



Measuring the outcomes of social care: why and how?

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What is social care?

- Usually for people with long-term conditions
....often deteriorating over time....often multiple
- Services aim to:
 - Substitute for what individuals would have done
 - Home care/personal assistance, care homes/assisted living etc.
 - Enable people to live independently
 - Assistive technology
 - Prevent avoidable deterioration/ health problems
 - Through meeting needs (e.g. reducing isolation)

Demand for aged care in Australia

- Ageing population
- Alzheimer's Australia 2016 report:
 - 353 800 people living with dementia in Australia
 - Rising to 900, 000 by 2050
 - Currently second leading cause of death in Australia
- Approx 10% of population aged 65 and over receive home care or live in aged care.
 - Approx 354, 040 people in 2013/14
 - Set to rise as the population over 85 years of age increases

What's life without quality?



Some aged care headlines 2016

- “Why are elderly Australians taking their own lives?”
- “Budget 2016: Dementia spending set to skyrocket to \$21b by 2030 as wave of new patients rely on care”
- “Calls for greater transparency in aged care”
- “Stakeholders welcome proposals for shake-up of aged care quality”
- “Dementia set to become leading cause of death in next few years”

Need a measure that is....

- Sensitive to impact of social care
- Applicable across all care settings
 - Ideally including carers
- Valid and reliable
- Able to reflect importance of different outcome states
- Accessible to people with complex needs (the most vulnerable in the population)

ADULT SOCIAL CARE OUTCOMES TOOLKIT (ASCOT)

Development of ASCOT

- Led by Professor Ann Netten
- Over a series of projects the domains were developed and tested to ensure sensitivity and relevance to social care services and users.
- Resulted in 8 domains of social care-related quality of life.....

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

Outcome states

- Ideal state
- No needs
- Some needs
- High needs

Occupation

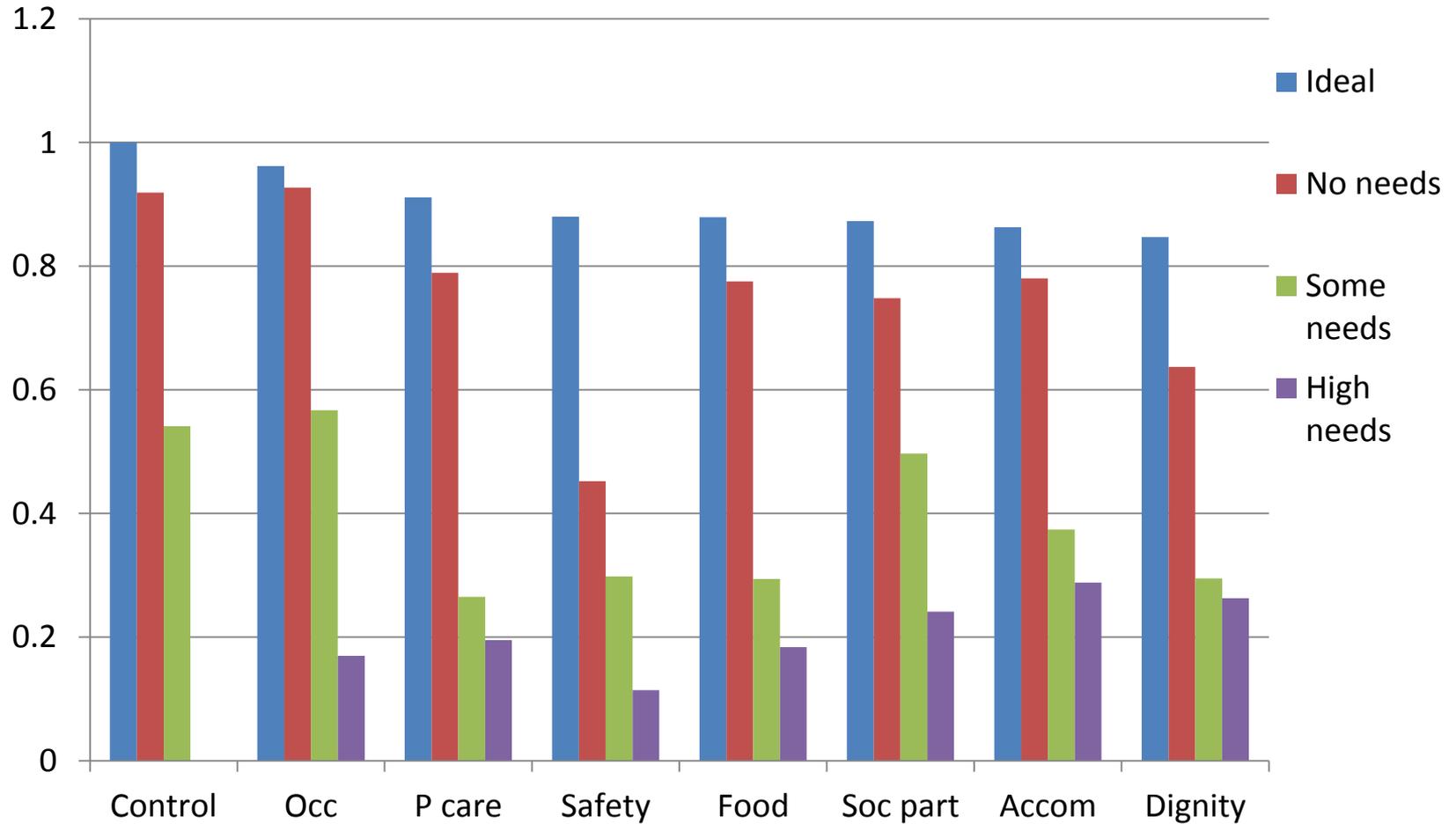
Which of the following statements best describes how you spend your time?

- 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

But not all states are equal

- Most quality of life measures treat these levels or outcome states as 'equal'
- Ideal state for social is considered the same (just as important) as the ideal state for food and drink.
- But we know that in reality this is not true
- Wanted the outcomes to be 'weighted' according to how they are valued.....

General population preferences



Measuring outcome

- Scale
 - 0 = 'being dead'; 1 = 'ideal' SCRQoL
 - Range = -0.17-1.00
- What does a score of less than zero mean?
- General population in the UK: 0.86
- Mean score for care homes: 0.71
- But how can we measure the impact services are having on this quality of life?

Expected SCRQoL

- Innovative method
- Data suggests it works well
- Imagine you didn't have the help and support from (services) that you do now. What would your life be like then (in this domain)?
- Estimate the 'expected' SCRQoL in absence of services.
- $\text{Current SCRQoL} - \text{expected SCRQoL} = \text{impact}$

What ASCOT can tell us

- Current SCRQoL
 - Experienced quality of life
- Current SCRQoL before and after
 - Change in experienced quality of life
- Expected SCRQoL
 - Need for intervention
 - Associated with ADLs & informal care
- SCRQoL gain
 - Impact of intervention at that point in time
- Expected SCRQoL before and after
 - Change in need for intervention

Range of instruments available

| | SCT4 | INT4 | CH3 | Carers |
|---------------------|--|--|---|---|
| Format | Self-completion questionnaire | Face to face interview | Mixed methods | Face to face interview |
| Number of levels | 4 | 4 | 3 | 4 |
| Current SCRQoL | Yes | Yes | Yes | Yes |
| Expected SCRQoL | No** | Yes | Yes | Yes |
| Number of questions | 9 | 23 | n/a | 21 |
| Intended use | All services where service users able to self-complete a questionnaire | All services where service users able to participate in a face to face interview | Residential setting such as care or nursing homes | With carers of adults who are supported by social care services |

Newest measures (beta versions)

- ASCOT easy-read:
 - 9 questions
 - Self-report
 - Plain language
 - Simple layout and format
 - Use of images to illustrate key messages
- Proxy measure
 - 8 questions
 - Use in surveys
 - Potential for bias from gaming
- Current SCRQoL only at this stage

HOW IS ASCOT BEING USED?

In the UK

- Adult Social Care Outcomes Framework
- Adult Social Care Survey (ASCS)
 - Annual survey since 2011
 - All service user groups (about 60,000)
 - Excludes those without mental capacity to consent
 - Includes ASCOT measure of SCRQoL
- To review QoL in care homes in Wales
- Extra Care Housing research
- Individual budgets/reablement studies
- Care homes research
- Providers in care planning (new)

International developments

- Used in research around the world
- International projects
 - Netherlands – Dutch ASCOT
 - NORFACE – Finland, Austria and England
 - Both including preference studies
- Translations undertaken or underway:
 - Finnish, Italian, Danish, Dutch, Japanese
 - Enquiries from Spain, China and Thailand.
- Finnish mental health service provider
 - Evaluating outcomes of service users

Use in Australia

- Quality indicator pilot
- Interest from quality agency
- Whiddon piloting use in care planning
- Recent and ongoing research studies:
 - Michael Fine and colleagues (Wollongong and Macquarie): Ageing well at home: measuring the impact of community care for older people (ACCOM)
 - Rachel Milte and colleagues (Flinders) : INSPIRED: Investigating services provided in the residential care environment for dementia.
 - Brendan Mulhern (UTS): Measuring and valuing wider impact of health interventions.

Some Australian references

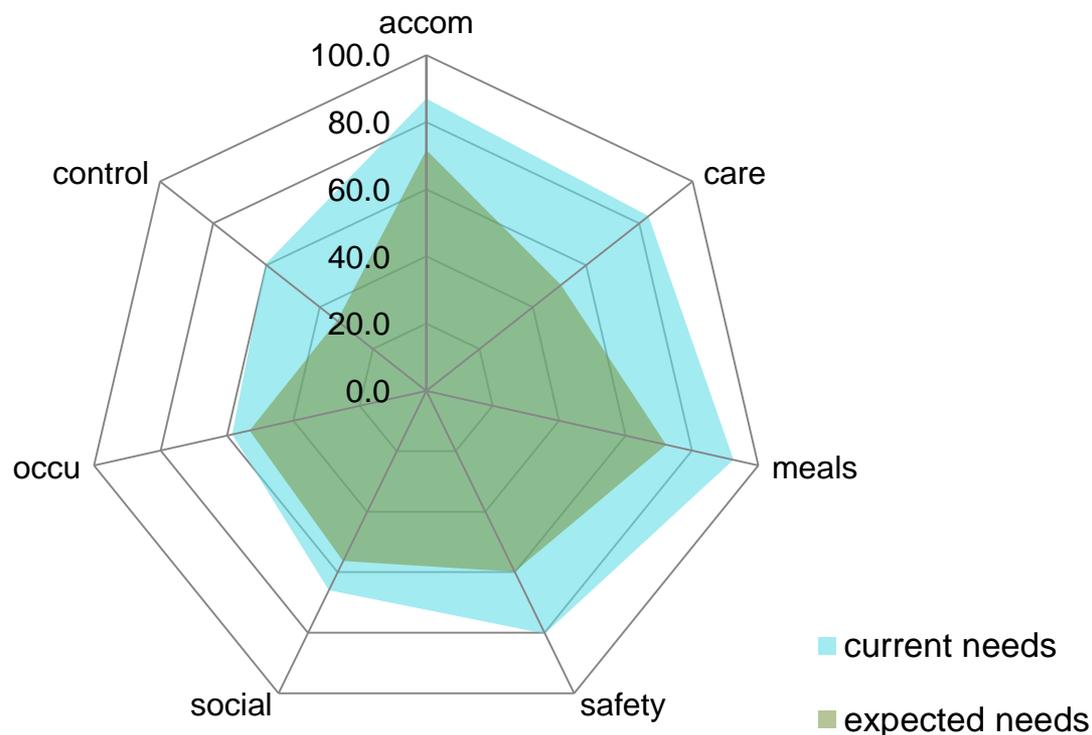
- Bulamu N B, Kaambwa B, Ratcliffe J (2015) A systematic review of instruments for measuring outcomes in economic evaluation within aged care, *Health and Quality of Life Outcomes*, 13:179, DOI: 10.1186/s12955-015-0372-8
- Kaambwa B, Gill L, McCaffrey N, Lanscar E, Cameron I D, Crotty M, Gray L, Ratcliffe J (2015) An empirical comparison of the OPQoL-Brief, EQ-5D-3 L and ASCOT in a community dwelling population of older people. *Health and Quality of Life Outcomes*, 13:164, <http://hqlo.biomedcentral.com/articles/10.1186/s12955-015-0357-7>
- Makai P, Brouwer W B F, Koopmanschap M A, Stolk, E A, Nieboer, A P (2014) Quality of Life instruments for economic evaluations in health and social care for older people: a systematic review, *Social Science & Medicine*, 102, 83 – 93, DOI: 10.1016/j.socscimed.2013.11.050.
- [Milte CM](#)¹, [Walker R](#), [Luszcz MA](#), [Lanscar E](#), [Kaambwa B](#), [Ratcliffe J](#). (2014) How important is health status in defining quality of life for older people? An exploratory study of the views of older South Australians. *Applied Health Econ Health Policy*, 12(1) ,73-84, DOI 10.1007/s40258-013-0068-3
- Ratcliffe et al. "Does one size really fit all? Assessing the preferences of older and younger Australians for dimensions of quality of life for economic evaluation." Flinders Centre for Clinical Change and Health care Research, Working paper No. 01/15. Available at: http://www.flinders.edu.au/fms/test/Flinders_WP_01_20152.pdf (accessed 9 May 2016)

RESEARCH EVIDENCE

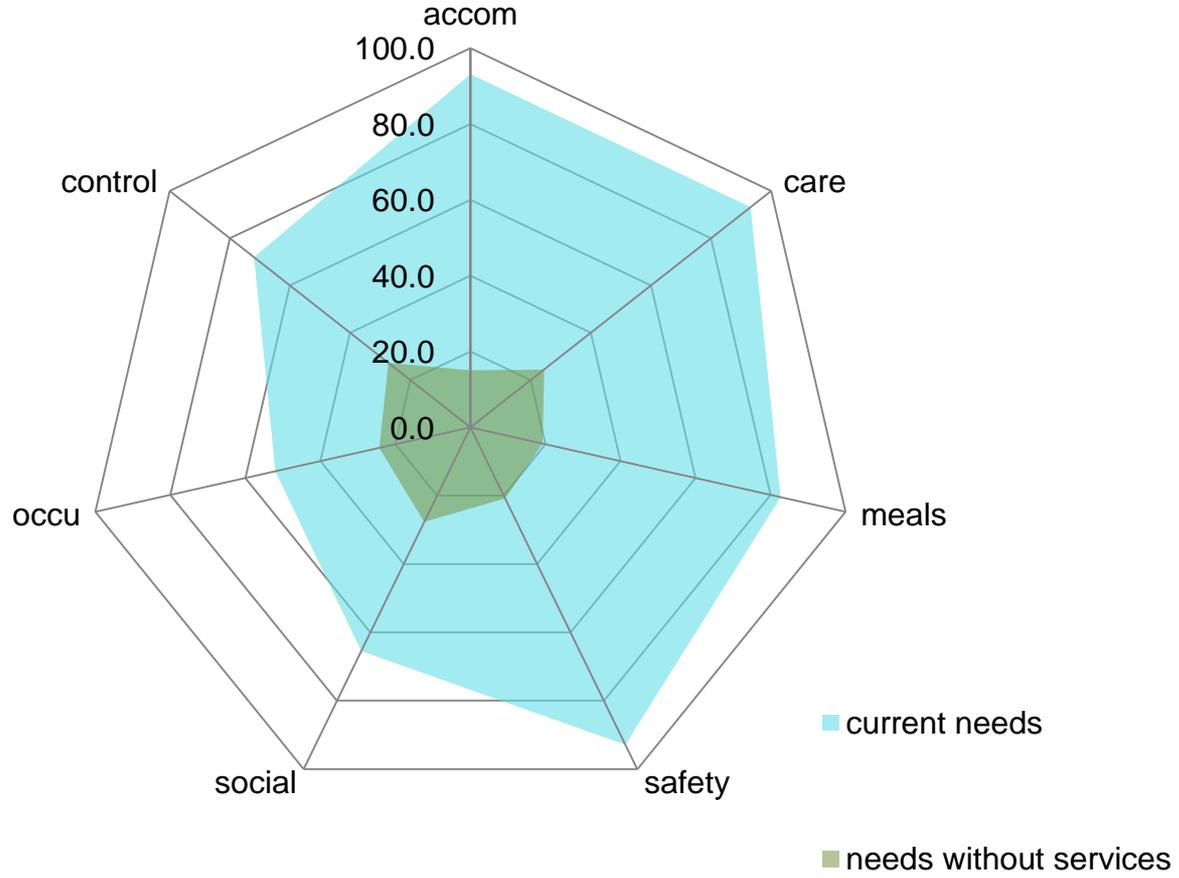
Survey data from UK

- Full range of SCRQoL scores among service users
 - 2013 - 169 people, 0.28% worse than 'being dead'
- Services much better at delivering 'basic' domains
 - Social participation, control and occupation relatively poor
- Older people living at home (30,000)
- Better SCRQoL associated with
 - Accessibility of information and advice
 - Better home design
 - Accessibility of local area

Older home care users' needs and outcomes



Older care home residents' needs and outcomes



Measuring outcomes in care homes

- Training
 - Observation
 - What are residents lives actually like?
- Anecdotal evidence about impact on quality
- Reported changes in practice following ASCOT feedback
- Difficult to demonstrate improvement in current SCRQoL because residents health declining rapidly
- Better to look at 'gain' in care homes?

Where next with ASCOT?

- Validate and test new measures
 - Including a 4 level care homes toolkit
- Set up partnerships for training and support with international partners
- Care regulators starting to show an interest
- ASCOT in care planning – new study for 2017
- Challenges:
 - Data sharing
 - Protecting integrity and quality of the tool
 - Funding support

ASCOT Team at the PSSRU

Ann-Marie Towers

(ASCOT lead, care homes, training)



Juliette Malley

(Preference studies, translations)



Nick Smith

(Training lead, care homes, dementia)



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(Support and translations)



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Some relevant 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)
- 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
- Rand S & Malley J (2014) Carers' quality of life and experiences of adult social care support in England, *Health and Social Care in the Community*, 22(4), 375-385, DOI: <http://dx.doi.org/10.1111/hsc.12089>
- Towers A, Smith N, Palmer S, Welch E, & Netten A (2016) The accessibility and feasibility of using the Adult Social Care Outcomes Toolkit (ASCOT) to inform practice in care homes. *BMC Health Services Research*, 16:523, (available online 29 September 2016), DOI: 10.1186/s12913-016-1763-1
- Rand, S & Malley J (2016) The factors associated with care-related quality of life of adults with intellectual disabilities in England: implications for policy and practice, *Health and Social Care in the Community*, DOI: <http://dx.doi.org/10.1111/hsc.12354>