

# Substitute decision making for elderly people with dementia. Formal and informal representatives and the importance of surrogates for the elderly, relatives and the authorities concerned

<https://neurodegenerationresearch.eu/survey/substitute-decision-making-for-elderly-people-with-dementia-formal-and-informal-representatives-and-the-importance-of-surrogates-for-the-elderly-relatives-and-the-authorities-concerned/>

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### Country

Sweden

## Title of project or programme

Substitute decision making for elderly people with dementia. Formal and informal representatives and the importance of surrogates for the elderly, relatives and the authorities concerned

## Source of funding information

Forte, the Swedish Research Council for Health, Working Life and Welfare

## Total sum awarded (Euro)

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## Start date of award

01/01/2016

## Total duration of award in years

3.0

## The project/programme is most relevant to:

## Alzheimer's disease & other dementias

### Keywords

### Research Abstract

Many elderly with dementia are depending on others to take care of their legal rights and demands. Older people's legal rights, is an area of research that is neglected. The Swedish legislation stresses individual autonomy, which means that the framework does not account for the large group of people who lack decision-making capacity. Sweden has three coexisting forms of representatives; however there is lack of knowledge of the consequences each individual face in this system. A family member, for example, can be an informal representative, without a legal mandate. The latter is the most common form for older people. A court decision is required in order to obtain a legal representative. According the Code relating to Parenthood and Guardianship it is either a support through legal guardian or a replacement by a trustee. There is a lack knowledge of the ethical, practical, economic and health consequences of any form of representatives. The purpose of this exploratory study is to describe and analyze the meaning and significance for older people with dementia to have a representative. The aim is to understand the role both for the older self and for the next of kin. Further issues to analyse are; the elderly person's experience of having a proxy and the relative's description of being a representative as well as having the support of a legal guardian/trustee in the family. The study should also provide an answer to who represent an elderly person with dementia, in which situation and with what mission. The study is based on a mixed methods design with recognition theory as a framework. Four sub studies are planned; Two sub-studies based on personal interviews with elderly with dementia and their family members. An other sub study involves focus group interviews with relatives, formal deputies and chief guardians. Study four is an analyse of social municipality records to examine content, the elderly person influence and the role of representatives involved

### Lay Summary

**Further information available at:**

#### Types:

Investments > €500k

#### Member States:

Sweden

#### Diseases:

Alzheimer's disease & other dementias

#### Years:

2016

#### Database Categories:

N/A

#### Database Tags:

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