

# 'QUALITY OF LIFE FROM THE PERSPECTIVE OF OLDER ADULTS LIVING AT HOME, AND THE ROLE OF SERVICES'

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Faculteit der  
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# OUTLINE

- Dutch care context
- ASCOT-NL project
- Review
- Empirical study

# PROJECT TEAM

Cooperation Medical Humanities (VU Medical Center) and Faculty of Earth and Life Sciences (VU University):



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## Societal partners



## Advisors:

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# DUTCH CONTEXT

## **Social Support Act (2007, 2015)**

- > Municipalities responsible for enabling people to live independently and participate in society for as long as possible
  - > Deinstitutionalization
  - > Cuts
  - > 'Clients in control'
- > Covers general accessible facilities and assistance at home, *eg: social activities, transport, information, support for informal caregivers, assistance with household activities, community centers*

# ASCOT-NL PROJECT

Netherlands Organisation for Scientific Research (NWO)

- > Quality of Life and Health programme
- > Collaboration Humanities and Medical Science

Broader focus required in evaluation of long-term care services

- > Quality of Life rather than health

Focus: evaluation Quality of life of older adults living at home.

- Perspective of older adults
- Role of care services

# ASCOT

ASCOT: Adult Social Care Outcomes Toolkit

PSSRU: Personal Social Services Research Unit (Uni of Kent, LSE)

Measures 'social-care related Quality of Life'

*"What are social services trying to do?"*



- 8 domains
- control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation cleanliness and comfort and dignity
- Translation:
  - Dutch translation and cross-cultural validation of the Adult Social Care Outcomes Toolkit (ASCOT). Van Leeuwen et al. (2015). Doi: 10.1186/s12955-015-0249-x
  - <http://www.pssru.ac.uk/ascot/>

# AIM ASCOT-NL

1. To develop the Dutch version of the ASCOT (ASCOT-NL)
  2. To develop a set of preference weights for the ASCOT-NL
  3. To assess the normative adequacy and applicability of ASCOT-NL for policy purposes
- > Evaluating care services for older adults living at home

Start: June 2014

Finish: June 2018



# APPLICATIONS ASCOT-NL

## ASCOT-NL toolkit

- Preference tool
  - Economic evaluations on macro-level
  - Allocation of resources
- Quality-tool
  - Monitoring and adjusting quality of care
  - For care services organisations and municipalities
  - Possible adjustment ASCOT domains



# ASCOT-NL PROJECT: 3 PHASES

## 1. Concept quality of life older adults

- a) Philosophical reflection
- b) Review qualitative studies
- c) Qualitative empirical research older adults and other stakeholders

## 2. Weighting

## 3. Application



Interdisciplinary project

Philosophical & clinimetric research and analysis

# FASE 1.2: SYSTEMATIC REVIEW

> Question: What are important elements of older adults' quality of life from their own perspective?

- Systematic review

- Selection of papers investigating domains of QoL important for older adults (qualitative)

1. Systematic search

- > Pubmed: 4009
- > Psychinfo: + 2377
- > CINAHL: + 1758

2. Full text sources: 93

3. Analysis 44 remaining articles



*“We feel rejected sometimes, old people. They want to get rid of us... no respect whatsoever. They think we’re in the way. You’re a nuisance, you’re too expensive. Yes it reduces our quality of life.”*

In: Meaning of quality of life for older adults: importance of human functioning components. Levasseur et al.(2009). Doi: 10.1016/j.archger.2008.08.013

# RESULTS: QOL DOMAINS

- **Autonomy**
  - I am able to manage on my own, implying a sense of dignity and not feeling a burden to others
- **Role and occupation**
  - I spend my time as I want with activities that I enjoy or that give me a sense of value
- **Health**
  - I feel healthy
- **Relationships**
  - I have close relationships which makes me feel supported, and I can mean something for others as well
- **Attitude and adaptation**
  - I look on the bright side of life
- **Emotional comfort**
  - I feel emotionally at peace
- **Spirituality**
  - My faith or spirituality helps me to cope, feel thankful and experience growth
- **Home and neighbourhood**
  - I feel secure at home and live in a pleasant and accessible neighbourhood
- **Financial security**
  - I don't feel restricted by my financial situation

## PHASE 1.3: EMPIRICAL QUALITATIVE STUDY

- What are important elements of older adults' quality of life from their own perspective?
  - How do care services contribute to quality of life according to older adults?
- Types of services
  - Help with physical problems such as nursing care
  - Help with mental health problems
  - Support with social problems/activities
  - Support and care for problems in everyday life such as housekeeping, meals services
- Interviews and focusgroups
  - Older adults living at home in different regions in the Netherlands
  - Stakeholder deliberation

# PRELIMINARY RESULTS QUALITATIVE STUDY 1

- Important policy focus: enabling older adults to remain living in their own homes
- Independence is also important for respondents
  - *R: 'You can't make it more difficult for other people. It's not possible. You should do everything you can do for yourself, and what you can't do, you just leave it. That is how we were raised.'*
- Home care services can enable living at home
  - by providing support in daily tasks
  - Supporting adaptation with tools (e.g. mobility scooter)

# PRELIMINARY RESULTS QUALITATIVE STUDY 2

- What people want is not always the same as the goals of services
  - *Regulations, descriptions of tasks*
  - *Computer skills of the domestic help*



*‘So i tell her: you’re quite smart with this thing [mvl computer] yes? So i say: look this up for me and tell me what it says. And so she does, cancelling my television guide. [..] And if I had to do it myself.. Well.. If I had to take care of it, I would not manage to do so. [.] I don’t know how to do these things. But they are not allowed to, so ‘don’t write it down!’*

# DISCUSSION

- Additional domains from qualitative studies
  - Health
  - Attitude and Adaptation
  - Emotional Comfort
  - Environment (home is included but not broader environment)
  - Financial Security
  - Spirituality
- Which domains should be the focus of policy?
  - Should we support QoL domains from the systematic review and/or interviews?
  - Should we evaluate services on these domains?
- What can be consequences of using ASCOT in resource allocation?



# CONCLUDING

## Contact information

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## More information ASCOT-NL

<http://www.emgo.nl/research/quality-of-care/research-projects/1515/measuring-and-valuing-quality-of-life-in-older-adults-with-the-ascot-nl/background/>

Twitter: @ascot\_nl

## ASCOT-UK

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