

# Measuring outcomes in community care – an international perspective

Ann Netten

AHRSI Wollongong 10 March 2015

# Measuring outcomes

International shift to focus on outcomes

Value for money not just about costs

Quality in terms of delivering outcomes

Patient-Centered Outcomes Research Institute (PCORI)

International Consortium for Health Outcomes Measurement (ICHOM)

Israel 'OOMPH' project

This presentation

Outcomes of community care

Adult Social Care Outcomes Toolkit (ASCOT)

Using outcomes and ASCOT

# Outcomes of community care

# The role of community care

Usually for people with long-term conditions

....often deteriorating over time....often multiple

....which result in impairment in activities of daily living

Most care provided by informal carers

Social care services:

Substitute for what individuals would have done

Home care/personal assistance, care homes/assisted living etc.

Improve individuals' 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/ social services

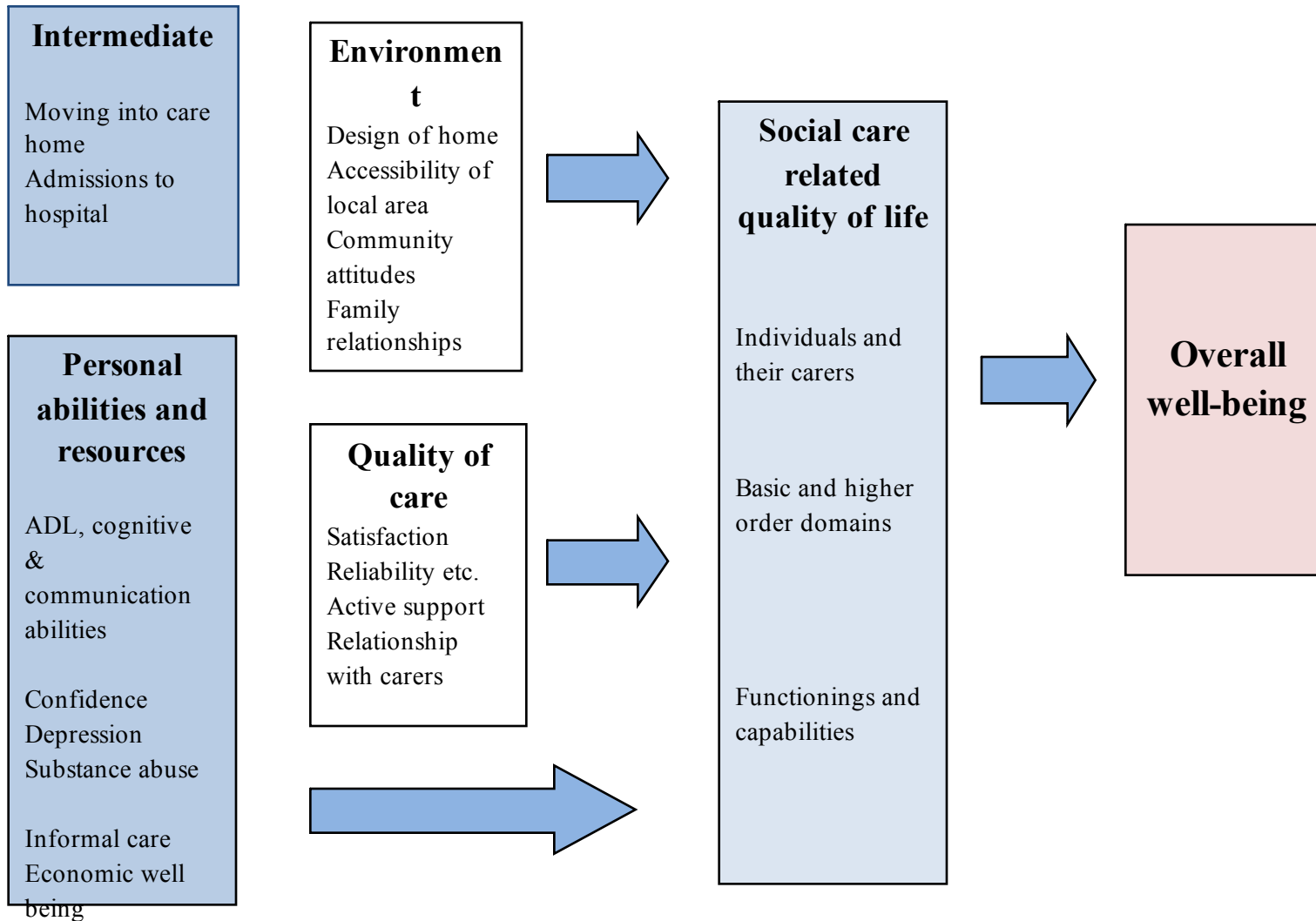
Compensation for impairment

Social care related quality of life (SCRQoL)

Personally clean, fed, socially engaged etc

Prevention

# 'Types' of social care outcome



International approaches to measurement

Activity/process

Reduced use of residential care

Take-up of services/ cash for care options

Inter RAI – long-term care

Changes in activities of daily living

Indicators of (poor) quality

Bedsore/weight loss etc

Experience and satisfaction

Satisfaction with assessment and services

Quality of care e.g. reliability and continuity

Growing interest in quality of life

# What do we want of quality of life outcome measures?

Sensitive to care effects

Applicable across all care settings

Ideally including carers

Valid and reliable

Reflect importance of dimensions of outcome

Meaningful

Facilitate comparability/ range of uses





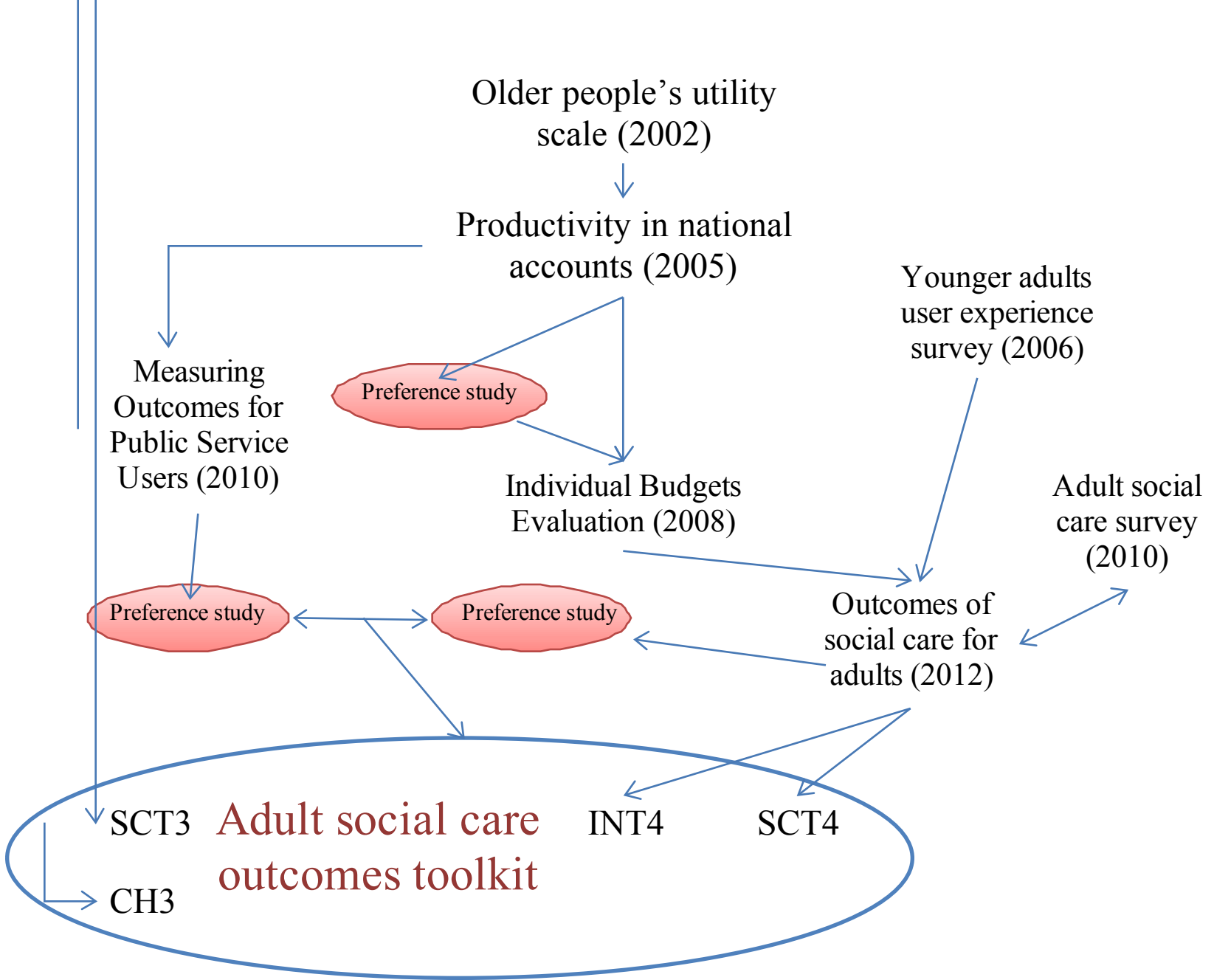
**<http://www.pssru.ac.uk/ascot/>**

Instruments & data entry tools

Guidance & FAQ & References

Feedback

Registration



# 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

# 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 (mustn'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

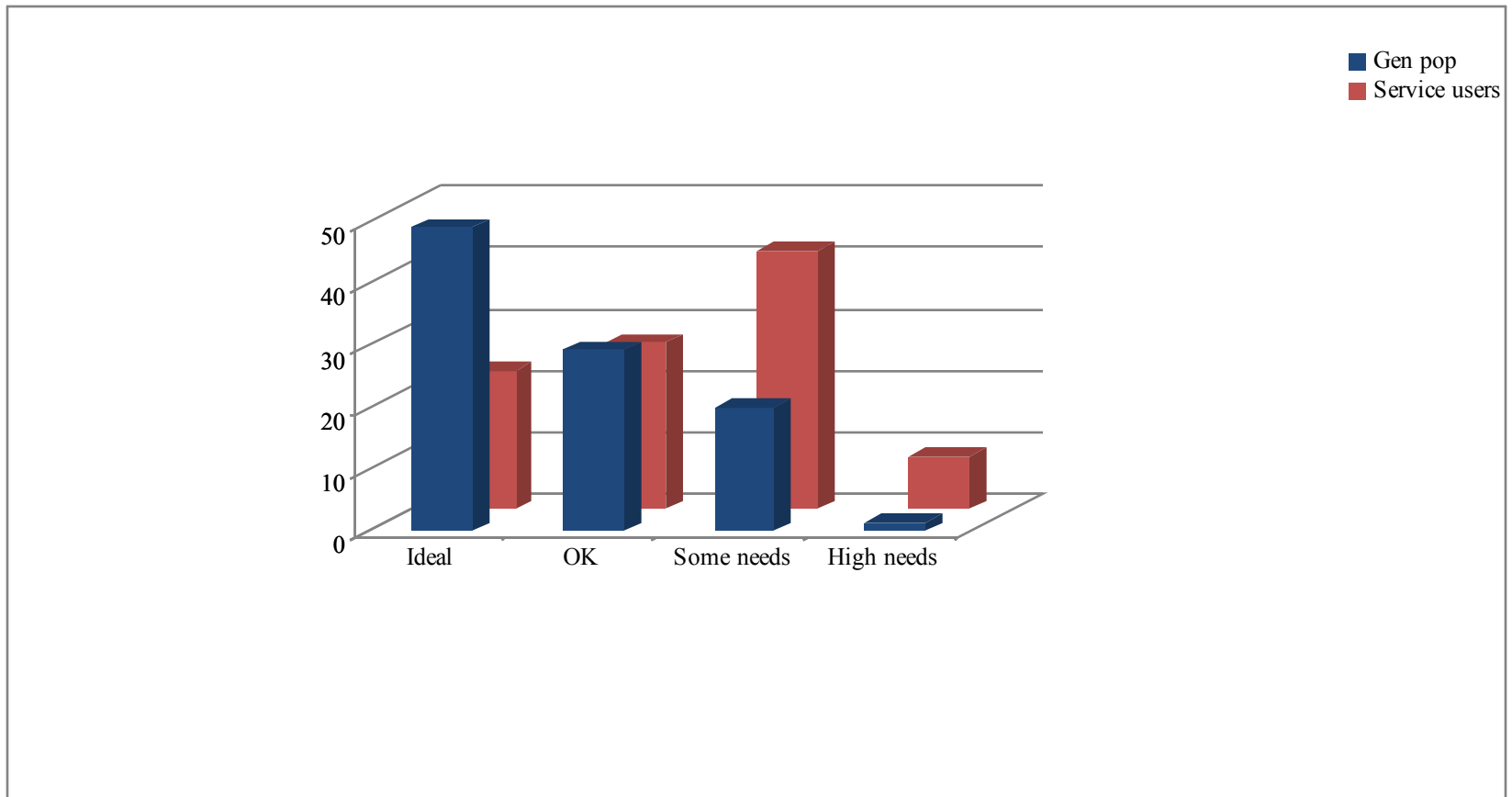
Associated with better SCRQoL

All domains

Significantly better control in 'ideal' level

Control over daily life

# Occupation





# Preference studies

- Objectives

Reflect relative importance of domains and levels

Meaningful scale

Best-worst scaling and Time Trade-Off

Consistent results across a number of samples

Service users (460) & general population (2 X 500)

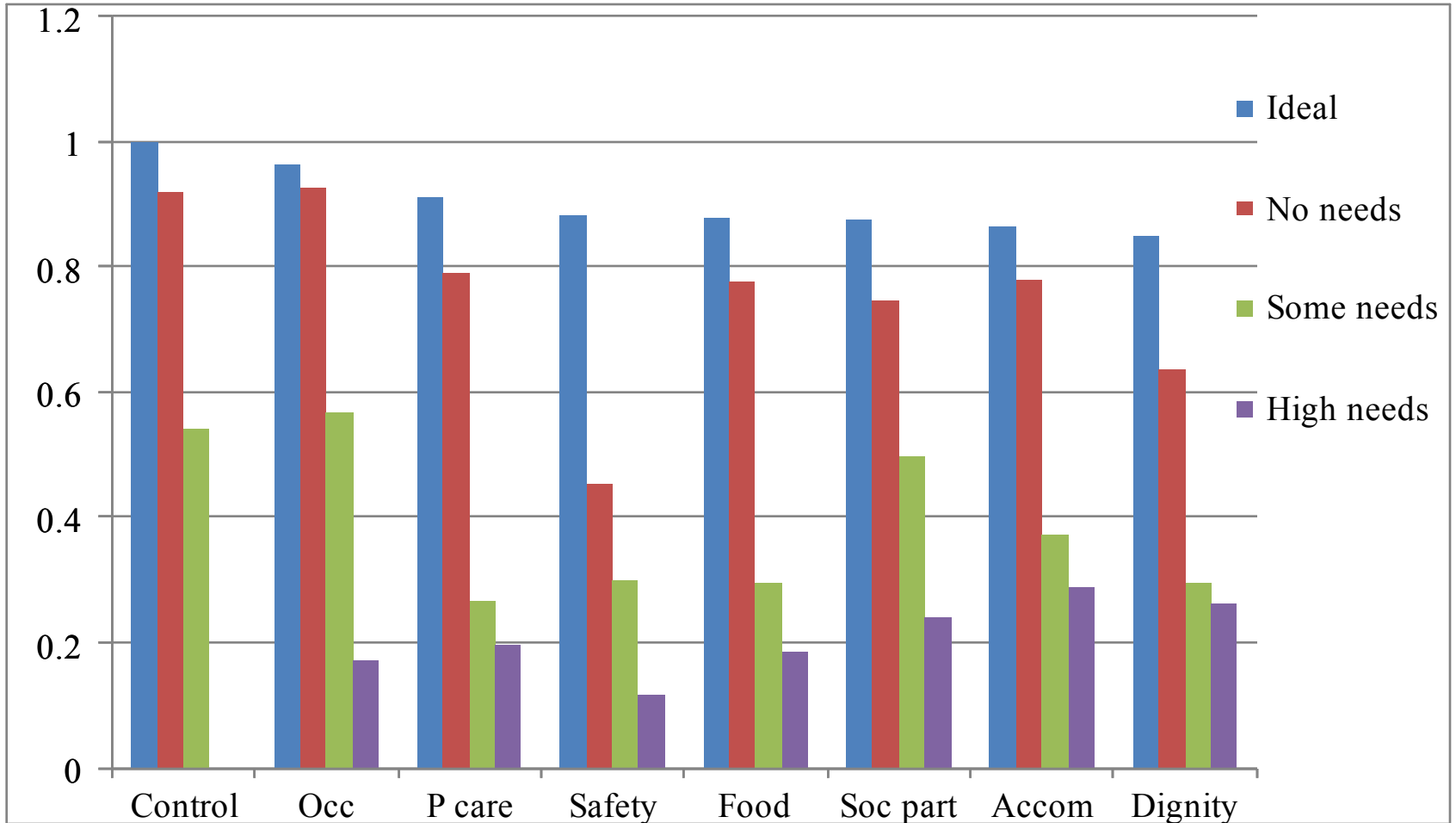
Service users vs general population

Only 6 of 30 levels statistically significant

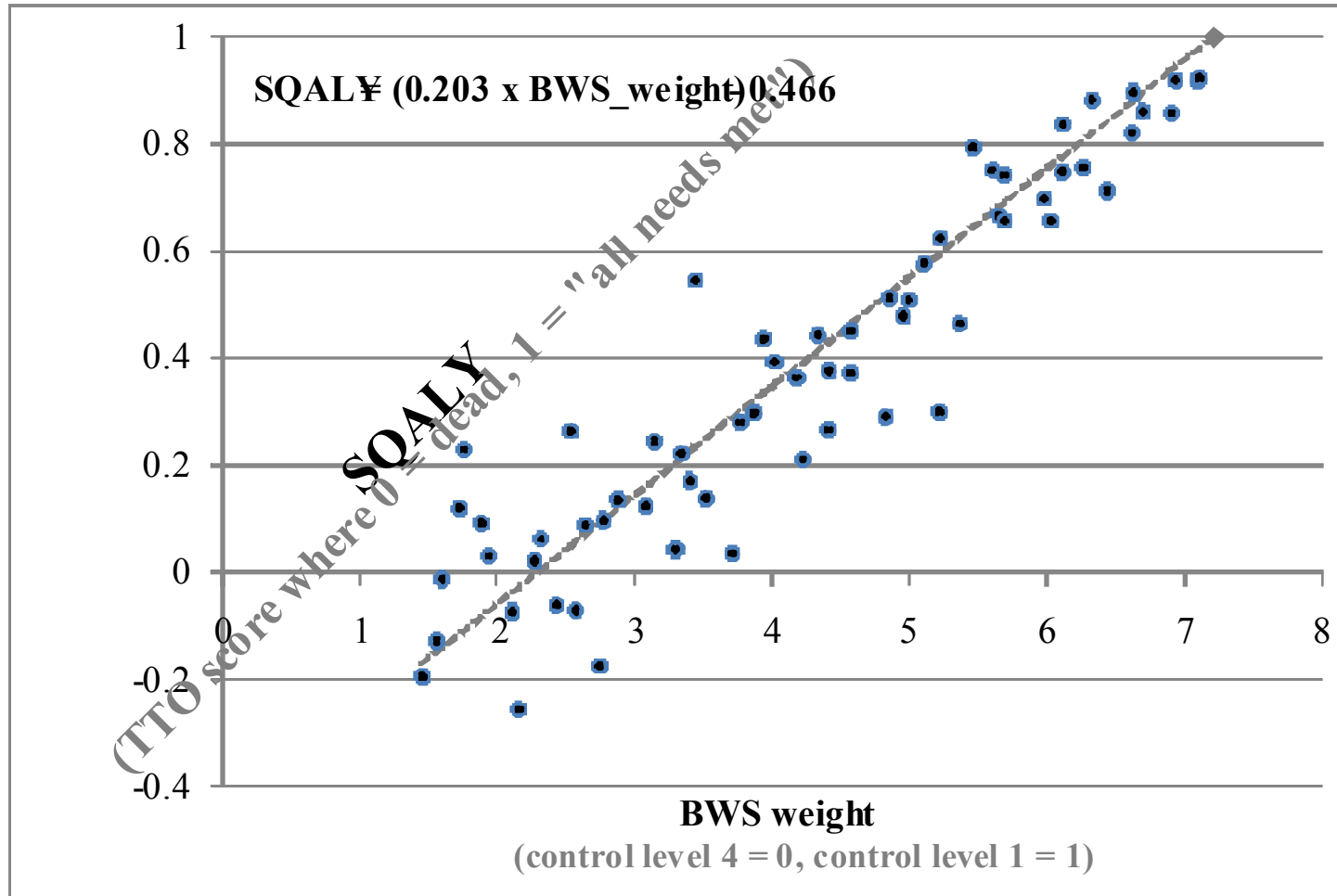
No large differences in absolute terms

Although differences in causes of variation

# General population preferences



## Anchoring the scale



Measuring outcome

Scale

0 = 'being dead'; 1= 'ideal' SCRQoL

Range = -0.17-1.00

'Current' SCRQoL before and after

Challenges to establishing counterfactual

Pragmatic approach in ASCOT

'Expected' - in absence of services/support

SCRQoL gain = Current-expected

## **The toolkit**

Self completion questionnaires

Interview schedule

Three part question for each domain

Current situation? Services affect? What if no service?

Care homes multi-method approach

Semi-structured interviews – residents/staff/relatives

Structured and unstructured observation

Evidence used to inform rating scale

Training

Scoring guidance

# Interpretation of measures

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

Carer ASCOT

Built on ASCOT

Similarly complicated history!

Consultations with carers

How relevant are domains?

What is missing?

Does wording work?

Cognitive testing and development

Including 'expected' in the absence of services

Validity testing

Due to be 'launched' shortly

# Using outcomes and ASCOT



ASCOT in research

Increasing use in evaluations

Economic evaluation of personal budgets

Extra care housing

‘Shared Lives’ for older people

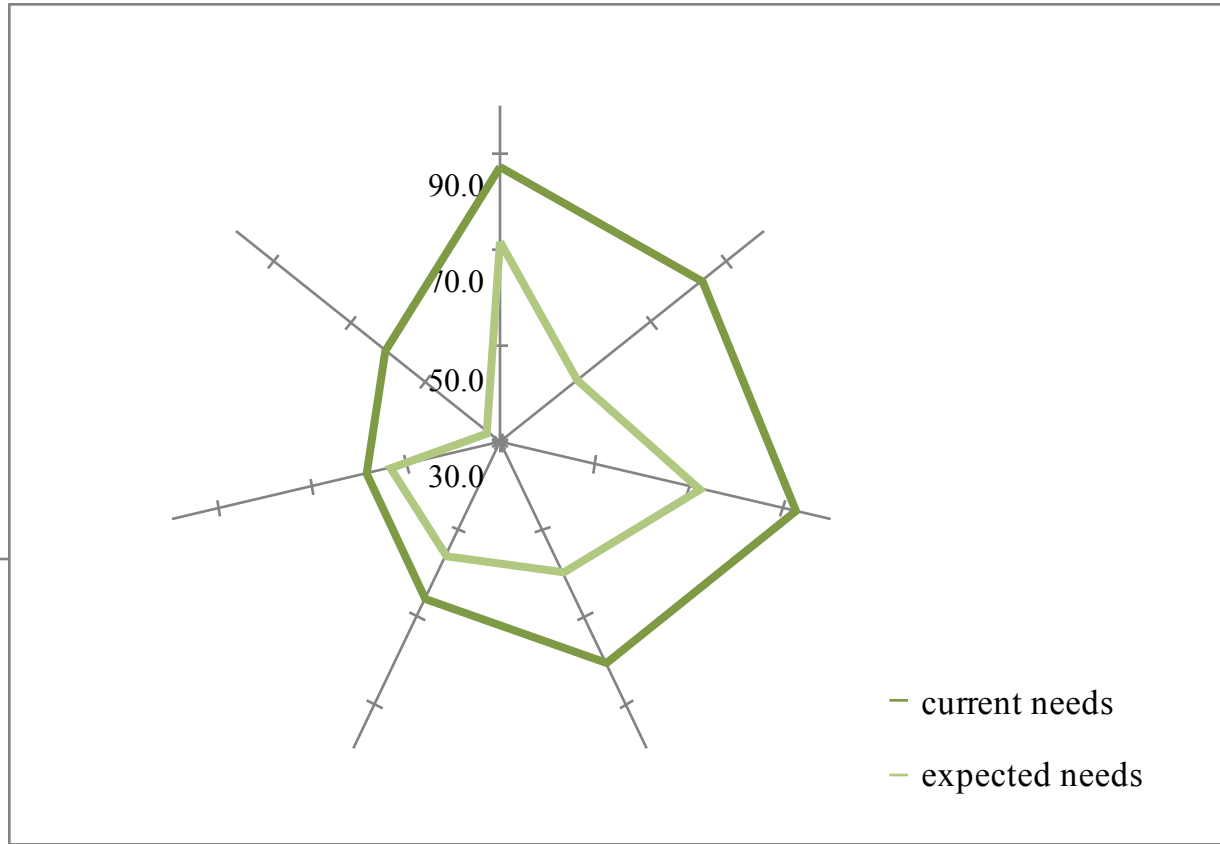
Development studies

What matters to people

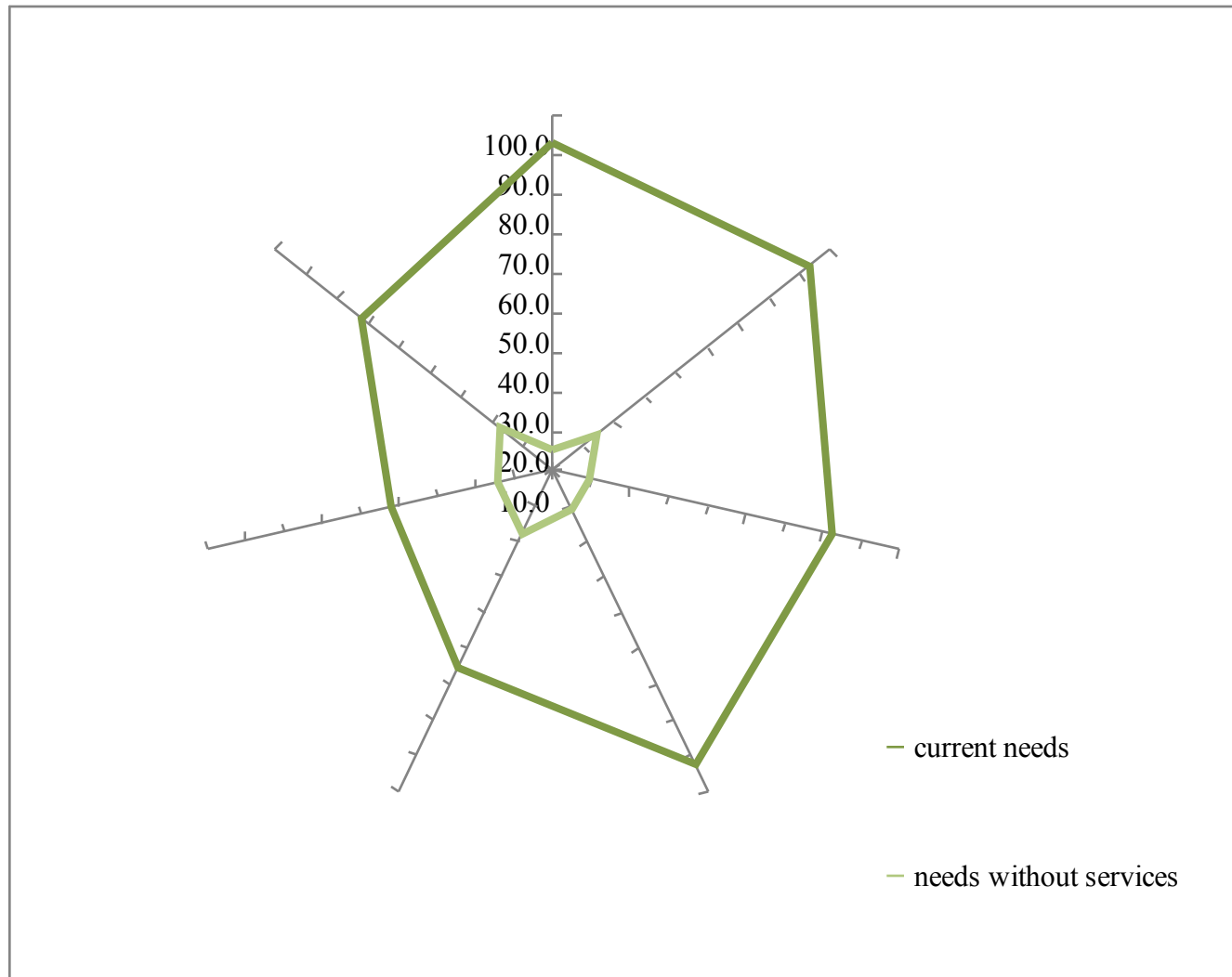
What affects what matters to people

Impact of services

# Older home care users' needs and outcomes



# Older care home residents' needs and outcomes



# Outcomes in policy

- English Adult Social Care Outcomes Framework

National monitoring and policy development

Local benchmarking and service improvement

Set of outcome measures

Enhancing quality of life for people with care and support needs

Delaying and reducing the need for care and support

Ensuring that people have a positive experience of care and support

Safeguarding people whose circumstances make them vulnerable and protecting from avoidable harm

*Not* national performance management tools

Emphasis on patient/service user reports

# Surveys

Conducted by individual local authorities

National guidance on sampling etc.

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

Carer experience survey

Every 2 years from 2012

Includes carer ASCOT equivalent SCRQoL measure

Evidence about SCRQoL

Full range of ASCOT 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

Analysis of older people living at home (30,000)

Better SCRQoL associated with

Accessibility of information and advice

# Outcomes and practice

‘Outcomes’ challenging to use in practice

Less specific than process indicators

MAX project

Practical guide for councils using ASCS data

Councils starting to use ASCOT

Quality monitoring

Commissioning?

Outcomes focused person centred planning

To encourage good practice and generate data

## Providers

Range of types of provider

Home care, day centres, men in sheds, LD, reablement..

A lot of interest from Australia

Most contact with care home providers

Training

Structured and unstructured observation

What are residents lives actually like?

Anecdotal evidence about impact on quality

Two studies generated

Study of impact of ASCOT on care home practice

‘Home level’ ASCOT for quality measurement



# Other ASCOT developments

Methods for wider inclusion

Easy read

Qualitative interviews

Proxy version

Multi-method approach for people living at home

‘Identifying the Impact of Adult Social Care’

Including ‘impact measures’ in ASCOF?

Investigating inclusion of carer outcomes

# International developments

International network and committee

Support for translations and applications

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

International projects

Netherlands – Dutch ASCOT

Current proposal – Finland, Austria and England

Both including preference studies

# Concluding thoughts

Move to outcome measurement creates the right incentives

Challenging in practice

Hearing service user and carers' voices

Generating data

What are service users and carers lives like?

Cost-effectiveness benchmarking

Next step

What does this mean? How can we improve?

# Acknowledgements

QORU is funded by the Policy Research Programme in the Department of Health (England). The views expressed in this presentation are not necessarily those of the Department

Australia and ASCOT

Julie Ratcliffe (Flinders) 2015

Australian population preferences

AQOL-4D, ASCOT and EQ5D

Gordon Duff (Sydney) 2013

NFP disability provider organization NDS

Provider outcome measurement

- Jack Allen (WA) 2012

Silver Chain home care survey

Eleanor Kennett-Smith (Adelaide) 2012

ECH Ltd Community services

Provider outcome measurement

<date>

Julie Ratcliffe (Flinders) 2015

# Publications

Van Leeuwen K M, Malley, J, Bosmans J E, Jansen A P D, Ostelo R W, Van Der Horst H E, Netten, A. (2014) What can local authorities do to improve the social care-related quality of life of older adults living at home? Evidence from the Adult Social Care Survey, *Health and Place*, 29 104-113

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>