

# Ageing with Cerebral Palsy- a study into citizenship

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To gain insight into how people with CP of 40 years or older experience their citizenship and how these adults can be supported in their citizenship. How their citizenship has changed over time. To develop posters for rehabilitation practice to gain...

<b>Ethical review</b>	Approved WMO
<b>Status</b>	Completed
<b>Health condition type</b>	Neurological disorders congenital
<b>Study type</b>	Observational non invasive

## Summary

### ID

NL-OMON49806

### Source

ToetsingOnline

### Brief title

Ageing with Cerebral Palsy and citizenship

### Condition

- Neurological disorders congenital
- Neurological disorders NEC

### Synonym

□ Infantile encephalopathy □ Spastic paralysis

### Research involving

Human

### Sponsors and support

**Primary sponsor:** Hogeschool Rotterdam, Kenniscentrum Zorginnovaties

**Source(s) of monetary or material Support:** Stichting Phelps voor Spastici

## Intervention

**Keyword:** □ Ageing, □ Cerebral Palsy, □ Citizenship, □ Participation

## Outcome measures

### Primary outcome

Before the interviews take place, participants are asked to express their opinion and / or experience of citizenship using the Photovoice method. The participants take pictures of their own lives in which they show what citizenship means to them and what it could or should mean. In the life-course interview, participants talk about the photos they have taken. Analyses will reveal themes of what is important considering ageing with CP and citizenship.

### Secondary outcome

NA

## Study description

### Background summary

Ageing with cerebral palsy (CP) appeals to the adaptive capacity of adults with CP, and healthcare services should be more sensitive to the context, expertise and autonomy of these adults. In other words, the link between citizenship and ageing with CP (from 40 years) seems to be relevant.

### Study objective

To gain insight into how people with CP of 40 years or older experience their citizenship and how these adults can be supported in their citizenship. How their citizenship has changed over time. To develop posters for rehabilitation practice to gain attention for citizenship.

### Study design

A qualitative interview study, using Photovoice. Background characteristics

are retrieved from patient records and a short questionnaire.

### **Study burden and risks**

Subjects will not benefit directly from participation in the study, this will be made clear in the informed consent. Because subjects are adults with CP, they will contribute to a raised awareness for citizenship and ageing in rehabilitation care. Taking photo\*s is embedded in their daily life, so the extra burden is minimal. The interview visit takes about 90 minutes, for which they receive a gift card of € 75,--.

## **Contacts**

### **Public**

Hogeschool Rotterdam, Kenniscentrum Zorginnovaties

Rochussenstraat 168  
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### **Scientific**

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## **Trial sites**

### **Listed location countries**

Netherlands

## **Eligibility criteria**

### **Age**

Adults (18-64 years)

Elderly (65 years and older)

## Inclusion criteria

- \* Documented CP diagnosis;
- \* Age 40 years or older;
- \* Good comprehension of Dutch language.

## Exclusion criteria

- \* Severe learning difficulties (an (estimated) IQ lower than 70) as documented in the patient record;
- \* Severe comorbidity (including depression, severe somatic disorders).

## Study design

### Design

**Study type:** Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

### Recruitment

NL

Recruitment status: Completed

Start date (anticipated): 15-09-2020

Enrollment: 20

Type: Actual

## Ethics review

Approved WMO

Date: 24-08-2020

Application type: First submission

Review commission: METC Leiden-Den Haag-Delft (Leiden)

## Study registrations

### Followed up by the following (possibly more current) registration

No registrations found.

### Other (possibly less up-to-date) registrations in this register

No registrations found.

### In other registers

Register	ID
CCMO	NL72958.058.20

## Study results

Date completed:	09-12-2020
Results posted:	26-11-2021
Actual enrolment:	19

**First publication**  
31-08-2021