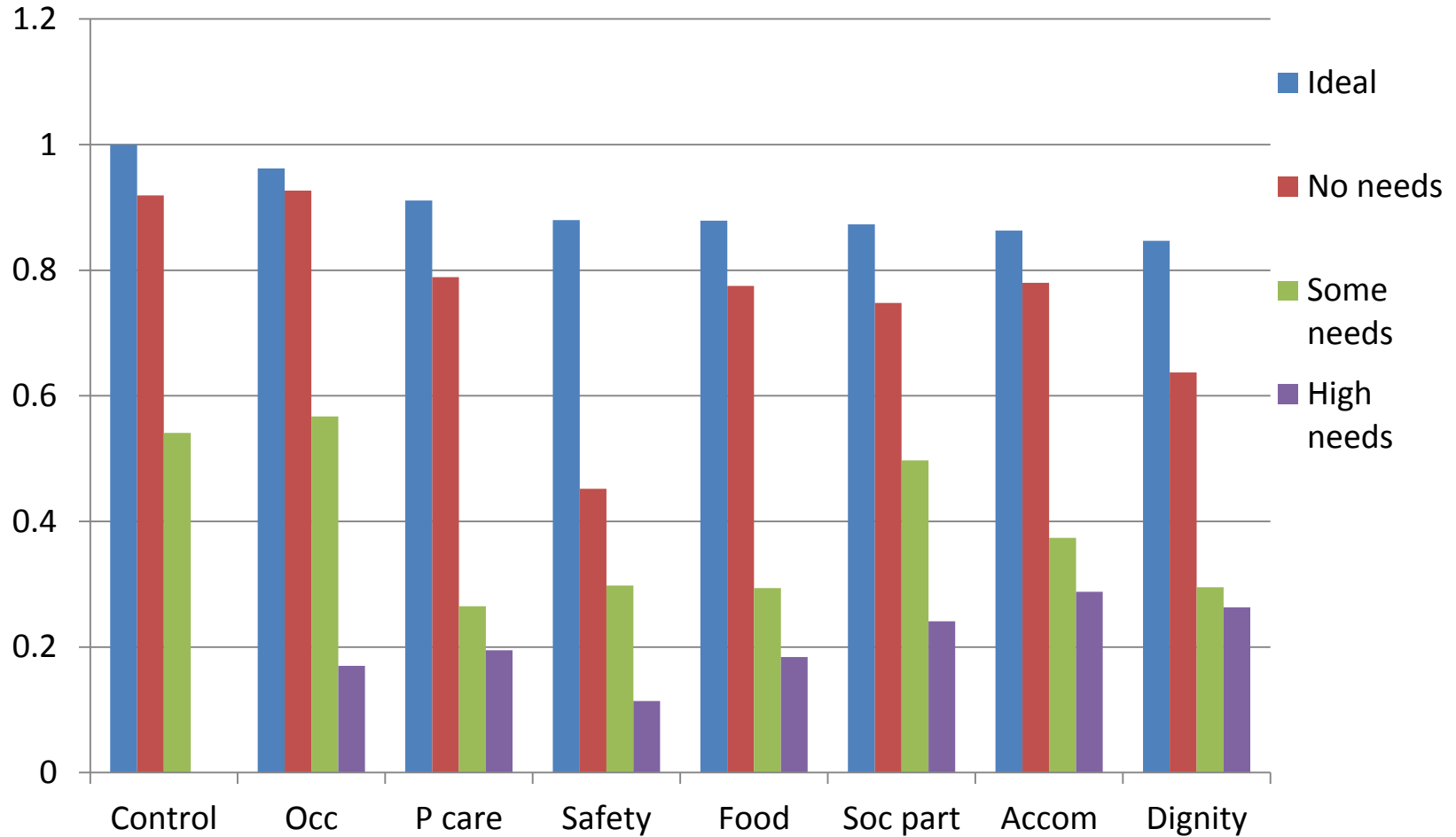
# Construct validity

- Tested with older users of home care services
  - QoL item, GHQ12, CASP-12 control & autonomy
- Overall quality of life and well-being
  - Associated with better SCRQoL
- All domains
  - Significantly better control in 'ideal' level
- Control over daily life
  - Significantly better control scores at each level

# Preferences

- Methods
  - Best-worst scaling
  - Time trade-off to anchor scale to 'being dead'
- Fieldwork
  - General population (two studies of 500)
  - Service users (one study – 460)
- Stable and consistent findings
- Service user preferences the same as general population
- Further validation of items

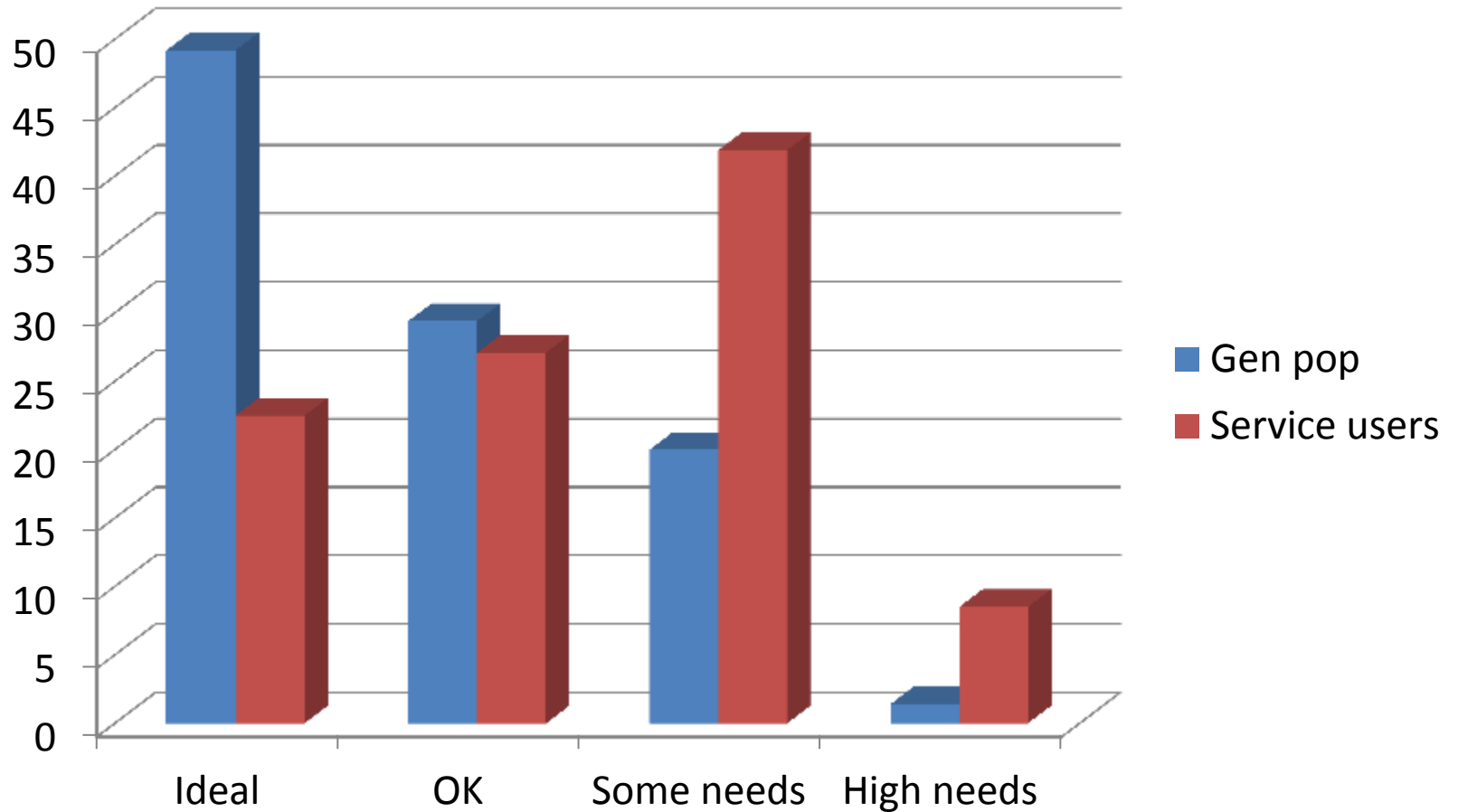
# General population preferences



# ASCOT index

- 0 = 'being dead'; 1 = 'ideal' SCRQoL
- Range = -0.17-1.00
- General population
  - Mean=0.86
- Equipment service users
  - Mean=0.73

# Occupation



# Care homes

- Multi-method approach
  - Semi-structured interviews – residents/staff
  - Observation
  - Rating scale
  - Training
- Care homes for older adults
  - Weak association with star ratings
    - driven by residential homes
  - Nursing homes poorer SCRQOL outcomes

# What does ASCOT contribute?

- Valid descriptive system of SCRQoL
  - Evidence that we are picking up 'capabilities'
- Robust & anchored utility index
  - An important step towards QALY in long-term care
- Supporting policy focus on outcomes
  - Annual adult social care survey since 2011
  - English Adult Social Care Outcomes Framework
- Creating the right incentives



# Challenges

- Carer outcomes
  - ..and how they link with the outcomes of those they care for
- Linking with health care outcomes
  - Pain, anxiety, ADL changes
- More methods for people 'hard to include'
  - E.g. people with dementia living in own home
- Use for performance monitoring
  - Interpretation and use of results
  - Including people with cognitive impairment

# Publications

- Netten, A., P. Burge, J. Malley, D. Potoglou, A.-M. Towers, J. Brazier, T. Flynn, J. Forder, and B. Wall. (2012). Outcomes of Social Care for Adults: Developing a Preference Weighted Measure. *NIHR HTA Final Report*. ([www.hta.ac.uk/research/HTAJournal.shtml](http://www.hta.ac.uk/research/HTAJournal.shtml))
- Malley, J., A.-M. Towers, A. Netten, J. Brazier, J. Forder, and T. Flynn (2012) An Assessment of the Construct Validity of the ASCOT Measure of Social Care-Related Quality of Life. *Health and Quality of Life Outcomes* , 10:21  
<http://www.hqlo.com/content/10/1/21>
- Netten A, Trukeschitz B, Beadle Brown J, Forder J, Towers A, Welch E (2012) Quality of life outcomes for residents and quality ratings of care homes: is there a relationship? *Age and Ageing* doi: 10.1093/ageing/afs050