



# 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

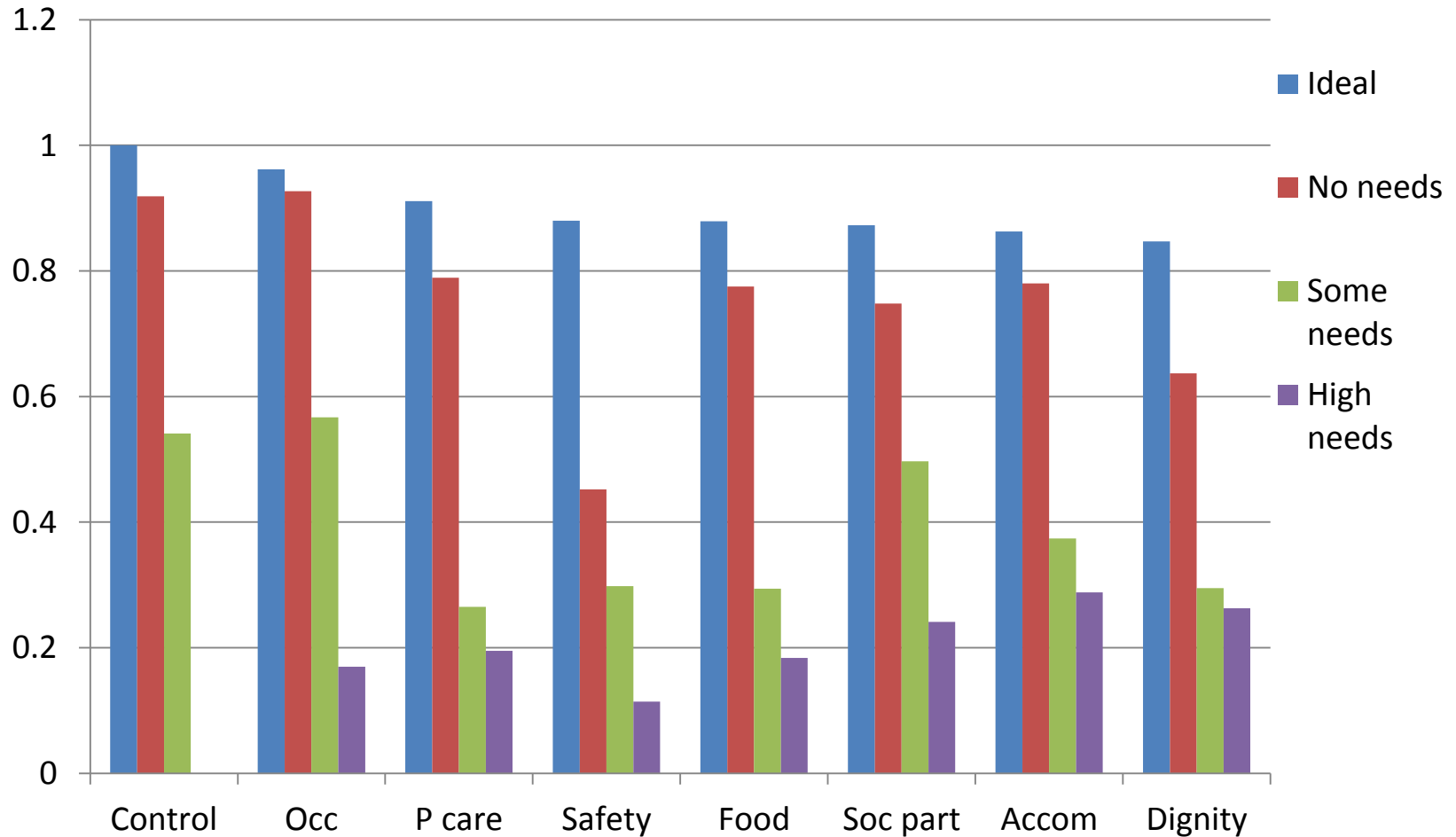
## Which of the following statements best describes how you spend your time?

- 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

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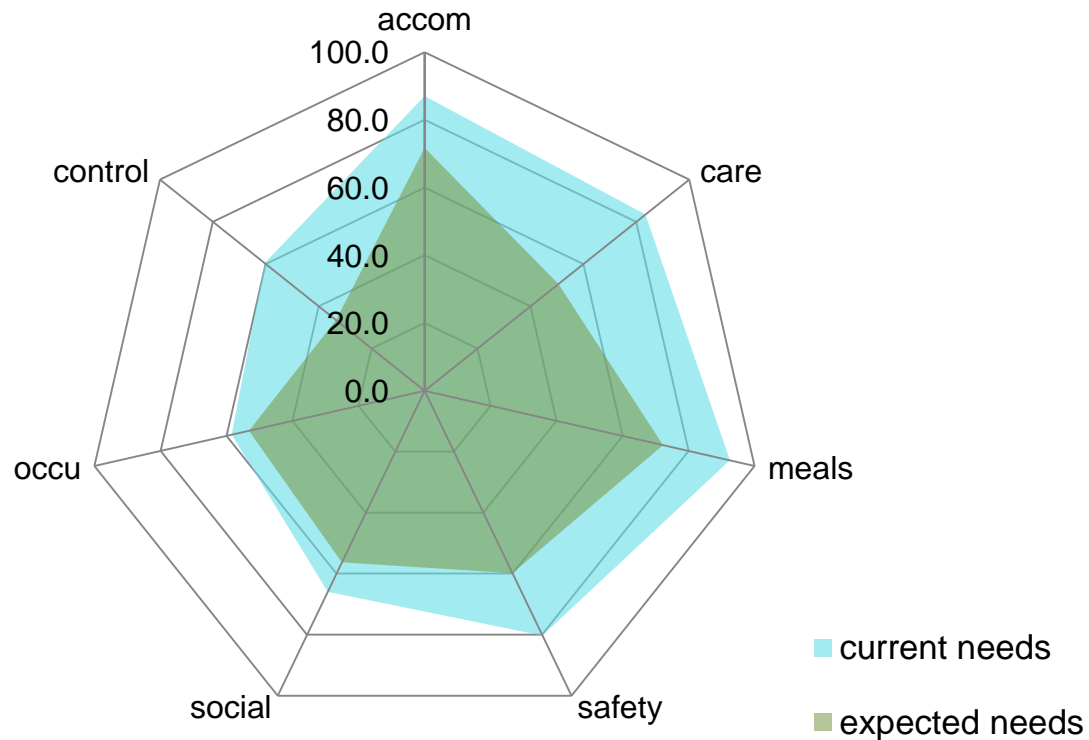
# RESEARCH EVIDENCE



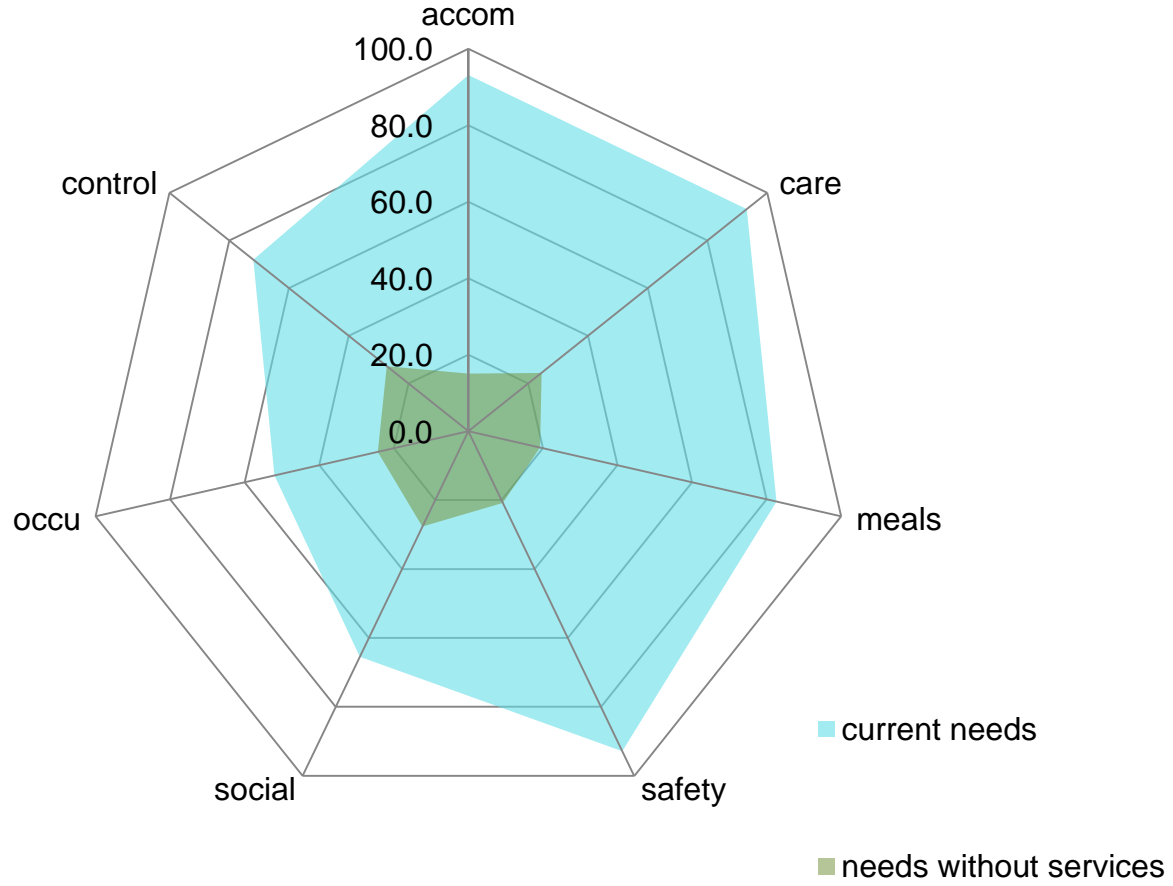
# Survey data from UK

- 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)



Kamilla Razik

(Support and translations)



Stacey Rand

(Validation, carers, proxy, training)



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(Easy read, proxy)



Ann Netten

(International developments)



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(IT manager)



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# Some relevant publications

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