# ONTARIO HEALTH TECHNOLOGY ASSESSMENT SERIES

## Continual Long-Term Physiotherapy After Stroke: A Health Technology Assessment

### KEY MESSAGES

*What Is This Health Technology Assessment About?*

Strokes are caused by an interruption in blood flow to any part of the brain, damaging the brain cells. Each year, more than 50,000 people in Canada are estimated to have a first stroke. Most people (83%) survive but experience damage to their motor skills.

Evidence shows that people may experience better recovery after stroke if they follow a short-term physiotherapy program as part of a multidisciplinary rehabilitation program that focuses on improving strength, balance, coordination, endurance, and flexibility.

This health technology assessment attempted to determine how effective continual long-term physiotherapy (more than 12 weeks) is for people who have had a stroke, if it is cost-effective, and the budget impact of publicly funding continual long-term physiotherapy for recovery from stroke. It also looked at the experiences, preferences, and values of people who have had a stroke.

*What Did This Health Technology Assessment Find?*

We were unable to find published evidence on the clinical effectiveness of continual long-term physiotherapy for recovery after stroke, and we were unable to determine its cost-effectiveness.

We estimated that publicly funding continual long-term post-stroke physiotherapy in Ontario over the next 5 years would lead to additional costs of $445,000 in the first year, increasing to $888,000 in the fifth year, assuming that the additional therapy is used by 8% of eligible people at the start of the program, increasing to 16% after 5 years.

People we spoke with who had experienced a stroke felt that they had benefitted from continual long-term physiotherapy and reported losing some flexibility and coordination after stopping physiotherapy. They also spoke of cost and access barriers to receiving continual long-term physiotherapy.

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# ABSTRACT

## Background

Stroke is a serious health issue in which an interruption in blood flow to any part of the brain damages brain cells. About 83% of people survive with substantial morbidity after their first stroke. We conducted a health technology assessment of continual long-term physiotherapy for people with a diagnosis of stroke, which included an evaluation of effectiveness, safety, cost-effectiveness, the budget impact of publicly funding continual long-term physiotherapy for people with a diagnosis of stroke, and patient preferences and values.

## Methods

We performed a systematic literature search of the clinical evidence. We also performed a systematic literature search of the economic evidence. We did not conduct a primary economic evaluation because there was insufficient clinical evidence. We also analyzed the budget impact of publicly funding continual long-term physiotherapy after stroke in Ontario. To contextualize the potential value of continual long-term physiotherapy after stroke, we spoke with people who had been diagnosed with stroke, as well as their caregivers.

## Results

We did not find any published studies that met the specific clinical inclusion criteria. We did not identify any studies that compared the cost-effectiveness of continual long-term versus short-term physiotherapy after stroke. The budget impact of publicly funding continual long-term physiotherapy after stroke in Ontario over the next 5 years ranges from $445,000 in year 1 at an uptake rate of 8% to $888,000 in year 5 at an uptake rate of 16%. The people who had been diagnosed with stroke with whom we spoke reported that they had benefitted from continual long-term physiotherapy.

## Conclusions

We did not identify studies that addressed the specific research question. Based on the clinical evidence review, we are unable to determine the benefits of continual long-term compared with short-term physiotherapy after stroke. The cost-effectiveness of continual long-term physiotherapy after stroke in Ontario is unknown. We estimate that publicly funding continual long-term physiotherapy after stroke in Ontario would result in additional costs of between $445,000 and $888,000 annually over the next 5 years. Patients and caregivers who we spoke with felt that patients who have experienced a stroke should be able to continue with physiotherapy.

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# OBJECTIVE

This health technology assessment evaluates the effectiveness and safety of continual long-term physiotherapy for adults after a diagnosis of stroke. It also evaluates the budget impact of publicly funding continual long-term physiotherapy after stroke and the experiences, preferences, and values of people who have had a stroke.

# BACKGROUND

## Health Condition

Strokes are caused by an interruption in blood flow to any part of the brain, damaging the brain cells. Stroke is a serious health issue that requires both immediate and long-term medical attention.

There are different types of stroke. The two major classifications are ischemic stroke and hemorrhagic stroke. Ischemic stroke occurs when an artery in the brain is blocked. Hemorrhagic stroke occurs when a blood vessel in the brain breaks open, interrupting blood flow in the brain.[1]

## Clinical Need and Target Population

In Canada, approximately 62,000 people suffer a stroke annually, and about 405,000 are living with the consequences of a stroke.[2] This number is expected to increase by 80% over the next two decades because of the aging population and improvements in acute care.[2] Each year, more than 50,000 people in Canada are estimated to have a first stroke. A majority of strokes occur in people over the age of 65 years.[3]

Most people (83%) survive their first stroke, but with substantial morbidity.[4] It is common for people to experience weakness of the upper and lower limbs after stroke, in addition to a loss of cognitive functions. This weakness can affect people's ability to walk and to use their upper limbs for daily activities. Approximately two-thirds of stroke survivors have residual neurological deficits that affect function, and approximately half present with disabilities that affect activities of daily living.[3] Approximately 30% of people with persisting disabilities may benefit from access to long-term stroke recovery services. Recovery services are multidisciplinary and include physiotherapy services, which are available in many places, including some hospitals with a dedicated rehabilitation stroke unit, rehabilitation hospitals, and clinics and offices in the community, as well as in the home.[1]

Recovery from neurophysiological changes after stroke can be variable. Recovery usually starts within the first 1 to 2 weeks, depending on the type of stroke.[3] Recovery may continue for years after stroke; however, progress is perceived to be at a lower rate as time elapses.[3] Extrinsic factors such as age, existing comorbidities, and participation in formal physiotherapy sessions may also affect the speed and quality of recovery.[3] Personalized physiotherapy helps minimize disability after a stroke. Since some people present with persisting disabilities, long-term (i.e., chronic or maintenance) physiotherapy may reduce the risk of progressive worsening, as recovery may continue well beyond 3 months after stroke.[5] Continual assessment and tracking of functional status over time is important when determining the need for continual therapy.[5]

# Health Service Under Review

## *Physiotherapy After Stroke*

Physiotherapy (also sometimes known as physical rehabilitation) is delivered by physiotherapists (also sometimes known as physical therapists) in many different practice settings, including acute care and rehabilitation hospitals, outpatient clinics, long-term care homes, and primary care facilities. The goal of therapy after stroke is to improve strength, balance, coordination, proprioception, endurance, and flexibility, as well as to promote general health and physical conditioning.[6] Physiotherapists mobilize the patient's trunk to reduce spasticity and achieve improved proximal/core stability, which, in turn, encourages more normal movement of extremities. Rehabilitation of gross motor skills, such as rolling, lying to sitting, and sitting to standing, is often the precursor to standing and walking. Gait rehabilitation aims to restore a normal walking pattern. If walking is not achievable, a secondary goal of physiotherapy is to strengthen muscles to allow for maximizing function.[3]

Physiotherapists use a range of evidence-based treatment interventions to improve overall function. Interventions may include, for example, progressive resistive exercises, aerobic training, mirror therapy, virtual reality, and task-oriented training for balance, walking, and upper limb function. Upper limb paralysis is observed in about one third of people who suffer a stroke. Maximizing upper limb recovery after stroke requires significant time and effort by the patient and the physiotherapy team. Constraint-induced movement therapy, in which an unaffected limb is restrained (e.g., with a bandage or sling) and the weakened limb is rigorously exercised is one example of a physical therapy treatment that aims to improve upper extremity motor functions after a stroke.[7] Functional electrical stimulation is also used by physiotherapists to address upper and lower extremity weakness, as well as hemiplegic shoulder pain.[6]

# Ontario Context

In Ontario, physiotherapy is commonly delivered in acute care, inpatient, and outpatient settings, as well as in home and community care settings. After a stroke, physiotherapy typically begins in acute care with a focus on comprehensive assessment, and early mobilization to optimize safe and independent capacity for bed mobility, transfers, and walking. Patients transferred to inpatient rehabilitation will receive multiple physiotherapy interventions guided by Canadian best practice recommendations for stroke, which promote the use of effective treatments for strengthening, balance retraining, aerobic training, and task-oriented training of mobility before transition to outpatient care.[8] Community-based rehabilitation services are provided as outpatient services either in home or in an outpatient clinic, in either a group or individual setting. Community-based exercise programs that incorporate a partnership with a physiotherapist, such as Together in Movement and Exercise (TIME), have emerged throughout Ontario.[9] In these group-based programs, fitness instructors, trained and supported by physiotherapists, deliver task-oriented exercise classes targeting balance and mobility to maintain gains made during the active rehabilitation phase after stroke.[10-15] Group physiotherapy should generally include people who have similar levels of mobility and functionality as well as similar recovery goals.

Previously, Health Quality Ontario recommended initiating intensive physiotherapy within 6 weeks after stroke to optimize upper-limb function recovery and activities of daily living in Ontario.[2,16] In 2016, Health Quality Ontario released an update to the *Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute)* ("clinical handbook"; originally published in 2015), which recommended that before discharge from a hospitalization for stroke,

people should be assessed by an interprofessional team and that people "with residual impairment identified as having further rehabilitation needs should receive therapy services to set new goals and improve task-oriented activity."[16] The clinical handbook also recommended that patients be given two to three physiotherapy sessions each week for 8 to 12 weeks (combined with community-based clinic services, including from hospitals, whenever appropriate).

Service provision during this period is publicly funded; however, the delivery of community-based physiotherapy is not consistent across the province. After 12 weeks, the availability of and access to publicly funded physiotherapy is variable and often unclear to patients and health care professionals.

There are more than 240 clinics in Ontario that have agreements with the Ministry of Health to use an episode-of-care (EOC) model.[17] An EOC is defined in policy as one group of condition- or diagnosis-specific, time-limited, goal-oriented physiotherapy services that may be provided to a specific person. These clinic-based services provide care under the EOC model to a limited number of people each year. Each clinic manages its resources and allocations, but there are specified eligibility criteria. Services funded under this program are not intended to maintain existing function but rather to address recent acute episodes resulting from a previous illness, injury, accident, surgery, or flare-up of chronic disease that led to a worsening of symptoms or a decrease in function or mobility. According to the ministry's *Community Physiotherapy Clinic Program Policies for an Episode of Care* (January 2018),

> *A patient who has had a stroke is not eligible for an EOC if the treatment is for acute post-stroke rehabilitation, long-term rehabilitation, or maintenance therapy. They could receive an EOC if they have had a stroke in the past and have recently experienced a decrease in their function or mobility and providing some short-term physiotherapy treatment has the potential to return them to that previous level of function, which they recently lost.*[18]

## Expert Consultation

We engaged with experts in the specialty areas of stroke and physiotherapy to help inform our understanding of aspects of the health service and our methodologies and to contextualize the evidence.

## PROSPERO Registration

This health technology assessment has been registered in PROSPERO, the international prospective register of systematic reviews (CRD # 118601), available at https://www.crd.york.ac.uk/PROSPERO.

# CLINICAL EVIDENCE

## Research Questions

- What are the effectiveness and safety of physiotherapy delivered continually over periods greater than 3 months compared with physiotherapy delivered for periods of 3 months or less for the treatment of adults with a diagnosis of stroke?

- What are the effectiveness and safety of physiotherapy delivered continually over periods greater than 6 months compared with physiotherapy delivered for periods of 6 months or less for the treatment of adults with a diagnosis of stroke?

## Methods

### *Clinical Literature Search*

We performed a clinical literature search on October 29, 2018, to retrieve studies published from inception until the search date. We used the Ovid interface to search the following databases: MEDLINE, Embase, the Cochrane Central Register of Controlled Trials, the Cochrane Database of Systematic Reviews, the Health Technology Assessment database, and the National Health Service Economic Evaluation Database (NHS EED). We used the EBSCOhost interface to search the Cumulative Index to Nursing & Allied Health Literature (CINAHL).

A medical librarian developed the search strategies using controlled vocabulary (e.g., Medical Subject Headings) and relevant keywords. Methodological filters were used to limit retrieval to systematic reviews, meta-analyses, health technology assessments, and randomized controlled trials. The final search strategy was peer reviewed using the PRESS Checklist.[19]

We created database auto-alerts in MEDLINE, Embase, and CINAHL and monitored them for the duration of the assessment period. We also performed a targeted grey literature search of health technology assessment agency websites as well as clinical trial and systematic review registries. See Appendix 1 for the literature search strategies, including all search terms.

### *Eligibility Criteria*

#### Studies

*Inclusion Criteria*

- English-language full-text publications
- Studies published from database inception until October 29, 2018
- Randomized controlled trials, systematic reviews, and meta-analyses

*Exclusion Criteria*

- Non-randomized or descriptive studies
- Animal and in vitro studies
- Non-systematic reviews, narrative reviews, abstracts, editorials, letters, case reports, and commentaries

### Participants

Adults (≥ 18 years of age) who have had a diagnosis of stroke (hemorrhagic or ischemic) and are receiving physiotherapy were included. Children (< 18 years of age) and people who have experienced transient ischemic attacks (TIA) were not considered.

### Interventions

- Physiotherapy delivered by a registered physiotherapist from the time of stroke and provided continually for more than 3 months after stroke
- Physiotherapy delivered by a registered physiotherapist from the time of stroke and provided continually for more than 6 months after stroke
- Any type of physiotherapy, any frequency and intensity, for any number of times per week
- Physiotherapy interventions targeting the trunk, upper limb, and lower limb

Any other type of therapy will not be considered (e.g., massage, chiropractic, physiotherapy services using experimental technologies such as robotics)

### Comparator

- Physiotherapy delivered by a registered physiotherapist from the time of stroke and provided for up to 3 or 6 months after stroke

### Outcome Measures

- Quality of life as reported by the primary study
- Activities of daily living as reported by the primary study
- Physical functioning of the upper limb
- Physical functioning of lower limb
- Mobility, including gait
- Balance improvement
- Caregiver burden
- Reported adverse events

## *Literature Screening*

A single reviewer conducted an initial screening of titles and abstracts using Covidence[20] and then obtained the full texts of studies that appeared eligible for review according to the inclusion criteria. A single reviewer then examined the full-text articles and selected studies eligible for inclusion. The reviewer also examined reference lists and contacted study authors and experts in the field for additional relevant studies not identified through the search.

## *Data Extraction*

We did not identify any studies that met our inclusion criteria and were thus unable to conduct data extraction.

## *Statistical Analysis*

We did not identify any published studies that met our inclusion criteria and were not able to conduct a statistical analysis.

## *Critical Appraisal of Evidence*

We did not identify any published studies that met our inclusion criteria and were not able to conduct a critical appraisal of the evidence.

# Results

## *Clinical Literature Search*

The literature search yielded 4,404 citations published from inception to October 29, 2018, after removing duplicates. We identified no studies that met our inclusion criteria. Figure 1 presents the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram for the clinical literature search.

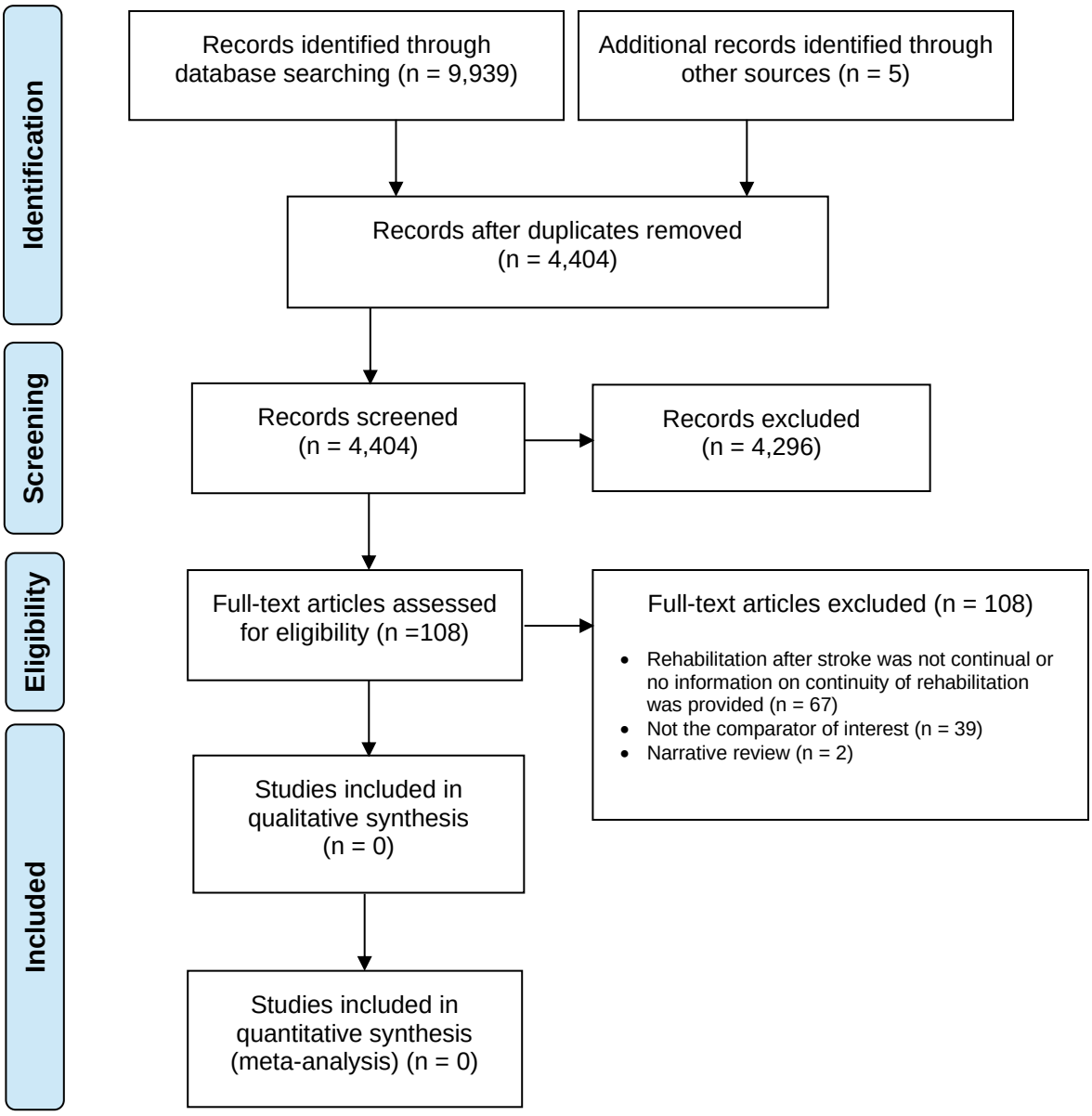


**Figure 1: PRISMA Flow Diagram—Clinical Search Strategy**

*Source: Adapted from Moher et al.*[8]

## *Ongoing Studies*

We are unaware of any ongoing studies that meet the inclusion criteria.

# Discussion

Although we did not find any studies that met the specific inclusion criteria for this review, there are guidelines, reports, and studies suggesting that physiotherapy may be effective when initiated late (e.g., after 6 months) in people with a diagnosis of stroke.[15,21-24] In their systematic review and meta-analysis of 467 randomized controlled trials, Veerbeek et al[24] concluded that there is evidence to support the use of physiotherapy in all phases of rehabilitation after stroke. The authors categorized four post-stroke phases: (1) the hyperacute or acute phase (< 24 h after stroke); (2) the early rehabilitation phase (24 h to 3 mo); (3) the late rehabilitation phase (3–6 mo); and (4) the chronic phase (> 6 mo). Most studies included people in the early rehabilitation phase (n = 198) or chronic phase (n = 202). None of the randomized controlled trials included in the systematic review and meta-analysis met our inclusion criteria because participants did not receive continual physiotherapy after stroke (i.e., there was a gap in the provision of physiotherapy). The 202 studies that included people with stroke in the chronic phase recruited participants into their study after a period of time during which no physiotherapy was provided after stroke. This made the studies ineligible for inclusion in our review.

We identified one randomized controlled trial for which the intervention arm of the trial met our definition of continual physiotherapy. Nadeau et al[25] recruited adults with a diagnosis of stroke to participate in a multicentre, single-blind randomized controlled trial within 2 months after the onset of stroke (the LEAPS trial). Participants were eligible to participate in the study if they had undergone continual post-stroke physiotherapy. However, this study did not meet our inclusion criteria because there was no comparison between short- and long-term physiotherapy (all three arms of the trial underwent continual physiotherapy for 6 months).

The clinical experts we consulted generally felt that although the greatest gains may be seen in the earlier months, there is still potential for those with moderate or severe stroke to make functional gains with specialized stroke-specific therapies that continue for 3 months or more after a stroke. The clinical experts and researchers we consulted also agree that there is a gap in access to stroke rehabilitation for people who have been discharged from inpatient rehabilitation.

# Conclusions

We did not identify any studies that addressed the specific research question. We are unable to determine the benefits of continual long-term physiotherapy after stroke compared with short-term physiotherapy.

# ECONOMIC EVIDENCE

## Research Question

What is the cost-effectiveness of physiotherapy delivered continually over periods greater than 3 months compared with physiotherapy delivered for periods of 3 months or less for the treatment of adults with a diagnosis of stroke?

## Methods

### *Economic Literature Search*

We performed an economic literature search on October 31, 2018, to retrieve studies published from inception until the search date. To retrieve relevant studies, we developed a search using the clinical search strategy with an economic and costing filter applied.

We created database auto-alerts in MEDLINE, Embase, and CINAHL and monitored them for the duration of the assessment period. We also performed a targeted grey literature search of health technology assessment agency websites, clinical trial and systematic review registries, and the Tufts Cost-Effectiveness Analysis Registry. See Clinical Literature Search, above, for further details on methods used. See Appendix 1 for the literature search strategies, including all search terms.

### *Eligibility Criteria*

#### Studies

*Inclusion Criteria*

- English-language full-text publications
- Studies published from database inception until October 31, 2018
- Cost–benefit analyses, cost-effectiveness analyses, cost-minimization analyses, and cost–utility analyses

*Exclusion Criteria*

- Unpublished studies, narrative reviews of the literature, study protocols, guidelines, conference abstracts, and editorials

#### Population

- Adults (≥ 18 years of age) who have received a diagnosis of stroke (hemorrhagic or ischemic) and who are receiving physiotherapy

#### Interventions

- Continual long-term physiotherapy (> 3 months)

### Comparator

- Short-term physiotherapy (≤ 3 months)

### Outcome Measures

- Mean estimates of effects and costs
- Incremental costs
- Incremental effectiveness outcomes (e.g., quality-adjusted life-years)
- Incremental cost-effectiveness ratio
- Incremental net benefit

## *Literature Screening*

A single reviewer reviewed titles and abstracts and did not identify any studies that met the eligibility criteria.

# Results

## *Literature Search*

The literature search yielded 637 citations published from inception to October 31, 2018, after removing duplicates. We did not identify any studies that met our inclusion criteria. Figure 2 presents the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram for the economic literature search.

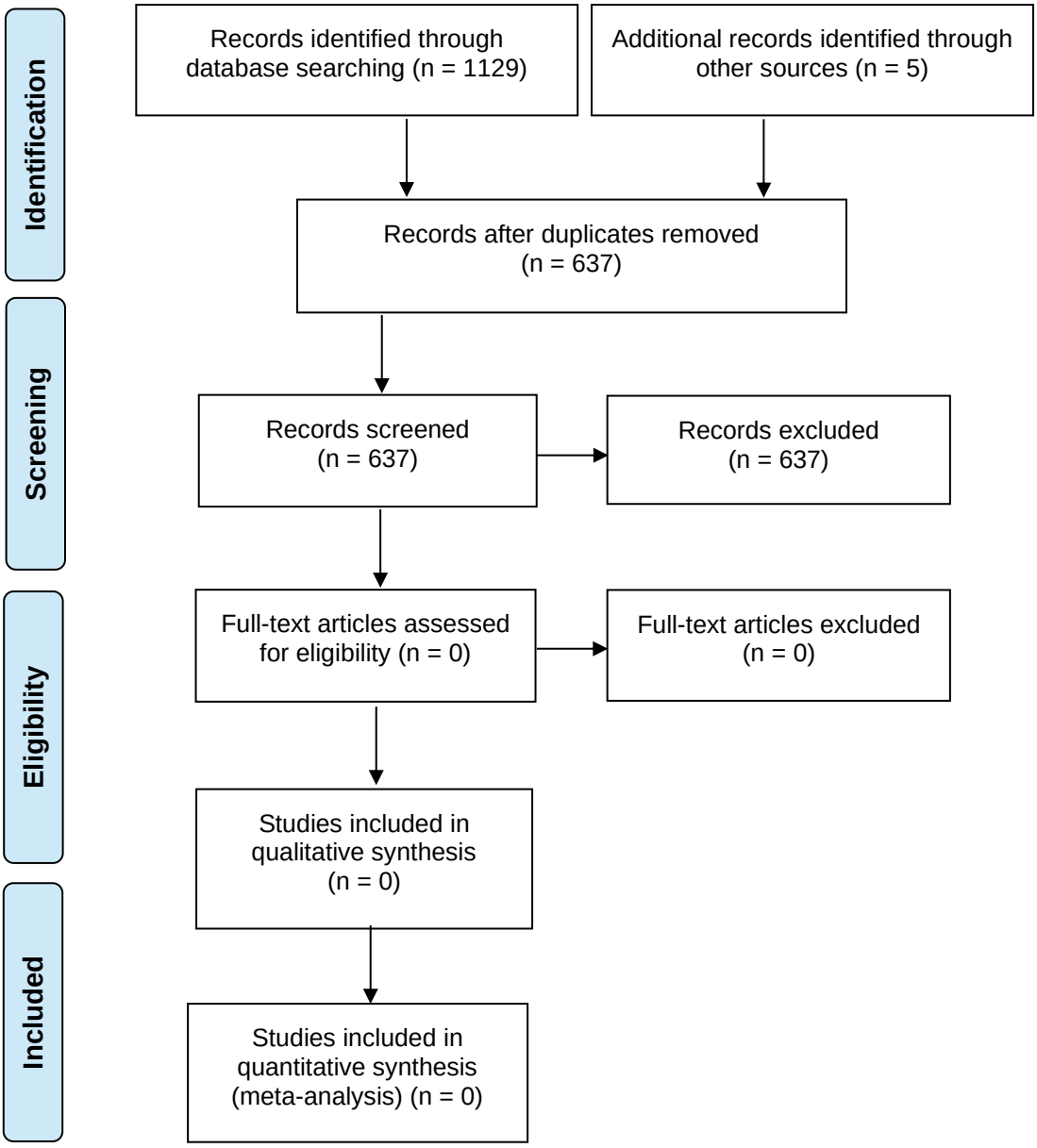


**Figure 2: PRISMA Flow Diagram—Economic Search Strategy**

*Source: Adapted from Moher et al, 2009.*[8]

### *Overview of Included Economic Studies*

We did not identify any studies that evaluated the cost-effectiveness of continual long-term (> 3 months) versus short-term (≤ 3 months) physiotherapy for people who have been diagnosed with stroke.

## Conclusions

We were unable to estimate the cost-effectiveness of continual long-term physiotherapy (> 3 months) in Ontario or elsewhere.

## PRIMARY ECONOMIC EVALUATION

Based on the results of the clinical evidence review, the benefit of continual long-term compared with short-term physiotherapy after stroke cannot be determined. We also did not find any economic evaluations that compared short-term with continual long-term physiotherapy. Therefore, we decided to forgo conducting a primary economic evaluation and focus only on the budget impact analysis.

# BUDGET IMPACT ANALYSIS

## Research Question

What is the potential 5-year budget impact for the Ontario Ministry of Health of publicly funding continual long-term physiotherapy for up to an additional 9 months for adults who have been diagnosed with stroke and who have received 8 to 12 weeks of community-based physiotherapy?

## Background

The following issues should be taken into account when reviewing the analysis:

- The Ministry of Health does not presently have an established provincial program with dedicated funding for post-stroke physiotherapy. The ministry has agreements with 240 clinics in Ontario to use an episode-of-care (EOC) model. However, at this time, post-stroke rehabilitation (i.e., acute, long-term, or maintenance) falls outside the scope of services provided through the EOC model (see Ontario Context, above).[17,18]
- In clinical practice, health care providers commonly refer to the clinical handbook, which recommends 8 to 12 weeks of physiotherapy in the community (short-term physiotherapy) for people discharged from hospital post-stroke.[16] In this report, we evaluate the budget impact of publicly funding physiotherapy for more than 3 months (continual long-term physiotherapy) for adults who have been diagnosed with stroke and who have received 8 to 12 weeks of physiotherapy. The program elements proposed in our budget impact analyses should not be considered the "optimal" program, as physiotherapy is highly individualized in practice and should be tailored to the individual goals of the patient.
- There are no well-established parameters defining short- or long-term physiotherapy. As such, our clinical and economic evidence reviews adopted a broader definition, setting wider inclusion criteria to capture relevant literature. Our budget impact analysis adopted a narrower definition to provide a meaningful cost estimate that aligns with the type of settings and service provisions (including frequency and duration) of physiotherapy programs that are specific to the Ontario context.
- While some individuals diagnosed with stroke may be discharged to a long-term care home, we excluded this population from our analyses for the following reasons:
    - The long-term care discharge destination is intended for people who have demonstrated a need and met the admission criteria for the comprehensive care provided in a long-term care home. In other words, people admitted to hospital after an episode of stroke are considered for discharge to a long-term care home only after a comprehensive assessment of their overall health functions and individual care needs beyond those that are uniquely attributed to stroke, including cognitive performance, physical health, and the availability social and caregiver support.
    - In Ontario, the provision of physiotherapy service delivery and funding for long-term care homes is separate from that of other settings. The current Long-Term Care Home Physiotherapy Funding Policy stipulates that long-term care homes are funded to arrange physiotherapy services at a rate of $828 per bed (as of 2018) on an annual basis to any long-term care resident assessed to require physiotherapy as part of their care plan to improve, develop, or restore physical function or to prevent functional or clinical decline.[26]

    - Individuals diagnosed with stroke who are discharged to long-term care homes are relatively older and are associated with higher or more severe comorbidities and significant loss of cognitive function. In general, they experience poorer functional outcomes as compared with people discharged to other community settings, and may be less likely to tolerate physiotherapy.
- Our analysis does not describe the current funding landscape and level of accessibility of physiotherapy services for people who have been diagnosed with stroke in Ontario. Currently, there is unequal distribution and inadequate access to community-based physiotherapy across the province. Our analysis addresses the potential budget impact independently of a needs assessment of the current landscape of short-term physiotherapy for this population.
- The lack of studies meeting our clinical inclusion criteria and the variability of eligibility criteria for current physiotherapy programs in Ontario made it challenging to estimate the volume of our target population and the per-patient costs associated with continual long-term physiotherapy. We developed a rough approximation of the budget impact based on the relevant evidence and consultations with key experts. Critical and simplifying assumptions introduced uncertainty into our parameter estimates.
- The lack of studies evaluating the downstream effects of short- versus long-term physiotherapy after stroke on health care resources (e.g., rehospitalization, ambulatory care) prevented us from including these costs in our analysis.

# Methods

## *Analytic Framework*

We estimated the budget impact of public funding continual long-term physiotherapy after stroke using the cost difference between two scenarios: (1) current clinical practice without public funding for continual long-term community-based physiotherapy, and (2) anticipated clinical practice with public funding (the new scenario).

We conducted a reference case analysis and sensitivity analyses. Our reference case analysis represented the analysis with the most likely set of input parameters and model assumptions. Our sensitivity analyses explored how the results are affected by varying input parameters and model assumptions.

## *Intervention Evaluated*

Continual long-term physiotherapy occurs in the late subacute phase (3–6 months post-stroke) and/or chronic phase (> 6 months post-stroke).[27] The clinical handbook recommends that patients be given two to three physiotherapy sessions per week for 8 to 12 weeks after discharge from hospital (acute care or rehabilitation hospital).[16] No explicit guidance was given for continual long-term physiotherapy (i.e., > 12 weeks).

In general, physiotherapy programs can vary in model (i.e., mode of delivery) and design (i.e., frequency, duration, and techniques used), as they are determined in part by the functionality and goals of the individual patient. In addition, Canadian clinical practice guidelines for stroke (i.e., the clinical handbook, the *Canadian Stroke Best Practice Recommendations*[28]) make no explicit recommendations to help guide an extended duration of physiotherapy. As such, it is challenging to estimate specific resource and cost parameters of continual long-term physiotherapy after stroke. We therefore made assumptions concerning potential key program elements based on the best available literature[29] and consultation with experts. The program

elements proposed in our budget impact analyses should not be considered the "optimal" program. Due to practical constraints (e.g., health care resources), we assumed the following program elements for continual long-term physiotherapy after stroke:

- Participants: people diagnosed with stroke who have completed short-term community-based physiotherapy after hospital discharge (see Target Population, below)
- Providers: physiotherapists and physiotherapist assistants
- Settings: Outside-of-home and in-home community-based physiotherapy[30]
  - Outside of home: physiotherapy delivered in various community settings (e.g., hospital outpatient services)
  - In home: physiotherapy delivered by various providers at the patient's residence
- Total visits: an average of 24 sessions per patient (one session per week for 24 weeks)
- Intensity and duration: 1 hour per session, up to three sessions per week, for up to 9 months. We assumed that the overall frequency of sessions associated with continual long-term physiotherapy would be less than what is recommended by the clinical handbook[16] for short-term physiotherapy rehabilitation, but that the duration of time could be longer
- Components: There are a range of physiotherapy techniques designed to the improve functional well-being of people diagnosed with stroke. These may include gait training, repetitive task training, constraint-induced movement therapy, and others.[16] The specific techniques used in physiotherapy rehabilitation are determined by the health care provider as part of each patient's individualized recovery plan. Because our estimates focus on the time for the professional service, the type of physiotherapy technique adopted would not meaningfully impact costs

In summary, physiotherapy services provided at long-term care homes are broad in scope and are part of a range of restorative services mandated to promote independence and quality of life for any condition, including stroke. There are currently no administrative data on the specific delivery provisions of this service in long-term care homes; as such, treatment goals and the intensiveness and duration of therapy are unknown.

## *Key Assumptions for Reference Case*

- All patients complete the physiotherapy sessions assigned
- Patients do not experience major clinical events that impact or interrupt continual long-term physiotherapy

## *Target Population*

We estimated that 2,600 people are likely to benefit each year from continual long-term community-based physiotherapy after stroke. Note: The target population does not include those who have been discharged to (or admitted to) complex continuing care or long-term care homes.

People in Ontario who are eligible to receive continual long-term community-based physiotherapy have already received 12 weeks of physiotherapy after being diagnosed with stroke. We excluded people who were admitted to hospital for transient ischemic attack, as it is characterized as a minor and nondisabling type of stroke,[16] and focused on people who were admitted for either ischemic or (intracerebral or subarachnoid) hemorrhagic stroke.

## Post-Stroke Rehabilitation Statistics in Ontario, by Setting

According to the 2016 Ontario Stroke Evaluation Report, there were 14,287 people hospitalized in acute care due to stroke in 2014/2015, 88% (12,604) of whom were discharged alive.[29] Of these, 4,418 (35%) were discharged to inpatient rehabilitation at an inpatient hospital setting. Among those people receiving inpatient rehabilitation, 1,896 were later discharged and provided rehabilitation at an in-home setting. An additional 2,090 (17%) were discharged and received rehabilitation in an in-home setting. The proportion of people discharged from inpatient rehabilitation to an outside-of-home community setting is unknown.[29] The actual percentage of people discharged to community-based rehabilitation (either outside of home or in-home) is likely higher than what was reported, because only rehabilitation services provided by Local Health Integration Network (LHIN) Home and Community Care services were captured in this report. In current practice, community-based rehabilitation services are also provided through physiotherapy delivered in other community settings, such as hospital outpatient programs or specialized programs in the community.[29]

To date, there are no administrative data that fully capture community-based physiotherapy after discharge from hospital acute care or inpatient rehabilitation for people diagnosed with stroke at the provincial level.[29] As a result, many aspects of community-based physiotherapy are unknown, including the proportion of people accessing physiotherapy in an in-home setting, an outside of home setting, or a hybrid model of both settings.

Lastly, it should be noted that while our budget impact analyses consider the most recent and reliable data reported for stroke rehabilitation in Ontario, these data are several years old (2014/2015). Some community-based rehabilitation programs have been developed since then. As such, the actual physiotherapy volume for stroke is likely higher today.

## Framework for Estimating the Volume of Target Population for Continual Long-Term Community-Based Physiotherapy After Stroke

Recently, the Ontario regional stroke networks (partners with CorHealth Ontario) released a framework for estimating patient volumes and referral considerations for outpatient and in-home stroke rehabilitation services in Ontario.[27] The primary aim of this framework was to help regions better understand the rehabilitation needs of people diagnosed with stroke and manage resource capacity planning according to their geographic catchment area.[27] We adapted this framework in our budget impact analyses to estimate projected size of our target population (Figure 3).

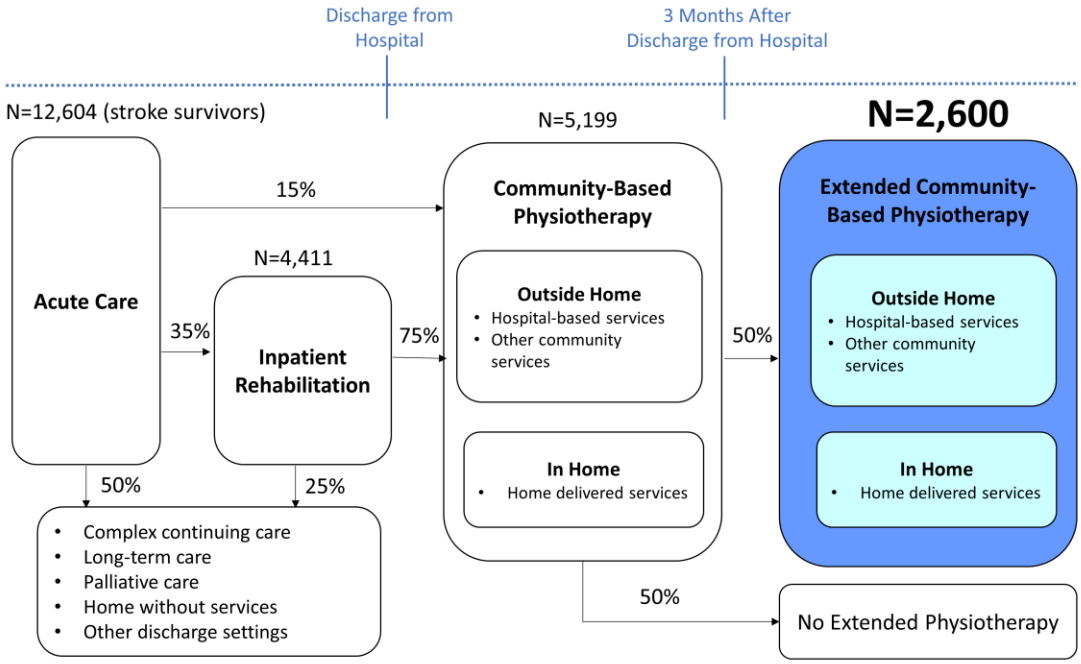


**Figure 3: Framework for Estimating the Target Population for Continual Long-Term Community-Based Physiotherapy After Stroke in Ontario**[a]

[a]This framework estimates community-based rehabilitation volumes based on the estimated proportion of people discharged to inpatient rehabilitation from acute care in 2014/2015. This estimate may be limited by resource capacity.

Based on this framework, the proportion of people discharged annually to inpatient rehabilitation and community-based rehabilitation from acute care after stroke is estimated to be around 35% and 15%, respectively.[27] Of those discharged to inpatient rehabilitation, we estimated that around 75% would require continued rehabilitation at community-based settings (either outside of home or in-home). The remaining 50% of patients in acute care and 25% of the people discharged to inpatient rehabilitation are assumed to be discharged to complex continuing care, long-term care, palliative care, home without services, or 'other' discharge settings. The authors of the original framework estimated that 90% of patients receiving inpatient rehabilitation would require further physiotherapy rehabilitation after discharge. Given that our scope is specific to people who require further physiotherapy after discharge from a community-based setting, we adjusted this to 75% to account for people triaged to discharge destinations that are not considered in our analysis, such as complex continuing care and long-term care homes (according to the 2018 Ontario Stroke Evaluation Report, of the 4,418 people receiving inpatient rehabilitation in 2014/2015, 369 [8.4%] and 464 [10.5%] patients were discharged to complex continuing care and long-term care homes, respectively).[27,31]

Assuming that the annual number of stroke survivors (n = 12,604) reported in the 2016 *Ontario Stroke Evaluation Report* remains relatively stable through the next 5 years,[32] we estimated that each year around 5,200 people (discharged from acute care and inpatient rehabilitation) will receive community-based physiotherapy after stroke. We further estimated that continual long-term physiotherapy would be offered to about 50% of this population. This estimate is based on the assumption that about 50% of the population would either not require physiotherapy rehabilitation beyond the current service provisions stipulated by the Quality-Based Procedures[16] or would not be medically stable enough to tolerate the long-term physiotherapy

rehabilitation.[30] Thus, the annual target population for continual long-term community-based physiotherapy after stroke is estimated to be approximately 2,600 people.

## *Uptake of the New Intervention*

According to expert consultations (Esme French, MScPT; Jennifer Fearn, MScPT; Shelley Huffman BScPT, oral communication, February 2019) and the 2018 Ontario Regional Stroke Network's report *Community and Outpatient Stroke Rehabilitation Services*,[27] some regions are considerably limited by their resource capacity to meet the level of stroke rehabilitation recommended in the clinical handbook.[16] For instance, the clinical handbook recommends two to three visits per week for 8 to 12 weeks for physiotherapy rehabilitation. However, the number of physiotherapy sessions reported in practice was significantly lower. In the 2014/15 fiscal year, the Community Care Access Centres provided an average of only five in-home rehabilitation visits to individuals following an acute stroke.[29] Resource capacity for stroke rehabilitation varies widely between regions, and some regions have additional service delivery challenges in remote or rural areas.

Because the health benefits of continual long-term physiotherapy have not been well established, we assumed that the overall uptake of continual long-term physiotherapy would be low in next 5 years in Ontario, with 8% (208 patients) in year 1, gradually increasing to 16% (416 patients) in year 5.

Further, we estimated the proportion and annual volume of the target population (Table 1) for continual long-term community-based physiotherapy by delivery model:

- 35% of patients would receive physiotherapy in the home
- 35% of patients would receive physiotherapy outside of the home (in a community setting)
- 20% of patients would receive physiotherapy in a combined in-home (eight sessions) and outside-of-home (16 sessions) setting
- 10% of patients would receive group physiotherapy (the staff-to-participant ratio would range from 1:3 to 1:6,[33] with an average of four participants per group)[a]

**Table 1: Target Population for Continual Long-Term Physiotherapy**

| | Year 1 | Year 2 | Year 3 | Year 4 | Year 5 |
|---|---|---|---|---|---|
| Total Population (N) | 2,600 | 2,600 | 2,600 | 2,600 | 2,600 |
| Uptake rate (%) | 8 | 10 | 12 | 14 | 16 |
| Target population in the reference case (n) | **208** | **260** | **312** | **364** | **416** |
| In-home (35%) (n) | 73 | 91 | 109 | 127 | 146 |
| Outside of home (35%) (n) | 73 | 91 | 109 | 127 | 146 |
| Mix of in-home and outside of home (20%) (n) | 42 | 52 | 62 | 73 | 83 |
| Group physiotherapy (10%) (n) | 20 | 26 | 32 | 37 | 41 |

Note: Numbers may be inexact due to rounding.

[a]Facilitators should have the capacity to provide personalized adjustments during group physiotherapy. The staff-to-participant ratio is based on Ontario Stroke Network recommendations.

## *Resources and Costs*

While there are already established community-based rehabilitation programs in Ontario, additional programs may be needed to meet the service delivery requirements for an extended duration of physiotherapy .[34] The capital investment required to establish new programs for rehabilitation is determined by a variety of factors (e.g., space, maintenance, administration, and overhead). After the initial investment, equipment costs would be marginal because large equipment (e.g., treadmills, weights) have a long lifespan. For example, if we assume that the cost of purchasing a new treadmill with a 5-year anticipated lifespan is $2,000 (actual cost can vary widely, from several hundreds of dollars to about $6,000) and that, on average, one treadmill is used by eight persons per day and there are 260 business days in a year, then the cost per use is about $0.19 ($2,000/[8 × 260 × 5]). For simplicity, we excluded capital depreciation, equipment costs, and other facility costs, and focused on the costs of health care provider services (i.e., salary plus benefits) and transportation costs for physiotherapy delivered in the home.

We estimated the average amount of health care provider time per patient for the long-term physiotherapy programs and then assigned a value using their unit price. We estimated that the average annual salary of a physiotherapist is around $80,000. The cost of employee benefits, such as employment insurance, pension plans, and extended health coverage were estimated to be 33% of salaries.[35] We therefore approximated a total annual cost of a physiotherapist to be $106,400. According to Ontario Regional Stroke Networks, one full-time equivalent physiotherapist can be expected to provide 1,380 hours of therapy time to patients in a community-based setting, or 920 hours in the home.[27] We therefore estimated that the physiotherapist cost per 1-hour session would be approximately $77 and $116 (not including reimbursement for travel costs to patients' homes) for outside of home and in-home physiotherapy, respectively, for services delivered by a physiotherapist.

Other costs include the following:

- Physiotherapist assistant: $30 per hour, including salary and benefits
- Administrative staff: $30 per hour, including salary and benefits
- Transportation costs (associated with home-based physiotherapy): $16.50 per visit. We estimated average travel distance to be about 30 kilometres per visit (40 minutes per round trip). The current reimbursement rate is about $0.55 per kilometre[35]

In some regions of Ontario, physiotherapist assistants may independently carry out a physiotherapy program prescribed by a physiotherapist, provided that all supervisory standards have been met.[36] For example, physiotherapists may first guide patients through more complex treatments, such as high-level balance training, and the physiotherapist assistants would subsequently take over the session and assist patients with routine strengthening exercises (Esme French, MScPT, Jennifer Fearn, MScPT, and Shelley Huffman, B.Sc.PT, e-mail communication, March 2019). To account for this scenario, we estimated that for individual physiotherapy, 20 sessions would be delivered by a physiotherapist and four would be delivered by a physiotherapist assistant.

For group-based physiotherapy, we estimated that one physiotherapist would lead all 24 sessions, with a physiotherapist assistant assisting in 50% of the sessions.

Table 2 shows that the average cost per person would be $2,976 and $1,720 for physiotherapy in the in-home and outside of home settings, respectively. We also accounted for group

physiotherapy in our budget impact analyses at an average cost per person of $612 with a group size of four patients. Lastly, we considered the cost of community-based physiotherapy delivered as a combination of sessions in the home (eight sessions) and outside the home (16 sessions) would be an average of $2,139 per patient.

All costs are reported in 2019 Canadian dollars.

**Table 2: Average Cost and Professional Time per Patient for Continual Long-Term Physiotherapy**

| | Physiotherapy | | |
|---|---|---|---|
| | **In-Home** | **Community-Based Individual** | **Community-Based Group** |
| **Professional Time** | | | |
| Physiotherapist | 20 hours of service plus transportation time of 13.3 hours for 20 visits | 20 hours | 6 hours (assuming the group size of 4) |
| Physiotherapist assistant | 4 hours of service plus transportation time of 2.7 hours for 4 visits[a] | 4 hours | 3 hours (assuming 50% sessions need assistance) |
| Administrative staff | 2 hours | 2 hours | 2 hours |
| **Average cost per session** | **$124.00** | **$71.70** | **$25.50** |
| **Average total cost** | **$2,976.00** | **$1,720.00** | **$612.00** |

Note: Numbers may be inexact due to rounding.

[a]The total cost of physiotherapy delivered by a physiotherapist assistant was $66.50 per session (including 1.667 hours service and transportation time at the rate of $30 per hour [$50] and travelling reimbursement [$16.5]).

## *Analysis*

The budget impact was calculated as the cost difference between the current scenario (no public funding for continual long-term physiotherapy) and the new scenario (public funding for continual long-term physiotherapy). The total cost for each scenario was calculated using the average cost per patient multiplied by the target population per year. We assumed that the costs associated with the current scenario are zero. We calculated the annual budget impact for the next 5 years.

In addition to the reference case, we also calculated the budget impact for the following scenarios:

- Scenario 1: a reduced average number (12) of physiotherapy sessions allotted for the extended duration of community-based physiotherapy
- Scenario 2: an increased average number of physiotherapy sessions (36) allotted for the extended duration of community-based physiotherapy
- Scenario 3: a greater proportion of patients (20%) allotted to group physiotherapy, with a smaller proportion (30%) allotted to in-home and outside of home physiotherapy
- Scenario 4: a higher unit cost per physiotherapy session (25% higher) in consideration of possible overhead costs, equipment costs, and higher salary rates for physiotherapists and physiotherapist assistants
- Scenario 5: a lower unit cost per physiotherapy session (10% lower) in consideration of possible lower salary rates for physiotherapists and physiotherapist assistants

- Scenario 6: higher uptake rates than in the new scenario (10% in year 1, 20% in year 2, 30% in year 3, 40% in year 4 and 50% in year 5)
- Scenario 7: an increase in the total population for continual long-term physiotherapy rehabilitation of 3% annually
- Scenario 8: assumed downstream savings in health care costs of $1,000 per patient in the first year post-stroke (e.g., through a reduction in rates of rehospitalization)

# Results

## *Reference Case*

Table 3 presents the projected annual costs associated with publicly funding continual long-term physiotherapy over 5 years. The initial budget impact was $444,872 for 208 participants in year 1 at an uptake rate of 8%. The annual budget impact increased to $888,217 in year 5 for 416 participants at an uptake rate of 16%.

**Table 3: Budget Impact Analysis Results, Reference Case**

| | Budget Impact[a,b] | | | | |
|---|---|---|---|---|---|
| **Scenario** | **Year 1** | **Year 2** | **Year 3** | **Year 4** | **Year 5** |
| Cost of continual long-term physiotherapy in the current scenario | 0 | 0 | 0 | 0 | 0 |
| Cost of continual long-term physiotherapy in the new scenario | 444,872 | 554,459 | 664,045 | 775,159 | 888,217 |
| In-home | 217,248 | 270,816 | 324,384 | 377,952 | 434,496 |
| Community based | 125,560 | 156,520 | 187,480 | 218,440 | 251,120 |
| Mixed[c] | 89,824 | 111,211 | 132,597 | 156,123 | 177,509 |
| Group | 12,240 | 15,912 | 19,584 | 22,644 | 25,092 |
| **Total budget impact** | **444,872** | **554,459** | **664,045** | **775,159** | **888,217** |

[a]In 2019 Canadian dollars.
[b]Numbers may be inexact because of rounding.
[c]In-home and community-based continual long-term physiotherapy.

## *Scenario Analysis*

Table 4 presents the results of the eight scenario analyses. The budget is impacted by the average number of sessions, the number of target population, the uptake rate and unit cost per session of physiotherapy rehabilitation.

**Table 4: Budget Impact Analysis Results, Scenario Analyses**

| | Budget Impact[a,b] | | | | |
|---|---|---|---|---|---|
| | **Year 1** | **Year 2** | **Year 3** | **Year 4** | **Year 5** |
| **Scenario 1:** an average of 12 physiotherapy sessions per patient | | | | | |
| Budget impact | 222,436 | 277,229 | 332,023 | 387,579 | 444,109 |
| **Scenario 2:** an average of 36 physiotherapy sessions per patient | | | | | |
| Budget impact | 665,350 | 831,688 | 998,026 | 1,164,363 | 1,330,701 |
| **Scenario 3:** 20% of patients allotted to group physiotherapy | | | | | |
| Budget impact | 406,680 | 509,323 | 611,965 | 712,663 | 815,305 |
| **Scenario 4:** 25% higher cost of physiotherapy than the reference (e.g., including overhead) | | | | | |
| Budget impact | 556,090 | 693,073 | 830,057 | 968,948 | 1,110,272 |
| **Scenario 5:** 10% lower cost of physiotherapy than the reference (lower salary rate) | | | | | |
| Budget impact | 400,385 | 499,013 | 597,641 | 697,643 | 799,396 |
| **Scenario 6:** higher uptake rates (10% in year 1, increasing to 50% in year 5) | | | | | |
| Budget impact | 554,459 | 1,108,917 | 1,663,376 | 2,217,835 | 2,772,293 |
| **Scenario 7:** the total population increases 3% annually | | | | | |
| Budget impact | 444,872 | 572,824 | 706,084 | 848,317 | 999,331 |
| **Scenario 8:** assumed downstream cost savings of $1,000 per patient in the first year (e.g., reduced rates of rehospitalization) | | | | | |
| Budget impact | 236,872 | 294,459 | 352,045 | 411,159 | 472,217 |

[a]In 2019 Canadian dollars.
[b]Numbers may be inexact because of rounding.

## Discussion

In our analysis, we estimated the budget impact of publicly funding continual long-term physiotherapy for people diagnosed with stroke and described our critical and simplifying assumptions, as well as the uncertainty in our parameter estimates. When estimating our target population, we found that there was limited data on patient access to physiotherapy in the community after discharge from hospital. For instance, the volume of physiotherapy services delivered in the various community settings (e.g., hospital outpatient setting) in Ontario is not easy to determine. Further, eligibility criteria is less straightforward than is typical of other interventions, such as pharmacological or surgical treatments.[29]

The availability of physiotherapy care varies significantly across the province.[29] We proposed parameters at the provincial level, such as proportions of group versus individual physiotherapy by delivery model and the average salary of physiotherapists. Our assumptions may not reflect the situation in every specific region. For example, group-based physiotherapy may be difficult to conduct in rural regions, where the proportion of in-home physiotherapy is likely higher than our overall estimate of 35%. There is also variation in the wages of physiotherapists in different care facilities and in different regions. Therefore, the costs of continual long-term physiotherapy are expected to be different in each case. In addition, if we account for the capital investment that may be required to support the implementation of continual long-term physiotherapy (e.g., space, maintenance, administration, and overhead) across the province, then our reference case budget impact results will be significantly greater.

The objective of our analysis was to estimate the potential budget impact of publicly funding continual long-term community-based physiotherapy after stroke. The current funding landscape and the level of accessibility of physiotherapy rehabilitation services is out of scope. There is a gap between the short-term rehabilitation recommended by the clinical handbook and the programs available in some regions.[16,29] However, there are no reliable published data available on the volume and proportion of people with adequate access to this service as the collection of administrative data on people diagnosed with stroke post-discharge is limited and variable. The overall consensus from our expert consultations are in agreement with the scarcity of data and the challenges posed. However, we did determine that the volume of physiotherapy services has increased year over year,[29] and new community-based rehabilitation programs have been developed in recent years. Considering the known capacity issues, we used a relatively low uptake rate in the reference case: 8% in year 1, rising to 16% in year 5.

## *Strengths and Limitations*

Our study had the following strengths:

- We used local Ontario data to estimate key parameters and provided the overall budget estimate of continual long-term physiotherapy after stroke at the provincial level
- Our key parameters and main assumptions were verified by experts in Ontario
- Our analyses covered many possible scenarios. Cost estimates can easily be extended for further analyses

The following limitations should be noted when interpreting the findings of this analysis:

- Given the variability of the practice of physiotherapy after stroke, our current scenario at the provincial level may not reflect the practice at individual stroke care centers in Ontario
- Our analyses were mainly based on assumptions and expert consultation. There were no randomized clinical trials to demonstrate the potential downstream savings of continual long-term physiotherapy after stroke
- There are no studies establishing the most appropriate components, structure, type, intensity, and duration of continual long-term physiotherapy after stroke. The physiotherapy modeled in our analysis cannot be treated as the standard or optimal practice
- There were no administrative data to provide a complete picture of community-based rehabilitation in the province. The actual volume of community-based long-term physiotherapy may be outside our range of estimates
- We did not separate the target population into subgroups by type or severity of stroke due to the lack of available data
- The most recent data on our target population is from 2014/2015. The historical data (e.g., the average volume of in-home rehabilitation) were impacted by service capacity and do not necessarily reflect medical need

# Conclusions

Publicly funding the continual long-term physiotherapy after stroke in Ontario would lead to additional costs of $445,000 to $888,000 annually over the next 5 years.

# PATIENT PREFERENCES AND VALUES

## Objective

The objective of this analysis was to explore the underlying values, needs, impacts, preferences, and perceptions of those who have lived experience with continual long-term physiotherapy after stroke.

## Background

Exploring patient preferences and values provides a unique source of information about people's experiences of a health condition and the health technologies or interventions used to manage or treat that health condition. It includes the impact of the condition and its treatment on the person with the health condition, their family and other caregivers, and the person's personal environment. Engagement also provides insights into how a health condition is managed by the province's health system.

Information shared from lived experience can also identify gaps or limitations in published research (e.g., outcomes important to those with lived experience that are not reflected in the literature).[37-39] Additionally, lived experience can provide information and perspectives on the ethical and social values implications of health technologies or interventions.

Because the needs, priorities, preferences, and values of those with lived experience in Ontario are not often adequately explored in published literature, we speak directly with people who live with a given health condition, including those who may have experience with the intervention we are exploring.

Continual long-term physiotherapy in a community-based rehabilitation setting is a form of treatment for people who have had a stroke. Patients, usually with the advice of their health care practitioner, are referred to physiotherapy to improve movement in the arm and leg that was lost as a result of the stroke. The goal is to enable the person to perform simple day to day tasks.

## Methods

### *Engagement Plan*

The engagement plan for this health technology assessment focused on consultation to examine the experiences of people who have been diagnosed with stroke, and those of their families or other caregivers. We engaged people via telephone interviews and follow-up was done through email.

We used a qualitative interview, as this method of engagement allowed us to explore the meaning of central themes in the experiences of people who have been diagnosed with stroke and have experience with physiotherapy in inpatient and long-term community-based rehabilitation settings, as well as those of their families and caregivers.[40] The sensitive nature of exploring people's experiences of a health condition and their quality of life are other factors that support our choice of an interview methodology.

## *Participant Outreach*

We used an approach called purposive sampling,[41-44] which involves actively reaching out to people with direct experience of the health condition and health technology or intervention being reviewed. We approached a variety of partner organizations to spread the word about this engagement activity and to contact people who have undergone long- or short-term physiotherapy after stroke, along with family members and caregivers, including those with experience of physiotherapy after stroke.

## *Inclusion Criteria*

We sought to speak with people and their caregivers who have been actively managing their condition after having a stroke and are receiving physiotherapy.

## *Exclusion Criteria*

We did not set specific exclusion criteria.

## *Participants*

For the project, we spoke with 25 people living in Ontario, including both patients who had been diagnosed with stroke and caregivers who identified patients that had been diagnosed with stroke. Participants were from different socio-economic backgrounds and genders. Of the 25 people who had had a stroke, 13 received continual long-term physiotherapy, either through private physiotherapy clinics or group-based physiotherapy programs.

## *Approach*

At the beginning of the interview, we explained the role of our organization, the purpose of the health technology assessment, the risks of participation, and how participants' personal health information would be protected. If requested, we also gave this information to participants in a printed letter of information (Appendix 3). We then obtained participants' verbal consent before starting the interview. With participants' consent, we audio-recorded and then transcribed the interviews for relevant information.

Interviews lasted 30 minutes. Interviews were loosely structured and consisted of a series of open-ended questions. Questions were based on a list developed by the Health Technology Assessment International Interest Group on Patient and Citizen Involvement in Health Technology Assessment.[9] Questions focused on the impact of stroke on the quality of life for people who have been diagnosed with stroke and their perceptions of the benefits or limitations of using physiotherapy as a treatment to manage their condition. For family members and caregivers, questions focused on their perceptions of the impact of stroke and physiotherapy on the quality of life of the person diagnosed with stroke, as well as the impact of the person's health condition and treatments on the family members and caregivers themselves. See Appendix 4 for our interview guide.

## *Data Extraction and Analysis*

We used a modified version of a grounded-theory methodology to analyze interview transcripts. The grounded-theory approach allowed us to organize and compare information on experiences across participants. This method consisted of a repetitive process of obtaining, documenting,

and analyzing responses while simultaneously collecting, analyzing, and comparing information.[45,46] We used the qualitative data analysis software program NVivo[47] to identify and interpret patterns in the data. The patterns we identified allowed us to highlight the impact of stroke and physiotherapy on the patients, family members, and caregivers we interviewed.

## Results

During the interviews, patients and caregivers emphasized the significant impact that stroke had on their quality of life. Patients described the impact stroke had on their day-to-day lives, especially the reduced functioning of their arm or leg or, in some cases, both arms and legs. Patients also had to depend on caregiver assistance to conduct daily tasks.

After receiving care in acute-care hospitalization, patients began physiotherapy in an inpatient rehabilitation program in the hospital or rehabilitation facility. After receiving physiotherapy for a short period of time, patients reported that they gained back some movement in their arm and/or leg and were able to perform simple tasks such as walking, getting up and down from a chair, or eating. Caregivers discussed the financial and social impact of stroke on their lives. Some had to leave their jobs to take care of the person recovering from stroke. This impacted their finances and their standard of living. Caregivers also stated that they became more isolated from friends and other family members, which had an emotional impact on their daily life.

Of the 25 people diagnosed with stroke with whom we spoke, 13 were receiving physiotherapy in a community-based setting many months after their stroke. These individuals paid for the physiotherapy either out of pocket or through private insurance. A majority of patients who provided input on the type of physiotherapy they would like to receive indicated a preference for physiotherapy in a clinic or group setting. A smaller number expressed a preference for physiotherapy in the home. The 13 people who were receiving physiotherapy many months after their stroke reported that the physiotherapy had a positive impact on their quality of life, helping them to perform simple to moderate daily tasks effectively. They stated that they felt fortunate to regain some movement and function. However, despite the improvement, they still needed caregiver support, but the caregivers reported feeling less burdened owing to the benefits of the physiotherapy.

The 12 patients we spoke with who did not receive physiotherapy after discharge from inpatient rehabilitation reported negative impacts, including stiffening of muscles and loss of movement or sensation that they had regained during inpatient rehabilitation. Lack of access to continual long-term physiotherapy could thus be seen to have a major impact on the health and quality of life of people who have had a stroke. The most significant reported barrier to receiving continual long-term physiotherapy in community-based settings was cost.

### *Impact of Stroke on Patients and Caregivers*

Patients and caregivers highlighted the significant impact that stroke had on their quality of life. Caregivers described the changes they had to make to their personal and professional lives to care for a family member who had suffered a stroke. Patients reported that the loss of movement caused by their stroke had a long-term impact on their physical condition and quality of life. Their limited mobility and functionality did not just affect their work life, it also had emotional and social impacts.

## Physical Impact of the Stroke Event

The physical effects of a stroke set in immediately and are often the initial signs indicating that a stroke has taken place. The patients we spoke with described the physical sensations they experienced during their stroke. Some said that they were not able to effectively speak or communicate with their family members and could not describe the symptoms of the stroke as it was happening.

> *My husband came home from work about 10 o'clock, had a snack, and then went to sleep at about midnight. He woke me up about 3:30 and his speech was slurred. He could not, he did not have full range of motion of his left arm.*

> *The second one was worse because, in the morning when I got up, my daughter phoned. When he was talking on the phone, I heard he was slurring.… I saw that his face was drooped. I knew that it was another stroke.*

> *I was playing with my cats in the bed and then I dozed off. An hour later when I woke up, I could not move my right leg, but thank goodness I had my mobile phone on my bed, so I was able to call for help.*

Some patients described a loss of sensation in a hand or leg, or both, but only on one side. This sometimes led to them losing balance and mobility.

> *Initially my left arm and my left leg when I was in the hospital, if I couldn't see my left arm and my left leg, I had no idea where they were… My [sense of where my limbs were] was really lacking.*

## Physical Impact After the Stroke Event

The loss of function, balance, and mobility continued past the stroke event, and patients faced the challenge of regaining full limb function. As one caregiver noted:

> *Her left arm was basically useless, [she] had no intentional muscle control and very little in her left leg, although she does have the capability of extending her calf muscle and her knee out, but [she] cannot walk, cannot put her foot forward. [She] was paralysed on her right side and she still suffers with aphasia.*

Some patients reported a misdiagnosis of their condition, and this led them to seek treatment that did not address their needs. This delay in proper treatment had a negative impact on their recovery.

> *The stroke itself was probably not—well, I guess it was serious, but it wouldn't have been all that serious except that I was misdiagnosed with vertigo. And by the time I got properly diagnosed, which was a couple of days later, I had to have emergency surgery and a piece of my brain removed…. It was due to the fact that it had gone untreated for so long that it was an emergency situation and they just had to go in and cut out the thrombosis so that it didn't burst. If it had burst, I was basically a goner.*

> *I went to [hospital] for tests first, and the tests, they didn't complete the tests. I saw the report on them, and they hadn't finished everything. But they sent me to [hospital] for an angiogram. They gave me an angiogram. [They] couldn't find any plaque, so they went through the heart to the aorta and…when I came out of this, I couldn't really walk. I had no balance. I was worse and worse.*

## Work-Life Impact

Patients also described the impact that stroke had on their careers. Most indicated that since their stroke, they experienced physical changes that interfered with their ability to work. First, they were not able to move as easily as they could before, which made it a challenge if they worked in a physically demanding job. Second, they reported experiencing limitations to their cognition, which interfered with their ability to perform tasks effectively. This had a serious impact on their ability to work. All the patients we spoke with had to give up their careers due to the decline in their physical and cognitive abilities.

> *I was an insurance adjuster; I was a fire, explosion, and arson investigator; I was a catastrophe adjuster. I would get sent to multi-vehicle car accidents where everybody is dead and there're no witnesses, and my job was to try and figure out what happened…. My brain just didn't work. There would be simple little things that I needed to know and I just couldn't do it, and the more I couldn't do it, the madder I got.*

> *It had a huge impact. I couldn't work. So, financially, we were dependent on my husband entirely, which has been adequate. I mean, it still affected us; it's been nine years, and I still can't go back to work.*

> *She'd lost her job, she lost her home, she lost her husband, she really didn't have her kids on a full time basis. That was something that we had to deal with.*

## Impact on Caregivers

Caregivers highlighted the social impact of caring for someone who had been diagnosed with stroke. Caregivers stated that it was a challenge keeping up with their regular social activities and they sometimes had to step out of their commitments.

> *I was—we were both retired when this event occurred, and I had a volunteer job that I gave up. I could not continue on any out-of-home volunteer functions whatsoever.*

> *Everybody kind of—they don't really know how to deal with you because they know you seem different, so they're awkward, they don't feel as comfortable with you. A lot of my friends, like the girls that I worked with, they held my job for me, I was hoping to be able to go back to work. I worked in an insurance office. It was hard after a whole year of struggling with this. I couldn't believe the fatigue. The fatigue is just so severe.*

Caregivers also discussed the role they play in a patient's recovery, starting with the initial hospitalization and diagnosis to helping the patient function in their day to day lives after they

suffered a stroke. Caregivers provided details about the tasks they were responsible for and the emotional, physical, and social impact this had on their lives.

> *I do everything…. The [personal support worker] isn't allowed to do nails and that's not part of what they do, and you're on a fixed income so you don't want to bring in somebody from outside, and I think, you know, I'm an 84-year-old woman doing my husband's toenails and this doesn't make a whole lot of sense to me.*
>
> *Oh it's worn me down; I've aged quite a bit to be honest with you. My wife, I would imagine, the stress of what's going on, has contributed to her heart attack, as far as I'm concerned.*
>
> *I can't really describe it, you know, basically your whole life changes but you don't have…I mean you do have choices, but in order to keep her as comfortable as possible, as safe as possible, it required a tremendous amount of work, because basically your kind of running a little nursing home.*

Some caregivers reported that they had become isolated. They could not do the things they had planned to do after retiring and had to step in to support not only the person who had a stroke, but sometimes had to take care of other family members too. One caregiver felt that she had no time for any other social activities and had to rely on external help from community services to get household chores done.

> *Well it's better than it was, because this has been an ongoing thing for seven years, I sort of got out of contact with my friends and I'm certainly not doing the things that I had planned on doing when I retired. Supporting [daughter] and her kids, she is a single mom and being a single mom with three kids without a handicap is a full time job and being handicapped is…she needs a little more support.*
>
> *Oh, I'm tied to the house with him. I have no time to myself whatsoever, unless I can get a friend or—the government is now providing me 3 hours of respite a week, so I get—which didn't start initially. After I had the LHIN people come out, they agreed that I needed some time at least to go grocery shopping and do things that I had to do, go to the bank and stuff like that. So they provide me 3 hours a week of respite time that I can get out and do that.*

One caregiver highlighted the emotional impact of taking care of a person who had had a stroke.

> *Oh, don't even start. Yes, it's been totally overwhelming because I've been doing all the things that [my husband] would normally do, so now I'm doing things that I would do in the marriage household, and I'm also doing things that he used to do. Some things I wasn't capable of doing, and then I had to find somebody to help me. But it was exhausting, it was overwhelming. I think I had more… like, even now it's hard for me to deal with it.*

Some caregivers also found that they were unable to continue working for periods of time due to the burden of caring for a person after they had a stroke.

> *I stopped working for a couple of years because working, it was just something that, you know, I couldn't do that and also take care of her. But eventually I did go back. After a couple of years, I went back. You know, with the caregivers, I guess in the beginning I didn't know how many caregivers you needed to take care of somebody, I thought you could do it with one, whilst in fact it turned out my mother needed three.*

> *Well, to be honest with you, here's what I was doing. I was the director of training for the plumbers and pipe fitters and so I retired off of there, but I was on different boards and the boards of directors and I was a trustee and that kind of thing. …I was busy, quite busy, and they had me flying around and all of that and I resigned from the boards and resigned from the trustees. I just couldn't do it.*

## *Currently Available Treatment*

In Ontario, people who have been diagnosed with stroke may receive physiotherapy in various settings, including in the hospital. With the support of a physiotherapist, patients go through a set of exercises designed to help them regain functionality in their arms and legs. When the patient is ready for discharge, they may continue physiotherapy in the community, either in a community-based or home setting.

### Process of Receiving Physiotherapy

Physiotherapy focuses on the physical impairment caused by stroke. This usually includes exercises designed to improve the movement of the arm and/or leg that was affected by the stroke. Patients reported receiving different levels of physiotherapy, depending on the severity of their stroke. The exercises may focus on specific tasks such as moving from the bed to the wheelchair, exercising the leg to enable walking, or moving the arm. As caregivers described the process:

> *At the hospital, they had somebody help him stand up and try to get his leg moving. They were working on him, I think, once or twice a week after, about a month and a half or so, and once he was out of the hospital, he was supposed to go down to….I think it was 1 hour a week we were supposed to go—and then they helped him up there for a while and he was slowly coming around, he could pull himself, he held up to a rail, he was able to take a step.*

> *He did actual physiotherapy, like they stood him up first, as they stood him up, they had to use the sling and all that sort of stuff to stand up, so they had him in some sort of a traction thing. Then they put him in some sort of a bike and so he did the exercise on there and then they did all sorts of hand exercises like coordination and stuff like that and he also had speech therapy.*

> *First, I had to learn how to sit in a chair. Then I learned, then they taught me how to stand, and then dress myself, and then, eventually, walk. I didn't walk, take my first steps, until I was there for about six weeks…. At first, it was five steps, and then 10 steps, and so on. And when I left the hospital at that point, I could not walk on my own, I still needed supervision to walk on my own, but I could dress and I could transfer myself from a chair to…I was still wheelchair*

> *bound when I left the hospital, but I came in on a stretcher and I left in a wheelchair.*

Some patients were referred to a rehabilitation centre instead of continuing physiotherapy at the hospital.

> *I was transferred to [the rehabilitation] centre, and then things started to happen, seemed to come together. I was in a wheelchair and that week I went from a wheelchair to a walker to a cane. Once they realized that this, what I was supposed to be doing, then it happened. Then I had to work on strength and stamina, and I am still working on, and probably always will be working on it.*

> *He was so grateful when they could move him back to the [hospital], which they did for about a week, where a therapist, an occupational therapist, would get him up and walk him in the hallway. Then he was transferred from there to [a rehabilitation unit], which was the stroke rehab floor at [the hospital], and he was there till early in the new year.*

## Benefits of Receiving Physiotherapy in Inpatient Rehabilitation

Everyone who received physiotherapy through inpatient rehabilitation reported following a program designed to address their individual needs. Patients and caregivers reported that, over time, the physiotherapy had a positive impact on the patients' physical functioning. Most of the patients reported that physiotherapy helped restore at least some movement in their arm or leg, or both.

> *I was far more dependent on others. In that timeframe, however, I graduated from wheelchair to pushing a walker as if it were a wheelchair or using a walker as if it were a wheelchair, to—especially when I was at the retirement home—dressing myself, walking with the cane or the walker to the dining room, and sitting down like a normal person.*

> *That helped quite a bit…not so much the arm but more the leg and the knee and the foot, and so that allowed him now to start taking a step up over the stairs in my house…exercise there with the physio, with the masseuse, allowed him to get enough flexibility in his foot and his leg to be able to pull himself up to the top landing where I could put him in his wheelchair and then take him into his bed when he goes to bed at night.*

> *She couldn't, like I said, she couldn't walk, she couldn't swallow, she couldn't do anything and at the end they had her walking, which was a miracle as far as I was concerned. But [she] had a lot of problems, so I mean they couldn't resolve it all in 3 months, but she was a lot stronger when she came home and they'd worked quite a bit with her arm and some of her hand, but, yes, definitely a big improvement by the time she got home.*

## Limitations to Receiving Physiotherapy in Inpatient Rehabilitation

Patients and caregivers also reported challenges when going through the exercises that they were required to do in physiotherapy. Information provided to them during and after the physiotherapy was sometimes inadequate to help them understand what they needed to do.

### *Physical Limitations of Inpatient Rehabilitation*

Patients and caregivers commonly reported on the struggle to perform certain exercises and tasks. Even though many patients felt the exercises were essential to regain some function in their arm and/or leg, the physical challenge was a significant barrier for the first few days. Eventually they would get used to the movement.

> *At first, yes, it was hard at first for her. I remember the first day that they had her up and she took that first step with like two physiotherapists helping her and it brought tears to my eyes and I could see how hard it was for her, but they really worked hard with her and got her walking.*
>
> *It was hard to do some lifting, a little bit of lifting that they had me do. And just various little odd jobs, like opening cans and stuff like that.*

Some patients reported the opposite experience. They felt they were not pushed to their full potential to gain back their movement, and that their physiotherapists were not trained to provide physiotherapy to people diagnosed with stroke. Some caregivers reported that proper instructions, particularly information on how to take care of the patient and what to do to keep them from losing the movement that they had worked on, were not provided upon discharged.

> *[When] he was discharged,…nobody said anything to him about what would happen when he got home…. There should be a much better introduction to what would happen when he got out of the hospital. [There was no] planning ahead of time. None of that happened.*
>
> *The stay in the hospital was very—it was wasteful. There was so much time when I could have had some conversation with somebody about what would happen afterwards. It was wasted because it never happened, and you felt like you were in a hotel or something.*
>
> *They were just trying to get me to do an exercise and they wouldn't, they weren't actually helping me do anything else.*
>
> *And then they cut us off from that, and sent us back to the outpatient programme at the hospital. The occupational therapist worked with his arm. Physiotherapy, we were a little bit disappointed in. We seemed to get people who were in training most of the time, and probably didn't get as much out of it as we did out of any other physio that we had had at that point.*

## Barriers to Receiving Physiotherapy in Inpatient Rehabilitation

In addition to reporting the impacts of inpatient physiotherapy, patients and caregivers also described barriers they faced while receiving services. The barriers to inpatient rehabilitation were limited compared to the barriers reported in community-based rehabilitation.

### *Logistical Barriers*

One caregiver reported difficulties in attending rehabilitation sessions that they needed to attend only because the patient could not drive himself until he was able to requalify for a drivers license. After the patient had a second stroke, he had to rely on others for transportation.

> *When he had the first stroke, his licence was suspended and he had to go back to driving school. He had to go to physio first, and then he went to driving school and he got his licence back…. This time, I would not trust him to drive at all…. [The licence is] still valid, but…I wouldn't trust him...behind the wheel at all.*

### *Financial Barriers*

Some patients and caregivers found that costs associated with attending rehabilitation sessions (e.g., gas, parking) were an additional challenge.

> *I had to pay for the parking because I thought maybe okay, he's going there for physio. It would be cheap and I had to pay for it…[but] it's not cheap. Even if it's $15 a day or $25 a day, that's a lot of money. Especially when you're on a fixed income.*

One caregiver reported that attending rehabilitation sessions required staying at a retirement residence for six weeks.

> *We stayed at the [retirement residence], which was extremely expensive, but [patient] had to be released to a place that had medical facilities. I'm not sure why, but…that meant to a hospital or some place that had a nurse or whatever. We had a son in Thunder Bay, but he wouldn't be released to my son, so we had to go to this other place. And as I said, it was very expensive…. Well we were one of the lucky ones, we had actually sort of prepared for emergencies like that. So, we were able to pay, but as I said, for six weeks, it was $7,000.*

## *Continual Long-Term Physiotherapy in Community-Based Settings*

Of the 25 patients we spoke to, 13 were currently receiving physiotherapy in community-based settings that included both group physiotherapy and individual therapy in clinics.

### Process of Receiving Continual Long-Term Physiotherapy in Community-Based Settings

Community-based rehabilitation is available in different settings, including in clinics, at home, at a retirement home, and at a local school (usually in the gymnasium). The length of physiotherapy varies for each patient, from 6 months up to 18 months. Each patient has specific plan to meet their individual needs. Some plans focus on increasing functionality and mobility, while others focus on one type of function. Most patients and caregivers have to find the appropriate location to receive physiotherapy themselves, with the help of community-based centres.

> *It's quite a bit of sitting to standing therapy and stretching…so we then needed to align our physiotherapy [goals] to make sure that she was able to provide some assistance or at least would remain flexible enough…and the physiotherapist understood that I wanted them to ensure that [patient] was going to be exercised enough in order for her to have her core strong enough and to be comfortable in a sitting to standing function in order to get in and out of the car.*

> *After the, I will say, 10 sessions in 12 weeks with the [physiotherapist] and the [occupational therapist] at the hospital, there is an…active living clinic. It's a physiotherapy office but also a gymnasium ….so it's an out-patient facility, I'm assuming.*
>
> *After the 12 weeks of [physiotherapist] and [occupational therapist] appointments at Civic Hospital, I had the assessment at the physiotherapy place, and I went there at least once a week. Either it is a one-on-one session for a half-hour or an hour—usually an hour—with the physiotherapist or they have a…well, call it a "falls prevention" class, a group workout, and that's about a 50-minute session, and it's geared to the skill and balance level of the individual.*
>
> *[N]ow I go to the gym four days a week, which I couldn't do back then because I couldn't do it independently, which I can do now…mostly gait training.*
>
> *Initially, we had physio twice a week with two different physiotherapists. One was coming into the house, and one we were going out to their office. The one that was coming into the house was doing similar things that the outreach programme did; he was very good with him. He got him walking. Well, he got him walking around the house and more going up and down the stairs, and more. We bought the step-up and he got him doing that at home, and…stuff like that. The one that we go to—he worked more on the walking and the leg.*

## Benefits (Physical Impact) of Receiving Continual Long-Term Physiotherapy in Community-Based Settings

Patients and caregivers observed the positive impact of continual long-term physiotherapy even though patients were not able to return to a normal full life and could not return to work. Based on the severity of the stroke, some patients were able to make significant improvements in their functionality. Others achieved only minimal improvement to their condition, but it was still identified by them as a positive outcome. Patients and caregivers agreed that the most important positive result of physiotherapy is the ability to walk properly. Patients also enjoyed the ability to do simple chores, such as going grocery shopping. They highlighted that they were starting to be more sociable and independent. Some joined support groups or attended a group-based physiotherapy.

> *Well, the first one I have noticed is cutting a piece of bread from a loaf. Now, using my bad hand, the loaf doesn't slide across the counter while I am trying to cut a piece of bread off of it. As we are talking right now my bad hand, the left one, has been holding the phone for the entire conversation.*
>
> *We can see that big time ourselves when he was going to the training, what we were doing, I was taking him out to the Ability Centre about 5 days a week and with this 5 days a week, several things were happening. He was socialising and becoming a little more independent and wanted to do it…. He would go into the training room by himself and start working on the machines and helping his arm and helping his leg, but he got used to the people and they got used to him and he gained that confidence within himself to be able to be away from me. But I'm still in the area, you know what I mean?*

> *I need someone to do a big grocery order, but if I did go to the drug store, if I need to go get milk or something, I can go do that on my own. I don't walk with a cane anymore so I can—I have my hand free that I can carry things if need be. So, I have my independence now.*

## Limitations of Continual Long-Term Physiotherapy in Community-Based Settings

Despite experiencing a positive impact on their quality of life, patients did not gain full recovery of their mobility and ability to perform certain tasks. Patients still had to rely on support from caregivers or would have to walk using a cane.

> *I do have several bits of equipment to help me with the finger manipulation, but doing say…it's 15 stairs to the basement and I definitely need someone sturdier who can catch me in case something bad happens. I am very sure that if I had to, I could walk down the stairs. It may take me 10 minutes to do so, but I am physically capable of doing it. It's a confidence thing, [but there is] a risk of rushing and slipping.*

> *For a proper physiotherapy session, yes [I need someone there as a support], but to go outside and take the blue box to the street, or go out the back landing and open the tool shed—I've got my cane as a security blanket and, barring ice or rain, I am doing that on a daily basis.*

> *I still receive physio because I still have a lot of problems…. And about 40% of patients, stroke survivors, experience this, and they have chronic disabilities and they're not, you know, improving. Or they are improving, but it's very slow.*

## Barriers to Receiving Continual Long-Term Physiotherapy in Community-Based Settings

The two main barriers identified by patients and caregivers were cost and access.

### *Logistical Barriers*

Continual long-term physiotherapy requires many sessions. Because most people who have had a stroke are unable to transport themselves to their appointments, the caregiver is usually required to take them. This exposes the caregiver to recurring costs for gas and sometimes taxis. Patients and caregivers often found it a challenge to attend their appointments during bad weather, especially in winter. Snow could interfere with locating disabled parking, which makes it harder for the patient to walk to the building.

> *We started that again, so after—in the New Year, we started it. The problem is, because of bad weather and ice, they can't get him out, but for the most part we've been there.*

> *I don't charge him for running back and forth and using my gas and everything and my time, I am just taking care of him and my wife and looking after myself.*

> *I was fortunate to have support from friends and family to drive me places. And, you know, when they weren't available, then I had to pay for taxis, which were another financial thing. Wheeltrans is good, except that it's, there's lots of time waiting, so, if you want to, if you had an appointment for 9 o'clock, and*

> *it's a 20-minute drive, they're going to pick you up at possibly 8 o'clock in the morning. And then, if your appointment is, let's say, 9 to 10, they may not pick you up at 10, they'll pick you up at 11. So, it's basically, you spend four hours for a 1-hour appointment.*
>
> *When there's no snow, it's easier. With the snow, it's—I can't go places because I can't get over the snowbanks. So, I have to walk along the road and risk my safety and [it's] terrible. They don't shovel the snow in front of [the rehabilitation hospital] and they don't shovel it in front of Toronto Rehab, so you—parking is terrible. And then, if I don't park in front, on University Avenue, then I have to park in a lot, which is a long walk.-*

### *Financial Barriers*

Patients faced large out-of-pocket costs for physiotherapy if they did not have insurance benefits to supplement or cover. This burden is complicated by the career impacts of stroke—most people who have had a stroke or are a caregiver are retired or otherwise not working. Most people we spoke to said that physiotherapy is an expensive service and most of their income goes into it. As a result, they had to plan out how they would pay for other things they might need.

> *[For] the first 3 years, I probably spent $30,000 to $40,000 a year in physiotherapy and occupation therapy. And now, I probably spend $10,000 to $15,000 a year.*
>
> *Our social life is non-existent. The private physiotherapy is a huge drain on our retirement resources. But we were so fortunate in getting a private physiotherapist who was well-trained, well-experienced in stroke survivors, and we are going to continue one way or the other.*
>
> *It is a burden, that's for sure. I mean, I would certainly much rather spend the money going on vacation someplace if it were possible, but I mean we haven't been on a vacation since before he had the stroke because…it's expensive.*

Some patients and caregivers expressed concern about not having funds to continue physiotherapy as long as needed.

> *We have sufficient funds for a few years. We're both believers in physiotherapy, and if it comes to it, you know, we'll sell the house.*
>
> *If they raise the price, it would be harder for us, for him, to receive physiotherapy.… I paid $9,000 in medical expenses last year. I can't afford to pay any more than that. So it's difficult.*

## Free Community-Based Programs

Some people who could not afford to continue with physiotherapy following inpatient rehabilitation enrolled in free exercise or educational programs available in the community. Patients stated that they had to find programs through their own research. These free programs, which included aphasia classes and exercise classes, helped patients gain some independence and improvement in their quality of life beyond what they achieved in inpatient therapy.

> *I did it on my own. It was really just kind of pure luck. Somebody suggested, a few people suggested, why don't I try Tai Chi because, having lost part of my cerebella, I had problems with balance and a few other things. I didn't know that there are, you know, dozens or hundreds of different types of Tai Chi. It just so happened that in my little local community, the Taoist Tai Chi society started a class. So I signed up and, lo and behold, it was the perfect type of Tai Chi for health recovery.*

> *What we were doing,…I couldn't afford a physiotherapist, so we had trainers [who] would work with people and so Sunday mornings, I would take him out and he would have a one on one with the trainer and they would stretch his legs and stretch his ankles and work his arms and work his shoulder and that was a big [help].*

> *She uses a program called Revved Up…. Well I think it's more of a strength training program. She uses machinery, she doesn't really do exercises. She does some floor exercises, but it's a lot with machines and she works a little bit on the treadmill and a bike and some other strength training equipment.*

### Impact of Not Continuing With Long-Term Physiotherapy

Patients and caregivers who stopped physiotherapy reported a decline in their overall health and a stiffening of the patient's arm and/or leg.

> *When I'm away, when I've travelled, and I'm gone for a couple of weeks, and I haven't received my regular—I haven't been working out and doing my rehab…I get stiffer. There was one time I was away and towards the end of my trip, I wasn't stretching as much, I kept forgetting to do it, and then all of a sudden, I noticed towards the last few days, I was having trouble walking because I was so stiff, I couldn't bend my knee.*

> *Because of the limitations of his ODSP [Ontario Disability Support Program], and…since I haven't been able to get him out to the physio or to the time program thing, what's happening is that I noticed that everything is stiffening up again, makes it more difficult now for him to move around and to get up the stairs. I had to forcibly pull his leg back so his leg won't hit the wall when he's coming up on the chair, because it's so stiff, so there's issues there that we're going to have to deal with, you know.*

> *Whenever I get down or lazy and don't exercise for a few days, I start getting stiff and sore. And I think of these people and what they did for me and I laugh and get out there, go for a walk, or do some other exercise. The therapists and counselors at [the physiotherapy clinic] are phenomenal. They teach stroke survivors how to cope out in the world and at home. They also give help for caregivers.*

## *Patient and Caregiver Perspectives on Different Types of Physiotherapy*

Throughout the course of this engagement, we learned about the type of physiotherapy that patients would like to receive and what the caregivers think would be a better option. When

provided different options, most patients preferred physiotherapy at a clinic or rehabilitation facility, with the support of a physiotherapist. Patients felt that by receiving supported physiotherapy, they would have more motivation to maintain their regimen and would experience greater improvements in their quality of life.

> *I would pick going to some place. I didn't try home physio all that well because I knew I could just walk away and ignore it, but when I go to a place, I am kind of obliged to do it. I can get lazy fairly easily, and I could even before the stroke. But if I am cornered, I'll put my all into it.*

> *When I take him from here to another place and a professional takes over, he is devoted to doing the exercise with that person. He won't shy away from it and he feels compelled. He's got to do it because this professional is saying it; he'll believe that and want to do it much more than with me telling him to do it.*

> *The exercises at a clinic…yeah, because I'm able to get there. So, for me, that would be good. And if there's a group, I work better in a group, rather than one-on-one because I don't remember. I have the short-term memory thing, right? So unless I get a sheet of paper with everything on it, I won't remember.*

On the other hand, some patients preferred to have physiotherapy at home with the support of a physiotherapist. This preference was highlighted by one caregiver, who felt that the patient would be much more comfortable being in that environment.

> *I want it at home, I would like that—if someone could come and do some exercise, like again…. Maybe he would feel more comfortable.?*

> *Doing the exercises at home, because I think he is much more comfortable with just me and the fact that I can do them properly. I'm not properly trained to do it, but I was taught how to do it and I think I was a [pretty good client].*

## Discussion

Patients and caregivers shared their personal experiences about the burden and struggle of life after stroke. The stroke event had an impact on both the patients' and caregivers' quality of life and well-being. There was great interest from patients and caregivers to share their experiences on this topic. As a result, we were able to speak with a large number of individuals with experience of having a stroke and/or going through physiotherapy.

All the patients that we interviewed had direct experience with the process of acute care hospitalization and inpatient rehabilitation. Patients and caregivers cited improved mobility as a major benefit of inpatient rehabilitation. Despite showing some improvement, patients also reported barriers and limitations with inpatient rehabilitation, including cost.

Of the 25 patients we spoke with who had received inpatient rehabilitation, 13 went on to receive continual long-term physiotherapy in a community-based setting. These patients felt they gained significant improvement in their movement and were able to walk and perform simple tasks. However, even though they improved over time, they did not recover fully. They also reported access barriers to continuing physiotherapy. Some patients who did not continue with therapist-guided physiotherapy had to rely on free community programs.

Reporting was limited on those patients who did not continue with therapy of either type. However, patients who discontinued physiotherapy entirely (whether temporarily or permanently) observed that their muscles stiffened up and they slowly lost movement in the arm and leg. As a result, these patients indicated that they would prefer continuing physiotherapy.

Patients also provided information on the kinds of physiotherapy they would like to receive. Some patients preferred physiotherapy in a clinic with the support of a physiotherapist; others preferred to physiotherapy in their own home with the support of physiotherapist.

## Conclusions

Patients and caregivers were greatly affected by their experiences with and after a stroke event, reporting that it had had a large impact on their daily lives. After acute-care hospitalization, patients went on to receive inpatient physiotherapy, through which they were able to gain some improved movement. There were differences in preferences expressed regarding the type of physiotherapy patients would like to receive. Some preferred to receive physiotherapy at a clinic with the support of a physiotherapist, whereas other preferred to receive physiotherapy at home. The patients we spoke with who had received continual long-term physiotherapy felt that their functional ability improved. Those we spoke with who did not receive continual long-term physiotherapy felt that their functional ability declined after they stopped receiving physiotherapy.

## CONCLUSIONS OF THE HEALTH TECHNOLOGY ASSESSMENT

After a systematic search of the clinical literature, we were unable to identify any studies that answered the question that was the focus of this assessment; that is, whether extending continual long-term physiotherapy beyond 3 or 6 months has benefit. Thus, we were unable to determine the benefits of continual long-term compared with short-term physiotherapy after stroke.

We did not identify any studies comparing the cost-effectiveness of continual long-term physiotherapy with short-term physiotherapy for people with a diagnosis of stroke. Owing to limited clinical evidence, we did not conduct a primary economic evaluation to assess continual long-term versus short-term post-stroke physiotherapy. The cost-effectiveness of continual long-term post-stroke physiotherapy in Ontario is thus unknown. We estimated that publicly funding continual long-term physiotherapy for people with a diagnosis of stroke in Ontario would lead to additional costs of $445,000 to $888,000 annually over the next 5 years.

Patients and caregivers with whom we spoke reported that the stroke event had a large impact on their daily lives and that physiotherapy after hospitalization for stroke provided improvements in their movement and functioning. Those patients who received continual long-term physiotherapy felt that their functional ability improved. Those who stopped receiving continual long-term physiotherapy felt that their functional ability declined.

# GLOSSARY

| | |
|---|---|
| **Budget impact analysis** | A budget impact analysis estimates the financial impact of adopting a new health care intervention on the current budget (i.e., its affordability). It is based on predictions of how changes in the intervention mix impact the level of health care spending for a specific population. Budget impact analyses are typically conducted for a short-term period (e.g., 5 years). The budget impact, sometimes referred to as the net budget impact, is the estimated cost difference between the current scenario (i.e., the anticipated amount of spending for a specific population without using the new intervention) and the new scenario (i.e., the anticipated amount of spending for a specific population following the introduction of the new intervention). |
| **Cost-effective** | A health care intervention is considered cost-effective when it provides additional benefits, compared with relevant alternatives, at an additional cost that is acceptable to a decision-maker based on the maximum willingness-to-pay value. |
| **Incremental cost-effectiveness ratio (ICER)** | In economic evaluations, the incremental cost-effectiveness ratio (ICER) is a summary measure that indicates, for a given health care intervention, how much more a consumer must pay to get an additional unit of benefit relative to an alternative intervention. It is obtained by dividing the incremental cost by the incremental effectiveness. Incremental cost-effectiveness ratios are typically presented as the cost per life-year gained or the cost per quality-adjusted life-year gained. |
| **Quality-adjusted life-year (QALY)** | The quality-adjusted life-year is a generic health outcome measure commonly used in cost–utility analyses to reflect the quantity and quality of life-years lived. The life-years lived are adjusted for quality of life using individual or societal preferences (i.e., utility values) for being in a particular health state. One year of perfect health is represented by one quality-adjusted life-year. |
| **Reference case** | The reference case is a preferred set of methods and principles that provide the guidelines for economic evaluations. Its purpose is to standardize the approach of conducting and reporting economic evaluations, so that results can be compared across studies. |

# APPENDICES

## Appendix 1: Literature Search Strategies

### *Clinical Evidence Search*

**Search date:** October 29, 2018

**Databases searched:** Ovid MEDLINE, Embase, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, the Health Technology Assessment database, National Health Service Economic Evaluation Database, Cumulative Index to Nursing & Allied Health Literature

**Database:** EBM Reviews - Cochrane Central Register of Controlled Trials <September 2018>, EBM Reviews - Cochrane Database of Systematic Reviews <2005 to October 24, 2018>, EBM Reviews - Health Technology Assessment <4th Quarter 2016>, EBM Reviews - NHS Economic Evaluation Database <1st Quarter 2016>, Embase <1980 to 2018 Week 44>, Ovid MEDLINE(R) ALL <1946 to October 25, 2018>

**Search strategy:**

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1 *brain ischemia/ (101733)
2 exp *intracranial hemorrhages/ (93436)
3 exp *stroke/ (160327)
4 *Stroke Rehabilitation/ (9362)
5 (stroke* or poststroke or CVA or CVAs).ti. (253688)
6 ((cerebrovascular or cerebro vascular or cerebral vascular) adj2 (apoplex* or accident* or infarct*)).ti. (3461)
7 ((brain or cerebral or intracerebral or arachnoid or subarachnoid or intracranial or cranial) adj2 (infarct* or isch?emi* or h?emorrhag*)).ti. (109179)
8 ((post acute or postacute or chronic) adj5 (stroke* or poststroke)).ti,ab,kf. (17139)
9 (((post acute or postacute or chronic) adj5 (hemipare* or paretic or paresis or phase or phases or stage or stages or state or states or condition or paraly* or spastic*)) and (stroke* or poststroke)).ti,ab,kf. (6681)
10 or/1-9 (474515)
11 Exercise Therapy/ (68993)
12 Physical Therapy Modalities/ (103351)
13 Exercise Movement Techniques/ (27319)
14 Electric Stimulation Therapy/ (22043)
15 (physiotherap* or physio therap* or CIMT or mCIMT or FES or NMES).ti,ab,kf. (89364)
16 (electric* adj3 stimulation).ti,ab,kf. (123982)
17 ((movement or mobility or mobilization or mobilisation or physical or fitness or exercise or treadmill* or upper limb* or lower limb* or upper extremit* or lower extremit* or balance or gait or strength or strengthening or aerobic* or cardiovascular or cardio vascular or task specific or task oriented or taskoriented or dual task or dualtask or bilateral) adj2 (training or retraining or program* or therap* or rehabilitation)).ti,ab,kf. (232859)
18 exp exercise/ (479399)
19 (training or retraining or program* or therap* or rehabilitation).ti,ab,kf. (8610715)
20 18 and 19 (180691)
21 or/11-17,20 (617856)
22 10 and 21 (22372)

23 Meta-Analysis/ or Meta-Analysis as Topic/ or exp Technology Assessment, Biomedical/ (307012)
24 Meta Analysis.pt. (94097)
25 (((systematic* or methodologic*) adj3 (review* or overview*)) or pooled analysis or published studies or published literature or hand search* or handsearch*
or medline or pubmed or embase or cochrane or cinahl or data synthes* or data extraction* or HTA or HTAs or (technolog* adj (assessment* or overview* or appraisal*))).tw. (695839)
26 (meta analy* or metaanaly* or health technolog* assess*).mp. (452431)
27 Clinical Trials as Topic/ or Randomized Controlled Trials as Topic/ (490019)
28 (randomized controlled trial or controlled clinical trial).pt. (1102733)
29 trial.ti. (670349)
30 (randomi#ed or randomly or RCT$1 or placebo* or sham).tw. (2958510)
31 or/23-30 (4350419)
32 exp Animals/ not Humans/ (15652830)
33 31 not 32 (3260655)
34 22 and 33 (7372)
35 Case Reports/ or Comment.pt. or Editorial.pt. or Letter.pt. or Congresses.pt. (5017890)
36 34 not 35 (7307)
37 limit 36 to english language [Limit not valid in CDSR; records were retained] (6339)
38 37 use medall,cleed (2646)
39 Case Reports/ or Comment.pt. or Editorial.pt. or Letter.pt. or conference abstract.pt. (8183671)
40 22 not 39 (18365)
41 limit 40 to english language [Limit not valid in CDSR; records were retained] (15522)
42 41 use coch,cctr,clhta (2431)
43 38 or 42 (5077)
44 remove duplicates from 43 (3428)
45 *brain ischemia/ (101733)
46 exp *brain hemorrhage/ (92657)
47 exp *cerebrovascular accident/ (156468)
48 *stroke rehabilitation/ (9362)
49 (stroke* or poststroke or CVA or CVAs).ti. (253688)
50 ((cerebrovascular or cerebro vascular or cerebral vascular) adj2 (apoplex* or accident* or infarct*)).ti. (3461)
51 ((brain or intracerebral or cerebral or arachnoid or subarachnoid or intracranial or cranial) adj2 (infarct* or isch?emi* or h?emorrhag*)).ti. (109179)
52 ((post acute or postacute or chronic) adj5 (stroke* or poststroke)).tw,kw. (17264)
53 (((post acute or postacute or chronic) adj5 (hemipare* or paretic or paresis or phase or phases or stage or stages or state or states or condition or paraly* or spastic*)) and (stroke* or poststroke)).tw,kw. (6937)
54 or/45-53 (473956)
55 kinesiotherapy/ (26510)
56 physiotherapy/ (72039)
57 home physiotherapy/ (270)
58 constraint induced therapy/ (486)
59 arm exercise/ (1454)
60 leg exercise/ (1799)
61 movement therapy/ (2854)
62 muscle training/ (12654)
63 electrostimulation/ (60707)
64 (physiotherap* or physio therap* or CIMT or mCIMT or FES or NMES).tw,kw,dv. (93180)

65 (electric* adj3 stimulation).tw,kw,dv. (125436)
66 ((movement or mobility or mobilization or mobilisation or physical or fitness or exercise or treadmill* or upper limb* or lower limb* or upper extremit* or lower extremit* or balance or gait or strength or strengthening or aerobic* or cardiovascular or cardio vascular or task specific or task oriented or taskoriented or dual task or dualtask or bilateral) adj2 (training or retraining or program* or therap* or rehabilitation)).tw,kw,dv. (236249)
67 exp exercise/ (479399)
68 (training or retraining or program* or therap* or rehabilitation).tw,kw,dv. (8589239)
69 67 and 68 (182453)
70 or/55-66,69 (609107)
71 54 and 70 (21751)
72 Meta Analysis/ or "Meta Analysis (Topic)"/ or Biomedical Technology Assessment/ (301682)
73 (((systematic* or methodologic*) adj3 (review* or overview*)) or pooled analysis or published studies or published literature or hand search* or handsearch*
or medline or pubmed or embase or cochrane or cinahl or data synthes* or data extraction* or HTA or HTAs or (technolog* adj (assessment* or overview* or appraisal*))).tw. (695839)
74 (meta analy* or metaanaly* or health technolog* assess*).mp. (452431)
75 exp "controlled clinical trial (topic)"/ (157338)
76 randomized controlled trial/ or controlled clinical trial/ (1254837)
77 trial.ti. (670349)
78 (randomi#ed or randomly or RCT$1 or placebo* or sham).tw. (2958510)
79 or/72-78 (4240303)
80 (exp animal/ or nonhuman/) not exp human/ (10043549)
81 79 not 80 (3875703)
82 71 and 81 (9299)
83 Case Report/ or Comment/ or Editorial/ or Letter/ or conference abstract.pt. (10000790)
84 82 not 83 (7933)
85 limit 84 to english language [Limit not valid in CDSR; records were retained] (6891)
86 85 use emez (2579)
87 44 or 86 (6007)
88 87 use medall (1124)
89 87 use coch (29)
90 87 use cctr (2258)
91 87 use clhta (12)
92 87 use cleed (5)
93 87 use emez (2579)
94 88 or 93 (3703)
95 remove duplicates from 94 (2989)
96 89 or 90 or 91 or 92 or 95 (5293)
97 remove duplicates from 96 (4138)

**CINAHL**

| # | Query | Results |
|---|---|---|
| S1 | (MM "Cerebral Ischemia+") | 11,167 |
| S2 | (MM "Intracranial Hemorrhage+") | 8,699 |
| S3 | (MM "Stroke+") | 43,363 |
| S4 | (MH "Stroke+/RH") | 10,207 |
| S5 | TI(stroke* OR poststroke OR CVA OR CVAs) | 45,347 |
| S6 | TI((cerebrovascular OR cerebro vascular OR cerebral vascular) N2 (apoplex* OR accident* OR infarct*)) | 382 |
| S7 | TI((brain OR cerebral OR intracerebral OR arachnoid OR subarachnoid OR intracranial OR cranial) N2 (infarct* OR ischemi* OR ischaemi* OR hemorrhag* OR haemorrhag*)) | 8,456 |
| S8 | ((post acute or postacute or chronic) N5 (stroke* or poststroke)) | 3,211 |
| S9 | ((post acute OR postacute OR chronic) N5 (hemipare* OR paretic OR paresis OR phase OR phases OR stage OR stages OR state OR states OR condition OR paraly* OR spastic*)) AND stroke* | 1,499 |
| S10 | S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 | 70,208 |
| S11 | (MH "Physical Therapy") | 30,179 |
| S12 | (MH "Constraint-Induced Therapy") | 602 |
| S13 | (MH "Electrotherapy+") | 18,640 |
| S14 | (MH "Functional Training") | 909 |
| S15 | (MH "Gait Training+") | 1,713 |
| S16 | (MH "Home Physical Therapy") | 420 |
| S17 | (MH "Therapeutic Exercise") | 19,279 |
| S18 | (MH "Aerobic Exercises+") | 35,230 |
| S19 | (MH "Muscle Strengthening") | 11,830 |
| S20 | physiotherap* OR physio therap* OR CIMT OR mCIMT OR FES OR NMES | 21,319 |
| S21 | electric* N3 stimulation | 14,797 |
| S22 | ((movement OR mobility OR mobilization OR mobilisation OR physical OR fitness OR exercise OR treadmill* OR upper limb* OR lower limb* OR upper extremit* OR lower extremit* OR balance OR gait OR strength OR strengthening OR aerobic* OR cardiovascular OR cardio vascular OR task specific OR task oriented OR taskoriented OR dual task OR dualtask OR bilateral) N2 (training OR retraining OR program* OR therap* OR rehabilitation)) | 114,914 |
| S23 | (MH "Exercise+") | 92,464 |
| S24 | training OR retraining OR program* OR therap* OR rehabilitation | 1,817,959 |

| | | |
|---|---|---|
| S25 | S23 AND S24 | 45,651 |
| S26 | S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S25 | 186,637 |
| S27 | (MH "Meta Analysis") | 33,946 |
| S28 | (PT "Meta Analysis") or (PT "Systematic Review") | 84,359 |
| S29 | ((systematic* or methodologic*) N3 (review* or overview*)) or pooled analysis or published studies or published literature or hand search* or handsearch*<br>or medline or pubmed or embase or cochrane or cinahl or<br>data synthes* or data extraction* or HTA or HTAs or (technolog* N1 (assessment* or overview* or appraisal*)) | 156,384 |
| S30 | (PT "randomized controlled trial") | 84,187 |
| S31 | TI trial | 83,097 |
| S32 | (randomi?ed or randomly or RCT or RCTs or placebo* or sham) | 267,760 |
| S33 | S27 OR S28 OR S29 OR S30 OR S31 OR S32 | 421,036 |
| S34 | (MH "Animals+") not (MH "Animals+" and MH "Human") | 69,667 |
| S35 | S33 not S34 | 417,697 |
| S36 | S10 AND S26 AND S35 | 2,432 |
| S37 | PT(Case Study or Commentary or Editorial or Letter or Proceedings) | 924,103 |
| S38 | S36 NOT S37 | 2,346 |
| S39 | S36 NOT S37<br>Limiters - English Language | 2,283 |

## *Economic Evidence Search*

**Search date:** October 31, 2018

**Databases searched:** Ovid MEDLINE, Embase, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, the Health Technology Assessment database, National Health Service Economic Evaluation Database, Cumulative Index to Nursing & Allied Health Literature

**Search strategy:**

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1 *brain ischemia/ (101756)
2 exp *intracranial hemorrhages/ (93464)
3 exp *stroke/ (160389)
4 *Stroke Rehabilitation/ (9367)
5 (stroke* or poststroke or CVA or CVAs).ti. (253805)
6 ((cerebrovascular or cerebro vascular or cerebral vascular) adj2 (apoplex* or accident* or infarct*)).ti. (3459)
7 ((brain or cerebral or intracerebral or arachnoid or subarachnoid or intracranial or cranial) adj2 (infarct* or isch?emi* or h?emorrhag*)).ti. (109209)

8 ((post acute or postacute or chronic) adj5 (stroke* or poststroke)).ti,ab,kf. (17148)
9 (((post acute or postacute or chronic) adj5 (hemipare* or paretic or paresis or phase or phases or stage or stages or state or states or condition or paraly* or spastic*)) and (stroke* or poststroke)).ti,ab,kf. (6685)
10 or/1-9 (474703)
11 Exercise Therapy/ (69031)
12 Physical Therapy Modalities/ (103370)
13 Exercise Movement Techniques/ (27319)
14 Electric Stimulation Therapy/ (22049)
15 (physiotherap* or physio therap* or CIMT or mCIMT or FES or NMES).ti,ab,kf. (89441)
16 (electric* adj3 stimulation).ti,ab,kf. (124011)
17 ((movement or mobility or mobilization or mobilisation or physical or fitness or exercise or treadmill* or upper limb* or lower limb* or upper extremit* or lower extremit* or balance or gait or strength or strengthening or aerobic* or cardiovascular or cardio vascular or task specific or task oriented or taskoriented or dual task or dualtask or bilateral) adj2 (training or retraining or program* or therap* or rehabilitation)).ti,ab,kf. (233022)
18 exp exercise/ (479591)
19 (training or retraining or program* or therap* or rehabilitation).ti,ab,kf. (8615916)
20 18 and 19 (180774)
21 or/11-17,20 (618182)
22 10 and 21 (22385)
23 economics/ (249612)
24 economics, medical/ or economics, pharmaceutical/ or exp economics, hospital/ or economics, nursing/ or economics, dental/ (793556)
25 economics.fs. (411194)
26 (econom* or price or prices or pricing or priced or discount* or expenditure* or budget* or pharmacoeconomic* or pharmaco-economic*).ti,ab,kf. (824719)
27 exp "costs and cost analysis"/ (558526)
28 (cost or costs or costing or costly).ti. (247949)
29 cost effective*.ti,ab,kf. (300220)
30 (cost* adj2 (util* or efficacy* or benefit* or minimi* or analy* or saving* or estimate* or allocation or control or sharing or instrument* or technolog*)).ab,kf. (196929)
31 models, economic/ (11867)
32 markov chains/ or monte carlo method/ (75762)
33 (decision adj1 (tree* or analy* or model*)).ti,ab,kf. (38666)
34 (markov or markow or monte carlo).ti,ab,kf. (120592)
35 quality-adjusted life years/ (36790)
36 (QOLY or QOLYs or HRQOL or HRQOLs or QALY or QALYs or QALE or QALEs).ti,ab,kf. (65712)
37 ((adjusted adj1 (quality or life)) or (willing* adj2 pay) or sensitivity analys*s).ti,ab,kf. (106933)
38 or/23-37 (2402847)
39 22 and 38 (1151)
40 Case Reports/ or Comment.pt. or Editorial.pt. or Letter.pt. or Congresses.pt. or conference abstract.pt. (8249986)
41 39 not 40 (921)
42 exp Animals/ not Humans/ (15654062)
43 41 not 42 (715)
44 limit 43 to english language [Limit not valid in CDSR; records were retained] (648)
45 44 use medall,coch,cctr,clhta (453)
46 limit 22 to english language [Limit not valid in CDSR; records were retained] (19497)

47 46 use cleed (6)
48 45 or 47 (459)
49 *brain ischemia/ (101756)
50 exp *brain hemorrhage/ (92685)
51 exp *cerebrovascular accident/ (156530)
52 *stroke rehabilitation/ (9367)
53 (stroke* or poststroke or CVA or CVAs).ti. (253805)
54 ((cerebrovascular or cerebro vascular or cerebral vascular) adj2 (apoplex* or accident* or infarct*)).ti. (3459)
55 ((brain or intracerebral or cerebral or arachnoid or subarachnoid or intracranial or cranial) adj2 (infarct* or isch?emi* or h?emorrhag*)).ti. (109209)
56 ((post acute or postacute or chronic) adj5 (stroke* or poststroke)).tw,kw. (17273)
57 (((post acute or postacute or chronic) adj5 (hemipare* or paretic or paresis or phase or phases or stage or stages or state or states or condition or paraly* or spastic*)) and (stroke* or poststroke)).tw,kw. (6941)
58 or/49-57 (474144)
59 kinesiotherapy/ (26510)
60 physiotherapy/ (72039)
61 home physiotherapy/ (270)
62 constraint induced therapy/ (486)
63 arm exercise/ (1454)
64 leg exercise/ (1799)
65 movement therapy/ (2854)
66 muscle training/ (12654)
67 electrostimulation/ (60707)
68 (physiotherap* or physio therap* or CIMT or mCIMT or FES or NMES).tw,kw,dv. (93254)
69 (electric* adj3 stimulation).tw,kw,dv. (125462)
70 ((movement or mobility or mobilization or mobilisation or physical or fitness or exercise or treadmill* or upper limb* or lower limb* or upper extremit* or lower extremit* or balance or gait or strength or strengthening or aerobic* or cardiovascular or cardio vascular or task specific or task oriented or taskoriented or dual task or dualtask or bilateral) adj2 (training or retraining or program* or therap* or rehabilitation)).tw,kw,dv. (236411)
71 exp exercise/ (479591)
72 (training or retraining or program* or therap* or rehabilitation).tw,kw,dv. (8594325)
73 71 and 72 (182534)
74 or/59-70,73 (609397)
75 58 and 74 (21764)
76 Economics/ (249612)
77 Health Economics/ or Pharmacoeconomics/ or Drug Cost/ or Drug Formulary/ (124114)
78 Economic Aspect/ or exp Economic Evaluation/ (436291)
79 (econom* or price or prices or pricing or priced or discount* or expenditure* or budget* or pharmacoeconomic* or pharmaco-economic*).tw,kw. (849106)
80 exp "Cost"/ (558526)
81 (cost or costs or costing or costly).ti. (247949)
82 cost effective*.tw,kw. (311341)
83 (cost* adj2 (util* or efficac* or benefit* or minimi* or analy* or saving* or estimate* or allocation or control or sharing or instrument* or technolog*)).ab,kw. (204690)
84 Monte Carlo Method/ (60626)
85 (decision adj1 (tree* or analy* or model*)).tw,kw. (42362)
86 (markov or markow or monte carlo).tw,kw. (125561)
87 Quality-Adjusted Life Years/ (36790)

88 (QOLY or QOLYs or HRQOL or HRQOLs or QALY or QALYs or QALE or QALEs).tw,kw. (69517)
89 ((adjusted adj1 (quality or life)) or (willing* adj2 pay) or sensitivity analys*s).tw,kw. (126481)
90 or/76-89 (2051706)
91 75 and 90 (1200)
92 Case Report/ or Comment/ or Editorial/ or Letter/ or conference abstract.pt. (10004162)
93 91 not 92 (987)
94 (exp animal/ or nonhuman/) not exp human/ (10044781)
95 93 not 94 (986)
96 limit 95 to english language [Limit not valid in CDSR; records were retained] (917)
97 96 use emez (377)
98 48 or 97 (836)
99 98 use medall (319)
100 98 use coch (2)
101 98 use cctr (131)
102 98 use clhta (1)
103 98 use cleed (6)
104 98 use emez (377)
105 remove duplicates from 98 (542)

**CINAHL**

| # | Query | Results |
|---|---|---|
| S1 | (MM "Cerebral Ischemia+") | 11,177 |
| S2 | (MM "Intracranial Hemorrhage+") | 8,701 |
| S3 | (MM "Stroke+") | 43,389 |
| S4 | (MH "Stroke+/RH") | 10,211 |
| S5 | TI(stroke* OR poststroke OR CVA OR CVAs) | 45,403 |
| S6 | TI((cerebrovascular OR cerebro vascular OR cerebral vascular) N2 (apoplex* OR accident* OR infarct*)) | 382 |
| S7 | TI((brain OR cerebral OR intracerebral OR arachnoid OR subarachnoid OR intracranial OR cranial) N2 (infarct* OR ischemi* OR ischaemi* OR hemorrhag* OR haemorrhag*)) | 8,459 |
| S8 | ((post acute or postacute or chronic) N5 (stroke* or poststroke)) | 3,214 |
| S9 | ((post acute OR postacute OR chronic) N5 (hemipare* OR paretic OR paresis OR phase OR phases OR stage OR stages OR state OR states OR condition OR paraly* OR spastic*)) AND stroke* | 1,501 |
| S10 | S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 | 70,278 |
| S11 | (MH "Physical Therapy") | 30,188 |
| S12 | (MH "Constraint-Induced Therapy") | 602 |

| | | |
|---|---|---|
| S13 | (MH "Electrotherapy+") | 18,651 |
| S14 | (MH "Functional Training") | 909 |
| S15 | (MH "Gait Training+") | 1,713 |
| S16 | (MH "Home Physical Therapy") | 421 |
| S17 | (MH "Therapeutic Exercise") | 19,285 |
| S18 | (MH "Aerobic Exercises+") | 35,254 |
| S19 | (MH "Muscle Strengthening") | 11,833 |
| S20 | physiotherap* OR physio therap* OR CIMT OR mCIMT OR FES OR NMES | 21,334 |
| S21 | electric* N3 stimulation | 14,805 |
| S22 | ((movement OR mobility OR mobilization OR mobilisation OR physical OR fitness OR exercise OR treadmill* OR upper limb* OR lower limb* OR upper extremit* OR lower extremit* OR balance OR gait OR strength OR strengthening OR aerobic* OR cardiovascular OR cardio vascular OR task specific OR task oriented OR taskoriented OR dual task OR dualtask OR bilateral) N2 (training OR retraining OR program* OR therap* OR rehabilitation)) | 114,986 |
| S23 | (MH "Exercise+") | 92,524 |
| S24 | training OR retraining OR program* OR therap* OR rehabilitation | 1,819,547 |
| S25 | S23 AND S24 | 45,682 |
| S26 | S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S25 | 186,763 |
| S27 | S10 AND S26 | 7,822 |
| S28 | (MH "Economics") | 11,957 |
| S29 | (MH "Economic Aspects of Illness") | 7,744 |
| S30 | (MH "Economic Value of Life") | 557 |
| S31 | MH "Economics, Dental" | 115 |
| S32 | MH "Economics, Pharmaceutical" | 1,914 |
| S33 | MW "ec" | 154,194 |
| S34 | (econom* or price or prices or pricing or priced or discount* or expenditure* or budget* or pharmacoeconomic* or pharmaco-economic*) | 242,153 |
| S35 | (MH "Costs and Cost Analysis+") | 96,140 |
| S36 | TI cost* | 44,559 |

| | | |
|---|---|---|
| S37 | (cost effective*) | 33,094 |
| S38 | AB (cost* N2 (util* or efficacy* or benefit* or minimi* or analy* or saving* or estimate* or allocation or control or sharing or instrument* or technolog*)) | 25,017 |
| S39 | (decision N1 (tree* or analy* or model*)) | 6,394 |
| S40 | (markov or markow or monte carlo) | 4,480 |
| S41 | (MH "Quality-Adjusted Life Years") | 3,547 |
| S42 | (QOLY or QOLYs or HRQOL or HRQOLs or QALY or QALYs or QALE or QALEs) | 8,703 |
| S43 | ((adjusted N1 (quality or life)) or (willing* N2 pay) or sensitivity analys?s) | 13,703 |
| S44 | S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 | 325,525 |
| S45 | S27 AND S44 | 314 |
| S46 | PT (Case Study or Commentary or Editorial or Letter or Proceedings) | 924,565 |
| S47 | S45 NOT S46 | 296 |
| S48 | (MH "Animals+") NOT (MH "Animals+" AND MH "Human") | 69,733 |
| S49 | S47 NOT S48 | 296 |
| S50 | S47 NOT S48<br>Limiters - English Language | 293 |

## *Grey Literature Search*

**Performed:** October 11–November 6, 2018

**Websites searched:**
HTA Database Canadian Repository, Alberta Health Technologies Decision Process reviews, BC Health Technology Assessments, Canadian Agency for Drugs and Technologies in Health (CADTH), Institut national d'excellence en santé et en services sociaux (INESSS), Institute of Health Economics (IHE), Laval University, McGill University Health Centre Health Technology Assessment Unit, National Institute for Health and Care Excellence (NICE), Agency for Healthcare Research and Quality (AHRQ) Evidence-based Practice Centers, Australian Government Medical Services Advisory Committee, Queensland Health Technology Evaluation, Centers for Medicare & Medicaid Services Technology Assessments, Institute for Clinical and Economic Review, Healthcare Improvement Scotland, Ireland Health Information and Quality Authority Health Technology Assessments, Washington State Health Care Authority Health Technology Reviews, ClinicalTrials.gov, PROSPERO, EUnetHTA, Tuft's Cost-Effectiveness Analysis Registry

**Keywords used:** stroke, physiotherapy, physio therapy, physical therapy, rehabilitation, timing, duration, long term, longterm, prolonged

**Results (included in PRISMA):** 5

**Ongoing clinical trials (ClinicalTrials.gov):** 14

**Ongoing HTAs (PROSPERO/EUnetHTA):** 3

## Appendix 2: Selected Excluded Studies—Clinical Evidence

For transparency, we provide a list of studies that readers might have expected to see but that did not meet the inclusion criteria, along with the primary reason for exclusion.

| Citation | Primary Reason for Exclusion |
|---|---|
| Veerbeek JM, Van Wegen E, Van Peppen R, Van Der Wees PJ, Hendriks E, Rietberg M, et al. What is the evidence for physical therapy poststroke? A systematic review and meta-analysis. PloS One. 2014;9(2). | People included in this study were not on continual physiotherapy |
| McIntyre A, Viana R, Janzen S, Mehta S, Pereira S, Teasell R. Systematic review and meta-analysis of constraint-induced movement therapy in the hemiparetic upper extremity more than six months post stroke. Top Stroke Rehabil. 2012;19(6):499-513. | People included in this study were not on continual physiotherapy |
| Salbach NM, Mayo NE, Wood-Dauphinee S, Hanley JA, Richards CL, Cote R. A task-orientated intervention enhances walking distance and speed in the first year post stroke: a randomized controlled trial. Clin Rehabil. 2004;18(5):509-19. | People included in this study were not on continual physiotherapy |
| Caliandro P, Celletti C, Padua L, Minciotti I, Russo G, Granata G, et al. Focal muscle vibration in the treatment of upper limb spasticity: a pilot randomized controlled trial in patients with chronic stroke. Arch Phys Med Rehabil. 2012:93(9):1656-61. | People included in this study were not on continual physiotherapy |
| Lohse KR, Lang CE, Boyd LA. Is more better? Using metadata to explore dose-response relationships in stroke rehabilitation. Stroke. 2014;45(7):2053-58. | People included in this study were not on continual physiotherapy |
| Ferrarello F, Baccini M, Rinaldi LA, Cavallini MC, Mossello E, Masotti G, et al. Efficacy of physiotherapy interventions late after stroke: a meta-analysis. J Neurol Neurosurg Psychiatry. 2011;82(2):136-43. | People included in this study were not on continual physiotherapy |
| Wolf SL, Thompson PA, Winstein CJ, Miller JP, Blanton SR, Nichols-Larsen DS, et al. The EXCITE stroke trial: comparing early and delayed constraint-induced movement therapy. Stroke. 2010;41(10):2309-15. | People included in this study were not on continual physiotherapy |
| Nadeau SE, Wu SS, Dobkin BH, Azen SP, Rose DK, Tilson JK, et al. Effects of task-specific and impairment-based training compared with usual care on functional walking ability after inpatient stroke rehabilitation: LEAPS trial. Neurorehabil Neural Repair. 2013;27(4):370-80. | People in the three arms of the trial had physiotherapy as part of usual care |
| Chervyakov AV, Poydasheva AG, Lyukmanov RH, Suponeva NA, Chernikova LA, Piradov MA, et al. Effects of navigated repetitive transcranial magnetic stimulation after stroke. J Clin Neurophysiol. 2018;35(2):166-72. | People included in this study were not on continual physiotherapy |
| Chaiyawat P, Kulkantrakorn K. Effectiveness of home rehabilitation program for ischemic stroke upon disability and quality of life: a randomized controlled trial. Clin Neurol Neurosurg. 2012;114(7):866-70. | People included in this study were not on continual physiotherapy |
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## Appendix 3: Letter of Information[b]

**LETTER OF INFORMATION**

Health Quality Ontario is conducting a review of **Long-Term Physiotherapy** for people who have had a stroke. The purpose is to understand whether this type of physiotherapy should be publicly funded in Ontario.

An important part of this review involves gathering perspectives of patients and caregivers with experience with physiotherapy for up to 3 months, between 3-6 months or more than 6 months after stroke. They could be receiving or have received physiotherapy, either recently or in the past, and people who could be considering it in the future.

### WHAT DO YOU NEED FROM ME

- ✓ Willingness to share your story
- ✓ 30 minutes of your time for a telephone conversation
- ✓ Permission to audio- (not video-) record the interview

### WHAT YOUR PARTICIPATION INVOLVES

If you agree to share your experiences, you will be asked to have an interview with Health Quality Ontario staff. The interview will last about 30 minutes. It will be held over the telephone. With your permission, the interview will be audio-recorded. The interviewer will ask you questions about your or your loved one's condition and your perspectives about treatment options in Ontario.

Participation is voluntary. You may refuse to participate, refuse to answer any questions or withdraw before or at any point during your interview. Withdrawal will in no way affect the care you receive.

### CONFIDENTIALITY

All information you share will be kept confidential and your privacy will be protected except as required by law. The results of this review will be published, however no identifying information will be released or published. Any records containing information from your interview will be stored securely until project completion. After the project completion, the records will be destroyed.

### RISKS TO PARTICIPATION

There are no known physical risks to participating. Some participants may experience discomfort or anxiety after speaking about their experience.

### IF YOU ARE INTERESTED, PLEASE CONTACT US BEFORE JANUARY 31ST, 2019:

[b] Health Quality Ontario is now the Quality business unit at Ontario Health.

# Appendix 4: Interview Guide

*Interview Questions for Continual Long-Term Post-Stroke Physiotherapy*

## Introduction

Health Quality Ontario[c] is a provincial advisor to the Ministry of Health. We do a few things for the Ministry, but one of the roles that we have is to conduct health technology assessments, which look at new technologies and new health services. We review these technologies and health services to help determine whether they should be considered for public funding. If any of the questions seem to cause a little emotional distress or discomfort, please let me know, and you can feel free to either not answer the question or say as little as you like.

### History of condition (stroke)

- What kind of stroke did you have?

### Experience with condition (stroke)

- What was the experience like in the hospital?
- How long were you in the hospital? When were you discharged?
- When did you receive physiotherapy in the hospital and for how long?
- What type of physiotherapy did you receive? (Please describe any exercises you did.)
- What were the benefits of receiving physiotherapy?
- What were the limitations and barriers to receiving physiotherapy?

**Lived experience with stroke. These questions relate to the time between receiving physiotherapy at the hospital or other facility and coming back home after the stroke. If you are a caregiver, please answer these questions from your own perspective.**

- How was your day-to-day routine?
- What has been the impact and effect on quality of life?
- Did you see any loss of independence?
- Did it have an impact on your loved one, work, friends? After stroke?
- If you worked before caring for someone who was diagnosed with a stroke, did it impact your ability to work?

**Lived experience of continual long-term physiotherapy. These questions relate to the time after in-hospital (acute-stage) physiotherapy. Please try to provide details of the time frame of receiving physiotherapy. If you are not receiving physiotherapy, please use the first three questions below to speak about your experience with currently available methods—this includes any free-of-cost community program that you are part of—before proceeding to "Currently available methods."**

- How is your day-to-day routine now?

[c] Health Quality Ontario is now the Quality business unit at Ontario Health.

- What has been the impact and effect on quality of life over the past few months or years?
- Did you see any sort of loss of independence? Or are you more independent now?
- When did you start having physiotherapy after you had come back home? Was it immediately after being released from the hospital or was it a few months after?
- Where did you receive physiotherapy (e.g., rehab hospital as an inpatient, hospital outpatient/ambulatory programs, long-term care homes, interdisciplinary primary care setting, or through region-funded home and community care services provided in your home)?
- What type of physiotherapy did you receive? (Please describe any exercises you have done and are doing now.)
- What was the impact of the physiotherapy? How long did you receive it for? Or how long do you think you would like to receive it for?
- What were the benefits?
- What were the limitations and barriers?
- Did your physiotherapist/doctor think you needed more?
    - If yes, and you did not continue receiving physiotherapy, why didn't you get more? What were the barriers preventing you from getting more?
- How did you deal with your symptoms if not with physio?
    - Was this helpful?
- In your opinion, what are the potential benefits and risks of the different treatments?
- Was it difficult to weigh potential risks/benefits with the type of treatment?
- Caregivers (please fill this in only if you are a caregiver): What was it like caring for someone who has had a stroke (physical, emotional, social, and other impacts)?
- What impact did the physiotherapy have on the person you were caring for? Did the physiotherapy affect you in any way?

**Currently available methods; this includes any free-of-cost community programs that you are part of. Please make sure to describe the type of activities you are currently doing.**

- Do you receive any other type of therapy? Please explain.
- Are you part of any community exercise or other programs? Please explain.
- Is it meeting your needs to improve function or other physical abilities?
- What has been the impact of receiving/not receiving physiotherapy on your quality of life?
- Have you noticed a loss or gain of independence since you received/did not receive physiotherapy?
- What are your limitations and barriers of not receiving physiotherapy?
- Were there issues related to cost, access, knowledge of health care system, etc.?

**Barriers/challenges to receiving physiotherapy or attending an exercise program in the community or any other facility**

- Did you face any sort of barrier in terms of distance of travel? Accessibility of any services?

**Additional question: Receiving physiotherapy**

- We would like to know what kind of care you want to receive. Below is a list of options that you may choose from.

  - At home with the support of a physiotherapist
  - At a clinic
  - Any resource that includes exercises
  - Phone support
  - Virtual learning, following exercises on a computer

- Please indicate below why you would like to receive this type of physiotherapy.

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# About Us

This health technology assessment was produced by the Quality business unit at Ontario Health, the government agency that when fully established will be responsible for ensuring all Ontarians receive high-quality health care where and when they need it.

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