

# Developing a Core Outcome Set for Evaluative Research in Adult Social Care

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# Disclaimer

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# Rationale of study

- Core outcome set seldom applied in research in social care
- A few exceptions; Reilly et al. (2020), COS for non-pharmacological interventions for people with dementia at home
- NICE approached us to explore possibilities in social care; NICE having substantial responsibilities to synthesise and use evidence of interventions in social care

# What is a core outcome set

- An agreed standardised set of outcome measures to be used in trials and evaluative research
- Does not preclude additional measures, beyond required core
- Advantages:
  - Easier to analyse and synthesise results
  - Shared language and understanding
- Widely used in health research (370 +published)
- International Consortium for Health Outcomes Measurement [ICHOM]
- Core Outcome Measures in Effectiveness Trials (COMET)

# Components of Core Outcome Sets

- **Domains**

Key areas of life, health, to be measured

- **Measures**

Specific measures for identified domains

- Achieved by:

- Consensus process
- Gathering relevant literature (evidence) on outcomes

# Challenges in social care

- Relative absence of trials
- Evidence-based practice
- Heterogeneity of social care
- Dominance of other methods (qualitative methods, theoretical approaches)
- Ethical concerns about trials

# Methods

## Step One:

- Scoping review to identify domains
- Recruitment of panel

## Step Two:

- Survey one to test approach & domains
- Online via Microsoft Forms

## Step Three:

- Analysis of survey one : Consensus defined as at least 70% agreement
- Revision of domains
- Identification of measures to assess the domains

## Step Four:

- Survey two to test domains & measures
- Online via Microsoft Forms

## Step Five:

- Analysis of survey two
- Final recommendations on domains & measures

# Results:

## Identification of domains

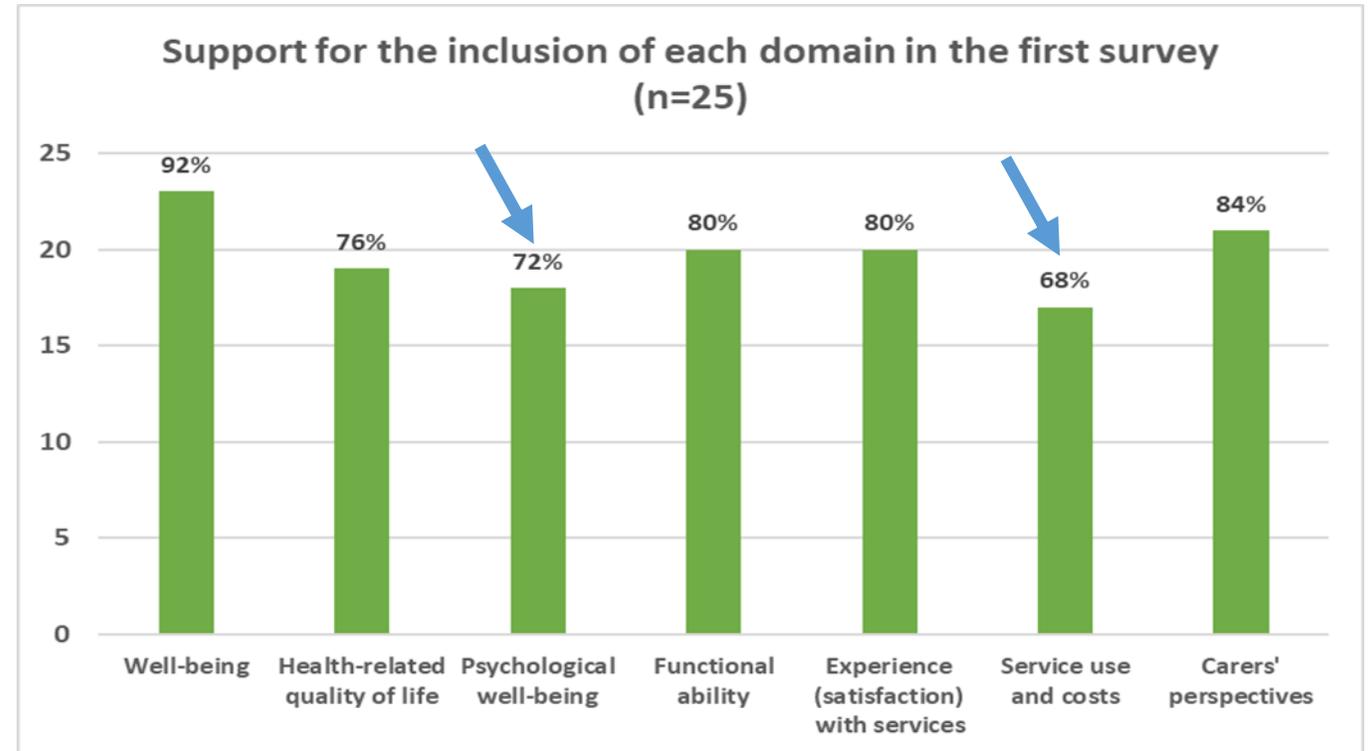
- 7 domains identified
  - Wellbeing
  - Health related quality of Life (HRQoL)
  - Psychological wellbeing
  - Functional ability
  - Experiences with services
  - Service use and costs
  - Carers' perspectives

# Panel recruitment

- NIHR national collaborative group to address research in adult social care
  - Practitioners, providers & researchers
- Network of DHSC Policy Research Units with an interest in adult social care
  - Patient and Public Involvement network & researchers

# Survey one

- 25/30 (83%) participated
  - 11 researchers
  - 8 members of the public
  - 6 social care professionals/managers
- Majority (20/25, 80%) supported overall approach



# Revision of domains

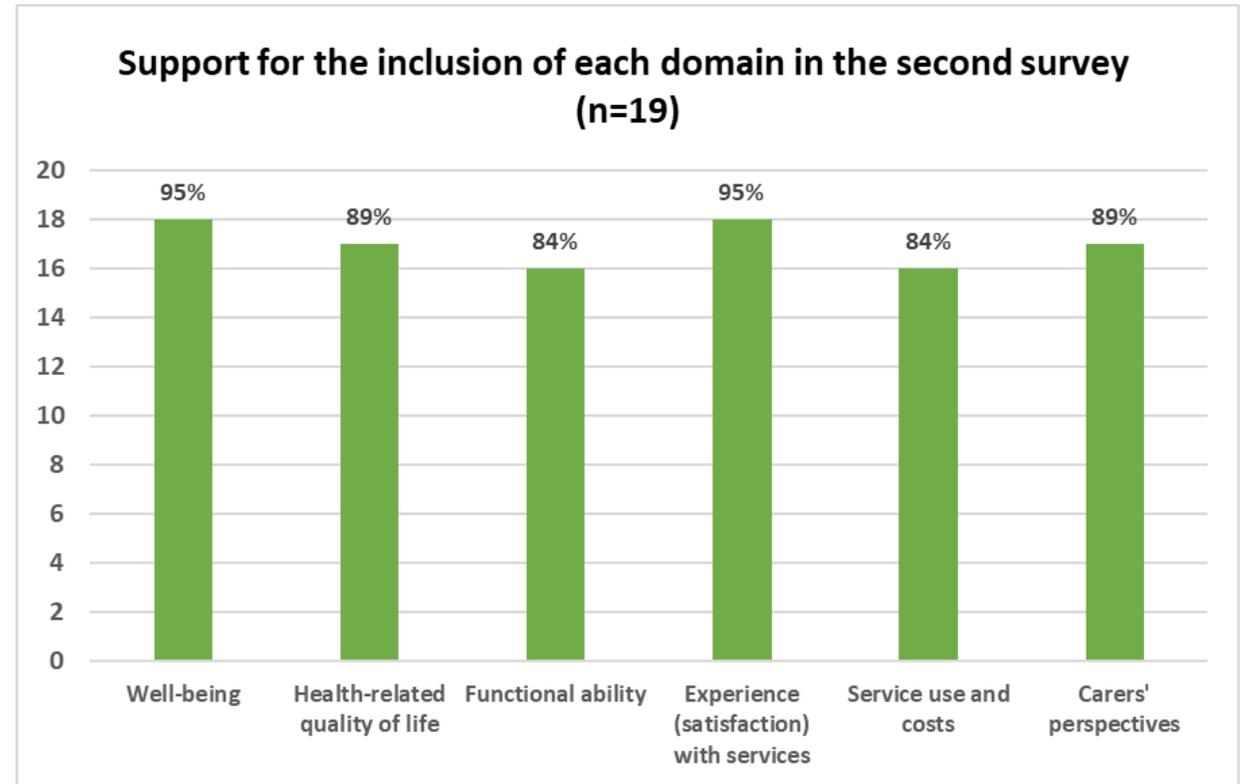
- Psychological wellbeing merged with wellbeing domain
- Service use and costs domain retained
- No new domains added

# Identification of measures

Domain	Measures
Well-being	ICECAP & ASCOT recommended as alternative options
HRQOL	EQ-5D
Carers' perspective	ASCOT-Carer
Functional ability	<u>Basic ADLS</u> Barthel Index & Katz Index of Independence (Katz ADL) recommended as alternative options <u>More complex, instrumental ADLS</u> Lawton IADL
Experience (satisfaction) with services	No measure recommended
Service use and costs	No measure recommended; UCH&SC report highlighted

# Survey two

- 19/30 (63%) responded
  - 10 researchers
  - 8 members of the public
  - 1 social care professionals/managers



# Final recommendations

Domain	Measures
Well-being	ICECAP & ASCOT recommended as alternative options
HRQOL	EQ-5D
Carers' perspective	ASCOT-Carer
Functional ability	<u>Basic ADLS</u> Barthel Index (for older adults only) <u>More complex, instrumental ADLS</u> Lawton IADL
Experience (satisfaction) with services	No measure recommended
Service use and costs	No measure recommended; UCH&SC report highlighted

# Conclusions

- Broadly feasible and acceptable as process
- Broad agreement reached & consistent with more traditional structured reviews (Makai, 2014; Bulamu et al., 2018)
- A similar consensus process on outcomes for long term care sector emphasised many similar measures: ASCOT, ICECAP, EQ 5D (Edvardsson et al., 2019)

# COS for public health

## Interventions to promote physical activity: Contrasting, weaker result

- Thirteen different domains were reviewed and discussed by the panel

BUT

- Agreement was reached on only two domains and recommended measure:

### **Domain**

Objective assessment of physical activity

Health-related quality of life

### **Specific measure**

Accelerometer

EQ-5D

(Crocker et al 2022)

## Some reservations

‘I am concerned that your starting point in this project appears to be 'established' domains conceptualised by professionals and measures that are already in existence.’

‘..there is a language of social care, such as strengths and assets, that I suspect many would see as outcomes in themselves and would expect to see explicitly in a COS’

Social inequalities not addressed

## Some reservations

‘...feels led by a biomedical model’

‘I feel positive about wider use of outcomes measures, but am somewhat concerned that their mandatory use may fuel a prevalent biomedical view that qualitative research/evaluation is of poor quality unless it includes a core outcome set.’

‘Social care is so broad that making something essential is very difficult’

# Study limitations

- Lack of evidence from RCTs; relied on other types of studies
- Size of panel
- Some attrition (study carried out in year of covid pandemic)

# Dissemination & impact

- Published (Sugavanam et al. 2021)
- Study and results shared with NICE
- Shared results in range of DHSC NHSE, HSR seminars
- *Impact of COS largely determined by use by research funders, researchers, policy makers*

# Brief mention of other issues

- Relevant to other research study designs: comparative observational studies
- Is a COS relevant to routine services?
- Cost and burden of self-reported data

# References

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Thank you

Questions?