

Cover illustration by Adam Viktorsson

A standardised follow-up model to support people after stroke

© 2022 Emma Kjörk

emma.kjork@gu.se, <http://orcid.org/0000-0002-1005-7444>

ISBN 978-91-8009-859-5 (PRINT)

ISBN 978-91-8009-860-1 (PDF)

<http://hdl.handle.net/2077/72553>

Printed in Borås, Sweden 2022
Stema Specialtyprint AB



Illustration “heart and brain” by Michael Wide



"Research is actually to a large extent a structured curiosity"

*Christian Blomstrand,
professor emeritus in neurologi*

A standardised follow-up model to support people after stroke

Development and application using
the post-stroke checklist

Emma Kjörk

*Department of Clinical Neuroscience,
Institute of Neuroscience and Physiology
Sahlgrenska Academy, University of Gothenburg
Gothenburg, Sweden*

ABSTRACT

Background: 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 (e.g., cognition, mobility) and provide guidance for further interventions. Physical, cognitive, and psychosocial impairments can lead to unmet needs and limited use of health information, which in turn negatively affects the health. A thorough Swedish model for standardised follow-up after stroke, including patient preparedness and people with various level of dependency, is lacking. 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: To develop and evaluate a model for standardised follow-up, 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 in connection with follow-up visits (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 to investigate perceived usability regarding pilot versions of the tool in study IV. Qualitative data were analysed thematically according to the focus group and framework methods. Quantitative data were analysed descriptively.

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 of crucial importance. This model could contribute to a more equal follow-up and enhanced patient engagement, in accordance with stroke guidelines.

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

SAMMANFATTNING PÅ SVENSKA

Bakgrund: Behovet av en standardiserad uppföljning har ökat i takt med att fler personer överlever efter en stroke. I de svenska nationella strokeriklinjerna rekommenderas Post-stroke checklistan (PSC) för att identifiera vanliga hälsoproblem (exempelvis inom kognition, rörlighet) och ge vägledning för vidare insatser. Det är vanligt med fysiska, kognitiva och psykosociala hälsoproblem efter en stroke. Dessutom kan svårigheter att använda hälsoinformation påverka hälsan negativt. Det saknas en modell för strukturerad uppföljning som inkluderar digital patientförberedelse och omfattar personer med olika grad av beroende efter stroke. Syftet med avhandlingen var att undersöka användningen av PSC med olika tillvägagångssätt, direkt patientmöte, via personal eller digitalt, för att förstå den upplevda användbarheten av en modell för uppföljning inom hälso- och sjukvården i Sverige. Ett ytterligare syfte var att identifiera hälsorelaterade behov hos personer med stroke.

Metod: För att kunna utveckla och utvärdera en modell för strukturerad uppföljning genomfördes fyra delstudier med en kombination av kvalitativa och kvantitativa metoder. Fokusgruppsdiskussioner genomfördes med personer som haft stroke och vårdpersonal för att belysa behovet av uppföljning (studie I) och upplevelsen av att använda PSC i samband med uppföljningsbesök (studie II). Upplevda hälsoproblem identifierades via PSC bland personer som bor i eget boende (studie II) och på särskilda boenden (studie III). Dessutom besvarades en enkät gällande upplevd nöjdhet med PSC (studie II och III). Studie IV är en deltagarbaserad studie där ett digitalt verktyg baserat på PSC, Strokehälsa™, utvecklats i nära samarbete med patientpartner och användare. Data samlades in via fokusgruppsdiskussioner, individuella intervjuer och en webbenkät för att undersöka upplevd användbarhet av verktyget bland personer med stroke. Kvalitativ data analyserades tematiskt enligt fokusgruppsmetoden och framework metoden. Kvantitativ data bearbetades deskriktivt.

Resultat: PSC upplevdes användbar av patienter och personal. Samtidigt betonades vikten av dialog och personalens kompetens för att fånga hälsoproblem och initiera fortsatta insatser (studie II). Det digitala verktyget Strokehälsa™ finns nu tillgängligt via 1177 och har potential att hjälpa patienten att förbereda sig inför ett uppföljningsbesök (studie IV). Behovet av uppföljning stärks av att personer känner sig övergivna, upptäcker nya hälsoproblem efter utskrivning och upplever hinder för att själva söka vård (studie I). Hos majoriteten av deltagarna identifierades minst ett hälsoproblem

med stöd av PSC oavsett strokens svårighetsgrad. En median på minst fyra hälsoproblem per person visar på vikten av uppföljning och relevansen av att använda PSC (studie II och III).

Konklusion: Denna avhandling visar på en modell för strukturerad uppföljning med stöd av PSC, som sträcker sig från personer som kan använda ett digitalt verktyg till de med stort hjälpbeför där personal för deras talan. Även om resultaten visar att PSC identifierar hälsoproblem och upplevs användbar är det viktigt att vara medveten om att dialogen med patienten och personalens kompetens är av avgörande betydelse. Denna modell kan förhoppningsvis bidra till ökad patientdelaktighet och en mer jämlig uppföljning, i enlighet med strokeriklinjer och hälso- och sjukvårdslagen.

List of papers

This thesis is based on the following studies, referred to in the text by their roman numerals. The papers are published in open access journals and reprinted accordingly.

- 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.
<https://doi.org/10.1371/journal.pone.0223338>
- 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. <https://doi.org/10.1136/bmjopen-2018-028218>.
- 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).
<https://doi.org/10.1186/s12872-022-02466-3>.
- 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.
<https://doi.org/10.2196/35478>.

CONTENT

INTRODUCTION	6
Theoretical perspectives	7
Patient participation in healthcare	7
Health literacy and e-health literacy.....	8
The International Classification of Functioning, disability, and health (ICF)	9
Rehabilitation	10
Stroke and long-term consequences	11
Stroke.....	11
Long-term consequences	11
The healthcare continuum and access to services after stroke.....	13
Access to services according to the needs	13
The Post stroke checklist (PSC)	15
Recommendations for follow-up	16
Knowledge gaps	17
AIMS	17
METHODS	18
Research design and overview.....	18
Development and feasibility assessment	19
Exploring participant experience.....	22
Participants, sampling and setting	24
Procedure and data collection	28
Procedure.....	28
Interview-guide.....	30
Instruments and characteristics.....	30
Data analysis.....	32
Theoretical and epistemological positions.....	33
Ethical considerations	34
RESULTS	35

Participants characteristics.....	35
Need for information and follow-up.....	37
Development and adaptation based on user needs.....	38
Identified health problems and relevance of the PSC.....	41
Different modes of delivery: user experiences and prerequisites	43
DISCUSSION	45
Facilitating patient engagement and increased health literacy.....	45
A common base for follow-up to be individualized	47
Health problems and needs for follow-up.....	50
A complex follow-up intervention: is it feasible?.....	51
Methodological considerations	53
CONCLUSIONS.....	59
FUTURE PERSPECTIVES	60
ACKNOWLEDGEMENT.....	61
FUNDING.....	62
REFERENCES	64
Appendix	

LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
BI	Barthel Index
ICF	International Classification of Functioning, Disability and Health
mRS	modified Rankin Scale
NIHSS	National Institutes of Health Stroke Scale
PSC	Post-stroke checklist
Strokehälsa™	A digital pre-visit tool based on the Post-stroke checklist
SKR	Swedish Association of Local Authorities and Regions
TIA	Transient Ischemic Attack
VGR	Region Västra Götaland
WHO	World Health Organisation
WSO	World Stroke Organisation

DEFINITIONS IN SHORT

Health literacy	The degree to which individuals have the ability to obtain, understand and use health information to make health-related decisions and actions.
Person-centered care	Person-centered care is focused on the needs of the person. Decisions are guided by values, beliefs, and preferences, which in turn support patient engagement.
Patient engagement	This is an umbrella term including patients' active involvement regarding gathering information and decision-making about their health.
Shared decision-making	Patients and healthcare professionals make decisions together.
People with stroke	People who have experienced a stroke
Health problems	In this thesis, both the terms unmet needs and health problems refer to health-related issues perceived by people with stroke. Health problems can be acknowledged as a perceived unmet need.
PSC	Post-stroke checklist includes 11 items and is an easy tool to identify common health problems after stroke during a follow-up visit.
Strokehälsa™ [Strokehealth]	A digital pre-visit tool based on the PSC and health related information.
Digitalisation	Describes a process where digital technologies are used to change e.g., health care to a digital organization.

INTRODUCTION

It is essential to identify people at risk of a recurrent stroke and other health problems to ensure that they receive secondary prevention, optimal treatment, and support after stroke.¹ Accordingly, these multi-faceted needs of people living with stroke demand a proactive approach. Long-term follow-up including a patient who is prepared for the visit and a proactive healthcare team using tools to structure their care, is highly recommended for people with long-term conditions.² In recent years, the awareness of stroke as a long-term condition has been reinforced,³ with growing evidence showing persistent disability⁴ and unmet medical care needs.⁵⁻⁷ Presently, at least 101 million people have had a stroke globally,⁸ and many live with post-stroke consequences due to various long-term physical, cognitive, and emotional disabilities.³ In Sweden, about 25,000 individuals are diagnosed with stroke each year,⁹ and with an aging population the number of people requiring recurrent support from healthcare services is expected to increase.⁸

Easy access to health services is particularly important among people with stroke since their ability to understand the health information and actively engage with health services can be limited.^{10,11} Given that regular follow-up is recommended for people with long-term conditions,² including stroke,¹ one could think a model for follow-up should already be broadly implemented. However, further actions are required. Long-term follow-up after stroke is lacking in most parts of Europe.¹² A re-design of healthcare structure is needed to ensure equitable follow-up adapted to the local context² and current values.¹³ The re-design of healthcare is influenced by increasing focus on person-centered care,¹³ digital health services,¹⁴ and national pathways and guidelines.^{15,16} Implementation of such a complex intervention as follow-up can be supported by easy-to-use tools such as checklists. The 11-item Post-Stroke Checklist (PSC) is a tool which can facilitate the dialogue between the patient and healthcare professionals during a follow-up visit.¹⁷ This thesis aimed to evaluate the use of PSC.

In this thesis, an evaluation and application of the PSC was performed in Swedish context, which included a variety of settings through the healthcare continuum, also encompassing a digital version. The participatory approach is a key element for developing user-friendly and feasible tools.¹⁸ Further, this thesis align with concepts related to the framework for complex interventions¹⁹ and health literacy.²⁰ Factors important for the development and application of a tool such as the PSC will be described along with illumination on how the patient involvement can be enhanced.

Theoretical perspectives

Patient participation in healthcare

Patient-preparedness and a proactive healthcare team is essential to meet the needs of people with long-term conditions.² Accordingly, organisational and individual perspectives must be considered to provide care and support on equal terms in the population. The Swedish Association of Local Authorities and Regions (SKR) has proposed a change in Swedish healthcare system to shift focus from organization to patients, in line with the primary care reform ‘good and close care’.²¹ Hence, a change in the way of working is required, with increased collaboration between municipalities and regions, development of digital tools, competence provision, and supporting self-management. The core to this healthcare shift includes a proactive and person-centered approach.

Person-centred care

Person-centred care is a holistic approach that incorporates people’s contexts, their values, beliefs, and preferences, which in turn support the active engagement.²² Listening to the patient’s narrative, one’s own experiences, is the first step towards a partnership between the patient and the professional. This partnership is central for shared decision-making, where the patient and health professional decide the health choices together. In addition, documentation of person-centred care in the patients’ record is important to emphasize the patient perspective of care. Consequently, when documenting a health plan, which is meaningful for the patient, the patient’s narrative should be combined with clinical investigations. In addition, the plan for long-term follow-up should be included.²² A recent umbrella review highlighted the need for clinician empowerment and cultural change in the healthcare systems to implement person-centred care.¹³ Thus, clinicians need appropriate tools and systems to support person-centred care, including training to increase clinical expertise. Further, collaboration with patients as partners in co-design of healthcare is suggested to improve quality in healthcare systems and provide a foundation for person-centred care.²³

E-health and digital participation

The government and the SKR made an agreement (2016) on an e-health vision stating that Sweden will be the world leader in e-health area. The vision includes “to make it easier for people to achieve good and equal health and welfare, and to develop and strengthen their own resources for increased independence and participation in the life of society.”¹⁴ An important strategy to achieve this goal is to observe patients as co-creators. Thus, prerequisites must be placed so that people can be informed and actively engaged with the

healthcare services. Digitalisation in healthcare requires consideration of several perspectives such as equitability, efficiency, and gender-equality. Furthermore, digital solutions should be user-friendly, in accordance with security regulations, and accessible to the users.¹⁴

Accessibility of the digital systems can increase if they are designed for a wide range of potential users.^{14,24} The concept “design for all” or “universal design” is recommended and implies that people should be able to use the digital services regardless of functional difficulties, disability, or age. Consequently, the attempt is to design digital solutions which are easily accessible to most people without adaptations. In Sweden, the virtual national patient portal 1177 has been broadly used and incorporates several services and tools such as pre-visit forms to be filled in before a clinical visit.²⁵ The tools are accessible to anyone who has an account at 1177.se.

Health literacy and e-health literacy

Health literacy can be defined as “the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others”.²⁰ Health literacy is an important determinant of health as it empowers individuals to take responsibility for their own health.²⁶ Importantly, research shows that people with long-term conditions, such as stroke, have more difficulties to read and understand the health information compared to a normal population.¹¹ This limits their capacity to engage with healthcare services, impacting their health outcomes. A person’s capacity to obtain and use health information can also vary depending on the context, culture, and setting.²⁶ Accordingly, both personal and organizational factors are involved such as the communication skills, health related knowledge, and healthcare settings characteristics.

Health literacy can include both the personal and organisational health literacy.²⁰ An important part of *personal health literacy* is the ability to make informed decisions, use health information, and choose appropriate services. *Organisational health literacy* is important to equally enable individuals to understand and use the health information.²⁰ Examples of attributes for health literate organisations include use of strategies in interpersonal communication, confirming patients’ understanding of information, provide easy access to health information and services, and design materials that are easy to understand and actionable.²⁷ Digital health services has become more common and demonstrate a risk of inequalities for people with low *e-health literacy*, and hence, difficulty in using the digital health services.²⁸ Therefore, when developing e-health services, following domains in the e-health literacy

framework are suggested to be considered: capability to process information, feeling safe and in control, and motivation to use and engage with the digital services.²⁹

People with complex health conditions can be easily overlooked within health organisations. Thus, organisations should be responsive to the patients' needs and should make the health information accessible, simultaneously adapting to health literacy strengths and limitations.³⁰ A service that is responsive enables the patients to understand their own health needs and to actively engage with the health professional. After a stroke, commonly a person approaches a primary healthcare and receives a service (Figure 1). However, is the health service responsive to patient's needs?

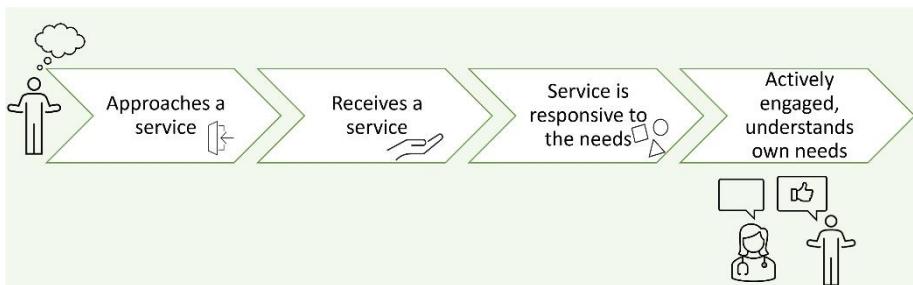


Figure 1. An illustration showing active engagement of patients towards own health when health services are responsive to patient needs.

After a stroke, people may have difficulties in accessing health services, and hence, involved in their own care.¹⁰ Therefore, special focus should be on standardising and optimising strategies to help people. The standardised follow-up model presented in this thesis, including the PSC, aim to increase health literacy by providing opportunities to address issues and actively engage. A healthcare service adapting to people's multidimensional health literacy needs is well in line with a person-centred care.

The International Classification of Functioning, disability, and health (ICF)

As per World Health Organization (WHO): health can be defined as “a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity”.³¹ The International Classification of Functioning, disability, and health (ICF)³² is based on a bio-psycho-social approach where disability includes both the medical and societal perspectives. There are two main parts in ICF: (1) functioning (body function and structures,

activities, and participation) and (2) contextual factors (environmental and personal) (Figure 2).³²

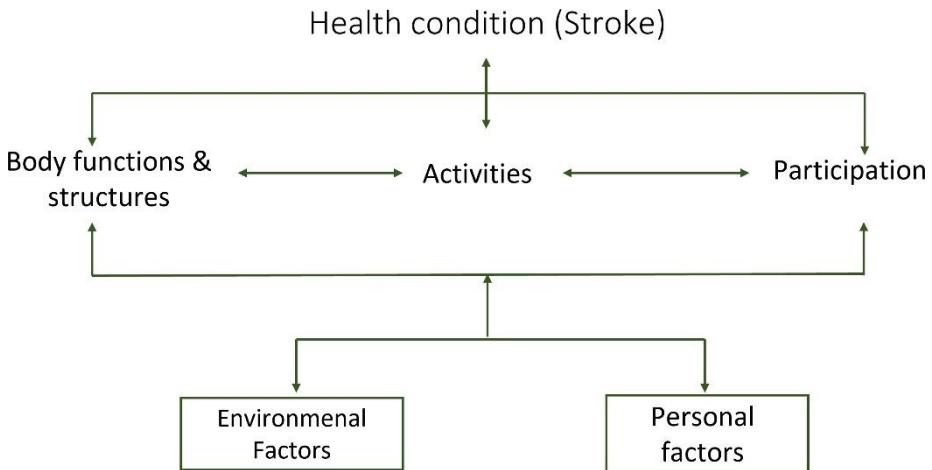


Figure 2. An illustration of the International Classification of Functioning, disability, and health (ICF) framework and how different parts are connected and influences one another.

In this thesis, the dynamic ICF framework is the basis of my view on how a health condition such as stroke can be understood. Further, different parts of ICF are connected and influenced by one another, e.g., functioning can be restricted by motor impairment, leading to an activity limitation, which in turn reduces the level of participation e.g., working. However, contextual factors (environmental factors such as follow-up services) can affect the body function, activity, and participation, and thereby have influence on people's health.

Rehabilitation

According to WHO: "Rehabilitation addresses the impact of a health condition on a person's everyday life by optimizing their functioning and reducing their experience of disability. Rehabilitation expands the focus of health beyond preventative and curative care to ensure people with a health condition can remain as independent as possible and participate in education, work, and meaningful life roles."³³ Notably, people may need rehabilitation for different reasons, for instance, after a disease or due to age-related decline in function.

Normally, rehabilitation after a stroke involves several professionals such as occupational therapist, physiotherapist, nurse, speech therapist, and psychologist. However, this thesis mainly focuses on patient needs rather than

on professionals involved in addressing those needs. In Sweden, as in other countries, contextual variations exist regarding the availability of various professionals in the multi-disciplinary team.

Stroke and long-term consequences

Stroke

Stroke is characterized as “rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin”.³⁴ Furthermore, stroke includes different subtypes (ischemic or haemorrhagic) based on the disease mechanism. Ischemic stroke occurs when a blood vessel is obstructed leading to disturbed blood flow to the brain. Haemorrhagic stroke is caused by a focal collection of blood due to a rupture of a vessel, in the absence of a trauma. The haemorrhagic stroke is classified as intracerebral or subarachnoid depending on the site of the bleeding.³⁵ In 2020, about 86% and 13% individuals had ischemic stroke and intracerebral haemorrhage, respectively, in Sweden.⁹

Globally, stroke is one of the most common medical conditions and the third largest cause of death and disability.⁸ Lately, medical treatments have improved, leading to more people surviving a stroke. Additionally, the global trend shows that the absolute number of people with stroke has increased and will continue to increase due to growing and aging population.⁸ Moreover, people with stroke often live with various consequences for many years, making stroke as one of the conditions with the third highest need for rehabilitation globally.⁴ Each year in Sweden, about 25,000 individuals are diagnosed with stroke and 1 in 5 is at age of <65 years.³⁶ In 2020, the mean age for stroke was 75 years. As compared to men, females were in average four years older and lived more often in nursing home before stroke. Out of all patients with stroke who assessed with National Institutes of Health Stroke Scale (NIHSS) during hospitalisation, 66% had a mild stroke (0–5 points) with a median of 3 point and only 5% had a severe stroke (≥ 24 points).⁹

Long-term consequences

Recovery and rehabilitation process

The long-term outcome after a stroke is influenced by the size and site of the acute stroke and the recovery process.³⁷ In the acute phase after a stroke, various neurological deficits are common with various levels of impairments, including motor function (50-85%), cognitive (50%), and communication

difficulties (30%).¹ It has been suggested that the stroke recovery (body function and activity) follows a pattern with initial fast recovery followed by a plateau after 6 months, defined as the chronic phase.³⁷ However, the recovery process is complex; constrained induced therapy has shown that functions at the body and activity levels can improve in the chronic phase as well.¹⁶ However, it is important that both the patients with stroke and caregivers report unmet needs beyond medical aspects such as those related to information and re-integration into the community.⁶

Growing evidences show persisting long-term consequences after a stroke, well beyond the first year post-stroke,³⁸ and ‘life after stroke’ has recently been expressed as a priority target according to the Stroke Action plan for Europe 2030.¹ About 20% of people with stroke live at least 15 years after the event and many have various functional, cognitive, and psychological issues.³ Furthermore, a stroke can also be defined as mild, with less visible symptoms such as attention issues, fatigue, anxiety, and memory problems.³⁹ Altogether, a stroke often affects people’s lives in many ways, leading to limited participation in work and other activities.³⁹ Accordingly, rehabilitation after a stroke is a continuous gradually adjusting process and with time people tend to focus more on daily life and family issues rather than the manifestations of stroke.⁴⁰ Furthermore, one-third of the patients with stroke suffer from depression within five years after stroke.⁴¹

Perceived health problems and unmet needs

People with stroke have long-term needs including need for healthcare services such as rehabilitation, home care, and various kinds of support, according to the ICF framework.⁴² However, the term unmet needs and post-stroke health problems are defined and used in different ways in research.^{6,7,17,43} In this thesis, both the terms unmet needs and health problems refer to health-related issues perceived by people with stroke. Health problems identified using the PSC can be acknowledged as a perceived unmet need during the face-to-face conversation with the health professional.¹⁷ However, patients do not always consider health issues as unmet needs that require intervention by the healthcare services.⁴⁴

In a systematic review of unmet needs perceived by people with stroke, a median of 74% patients reported at least one unmet need. Common unmet needs were related to cognition (74.6%), memory/attention/concentration (45.0%), fatigue (47.4 %), emotion/mood (39.0%), swallowing (31.2%), pain (19.4%), continence (19.3%), mobility (20.7%), daily occupation/living (19.3%), and leisure/hobbies (22.1%).⁷ When health problems were identified with the PSC across seven countries, cognition (44.3%), life after stroke (such

as work and participation) (42.9%), mood (39.0%), mobility (38.0%), and activities of daily living (36.6%) were most commonly reported.⁴⁵ Both of these studies reflected the wide range of health problems among community dwelling people with stroke.^{7,45} However, the complex needs faced by people living in nursing homes with severe stroke and high level of dependency may not be addressed adequately. According to a review, stroke specific care, rehabilitation, and secondary stroke prevention are often insufficient in long-term facilities.⁴⁶ Furthermore, unfulfilled rehabilitation needs are associated with dependency, higher age, depression, and pain,⁴⁷ and observed with residents in nursing homes.^{48,49}

The need for a standardised follow-up is confirmed by research showing that 1/6 patients deteriorate in Activities of daily living (ADL) between 3 and 12 months after stroke,⁵⁰ and a large proportion of these patients showed unmet long-term needs.^{5,47} Nevertheless, perceived involvement in care and treatment, and a lower impact on participation are important factors for meeting rehabilitation needs six years after a stroke.⁵¹ Thus, modifiable factors such as perceived patient involvement can guide the design of a long-term follow-up model.

The healthcare continuum and access to services after stroke

Access to services according to the needs

Organisation of health, social services, and welfare in Sweden

The National Board of Health and Welfare works to “ensure good health, social welfare and high-quality health and social care on equal terms for the whole Swedish population”.⁵² Thus, health and medical care, social services, and disease prevention are heavily subsidised in Sweden. The welfare system provides financial security to people who are sick or elderly. Furthermore, society’s social services include care and support to people with disabilities and the elderly. Although equality is the goal, local variations may exist in the application of services. In Sweden, there are three levels of government administrations: national, regional (includes 21 counties), and local (includes 290 municipalities).⁵²

Access to stroke services

Dedicated stroke units with a multi-disciplinary team approach have been found beneficial in the acute phase as well as in long-term care after stroke. Thus, people treated at stroke units were more likely to be alive, live in their

own home, and independent in daily life, one year post-stroke.⁵³ In 2020, the median stay in the acute hospital setting was 7 days in Sweden.⁹ Twenty percent were discharged to nursing homes, and after three months, 10% were living in permanent nursing homes. Currently, organised rehabilitation units after the acute care are lacking in many places in Sweden and not equally accessible for all. A feeling of being abandoned is common in people with stroke and their care givers, according to a comprehensive review of qualitative studies in a primary and community context.¹⁰ Furthermore, people have difficulties to access the health services over time. One reason can be cognitive impairment,⁵⁴ leading to difficulties in understanding the health information, finding health services, and communicating the needs in relation to treatment options.^{10,11} Moreover, problems perceived as invisible to others challenges patients' ability to explain their experience.⁵⁵

Insufficient follow-up and inappropriate information constitute barriers for people to access the health services. Accordingly, suggested improvements include: (1) follow-up to increase access to services and for continuity of care and (2) timely provision of providing stroke-related information to patients to enhance self-management and health literacy.¹⁰ Recurrent information and active involvement with possibility to ask questions have shown effects on the patients' mood.⁵⁶ Potentially, digitalization in healthcare can further aid involvement of patients in their own care and self-management.¹⁴ However, e-health literacy is often low among people with long-term conditions, including stroke,¹¹ which in turn can lead to a digital exclusion.^{28,57} Digital pre-visit tools have been developed for various conditions to enhance patient involvement.^{58,59} However, a focus on user experiences and service design is often lacking in advanced technologies e.g., health platforms.⁶⁰ Hence, digital tools should be designed to increase the usability and accessibility.

Currently, in Sweden, a standardised follow-up is not broadly implemented for all patients with stroke. Unfortunately, national data on follow-up is scarce and not well validated. Furthermore, the content of the visits or compliance to suggested national guidelines are not registered. Based on the clinical experience and collegial communication, there are considerable variations among the health services regarding time points and content of the follow-ups. Follow-up visits are offered in primary or specialised out-patient care. However, all patients with stroke are not included in these follow-ups e.g., residents living in nursing homes. There is a risk of people being overlooked in the healthcare system that lacks the intervention and support.^{10,61}

The Post stroke checklist (PSC)

The PSC is the main topic of this thesis (see appendix 1). The PSC⁴³ is endorsed by the World Stroke Organisation (WSO) and comprises 11 items created for identifying post-stroke problems. The PSC was developed by the Global Stroke Community Advisory Panel (GSCAP) that includes 21 stroke experts from Europe, Canada, Asia, Australia, and the United States of America. Further, the PSC was developed according to a Delphi process and was in line with the ICF core sets for stroke. The GSCAP included experts in neurorehabilitation, stroke neurology, physical medicine, older adults care, and rehabilitation. Furthermore, stakeholders representing the post-stroke care continuum and people with stroke were represented in the development process. Problem areas, to be included in the checklist, were selected based on the impact on patients' quality of life in combination with availability of evidence-based interventions.⁴³

The final version of the PSC was completed when consensus was reached on the following items: secondary prevention, activities of daily living, mobility, spasticity, pain, incontinence, communication, mood, cognition, life after stroke, and relationship with family. The response scale includes 'yes' and 'no' and recommended referrals adjacent to each problem area. An example of a question is: "Since your stroke or last assessment, are you finding it more difficult to communicate with others?" with a referral option: "If yes, refer to specialist Speech and Language Therapist for further assessment".⁴³

The PSC is recommended in the national guidelines in Sweden¹⁶ and is currently used in several countries such as Australia, China, Italy, Singapore, Germany, and the United Kingdom.⁴⁵ Various mode of PSC delivery to patients has been applied such as face-to-face administration by the healthcare staff with a paper version¹⁷ or a digital mode,⁶² by telephone, or sent and completed by patients via email.⁴⁵ Furthermore, adapted versions have been used in conjunction with comprehensive follow-up approaches,⁶³⁻⁶⁵ including video consultation,⁶⁴ or a digital platform completed by the patient before a visit.^{60,65} There are checklists based on the PSC which include additional items, revised text, and layout.^{63,66} Notably, standardised procedures and cross-cultural validations of modified versions are lacking. Furthermore, patients, next-of-kin, or caregivers are suggested to complete the checklist despite its content directed to staff.⁶⁶ However, one patient checklist has been developed, and is based on focus group discussions with people with stroke.⁶⁷ Accordingly, information, items, and amendments are directed to patients, and differ from the PSC originally developed to support the dialogue during a follow-up visit.

Recommendations for follow-up

Long-term follow-up and support after stroke are insufficient in most parts of Europe¹² even though recommended in Action Plan for stroke in Europe 2018–2030¹ and national stroke guidelines.¹ As stroke is associated with many aspects and prolonged consequences, long-term care for patients with stroke has to be multifaceted rather than with a narrow focus on reducing mortality.³ Accordingly, a standardised comprehensive follow-up program is required to prevent another stroke, reduce complications, support recovery, prevent physical decline, and improve quality of life.¹

Action plan for stroke target 2030 recommends holistic coordinated support with follow-ups at three to six-months and annually thereafter.¹ Action plans and roadmaps are developed to enhance the delivery of more equitable stroke care, and to be further adapted to the local and culturally relevant standards. In Sweden, a person-centred pathway for stroke and Transient ischemic attack (TIA) has recently been launched, which includes recommendations for structured follow-up.¹⁵ The recommendations suggest: (1) patient preparation, (2) a follow-up visit using a validated checklist e.g., the PSC, and (3) a team assessment with easy access to multi-disciplinary team members. This model aims to prompt referrals, support possibility for recurrent rehabilitation, and deliver targeted interventions after the acute phase.

In a recent randomised study (the CARD study), a comprehensive 3-month follow-up with a multi-disciplinary team reduced the cardiovascular risk, and improved the functional outcome and health-related quality of life among people after stroke.⁶⁰ Furthermore, the feasibility of implementing a comprehensive follow-up has been shown in a Swedish context. Accordingly, a face-to-face visit using a modified version of the PSC followed by a multi-disciplinary team round suggested interventions related to the identified health problems or secondary prevention for 85% of the patients.⁶³ Less is known regarding information provision in connection with follow-up and its impact on self-management and behavioural changes.⁶⁸ A policy analysis of six-month follow-ups in the UK suggests the format and timing to be patient-led. Further, in a rehabilitation context, more consistent information and integrated self-management can be provided through-out the follow-up care pathway. Moreover, the authors suggest considering targeted follow-up, especially because the stroke population is heterogenous, and people often are associated with co-morbidities.⁶⁸

Knowledge gaps

The validated and widespread PSC has been suggested as a tool to identify post stroke health problems and facilitate referrals after stroke.⁴³ Although the PSC was previously evaluated as feasible and useful,¹⁷ knowledge about the use of PSC in a Swedish healthcare context was lacking during initiation of current studies. In addition, research on incidences of specific post-stroke problems in a long-term perspective,¹ also including people living in nursing homes, were scarce. Studies in this thesis were collected when stroke guidelines were revised and pathways for stroke and TIA were in development in Sweden, and hence, the findings were incorporated in parallel during the preparation of this thesis. In conclusion, the high prevalence of people with stroke and the risk of unmet needs highlights the importance of a standardised follow-up model.

AIMS

Follow-up after stroke is influenced by several factors such as patients, healthcare professionals, and healthcare systems. Overall, 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 healthcare settings after stroke in Sweden. Furthermore, the aim was to explore and identify the health needs among people with stroke.

The specific objectives were:

- I. To explore the experiences, needs, and preferences regarding follow-up perceived by people with stroke and healthcare professionals.
- II. To evaluate how people with stroke and healthcare professionals perceive the use of the PSC, with a focus on feasibility and relevance.
- III. To use the PSC to identify the extent of health problems, and how they were addressed in nursing home residents (who have had stroke) in Sweden. Additionally, to investigate the feasibility of the checklist in context to a nursing home.
- IV. To develop a digital pre-visit tool and explore potential end user's perceptions prior to testing it in a clinical setting, using a participatory approach with stroke as a case example.

METHODS

Research design and overview

The overall study design in the thesis is explorative with a combination of qualitative and quantitative methods.⁶⁹ The various data collection methods and samples, in the four studies, provide a deeper understanding of the need for follow-ups and feasibility of using the PSC in different contexts in Sweden (Table 1). Study I explored the perceived need of follow-ups. In study II, the PSC was delivered face-to-face during consultation with the patient, while the PSC was completed solely by proxy, the nursing home staff, in study III. Further, a digital mode of the PSC was completed by people with stroke in study IV.

Table 1. Overview of the four studies.

	Study I	Study II	Study III	Study IV
Period	2015	2015	2019-2020	2017-2020
Study design	Qualitative explorative	Qualitative and quantitative explorative (Feasibility)	Cross-sectional observational (Mapping/ feasibility)	Participatory design with qualitative and quantitative (Development)
Recruitment	Purposive	Consecutive and purposive	Convenience	Purposive
Population and sample size (n)	People with stroke (n=10) and HP (n=8), out-patient care	People with stroke (n=46) and HP (n=10), out-patient care	Residents with stroke (n=49) and staff (n=45)	People with stroke, community dwelling (n=22)
Setting	Clinical follow-up visit after stroke.	Clinical follow-up visit after stroke.	Nursing homes.	Rehabilitation primary care and patient org.
Data collection	Focus-groups	PSC Focus-groups Questionnaires	PSC Barthel mRS	PSC (digital) Focus-groups Interviews Questionnaire
Analysis	Focus group analysis	Focus group analysis Descriptives	Descriptives	Frame-work analysis. Descriptives
Ethical approval	2014: 521-14	2014: 521-14	2018: 219-18/ 2019-00960	2017: 556-17/ 2020-03324
Publication	Published	Published	Published	Published

PSC=Post-stroke checklist. mRS=modified Rankin Scale. HP=Health professionals.

Development and feasibility assessment

Complex interventions

The new Medical Research Council (MRC) framework for developing and evaluating complex interventions supports researchers when designing interventions and choosing appropriate methods¹⁹ (Figure 3).

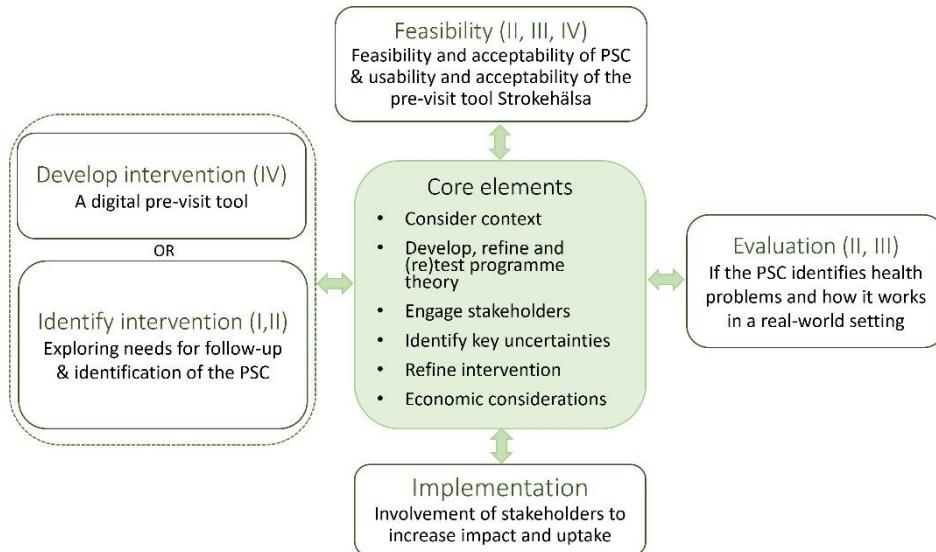


Figure 3. A description of the studies included in this thesis in relation to the new model for the development and evaluation of complex interventions. The figure is modified based on the model updated in 2021 (Skivington, Craig et.al <https://creativecommons.org/licenses/by/4.0/>).

The process is divided into four phases.¹⁹ (1) The *developing or identifying phase* involves the entire design process including conceptualisation and planning of an intervention. This can also include adaptations of an intervention to another application, context, or population. (2) The *feasibility phase* assesses the intervention and the accepted benefits on aspects such as content, acceptability, and if providers have the capacity to use the intervention. The results can bring insights for refinements before a larger evaluation. (3) The *evaluation phase* assesses aspects such as effectiveness of the intervention, how the intervention works in relation to the real-world context, and if the intervention leads to a system change. Mixed methods and qualitative studies can be well suited for such research. (4) The *implementation phase* focuses on analysing the feasibility of adoption and use of the intervention in real world situations. It is suggested that the implementation factors should be considered early in the development process and through different phases. The core elements presented in Figure 3 should be considered

before deciding on the research process,¹⁹ e.g., if stakeholders find the intervention difficult to understand during pilot-testing, the research should be refined before moving on to the evaluation phase.

The MRC can be related to the studies in this thesis as follows: The need for follow-up was *identified* through a qualitative design in study I. Further, the internationally developed PSC⁴³ was *identified* as a potential tool to enhance follow-up. Work conducted prior to study II included a forward-back-word translation and validation of the PSC in a Swedish context. The *feasibility* of using the PSC to aid follow-up and identify health problems were *evaluated* in study II and study III within different clinical settings. Knowledge gained from stakeholders, people with stroke, and health professionals in the first two studies led to the *identification* of a need for patient-preparedness before a follow-up visit. Accordingly, a digital pre-visit tool called Strokehälsa™, in study IV, was *developed* and pilot-tested through a participatory co-design approach^{18,70} using mixed methods.⁶⁹ According to the MRC, continuous refinements and re-tests were applied together with the stakeholder engagement, as per the participatory and service design approaches (see section below).

Participatory and service design

A participatory approach was chosen for the studies in the thesis in line with the MRC framework, emphasizing the stakeholder engagement.¹⁹ Further, participatory co-design approaches emphasize a collective creativity where stakeholders, e.g., researchers, patients, and healthcare staff, work together throughout the design process.¹⁸ Potential end-users are visualised as experts based on their experiences and engagement; some users can become partners in the research team.^{18,70} In study IV, when Strokehälsa™ was co-designed, a patient partner was involved and part of our research team.

A combination of service design and co-design approaches was shown to be beneficial to understand the users' needs in relation to technologies or processes.⁷¹ Service design is a creative, human-centred approach which emphasises on understanding the patients' experiences in order to find solutions to complex problems.⁷² One example of a solution is development of digital health tools. This holistic service design approach is important to capture the experience of multiple stakeholders. Furthermore, the emphasis is on the holistic experience of the service rather than on separate elements (such as only the text not incorporated in a digital tool).

Service design principles were followed in study IV, which were in line with the MRC frameworks, emphasizing the re-fine and re-test of an intervention.¹⁹

The six service design principles are: (1) Human-focused; exploring experiences of potential users, (2) collaborative; active engagement of stakeholders, (3) iterative; explorative and adaptive towards implementation, (4) sequential; visualize a service as a set of interrelated actions, (5) real; needs and ideas should be explored and prototyped in real e.g., a digital reality, (6) holistic; meet the needs of stakeholders through the whole service. For a successful implementation, the meaning value for all users must be taken into account and how the team can use the tool as a way to change their routines to improve the services.⁷³ The “real problem” and specific goals of the project are important to identify before selecting tailored methods and stakeholder involvement in different phases.^{71,72}

A range of different methods can be applied to create experiences and aid a design process, such as personas, mapping the patient journey, qualitative research, and prototypes.⁷² Several of these methods were used in study IV: first, different ‘*personas*’ was created to represent people in the potential user group to understand the users’ needs (Figure 4).

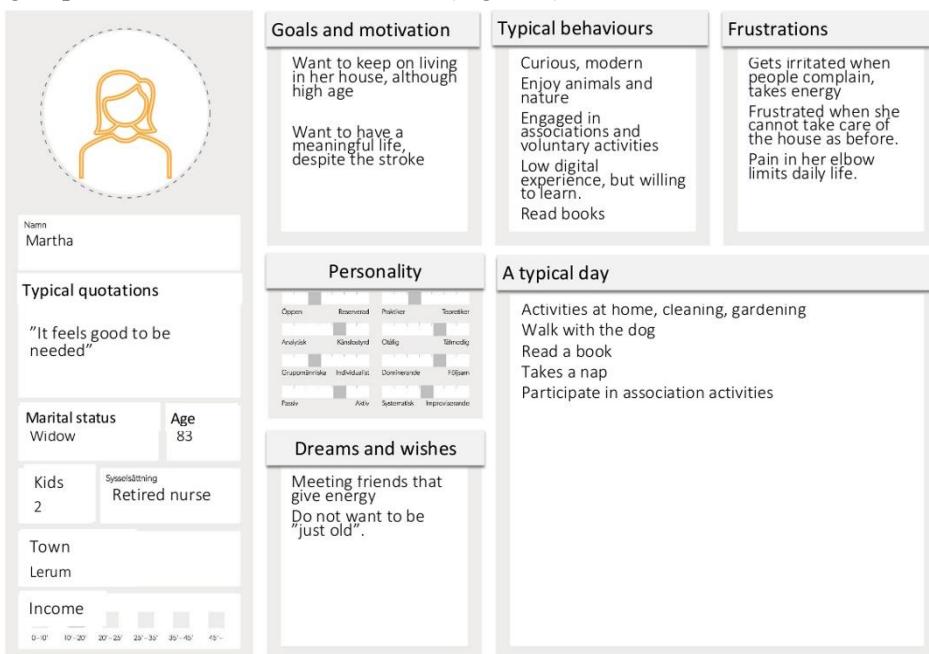


Figure 4. An example of a persona created, in study IV, to increase empathy for the potential user group.

Second, mapping a *patient journey*, including touch points for the patients in context to follow-up, e.g., 1) discharge, 2) at home, 3) invitation and preparation, 4) follow-up using the PSC 5) agreement regarding further plans,

6) access to a multi-disciplinary team 7) followed by support and self-management including appropriate visits and referrals (Figure 5). Third, focus groups and individual interviews were used to explore stakeholders needs, create new ideas, and inform prototypes. Finally, *prototypes* and pilot versions of Strokehälsa™ were created and evaluated by stakeholders to find alternative solutions.

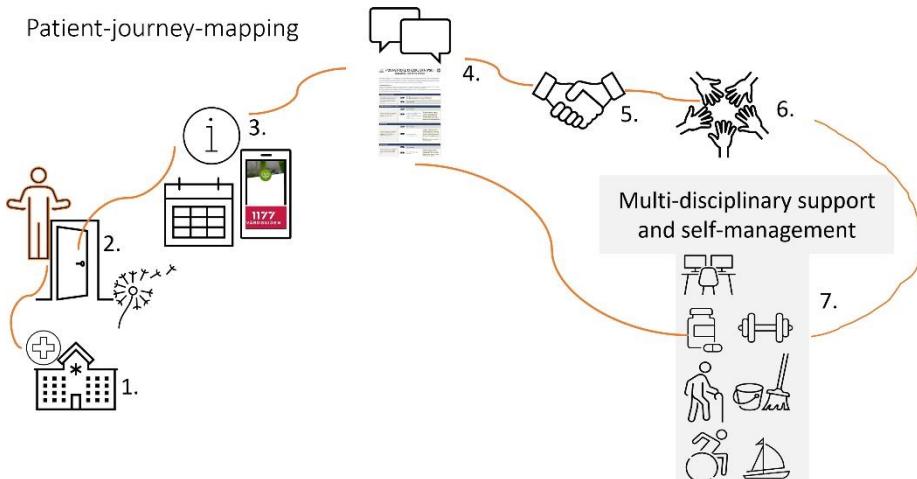


Figure 5. Illustration of a patient-journey-mapping created in study IV, comprising patients' potential touchpoints from discharge to follow-up and further interventions or support.

Exploring participant experience

Qualitative interviews and focus groups

In qualitative research peoples' subjective experiences of a phenomenon are explored.⁷⁴ To explore the phenomenon under study, the PSC, participants' experiences related to the use as well as their experience of a specific 'thing' (the PSC), referred to as an interpretative approach, was applied to understand these complex interventions.⁷⁵ Interviews are a common qualitative method used to explore people's feelings, thoughts, and experiences of the phenomenon under study.⁷⁶ Hence, during the interview situation, it is important to create an open atmosphere to build trust and facilitate participants' willingness to share their views.

Focus group discussions^{77,78} is an established method commonly used for instrument development, feasibility studies,⁷⁹ and disability research.⁸⁰ Focus group methodology can provide a broad understanding,⁷⁸ explore user perceptions, and identify suggestions⁸⁰ e.g., identifying suggestions related to follow-up using the PSC. When deciding the composition of focus groups, it

is recommended to aim for homogeneity i.e., patients who have had a stroke and heterogeneity i.e., demographics. The group interaction stimulates the participants to share their views in interaction with others, which contributes to a collective understanding leading to new knowledge.^{77,78} The moderator's role in the focus groups is to deepen the discussions according to the aim and ensure everyone is heard. Participants are encouraged to respond and compare experiences with each other openly, stimulating different opinions.

In contrast, *individual interviews* can provide a deeper understanding of individual experiences and create conditions to talk about different subjects or possible misunderstandings⁷⁶ that can be missed in a group discussion. Furthermore, *cognitive interviewing* is a commonly used method to evaluate how well the questions meet the purpose of the questionnaire.⁸¹ Within cognitive interviewing, techniques such as 'think aloud' and 'probes' can be used. People are encouraged to 'think aloud' while answering to the specific questions in the questionnaire, which is often followed by probes to further deepen the information. The data from cognitive interviews can provide insights on how participants interpret, if they have understanding difficulties, or other factors influencing the patients' ability to answer.

To ensure that the interviews and focus groups follow the topic, a semi-structured interview guide consisting of open-ended questions are recommended.^{76,77} During the interviews and focus group discussions, supplementary questions and probes can be applied by the interviewer/moderator to ensure depth in the descriptions.⁷⁶ Moreover, the validity can be enhanced by asking participants if the information was correctly understood and sum up at the end of the interviews or focus groups.^{76,77}

To maintain trustworthiness in a qualitative study, the following criteria should be considered: credibility, dependability, confirmability, and transferability.^{82,83} Quantitative equivalent of these terms are mentioned in the brackets in further description. *Credibility* (internal validity) demonstrates how well the findings describe the participants' experiences and reflect the situation explored. *Dependability* (reliability) reflects on whether the process is described in a way so that the study can be repeated. A thorough description of the procedure, an interview guide, and reading transcripts by several authors increases dependability. *Confirmability* (objectivity) displays if the findings can be confirmed by other researchers and to what extent the findings matches according to participants own words. To maintain credibility and confirmability, a close collaboration and discussion between authors regarding alternative interpretation of data is recommended. *Transferability* (external validity) indicates if the findings are described in a way that others can judge

if the findings can be applicable in other contexts. A purposive sampling together with a thorough description of the study context and participants increases transferability.⁸² *Reflexivity* includes awareness on preconceptions such as researchers' prior knowledge and experience. Preconceptions are deemed as an element that influences the data analysis and interpretation. To enhance rigor and reflexivity, systematic notes including reflections can be used alongside the data collection and analysis.⁸³

Participants, sampling and setting

In this thesis, the term people, or residents 'with stroke' is used to describe people who have had a stroke. Community dwelling people with stroke refers to people who are living in their own homes, while residents refer to people with stroke living in nursing homes. Healthcare professionals are people involved in out-patient clinics in specialized or primary healthcare and care staff refers to professionals working in a nursing home setting. Participants refer to either people who experienced a stroke or professionals included in the studies.

Study participants were recruited between 2015 and 2020 from two regions in Sweden (Västra Götaland (VGR) and Södermanland). Participants were recruited from a range of settings, representing urban and rural, and included university hospital, primary healthcare and primary care rehabilitation unit, local organisations, and nursing homes (Figure 6). All participating people with stroke lived in their own home except in study III where residents lived in nursing homes. In this thesis, people with stroke range from those in need of continuous assistance to those having potential to take responsibility of their own health and can use digital devices.

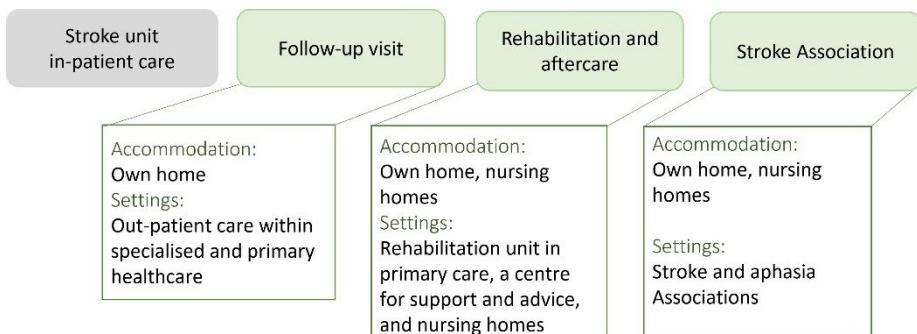


Figure 6. Overview of the population and study settings represented in the thesis through the continuum of care in the sub-acute and long-term perspective.

Study I: Based on the community-dwelling people with stroke in study II, a purposive sampling was performed of those willing to participate in a focus group (Figure 7). Inclusion criteria were people with stroke and healthcare professionals, participating in a clinical follow-up visit after stroke. Due to the focus group design, people with severe cognitive impairment or insufficient Swedish were excluded. A total of 18 participants (10 people with stroke and 8 health professionals) were included.

Study II: People with stroke were consecutively recruited at three selected outpatient care settings in primary or specialized care related to a stroke unit. These follow-up visits were directed to people living in their own home in VGR in Sweden. The healthcare professionals responsible for the visits at each site, a physician, occupational therapist, or nurse, were recruited to the study. Patients received oral and written information about the study before the follow-up visit when the PSC was to be used. To achieve a variance in the groups regarding demographics, a purposive sampling was performed among those willing to participate in a focus group. Inclusion criteria were people who have had a stroke, regardless of the time of onset. Cognitive impairment or insufficient Swedish would have made the response to the PSC items unreliable, and hence, excluded from the study. Additionally, patients and Healthcare professionals were invited to participate in a focus group discussion (see study I). A total of 46 patients and 10 healthcare professionals participated in study II (Figure 7).

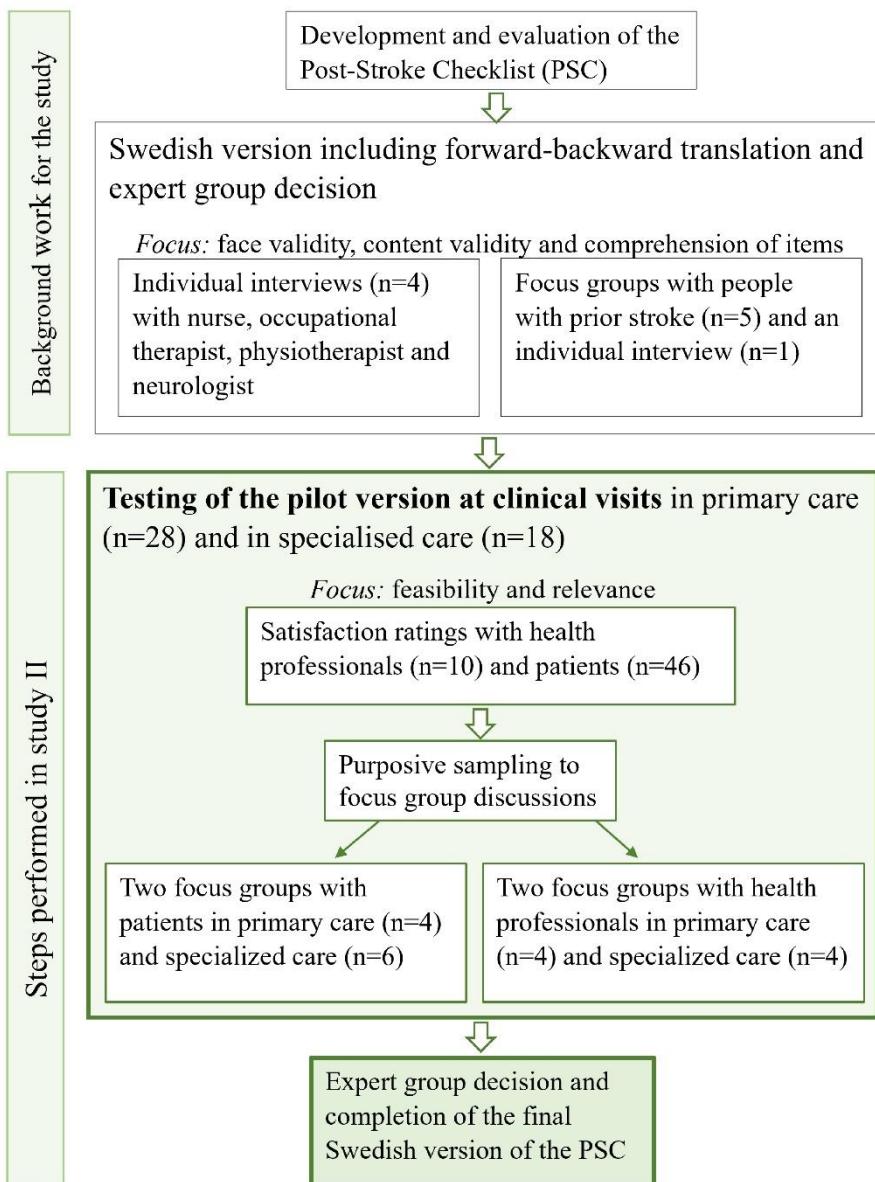


Figure 7. Flowchart of the participants' recruitment and sampling in study I and II (adapted from paper II).

Study III: Managers in the nursing homes and selected nurses were contacted through e-mail as well as telephone by the researchers (EK, MG) regarding participation. Of the 54 approached nursing homes in VGR and the region of Södermanland, 20 participated (Figure 8). Eligible residents were identified by

nurses via resident charts at the nursing home. Before data collection, residents or next-of-kin provided the informed consents. Inclusion criteria were health professionals who were responsible for continuous care of the residents, and residents who have had a stroke within approximately 3 years. In total, 49 residents and 45 staff members were included based on a convenient sampling.

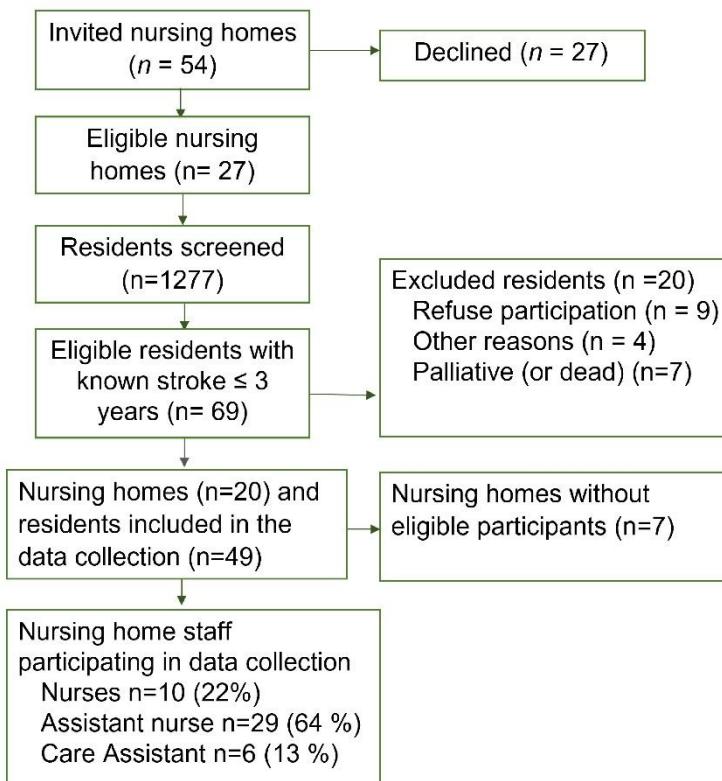


Figure 8. Flowchart of the recruitment process in study III (adapted from paper III)

Study IV: Community-dwelling people with stroke were recruited from the local stroke organisations and a primary care out-patient rehabilitation center. Potential participants received brief oral information about the study either individually, from the staff at each setting, or from the researcher (EK) at patient organization's meetings. A purposive sampling was applied to achieve heterogeneity and homogeneity (based on age, sex, and level of communication difficulties). These participants were subsequently contacted to receive the detailed information. Inclusion criteria were patients who have had a stroke, while patients with severe cognitive or communication difficulties were excluded as these patients would have made participation

impossible, even together with next-of-kin or in a small group discussion. In total, 22 people with stroke participated in study IV.

Procedure and data collection

Procedure

Study I and II:

Data was gathered in two steps. First, the PSC was administered by health professionals during a clinical follow-up visit. Patients and health professionals immediately rated the satisfaction with the PSC after each visit. Second, participants willing to participate in a focus group discussion were contacted by the researcher (EK) for further information and scheduling the appointment within 1-2 months after the follow-up. Two focus groups were conducted with patients and two with health professionals in healthcare facilities. The discussions focused on open-ended questions regarding the perceived need for follow-up and use of the PSC. Data gathered from the focus groups informed the decisions and amendments in the PSC before the official Swedish version of the PSC was published at WSO website (see flowchart Figure 7).

Study III:

The data collection was conducted at nursing homes during face-to-face meetings of the researcher with a nursing staff having knowledge on the included residents. The staff received the PSC in advance so that they could discuss the health problem areas with the residents or next-of-kin before the face-to-face meeting. The data collection was completed by the researcher on the basis of staffs' reports concerning the included residents, which included details on the presence of health problems and dependency. The data collection included perceived health problems, ADL, level of disability, and clinical and background information.

Study IV

The digital pre-visit tool Strokehälsa™ was designed together with people with stroke, healthcare professionals, web-designers and researchers (in the expert group and the authors) (Figure 9). The design was based on patients' experiences in accordance with a human-centered service design approach.^{72,84} Various service design tools were applied to inform the development (such as 'personas'), which exemplified the needs of the potential user group, while prototypes or pilot versions visualised possible solutions to improve the tool. Development and data collection processes were performed simultaneously; the qualitative findings and expert panel feedback informed the tool design.

Members in the expert panel were purposively recruited to represent different professions and part of the healthcare continuum (n=11, 8 women, median age of 55 years). There were occupational therapist (n=3), nurse (n=1), physiotherapist (n=1), physician (n=1), speech therapist (n=2), neuropsychologist (n=1), patient partner (n=1), and service designer (n=1). The development workshops included members of the research team, including the patient partners (EK, GC, KSS and AA). These workshops were completed in parallel with the formal data collection. Feedback from participants and an expert panel were discussed and formed a basis for the decisions regarding amendments in Strokehälsa™, such as adding and revising text.

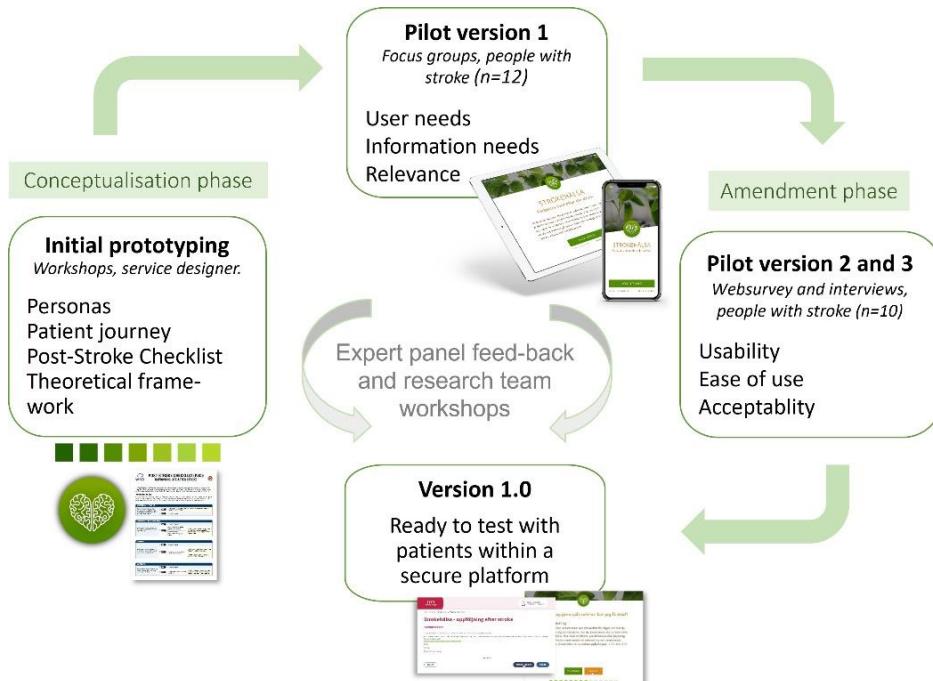


Figure 9. An overview of the design process including prototyping, pilot versions and data collection methods.

Development process: Initial prototype Strokehälsa™ comprised the PSC and was informed by research on person-centred care and stroke. Three pilot versions were created based on data collected from people with stroke and an expert panel. Development workshops with the research team, including a patient partner, were held to discuss the findings and make decisions to implement changes in the tool e.g., adjustments in the texts.

Data collection: We wanted to conceptualise a digital pre-visit tool. In the conceptualisation phase, three focus group discussions were conducted face-to-face with people who have had a stroke to explore user needs and relevance of a first pilot version. In the amendment phase, additional pilot versions were tested by people with stroke before the data collection. A web survey was completed before an individual interview, focusing on perceived usefulness, ease of use, and acceptance. The interviews were conducted via telephone and participants could ‘think-aloud’⁸¹ while using the tool. At the end, participants provided the demographic and clinical data.

Interview-guide

Semi-structured interviews and focus group discussions were conducted in study I, II, and IV. Interview guides consisted of open-ended questions on the topics of each study. For example, follow-up experiences and aspects of using the PSC. During interviews, supplementary questions and probes were applied by the interviewer/moderator.⁷⁶ Furthermore, to enhance the validity, the interviewer asked participants if the information was correctly understood and summed up the information at the end of the interviews. All focus group discussions were conducted in healthcare environments. Due to the COVID-19 pandemic, individual interviews were conducted via telephone and audio recorded in study IV. The first author (EK) was the moderator in the focus groups and the interviewer during the individual interviews. The focus group discussions lasted around 1.5 hours, while the duration of individual interviews was between 25 min to 1.5 hours.

Instruments and characteristics

Demographics and clinical data

Socioeconomic and clinical data were collected to enable a description of included participants. Basic demographics characteristics in studies I-IV were collected using the questionnaires, and included details on sex, age, educational level, and country of birth. Further, for people with stroke, additional characteristics noted were previous experience of using internet, source of income, inability to speak Swedish and pre-stroke living conditions. Information collected on the health professionals included the stroke expertise, professional role, and time working in nursing homes. The information regarding the nursing home characteristics was collected in study III, and included the focus of care, number of residents, number of regular activities provided, access to rehabilitation, and care-plans.

Background and clinical data were derived from hospital medical charts in study I-III. In study IV, background data were collected by a web survey and

clinical data were self-reported during the interviews. Clinical data included previous stroke, time since stroke, stroke severity, type and location of stroke, length of hospitalisation, comorbidities, stroke related neurological symptoms and health problems (swallowing, visual impairment, neglect, communication difficulties, or aphasia), ADL-dependency, and wheelchair use.

Stroke related health problems- PSC

The 11-item PSC⁴³ was used in three of the studies (Appendix 1). The PSC contains response options ('yes' and 'no') to each item. In study III, to fulfill the aim of the study, an extra response category ("don't know") was added (Appendix 2). This modification was required to be made to reflect uncertainty as the care-staffs were answering on residents' behalf. Furthermore, after the recommended referrals in the PSC, the response categories (yes, no, and don't know) were added. Staffs were asked if any prior actions were addressed according to these recommended referrals before the data collection. These modifications were specific for study III in this thesis and not incorporated in the national Swedish version.

Stroke severity, level of activity, and disability

Stroke severity was assessed with the NIHSS^{85,86} at the acute stroke ward. NIHSS is a quick neurological screening and includes 11 items.⁸⁵ With the NIHSS, several neurological functions related to stroke can be assessed such as consciousness, motor function, and speech. The scale goes from 0-42 where 0 indicates no neurological symptoms. In study I-III, the NIHSS score was extracted from the hospital medical charts or estimated in accordance with a standardised procedure.⁸⁷ In study III, the NIHSS scores were stratified into four subgroups, indicating mild (0-5), moderate (6-14), severe (15-24), very severe strokes (≥ 25).⁸⁸

Functional outcomes after stroke were evaluated with the modified Rankin scale (mRS) and the Barthel Index, commonly used instruments in stroke related research as well as clinical practice.⁸⁹ ADL was assessed using the Barthel (BI).⁹⁰ The BI assesses the level of assistance needed in basic ADL and includes 10 items such as bathing, toilet use, and feeding. The total score ranges from 0-100, where 100 indicates independence. BI has a strong focus on movement ability.⁹⁰ BI score of 75 corresponds to mRS score of 3.⁹¹

The level of global disability was assessed with the mRS (including other causes for restrictions).⁹² The scale runs from 0-6 where 0 and 6 indicate no symptoms and death, respectively. In this study, mRS scale from 0-5 was relevant where 5 indicated severe symptoms. The simplified mRS

questionnaire⁹³ was used during the face-to-face meeting with care-staff in study III. However, the reliability of the scores between 3-5 were lower, and explained by lack of specification regarding what's meant by walking unassisted and being bedridden and needing constant supervision.⁹³ Therefore, the scale was further modified to clarify this issue.⁹⁴

All instruments used in this thesis are valid and reliable, and widely used to assess the research outcomes.⁹³ NIHSS and mRS have been associated with floor effects, while BI shows ceiling effects. Consequently less sensitive to detect overall ADL problems after stroke.⁹⁵ For instance, people may be independent according to BI, but dependent for cooking.

Study specific questionnaires: self-reported satisfaction

Satisfaction ratings were used to identify the feasibility⁷⁹ of using the PSC in study II and III. These ratings provided information on the extent of participants' satisfaction with the results of the PSC in identifying the health problems, providing guidance for referrals (or confident to receive support), and general use, in line with a previous study.¹⁷ A Likert scale was used where 1 indicated not satisfied and 5 completely satisfied. In study IV, a web survey was conducted inspired by Technological Acceptance Model (TAM) to evaluate perceived usefulness, ease of use, and acceptance of the digital tool.⁹⁶ The responses to the questions included very satisfied, satisfied, dissatisfied, very dissatisfied, and don't know.

Data analysis

The qualitative analysis was based on focus group discussions and individual interviews in study I, II, and IV, which were recorded and transcribed verbatim. The software NVivo 11 and 12 pro were used to organise and sort the data. Different analyses methods were performed to discover patterns of meaning in the data and to create a thematic structure. Focus group data were collected and analysed in line with Krueger.⁷⁷ Processing of data from focus group discussions is a systematic analysis process where the conversation between participants and the context are of particular interest. To embrace the content of all the discussions, the transcripts were read by the authors as a starting point of the analysis. Data were grouped in preliminary categories and sub-categories before the content was summarised. Finally, to create themes based on the deeper meaning of the data, interpretation was made across all focus group discussions.

The pragmatic framework method, used in study IV, enabled analyses of data collected from different sources and pre-conditions, individual interviews, and

focus groups.⁹⁷ Furthermore, it is encouraged to combine the framework method with appropriate frame of reference such as focus group methodology⁷⁷ and thematic analysis.^{97,98} The substantive cross-sectional data analysis was performed according to the framework method and included five steps: (1) familiarisation with data by reading transcripts, (2) constructing the initial framework including, e.g., answering, introductory information, (3) data were “coded” and sorted in the initial framework, (4) review of data extracts to ascertain similar content was sorted together and revision of theme titles, and (5) each subtheme was summarised and presented in a matrix in a word document before the final themes were created.

All qualitative data were coded and analysed in close collaboration with a co-author (GC) and all co-authors were involved in refinement of the themes. Furthermore, throughout the processes, reflections and alternate interpretations were documented in memos. The ambition was to provide a latent analysis, including interpretation and theorisation at a level appropriate for the pragmatic research questions. However, in study IV, the analysis could be viewed as inductive with deductive elements, given the demands in the co-design process. Accordingly, to enable improvements in the tool, the specific parts of the tool was considered during the initial coding of data e.g., introductory information. However, all data relevant for the aim were coded, and in the final steps, the themes were created across these initial categories.

Descriptive statistics were used in all studies to present participants and settings characteristics. Data collected from the PSC, clinical assessments, and questionnaires used in this project are mostly on an ordinal or nominal scale level. Accordingly, the statistics used were non-parametric, including frequencies, median, range, inter-quartile range, and percentage. When the total number of health problems was calculated for each individual, one of the items (secondary prevention) was excluded, and 10 items were included.

Theoretical and epistemological positions

This thesis includes a mix of methods that can be referred to different epistemology traditions. Simplified, the core of the thesis is to understand the complexity and to evaluate solutions to a clinical problem - *How to provide a model for follow-up based on patient needs*. Thereby, I find that the basic assumptions for all studies are compatible with a pragmatic approach using mixed methods⁶⁹ in line with the MRC framework.¹⁹ In contrast to a realist approach focusing on objective truth, a pragmatist approach focuses on outcomes of actions, experiences of actions, and shared beliefs.⁶⁹ In this thesis, participants were enabled to experience the PSC with different mode of

delivery, ‘in action’ and how it worked in different contexts. The meaning of an action is influenced by the contexts and can change if the situation changes, e.g., experiences of using the digital tool could change when amendments were accomplished. Furthermore, people can change their view over time. Moreover, actions are dependent on worldviews, which are specific for the individual and at the same time socially shared at some level.^{69,74} Shared beliefs are an important aspect of the focus-group methodology with social constructivism as an underpinning framework, emphasizing that knowledge is constructed in interaction with others by sharing views.^{78,99}

Ethical considerations

All studies were approved by the regional ethical review board in Gothenburg (Study I and II: 521-14 and 21-14-1, Study III: 219-18 and 2019-00960, Study IV: 556-17 and 2020-03324) and informed written consent was obtained from all the participants. Before the interviews and focus group discussions, additional information was provided to encourage them to share their views in a comfortable way. According to the Data Protection Regulation (GDPR), participants’ control over their personal data has been strengthened. To maintain personal integrity, regulations have been followed. When personal problems or ethical dilemmas were discovered, the researchers referred to appropriate support or intervention options.

In study III, a next-of-kin could provide the informed consent. However, since the data collection was performed via the care-staff, the study is considered to have little impact on the study’s participants compared to the benefits gained from the study. Furthermore, although the care-staff were encouraged to discuss the PSC items with participants, in some cases, participants were not directly involved in the study. However, to enable comparisons, it was important to collect data for all the participants in an identical manner, although some residents could have been able to participate by themselves. Overall, this thesis evaluated study designs to find a low risk and beneficial options for the participants.

RESULTS

This thesis illustrates how follow-up after stroke can be facilitated by PSC, with various mode of delivery, to fulfill patients' needs (Figure 10). To increase access to healthcare services and patients' involvement, it is essential to explore the perceived needs, and how the PSC is perceived in the actual context where it is intended to be used, given the complexity of these interventions. Qualitative and PSC results show that health problems can be identified by the PSC. Furthermore, results suggest that PSC and its use as Strokehälsa™ combined with a dialogue between patients and healthcare providers increase the likelihood of identifying health problems. These findings are integrated and presented across separate studies to gain a broader understanding of the role of PSC in increasing follow-ups after stroke.

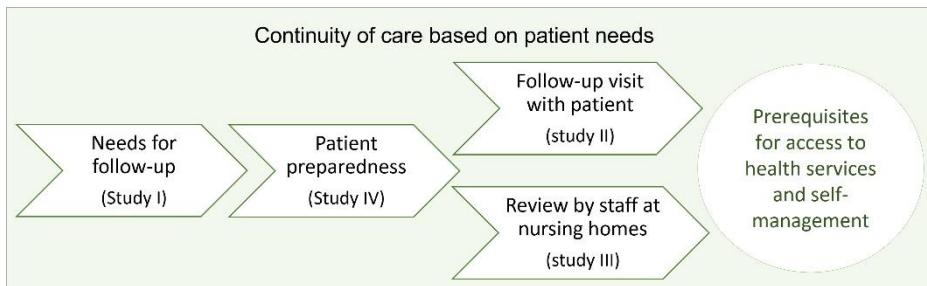


Figure 10. Illustration of how different modes of PSC delivery, used in this thesis, may facilitate the follow-up process and continuity of care.

Participants characteristics

Overall, the participants in the studies comprised community-dwelling people with stroke, residents with stroke in nursing homes, and healthcare professionals. In study II and IV with community-dwelling people, 59-72% were men, 31-64% were working or on sick leave, and 20-32% had university education. In study III, nursing home resident's median age was 86 years (41% were male), while community-dwelling people involved in the development of the digital pre-visit tool Strokehälsa™ (study IV) had a median age of 59 years (59% males).

Most of the people with stroke in study I and II suffered from a mild stroke (0-5) as compared to the residents of nursing homes, with more than half of the samples having moderate to severe stroke. Among the participants in the individual interviews or focus groups (study I, II, and IV), 30-36% had a stroke located in the left hemisphere, and 10-45% displayed some level of communication difficulties (aphasia).

The majority of the participating health professionals were women and represented various professions and educational backgrounds. Health professionals assigned to stroke follow-up have more experience in stroke than that of nursing home staff. None of the nursing homes had dedicated units for stroke, and only one of the staffs obtained formal stroke expertise (ongoing course).

Table 2. Participant characteristics in the four studies.

Participants, n (%)	Study I n=10	Study II n=46	Study III n=49	Study IV n=22
Age [mean (SD)]	68.7 (10.4)	68.5 (10.9)	83.6 (9.8)	60.0 (10.8)
[Median (min-max)]	73 (45-78)	70 (41-85)	86 (59-97)	59 (42-83)
Sex, male	9 (90)	33 (72)	20 (41)	13 (59)
Born in Nordic countries	9 (90)	43 (93)	44 (90)	21 (95)
Inability to speak Swedish	0	0	4 (8)	0
Own home pre-stroke	10 (100)	46 (100)	33 (75) ^a	22 (100)
Education at University	3 (30)	8 (20) ^b	-	7 (32)
Working or on sick leave	3 (30)	13 (31) ^c	-	14 (64)
Clinical characteristics				
Previous stroke	4 (40)	9 (21)	23 (47)	-
Months since stroke [median (min-max)]	3 (1-84)	3 (1-84)	18 (0-43)	51 (4-228)
Ischemic stroke	8 (80)	36 (88)	37 (82)	17 (77)
Location				
Right	6 (60)	19 (45)	24 (53)	10 (45)
Left	3 (30)	16 (38)	20 (45)	8 (36)
Posterior or bilateral	1 (10)	7 (17)	1 (2)	4 (18)
NIHSS [median (min-max)]	3 (1-10)	2 (0-16)	8 (1-31)	-
Communication difficulties, aphasia	1 (10)	9 (21)	26 (54) ^d	10 (45)
Independency in basic ADL	9 (90)	34 (74)	2 (4) ^e	18 (82)
Wheel-chair use	1 (10)	4 (8)	29 (62)	1 (4)
Professionals n (%)	Study I n=8	Study II n=10	Study III n=45	Study IV -
Age [median (min-max)]	45 (35-55)	46 (35-63)	-	-
Sex, male	1	3	11 (24)	-
Born in Sweden	8	9	34	-
Professional role				
Nurse/assistant	3/0	4/0	10/35	-
Rehabilitation staff	1	1	0	-
Physician	4	5	0	-
Stroke experience (years) ≥10	4	6	-	-

ADL, activities of daily living; NIHSS, National Institutes of Health Stroke Scale (mild 0=no symptoms, 0-5=mild stroke, 6-14=moderate stroke, 15-42=severe or very severe stroke); Missing data from medical records (n=4) in study I and study II. ^a(n=45). ^b(n=41) ^c(n=42) ^dnot defined type. ^eBarthel Index ≥90 at study inclusion.

Data are presented as numbers of persons and percent (%) unless stated otherwise.

Need for information and follow-up

In the focus group discussions, the need for follow-up and health information was identified. Follow-up routines (study I) and receiving the information (study IV) were important factors to increase access to healthcare services after returning home. Community-dwelling people with stroke and healthcare professionals in study I described various health problems and obstacles to access services after discharge. Within the discussions, experiences of being abandoned and a feeling of emptiness after returning home were raised and illustrated by following quotes:

P7: You're in hospital for a week and then you're just released into the wild. (...)

P7: Yes. So it feels like you're just in an empty space.

P12: Yeah, it's empty there, you're worried, and if you were worried before, you get even more worried.

(Group 2. Community-dwelling patient, study I)

Although majority of people with stroke involved in the focus groups had a mild stroke according to NIHSS (Table 2), they described how health problems became evident in everyday life after returning home. Areas mentioned were: changed personality, mood changes, fatigue, and consequences affecting the ability to work and drive. Additionally, patients expressed aggravated worries due to possible absence of follow-ups.

Study I showed that several obstacles prevented patients from communicating their own needs. At an individual level, perceived lack of knowledge on health problems and available support prevented people with stroke from seeking help. Furthermore, uncertainty of who to contact made it difficult to access the health services. Moreover, lack of initiative and memory problems were perceived as obstacles for patients' to communicate their needs during the visit. Further, perceptions of unequal access to health services at the organisational level were also reported. Although performed in the same geographic region, the follow-up processes, and experiences of receiving a coherent process differed between different settings in this study. In current practice, physicians in primary care stated that their focus was on secondary prevention and medical interventions.

Suggestions to improve follow-up and health information were discussed in study I and IV. The challenges related to perceived abandonment and difficulty to access care described in study I could be linked to the expressed need for health information in Strokehälsa™ (study IV). In study IV, people with stroke

stressed the need for accessible information and emphasized the goal of the information should be to confirm experiences and provide hope and guidance. The importance of providing advice regarding the available support was stressed, especially related to the specific questions in Strokehälsa™ (study IV). Both people with stroke and healthcare professionals suggested a comprehensive follow-up including patients discharged after a stroke (study I). The PSC was acknowledged to support a systematic routine and constitute a base for egalitarian follow-up (study II). Furthermore, the structure of the PSC was perceived as a more equal knowledge base, with more likelihood that patients' problems will be addressed (study II).

Development and adaptation based on user needs

An expert group completed the final Swedish version of the PSC, based on the data from study II. The amendments in the Swedish version were made with an attempt to be in correspondence to the original version, and hence, no additional items were added to the checklist. Further, insights gained from focus group discussions were the starting point for developing a digital solution to increase patient preparedness. Specifically, the findings showed difficulties in communicating one's own needs and accessing services (study I), and hence, suggestions of preparing a patients' version were provided (study II). The importance of modifying the PSC to fulfill needs of various users was illuminated in a focus group where one participant was looking at the original PSC including e.g., referral options and said:

It is very good that it is the healthcare that is on the checklist, that it is not the patient. The patient may feel really stupid in the head [if left alone with the checklist].

(Man with stroke, age 40 years, study II)

These findings, in combination with details of stroke and person centeredness, shaped the first steps of designing a digital pre-visit tool based on the PSC (study IV). *Development:* A participatory design approach was followed during the development process and alterations were applied through different pilot versions of the digital tool. An overview of the design process is shown in the method section (Figure 9). During the conceptual phase, initial prototyping was performed together with a service designer. Further, a pilot version was used to gather feedback from people with stroke, healthcare professionals, and researchers. During the amendment phase, further alterations were adopted. Different elements in the tool had to be integrated to

improve usability, e.g., changes in introduction affected experience of answering and further integration of these elements was required (Figure 11) shows a screenshot of the tool). Decisions were based on evidence, feedback gathered from focus groups, individual interviews, and the expert panel, and were made after dialogues in workshops and within the research team.

Version 1.0 of the pre-visit tool comprises: title Strokehälsa™ [Strokehealth] with specific logotype, introductory information, questions based on the PSC answered by yes/no/choose not to answer, a free-text option, explanatory text related to each question, advisory texts (support and self-management), and summary of results. Altogether, this rigor design process resulted in a digital tool that can be used by patients in a clinical context and was incorporated in the national platform 1177. Using this tool, healthcare professionals can invite patients to answer the questions via SMS or e-mail notifications before a clinical visit. In addition, the summary of results becomes available to the healthcare provider.

The themes created in the qualitative data analysis are presented in the article.¹⁰⁰ The following quotes and Figure 11 illustrate how the qualitative findings informed the amendments in the tool. To overcome the perceived complexity of answering, text adjustments were made according to the technical prerequisites available at the 1177 platform.

I told you a bunch of times that they're on the edge, that if you could squeeze in a third option, so it's yes or no, there's something in between, you heard I was in a grey zone several times (between yes and no), you can maybe put it like that.

(P11 man, 59 years old, study IV)

It would be if you could add some kind of comment somewhere. Because if none of the questions are appropriate you could just write something yourself. But that's usually the problem, that you don't write anything yourself, just answer yes/no, but the opportunity to write something would be good.

(P12 man, 56 years old, study IV)

No, it's enough that you just answer with a yes, if that yes gets some attention at a doctor's appointment.

(P7 Woman, 53 years old, study IV)

A standardised follow-up model to support people after stroke

The figure displays a screenshot of the Strokehälsa questionnaire - post-stroke follow-up tool. It includes the following sections:

- Header:** 1177 VÄRDGUIDEN, Start / Formulaär / Strokehälsa questionnaire - post-stroke follow-up, Tolvan Tolvansson Inloggning Logga ut.
- Logotype:** A green heart icon containing a brain, located above the title.
- Title:** STROKEHÄLSA
- Introductory text:** "How have you been affected by your stroke?" followed by explanatory text about the appointment and the opportunity to expand answers.
- Questionnaire section:**
 - Heading:** Mood/Mental health
 - Question:** "8. Do you feel more anxious or depressed after your stroke? (depersonalized) If yes, some people feel depressed or anxious, become more sensitive to stress, and experience mood swings after a stroke. More severe conditions can lead to depression, which is a medical condition that should be treated."
 - Answer options:** Yes, No, Choose not to answer.
 - Explanatory text:** "Some people feel depressed or anxious, become more sensitive to stress, and experience mood swings after a stroke. More severe conditions can lead to depression, which is a medical condition that should be treated."
- Footer:** Sida 9 av 16, BAKÅT, SPARA UTKAST, NÄSTA.
- Bottom section:** "With the right support, you can influence your health" followed by a numbered question 8. Mood/Mental health. Below it is a bulleted list of five items: Confirms, Self-management, Support, and Give hope. At the bottom are navigation buttons TILLBAKA and NÄSTA, and a series of colored dots.

Annotations:

- Revised text:** "opportunity to expand on your answers at the visit".
- Adjusted explanatory texts with examples.**
- An additional option:** "choose not to answer"
- A free-text option at the end**
- Web-link with advisory texts.**
- Encouraging active engagement and to ask for support.**
- Advisory text:** Points to the explanatory text below the question.

Figure 11. A screenshot of the elements in the pre-visit tool Strokehälsa™ (English version) and examples of adjustments made to improve the answering experience. The figure is adapted from paper IV.

Identified health problems and relevance of the PSC

Identified health problems

Most participants had at least one health problem identified using the PSC (87-98%) (study II and III). The PSC identified a wide range of stroke-related health problems among community-dwelling participants in study II as well as among residents in nursing homes in study III (Figure 12). A median of 6 health problems were identified per resident in nursing homes compared to a median of 4 in community-dwelling participants.

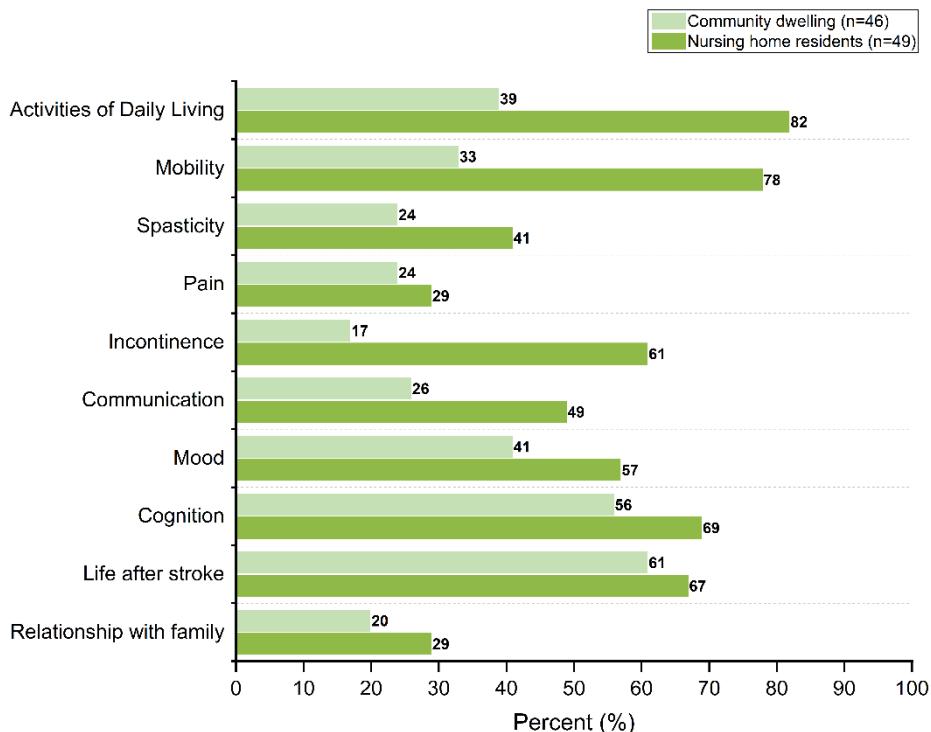


Figure 12. Proportion of identified health-problems with the PSC among community-dwelling people with stroke in study II, (n=46) and nursing home residents in study III, (n=49).

Health problems concerning ADL were twice as often reported among residents in nursing homes (82%) than that of community-dwelling participants (39%). Further, a high level of dependency was shown among residents according to the Barthel index with a median score of 35 (IQR 10-70) and a median of 4 (IQR 3-5) on mRS. Of the community-dwelling participants (study II), 74 % were independent in personal ADL activities.

The stroke severity at hospitalisation (the NIHSS scores) in relation to the number of health problems identified with the PSC is shown in Figure 13. These findings indicate that people with 0 or low scores can still perceive several health problems identified with the PSC. Health problems that may not be recognized by NIHSS in early stages were commonly reported (studies II and III), such as cognition (56-69%) and mood (41-57%).

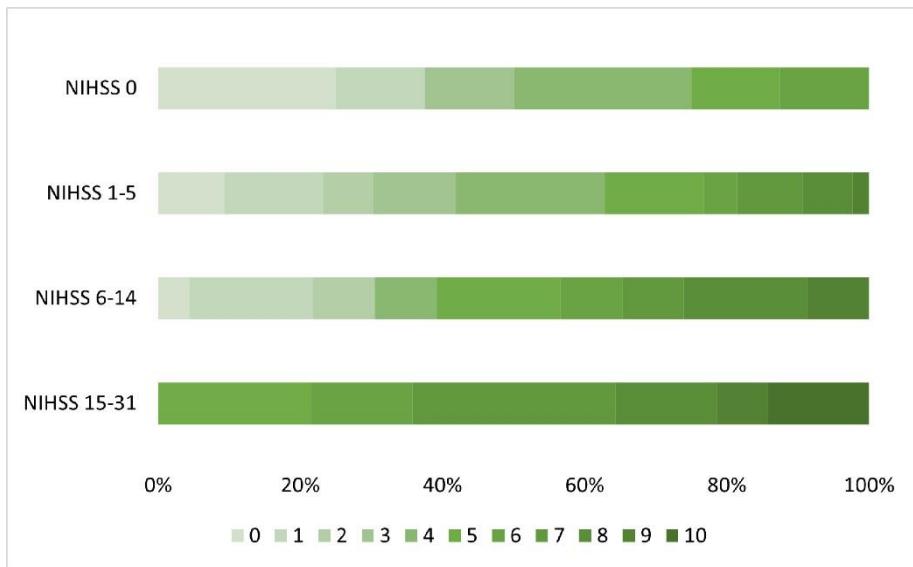


Figure 13. Number of health problems identified with the Post-stroke checklist in relation to National Institutes of Health Stroke Scale (NIHSS) scores based on data from study II and study III among those were NIHSS scores were available (n=88). (NIHSS is defined as: 0-5=mild stroke, 6-14=moderate stroke, 16-42=severe or very severe stroke).

Relevance of the items included in the PSC

The broad range of areas included in the PSC and Strokehälso™ were considered relevant, and generally the questions were perceived as easy to understand (study II and IV). However, participants also expressed fear that areas not mentioned in the PSC could be overlooked. In the qualitative findings, areas such as work, fatigue, irritability, sexuality, vision, and nutrition were missing. Furthermore, according to survey data among staffs in nursing homes, nutrition was the most reported area perceived as missing in the PSC. The qualitative analyses presented below provides a deeper understanding of individual and contextual factors that influence the identification of health problems.

Different modes of delivery: user experiences and prerequisites

The PSC and Strokehälsa™ were considered as relevant tools to identify health problems after stroke. In addition, findings suggested that the dialogue between the patient and the health professional can be supported. Specifically, first a perceived potential to enhance patient preparedness and involvement by the digital pre-visit tool was recognised (study IV). Second, the dialogue during a follow-up visit could be facilitated (study II), and third, the nursing home staff could be guided to give residents a voice of action (in study III).

Satisfaction ratings together with qualitative findings yielded a deeper understanding of individual and contextual factors, influencing the PSC use.

Satisfaction

Satisfaction ratings answered by community-dwelling people with stroke showed an overall high satisfaction (median 5, IQR 4–5); the health professionals were also satisfied (median 4, IQR 3–4) with the use of PSC at a clinical visit (in study II). However, among health professionals, the satisfaction with the PSC's ability to identify health problems differed depending on the patient (median 3, IQR 3–4). Among health professionals involved in follow-up visits, 6/10 had more than ten years of experience in stroke care (study II). In contrast, staff at nursing homes had no formal experience in stroke, and a higher proportion (11 [24%]) were born outside Sweden (Table 2). However, 34 (75%) health professionals considered that they had enough knowledge to use the PSC, and the majority (87–90%) were satisfied that the PSC identified health problems and would recommend its use in a nursing home context. In study IV, participants (n=10) were satisfied or very satisfied with the Strokehälsa™ in general. However, there were exceptions, which are better illustrated in Figure 3 in the published article¹⁰⁰ and within the qualitative findings below.

Qualitative findings

The themes created based on the qualitative data was summarized in two overarching themes. ‘Egalitarian follow-up through structure and dialogue’ concludes experiences and perceived usefulness of the PSC in context to a follow-up visit (study II). Further, ‘A multifaceted digital solution - essential to empower patients before a care visit’ comprises aspects in the design process and participants’ perceptions of the digital Strokehälsa™ (study IV).

The importance of the dialogue with the healthcare professional was emphasised by both the people with stroke and healthcare professionals (study

II). Although the PSC structure was observed as valuable, participants requested the possibility to elaborate on the areas in dialogue with a health professional with stroke expertise. This dialogue was perceived to increase the likelihood for health problems to be addressed, even the subtle issues. Furthermore, it was suggested that the questions be provided in advance to prepare for the visit. Moreover, in study IV, people with stroke generated insights into the potential use of Strokehälsa™ to prepare and facilitate patients to better communicate their needs in the dialogue at the visit.

The complexity of answering was described by community-dwelling people with stroke using Strokehälsa™ (study IV). The complexity included limiting answer options and sometimes uncertainty of the scope of each question in relation to their own situation. Thus, additional information related to each question was suggested to facilitate answering. Like the dialogue at the visit (study II), the content of the explanatory texts in Strokehälsa™ facilitated answering and identification of health problems (study IV). However, some people expressed they did not want to exaggerate their problems by answering “yes” to the questions, especially when they had minor issues. Notably, the tool was suggested to be used before a visit, not to replace it. Nevertheless, irrespective of mode of the questions, if only used as a quick check-up with tick-boxes a feeling of disappointment could be present (study II and IV). However, when the PSC questions were adequately used, it brought a feeling of being cared (study II).

The wider context was perceived as important in the studies, including questions in advance to prepare for the visit, opportunity for dialogue at a visit, and the importance to take care of the identified health problems with appropriate actions (study II and IV). Moreover, the information included in Strokehälsa™ was perceived to invite the patients’ participation towards their own health and care (study IV). However, at the nursing homes, the context and prerequisites differed markedly to the other studies with respect to the use of the PSC (study III). Most of residents had a high degree of dependence according to BI and mRS, and 22% living in nursing homes for people with dementia. The best available strategy was to assign the staff to capture the needs and to speak out on the behalf of the residents.

DISCUSSION

Overview of the main results

This thesis provides a follow-up model enabling patients to be prepared using a digital pre-visit tool and shows that the PSC is a useful tool during a face-to-face visit or with proxy at nursing homes. The main findings include: (1) The PSC is a feasible tool. Importantly, it was pointed out that the structure of the PSC should be combined with space for dialogue with a health professional to ensure identification of health problems (study II) (Figure 14), (2) The digital pre-visit tool, Strokehälso™, was co-designed with stakeholders to transform the PSC into future demands and support patient preparedness (study IV), and (3) People perceived health problems after discharge and a coherent follow-up were lacking in the actual settings in study I-III. The majority of participants had at least one health problem identified with the PSC despite initial stroke severity in study II and III.

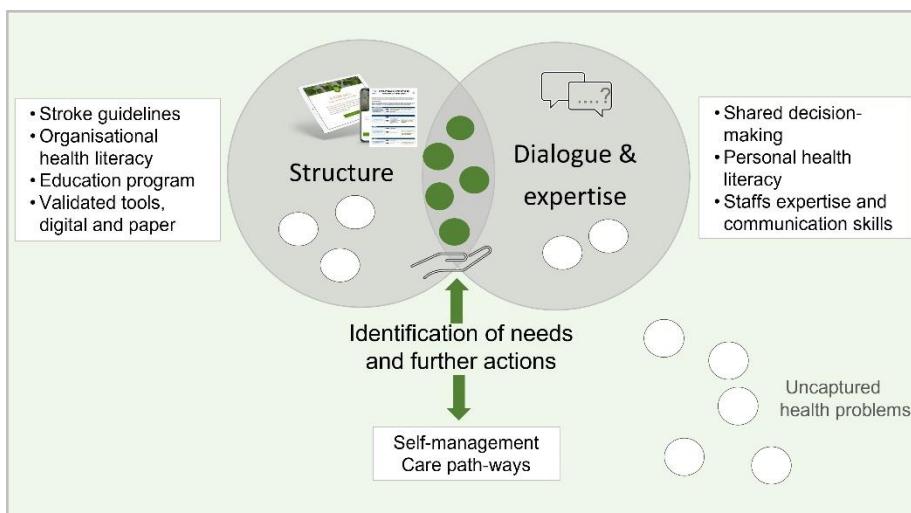


Figure 14. A prepared patient meeting a person-centred healthcare - an overview of the thesis in context. Information in boxes illustrates related theoretical concepts and organisational prerequisites for follow-up management and care.

For a successful implementation of the PSC and Strokehälso™, findings showed that several contextual factors in healthcare organisations need to be set-up (Figure 14). The model for follow-up suggested in this thesis is in accordance with the guidelines.¹⁵ However, to ensure identification of unmet needs, educational efforts directed to health professionals are needed to ensure that they have appropriate expertise. Furthermore, to make sure that PSC identified actions are appropriately addressed, locally adapted care pathways

must be clearly defined. Nevertheless, the findings in this thesis suggest that the PSC can play a key role in building a more health literate organisation so that they can engage people towards resolving health issues after stroke.

Facilitating patient engagement and increased health literacy

Active engagement and dialogue

The PSC was perceived to facilitate the dialogue between the patient and the health professional in a structural way in study II. Notably, dialogue and active engagement are important for enabling a shared-decision-making process.²² After a stroke, cognitive impairment and communication difficulties are common, which can interfere with people's ability to remember and initiate a dialogue about stroke related issues. The structure in the PSC with tick-boxes can facilitate and guide the dialogue even if there are communication barriers. As presented in study II, participants pointed out that attention should be placed specifically on the dialogue rather than just a ticking-box activity. When a checklist is used, it needs to be ensured that the checklist is used in the way that leads to a person-centred care and increased health outcomes.¹⁰¹ Consequently, the communication skills and stroke expertise among health professionals are important, as also highlighted in study II.

Strokehälsa™ was perceived to have the potential to further increase active engagement at the visit, as pointed out in study IV. A randomised controlled trial showed that patient-care provider communication can be improved by using a pre-visit digital tool.⁵⁸ The findings indicated that Strokehälsa™ could help the patients to shift from passive receiver of information to actively prepare and engage in their own health.²² In contrast to a ordinary invitation to a medical visit, Strokehälsa™ prepares patients with the intended focus of the visit. The decision-making process starts even before the actual visit e.g., when patients think about their health problems.⁸⁴ Accordingly, answering to questions in Strokehälsa™ stimulates patients thinking which in turn could prompt patient-provider communication and decision-making during the visit.⁸⁴ Furthermore, the patients' opportunities of self-management can be more easily enhanced. However, potential influence on the patient's self-management needs to be further evaluated in a clinical context.

Increased health literacy and a shared responsibility for health

The information in Strokehälsa™, although brief, aim to encourage people to take shared responsibility for their own health. This attempt is in line with the transformation towards 'good and close care;' where self-management and

digital tools are prioritized.^{14,21} Accordingly, health services need to direct people's ability to turn from understanding health information to make health related actions.²⁰ Thus, information in Strokehälsa™ suggests actions such as e.g., to take a walk or seek support. This is information that if given alone, without patients active involvement, may not lead to behaviour change or self-management.⁶⁸ However, when patients are actively involved in receiving information, such as having a chance to ask questions and get information more than once, it can have positive effect on their mood.⁵⁶ It is likely that the brief information in Strokehälsa™ can be a promoter for patients to ask questions at the follow-up visit and thereby have positive impact on patients' mood. This is further highlighted by that around half (41-57%) of participants in study II and III had identified problems related to mood, confirmed by worries expressed in study I. Furthermore, one third of people with stroke have depression up to five years after a stroke.⁴¹ This further emphasises the importance to provide information in a way that makes people actively engaged when receiving information.

Although active engagement is the goal, all people do not have the capacity e.g., due to complex needs.⁴⁶ Furthermore, low health literacy is common after stroke¹¹ and limited e-health literacy can lead to a digital exclusion with impact on health outcomes.²⁸ In the current thesis, the different modalities of the PSC aimed to overcome these barriers for patient engagement. First, by using the PSC at the visit, patient engagement can be prompted (study II). Second, when the staff administered the checklist among nursing home residents, the attempt was to give residents voice and to overcome low stroke related health literacy among staff (study III). Third, in the digital tool Strokehälsa™, the patient or the next-of-kin could use the tool and include tick-box to report who completed the answers (study IV). As we strive to have active engagement by the patients, we have recently developed a paper version that has been translated into several languages (but not scientifically evaluated yet). Altogether, the findings in the thesis suggest that the PSC with different modes of delivery can facilitate patients' active engagement with healthcare professionals in different ways.

A common base for follow-up to be individualized

Supports access to health services

In study I, community-dwelling people with stroke perceived difficulties to access the health services and communicate their own needs, which confirms the findings in a review of qualitative studies.¹⁰ This points out a barrier faced by the patients when they have to take the initiative and contact health services

on their own to have access to health services. In contrast, a proactive healthcare implies that the health provider is responsible for initiating pathways with services¹⁰² and meet the health literacy needs.²⁰ Health services that are easily accessible for all, and structured to decrease complexity, are in line with the universal design²⁴ and organisational health literacy.²⁰ Healthcare settings included in study I were lacking structures to support easy access to follow-up, particularly in primary care and nursing homes. A way to decrease complexity and reduce inequalities is by using screening tools to identify needs and referrals in targeted groups,¹⁰² such as people after stroke. A proactive approach using Strokehälsa™ and the PSC aligns with an intention to build the health literate organisations that equitably enable individuals to access the services.

Can we identify people in advance to target follow-up?

Most of the participants in the present thesis (87-98%) perceived at least one stroke related health problem according to the PSC. Nevertheless, this is not the same as having a perceived unmet need. Not all people report unmet long-term needs after stroke⁵ and even if impairments are present, not all want or need support from healthcare.⁴⁴ Findings in study IV showed that some of the participants did not want to exaggerate their problems when answering to the questions in Strokehälsa™, e.g., they had adapted their behaviour or environment without additional support from the healthcare providers.

Can groups at risk be identified in advance? One could argue for a more targeted follow-up towards groups in high risk of poor health outcomes e.g. age, sex, ethnicity, family history, and medical conditions.¹⁰² However, patients with conditions such as stroke may represent a population in a high need for rehabilitation⁴ and secondary prevention, and should be included in a comprehensive follow-up.¹ Follow-up that include patient preparedness, a clinical visit, and a multi-disciplinary team assessment improves functioning, quality of life, and reduces risk of recurrent stroke.⁶⁰ Moreover, a similar approach is suggested in the national pathways for stroke and TIA in Sweden.¹⁵ This is further reinforced by the findings in this thesis which showed that PSC is a feasible tool to identify health problems after stroke, with various mode of delivery.

'One size fits all' approach to be further individualised

The studies in the thesis indicated that the PSC can be used as a common base for follow-up, from people living in their own home to residents in nursing homes. However, the importance of tailoring follow-up was emphasized in study I. An individualised follow-up approach has been suggested⁶⁸ since people have different preferences regarding how they want their needs to be

met¹⁰³ or due to complex needs with comorbidities.⁶⁸ If health professionals are responsive to individual's needs and their capacity to engage with health providers,³⁰ follow-up can be better individualised.

Potentially, Strokehälsa™, digitally or a paper version, could facilitate a more proactive support or triage in a long-term rehabilitation context. Triage systems including advice by video, telephone, or online can guide patients before a face-to-face care visit.^{25,104} Moreover, e-health opens up for alternative follow-up where care visits can be performed virtually or combined with a physical visit when appropriate. Although, a physical face-to-face meeting is often preferred, some people want their needs to be met in other ways¹⁰³ and sometimes geographic prerequisites can prevent people from attending. Perhaps, online alternatives initiated by Strokehälsa™ can increase the possibility for patients e.g., in rural areas to meet a provider with stroke expertise virtually. Overall, the findings in this thesis suggest that the PSC is a good basis from where the follow-up can be locally adapted in different contexts and further individualised.

Using the PSC can be judged as a one-size-fit-all approach that not fully capture the range of needs e.g., for young people with issues related to finances and social participation^{44,103} Although not all issues are specifically mentioned in the PSC, the item 'Life after stroke' covers a broad range of issues to be further discussed in relation to the patients' situation, within the dialogue. Thereby, the PSC can be used as a screening for a wide range of people. Importantly, as illustrated in study III, for people with complex needs (e.g., residents in nursing homes), it is particularly important to ensure a structure where care-staff provides residents a voice at a follow-up. A targeted approach has been suggested with a checklist especially for young people with stroke.^{44,103} However, given the move towards the primary rather than specialised healthcare strengthens the importance of an easy, coherent, and practical follow-up model. Furthermore, the findings in this thesis points out the importance to individualise the follow-up with an emphasize on the dialogue at the visit.

Findings in study II suggest balancing diverse needs by the patient-professional communication complemented by other instruments when appropriate. Examples of complementing instruments to capture diverse needs can include occupational gaps in everyday life¹⁰⁵ or need for rehabilitation.¹⁰⁶ Hopefully, the combination of the PSC and Strokehälsa™, with possibility for free text, can facilitate a tailored likewise coherent approach. However, Strokehälsa™ needs to be tested in targeted groups such as young people to evaluate and make further amendments if needed.

Health problems and needs for follow-up

About half of the participants with low NIHSS score (0-1) in the acute phase still were identified with at least four health problems using PSC in study II and III. This shows that people can perceive health problems in the subacute or chronic phases, even though they were assessed to have mild stroke or no neurological symptoms in the acute phase. Notably, NIHSS scores could differ based on the stroke location^{85,86} e.g., right hemisphere or cerebellum strokes would have lower score on NIHSS; however, they may result in persisting consequences. Current findings confirm that cognitive impairment (with risk of limiting daily life activities) can be present among people evaluated as clinically recovered after the stroke.¹⁰⁷ Hence, it can be argued that particular attention should be placed on long-term consequences such as cognition, mood, and life after stroke.

Different study settings revealed various follow-up routines in this thesis. For physicians in primary care in study I, medical examinations and secondary preventions were the focus. In a previous study, patients asked for a more individualised support to address persisting health problems, and prevent recurrent stroke.¹⁰⁸ Beyond secondary prevention, the wide range of health problems identified in study II and III highlighted the need for a comprehensive follow-up, as also confirmed in other studies.^{5,7,45} The use of the PSC as a routine in follow-up, is a first step to ensure that the health problems are identified, in line with the recommended guidelines.^{1,16}

In nursing homes in study III, stroke-related problems associated with ADL, mobility, and spasticity were the most common. This was in contrast to community-dwelling people in study II where problems related to life after stroke, cognition, and mood were the most common. Notably, residents in nursing homes in study III had complex needs and care-staff assessed that they have a median of 6 health problems. This could however be an underestimation as care-staff may have faced difficulties in determining the perceived health problems in areas such as life after stroke or cognition. Nevertheless, study III provides additional knowledge on a group of people with stroke often neglected in research. The validated PSC has been suggested as a way to describe the long-term health problems on a group level.⁴⁵ Of note, in such descriptions, health problems not included in the PSC or only mentioned in the dialogue during the visit may be lacking. Nonetheless, the main purpose of the PSC is to identify health problems that can be addressed by targeted interventions rather than a “perfect estimate” of health problems.

A complex follow-up intervention: is it feasible?

Aspects to consider in the implementation of the PSC

The follow-up model in the thesis, using the PSC with different modes of delivery, includes complex interventions influenced by contextual and implementation factors. Hence, the context and how it affects acceptability and effectiveness needs to be considered.¹⁹ First, although PSC was perceived as a useful tool in study II and III, limited follow-up visits challenged the implementation, as also confirmed in other studies.¹⁷ Hence, having enough time to provide space for the essential dialogue and stroke expertise were contextual factors influencing acceptability and implementation in this thesis. By implementing the use of Strokehälsa™, the visit could potentially be more time efficient.

Depending on the local context, it might be preferable to select the most appropriate profession to administer the PSC. Rehabilitation staff has been suggested to carry out follow-ups to ensure continuous support for self-management over time.⁶⁸ In study II, an occupational therapist, and nurses, who were connected to a rehabilitation team, used the PSC. Furthermore, the follow-up in specialised out-patient care in the study II was perceived as well functioning, including a visit with a nurse followed by a visit with a physician at 3 months. Nevertheless, the continuity of support beyond the first three months after a stroke was less clear in the studies in this thesis.

Second, whether PSC leads to appropriate actions was perceived essential for the usefulness of the checklist, by participants in study II, and in accordance with the initial intention with the PSC.⁴³ Unfortunately, the number of actions or referrals rendered by the PSC was not explored in detail in current thesis. To facilitate further actions, a comprehensive follow-up, including a team round afterwards, has been shown feasible in a Swedish context.⁶³ Although health professionals in study I, II, and III could discuss patients with other professionals, none of the study settings had a formal team assessment, including easy access to a multi-disciplinary team, in accordance with the care pathway.¹⁵ A team approach to follow-up⁶⁰ is not broadly implemented and represents a huge implementation challenge, especially in primary care. Nevertheless, as described in most of the nursing homes in study III, existing team-meetings could be a good base to improve follow-up.

Third, engagement of stakeholders in evaluation of the PSC brought valuable insights for development and further implementation. Fourth, the refinements made in the Swedish PSC after test in a clinical context was minor. However, suggestions to extend the checklist items were put forth in the focus groups in

study II and the questionnaire in study III, and has been raised in other studies.^{63,67} Nevertheless, our attempt was to keep the version as consistent as possible with the original well-validated and easy-to-use PSC. Thus, instead of extending the checklists items, findings in this thesis suggest following contextual factors of importance for the feasibility: (1) used combined with a dialogue, (2) healthcare professionals' with stroke expertise and communication skills, (3) complemented by appropriate measurements, and (4) provision of different mode of delivery. Accordingly, identification of health problems is supported by the structure in PSC and Strokehälsa™, which in turn facilitate the patient-provider communication with potential of increased time-efficiency. However, further research is needed in a clinical context.

A digital solution perceived as meaningful for all users

A digitally supported follow-up involves both the patients and health professionals. Hence, the health professional sends Strokehälsa™ via 1177 to the patient who answers the questions before the visit. For a successful implementation, both patients and providers must see a value of the tool.⁷³ "What's in it for me?". Often the patient perspective is not sufficiently considered in advanced technologies design.⁸⁴ Advanced technical elements such as risk factor monitoring registered by patients are part of the preparedness before a follow-up visit^{60,109} e.g., in the CARD-study.⁶⁰ However, only 11.8 % used the digital platform, including an adapted version of the PSC, despite training.⁶⁰ Are patients motivated to use such platforms and are they user friendly?

During the time frame of our project, the digital maturity in the population increased, including in elderly,¹¹⁰ and the technical innovations have evolved enormously.¹⁴ Thus, the 1177 platform,²⁵ was better suited to meet the needs in project year 2021 as compared to the year before. However, compromises were applied during development to meet a national standard and ensure a personal integrity provided by 1177. Accordingly, the complexity of these new digital interventions demands iterative and holistic solutions.⁷² Particularly, it is important to ensure that all the stakeholders find a value in the solution created and are willing to change their routines, as shown in Figure 15.⁷³

The patients' perspective is of high priority because personal motivation for using the digital service is a key aspect of e-health literacy.²⁹ During the design of Strokehälsa™ in study IV, the attempt was to provide patients with a tool that not only asks them to answer questions but also provides suggestions for solutions. Accordingly, information is added to generate hope and active engagement.

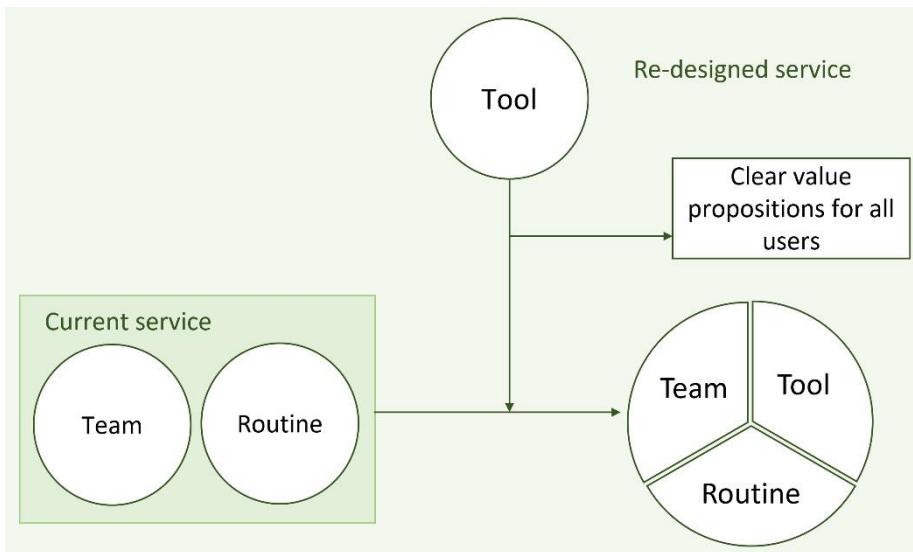


Figure 15. The team+tool+routine illustrates the importance of a tool that is perceived as meaningful by the team and integrated in the routines. (Adapted from Shaw et al, in line with license guidelines: <http://creativecommons.org/licenses/by/4.0/>)

The findings in study IV indicated the usefulness of Strokehälsa™; however, the study also emphasised the role of provider in addressing the needs. There are several aspects to reflect upon when designing user friendly tools while simultaneously maintaining the personal integrity. According to service design principles, the design always starts with patients' needs and experiences.⁷² In study IV, the development process started with the creation of 'personas.' By creating 'personas', people's preferences can be better understood⁷² e.g., some people value a quick answering process, while others prefer detailed information. According to universal design²⁴ and to promote health literate organisations,²⁰ the attempt was to develop an easy-to-use tool perceived as meaningful by the users in study IV.

Methodological considerations

The studies, included in this thesis, were explorative with a mix of qualitative and quantitative methods. The naturalistic design⁸² in study I, II, and III was chosen to improve the understanding of aspects that influence the follow-up and use of the PSC in a real clinical setting.

The settings in the studies were chosen with an intention to represent different sections of the care chain and various populations. In study I and II, outpatient clinics in primary and specialised outpatient care represented the urban as well

as rural areas. In study IV, community-dwelling people represented stroke organisations and helped us understand the perspective from people who had lived after stroke for a longer time. In study III, the focus was on people in nursing homes. The nursing homes were carefully selected to ensure a broad representation geographically and within areas with socioeconomic vulnerability. There are several strengths and limitations of the setting and design of the studies in this thesis that need to be further considered.

Study samples

All studies in this thesis included people living in Sweden and were primarily from one region in Sweden, and hence, a selection bias cannot be ruled out, and the results may not be a representative for Sweden as a whole. In study II, patients with an appointment with the selected healthcare professionals in the study were consecutively recruited; thus, the samples did not cover all available patients at the clinic as a whole. However, most people had a mild stroke, which is representative of the Swedish population.¹¹¹ In general, the recruitment of residents with stroke in nursing homes demonstrated a lack of knowledge regarding the stroke diagnosis. According to the study design, nurses provided information of available residents with stroke based on nurses' charts (study III). However, this information could be limited e.g., time since stroke, which could constitute a selection bias. Nonetheless, it reflected the reality in nursing homes. All kind of selection bias that may have occurred in any of the studies was unintentional, and efforts were made to overcome potential challenges e.g., by a close collaboration with staffs during the recruitment processes and selection of samples.

Since the purpose of study II was to explore experiences, it was important to include people with ability to participate actively during the visit where the PSC was used. In contrast, in study III, residents with limited ability of answering the PSC items were included. Furthermore, in the nursing homes, care-staffs were more often born abroad and may not know the local language fully and a majority of them were assistant nurses as compared to health professionals in study I and II. Thereby, the naturalistic design of the studies II-III mirrors reality and illuminate aspects of importance for the feasibility the PSC in different settings.

After a stroke, people can have difficulties in participating in studies due to cognitive impairment, complex needs, and communication difficulties. Accordingly, it was challenging to provide a representative sample while collecting satisfaction ratings and perceived usefulness of the PSC and Strokehälsa™. However, the use of different samples and methods in the studies together contributed to a deeper understanding. In accordance with the concept

of information power,¹¹² a purposive sampling was applied to achieve rich qualitative data according to the aim of each study. However, the purposive sampling became restricted for different reasons. For example, the predefined time between the visit and the focus groups in study I and II lead to inclusion of less number of women participants. Nevertheless, the people included were able to express their views which contributed to rich data.

Most people with stroke participating in study IV used internet on daily basis and were independent in ADL, and hence, they did not represent the stroke population in general. However, people active in the stroke organisation in study IV had often lived with stroke consequences for several years and had experience of meeting other people with stroke. Thereby, they could reflect on the usefulness of Strokehälsa™ also from other people's perspective. Nonetheless, people involved in organisations may represent a certain group of people only. Importantly, people from a rehabilitation clinic were also included in study IV, providing a range of participants who suffered from stroke between 4 months to 19 years ago. Furthermore, during sampling, special consideration was made to ensure that people with aphasia could participate e.g., a small focus group and participation with the support of next of kin in study IV. Altogether the people included in the studies in this thesis comprised a wide range of people; those independent in ADL and living in own home to people in nursing homes with high level of dependency. Furthermore, people with various time since stroke, stroke severity, and communication ability participated.

Quantitative methods

The cross-sectional data collected by the PSC and clinical data provided a description of common health problems after a stroke in the sub-acute and chronic phases after stroke. However, findings from the thesis should be handled with caution. Small sample sizes and local follow-up strategies influence the generalisation of these findings to other contexts. However, the sample size was considered adequate for the purpose of the studies, and were in accordance with similar studies.^{17,113} The validity of the PSC is strengthened by the delphi-process underlying the development of the PSC⁴³ and that the PSC has been shown feasible.¹⁷ Furthermore, the prior work with the Swedish version, including a forward-backward translation with feedback from different stakeholders, further strengthens the validity of the PSC.

Although, the PSC questions were in accordance with the original PSC, information bias or recall bias cannot be excluded e.g., when referring to the term 'since your stroke'. The intention with the PSC is to be an aid to facilitate the conversation between the patient and the care provider.⁴³ Hence,

clarification and conversation around each item is recommended and can help people to modify their responses to the PSC questions. It is likely that the data were influenced by the context and also depended on the individual who administered e.g., occupational therapist with expertise within stroke compared to primary care physician. Thereby the result from the PSC should be handled with caution and always in relation to its specific context.

In preparation for study III, nursing home staff were asked for their opinion about a pilot version of the study form and questionnaires. It was made clear that the PSC items potentially could be difficult to answer on the resident's behalf. To prevent uncertainty the response option "don't know" was added. Consequently, it is likely that stroke-related health problems were underestimated in study III, although staff were encouraged to talk with the resident or next-of-kin before the data collection.

Study IV included both the perceived satisfaction and if participants anticipated the Strokehälsa™ could be useful in a real clinical situation after stroke (acceptability). Acceptability should be assessed prior to an intervention, which differs from satisfaction, which is assessed retrospectively.¹¹⁴ Some people had difficulty to assess acceptability e.g., answered "don't know" in the web survey regarding the value of using the tool as a preparation for a clinical visit. Importantly, lack of prior experience of a service influences people's preferences.¹¹⁵ Nevertheless, by using service design principles and prototypes, people could experience the "real" digital service,⁷² although not as part of a clinical follow-up in study IV.

Qualitative methods

In this thesis, different methods were carefully chosen to address the specific research questions. First, the focus groups encouraged people to share their views and generate new ideas leading to a shared meaning about the topic e.g., Strokehälsa™. Second, the individual interviews in study IV provided a possibility to explore individual's experiences that may not have been captured in a group discussion e.g., potential misunderstandings. In addition, the "think aloud" method was used when answering to the questions fits well with an individual interview.

During the interviews, it is important to create an open atmosphere and facilitate participants' willingness to share their views.⁷⁶ The moderator has an important role in creating this atmosphere and to facilitate the discussion. The data gathered in the studies in this thesis were considered rich in relation to each aim. In study IV, in line with the co-design method, the members of the research team were actively involved and influenced the process.^{18,70} Although

participants were encouraged to discuss freely, the researcher's role in the project could have restricted people from expressing disadvantages. Nevertheless, the rich data and critical feedback gained indicate people shared their experiences openly to improve the tool. In all studies, rigor and reflexivity were enhanced by reflections and feedback systematically noted in memos.

Concerning reflexivity, pre-understanding is deemed as an element that influences the data analysis and interpretation.⁸³ The main analyses were performed by occupational therapists with experience in stroke and prior knowledge about PSC, health literacy, and the concept of person-centered care. This pre-understanding helped the researchers to think of various factors related to the interventions. Furthermore, all analysis were discussed with the whole research team, including patient partner in study IV, before final themes were created.

To ensure trustworthiness in a qualitative study, credibility, confirmability, dependability, and transferability must be considered.⁸² To maintain credibility participants were recruited from various settings where different mode of delivery of the PSC were applied by people with stroke and professionals. Participants represented different areas (urban and rural), demographics (including sex), and clinical characteristics, which resulted in a wide range of experiences regarding the PSC. Further, the credibility was increased by conducting the interviews in a known and safe environment. Due to the COVID-19 pandemic, the data was collected using a telephone interview, in study IV. This was not in line with the original project plan. However, the interviews gained rich information. Perhaps, participants' statements became even richer compared to a physical interview where things might seem more obvious for the interviewer. However, data collection by telephone could have affected the recruitment of participants. A weakness of the studies is the lack of people speaking other languages than Swedish.

Alternative interpretations were discussed during analysis and further elaborated with all co-authors to enhance credibility. To ensure confirmability, the influence of pre-understanding was continuously considered by co-authors to keep the analysis close to participants' words. Additionally, the possibility to go back and forth between transcripts and codes in the Nvivo program further strengthened the confirmability and supported a transparent analysis process among authors. To increase the dependability, a thorough description of the procedures was provided, and in each study, the same interview guide was used throughout. A systematic method adapted for focus group analysis was used since the discussion was in focus and not separate statements from one individual.⁷⁷ Further, the framework method was mainly used to enable a

flexible and combined analysis, including several sources. The possibility to read the transcripts several times by different authors further contributed to the dependability. One of the co-authors experienced in qualitative methods read the transcripts and were involved in the main part of the analyses. The COREQ guidelines¹¹⁶ were followed in study I and II to ensure consideration of important aspects in qualitative research. To enhance the transferability of the findings, the study context and participants were described thoroughly.

CONCLUSIONS

The model for follow-up demonstrated in this thesis was perceived as useful, including the use of the PSC during a face-to-face visit, with proxy and as a digital pre-visit tool. Importantly, the dialogue between the patient and health professional is essential when using the PSC to ensure that unmet needs are identified. Furthermore, the digital pre-visit tool, Strokehälsa™, was perceived useful and with potential to prepare patients before a follow-up visit. However, this needs to be evaluated clinically. The developmental process of the digital tool can serve as an example for others when designing digital health services. The study design in the thesis demonstrates how complex interventions can be developed and evaluated in line with a participatory approach with involvement of multiple stakeholders.

This thesis findings show, in line with previous research, that people with stroke not only experience health problems after returning to daily life but also feel being left-out. These patients also find it difficult to access healthcare services, representing a major risk for worse health after stroke. The data collected with the PSC among community-dwelling people and nursing home residents showed that most of the participants had persisting health problems after their stroke irrespective of the acute stroke severity. Residents in nursing homes often had complex needs with several health problems, which influenced their dependency in daily life.

Findings suggest that a comprehensive follow-up model, including different modes of delivery of the PSC, should be offered to people with stroke to facilitate an egalitarian support. The studies in the thesis were conducted in parallel with the development of the Swedish national stroke guidelines and the person-centered pathways for stroke and TIA; this is a priority area with high clinical relevance. Accordingly, the PSC and Strokehälsa™ is now recommended for the national person-centred pathways for stroke and TIA in Sweden.

FUTURE PERSPECTIVES

Currently, for people with stroke, it is difficult to navigate through the healthcare system. There is a gap between individuals' ability to use health information and how healthcare organizations respond to patient needs, and hence, healthcare providers have to meet the challenge of bridging this gap. This can be achieved by (1) designing universal services and health literate organisations, (2) providing education to healthcare staff regarding stroke and communication strategies which can improve follow-ups, and (3) translation of the PSC and Strokehälsa™ into other languages; paper version; an image supported version could further strengthen personal and e-health literacy.

The newly developed Strokehälsa™ needs to be tested in a clinical setting in conjunction with a follow-up appointment. Perspective of both the patients and healthcare providers should be investigated to further improve the service in the future. Furthermore, it would be interesting to explore how preparedness with Strokehälsa™ can enhance patients' active engagement with care providers and ability to take informed decisions.

The likelihood for patients' needs to be met is expected to increase when health problems are identified by the PSC. Current findings stress that identified health problems should lead to appropriate actions. Although health organisations may lack certain professionals or have limited resources, people have the right to be informed about timeframe and when to expect treatments according to the Swedish patient act¹¹⁷ and the person-centred pathway for stroke and TIA.¹⁵

A successful implementation of the entire follow-up model described in this thesis demands an evaluation of the local context. Changes in local routine practices (using different modes of PSC delivery) can support a more equal follow-up after a stroke. Furthermore, the potential of virtual follow-up visit is required to be further evaluated. New ways to deliver care are in line with the e-health vision¹⁴ and may offer solutions to deal with increased healthcare burden due to an aging population.⁸

ACKNOWLEDGEMENT

Vad vore en forskarvandring utan redan upptrampade stigar? Det har varit tryggt att få ta rygg på erfarna handledare som stöttat mig i att utforska min egen väg. **Katharina Stibrant Sunnerhagen** – tack för att du har trott på mig! Du har gett mig ett stort förtroende med en möjlighet för mig att utforska, utmanas och växa i min egen takt. Tack för att du så generöst delat med dig av ditt nätverk och sammanhang där jag fått nya erfarenheter. **Gunnel Carlsson**, du har alltid varit min trygga följeslagare. Tack för att jag fått reflektera tillsammans med dig! Ditt lyssnande har hjälpt mig att tänka klart, se saker från ett nytt perspektiv och se att jag ofta haft lösningen själv. Du har delat genuin glädje och nyfikenhet i analysen - en medskapare med fokus på personen bakom stroken. **Åsa Lungren Nilsson**, tack för att fångade upp mig och gav mig tillgång till forskargruppen! Du har hjälpt mig att se klart i en ibland snårig forskardjungel. Ditt sätt att ställa frågor till mig och din klarsynthet har hjälpt mig att bli tydligare och att våga fatta för mig svåra beslut.

Utan goda förebilder och chefer hade inte denna forskningsvandring varit möjlig. **Christian Blomstrand**, tack för att du inspirerade mig när du sa att man kan se forskning som ”en strukturerad nyfikenhet”. **Gunilla Kjellby Wendt**, tack för att du som ansvarig för arbetsterapi och fysioterapiverksamheten visar att forskning är en given del av vårt arbete och att du uppmuntrat mig på min väg. **Åsa Sand** och **Claes Gustafsson**, tack för att ni gjorde forskningen till en del av det kliniska arbetet genom TIA-projektet. Det var en viktig väg in i forskningen för mig. **Anneli Lernestål**, tack för att du såg mig och uppmuntrade mig att utvecklas på olika sätt genom kurser och andra utmaningar. Under våra gemensamma reflektionsstunder lärde du mig att det inte är så farligt att testa sig fram. **Lena Mårtensson**, tack för att du introducerade begreppet hälsolitteracitet för mig – det har blivit en viktig teoretisk referensram för mig i mina projekt. **Mats Abrahamsson**, tack för att du gett mig tid och utrymme att varva forskning och kliniskt arbete på ett flexibelt sätt. Tack för att du sett mig under stressade perioder och att du gett mig förutsättningar att hitta balansen.

Forskargruppen, vilken växtplats! Så många fina kollegor. Vi har delat upp och nedgångar, reject och accept. Generöst har vi lyssnat och delat erfarenheter med varandra. Vi har fått göra skillnad för varandra i stort som smått. När jag kom in i forskargruppen var peer-review och forskargruppträffar bara i sin linda, vilket nu känns som självklara inslag. Det har varit både roligt och krävande i en skön balans. Tack till alla kollegor i forskargruppen! Särskilt tack till er som funnits på plats, stöttat och delat de dagliga utmaningarna: **Adam Viktorisson**, **Annie Palstam**, **Alexandra Larsson**, **David Krabbe**,

Dogni Buvarp, Elisabeth Brodin, Elisabeth Åkerlund, Emma Westerlind, Hanna Persson, Lamprini Lili, Lena Rafsten, Linda Ashman, Maria Munoz, Malin Reinholdsson, Margit Alt Murphy, Netah Hussain, Sofi Andersson, Tamara Abzhandadze och Ulrika Jonsson. Tack för att jag fått reflektera och lära tillsammans med er! Jag vill också rikta ett stort tack till institutionen för stöd och hjälp. Tack IT-support för ert tålmodiga och proffsiga stöd- det har varit helt avgörande!

Alla medförfattare, tack för ett gott och roligt samarbete! Utöver mina handledare vill jag särskilt tacka **Martha Gustafsson** och **Nohad Elmanzalawy** för att ni bidrog med ert kunnande och vidgade perspektiv när vi gjorde studien på särskilda boenden. Särskilt tack till **Anders Andersson** för att du varit en egagerad patientpartner när vi utvecklade det digitala verktyget. Din medverkan har varit väldigt betydelsefull för resultatet. Jag vill också tacka webbkonsulten **Michael Wide** som hjälpte mig att navigera i den "digitala världen". Tack för att du gjorde det begripligt och för att du gjorde en fin layout. Tack **Robin Björk** som tålmodigt hjälpte till att se möjligheterna inom 1177.

Östrafamiljen, tack för att ni alltid funnits där och att jag alltid kännt mig välkommen när jag kommit och gått. Det har varit viktigt för mig att få träffa er i klinken och möta patienterna – vilket ju är drivkraften till varför jag forskar. Tack till alla enheter, patienter och personal som så generöst delat med er av er tid och era upplevelser. Tack till Strokeforum, Strokeföreningen och Strokeförbundet för att ni varit delaktiga och skapat förutsättningar för oss att genomföra studierna och verka för fortsatt implementering.

Tack till **släkt och vänner**. Tack för långa fjällvandringar, skogs promenader, häng på klipporna och middagar där vi samtalat med varandra och delat visioner. Utan dessa samtal om femårsplaner och vikten av att ta ett steg i taget hade jag aldrig varit där jag är idag. Tack för att ni står kvar.

Största tacket går ändå till min älskade **Johan** och mina fantastiska barn **Elias, Klara** och **Eskil**. Ni har hjälpt mig att få perspektiv och inse att livet är så mycket mer än accepterade artiklar och att befinna sig utanför sin bekvämlighetszon. Tack för att ni stått ut med mig. Jag älskar er!

Jag har alltid hävdat att vägen är målet, men lite bra känns det ändå att nå disputationsmålet...

Funding

This study was funded in part by grants from the Swedish Science Council (VR2017-00946), the Swedish state under the agreement between the Swedish government and the county councils, the ALF agreement (ALFGBG-718711/ 71980/ 943103)"; The innovation foundation West of Sweden, VGRINN-968305; the Local Research and Development Board for Gothenburg and Södra Bohuslän (VGFOUGSB-575721, VGFOUGSB-767121; Sahlgrenska Hospitals Foundation (SU-892141, SU-793481, SU-935222); the Swedish Heart and Lung Foundation; the Swedish Brain Foundation, the Swedish Stroke Association, Herman Svenssons Foundation; Hjalmar Svenssons Foundation; Göteborg Foundation for Neurological Research; Rune and Ulla Amlövs Foundation; Per-Olof Ahls Foundation; John and Brit Wennerströms Foundation; Swedish Neuro Foundation (Neuro); Dr Felix Neubergs Foundation and the Swedish state under the agreement of the Swedish government and the county councils, and unconditional grants from Allergan. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

REFERENCES

1. Norrving B, Barrick J, Dávalos A, et al. Action Plan for Stroke in Europe 2018-2030. *Eur Stroke J* 2018; **3**(4): 309-36.
2. Epping-Jordan JE, Pruitt SD, Bengoa R, Wagner EH. Improving the quality of health care for chronic conditions. *Qual Saf Health Care* 2004; **13**(4): 299-305.
3. Crichton SL, Bray BD, McKevitt C, Rudd AG, Wolfe CD. Patient outcomes up to 15 years after stroke: survival, disability, quality of life, cognition and mental health. *J Neurol Neurosurg Psychiatry* 2016; **87**(10): 1091-8.
4. Cieza A, Causey K, Kamenov K, Hanson SW, Chatterji S, Vos T. Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet* 2021; **396**(10267): 2006-17.
5. McKevitt C, Fudge N, Redfern J, et al. Self-reported long-term needs after stroke. *Stroke* 2011; **42**(5): 1398-403.
6. Zawawi NSM, Aziz NA, Fisher R, Ahmad K, Walker MF. The Unmet Needs of Stroke Survivors and Stroke Caregivers: A Systematic Narrative Review. *J Stroke Cerebrovasc Dis* 2020; **29**(8): 104875.
7. Chen T, Zhang B, Deng Y, Fan JC, Zhang L, Song F. Long-term unmet needs after stroke: systematic review of evidence from survey studies. *BMJ Open* 2019; **9**(5): e028137.
8. Collaborators GBDS. Global, regional, and national burden of stroke and its risk factors, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Neurol* 2021; **20**(10): 795-820.
9. Riksstroke årsrapport 2020. The Swedish Stroke Register. Available from: <https://www.riksstroke.org/eng/> (accessed Sept 20 2022).
10. Pindus DM, Mullis R, Lim L, et al. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services - A systematic review and meta-ethnography. *PLoS One* 2018; **13**(2): e0192533.
11. Friis K, Lasgaard M, Osborne RH, Maindal HT. Gaps in understanding health and engagement with healthcare providers across common long-term conditions: a population survey of health literacy in 29 473 Danish citizens. *BMJ open* 2016; **6**(1): e009627.
12. Stevens E, Emmett E, Wang DY, McKevitt C, Wolfe CD. The Burden Of Stroke In Europe Report London: SAFE Stroke Alliance For Europe 2017.
13. Grover S, Fitzpatrick A, Azim FT, et al. Defining and implementing patient-centered care: An umbrella review. *Patient Educ Couns* 2022; **105**(7): 1679-88.
14. Strategi för genomförde av e-hälsa vision 2025. [Strategies for the implementation of The EHealth vision 2025]. 2016. Available from <https://ehalsa2025.se/> (accessed September 19 2022).

15. Personcentrerat och sammanhållet vårdförflopp Stroke och TIA [Clinical pathways for Stroke and TIA]. 2022. Available from: <https://nationelltklinisktkunskapsstod.se/vardprogramochvardforlopp> (accessed Sept 20 2022).
16. Nationella riktlinjer för vård vid stroke [National Guidelines for Strokecare]. 2020. Available from: <https://www.socialstyrelsen.se/> (accessed Sept 20 2022).
17. Ward AB, Chen C, Norrvling B, et al. Evaluation of the Post Stroke Checklist: a pilot study in the United Kingdom and Singapore. *Int J Stroke* 2014; **9 Suppl A100**(A100): 76-84.
18. Sanders EBN, Stappers PJ. Co-creation and the new landscapes of design. *CoDesign* 2008; **4**(1): 5-18.
19. Skivington K, Matthews L, Simpson SA, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ* 2021; **374**: n2061.
20. Santana S, Brach C, Harris L, et al. Updating Health Literacy for Healthy People 2030: Defining Its Importance for a New Decade in Public Health. *Journal of public health management and practice : JPHMP* 2021; **27**(Suppl 6): S258-S64.
21. Nergårdh A AL, Eriksson J, et al. God och nära vård—En primärvårdsreform. [Good and close care - A primary care reform] Stockholm, 2018. Available from: <https://www.regeringen.se/>.
22. Ekman I, Swedberg K, Taft C, et al. Person-centered care—Ready for prime time. *Eur J Cardiovasc Nurs* 2011; **10**(4): 248-51.
23. Santana MJ, Manalili K, Jolley RJ, Zelinsky S, Quan H, Lu M. How to practice person-centred care: A conceptual framework. *Health Expect* 2018; **21**(2): 429-40.
24. Persson H, Åhman H, Yngling AA, Gulliksen J. Universal design, inclusive design, accessible design, design for all: different concepts—one goal? On the concept of accessibility—historical, methodological and philosophical aspects. *Universal Access in the Information Society* 2014; **14**(4): 505-26.
25. Healthcare guide 1177. Available from: <https://www.1177.se/om-1177/> (accessed Sept 20 2022).
26. Kickbusch I, Pelikan JM, Apfel F, Tsouros A. Health literacy: WHO Regional Office for Europe; 2013.
27. Brach C, Keller D, Hernandez LM, et al. Ten attributes of health literate health care organizations. *NAM perspectives* 2012.
28. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. *J Med Internet Res* 2012; **14**(1): e19.
29. Norgaard O, Furstrand D, Klokke L, et al. The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e-health systems. *Knowledge Management and E-Learning* 2015; **7**: 522–40.

30. Bröder J, Chang P, Kickbusch I, et al. IUHPE position statement on health literacy: a practical vision for a health literate world. 2018.
31. Constitution of the World Health Organisation (WHO). New York, 1946.
32. World Health Organization: Towards a common language for functioning, disability, and health (ICF). Geneva: World Health Organization; 2001.
33. Rehabilitation 2030 Initiative. 2022. Available from: <https://www.who.int/initiatives/rehabilitation-2030> (accessed Sept 20 2022).
34. Aho K, Harmsen P, Hatano S, Marquardsen J, Smirnov VE, Strasser T. Cerebrovascular disease in the community: results of a WHO collaborative study. *Bull World Health Organ* 1980; **58**(1): 113-30.
35. Sacco RL, Kasner SE, Broderick JP, et al. An updated definition of stroke for the 21st century: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke* 2013; **44**(7): 2064-89.
36. Statistik om stroke 2020. <https://www.socialstyrelsen.se/> (accessed Sept 20 2022).
37. Bernhardt J, Hayward KS, Kwakkel G, et al. Agreed definitions and a shared vision for new standards in stroke recovery research: the stroke recovery and rehabilitation roundtable taskforce. *Int J Stroke* 2017; **12**(5): 444-50.
38. Ytterberg C, Dyback M, Bergstrom A, Guidetti S, Eriksson G. Perceived impact of stroke six years after onset, and changes in impact between one and six years. *J Rehabil Med* 2017; **49**(8): 637-43.
39. Turner GM, McMullan C, Atkins L, Foy R, Mant J, Calvert M. TIA and minor stroke: a qualitative study of long-term impact and experiences of follow-up care. *BMC Fam Pract* 2019; **20**(1): 176.
40. Kirkevold M. The unfolding illness trajectory of stroke. *Disabil Rehabil* 2002; **24**(17): 887-98.
41. Hackett ML, Pickles K. Part I: frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies. *Int J Stroke* 2014; **9**(8): 1017-25.
42. Sumathipala K, Radcliffe E, Sadler E, Wolfe CD, McKevitt C. Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health. *Chronic Illness* 2012; **8**(1): 31-44.
43. Philp I, Brainin M, Walker MF, et al. Development of a poststroke checklist to standardize follow-up care for stroke survivors. *J Stroke Cerebrovasc Dis* 2013; **22**(7): e173-80.
44. Sapuppo D, Bernhardt J, Carvalho LB, Churilov L, Thijs V. Self-evaluation of personal needs by community-living young stroke survivors using an online English language questionnaire. *Disabil Rehabil* 2022: 1-6.
45. Olver J, Yang S, Fedele B, et al. Post Stroke Outcome: Global Insight into Persisting Sequelae Using the Post Stroke Checklist. *J Stroke Cerebrovasc Dis* 2021; **30**(4): 105612.

46. Teo K, Slark J. A systematic review of studies investigating the care of stroke survivors in long-term care facilities. *Disabil Rehabil* 2016; **38**(8): 715-23.
47. Ullberg T, Zia E, Petersson J, Norrving B. Perceived Unmet Rehabilitation Needs 1 Year After Stroke: An Observational Study From the Swedish Stroke Register. *Stroke* 2016; **47**(2): 539-41.
48. van Almenkerk S, Depla MF, Smalbrugge M, Eefsting JA, Hertogh CM. Pain among institutionalized stroke patients and its relation to emotional distress and social engagement. *Int J Geriatr Psychiatry* 2015; **30**(10): 1023-31.
49. Amy Y, MacLagan LC, Diong C, et al. Sex Differences in Care Need and Survival in Patients Admitted to Nursing Home Poststroke. *Can J Neurol Sci* 2020; **47**(2): 153-9.
50. Ullberg T, Zia E, Petersson J, Norrving B. Changes in functional outcome over the first year after stroke: an observational study from the Swedish stroke register. *Stroke* 2015; **46**(2): 389-94.
51. Ytterberg C, Kristensen H, Tistad M, Koch L. Factors related to met needs for rehabilitation 6 years after stroke. *PLoS One* 2020; **15**: e0227867.
52. National Board of Health and Welfare (Socialstyrelsen). Available from: <https://www.government.se/government-agencies/national-board-of-health-and-welfare--socialstyrelsen/>.
53. Langhorne P, Ramachandra S, Collaboration SUT. Organised inpatient (stroke unit) care for stroke: network meta-analysis. *Cochrane Database of Systematic Reviews* 2020; **4**(4): CD000197.
54. Cumming TB, Marshall RS, Lazar RM. Stroke, cognitive deficits, and rehabilitation: still an incomplete picture. *Int J Stroke* 2013; **8**(1): 38-45.
55. Carlsson GE, Möller A, Blomstrand C. Managing an everyday life of uncertainty—a qualitative study of coping in persons with mild stroke. *Disabil Rehabil* 2009; **31**(10): 773-82.
56. Forster A, Brown L, Smith J, et al. Information provision for stroke patients and their caregivers. *Cochrane database of systematic reviews* 2012; (11).
57. Digital tillgänglighet [Digital accessibility]. 2019. Available from: <https://www.mfd.se/verktyg/> (accessed Sept 20 2022).
58. Holt JM, Cusatis R, Winn A, et al. Impact of Pre-visit Contextual Data Collection on Patient-Physician Communication and Patient Activation: a Randomized Trial. *J Gen Intern Med* 2021; **36**(11): 3321-9.
59. Granström E, Wannheden C, Brommels M, Hvitfeldt H, Nyström ME. Digital tools as promoters for person-centered care practices in chronic care? Healthcare professionals' experiences from rheumatology care. *BMC Health Serv Res* 2020; **20**(1): 1-15.
60. Willeit P, Toell T, Boehme C, et al. STROKE-CARD care to prevent cardiovascular events and improve quality of life after acute ischaemic stroke or TIA: A randomised clinical trial. *EClinicalMedicine* 2020; **25**: 100476.

61. Tellier M, Rochette A. Falling Through the Cracks: A Literature Review to Understand the Reality of Mild Stroke Survivors. *Top Stroke Rehabil* 2009; **16**(6): 454-62.
62. Iosa M, Lupo A, Morone G, et al. Post Soft Care: Italian implementation of a post-stroke checklist software for primary care and identification of unmet needs in community-dwelling patients. *Neurol Sci* 2018; **39**(1): 135-9.
63. Ullberg T, Mansson K, Berhin I, Pessah-Rasmussen H. Comprehensive and Structured 3-month Stroke Follow-up Using the Post-stroke Checklist (The Struct-FU study): A Feasibility and Explorative Study. *J Stroke Cerebrovasc Dis* 2021; **30**(2): 105482.
64. Kamoen O, Maqueda V, Yperzeele L, et al. Stroke coach: a pilot study of a personal digital coaching program for patients after ischemic stroke. *Acta Neurol Belg* 2020; **120**(1): 91-7.
65. Toell T, Boehme C, Mayer L, et al. Pragmatic trial of multifaceted intervention (STROKE-CARD care) to reduce cardiovascular risk and improve quality-of-life after ischaemic stroke and transient ischaemic attack - study protocol. *BMC Neurol* 2018; **18**(1): 187.
66. BestPractices CS. Canadian Stroke best practices. <https://www.strokebestpractices.ca/resources/professional-resources> (accessed 22-05-11 2022).
67. Turner GM, Mullis R, Lim L, Kreit L, Mant J. Using a checklist to facilitate management of long-term care needs after stroke: insights from focus groups and a feasibility study. *BMC Fam Pract* 2019; **20**(1): 2.
68. Abrahamson V, Wilson PM. How unmet are unmet needs post-stroke? A policy analysis of the six-month review. *BMC Health Serv Res* 2019; **19**(1): 480.
69. Morgan DL. Integrating qualitative and quantitative methods: A pragmatic approach. 55 City Road, London: SAGE Publications, Inc.; 2014.
70. Cowdell F, Dyson J, Sykes M, Dam R, Pendleton R. How and how well have older people been engaged in healthcare intervention design, development or delivery using co-methodologies: A scoping review with narrative summary. *Health Soc Care Community* 2022; **30**(2): 776-98.
71. Steen M, Manschot M, De Koning N. Benefits of Co-design in Service Design Projects. *International Journal of Design* 2011; **5**(2): 53-60.
72. Stickdorn M, Hormess ME, Lawrence A, Schneider J. This is service design doing: applying service design thinking in the real world: " O'Reilly Media, Inc."; 2018.
73. Shaw J, Agarwal P, Desveaux L, et al. Beyond "implementation": digital health innovation and service design. *NPJ Digit Med* 2018; **1**(1): 48.
74. Patton MQ. Qualitative research & evaluation methods: Integrating theory and practice: Sage publications; 2014.
75. Thirsk LM, Clark AM. Using Qualitative Research for Complex Interventions: The Contributions of Hermeneutics. *International Journal of Qualitative Methods* 2017; **16**(1): 1609406917721068.

76. Kvale S, Brinkmann S. Interviews: Learning the craft of qualitative research interviewing: sage; 2009.
77. Krueger RA. Focus groups: A practical guide for applied research. 5th ed. London: Sage publications; 2014.
78. Ivanoff SD, Hultberg J. Understanding the multiple realities of everyday life: basic assumptions in focus-group methodology. *Scand J Occup Ther* 2006; **13**(2): 125-32.
79. Bowen DJ, Kreuter M, Spring B, et al. How We Design Feasibility Studies. *Am J Prev Med* 2009; **36**(5): 452-7.
80. Kroll T, Barbour R, Harris J. Using Focus Groups in Disability Research. *Qual Health Res* 2007; **17**(5): 690-8.
81. Beatty PC, Willis GB. Research synthesis: The practice of cognitive interviewing. *Public Opin Q* 2007; **71**(2): 287-311.
82. Lincoln YS GE. Naturalistic Inquiry. The Blackwell Encyclopedia of Sociology. Beverly Hills, Calif: Sage; 1985: 416
83. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001; **358**(9280): 483-8.
84. Griffioen I, Melles M, Stiggebout A, Snelders D. The potential of service design for improving the implementation of shared decision-making. *Design for Health* 2017; **1**(2): 194-209.
85. Goldstein LB, Samsa GP. Reliability of the National Institutes of Health Stroke Scale. Extension to non-neurologists in the context of a clinical trial. *Stroke* 1997; **28**(2): 307-10.
86. Brott T, Adams HP, Jr., Olinger CP, et al. Measurements of acute cerebral infarction: a clinical examination scale. *Stroke* 1989; **20**(7): 864-70.
87. Kasner SE, Chalela JA, Luciano JM, et al. Reliability and validity of estimating the NIH stroke scale score from medical records. *Stroke* 1999; **30**(8): 1534-7.
88. Lindley RI, Wardlaw JM, Whiteley WN, et al. Alteplase for acute ischemic stroke: outcomes by clinically important subgroups in the Third International Stroke Trial. *Stroke* 2015; **46**(3): 746-56.
89. Quinn TJ, Dawson J, Walters MR, Lees KR. Functional outcome measures in contemporary stroke trials. *Int J Stroke* 2009; **4**(3): 200-5.
90. Mahoney FI. Functional evaluation: the Barthel index. *Md State Med J* 1965; **14**: 61-5.
91. Uyttenboogaart M, Stewart RE, Vroomen PC, De Keyser J, Luijckx GJ. Optimizing cutoff scores for the Barthel index and the modified Rankin scale for defining outcome in acute stroke trials. *Stroke* 2005; **36**(9): 1984-7.
92. van Swieten JC, Koudstaal PJ, Visser MC, Schouten HJ, van Gijn J. Interobserver agreement for the assessment of handicap in stroke patients. *Stroke* 1988; **19**(5): 604-7.
93. Bruno A, Shah N, Lin C, et al. Improving modified Rankin Scale assessment with a simplified questionnaire. *Stroke* 2010; **41**(5): 1048-50.

94. Bruno A, Akinwuntan AE, Lin C, et al. Simplified modified rankin scale questionnaire: reproducibility over the telephone and validation with quality of life. *Stroke* 2011; **42**(8): 2276-9.
95. Dromerick AW, Edwards DF, Diringer MN. Sensitivity to changes in disability after stroke: a comparison of four scales useful in clinical trials. *J Rehabil Res Dev* 2003; **40**(1): 1-8.
96. Davis FD. Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology. *Mis Quarterly* 1989; **13**(3): 319-40.
97. Ritchie J, Lewis J, Nicholls CM, Ormston R. Qualitative research practice: A guide for social science students and researchers: sage; 2013.
98. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; **3**(2): 77-101.
99. Schwandt TA. Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics, and social constructionism. *Handbook of qualitative research*: SAGE Publishing; 2000: 189-213.
100. Kjörk EK, Sunnerhagen KS, Lundgren-Nilsson Å, Andersson AK, Carlsson G. Development of a Digital Tool for People With a Long-Term Condition Using Stroke as a Case Example: Participatory Design Approach. *JMIR Human Factors* 2022; **9**(2): e35478.
101. Morrissey M, Shepherd E, Kinley E, McClatchey K, Pinnock H. Effectiveness and perceptions of using templates in long-term condition reviews: a systematic synthesis of quantitative and qualitative studies. *Br J Gen Pract* 2021; **71**(710): e652-e9.
102. Strategies to reduce inequalities in access to planned hospital procedures. 2022. Available from: <https://www.midlandsdecisionsupport.nhs.uk/> (accessed Sept 20 2022).
103. Keating J, Borschmann K, Johns H, Churilov L, Bernhardt J. Young Stroke Survivors' Preferred Methods of Meeting Their Unique Needs: Shaping Better Care. *Neurology* 2021; **96**(13): e1701-e10.
104. Digital First Primary Care. 2019. Available from: <https://www.england.nhs.uk/gp/digital-first-primary-care/> (accessed Sept 20 2022).
105. Eriksson G, Aasnes M, Tistad M, Guidetti S, von Koch L. Occupational gaps in everyday life one year after stroke and the association with life satisfaction and impact of stroke. *Top Stroke Rehabil* 2012; **19**(3): 244-55.
106. Magaard G, Wester P, Levi R, et al. Identifying Unmet Rehabilitation Needs in Patients After Stroke With a Graphic Rehab-Compass(TM). *J Stroke Cerebrovasc Dis* 2018; **27**(11): 3224-35.
107. Jokinen H, Melkas S, Ylikoski R, et al. Post-stroke cognitive impairment is common even after successful clinical recovery. *Eur J Neurol* 2015; **22**(9): 1288-94.
108. Martinsen R, Kirkevold M, Sveen U. Young and midlife stroke survivors' experiences with the health services and long-term follow-up needs. *J Neurosci Nurs* 2015; **47**(1): 27-35.

109. Michalski D, Prost A, Handel T, et al. The PostStroke-Manager—combining mobile, digital and sensor-based technology with personal assistance: protocol of the feasibility study. *Neurological Research and Practice* 2021; **3**(1): 1-9.
110. The Digital Economy and Society Index (DESI). 2020. Available from: <https://digital-strategy.ec.europa.eu/en/policies/desi-sweden> (accessed Sept 20 2022).
111. Reinholdsson M, Palstam A, Sunnerhagen KS. Prestroke physical activity could influence acute stroke severity (part of PAPSIGOT). *Neurology* 2018; **91**(16): e1461-e7.
112. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res* 2016; **26**(13): 1753-60.
113. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine (Phila Pa 1976)* 2000; **25**(24): 3186-91.
114. Sekhon M, Cartwright M, Francis JJ. Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Serv Res* 2017; **17**(1): 1-13.
115. Lawton J, Rankin D, Elliott J. Is Consulting Patients About Their Health Service Preferences a Useful Exercise? *Qual Health Res* 2013; **23**(7): 876-86.
116. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. 2007; **19** (6): 349–57. *View Article PubMed/NCBI Google Scholar* 2015.
117. The Swedish patient act. 2014. Available from: <https://www.riksdagen.se/> (accessed Sept 20 2022).