

The Two Horizons of Research. Cultural Analysis of How Patients and Scientists Face Each Other in Clinical Trials within the Research on Parkinson's Disease

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Principal Investigators

Markus Idvall

Institution

Lund University

Contact information of lead PI

Country

Sweden

Title of project or programme

The Two Horizons of Research. Cultural Analysis of How Patients and Scientists Face Each Other in Clinical Trials within the Research on Parkinson's Disease

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Swedish Research Council

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€ 250,707

Start date of award

01-01-2014

Total duration of award in years

3.0

The project/programme is most relevant to:

Parkinson's disease & PD-related disorders

Keywords

Research Abstract

Syftet är att undersöka den kulturella förhandling som utspelar sig mellan forskare och patient vid kliniska försök inom den biomedicinska forskningen kring Parkinsons sjukdom i Sverige, Danmark, Norge och Nordamerika från 1980-tal fram till i dag. Fokus riktas mot två kritiska faser för denna förhandling: den initiala rekryteringen av forskningspersoner respektive den avslutande rapporteringen till de forskningspersoner som deltagit. Projektet ska på så vis kartlägga och analysera hur patienter rekryteras till och blir rapporterade om respektive hur forskare rekryterar till och rapporterar om kliniska försök. Projektet bygger på två grundläggande metoder: arkivstudier där målet är att gestalta etnografiskt händelser och sammanhang vid kliniska försök i det förflutna, samt tematiskt orienterade djupintervjuer med patienter och forskare. The aim is to investigate the cultural negotiation between researchers and patients in clinical trials in the biomedical research on Parkinson's disease in Sweden, Denmark, Norway and North America from the 1980s to the present day. The focus is on two critical phases for this negotiation: the initial recruitment of researchers and the final reporting to the research participants who participated. The project will thus map and analyze how patients are recruited and reported on and how researchers recruit and report on clinical trials. The project is based on two basic methods: archival studies where the aim is to form ethnographic events and contexts in clinical trials in the past, as well as thematically oriented deep interviews with patients and researchers.

Lay Summary

Further information available at:

Types:

Investments > €500k

Member States:

Sweden

Diseases:

Parkinson's disease & PD-related disorders

Years:

2016

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