

# **A standardised follow-up model to support people after stroke**

## Development and application using the post-stroke checklist

Akademisk avhandling

Som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentligen försvaras i Hälsovetarbacken, hus 2, i Lokal 2119, Arvid Wallgrens backe, den 18 november kl 9.00.

av Emma Kjörk

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Luleå tekniska universitet, Sverige

### **Avhandlingen baseras på följande delarbeten**

- I. Kjörk, EK, Carlsson. G, Lundgren-Nilsson, Å and Sunnerhagen KS. Experiences, needs, and preferences for follow-up after stroke perceived by people with stroke and healthcare professionals: A focus group study PLoS One 2019;14(10): e0223338.
- II. Kjörk, EK, Carlsson G, Sunnerhagen KS, Lundgren-Nilsson, Å. Experiences using the Post-Stroke Checklist in Sweden with a focus on feasibility and relevance: a mixed-method design BMJ Open 2019.
- III. Kjörk, EK., Gustavsson, M., El-Manzalawy, N., Sunnerhagen, KS. Stroke-related health problems and associated actions identified with the post-stroke checklist among nursing home residents. BMC Cardiovasc Disord 22, 50 (2022).
- IV. Kjörk, EK. Sunnerhagen, KS, Lundgren-Nilsson, Å, Andersson A.K, and Carlsson G. Development of a Digital Tool for People with a Long-Term Condition Using Stroke as a Case Example: A Participatory Design Approach. JMIR Human factors. 2022;9(2):e35478.

# A standardised follow-up model to support people after stroke

- Development and application using the post-stroke checklist

Emma Kjörk

## Abstract

**Objectives:** The need for a standardised follow-up has increased, as more people survive and live with stroke-related consequences. The Swedish national stroke guidelines recommend the use of the post-stroke checklist (PSC) to identify common health problems and provide guidance for further interventions. Physical, cognitive, and psychosocial impairments can lead to unmet needs and limited use of health information. This thesis aimed to explore different modes of PSC delivery, such as face-to-face and, proxy or digital, to understand the perceived usefulness of PSC in different settings after stroke in Sweden. Furthermore, the aim was to explore and identify the health needs among people with stroke.

**Methods:** Four individual studies were carried out using a combination of qualitative and quantitative methods. Focus group discussions were conducted with people, who had a stroke, and healthcare professionals to highlight the need for follow-up (study I) and the experience of using PSC (study II). Perceived health problems were identified via the PSC among people living in their own accommodations (study II) and in nursing homes (study III). In addition, a questionnaire regarding perceived satisfaction with the PSC was conducted (study II and III). Study IV had a participatory approach where a digital tool based on the PSC, Strokehealth™, was developed in close collaboration with patient partners and potential users. Data were collected via focus group discussions, individual interviews, and a web survey.

**Results:** The PSC was perceived useful by patients and healthcare professionals. At the same time, the importance of dialogue and the health professionals' expertise to capture health problems and initiate further efforts were emphasized (study II). The digital pre-visit tool StrokeHealth™ is now available via <http://www.1177.se> and has the potential to help patients prepare for a follow-up visit (Study IV). Findings highlight feelings of being left-out, new health problems discovered after discharge, and experiencing obstacles for seeking care (study I). PSC was able to identify at least one health problem in most participants regardless of stroke severity. A median of at least four health problems per person shows the importance of follow-up and relevance of using the PSC (study II and III).

**Conclusions:** This thesis demonstrates a model for standardised follow-up using the PSC, when used as a digital pre-visit tool, face-to-face, and proxy. Although the results show that the PSC identifies health problems and is perceived as useful, dialogue with the patient and healthcare professionals' expertise are also crucial.

**Keywords:** Stroke, Rehabilitation, Health literacy, Patient empowerment, Patient and care provider communication, Ehealth, Digital tool, Follow-up, Qualitative methods, Co-design, Focus groups

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