quality and outcomes of person-centred care research unit

## The Adult Social Care Outcomes Toolkit for Carers

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OF ECONOMICS AND POLITICAL SCIENCE



### **Introduction to ASCOT-Carer SCT4/INT4**

- Adult Social Care Outcomes Toolkit for Carers
  - Self completion (SCT4)
    - The social care-related quality of life (SCRQoL) of family/friend (unpaid) carers aged 18 years or older
  - Interview (INT4)
    - What effect does social care support have on unpaid carers' quality of life?

## **Development of the ASCOT-Carer (1)**

#### • Kent Carers Survey

- Six focus groups (four with carers)
- 56 interviews with carers
- Self-completion survey to capture carer experience and quality of life

Jacquetta Holder, Nick Smith and Ann Netten (2009)

### • Personal Social Services Survey of Adult Carers in England (PSS SACE)

- Pilot self-completion survey in 2009/10
- Analysis of pilot data to evaluate carer SCRQoL measure
  - Six (or seven) questions
  - Three response options to each question
- National survey every two years

Diane Fox, Jacquetta Holder and Ann Netten (2010) Juliette Malley, Diane Fox and Ann Netten (2010)

## **Development of the ASCOT-Carer (2)**

### • IIASC study: Phase One

- Interview version (INT4) with 'expected' questions
- Four levels of response to each question

Stacey Rand, Juliette Malley and Ann Netten (2012)

#### • IIASC study: Phase Two

- Survey of 387 carers in England
- Face-to-face or telephone interviews
- Construct validity and factor structure of the measure

Stacey Rand, Juliette Malley, Ann Netten & Julien Forder (2015)

## **ASCOT-Carer Domains**

Service User (SCT4/INT4)	Carer (SCT4/INT4)
Control over daily life	Control over daily life
Occupation	Occupation
Social participation and involvement	Social participation and involvement
Personal safety	Personal safety *
Personal cleanliness and comfort	Self-care
Food and drink	
Accommodation cleanliness and comfort	-
Dignity	-
-	Time and space to be yourself
-	Feeling supported and encouraged

\* Carer-specific personal safety (i.e. feeling safe from accidents, harm etc. as a result of caring role)

## What does ASCOT-Carer INT4 measure?

- Current QoL
- 'Expected' QoL
  - Self-rated SCRQoL in the absence of social care services
- 'Gain'
  - The difference between *current* and *expected* SCRQoL
  - The effect of services on the person's quality of life

# Measuring outcomes using ASCOT-Carer INT4

- Interviewer instructions
- Introduction
- 21 questions across 7 domains
- Three questions for each domain
  - Current SCRQoL
  - Filter question
    - If yes or don't know, then...
  - Expected SCRQoL

## **Interviewer Instructions**

- Define support and services according to your study
  - e.g. if want impact of short term breaks ask about short term breaks, carer support group ask about carer support group, etc.

### **Example: Occupation**

Q1. (Current): Which of the following statements best describes how you spend your time?

When you are thinking about how you spend your time, please include anything you value or enjoy, including leisure activities, formal employment, voluntary or unpaid work, and caring for others.

- I am able to spend my time as I want, doing things I value or enjoy
- I am 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 do not do any of the things I value or enjoy with my time.

**Q2. (Filter):** Do the support and services that *you* get from the *carers' support group* affect how you spend your time doing things you value and enjoy?

**Q3. (Expected):** Imagine *you* did not get the support and services from the *carers' support group* that you do now and no other help stepped in. In that situation, which of the following statements would best describe how you would spend your time?

# **Scoring the ASCOT-Carer INT4**

- Current score for each question Ideal state (3), No needs (2), Some needs (1), High-level needs (0)
- Total current SCRQoL = Sum of the score from the seven current SCRQoL questions
- Score from 0 (lowest) to 21 (highest)

# **Scoring the ASCOT-Carer INT4**

• Expected score for each question Ideal state (3), No needs (2), Some needs (1), High-level needs (0)

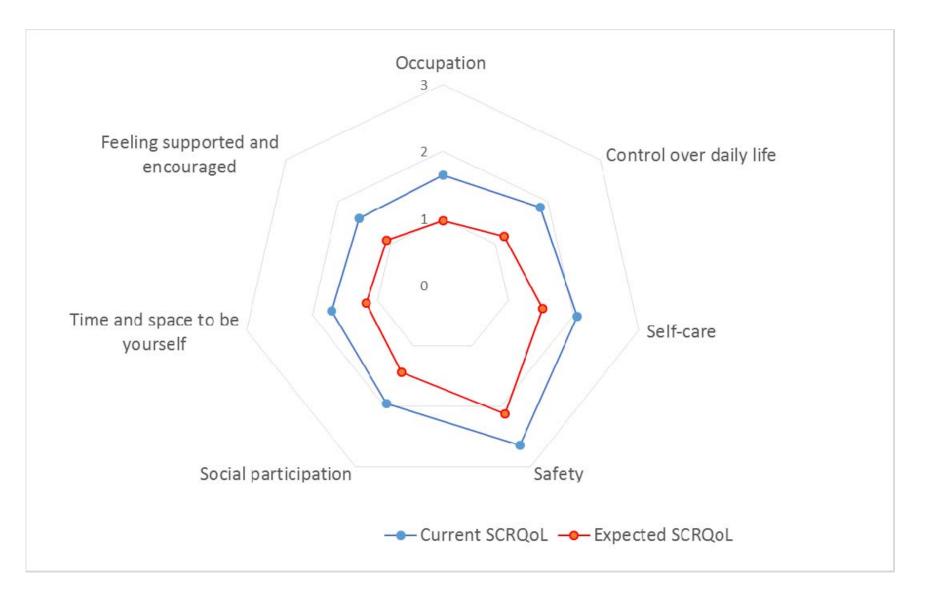
### Total expected SCRQoL =

Sum of the score from the seven expected SCRQoL questions If the expected question was not asked (i.e. filter question = no or don't know) then use the current SCRQoL score

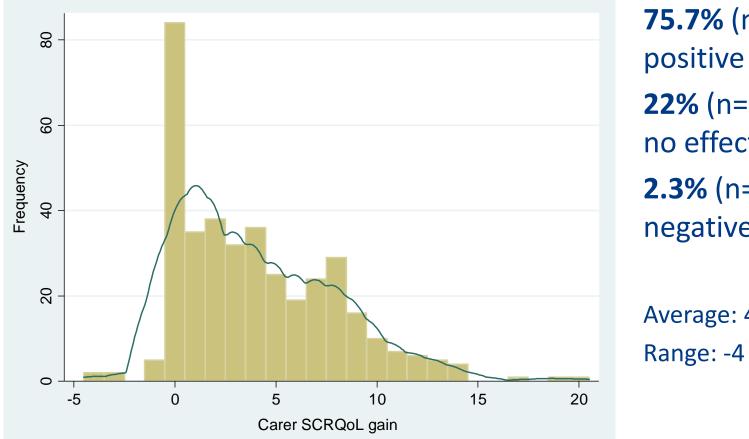
• Score from 0 (lowest) to 21 (highest)

SCRQoL 'gain' (effect of services) = Current SCRQoL – Expected SCRQoL

### IIASC Phase Two: ASCOT-Carer INT4 Scores by Question



### **IIASC Phase Two: ASCOT-Carer SCRQoL gain**



75.7% (n=289) positive effect 22% (n=84) no effect **2.3%** (n=9) negative effect

Average: 4.0 Range: -4 to +20 Next steps

- NORFACE EXCELC project
  - Translation
  - Preference weights
- Using ASCOT-Carer alongside ASCOT SCT4/INT4
  - What is the 'wider impact' of social care?

## **Contacts and Acknowledgements**

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