Measuring outcomes in community care – an international perspective

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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

Intermediate
- Moving into care home
- Admissions to hospital

Personal abilities and resources
- ADL, cognitive & communication abilities
- Confidence
- Depression
- Substance abuse
- Informal care
- Economic well-being

Environment
- Design of home
- Accessibility of local area
- Community attitudes
- Family relationships

Quality of care
- Satisfaction
- Reliability etc.
- Active support
- Relationship with carers

Social care related quality of life
- Individuals and their carers
- Basic and higher order domains
- Functionings and capabilities

Overall well-being
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
Bedsores/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

![Occupation Graph]

- **Occupation**
  - **Gen pop**
  - **Service users**

- **Occupation Levels**:
  - Ideal
  - OK
  - Some needs
  - High needs

- **Graph Details**
  - X-axis: Occupation Levels
  - Y-axis: Percentage
  - Color Coding:
    - Blue: Gen pop
    - Red: Service users
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

- Ideal
- No needs
- Some needs
- High needs

Control, Occ, P care, Safety, Food, Soc part, Accom, Dignity
Anchoring the scale

\[
\text{SQALY} = (0.203 \times \text{BWS\_weight})^{0.466}
\]

(TTO score where 0 = dead, 1 = "all needs met")

BWS weight

(control level 4 = 0, control level 1 = 1)
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

Hero Weston (SA) 2011
Publications

