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Nominal group technique to establish the core components of home-based rehabilitation for survivors of stroke with severe disability

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ABSTRACT

In the UK, over 20% of patients leaving hospital after a stroke will be severely disabled. Despite this, limited clinical guidance is available to teams tasked with providing support for this complex population at home. Additionally, many areas across the UK are not commissioned to treat this patient cohort, leaving them with no specialist support on discharge.

Objectives To establish core components of home-based rehabilitation for survivors of stroke with severe disability, based on expert panel consensus.

Setting Virtual nominal group technique (vNGT) across the UK.

Participants Experts in the field of stroke rehabilitation (n=14) including researchers, clinicians and those with lived experience.

Methods Two vNGT were completed using a freely available online platform, Microsoft Teams. The technique's five stages were completed virtually; introduction, silent idea generation, round robin, clarifications and scoring. Statements were analysed for consensus, those achieving consensus underwent content analysis to form rich overarching consensus statements.

Results A combined total of 421 statements achieved positive consensus (>75% in agreement), which formed 11 overarching consensus statements. These outline key components of home-based rehabilitation for survivors of stroke with severe disability including the structure and members of the team, as well as the skills and knowledge required.

Conclusion The consensus statements highlight the complexity of managing patients with severe stroke disability following discharge from hospital. This study has the potential to support the provision of services for this patient group, providing a benchmark for commissioners and clinicians as well as setting expectations for stroke survivors and their carers. What remains unknown is how many services currently offer this service to patients with severe disability.

Strengths and limitations of this study

- This is the first study to determine the key components of home-based rehabilitation for survivors of stroke with severe disability.
- Participating panelists represented the multidisciplinary team with highly experienced experts, both clinically and academic.
- Lay expert input in the round-robin stage, giving the opportunities for lived experience to be represented.
- A limitation of nominal group technique is the reliance upon small numbers, however, there was substantial convergence between the two panels, suggesting replicability amongst differing panels.

INTRODUCTION

Stroke remains the leading cause of disability in the UK.[1 2] Although the establishment of organised stroke units and recent medical interventions (eg, thrombolysis and thrombectomy) have reduced mortality rates, stroke survivors can be left with a number of impairments. These can affect motor, sensory, vision, language and cognition function, therefore, support for recovery to promote quality of life beyond survival also needs to be considered.[3 4] Comprehensive guidance exists for the rehabilitation of the stroke population in the community, however, the studies on which recommendations were based involve more abled stroke survivors, who meet the criteria for early support discharge (ESD).[5–7] There is a lack of evidence for more severely disabled stroke survivors, who are ineligible for these services, leading to substantial disparities in provision across the UK.[5 8]

Over 20% of patients were discharged from hospitals in the UK last year with severe disability, equating to approximately 20 000 lives irrevocably changed.[8 9] These individuals are commonly unable to stand without assistance and may have additional cognitive and communicative impairments combined with any pre-existing comorbidities, leading to a significant loss of independence.[10] While defining severity of stroke and disability can be complex, the modified Rankin scale (a score of 4 or 5) is an established measure used in research and practice and it was these criteria that were used to define the population of focus in the current study.[11]

Within the community setting this population often have a complex presentation with high rates of readmission and secondary complications leading to challenges with their management.[12] Previous research within the severely disabled stroke population has suggested that within the first 12 months following discharge, as many as 73% of stroke survivors with severe disability will experience a fall, 60% contractures and 55% pain.[13] Rigby *et al*[14] also found a significant correlation between disability severity and carer burden, which is attributed to serious health consequences for both carer and stroke survivor.[14] An eightfold increase in rates of institutionalisation following hospital admission compared with their less severe counterparts has also been reported.[15]

Rehabilitation in the community setting is a complex intervention, and as such, difficult to evaluate in order to generate robust recommendations. This is made more difficult due to the varied needs of such a heterogeneous population.[16] A recent systematic review of rehabilitation interventions for severely disabled stroke survivors in the hospital setting concluded there to be a paucity of high-quality research. However, much less research exists for this population in the community setting with authors again citing challenges associated with the population's heterogeneity.[17] A large phase III randomised controlled study reported neutral results when investigating the effects of a 3-month occupational therapy (OT) intervention in care homes.[18] The study alluded to challenges in engaging in therapy for individuals with such high levels of disability.

Guideline development is reliant on high-quality evidence on which to base recommendations.[19] Where gaps or poor evidence exist, structured consensus techniques using a panel of 'experts' has been advocated by the National Institute for Health and Care Excellence with the two most common being the nominal group technique (NGT) and Delphi method.[19] It is argued that the output of these methods has the potential to provide more in-depth and nuanced guidance which has greater utility in practice.[19] Previous research has achieved consensus on the core components of ESD and community stroke rehabilitation services for less disabled stroke survivors.[6 20] Improving stroke care in the community setting is a national priority, it is therefore paramount that guidance is available to inform provision of services for this so far neglected population group.[21 22]

This study is the first to determine expert consensus regarding key components of home-based rehabilitation for survivors of stroke with severe disability. The output of this consensus activity aims to support the provision of services for this population, informing commissioners and clinicians as well as setting expectations for patients and their carers. Therefore, the aim of this study was to establish the core components of community stroke rehabilitation delivered within the UK National Health Service (NHS) for survivors of stroke with severe disability, based on expert panel consensus.

METHODS

Design

The virtual NGT (vNGT) was used. This technique was specifically chosen over the Delphi technique due to its superior ability to inform areas where there is a dearth of pre-existing research.[23] Equally, NGT has been reported to create rich data owing to the face-to-face element creating a stimulating and elaborative environment.[23] This technique has also be used successfully within a similar population group.[24]

Participants

Panel members are known leaders in the field of stroke rehabilitation and were purposefully sampled through established clinical and academic networks to gain multidisciplinary representation from clinical, research and lay member groups.[25] Among the clinical and academic participants the following criteria were used to ensure sufficient specialism and skills, conforming to the notion of 'expert': over 10-years clinical or research experience within stroke rehabilitation with additional experience with the severe stroke population, understanding of the NHS, geographical representation of the UK and stroke multidisciplinary team (MDT) representation as documented in previous research.[26] Potential participants were approached via email.

Expertise from those with lived experience was sought from a stroke survivor and a spouse of a stroke survivor who were members of a Stroke Research Partnership group. On request, these participants met researchers prior to the panel meeting and generated a list of ideas associated with the nominal group questions. These were subsequently presented by the facilitator during the round robin phase (stage 3).

Research questions

The panels were asked to provide responses to the following questions:

> Question 1: 'From an organisational perspective, what should a rehabilitation service for survivors with severe stroke disability include in terms of structure, service delivery and outcome measures?'
>
> Question 2: 'From an intervention perspective, what treatments / techniques should be implemented in order to effectively rehabilitate this cohort of patients?'

Protocol

The NGT protocol used was Potter *et al*'s[27] adaption of the original which included five stages: introduction, silent idea generation, 'round robin', clarifications and scoring.[28] These were completed on a virtual basis using an online platform (Microsoft Teams) ensuring all methodological standards were maintained.[25]

As recommended in the literature, prior to the groups convening, preliminary information was sent to all panel members in the form of an e-booklet (online supplemental file 1). This comprised a scoping literature review, patient and carer experiences, a context statement, the vNGT questions and guidance on the process of the vNGT. The scoping literature review explored the evidence surrounding the rehabilitation interventions of severely disabled stroke survivors in the community following discharge from hospital. Papers were reviewed and synthesised by researchers LR and FR-B and presented into a summary table of evidence. Patient and carer experiences were presented as a word cloud which provides a visual representation of the experiences proffered from a Stroke Research Partnership patient and public involvement (PPI) group. The context statement, considered an important component within consensus generation, was produced by the research and collaborator teams, to set the scene from which participants were asked to base their ideas.[25] This included a definition of the study population, survivors of stroke with severe disability, defined as a modified Rankin scale of 4 or 5, in the immediate period postdischarge from inpatient rehabilitation.[11] The setting was defined as home-based rehabilitation (including nursing and residential settings) within the UK NHS.

The same vNGT process proceeded as follows for the two panels:

Stage 1. Introduction: An online presentation was completed with panel members, detailing the vNGT process, and restating the context in which to base ideas and the vNGT questions for deliberation. This also provided the opportunity for any questions or clarifications.

Stage 2. Silent idea generation: Panel members were provided approximately 15 min per question (during which participant microphones and video functions were turned off), and facilitators were available via the platform's chat function to answer any questions. To help organise the ideas generated, a list of domains (table 1) was displayed on screen alongside a 15 min timer. Domains were used to help organise responses during the round robin. These were informed by literature optimising patient follow-up following stroke.[29] It was made clear that domains were to be used for organisation of ideas and not intended to restrict responses and panel members were encouraged to respond freely.

Table 1 Domains used to help organise ideas

Question 1	Question 2
Team composition	Therapy
Time frames	Pain and spasticity
Outcome measures	Home environment and family and carer support
Communication	Skin and continence
Eligibility criteria	Mood, anxiety, sleep and relationships
Audit and reporting	Specialist seating and wheelchairs
Other	Other

Stage 3. Round Robin: With video and microphones enabled, a member of the research team (FR-B) facilitated each panel member to offer a single idea, in turn, in response to question 1. This process continued until all the ideas were exhausted before progressing on to question 2. During this process within panel 1, the facilitator presented the ideas generated previously by the lay experts, in turn with other participants. All ideas were typed by a second researcher (LR) on to a live document, based on the domains shared previously, visible to all members in real-time, through screen sharing.[30]

Stage 4. Clarification stage: This was facilitated domain by domain and idea by idea and included each participant in turn. The meeting concluded when all panel members were satisfied that there were no outstanding queries.

Stage 5. Individual scoring: Prior to sharing with the panel members, the previously live document was formatted, converting ideas into single statements for participants to rate by FR-B. It was ensured that the manifest content of the participants' ideas was maintained throughout through utilisation of their original words, these were subsequently checked by LR. An online questionnaire was sent to the participants within 72 hours following the online meeting.[31] In line with previous research,[25] a 9-point Likert scale was used from not important/do not agree (1) to important/strongly agree (9) for panel members to vote on generated statements.[27]

Analysis

This process is represented in figure 1, for further details refer to online supplemental file 2.

Establishing consensus

The scoring responses from the online questionnaire, for participants included in each of the two panels, were exported to Microsoft Excel to analyse for consensus. The level of agreement was set as 75% of all participants within the set ranges, 1–3, 4–6 and 7–9 not important, equivocal and important, respectively.[25] In the case of strong disagreement, defined as one panel member scoring 1 and another 9, outliers were removed, and the remainder reviewed for consensus.[25] The median and interquartile range for each individual statement and all statements which reached consensus were calculated to highlight dispersion around the consensus.[25]

Qualitative content analysis

Content analysis was used to distill the key categories from each panel to review commonalities and discordance between ideas generated by the two panels and to determine the salient core categories[32] (online supplemental file 3). This started with the familiarisation of the statements which reached consensus, followed by the primary coding (by researcher FR-B) and secondary coding (by researchers FR-B and LR) using tree nodes

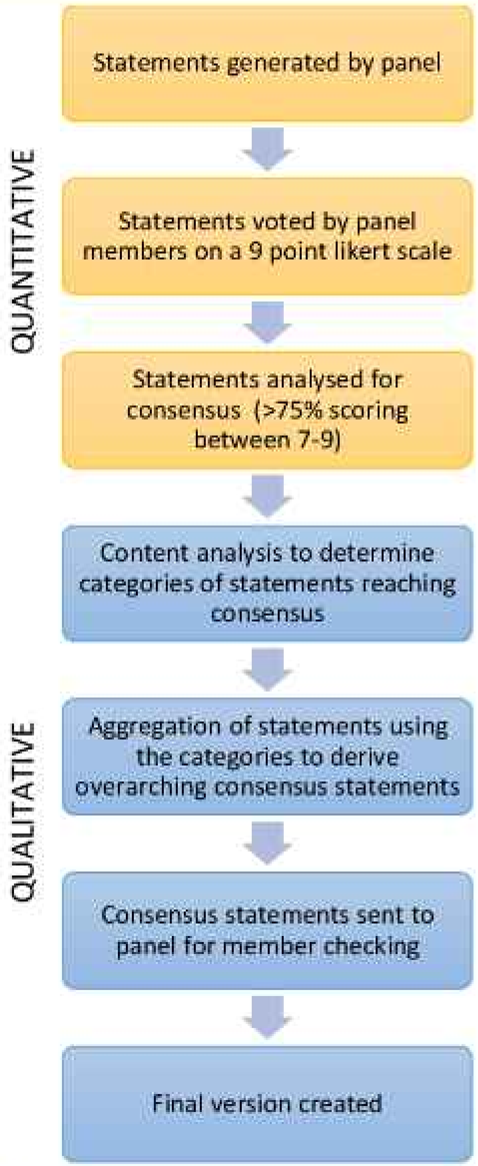

Figure 1 Representation of the analysis process.

(parent and child) in NVivo V.12 pro.[33] Both coders are clinical academic physiotherapists with a minimum of 8 years clinical experience working across the stroke pathway, including community rehabilitation. A combination of inductive and deductive coding was used, the deductive component resulting from the use of the domains (table 1). This initial secondary coding framework was presented to the wider research team for review. Following feedback, the initial secondary coding went through an iterative process of revision and reorganisation.[34] The second-order category codes were used to create a framework for aggregating the single statements (from each of the two panels) into larger overarching consensus statements (generated across both panels).

Individual statements associated with these categories were aggregated by a single researcher (LR) before iterative cycles of review by both researchers (LR and FR-B). Reorganisation of consensus statements occurred between the domains of question 1 and 2 to reduce repetition and aid clarity for the reader. No differential weighting was given to individual panel members.[25] Decisions were made to exclude any statements that fell outside the scope of the original question and condensed where the level of detail was deemed too great to aggregate.

Once finalised, the overarching consensus statements were the final summary of the views of both panels and were returned to the panel members for member-checking. This ensured the statements reflected the raw data, this included minor phrasing and ordering, no additions were made to the manifest content.[35]

Patient and public involvement

The Nottingham Stroke Research Partnership PPI group were involved in the design and conduct of this research and have been instrumental in the agreement of adaptions as a result of the COVID-19 pandemic. This included contributing to the e-booklet for the panel members. The lay members participated in the idea generation stage of the nominal group, providing a rich lived-experience.

FINDINGS

Participant characteristics

Twelve clinicians and academics confirmed they satisfied the inclusion criteria and consented to participate in a virtual nominal group. In total, two nominal groups were completed, each consisting of six synchronous expert panel members, with additional non-synchronous input from two lay members during panel 1. A range of disciplines were recruited, included physiotherapists (n=3), occupational therapists (n=3), speech and language therapist (n=1), nurses (n=2), physician (n=1), psychologist (n=1) and rehabilitation assistant (n=1).

Although efforts were made to balance the panels, ultimately there were differences based on individual availabilities (table 2).

Data were collected on two separate days, approximately 1 month apart, with each session lasting between 3 and 3.5 hours.

Table 2 Characteristics of members in each panel

Panel 1	Panel 2
Clinical occupational therapist	Academic neuropsychologist
Clinical academic physiotherapist	Academic physiotherapist
Clinical academic physiotherapist	Stroke consultant physician
Clinical rehabilitation assistant	Clinical academic nurse
Clinical speech and language therapist	Clinical nurse
Clinical occupational therapist	Clinical occupational therapist

Table 3 Categories determined during content analysis of ideas and generated statements

Categories		
First order	Second order	Third order
Organisation	Core MDT	
	Eligibility and focus of input	Eligibility
		Focus of input
	Cross organisational working	Accessing
		Collaborating with
		Seamless transitions
	Service structure	
	Communication	Patient communication
		Communication with other teams/services
	Clinical audit	
	Research involvement†	
Intervention	Education	Carer and patient education
		Care home education*
		Education of MDT and wider teams†
	Goal setting	
	MDT skills	
	Specific assessments and intervention	Pain and spasticity
		Psychology
		Equipment and environment
		Fatigue management
		Carer support*
		Seating and posture
		Skin and continence
		Dose and structure†
		Other
	Outcome measures	General points
		Specific measures
	Using evidence-based practice†	

*Were only present within panel 1.
†Within panel 2, full table available from lead author.
MDT, multidisciplinary team.

Consensus

A total of 492 statements were generated from ideas presented in the round robin stage (n=196and n=296 panels 1 and 2, respectively), with 421 statements (n=183and n=238) reaching consensus (>75% agreement). The overall score of those reaching consensus was median 9 and IRQ 1, for both panels. Ideas from panel 1 generated fewer statements (196 vs 296, panels 1 and 2, respectively), however, agreement was greater with fewer statements lost to non-consensus (7% vs 20%) as well as fewer instances of disagreement compared with the second group (2% vs 8%).

Qualitative content analysis

Two overarching categories were distilled from ideas and statements generated in both panels: organisation and intervention (table 3). These corresponded with the questions posed in the nominal group session, the former focusing on the components of the service and the latter with the content delivered. Under the first-order category of organisation 8 second-order categories were identified, 7 of which were the same across the two panels, with actively engaged in research only generated in panel 1. Similarly, under the first order category of intervention there were five common second order categories, with only evidence-based practice unique to the first panel group. While there was considerable overlap in content, differences between ideas and then statements generated between the two panels were also anticipated due to differences in group composition. The areas of convergence were summarised in the form of the consensus statements (table 4). While there were few areas of disagreement, there were areas of divergence of focus and these will now be discussed in further detail.

Areas of divergence

The importance of a seamless transition between inpatient and community stroke services was highlighted by both panels. Panel 2 went a step further, raising the concept of prehospital discharge involvement, ensuring the team are not only operational prior to discharge but actively inputting into discharge communication and decision making.

> There should be a discharge planning meeting with the community team, ward staff and family prior to discharge. Panel 2

Panel 1 raised the notion of 'patient-centred rehabilitation', suggesting that all aspects of the service and intervention should be related to the needs of that individual.

> Therapist should think more 'patient-need' orientated, being creative in their response to what they need. Panel 1

Despite the focus on close working with patients, panel 1 did not specifically mention therapeutic relationships between the patient or carer and the rehabilitation team. In contrast, panel 2 emphasised 'The service should create and provide a long-term relationship with family members.' acknowledging the long-term nature of their involvement.

When discussing communication between teams and patients, Panel 1 placed a greater emphasis on cross organisational elements, including patient held records and the use of a coordinated electronic base system.

Interestingly, neither research nor evidence-based practice were mentioned by panel 2, which included more academics. These areas reached consensus within panel 1, highlighting the importance of research in practice and suggesting that professions should challenge those who do not follow evidence-based practice.

> It is important to create and embed research into daily clinical practice Panel 1

Areas of discordance

The service structure was a dominant second order category within both panels, however, there was some discordance. Panel 2 suggested:

> The team should form part of an integrated specialist stroke service delivered by the same team that deliver Early Supported Discharge. Panel 2

Conversely, panel 1 suggests there should not be a distinction between the two, instead opening up the Early Supported Discharge service to all stroke patients.

> Early supported discharge teams should be available consistently across the country for all severe stroke, not limited to more able stroke survivors. Panel 1

The topic of inputting into national audits, in this case the Sentinel Stroke National Audit Programme (SSNAP) provoked strong responses from panel 1 reporting they felt 'SSNAP currently doesn't reflect community or [the] longer term aspect of stroke recovery'. In contrast, panel 2 emphasised the importance of contributing to the audit. Both panels made suggestions for the collection of additional metrics to demonstrate functional change in the population and service delivery, such as social care requirements (panel 1), unmet needs, hospital readmission, 90-day mortality, care home admission and return to home incidences (panel 2).

An additional point concerned 7-day working, with both panels agreeing that this should be in place, yet disagreement around who should be providing this.

> Support workers should be used to provide personalised care and offer weekend input Panel 1
>
> The team should have the ability to provide a seven day service if appropriate and acceptable to the stroke survivor and family. Panel 2

The panels adopted divergent approaches, with Panel 2 taking a more prescriptive approach than panel 1 who suggested a more needs-led approach.

> The patient should have a post discharge visit within 1 week to assess needs Panel 2
>
> Services should provide flexibility of input intensity and dose related to goal of task for example, time to settle once home, starting at specific point appropriate to their needs. Panel 1

Consensus statements

Eleven overarching consensus statements were formed using the second-order categories headings. Areas of divergence or discordance were resolved by the research team, referring to raw data where possible. These were then sent out to the panel for member-checking, with minor phrasing and ordering adaptations only, no changes were made to the manifest content. This resulted in the final version of consensus statements presented in table 4, a summarised infographic can be found in online supplemental file 4.

DISCUSSION

This study generated consensus statements defining the key components of home-based rehabilitation for survivors of stroke with severe disability. This is the first step in providing much needed guidance to support the provision of services, informing commissioners and clinicians as well as setting expectations for stroke survivors and their carers. A total of 421 statements derived from the vNGT process reached consensus identifying a breath of rehabilitation needs for this population, from restorative rehabilitation to end-of-life care and carer burden, with high levels of convergence between the two panels. These were distilled into 11 overarching consensus statements,

Table 4 The core components for the organisation of home-based rehabilitation for survivors of stroke with severe disability

1. Organisation

1.1 Core multidisciplinary team (MDT)

The MDT should consist of:

- Occupational Therapist
- Physiotherapist
- Psychologist
- Nurse
- Rehabilitation support worker/assistant practitioner
- Social care worker
- Dietician
- Speech and Language Therapist
- Administrative support
- Doctor

1.2 Service eligibility criteria

Individuals are eligible if they have:

- A diagnosis of stroke
- A modified Rankin score of 4 or above
- An identified stroke related need

Referrals into the service are not restricted:

- To healthcare professionals
- By time since stroke
- To patient's residence

Teams should have a broad focus, considering both restorative and compensatory approaches where appropriate to help patient and their carers:

- Participate in rehabilitation
- Maximise their quality of life and participation in leisure activities
- Manage their disability
- Prevent secondary complications
- Reduce carer burden

1.3 Service Structure

The MDT should:

- Form part of an integrated specialist stroke service that also delivers early support discharge (ESD).
- Complete an initial holistic assessment within 1 week of discharge from hospital
- Work in a coordinated manner, across disciplines and with established staffing ratios, in line with recognised ESD recommendations to provide rehabilitation over 7 days (Link to guidance[23])
- Work flexibly in response to patient need including episodes of input focussing on achieving a specific patient goal, or facilitating carer involvement and self-practice, to reach the desired level of intensity.
- Provide the opportunity for patients to receive five stroke specific sessions, 5 days a week, if deemed appropriate.
- Provide length of input related to patient rehabilitation needs and goals; initial input available for minimum of 6 months, where appropriate, with the potential for rereferral if required.
- Have strong leadership and weekly team meetings to review patient goals.
- Support staff through the use of a debriefing system.

1.4 Working across organisations

Teams should in-reach into acute trusts to proactively support the discharge process and providing continuity of care, such as, joint home visits, involvement in discharge planning meetings, making contact with the inpatient MDT, patients and carers prior to discharge, to support a seamless transition from inpatients to community.

Collaborate with:

- Care homes
- GPs
- Specialist teams such as tissue viability and palliative care services
- Social care and continuing health
- Community matron
- Voluntary agencies, for example, stroke association

Support patient and carers to access:

- Exercise groups and gyms
- Accessible transport
- Life after stroke, patient and carer support

1.5 Communication

Contact should be made with patient, or if applicable with family or carers within one working day of discharge from acute hospital. Contact details for team members should be available for patients, families and carers. Communication should be:

- Clear and transparent, in an accessible format for all patients, carers and healthcare professionals.
- Coordinated and timely between the MDT, other agencies and services, patients and their carers (including care home staff).

1.6 Audit

Teams should participate in the Sentinel Stroke National Audit Programme as well as other clinically relevant audit to inform clinical practice and regional commissioning of services.

Additional data captured could include:

- Unmet needs
- 90-day mortality
- Hospital readmissions (within 30 days)
- Social care requirements

Continued

Table 4 Continued

1.7 Research

Teams should be actively engaged in research, supporting patient enrolment and public and patient involvement throughout the process. Healthcare professionals should be leading research, disseminating findings and implementing them into clinical practice. This includes the sharing of case studies to demonstrate patient outcomes.

2. Intervention

2.1 Specific Interventions and MDT Skills

The MDT should have the knowledge and expertise to anticipate need for this patient group and in managing and preventing secondary complications. In addition to current national recommendations for the wider stroke population, the MDT should be able to offer the following specialist assessments and interventions specific to the needs of this patient group:

- Spasticity
- Pain
- Mobility transfers, including vehicle access
- Postural support and seating
- Skin integrity and continence
- Environment including adaptation and equipment
- Carer burden
- Activities of daily living including basic self-care tasks
- Cognition including apraxia
- Communication, including access to computer software
- Fatigue and sleep hygiene
- Mood disorders
- Sexual activity and relationships
- Upper limb impairments
- Medication management
- Financial guidance
- End of life care

The MDT should have sufficient training to recognise psychological problems (patient and carer), escalating when required, to ensure mood disorders are diagnosed appropriately.

If teams are unable to meet an identified patient or carer need, or more specialist expertise is required, they should access the appropriate service in a timely manner, such as:

- Video fluoroscopy
- Spasticity management clinics
- Pain management clinics
- Specialist seating/wheelchair services
- Orthotics
- District Nurses
- Stroke physician or GP
- Dietician
- Orthoptist/visual rehabilitation worker

Interventions should be:

- Based on the best available evidence.
- Building in self-management alongside carer management.
- Task specific and focused on patient goals. The dose, structure and format of interventions should be specific to the individual patient to reach the desired level of intensity.
- Facilitate carer and family involvement in rehabilitation to optimise opportunities for self-practice, where appropriate.
- Designed to support and meet the needs of family and carers as well as patients

2.2 Goal setting

Patients (and carers where appropriate) should be supported to engage in joint setting of goals with the MDT. Goals should be meaningful to the patient, aspirational and realistic, based on a holistic MDT assessment. Goals should link in with the foci of treatments detailed in section 1.2.

2.3 Outcome measures

Validated outcome measures should be used, these should be sensitive to change in this population and specific to the individual's impairment, participation and quality of life. Wherever possible, the use of patient-reported outcome measures and patient-reported experience measures should be supported. Outcome measures should be:

- Accessible for those with communication difficulties
- Recorded within 2 weeks of discharge from hospital
- Reviewed at time points agreed with the patient and carer
- Appropriate to individual needs.

2.4 Education and training

The team should be actively engaged in the education of:

- Commissioners and healthcare professionals regarding the rehabilitation needs and rehabilitation potential of this patient group. Raising awareness of meaningful outcomes for patients with severe disability following stroke, the impact of carer burden and the resources required.
- Patients, families and carers regarding longer-term self-management*, secondary prevention and prevention of secondary complications such as shoulder pain.
- Care Home staff, supporting ongoing rehabilitation across domains specific to the patient, including swallowing, positioning (including bed based), communication and moving and handling as well as enabling participation in leisure activities.
- Providing practical training and written information, in an accessible format, for non-stroke specialist healthcare professionals, family and carers where appropriate.

*A process whereby individuals gain knowledge, skills and strategies to manage the physical, psychological, emotional and social effects of their long-term condition.[47]

GPs, general practitioners.

a summarised, succinct format, which aims to optimise uptake and use in practice.

This study complements previous research in which consensus statements guiding the delivery of stroke ESD and community stroke rehabilitation, using modified Delphi approaches were generated.[6 20] The current consensus activity focused on provision of care to stroke survivors with severe disability, and choice of the NGT was based on the lack of evidence for this patient population. NGT has been widely used within healthcare for the generation of priorities and guidelines due to its highly structured processes, especially when there is a dearth of evidence within the field.[25]

The findings from this study are aligned to, and build on, recommendations made in previous consensus activities.[6 20 24] These include an emphasis on the need for a comprehensive MDT as well as predischarge involvement, weekly meetings[6] and the need for an integrated stroke care pathway, highlighting principles which are applicable for stroke services for any survivor of stroke. Both panels agreed on the need for rehabilitation delivery alongside ESD, however, with slight differences in opinion. One panel suggested expansion of current ESD criteria whereas the other panel suggested integration (offering ESD alongside community stroke rehabilitation) so that the service 'offers stroke rehabilitation at a range of intensities.' This aligns with the recommendation by the National Integrated Community Stroke Service model detailed in the current National Stroke Service Model.[22]

Sackley and Pound[24] previously used NGT within care homes for a similar stroke patient population and with a focus on transfer of care on hospital discharge. In the current community focused study, some similar themes were evident such as: the importance of cross team communication, equipment provision, written information and education of staff.[24] Community stroke teams have the potential to support the transfer of care between acute hospitals and care homes, as reflected by the consensus statements generated in this study regarding both in-reaching into acute hospitals and working collaboratively with care home staff as well as supporting family and carers within their homes.

Severely disabled stroke survivors are more likely to be discharged to care homes compared with less disabled survivors. Dutta *et al*[9] showed that 37.3% and 55.8% of stroke patients in the categories of modified Rankin scales of 4 and 5, respectively, were discharged to care homes compared with only 7.9% of patients with a modified Rankin scale of 3.[9] Only in recent years have clinical guidelines recommended that those resident in nursing homes should have access to specialist stroke services, however, these guidelines fall short of detailing the content of these services.[7] The lack of specialist stroke rehabilitation provided to survivors of stroke within these facilities has been highlighted; being classified as a 'resident' of long-term care facilities was associated with reduced access to rehabilitation.[36] A randomised controlled trial by Sackley *et al*[18] investigating the impact of a 3-month OT intervention on care home residents following stroke reported neutral results. However, their intervention, while individually customised, 'aimed to augment or maintain functional capacity in personal activities of daily living' with the primary outcome being the functional independence measure, the Barthel Index. The current consensus statements highlight that, for survivors of stroke with severe disability, interventions should be tailored to a variety of aims such as the reduction of secondary complications or access to leisure activities, interventions focusing on these may have seen a different outcome, however, to the authors knowledge no interventional research has been completed in these areas.

This study also emphasises that location should not be an exclusion criterion for rehabilitation in this population. The consensus statements provide important guidance for care provided to stroke patients in nursing or residential care homes (as well as those in their own home), focusing on the training needs of the staff to ensure safety yet equally not neglecting their quality of life, with the enablement of leisure activities.

Outside of the care home environment there is also a dearth of evidence. McGlinchey *et al*[37] recently reported a survey to describe the current practice of therapists with survivors of stroke with severe disability. The most frequently reported interventions, for both physiotherapists and OT's, were stroke survivor positioning and training of carers.[37] The authors highlighted the lack of trials researching these areas, arguing that existing research trials do not reflect actual clinical practice. Their findings closely reflects the findings from this study which indicates the need for carer training and education, prevention of secondary complications and posture and seating interventions.

The training of carers by community stroke teams has been proposed previously.[20] However, these consensus statements emphasise the importance of carers and go as far as to suggest that a goal of intervention, and eligibility for the service, could be to reduce carer burden. This reflects previous literature suggesting severity of functional disability significantly correlates with carer burden.[14] A Cochrane review conducted in 2011 concluded there was insufficient evidence of the impact of training interventions for carers.[38] However, none of the included papers involved a face-to-face intervention in the home setting, led by therapists. Kalra *et al*[39] demonstrated positive results with an inpatient training package for carers, however when replicated in a multicentre study no differences between the control and intervention were found. The authors concluded the intervention may be best delivered by the community team, in a patient's own home, which echo the findings of this study.

The present consensus statements are in agreement with the wider available literature, however, they succinctly offer guidance for healthcare professionals, commissioners and patients regarding the specialist needs of this under-represented patient group.

Strengths and limitations

The use of the adapted vNGT within this study, provided many benefits while ensuring methodological rigour.[40 41] These benefits included being able to include panel members from geographically distant locations, ensuring a breath of experience without the burden of travel or additional cost implications.[42] Equally, Kulczycki and Shewchuk[41] demonstrated high levels of acceptability among their panel members.

The strengths of this study include the use of a highly specialist panel, with collaborative working between different MDT members as well as input from those with lived experience.[43] Highly experienced experts within stroke rehabilitation, from across the country were involved in this study, both nationally and internationally renowned. It is suggested that this can influence the implementation by maximising the credibility and the validity of the results.[25] While we regard the inclusion of expert input from lay members as a strength of this study, involved with the idea generation, they did not participate in the scoring stage, at their request.

A long-standing debate in the use of the NGT is a reliance on the views of limited panel members.[44] While the selected panel has been highlighted as one of the strengths of the study, there is a potential that different panel members (representing different disciplines) may have yielded different conclusions. The use of two separate panels within this study has provided an insight into the replicability of these views, with high levels of replication and few incidences of disagreement among n=421 statements. This was achieved despite the significant difference in casemix between the two panels. While this does not confirm the reliability of the results, this helps to strengthen the outputs. Similar to the previous uses of vNGT, the approach was deemed successful.[40 41] An evaluation was completed seeking feedback from the panel members; however, results are to be published separately. In summary, the video conferencing platform enabled the face-to-face discussion synonymous with NGT. Using previous recommendations from virtual focus group literature and optimal nominal group panel sizes, this study purposely limited the groups (n=6) in order to support real-time discussion and generate sufficiently rich data.[25 45] This meant the need for two separate panels with the subsequent triangulation of their data, however, it was felt that this positively aided scheduling.

CONCLUSION

This study is the first to determine expert consensus regarding key components of home-based rehabilitation for survivors of stroke with severe disability. Globally, an increasing and ageing population coupled with a trend in reducing mortality rates, has led to increasing numbers with long-term disability following stroke.[46] The overarching consensus statements highlight the complexity of effectively managing patients with severe stroke disability following discharge from hospital. This study can be used to support the provision of services for this patient group, providing a benchmark for commissioners and clinicians as well as setting expectations for stroke survivors and their carers.

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Supplementary file 1 : Virtual Nominal Group Technique e-Booklet

The following e-Booklet was provided to all panel members approximately 2 weeks prior to convening the Nominal Group panel.

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HoRSSe
Home-Based Rehabilitation for Severe Stroke

Virtual Nominal Group Technique

e-Booklet

August 2020

Principal Investigator: Dr Rebecca Fisher Rebecca.fisher@nottingham.ac.uk

Table of Contents

Nominal group overview

Nominal group technique is a method for gaining formal consensus. It involves convening an expert panel and follows 5 distinct stages as detailed below[1]. These have been slightly adapted to be achievable through virtual means.

1
- Introductions and explanations
  - Aims and processes explained
  - Research Questions reiterated

2
- Silent idea generation
  - Panel members individually generate ideas associated with the question,
  - Panel members will be asked to remain connected to the MS teams meeting but with video and sound off, this will be for approximately 15 mins.

3
- Round Robin
  - Each panel member takes their turn to present one idea at a time. This will be completed in set order dictated by the facilitator.
  - These are written verbatim and viewed by all through screen sharing capabilities.

4
- Clarification
  - When all ideas have been exhausted the panel member discuss the ideas generated purely for clarification purposes
  - When this has been completed the MS teams meeting can finish

5
- Voting and ranking
  - Annoymous individual voting and ranking to be completed using an online ranking proforma. The link for this will be sent out the next day for return within the next 5 days.
  - Responses will then be analysed for agreement / consensus. Feedback will be provided at a later stage.

Questions for the Nominal Group

Please review these in conjunction with the context statement (page 5). A proforma for your ideas will be provided separately.

Question 1

From an organisational perspective, what should a rehabilitation service for survivors with severe stroke disability include in terms of structure, service delivery and outcome measures?

Question 2

From an intervention perspective, what treatments / techniques should be implemented in order to effectively rehabilitate this cohort of patients?

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Context Statement

Purpose

The purpose of this consensus building activity is to generate a set of core components to inform a severe stroke rehabilitation intervention. This document is to be used in conjunction with the nominal group questions to provide a contextual reference to aid idea generation. An additional longer-term aim of this nominal group is to build upon clinical guidelines for community rehabilitation services treating patients with severe stroke disabilities. Please see appendix 1 for an example output.

Population

The focus of this consensus activity is the immediate period post discharge from inpatient rehabilitation for stroke survivors with severe disability. For the purposes of this study severe disability is to be determined by the modified Rankin Score (mRS) with severe disability previously agreed to correspond to 4 or 5 on the scale (see appendix 2 for full scale)[2].

Example 1
72-year-old gentleman discharged home requiring a rotunda and 2 to transfer to a wheelchair, has moderate aphasia, low mood, cognitive impairment and requires a modified diet. He has a downstairs existence in a house with his increasingly anxious wife, supported by 2 carers 4 times a day

Example 2
89-year-old lady discharged to nursing home requires full hoist to specialist seating. Has evolving upper limb spasticity, grade 2 sacral sore and is PEG fed. Family are very supportive and keen for her to return home in the future.

Context:

The proposed interventions must be feasible within a community setting whether at home, care facility or alternative community setting for example a leisure centre. To be provided by a service also achievable in the community setting e.g. a multidisciplinary community rehabilitation service.

This consensus activity should be set within the context of the NHS, with the associated capabilities and capacity, being mindful of finite resources. This should also consider the wider picture of avoiding hospital readmission, long-term placement, and minimising societal burden.

Example 3
A multidisciplinary NHS community stroke team (whole time equivalent 22) responsible for a large geographical area with approximately 550 patients a year across al disability categories, 28% (155 patients) of which are have a Modified Rankin Scale of 4 or 5.

In the first instance, we are requesting views associated with a pre-COVID-19 environment, in a second stage, we will examine how COVID-19 has changed community stroke rehabilitation, further information regarding up-to-date COVID-19 advice will be provided prior to re-convening.

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Rehabilitation needs in the severe stroke population: a precis

Little evidence exists to inform the provision of rehabilitation for severely disabled stroke survivors in the community (3-5). The following is a summary from the literature surrounding the established needs of severely disabled stroke survivors when they are discharged from hospital:

Physical and stroke related problems
Agreement exists regarding the physical needs of these individuals such as physiotherapy, occupational therapy or speech and language therapy (6-9), although few studies discuss specific interventions within the therapy domains. Those documented include palliative care, pain management (10-12) and support with activities of daily life (13). The need for psychological support for severely disabled stroke survivors, their families and caregivers is well evidenced, ranging from the provision of reassurance and empathy to the treatment of affective and cognitive disorders. (7,9,14-18).

Information and education
Information and education needs have been identified by both severely disabled stroke survivors and their carers. This includes explanations of clinical interventions (17), signposting to other agencies (9) and individualised information, specific to the stroke survivor (13). Greater need for information is reported around the time of discharge from hospital and transfer of care between professionals (9,16,18-19).

Impact on social participation
Social needs are commonly reported in the literature, however insufficient detail is provided to establish the nature of these needs (7,9,16-18). Examples are given regarding communication and maintenance of relationships (14) and support in accessing day centres or respite care (9).

Organisational needs
Organisational factors such as access to "specialist expertise" (9,20) from coordinated and multidisciplinary teams who can provide "timely" input have been highlighted as important by this population (9,18,20). On discharge from hospital, stroke survivors and their carers identified organisational needs, such as the frequency of interventions, availability of rehabilitation teams and ease of contacting professionals. Individuals highlighted a desire to be involved in the planning of their rehabilitation; to have a sense of influence, if not control, over their rehabilitation (21).

Factors associated with need
A relationship between greater disability and increasing need following stroke is evident (6-8,10,12,15,22). Needs may fluctuate over time (8,12) and require regular reassessment (3).

Limitations
Methodological limitations exist in the literature when exploring the rehabilitation need of these individuals. For example: sample populations with minimal severely disabled stroke survivors, the exclusion of those unable to participate in focus groups, interviews or questionnaires as well as assumptions made regarding an individual's insight into their own needs. Many of the studies identified explore need from six months onwards following stroke (23,24). Therefore, a gap in the literature exists regarding the needs of this population on discharge from hospital, before six months, when community rehabilitation would ideally commence.

For this study, a pragmatic approach has been taken, using a panel of clinicians, academics as well as a stroke survivor and carer, chosen for their understanding of severely disabled stroke survivors. Panel knowledge and experience of the expressed, perceived, and normative needs of this population, will inform the core components of recommended rehabilitation for this population group in the community. Further feedback will be gained from stroke survivors and their carers later in work packages two and three, to enhance and shape outcomes.

Key themes of lived experience from our PPI collaboration

The word cloud below highlights the expressed priorities of members of the Nottingham Stroke Research Partnership Group, a group of stroke survivors and carers who work with stroke researchers from the University of Nottingham. The bigger and bolder the word appears, the more often it was mentioned within the meeting.

Summary of clinical guidelines from around the world

Summary of guidelines from the UK[25], USA[26], Canada[27] and Australia[28], these are for home-based rehabilitation services in general and not specific to those with severe disability following stroke.

Guidance	UK	USA	Can	Aus
Organisation				
Access to a Community Stroke Team	●⌘·	●‡	●·	●·
Specialist Neuro Multi-Disciplinary Team	●·	·	●·	
Responsive: Beginning 48 – 72 hours post discharge		·	●·	
Intensity	5 x 45 mins*	-	2-5 x 45mins	
Telecare		●·	●*	
Case manager / case co-ordination	●*	●·	●·	
Duration		5-9 sessions	8 weeks	
Secondary Prevention				
Secondary Prevention	●*	●*	●*	●*
Cardiovascular fitness	●*	●·	●*	●*
Splinting (AFOs / resting splints)	●*	●*	●*	●*
Spasticity management	●*	●*	●*	●*
Skin damage and contracture prevention	●*	●*	●*	●*
Rehabilitation				
Individually tailored programmes	●*	●·	●·	●*
Goal setting	●*	●·	●·	●*
Self-management strategies	●*	●·	●·	●*
Patient education	●*	●·	●·	●*
Carer support: • Education • Training • Counselling • Development of support structure • Financial assistance	·· ●* ●* ●* ●*	· ●· ●· ●· ●· ●·	●· ●·	●* ●* ●* ●*
Assessment of ADLs	●*	●··		●*
Evaluation of home environment		●·	●·	
Assessment of Mobility	●*	●·	●*	●*
Mobility rehabilitation	●*	●*	●*	●*
Fall prevention	●*	●*	●*	●*
Seating	●*	●*	●*	
Upper limb rehab	●*	●*	●*	●*

Promote engagement with leisure activities	●*	●*	●·	●*
Vocational rehab	●*	●*	●·	●*
Return to driving rehab	●*	●*	●·	●*
Perception and cognition assessments	●*	●*	●*	●*
Vision	●*	●*	●*	●*
Cognitive therapy	●*	●*	●*	●*
Assessment of sensation	●*	●*		●*
Compensations for neglect	●*	●*	●*	●*
Fatigue	●*	·		
Interventions for speech disorders	●*	●*	●*	●*
Dysphagia assessment and intervention	●*	●*	●*	●*
Assessment of depression and well-being	●*	●*	●*	●*
Neuro-Psych involvement for post stroke depression	●*	●*		●*
Pain management	●*	●*	●*	●*
Management of shoulder pain	●*	●*	●*	●*
Treatment of incontinence	●*	●*		●*
Sexual Function	●*	●·	●·	●*

* Not specifically within the community rehabilitation section, however, suggested that assessments cross hospital and community.

z Including patients residing within nursing homes.

‡ Exclusions include individuals with stroke who require daily nursing services, regular medical interventions, specialist equipment or interprofessional expertise.

Reviewing the guidelines there are clear differences in healthcare provision between countries. Whilst all countries report the necessity of home-based stroke services, there is a dearth of specific guidance for what this should include. The stroke rehabilitation guidelines for each country suggest they are relevant across both inpatient and community settings however there is a clear focus towards inpatient rehabilitation leading to challenges deciphering the salient points for community teams(25-28). All four guidelines lack specific guidance for home-based services for patients with severe post-stroke disability, despite differing needs to those with mild – moderate disability.

The USA and Canada provide the most detailed guidance, reporting the need for case-managers as a stable point of contact. Also, that families and carers should have training and education so they can be involved in the rehabilitation management, discharge planning and goal setting (26,27). However, guidelines substantially differ in suggested duration of services with USA suggesting 5-9 sessions whereas Canada advise 45mins 2-5 times a week for at least 8 weeks going further to suggest this should commence between 48-72 hours following inpatient discharge(26,27). Neither UK nor Australia suggest a time frame(25, 28).

The UK's RCP guidelines provide very little specific detail regarding home-based services other than ESD which is limited to those with mild-moderate disability only[25]. However, it is the only nation to specifically report that people residing in nursing homes should continue to have access to specialist services after leaving hospital but does not specify if this includes those with severe disability. The USA suggests "individuals with stroke who require daily nursing services, regular medical interventions, specialist equipment or interprofessional expertise" should be excluded from home-based services, but do not specifically report whether this includes patients in nursing homes[26].

Australia provides the least specific guidance, with only one sentence in their guidelines suggesting "home based rehabilitation may be considered as a preferred model" however report this is based on "weak" evidence[28].

Whilst all nations report the need for home-based community rehabilitation specific recommendations to what this includes encompasses a few sentences in total with no mention of those with severe disability following stroke. Further consensus is required to determine key components of a home-based rehabilitation for patients with severe disability following stroke.

Scoping review of Community Rehabilitation with Severe Stroke Survivors

Tabulated below is a summary of the articles retrieved in a scoping review. The aim was to explore and map research evidence relating to rehabilitation interventions of severely disabled stroke survivors in the community following discharge from hospital. Please refer to appendix 3 for the search terms and eligibility criteria. The initial review identified articles 8243 and after screening for eligibility n= 9 have been included in this review. The majority of articles were excluded due to patient severity, chronic stroke population or non-homebased settings. Studies were also excluded due to the intervention of focus being outside the reach of NHS services, e.g. robotics, virtual reality or equipment being too cumbersome. Pharmacological interventions in isolation were outside the scope of this review due to the medical focus compared with MDT rehabilitation, although their value within this population should not be overlooked.

There were challenges with the screening process as severity was not always assessed across all domains and so it was difficult to ascertain what cognitive or communicative impairments would fall into this category.

In general, there is a paucity of evidence within this population as these patients are often excluded from research. Studies which have been undertaken are often characterised by low sample sizes and high heterogeneity. It should be noted that many studies excluded may be transferable to this population and setting but this has not been explored. Despite 20% of patients being discharged from hospital with severe disability following stroke this population continues to be severely under-represented within the literature.

OCCUPATIONAL THERAPY	
Sackley et al., 2015[29]: An occupational therapy intervention for residents with stroke related disabilities in UK care homes (OTCH): cluster randomised controlled trial	
Comments	Community based and includes but limited to severe, however time since stroke not discussed - some potentially fall within 6/12
Origin	UK
Aim	To evaluate the clinical efficacy of an established programme of occupational therapy in maintaining functional activity and reducing further health risks from inactivity in care home residents living with stroke sequelae.
Population	1042 care home residents with a history of stroke or transient ischaemic attack, including those with language and cognitive impairments, not receiving end of life care.
Methodology	Pragmatic, parallel group, cluster randomised controlled trial.
Intervention	Targeted three-month programme of occupational therapy, delivered by qualified occupational therapists and assistants, involving patient centred goal setting, education of care home staff, and adaptations to the environment
Outcomes	The primary outcome measure did not differ significantly between the treatment arms. The adjusted mean difference in Barthel index score at three months was 0.19 points higher in the intervention arm (95% confidence interval −0.33 to 0.70, P = 0.48). Secondary outcome measures also showed no significant differences at all time points.
Key Findings	This large phase III study provided no evidence of benefit for the provision of a routine occupational therapy service, including staff training, for care home residents living with stroke related disabilities. The established three-month individualised course of occupational therapy targeting stroke related disabilities did not have an impact on measures of functional activity, mobility, mood, or health related quality of life, at all observational time points. Providing and targeting ameliorative care in this clinically complex population requires alternative strategies.

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Fletcher Smith et al., 2013[30]: Occupational therapy for care home residents with stroke	
Comments	Only 1 study included: Sackley 2006 - however time since stroke not explicit
Origin	Cochrane (worldwide)
Aim	To measure the effects of occupational therapy interventions (provided directly by an occupational therapist or under the supervision of an occupational therapist) targeted at improving, restoring and maintaining independence in ADL among stroke survivors residing in long-term institutional care, termed collectively as 'care homes'. As a secondary objective, the aim was to evaluate occupational therapy interventions for reducing complications such as depression and low mood.
Population	Residents of care homes who have had a stroke
Methodology	Systematic review
Intervention	This study included all occupational therapy and therapy-based interventions (delivered on an individual or group basis) provided directly by a qualified occupational therapist, or by an occupational therapy assistant under the direction of a qualified occupational therapist, that aimed to increase or maintain occupational performance and independence, and to improve function in ADL ('personal' ADL or 'extended' ADL, or both).
Outcomes	Outcome measures include, measures of independence with ADLs (Barthel Index, Mortality, mobility (Rivermead Index)
Key Findings	One study, involving 118 participants, met the inclusion criteria, and was included it in the review. One ongoing study that also met the inclusion criteria for the review, however the data were not yet available to include in the meta-analysis. Data were insufficient to allow determination of whether occupational therapy interventions can improve, restore and maintain independence in ADL for care home residents with stroke. A lack of evidence available precluded evaluation of occupational therapy interventions aimed at reducing complications such as depression and low mood, and those aimed at improving quality of life.
APHASIA	
Doesborgh et al., 2004[31]: Effects of semantic treatment on verbal communication and linguistic processing in aphasia after stroke	
Comments	Unclear where this treatment was administered although could be feasible within the community setting. No effect between the two approaches but within group improvements.
Origin	The Netherlands
Aim	The hypothesis was that semantic treatment would have a greater effect on everyday language than phonological treatment.
Population	n=58, age between 20-85 years old with semantic and phonological deficits following stroke. To minimize the effect of spontaneous recovery, patients were not included before 3 months after onset.
Methodology	RCT
Intervention	Participants were randomized to receive either semantic treatment or the control treatment focused on word sound (phonology). Treatment started at 3 to 5 months after onset and lasted until 10 to 12 months after onset. Treatment was comprised of 40 to 60 hours of individual treatment (1.5 to 3 hours a week in 2 or 3 sessions). The semantic treatment, is focused on the interpretation of written words, sentences, and texts. The phonological treatment, is focused on sound structure.
Outcomes	The primary outcome measure was the ANELT, scale A (understandability), a valid and reliable measure of verbal communicative ability. Verbal responses in 10 everyday language scenarios are scored on a 5-point scale for informational content.

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Key Findings	After treatment, the mean ANELT score improved significantly for both the semantic and phonological groups. No significant difference between the treatment groups was found for either final scores or mean improvement in ANELT scores.
Van der Meulen et al., 2014[32]: The efficacy and timing of melodic intonation therapy in subacute aphasia	
Comments	Unclear where this treatment was administered although could be feasible within the community setting.
Origin	The Netherlands
Aim	The aim of the present study was 3-fold. First, the efficacy of melodic intonation therapy (MIT) as a language production therapy for severe non-fluent aphasia was evaluated in the subacute phase. Second, investigation of whether the timing of MIT within the subacute phase affects therapy outcome.
Population	n=27, aphasic after left hemisphere stroke, time poststroke 2 to 3 months, pre-morbidly right-handed, age 18 to 80 years
Methodology	Waiting list RCT
Intervention	Between baseline (T1) and the first intervention period (T2), participants in the experimental group received intensive MIT (6 weeks; 5 h/wk); no other language therapy was allowed in this period. In the same way, participants in the control group received intensive control treatment only (6 weeks; 5 h/wk), thereby allowing comparison between MIT and the control therapy at T2. After T2, patients allocated to the control group received delayed MIT following the same protocol (6 weeks; 5 h/wk), allowing to examine the effect of timing of MIT. Patients in the experimental group resumed their regular therapy after T2. To ensure therapy intensity, homework assignments were provided for both the MIT and the control group. An iPod application was developed containing short videos of a mouth singing the target utterances; patients could sing along with the video or repeat the utterance afterwards. Homework assignments for the control group included paper-and-pencil tasks such as written sentence completion, word–picture matching, and word categorizing tasks. The minimum amount of face-to-face therapy time was 3 h/wk.
Outcomes	Outcome measures were the Sabadel story retelling task, he Amsterdam Nijmegen Everyday Language Test (ANELT) measuring verbal communication in daily life, the Achen Aphasia Test (AAT) subtests repetition and naming rated on a scale 0-5, and the MIT repetition task, a repetition task designed for the present study including 11 utterances trained during MIT and 11 matched untrained utterances.
Key Findings	There was no significant difference in treatment intensity between the 2 groups. At T2, the MIT group showed significant improvement on all tasks ($p<0.01$), except for the Sabadel task ($p=0.13$). The control group showed significant improvement only on the repetition of untrained MIT items. Finally, delaying MIT was related to less improvement in the repetition of trained material.
Rose et al., 2013[33]: A systematic review of gesture treatments for post-stroke aphasia	
Comments	Of the 23 studies only 2 included community dwelling participants with impairments other than mild aphasia, where interventions were not groups attendances. Raymer 2006 (n=9) Raymer 2011 (n=8)
Origin	Worldwide
Aim	The aim of the current project was to systematically evaluate the scientific evidence for the effects of symbolic and non-symbolic gestural training in post-stroke aphasia. Specifically, to evaluate the effects of gesture treatment for measures of verbal and nonverbal communication
Population	Studies that investigated gesture-based treatments for aphasia, including those that addressed treatments aimed at ameliorating language impairments, as well as treatments targeting nonverbal (gestural) communication. Searched terms for population were... Anomia, Dysphasia, Aphasia, Agrammatism

Methodology	Systematic review
Intervention	The types of gestures used in training were symbolic in all but four studies where non-symbolic intentional gesture movements were implemented. The non-symbolic movements consisted of complex reaching and turning movements, evolving to tapping or circular limb movements over time. Most symbolic gestures included in training were in the form of pantomimes and iconic gestures.
Outcomes	Boston Naming Test (BNT, a measure of naming 60 items), Western Aphasia Battery (WAB, assessment tool to examine linguistic skills and non-linguistic skills 0-80, higher the less severe), verb and noun production in discourse tasks, picture naming.
Key Findings	In summary, there is reasonable evidence from high-quality small case studies or small single-case experimental designs that combined symbolic gesture + verbal training has a positive impact on trained items for spoken language measures such as picture naming for both nouns and verbs. Although effects for untrained words were typically limited, some generalised language improvements were noted on standardised tests such as the BNT (9/30 individuals) and WAB (18/35 individuals for the Aphasia quotient). Further, a small number of studies have shown positive changes in verb (7/10 individuals) and noun production (4/8 individuals) in discourse tasks, suggesting that symbolic gesture training has some generalised impact for verbal language abilities in individuals with aphasia. There is also reasonable evidence that gesture training is effective for improving gesture production for trained pictures (24/31 individuals) with some success for untrained pictures as well (10/31 individuals), but inadequate evidence of training effects in discourse tasks. The use of symbolic gestures alone in training, without a verbal component, had limited impact on verbal language measures, although gesture improvements were strong. The evidence for non-symbolic gesture training is less conclusive.
MENTAL IMAGERY	
Braun et al., 2012[34]: A Multi-centre RCT to Compare Subacute 'Treatment as Usual' With and Without Mental Practice Among Persons With Stroke in Dutch Nursing Homes	
Comments	No effect but excluded if significant cognitive or communicative impairment
Origin	The Netherlands
Aim	This study investigated whether imagining the skilled movement systematically can contribute to a quicker and/or better recovery of stroke patients in long term care
Population	Subacute stroke pts in care homes
Methodology	RCT
Intervention	Study participants were randomly assigned to the control or experimental group. Over a 6-week intervention period, both groups received multi professional therapy as usual. Additionally, patients in the experimental group had instruction on mental practice with a 4-step framework embedded in regular therapy time
Outcomes	Outcomes were assessed at 6 weeks and 6 months with the patient-perceived effect on performance of daily activities (10-point Numeric Rating Scale). Six secondary outcomes on impairment and activity level were also assessed.
Key Findings	Thirty-six adult stroke patients (average age 77.8) participated in the trial. No effect in favour of the mental practice intervention on any outcome measure could be detected at either measuring points
WELLBEING AND DEPRESSION	
Forducey et al., 2012[35]: Videophone for older adults with stroke and caregivers	

Comments	Very low numbers n=11 in total. Researcher had to provide telehealth hardware to each participant.
Origin	USA
Aim	The aim was to compare the effects of home-based telehealth versus standard home care services on changes in emotional and physical health status for older persons with stroke.
Population	n= 11. Participants were included in the study if they: (a) had a first time medical diagnosis of acute stroke, (b) the onset of stroke was six months or less, (c) had either Medicare or Blue Cross and Blue Shield insurance coverage, (d) moderate deficits in the areas of self-care, functional mobility, transfers as documented by the Functional Independence Measure (FIM); (e) had a caregiver present to set up telehealth videophone device
Methodology	Prospective clinical randomised repeated measures design
Intervention	The technology deployed in this study was a desktop videophone using standard telephone lines. The treatment plan of care was identical for both groups and included education and highly structured intervention techniques for self-care; home modifications; functional mobility; and posture. Treatment focused on restoration of impaired segments through resolution of motor deficits. Specific strategies were left to the discretion of the PT and OT, but guidelines for sequencing and grading relative range demands, muscle demands, activity selection and input were employed. Written material regarding stroke risk factors, warning signs, and community-based support groups were provided to patients and their caregivers. On average, the telehealth subjects received 6.0 PT treatments and 6.75 OT treatments, whereas the standard of home care subjects received 10.6 PT treatments and 7.4 OT treatments.
Outcomes	FIM and Short form-12
Key Findings	Significant pre-post differences were found for both the videophone and standard of care treatment conditions on the FIM and SF-12 (all p's < .05). Both groups showed significant improvements on functional independence and mental and physical health status from pre to post treatment. In addition, no significant differences on the change scores of the two dependent measures were found between the videophone and the standard home care conditions. Furthermore, the number of treatment encounters was significantly lower in the telehealth intervention group than the control condition. This pattern of results suggests that telehealth may provide a cost-effective alternative to standard home care services.
Kirkness et al., 2017[36]: Randomised trial of telephone versus in-person delivery of a brief psychosocial intervention in post-stroke depression	
Comments	No difference between in-person or telephone, this was better than the control, but not statistically significant.
Origin	USA
Aim	The primary aim was to test whether the brief intervention delivered in-person or by telephone is superior to usual care in terms of post-stroke depression treatment response (percent reduction in depressive symptoms) or remission in the short-term (immediately following treatment) and at 1 year post treatment.
Population	One hundred people who were within 4 months of an ischemic or haemorrhagic stroke. Clinical depression was identified by the screening score of the Geriatric Depression Scale
Methodology	RCT
Intervention	Each group had one in-person orientation session with the psychosocial nurse practitioner therapist, either in their home or at our study offices. They received the participant manuals, discussed goals and expectations of each session, and learned how to fill out the homework sections. Following the in-person orientation

	session, each of the subsequent six sessions occurred either in-person, usually at the participant's home, or by telephone. Session length ranged from 10 to 80 min. A family member or informal caregiver could opt to participate and provide data with the participant's agreement.
Outcomes	Hamilton Depression rating scale
Key Findings	There was no statistical difference between the telephone versus in person interventions, these were therefore combined into "intervention" versus "control". The percentage decrease in HRSD scores and percentage of participants in remission were both greater in the combined intervention groups than in the usual care control at the first post-treatment time point, but the difference was not statistically significant.
Baker et al., 2018[37]: A systematic review of rehabilitation interventions to prevent and treat depression in post-stroke aphasia	
Comments	Some interventions that may improve depression outcomes for those with mild depression or without depression in post-stroke aphasia.
Origin	Australia
Aim	The aim of this systematic review was to analyse and synthesis the evidence regarding rehabilitation interventions to prevent and treat depression in patients with aphasia.
Population	Mixed but includes a number of studies in the hospital- community transition and varying degrees of severity
Methodology	Systematic review
Intervention	"Preventive interventions" target those at high risk of depression after stroke or those with early signs and symptoms but not fulfilling diagnostic criteria (indicated intervention). "Treatment interventions" target those who fulfil criteria for depression after stroke. The remaining studies did not specify preventive or treatment aims and commonly had depression outcomes as secondary measures. These interventions indirectly targeted depression as an outcome through stroke rehabilitation. These were classified as "stroke rehabilitation interventions".
Outcomes	Stroke Aphasic Depression Questionnaire (SADQ-21), Hospital Anxiety and Depression Scale (HADS), Centre of Epidemiological Studies Depression Scale (CES-D)
Key Findings	People with aphasia with mild depression may benefit from psychosocial-type treatments (based on 3 level ii studies with small to medium effect sizes). For those without depression, mood may be enhanced through participation in a range of interventions (based on 4 level ii studies; 1 level iii-3 study and 6 level iv studies). It is not clear which interventions may prevent depression in poststroke aphasia. No evidence was found for the treatment of moderate to severe depression in post-stroke aphasia.

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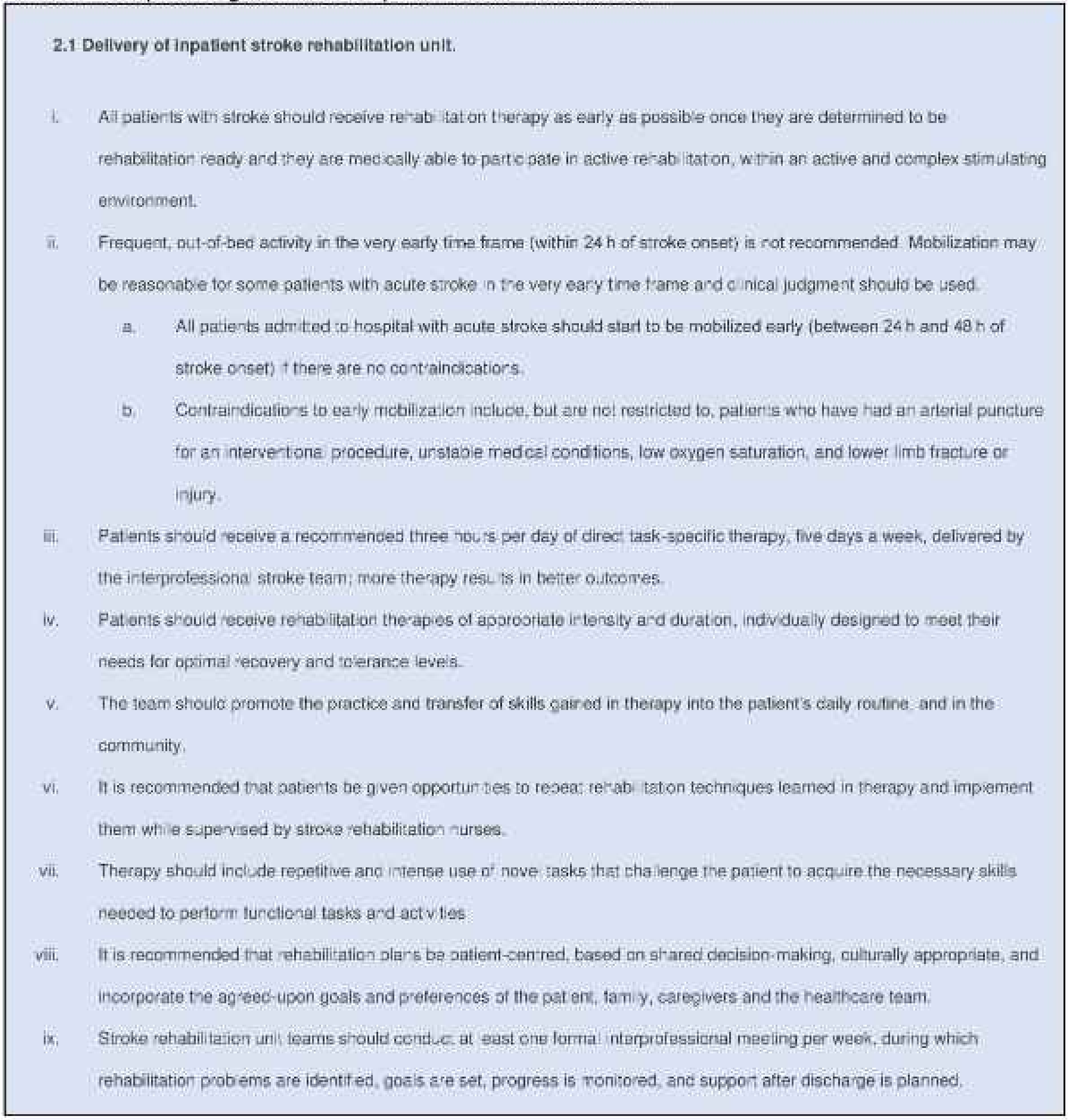
Appendices

Appendix 1

Canadian best practice guidelines for inpatient stroke rehabilitation[1].



2.1 Delivery of inpatient stroke rehabilitation unit.

i. All patients with stroke should receive rehabilitation therapy as early as possible once they are determined to be rehabilitation ready and they are medically able to participate in active rehabilitation, within an active and complex stimulating environment.

ii. Frequent, out-of-bed activity in the very early time frame (within 24 h of stroke onset) is not recommended. Mobilization may be reasonable for some patients with acute stroke in the very early time frame and clinical judgment should be used.

  a. All patients admitted to hospital with acute stroke should start to be mobilized early (between 24 h and 48 h of stroke onset) if there are no contraindications.

  b. Contraindications to early mobilization include, but are not restricted to, patients who have had an arterial puncture for an interventional procedure, unstable medical conditions, low oxygen saturation, and lower limb fracture or injury.

iii. Patients should receive a recommended three hours per day of direct task-specific therapy, five days a week, delivered by the interprofessional stroke team; more therapy results in better outcomes.

iv. Patients should receive rehabilitation therapies of appropriate intensity and duration, individually designed to meet their needs for optimal recovery and tolerance levels.

v. The team should promote the practice and transfer of skills gained in therapy into the patient's daily routine, and in the community.

vi. It is recommended that patients be given opportunities to repeat rehabilitation techniques learned in therapy and implement them while supervised by stroke rehabilitation nurses.

vii. Therapy should include repetitive and intense use of novel tasks that challenge the patient to acquire the necessary skills needed to perform functional tasks and activities.

viii. It is recommended that rehabilitation plans be patient-centred, based on shared decision-making, culturally appropriate, and incorporate the agreed-upon goals and preferences of the patient, family, caregivers and the healthcare team.

ix. Stroke rehabilitation unit teams should conduct at least one formal interprofessional meeting per week, during which rehabilitation problems are identified, goals are set, progress is monitored, and support after discharge is planned.

Appendix 2

0	No symptoms at all
1	No significant disability despite symptoms; able to carry out all usual duties and activities
2	Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
3	Moderate disability; requiring some help, but able to walk without assistance
4	Moderately severe disability; unable to walk and attend to bodily needs
5	Severe disability; bedridden, incontinent and requiring constant nursing care and attention
6	Dead

Appendix 3

Search terms

The following key words were identified through preliminary exploration of databases:

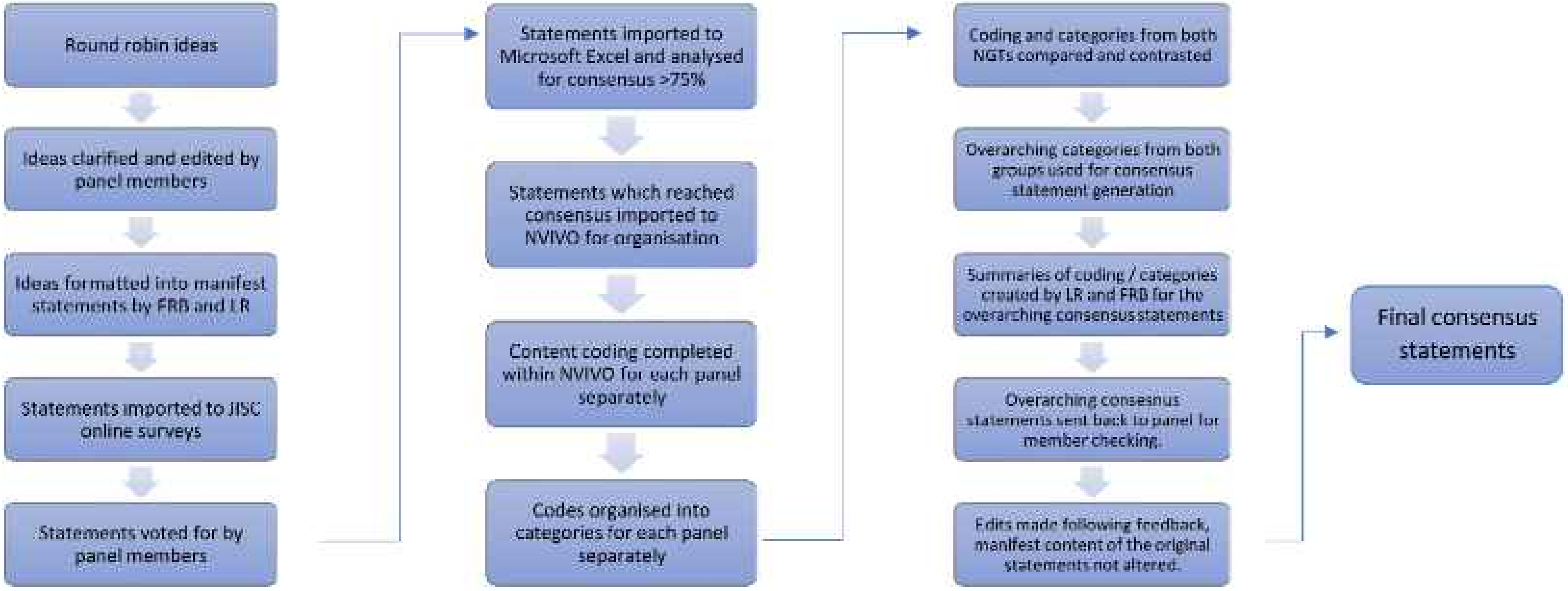
- Stroke
- Severe*
- Rehabilitation OR restoration OR therapy OR care OR support OR provision OR intervention OR treatment OR exercise OR adaptation OR aids OR training OR education OR Physiotherapy OR Occupational Therapy OR Speech Language Therapy OR Nursing OR Psychology

Eligibility

Study Design	Any
Participants	Adult (18+) Severe disability as a result of stroke (NIHSS >16, BI<45, MBI<9, FIM<40) Community setting (including care homes) Less than 1-year post stroke (Considering common standard operating procedures of community stroke teams)
Intervention	Rehabilitation Restoration Therapy Care Support Intervention Treatment Exercise Adaptation Aids Training Education Physiotherapy Occupational Therapy Speech and Language Therapy Nursing Psychology Provided by any healthcare professional (registered or non), formal or informal carers.
Comparator	Dependent on study design, if appropriate: Other intervention, No intervention, Usual care
Outcomes	Any measure of body function structure or impairment Any measure of activity or participation These may be either subjective or objective, originating from stroke survivors, their caregivers or healthcare professionals.

Supplementary file 2: Data collection and analysis process

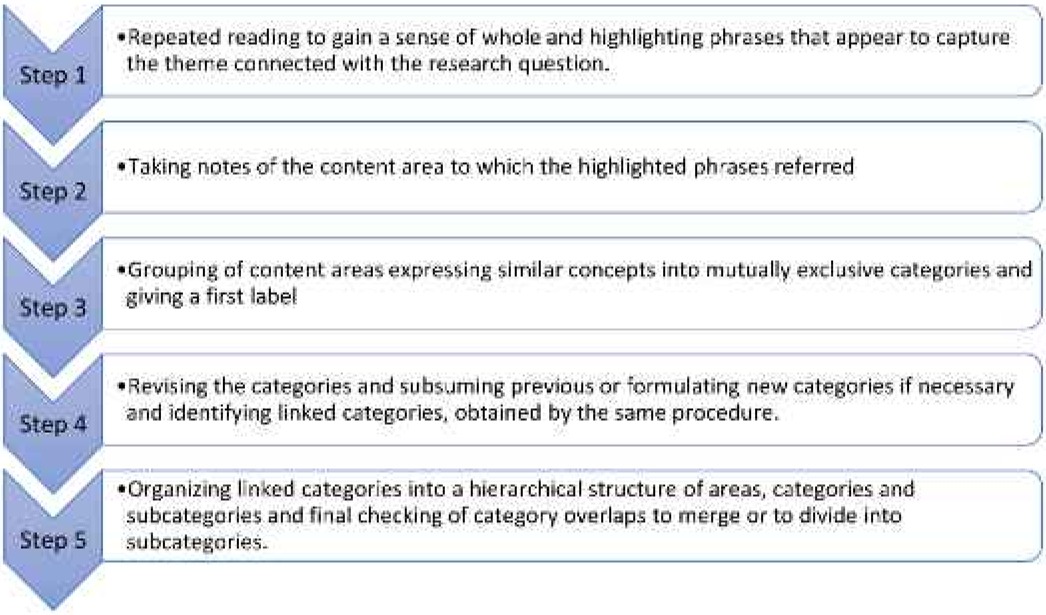
The following flow diagram details the full process from idea generation within the Nominal Groups to the final consensus statements including the combining of the two panel's data.



Supplementary file 3: Content analysis process

The flow diagram below details the qualitative content analysis coding process used for the Nominal Group Technique statements which reached consensus.

Steps taken from Moretti et al., (2011)



Step 1
- Repeated reading to gain a sense of whole and highlighting phrases that appear to capture the theme connected with the research question.

Step 2
- Taking notes of the content area to which the highlighted phrases referred

Step 3
- Grouping of content areas expressing similar concepts into mutually exclusive categories and giving a first label

Step 4
- Revising the categories and subsuming previous or formulating new categories if necessary and identifying linked categories, obtained by the same procedure.

Step 5
- Organizing linked categories into a hierarchical structure of areas, categories and subcategories and final checking of category overlaps to merge or to divide into subcategories.

Organisation of teams

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Core MDT

The core MDT should include:

- Occupational therapist
- Physiotherapist
- Speech and Language Therapist
- Psychologist
- Nurse
- Support worker
- Doctor
- Dietician
- Social care worker
- Admin

Service eligibility criteria

Modified Rankin Score **over 3.**

Referrals not restricted to health professionals, time since stroke or patient's residence.

Focus on:

- Rehabilitation
- Maximising quality of life
- Disability management
- Secondary complication prevention
- Reducing carer burden

Service structure

7 day working.

Holistic assessment completed within **1** week of discharge.

Integrated stroke services* with ESD.

Flexible working.

Working across organisations

Seamless transitions through in-reach into acute teams for:

- Joint home visits
- Discharge planning meetings

Collaboration with:

- Care homes
- Specialist teams
- Social care
- Community matron

Support access to:

- Exercise groups
- Accessible transport
- Voluntary groups*

Communication

Contact should be made with patient or carer/family within **1** working day from discharge.

Communication should be clear, accessible and co-ordinated.

Contact details for a key member should be available.

Audit

Teams should participate in **national audit programmes*** such as SSNAP or SSCA

Other data could include:

- Unmet needs
- 90-day mortality
- Hospital readmission 30 days
- Social care requirements

Research

Teams should:

- Encourage active involvement in research, both patients and staff.
- Share good practice through case studies
- Disseminate and implement research findings within practice.

MDT = Multidisciplinary Team
ESD = Early Supported Discharge
SSNAP = Sentinel Stroke National Audit Programme
SSCA = Scottish Stroke Care Audit

Version 1, 2021

Multidisciplinary interventions

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Specific interventions and MDT skills

The MDT should have the knowledge and expertise to offer the following specialist assessments and interventions.

- Skin integrity^ and continence
- Carer burden^
- Postural support and seating^
- Environment^ including adaptation & equipment
- Communication^
- Cognition^ including apraxia
- Sexual activity & relationships
- Mood disorders
- Activities of daily living including basic self-care tasks
- Spasticity and Pain^
- Mobility transfers, including vehicle access
- Upper limb^ impairments
- End of life care
- Financial guidance
- Medication management
- Fatigue and sleep hygiene

Goal setting

Patients (and carers) should be supported to engage in **joint** goal setting with the MDT.

Goals should be:

- Meaningful to the patient
- Aspirational
- Realistic
- Based on holistic MDT assessments

Outcome measures

Use validated outcome measures which are sensitive to change for both impairment and global function, e.g. quality of life.

Ensure measures are accessible for those with communication difficulties.

Recorded within **2 weeks** of discharge from the hospital and reviewed at agreed timepoints.

Education

- The team should be involved in raising the awareness of meaningful outcomes amongst commissioners and other healthcare professionals.
- Education should include self-management and reducing secondary complications amongst patients, families and carers (especially those in care homes).

* Areas which have been identified in the long-term plan https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

^ Areas which have been identified by the James Lind Alliance and Stroke Association as priorities for further investment in research priorities_in_stroke_rehabilitation_and_lon-term_care.pdf

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