

REVIEW

Open Access



Assessing stroke survivors' knowledge: a scoping review of tools and influencing factors

Allam Harfoush^{1,2*} , Kausik Chatterjee^{1,3} and Hanady Hamdallah⁴

Abstract

Background Stroke survivors' knowledge of their condition is essential for self-management and adherence to secondary prevention strategies. However, current methods for assessing stroke knowledge are not consistent. This scoping review aimed to review existing assessment tools, evaluate their characteristics, and identify factors associated with stroke knowledge to inform the development of more effective, patient-centred educational strategies.

Review design and methods A scoping review was conducted to evaluate existing methods used to assess stroke knowledge and the factors influencing patients' knowledge among stroke survivors. Systematic searches of PubMed, Cochrane, and CINAHL were performed from inception to June 2025. Studies assessing stroke survivors' knowledge were included. Data were extracted on tool characteristics, assessed themes, administration methods, readability, validation, and knowledge-associated factors. Findings were qualitatively synthesised.

Results Thirty-nine studies were included. Most studies assessed mixed cohorts of ischaemic, haemorrhagic, and TIAs. Stroke symptoms and risk factors were the most frequently assessed themes, while rehabilitation, medications, and lifestyle behaviours were less explored. Tools were primarily self-administered questionnaires, typically completed in under 15 min, but often lacked standardised cut-off values and demonstrated limited reporting of development processes. Factors positively associated with knowledge included higher education, younger age, and healthier lifestyles.

Conclusion Existing assessments of stroke survivors' knowledge have considerable variability, limited validation, and inconsistent alignment with survivors' information needs. Developing standardised, validated, and patient-centred assessment tools that are tailored to stroke type and accessible across literacy levels is essential for advancing stroke education and supporting long-term recovery. These findings can inform policymakers in tailoring education efforts and designing interventions that directly address knowledge gaps across diverse stroke survivor populations. Future research should prioritise longitudinal evaluation of knowledge and its impact on clinical outcomes.

Keywords Cerebrovascular disorders, Health knowledge, Attitudes, Practice, Patient education

*Correspondence:

Allam Harfoush
a.harfoush@chester.ac.uk

¹The Faculty of Health, Medicine, and Society, University of Chester,
Chester CH1 4BJ, UK

²North Bristol NHS Foundation Trust, Southmead Road, Bristol
BS10 5NB, UK

³Aintree University Hospital, Lower Ln, L9 7AL Fazakerley, Liverpool, UK

⁴UCL Primary Care & Population Health, UCL, Gower St,
London WC1E 6BT, UK



© Crown 2025. **Open Access** This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>.

Background

Stroke is one of the leading causes of death and long-term disability worldwide. According to the World Stroke Organisation, over 12 million people experience a stroke each year [1]. Beyond its physical and cognitive effects, stroke places a significant economic and social costs [2]. This burden is particularly evident in the UK, where the annual cost exceeds £26 billion [3]. Furthermore, nearly 40% of strokes in the UK affect individuals of working age, contributing to reduced workforce participation and increased demand on social support [4].

Although medical advancements have improved acute stroke care, effective recovery and secondary prevention require strategies that go beyond immediate clinical interventions. Optimal post-stroke management depends on survivors' active involvement in their treatment plans [5]. Patients who are well-informed are more likely to engage in their care, make informed decisions, and integrate preventive measures into daily routines [6–8].

However, despite its importance, stroke survivors' knowledge remains an often-overlooked component of long-term care. Knowledge gaps persist due to inconsistent information delivery, limited time for patient education in clinical settings, and variability in the quality of educational resources [9]. This suggests the need to review existing assessment tools to inform the development of high-quality tools to be aligned with the emerging field of precision medicine [10]. While previous reviews have summarised the methods used to assess stroke knowledge, factors associated with knowledge have not been comprehensively reviewed. Therefore, this scoping review was conducted to address the following questions: What tools are currently used to assess stroke survivors' knowledge, and what are their characteristics and what individual and contextual factors are associated with variations in stroke knowledge among survivors. By answering these questions, this review aims to inform the design of standardised, validated, and patient-centred assessment tools and support the development of targeted education strategies for stroke survivors.

Literature search

Search strategy

A literature search was undertaken across three databases, PubMed, Cochrane Library, and CINAHL, from inception till June 2025. The search strategy included the following keywords (stroke[Title/Abstract] OR cerebrovascular disease[Title/Abstract] OR transient ischaemic attack[Title/Abstract] OR TIA[Title/Abstract]) AND (education[Title/Abstract] awareness[Title/Abstract] OR knowledge[Title/Abstract] OR understanding[Title/Abstract]) AND (questionnaire[Title/Abstract] OR scale[Title/Abstract] OR survey[Title/Abstract]). The search strategy was piloted first by trailing several

combinations of keywords. No language restrictions or additional database filters were applied at the initial search stage. Manual screening of the reference lists of the included studies was also used to identify any further relevant studies (other methods in the PRISMA flow chart).

Selection criteria

Before the search, a set of inclusion and exclusion criteria was established. The inclusion criteria were studies evaluating stroke survivors' disease knowledge at any stage of their condition, involving participants aged 18 or older. While studies exclusively assessing stroke knowledge in the general public without inclusion of stroke survivors, studies that included interventions, studies that focused on a certain non-stroke focused aspect of knowledge (e.g. obstructive sleep apnoea, depression) were excluded. Grey literature, such as unpublished theses, conference abstracts, and institutional or government reports, was excluded to maintain a focus on studies that had undergone formal peer review, to ensure a minimum level of methodological transparency and reporting quality. This decision was made because such sources often lack sufficient detail on study design, sample characteristics, and statistical analysis, making it difficult to assess the validity of findings or include them meaningfully in synthesis, which could compromise the consistency and reliability of the review's findings. However, we acknowledge that excluding grey literature may have led to disregarding of potentially relevant outcomes and we do acknowledge the potential for publication bias in this review. Similar exclusion criterion has been applied in other literature reviews on stroke-related knowledge and education [55].

Data extraction

The studies were screened based on their titles and abstracts to identify eligible publications. If the title and abstract were inconclusive, a thorough full-text review was conducted. Additionally, duplicates were manually removed by cross-referencing the title, publication date, author names, and abstracts. Selection procedures adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Themes of the scoping review

Data were extracted using a structured Excel sheet, collecting study- and participant-related characteristics. At the study level, extracted data included the country of origin, sample size, and included population for each study. The assessment tools used to measure stroke knowledge were also recorded, including the tool's name, year of development, and the method by which it was created. Additionally, the themes covered by each tool, administration method, and, where available, the number

of questions, question type, and Flesch readability score were also documented. Moreover, data on whether the tool had any form of optimisation to assess reliability and validity were included where available. In addition, participant-related variables that associated with stroke knowledge were extracted, including demographic, medical, and lifestyle factors.

The rationale behind using narrative synthesis

Although meta-analysis would be a valuable method for synthesising quantitative findings across studies, it was not appropriate in this review due to substantial heterogeneity across included studies. Specifically, the variability in outcome measures, statistical reporting, and methodological approaches. Firstly, there was considerable variation in how stroke awareness and symptom recognition were reported. For example, Wongwiangjunt et al., 2015 [29] and Mosley et al., 2013 [33] reported adjusted odds ratios (ORs) with 95% confidence intervals for factors associated with stroke awareness, enabling direct statistical comparison. In contrast, Slark et al., 2012 [34] and Sloma et al., 2010 [36] presented only descriptive data in the form of percentages, such as the proportion of participants recognising FAST symptoms or identifying stroke risk factors, without statistics or variance estimates. This lack of effect size reporting meant that essential statistical inputs for a meta-analysis were unavailable. Secondly, the inconsistency

in statistical reporting further limited synthesis. While Wongwiangjunt et al., 2015 [29] and Mosley et al., 2013 [33] used multivariable logistic regression, Widjaja et al., 2021 [15] reported chi-square test results and Spearman's correlation coefficients, without ORs or standard errors. Soto-Cámara et al., 2020 [16] provided raw frequencies and p-values for symptom recognition, but insufficient data to reliably calculate or standardise effect sizes across studies. Furthermore, numerical reporting formats varied widely, with some studies presenting mean $\pm$ SD, others reporting median with interquartile range, and some not reporting obvious numerical outcomes. While statistical methods exist to approximate means and SDs from medians and IQRs [11], these rely on assumptions of normality that may not hold for knowledge data, which is often skewed [12]. Additionally, pooling results across incompatible measurement scales would risk producing misleading outcomes. Due to these methodological and statistical inconsistencies, a narrative synthesis was chosen as the most appropriate approach to integrate and interpret the available evidence.

Overview of reviewed studies and factors influencing stroke knowledge

Thirty-nine studies published between 1997 and 2024 (Fig. 1, PRISMA flowchart) were included. Table 1 summarises the study characteristics and the tools used to assess stroke knowledge.

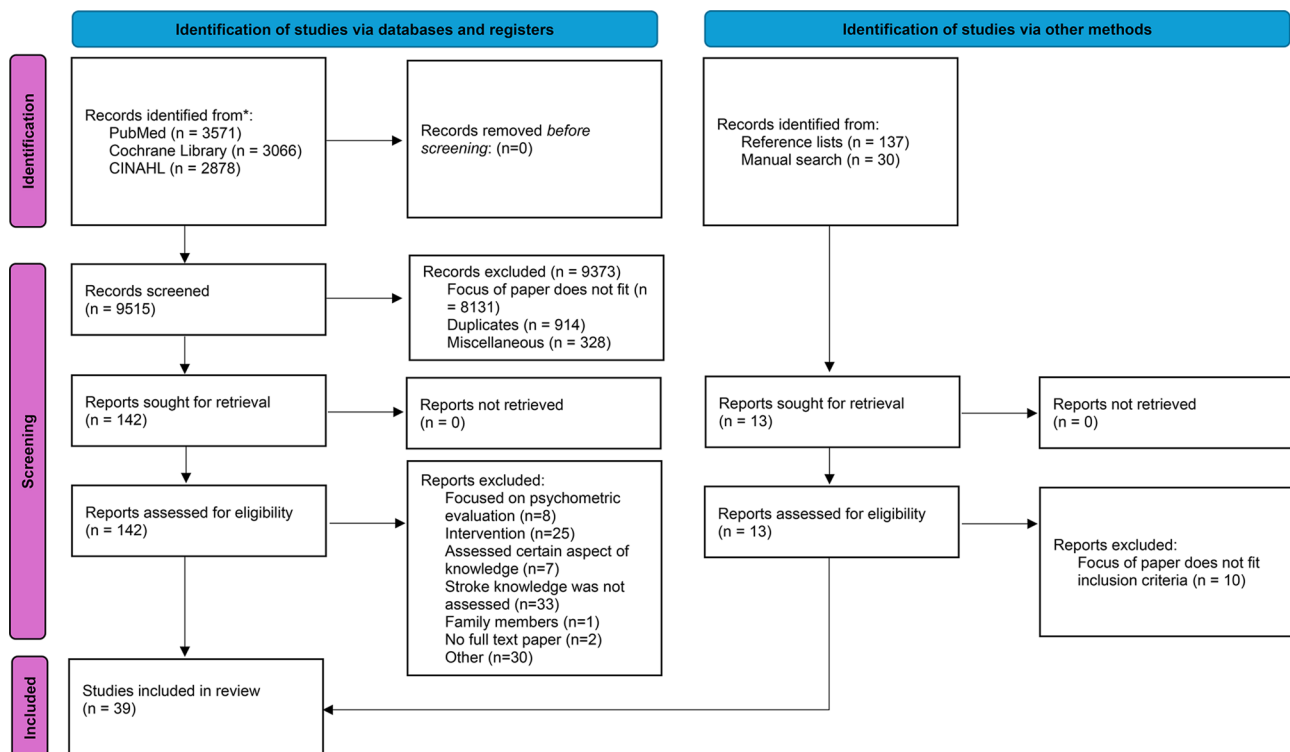


Fig. 1 The PRISMA flowchart of this scoping review

Table 1 The outcomes of the reviewed studies

Study	Country	Sample	Population	Exclusion Criteria	Tool	Question Format (No.)	Readability (Score)	Access	Mean Score / Cut-off Value	Optimisation
Bhutta et al., 2024 ¹³	Qatar	165	Stroke	clinically unstable, Aphasia	Act FAST	Open ended (12)	70.5	Yes	Recalling >3 of FAST	NS
Haque et al., 2021 ¹⁴	Bangladesh	50	Stroke	NS	NS	Open ended (7)	NS	No	Correct answers to ≥4 out of 7 questions	No
Widjaja et al., 2021 ¹⁵	Indonesia	215	Recurrent stroke	Aphasia, dementia	SKT	MCQ (20)	91.5 (very easy, grade 5)	Yes	7.89±3.38/20 (0–10: low, 11–20: high)	Yes
Soto-Cámara et al., 2020 ¹⁶	Spain	529	Stroke/TIA	Anamnesis, dementia	Self-designed	2 open ended and 1 MCQ (3)	65.5 (standard, grade 8-9)	Yes	NS	Yes
Ranawaka et al., 2020 ¹⁷	Sri Lanka	164	Stroke/TIA	Previous stroke/IHD, Aphasia	Self-designed	NS (40)	NS	No	(47.79%±14.6) <50%: poor, 50-75%: good, >75%: very good	No
Alhusayni et al., 2020 ¹⁸	Saudia Arabia	82	Stroke/TIA	NS	Self-designed	2 MCQ and 1 open ended (3)	58.4 (difficult, grade 10 to 12)	Yes	NS	No
Alexandrov et al., 2019 ¹⁹	USA	1029	Stroke/TIA	Other than stroke	Self-designed	MCQ (2)	85.2 (easy, grade 6)	No	NS	Yes
Faiz et al., 2019 ²⁰	Norway	282	Stroke/TIA	NS	Self-designed	Open ended and MCQ (4)	65 (standard, grade 8-9)	Yes	NS	No
Faiz et al., 2018 ²¹	Norway	173	Stroke/TIA	Previous thrombolysis/IHD, Aphasia	Self-designed	2 MCQ and 3 open ended (5)	82.2 (easy, grade 6)	Yes	NS	No
Wang et al., 2018 ²²	China	1531	Acute ischaemic stroke	TIA	Self-designed	Yes/no (24)	27.7 (Very difficult, graduate)	Yes	15.6/25	Yes
Kaddumukasa et al., 2017 ²³	Uganda	81	Stroke/TIA	NS	Self-designed	NS	NS	NS	NS	No
Saengsuwan et al., 2017 ²⁴	Thailand	140	Recurrent stroke/TIA	Aphasia/dementia	Self-designed	5 open ended and 17 Yes/no (22)	65.3 (Plain English, grade 8-9)	Yes	NS	Yes
Mellon et al., 2016 ²⁵	Ireland	149	Ischaemic stroke	Haemorrhage/TIA, Aphasia	SAQ	Open-ended (2)	96 (very easy, grade 5)	Yes	Naming >2 symptoms and >2 RF	Yes
HA et al., 2016 ²⁶	China	328	Stroke/TIA	Confusion	STAT	MCQ (21)	74.1 (easy, grade 7)	Yes	NS	Yes
Onabajo & Moses 2016 ²⁷	Nigeria	69	Stroke	NS	Self-designed	Open ended	NS	No	Naming one or more correct RF	Yes
Shravani et al., 2015 ²⁸	India	100	Stroke	TIA	Self-designed	Open ended	NS	No	NS	No
Wongwiangjunt et al., 2015 ²⁹	Thailand	217	Acute stroke/TIA	NS	Self-designed	Open ended (7)	90.9 (very easy, grade 5)	Yes	NS	No
Sanders et al., 2014 ³⁰	USA	100	Acute ischaemic stroke	Prisoners and aphasia	SPER	Open ended (5)	90.6 (very easy, grade 5)	Yes	NS	NS
Sundseth et al., 2014 ³¹	Norway	287	Acute stroke/TIA	SAH, hospital stroke	Self-designed	Close and open ended (2)	93.8 (very easy, grade 5)	Yes	Naming the FAST symptoms and >2 RF	NS
Panício et al., 2014 ³²	Brazil	104	Acute stroke/TIA	extra-axial hematomas	Self-designed	NS	NS	No	NS	NS
Mosley et al., 2013 ³³	Australia	198	Stroke/TIA	Members of ES	Self-designed	Open ended (3)	NS	Yes	Identify it was a stroke, seek emergency	NS
Slark et al., 2012 ³⁴	UK	622	Stroke/TIA	NS	Self	NS	NS	No	NS	NS
Zeng et al., 2012 ³⁵	China	1200	Stroke/TIA	NS	Self-designed	Yes/no (21)	13.9 (difficult, college)	Yes	<5 answers: low, 5-15: mid, >15: good	No
Sloma et al., 2010 ³⁶	Sweden	182	Stroke/TIA	SAH	Self-designed	Yes/no/don't know (17)	1 (difficult, college)	Yes	NS	Yes
Stead et al., 2008 ³⁷	USA	400	Ischaemic/TIA	NS	Self-designed	4 Yes/no, 1 open ended, 1 MCQ (6)	81.6 (easy, grade 6)	Yes	NS	Yes
Maasland et al., 2007 ³⁸	Netherlands	57	TIA	Members of ES, aphasia	Self-designed	NS	NS	No	41.2 ±10.4/71	NS
Das et al., 2007 ³⁹	India	660	Stroke/TIA	NS	Self-designed	MCQ (2)	42.2 (Difficult, college)	Yes	NS	No
Hoffmann et al., 2007 ⁴⁰	Australia	138	Stroke/TIA	Aphasia, dementia	Self-designed	NS	NS	NS	16/25	NS
Pandian et al., 2006 ⁴¹	India	147	Stroke/TIA	NS	Self-designed	NS	NS	NS	NS	NS
Lowe et al., 2006 ⁴²	UK	100	Acute stroke	Aphasia	SKQ	1 MCQ, 1 Open, 6 Yes/no (8)	73.6 (fairly easy, grade 7)	Yes	7.3	Yes
Croquelois & Bogousslavsky, 2006 ⁴³	Switzerland	164	Stroke/TIA	Aphasia, dementia	NS	Yes/no (2)	17 (Very difficult, college)	Yes	NS	No
Barr et al., 2006 ⁴⁴	Australia	150	Stroke/TIA	Aphasia	RSSQ	NS	NS	NS	NS	NS
Smith et al., 2004 ⁴⁵	UK	170	Stroke/TIA	Aphasia	Self-designed	Yes/no/don't know (17)	69 (Standard, grade 8-9)	Yes	10/17	No
Carroll et al., 2004 ⁴⁶	UK	40	Stroke/TIA	SAH, aphasia	Self-designed	NS	NS	NS	40%	NS
Cheung, 2001 ⁴⁷	Hong Kong	71	Stroke/TIA	Aphasia/dementia	Self-designed	NS	NS	NS	NS	NS
Weltermann et al., 2000 ⁴⁸	Germany	133	Stroke/TIA	NS	Self-designed	NS	NS	NS	NS	NS
Clark & Smith 1998 ⁴⁹	Australia	60	Stroke in rehabilitation	Lived alone, aphasia	SCIT	NS	NS	No	NS	Yes
Williams et al., 1997 ⁵⁰	USA	67	Stroke/TIA	NS	Self-designed	NS	NS	NS	NS	NS
Kothari et al., 1997 ⁵¹	USA	163	Stroke/TIA/SAH	Aphasia/dementia	Self-designed	NS	NS	NS	NS	NS

Colour coding Blue: self-designed Grey: MCQ, Light yellow: yes/no, Light blue: open-ended Red: difficult, green: easy Yellow: available

NS: not stated, No: number, SKT: Stroke Knowledge Test, MCQ: multiple choice question, TIA: Transient ischaemic attack, IHD: Ischaemic heart disease, SAQ: Stroke Awareness Questionnaire, STAT: Stroke Action Test, SPER: Stroke Patient Education Retention, SKQ: Stroke knowledge questionnaire, RSSQ: Response to Stroke Symptoms Questionnaire, SCIT: Stroke Care Information Test

Characteristics of the studies

The targeted population

The studies included a diverse population, mostly patients with haemorrhagic and ischaemic strokes, as well as transient ischaemic attacks (TIAs). However, three studies focused exclusively on patients with ischaemic strokes [22, 25, 30], one study on individuals with only TIAs [38], and another on patients with recurrent stroke [15]. This diversity could lead to overgeneralisation, as each group has different stroke aetiology, risk factors, and management plans [52]. For example, ischaemic strokes are often associated with atherosclerosis and cardioembolic events, while haemorrhagic strokes are more commonly linked to hypertension and vascular malformations [53], suggesting that a one-size-fits-all approach may overlook important differences in patients' knowledge across stroke types.

Additionally, some studies recruited participants within the first 48 h of admission. Cognitive deficits such as memory loss, confusion, and reduced attention are common in the acute phase of stroke and can impact comprehension, which can underestimate survivors' true knowledge [54]. Additionally, most reviewed studies excluded survivors with aphasia and communication disorders. The observed heterogeneity highlights the need for future research to adopt more homogeneous samples, focusing on specific stroke types to improve the interpretability of findings.

The explored themes

While stroke symptoms and risk factors were the most commonly assessed themes (Fig. 2, which shows that certain themes are less explored in the literature), other equally important areas, such as rehabilitation, medications, and lifestyle behaviours, received less attention.

This narrow focus may limit the clinical effectiveness of information, as survivors often face challenges navigating post-discharge care without adequate support and potentially leading them to social isolation [8, 55, 56]. A broader exploration of such themes could better identify knowledge gaps and highlight areas where survivors need support, positively impacting their recovery and long-term health.

Method of administration

Most studies used self-administered questionnaires, reflecting their convenience and cost-effectiveness. In contrast, interviews, though helpful for clarifying responses, were less common due to higher costs and logistical complexity. In the literature, the method of administration (self-administered vs. interviews) generally did not significantly affect questionnaire scores [57]. However, self-administered tools tend to be more reliable for sensitive topics [58], as respondents may feel more comfortable and honest without an interviewer present, reducing social desirability bias and improving response accuracy.

Questionnaire format & administration time

While completion time data was not available for most studies, those reported it had an average time of less than 15 min. This suggests a design focused on conciseness and user-friendliness, which can increase participant engagement and minimise respondent fatigue, thus supporting higher-quality responses [59]. This is especially important in clinical and research settings where time and participant adherence are essential. However, such brevity may limit the depth of information collected, requiring a balance between efficiency and comprehensiveness.

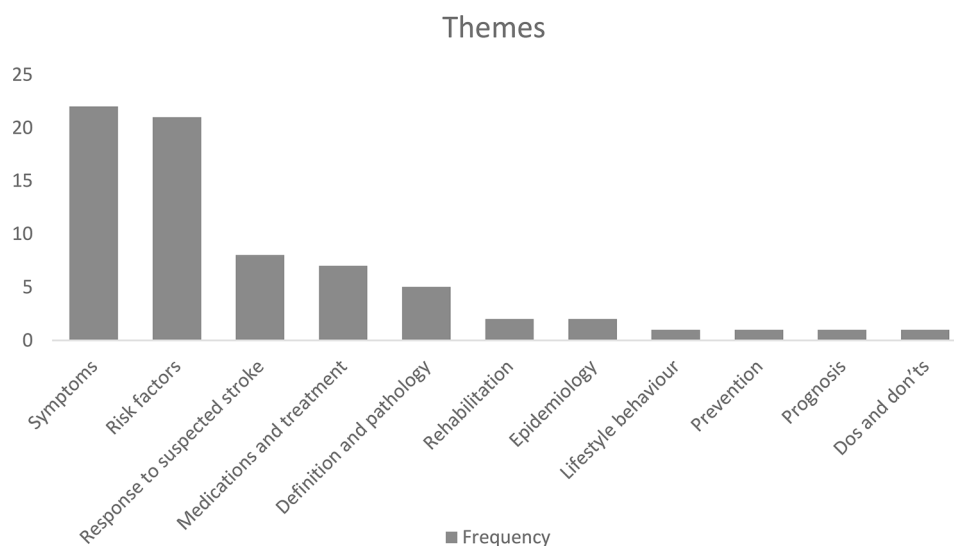


Fig. 2 The frequency of the explored themes in our review

The number of questions across studies varied widely, from 2 to 40, and included formats such as yes-or-no, multiple-choice (MCQs), and open-ended questions. This reflects variable research aims and contexts, which affects the scope and depth of each questionnaire, as too many questions or overly complex formats may lead to respondent fatigue and lower completion rates [59]. Each questionnaire format has advantages and disadvantages. Yes-or-no formats are straightforward and quick, ideal for gathering basic information or assessing binary outcomes [60]. Multiple-choice questions allow a broader range of responses, enabling a more detailed assessment of understanding and reducing guesswork compared to yes-or-no formats [61]. Open-ended questions allow in-depth knowledge assessment but can be more challenging to analyse quantitatively [62].

The number and type of questions should align with the study's objectives. Researchers might favour yes-or-no questions for basic knowledge, while deeper insights may require multiple-choice or open-ended formats [63]. Consideration of the target population and administration context is also essential; for example, shorter, simpler questionnaires may be more suitable for individuals with cognitive or reading difficulties.

Tool reporting, readability, and validation

Most questionnaires were not published in the original articles or their appendices, creating challenges for researchers looking to build on these studies' findings. While some studies gave descriptions or question examples in the methodology sections, this does not replace accessing the full questionnaires. Sharing full questionnaires ensures consistent data collection, facilitates cross-study validation, and enables future research to build on robust foundations. All available extracted questionnaires are presented in Appendix A.

Most included questionnaires scored ≥ 60 on the Flesch scale (grade 8–9), indicating general readability [64]. However, some exceeded grade 9, posing potential challenges for stroke survivors, who often read at grade 7–8 levels [65]. Readability is essential, as complex language causes misunderstandings, incomplete responses, and less reliable data [66], especially that stroke survivors may have visual and reading difficulties [67].

Only seven questionnaires from the reviewed studies specified cut-off values for knowledge scores. These values categorise varying knowledge levels and inform educational interventions. However, the methods used to determine these cut-off values were not reported, which is essential to accurately interpret knowledge assessments and identify individuals who require additional educational input [68]. This should include statistical justifications, evidence from prior research, or expert opinions.

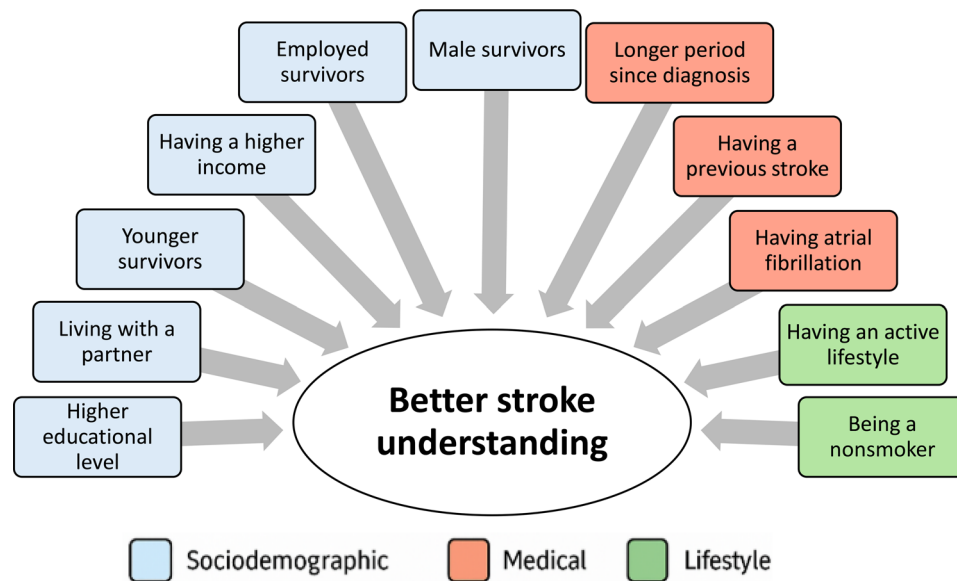
Nearly half of the tools used did not report the optimisation process. This process confirms that the questionnaire is clear, reliable, and valid before full administration [69]. Addressing these problems beforehand reduces the risk of data collection errors. Additionally, it allows researchers to test logistical aspects of the study, including completion time, ease of administration, and the overall data collection process [70].

Factors affecting stroke survivors' knowledge

We identified several factors influencing survivors' knowledge, categorised into three groups: sociodemographic, medical, and lifestyle-related factors. As illustrated in Fig. 3, stroke knowledge is shaped by a combination of elements such as education, social support, health behaviours, and medical history. However, generalising these results is challenging since each assessment tool evaluated different aspects of stroke knowledge. Nonetheless, our findings may reflect a general trend regarding these factors, with a detailed presentation provided in Table 2. During data extraction, we intended to conduct a meta-analysis of factors influencing knowledge using the data in Table 2, but methodological and statistical heterogeneity prevented this. Many studies lacked sufficient detail, with inconsistent reporting and missing statistics such as standard deviations and confidence intervals. Consequently, we performed a qualitative synthesis, identifying three categories of influencing factors: sociodemographic, medical, and lifestyle-related (Fig. 3). These factors emerged as significant across several studies, despite variations in design, sample size, and methodology, suggesting a potential trend.

Sociodemographic-related (Blue)

There is a positive association between higher education levels and increased stroke knowledge, as educated individuals are more likely to understand and use health information effectively, adopt healthier lifestyles, and access health-related resources [71]. Additionally, patients living with a partner tend to have a deeper knowledge of stroke due to the support provided by their partners [72]. This support can lead to better communication, emotional support, and assistance in managing health-related issues. Younger survivors often engage more actively in managing their health by seeking information, while older patients may rely more on healthcare providers for decision-making [73]. Furthermore, individuals with higher incomes typically have better access to education and healthcare services, improving their stroke knowledge [74]. Employment is also linked to reduced social isolation, contributing to better disease knowledge by providing social interaction and access to information [75]. Lastly, male survivors can have greater access to and use of health information [76], which can

**Fig. 3** Factors influencing knowledge levels**Table 2** The knowledge outcomes in the included studies

Study	Lower education	Having a partner	Older age	Higher income	Employed	Male	Previous stroke	Longer period	Disability	AF	Smoking	BMI	Sedentary lifestyle	DM	Hyperlipidaemia	HTN
Bhutta et al., 2024 ¹³																
Haque et al., 2021 ¹⁴																
Widjaja et al., 2021 ¹⁵	■							■	■							
Soto-Cámara et al., 2020 ¹⁶	■	■	■	■	■	■	■				■	■	■	■	■	■
Ranawaka et al., 2020 ¹⁷	■															
Alhusayni et al., 2020 ¹⁸	■	■						■			■		■			
Alexandrov et al., 2019 ¹⁹	■															
Faiz et al., 2018 ²¹	■															
Wang et al., 2018 ²²				■			■	■					■			
Kaddumukasa et al., 2017 ²³	■	■	■			■	■	■								
Saengsuwan et al., 2017 ²⁴	■	■	■			■										
Mellon et al., 2016 ²⁵																
HA et al., 2016 ²⁶																
Onabajo & Moses 2016 ²⁷	■		■			■										
Shravani et al., 2015 ²⁸	■					■										
Wongwianjunt et al., 2015 ²⁹		■				■				■				■	■	■
Sanders et al., 2014 ³⁰	■		■	■	■	■										
Sundseth et al., 2014 ³¹	■	■	■	■		■	■									
Panício et al., 2014 ³²	■		■	■		■										
Mosley et al., 2013 ³³			■			■										
Slark et al., 2012 ³⁴			■			■										
Zeng et al., 2012 ³⁵	■		■			■										
Sloma et al., 2010 ³⁶		■	■			■				■						
Stead et al., 2008 ³⁷			■			■										
Maasland et al., 2007 ³⁸	■		■			■	■									
Das et al., 2007 ³⁹	■		■			■										
Hoffmann et al., 2007 ⁴⁰	■		■	■												
Pandian et al., 2006 ⁴¹	■		■	■												
Lowe et al., 2006 ⁴²			■													
Croquelis & Bogousslavsky, 2006 ⁴³			■													
Barr et al., 2006 ⁴⁴	■	■	■		■	■	■			■	■	■		■	■	■
Smith et al., 2004 ⁴⁵			■													
Carroll et al., 2004 ⁴⁶			■													
Cheung, 2001 ⁴⁷	■		■			■	■									
Weltermann et al., 2000 ⁴⁸		■	■			■	■									
Clark & Smith 1998 ⁴⁹			■			■										
Williams et al., 1997 ⁵⁰			■			■	■									
Kothari et al., 1997 ⁵¹	■		■	■		■										
Summary	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■

■ Red for lower stroke knowledge, ■ Green for higher stroke knowledge, ■ Grey for no statistically significant association

be influenced by various social, cultural, and economic factors.

Additional underexplored area identified in this review is the role of cultural and regional differences in shaping stroke survivors' knowledge.

Medical-related factors (Red)

Individuals with a history of stroke might have better knowledge due to their prior experiences with the warning signs and necessary lifestyle adjustments. Experiencing a stroke firsthand can motivate survivors to learn more about the condition to prevent recurrence. Additionally, a longer period since diagnosis could lead to

better knowledge, as survivors gradually adapt to managing the condition and typically become more familiar with essential lifestyle changes, treatment, and risk factors over time [77]. Those managing atrial fibrillation also tend to engage in proactive information-seeking behaviours, due to the complexities of managing it, and since it increases stroke risk, people are often motivated to seek detailed information on both conditions [78].

Lifestyle-related factors (Green)

Smokers tend to show lower levels of stroke knowledge, possibly due to reported limitations in literacy when compared to non-smokers [79]. Smoking has been associated with negative health outcomes and cognitive decline, which may impair the ability to retain health information. Similarly, physical activity often correlates with proactive health-seeking behaviours, leading to higher levels of health knowledge [80]. Those who engage in regular physical activity may manage their health more actively.

The development of a formal conceptual framework to illustrate the interactions among these factors is planned as a subsequent step, building on the findings presented here.

Identified gaps and proposed actions

Based on this scoping review, several gaps in existing assessments of stroke survivors' knowledge were identified

First, the concept of "stroke survivor knowledge" remains inconsistently defined across studies, making it difficult to compare findings [81]. We propose conceptualising this concept prior to designing the methodology to evaluate stroke survivors' knowledge. In our future work, we propose a definition that involves two core elements: self-management, reflecting survivors' ability to independently manage their condition [82, 83], and relevant information, aligned with survivors individualised information needs [84, 85]. Importantly, many existing assessments did not adequately reflect on survivors' real-world priorities and focused narrowly on symptoms and risk factors, neglecting equally important domains such as medications, rehabilitation, and lifestyle behaviours.

Second, current assessment tools often take a one-size-fits-all approach, overlooking the distinct needs of survivors with different stroke types. Additionally, few studies clearly report how knowledge cut-off values were determined, limiting the ability to identify those who would benefit from targeted interventions. We propose tailoring questionnaires for different stroke types and applying transparent, standardised statistical methods to define cut-off values (e.g. using the ROC curve method).

Finally, the reporting and accessibility of tools remain limited, with many studies failing to publish full

questionnaires, detail their optimisation processes, or assess readability. Furthermore, important sociodemographic and behavioural factors, such as education, employment, smoking, and physical activity, were not consistently included, despite their potential influence on health knowledge.

Based on the limitations identified in this review, a future gold-standard stroke knowledge assessment tool should differ from existing instruments in several areas. First, it should have clearly defined and theory-informed conceptual framework of stroke knowledge. Second, it should include a broader set of domains, like stroke symptoms, risk factors, rehabilitation, medications, and lifestyle behaviours, reflecting the real-world priorities of survivors. Third, the tool should be tailored to stroke type (e.g., ischaemic vs. haemorrhagic) and designed with accessible readability thresholds (ideally at a Grade 7 level). Fourth, psychometric validation (e.g., construct validity, internal consistency) and transparent statistical techniques (e.g., ROC analysis to determine cut-off scores) should be added into the development process. Finally, it should systematically include sociodemographic and behavioural data to support risk stratification and targeted education strategies. These considerations are essential for developing a valid, patient-centred, and clinically useful tool that addresses current gaps and supports tailored post-stroke education.

Limitations, future direction, and clinical practice implications

This review has several limitations. First, the exclusion of grey literature may have led to missing valuable insights from non-peer-reviewed sources, such as clinical reports or government publications. Second, only English-language studies were included, which may have introduced language bias and limited the representation of stroke knowledge assessment practices from non-English-speaking regions. Third, several included studies had relatively small sample sizes, which may limit the statistical power and generalisability of their findings. Additionally, many studies lacked detail on questionnaire development or optimisation, affecting our ability to fully evaluate tool validity or reproduce their methodology. Finally, although a meta-analysis could have provided quantitative estimates of associations between influencing factors and stroke knowledge, the substantial heterogeneity in study designs, measurement tools, and reporting formats precluded direct comparisons and limited the generalisability of our findings.

Future research should prioritise the development of a validated assessment tool with clearly defined domains and appropriate psychometric properties. Studies should also explore and evaluate tailored educational interventions for stroke survivors that implement emerging

technologies, such as artificial intelligence, to personalise content based on individual knowledge gaps, cognitive and literacy levels, and learning preferences. Longitudinal designs could help assessing the sustained impact of such interventions on knowledge retention, adherence to secondary prevention strategies, functional recovery, and recurrence rates over time. In addition, future work should address the current gaps in accessibility and inclusivity by making full assessment tools available through appendices or supplementary materials to facilitate replication and refinement, and by including diverse survivor populations, particularly those from underrepresented socioeconomic and geographic groups. Finally, and to enable direct quantitative syntheses in the future, researchers should report statistical outcomes fully and consistently.

The findings of this review have direct implications for clinical practice. The identified gaps in knowledge domains, such as rehabilitation, highlight areas where targeted educational interventions can be developed to address survivors' information needs. Moreover, understanding how sociodemographic and medical factors influence knowledge might allow clinicians to tailor education based on patient characteristics, thereby improving engagement and supporting personalised recovery pathways.

Conclusion

This scoping review mapped and evaluated existing tools for assessing stroke survivors' knowledge, suggesting substantial variation in reliability, validity, and content domains. While the Stroke Knowledge Test demonstrated the strongest psychometric profile, no universally reliable and standardised instrument currently exists. This represents the need for a rigorously validated, adaptable tool grounded in precision medicine principles. The findings of this review can guide policymakers in selecting or developing more effective, inclusive, and evidence-based tools to improve patient education. Future research is needed to develop and validate a standardised, adaptable knowledge assessment tool and to examine how improved knowledge retention may influence health outcomes.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s41043-025-01046-3>.

Supplementary Material 1

Acknowledgements

AH would like to acknowledge the Council for At-Risk Academics (Cara) for their support and efforts.

Author contributions

A.H: Conceptualisation, Methodology, Project administration, Resources, Writing – original draft.K.C: Validation, Methodology, Project administration, Writing – review and editing.H.H: Validation, Methodology, Project administration, Writing – review and editing.

Funding

None received.

Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

This manuscript is a review of previously published articles and does not involve any new data collection, human participants, or animal studies. All data reviewed and discussed within this paper are publicly available in the original publications, and appropriate citations have been provided. Consequently, no ethical approval or informed consent was required for this study.

Consent for publication

All authors reviewed and agreed this version for publication.

Competing interests

The authors declare no competing interests.

Received: 7 March 2025 / Accepted: 8 August 2025

Published online: 26 September 2025

References

1. World Stroke Organization. Global stroke fact sheet 2022. *Int J Stroke*. 2022;17(1):18–29. <https://doi.org/10.1177/17474930211065917>.
2. Portegies MLP, Koudstaal PJ, Ikram MA. Cerebrovascular disease. In: Aminoff MJ, Boller F, Swaab DF, editors. *Handbook of clinical neurology*. Volume 138, 1st ed. Elsevier; 2016. pp. 239–61. <https://doi.org/10.1016/B978-0-12-802973-2.00014-8>.
3. Saka O, McGuire A, Wolfe C. Cost of stroke in the United Kingdom. *Age Ageing*. 2009;38(1):27–32. <https://doi.org/10.1093/ageing/afn281>.
4. Patel A, Berdunov V, Quayyum Z, King D, Knapp M, Wittenberg R. Estimated societal costs of stroke in the UK based on a discrete event simulation. *Age Ageing*. 2020;49(2):270–6. <https://doi.org/10.1093/ageing/afz162>.
5. Jaracz K, Grabowska-Fudala B, Górna K, Kozubski W. Consequences of stroke in the light of objective and subjective indices: a review of recent literature. *Neurol Neurochir Pol*. 2014;48(4):280–6. <https://doi.org/10.1016/j.jnnns.2014.07.004>.
6. Amdie FZ, Sawhney M, Woo K. The weakness of will: the role of free will in treatment adherence. *Patient Prefer Adherence*. 2022;16:1131–9. <https://doi.org/10.2147/PPA.S362706>.
7. ALAhmadi AF, ALSaedi MF, Alahmadi AE, Alharbi MG, Alharbi IH, Radman Al-Dubai SA. Pre-hospital delay among patients with acute myocardial infarction in Saudi arabia: a cross-sectional study. *Saudi Med J*. 2020;41(8):819–27. <https://doi.org/10.15537/smj.2020.8.25185>.
8. Nadila I, Syahrul S, Suherman S, Mamfaluti T, Firdaus S. Rehabilitation-related knowledge correlate to visit compliance in post-ischaemic stroke patients in an outpatient rehabilitation clinic. *Bali Med J*. 2021;10(2):549–52. <https://doi.org/10.15562/bmj.v10i2.2409>.
9. Nicholson TE, Edwards L, McArdle P. Knowledge is power: a quality improvement project to increase patient Understanding of their hospital stay. *BMJ Qual Improv Rep*. 2017;6(1):u207103w3042. <https://doi.org/10.1136/bmjquality.u207103.w3042>.
10. Delpierre C, Lefèvre T. Precision and personalized medicine: what their current definition says and silences about the model of health they promote. *Front Sociol*. 2023;8:1112159. <https://doi.org/10.3389/fsoc.2023.1112159>.
11. Wan X, Wang W, Liu J, Tong T. Estimating the sample mean and standard deviation from the sample size, median, range and/or interquartile range. *BMC Med Res Methodol [Internet]*. 2014;14(1):135. Available from: <https://doi.org/10.1186/1471-2288-14-135>

12. Nandy A, Basu A, Ghosh A. Robust inference for skewed data in health sciences. *J Appl Stat* [Internet]. 2022;49(8):2093–123. Available from: <https://doi.org/10.1080/02664763.2021.1891527>
13. Bhutta ZA, Pathan SA, Puolakka T, Akhtar N, Thomas SH, Harris T, et al. Assessing stroke awareness and behavioural response following the National 'act fast' stroke awareness campaign: insights from a cross-sectional survey in Qatar. *J Patient Exp*. 2024;11:23743735241242717.
14. Haque R, Kabir K, Hossain M, Habib MB, Khan AS, Hasan MJ. Knowledge of stroke and its risk factors among stroke survivors: a hospital-based study. *Mymensingh Med J*. 2021;30(2):376–86.
15. Widjaja KK, Chulavatnatol S, Suansanee T, Wibowo YI, Sani AF, Islamiyah WR, et al. Knowledge of stroke and medication adherence among patients with recurrent stroke or transient ischaemic attack in indonesia: a multi-center, cross-sectional study. *Int J Clin Pharm*. 2021;43(3):666–72. <https://doi.org/10.1007/s11096-020-01178-y>.
16. Soto-Cámara R, González-Bernal JJ, González-Santos J, Aguilar-Parra JM, Trigueros R, López-Liria R. Knowledge on signs and risk factors in stroke patients. *J Clin Med*. 2020;9(8):2557. <https://doi.org/10.3390/jcm9082557>.
17. Ranawaka U, Mettananda C, Thilakarathna C, Peiris A, Kasturiratna A, Tilakaratna Y. Stroke awareness in patients with incident stroke compared to patients without stroke or ischaemic heart disease. *J Stroke Cerebrovasc Dis*. 2020;29(6):104790. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2020.104790>.
18. Alhusayni SF, Abanmi NM, Abanemai NA, Alharbi RM, AlAtiyah FA, Abdalla SM, et al. Secondary stroke prevention among stroke survivors in Riyadh city, Saudi arabia: risk knowledge, adherence to stroke discharge medications and preventive strategies. *Neurosciences (Riyadh)*. 2020;25(2):118–28. <https://doi.org/10.17712/nsj.2020.2.20190059>.
19. Alexandrov AW, Brewer BB, Moore K, Grau C, Beenstock DJ, Cudlip F, et al. Measurement of patients' perceptions of the quality of acute stroke services: development and validation of the STROKE perception report. *J Neurosci Nurs*. 2019;51(5):208–16. <https://doi.org/10.1097/JNN.0000000000000471>.
20. Faiz KW, Labberton AS, Thommessen B, Rønning OM, Barra M. Stroke-related knowledge and lifestyle behaviour among stroke survivors. *J Stroke Cerebrovasc Dis*. 2019;28(11):104359. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2019.104359>.
21. Faiz KW, Sundseth A, Thommessen B, Rønning OM. Patient knowledge on stroke risk factors, symptoms and treatment options. *Vasc Health Risk Manag*. 2018;14:37–40. <https://doi.org/10.2147/VHRM.S152173>.
22. Wang MD, Wang Y, Mao L, Xia YP, He QW, Lu ZX, et al. Acute stroke patients' knowledge of stroke at discharge in china: a cross-sectional study. *Trop Med Int Health*. 2018;23(11):1200–6. <https://doi.org/10.1111/tmi.13148>.
23. Kaddumukasa MN, Katabira E, Sajatovic M, Pundik S, Kaddumukasa M, Goldstein LB. Influence of dietary salt knowledge, perceptions, and beliefs on consumption choices after stroke in Uganda. *J Stroke Cerebrovasc Dis*. 2017;26(12):2935–42. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2017.07.016>.
24. Saengsuwan J, Suangpho P, Tiamkao S. Knowledge of stroke risk factors and warning signs in patients with recurrent stroke or recurrent transient ischaemic attack in Thailand. *Neurol Res Int*. 2017;2017:8215726. <https://doi.org/10.1155/2017/8215726>.
25. Mellon L, Doyle F, Williams D, Brewer L, Hall P, Hickey A. Patient behaviour at the time of stroke onset: a cross-sectional survey of patient response to stroke symptoms. *Emerg Med J*. 2016;33(6):396–402. <https://doi.org/10.1136/emered-2015-204806>.
26. Ha M, Qian X, Yang H, Huang J, Liu C. Reliability and validity of a Chinese version of the stroke action test: a new instrument for assessment of stroke knowledge and response. *Iran J Public Health*. 2016;45(12):1595–603.
27. Onabajo G, Moses T. Knowledge of stroke risk factors among stroke survivors in Nigeria. *Stroke Res Treat*. 2016;2016:1902151. <https://doi.org/10.1155/2016/1902151>.
28. Shrivani K, Parmar MY, Macharla R, Mateti UV, Martha S. Risk factor assessment of stroke and its awareness among stroke survivors: a prospective study. *Adv Biomed Res*. 2015;4:187. <https://doi.org/10.4103/2277-9175.164011>.
29. Wongwiangjunt S, Komoltri C, Pongvarin N, Nilanont Y. Stroke awareness and factors influencing hospital arrival time: a prospective observational study. *J Med Assoc Thai*. 2015;98(3):260–4.
30. Sanders K, Schnepel L, Smotherman C, Livingood W, Dodani N, Antonios N, et al. Assessing the impact of health literacy on education retention of stroke patients. *Prev Chronic Dis*. 2014;11:E55. <https://doi.org/10.5888/pcd11.130259>.
31. Sundseth A, Faiz KW, Rønning OM, Thommessen B. Factors related to knowledge of stroke symptoms and risk factors in a Norwegian stroke population. *J Stroke Cerebrovasc Dis*. 2014;23(7):1849–55. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2014.02.026>.
32. Panício MI, Mateus L, Ricarte IF, Figueiredo MM, Fukuda TG, Seixas JC, et al. The influence of patient's knowledge about stroke in brazil: a cross sectional study. *Arq Neuropsiquiatr*. 2014;72(12):938–41. <https://doi.org/10.1590/0004-282X20140167>.
33. Mosley I, Nicol M, Donnan G, Thrift AG, Dewey HM. What is stroke symptom knowledge? *Int J Stroke: Official J Int Stroke Soc*. 2014;9(1):48–52. <https://doi.org/10.1111/ijss.12024>.
34. Slark J, Bentley P, Majeed A, Sharma P. Awareness of stroke symptomatology and cardiovascular risk factors amongst stroke survivors. *J Stroke Cerebrovasc Diseases: Official J Natl Stroke Association*. 2012;21(5):358–62. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2010.09.010>.
35. Zeng Y, He G-P, Yi G-H, Huang Y-J, Zhang Q-H, He L-L. Knowledge of stroke warning signs and risk factors among patients with previous stroke or TIA in china: knowledge of stroke warning signs and risk factors among patients. *J Clin Nurs*. 2012;21(19–20):2886–95. <https://doi.org/10.1111/j.1365-2702.2012.04118.x>.
36. Sloma A, Backlund LG, Strender L-E, Skånér Y. Knowledge of stroke risk factors among primary care patients with previous stroke or TIA: a questionnaire study. *BMC Fam Pract*. 2010;11(1):47. <https://doi.org/10.1186/1471-2296-11-47>.
37. Stead LG, Vaidyanathan L, Bellolio MF, Kashyap R, Bhagra A, Gilmore RM, Decker WW, Enduri S, Suravaram S, Mishra S, Nash D, Wood HM, Yassa AS, Hoff AM, Brown RD. Knowledge of signs, treatment and need for urgent management in patients presenting with an acute ischaemic stroke or transient ischaemic attack: a prospective study. *Emerg Med J*. 2008;25(11):735–9. <https://doi.org/10.1136/emj.2008.058206>.
38. Maasland L, Koudstaal PJ, Habbema JDF, Dippel DWJ. Knowledge and Understanding of disease process, risk factors and treatment modalities in patients with a recent TIA or minor ischaemic stroke. *Cerebrovasc Dis*. 2007;23(5–6):435–40. <https://doi.org/10.1159/000101468>.
39. Das K, Mondal GP, Dutta AK, Mukherjee B, Mukherjee BB. Awareness of warning symptoms and risk factors of stroke in the general population and in survivors stroke. *J Clin Neuroscience: Official J Neurosurgical Soc Australasia*. 2007;14(1):12–6. <https://doi.org/10.1016/j.jocn.2005.12.049>.
40. Hoffmann T, McKenna K, Worrall L, Read SJ. Randomised trial of a computer-generated tailored written education package for patients following stroke. *Age Ageing*. 2007;36(3):280–6. <https://doi.org/10.1093/ageing/afm003>.
41. Pandian JD, Kalra G, Jaison A, Deepak SS, Shamsher S, Singh Y, Abraham G. Knowledge of stroke among stroke patients and their relatives in Northwest India. *Neurol India*. 2006;54(2):152–6. discussion 156.
42. Lowe DB, Sharma AK, Leathley MJ. The carefile project: a feasibility study to examine the effects of an individualised information booklet on patients after stroke. *Age Ageing*. 2007;36(1):83–9. <https://doi.org/10.1093/ageing/af145>.
43. Croquelois A, Bogousslavsky J. Risk awareness and knowledge of patients with stroke: results of a questionnaire survey 3 months after stroke. *J Neurol Neurosurg Psychiatry*. 2006;77(6):726–8. <https://doi.org/10.1136/jnnp.2005.07.8618>.
44. Barr J, McKinley S, O'Brien E, Herkes G. Patient recognition of and response to symptoms of TIA or stroke. *Neuroepidemiology*. 2006;26(3):168–75. <https://doi.org/10.1159/000091659>.
45. Smith J, Forster A, Young J. A randomized trial to evaluate an education programme for patients and carers after stroke. *Clin Rehabil*. 2004;18(7):726–36. <https://doi.org/10.1191/0269215504cr790oa>.
46. Carroll C, Hobart J, Fox C, Teare L, Gibson J. Stroke in devon: knowledge was good, but action was poor. *J Neurol Neurosurg Psychiatry*. 2004;75(4):567–71. <https://doi.org/10.1136/jnnp.2003.018382>.
47. Cheung RT. Hong Kong patients' knowledge of stroke does not influence time-to-hospital presentation. *J Clin Neuroscience: Official J Neurosurgical Soc Australasia*. 2001;8(4):311–4. <https://doi.org/10.1054/jocn.2000.0805>.
48. Weltermann BM, Homann J, Rogalewski A, Brach S, Voss S, Ringelstein EB. Stroke knowledge among stroke support group members. *Stroke*. 2000;31(6):1230–3. <https://doi.org/10.1161/01.str.31.6.1230>.
49. Clark MS, Smith DS. Knowledge of stroke in rehabilitation and community samples. *Disabil Rehabil*. 1998;20(3):90–6. <https://doi.org/10.3109/09638289809166061>.
50. Williams LS, Bruno A, Rouch D, Marriott DJ, Mas J. Stroke patients' knowledge of stroke: influence on time to presentation. *Stroke*. 1997;28(5):912–5. <https://doi.org/10.1161/01.str.28.5.912>.

51. Kothari R, Sauerbeck L, Jauch E, Broderick J, Brott T, Khoury J, Liu T. Patients' awareness of stroke signs, symptoms, and risk factors. *Stroke*. 1997;28(10):1871–5. <https://doi.org/10.1161/01.str.28.10.1871>.
52. Unnithan AKA, Das JM, Mehta P. Hemorrhagic stroke. StatPearls Publishing; 2022.
53. Salvadori E, Papi G, Insalata G, Rinnoci V, Donnini I, Martini M, Falsini C, Hakiki B, Romoli A, Barbato C, Polcaro P, Casamorata F, Macchi C, Cecchi F, Poggesi A. Comparison between ischaemic and hemorrhagic strokes in functional outcome at discharge from an intensive rehabilitation hospital. *Diagnostics* (Basel Switzerland). 2020;11(1):38. <https://doi.org/10.3390/diagnostics11010038>.
54. Dros J, Kowalska K, Pasińska P, Klimkowicz-Mrowiec A. Transient cognitive impairment in the acute phase of stroke - prevalence, risk factors and influence on long-term prognosis in population of patients with stroke (research study - part of the PROPOLIS study). *BMC Neurol*. 2023;23(1):75. <https://doi.org/10.1186/s12883-023-03120-x>.
55. Dalli LL, Andrew NE, Kim J, Cadihac DA, Sanfilippo FM, Thrift AG, Nelson MR, Lannin NA, Olaiya MT, Ryan OF, Booth B, Gall S, Kilkenny MF. PRECISE investigators. Understanding of medications and associations with adherence, unmet needs, and perceived control of risk factors at two years post-stroke. *Research in Social & Administrative Pharmacy: RSAP*; 2022; 18(9): 3542–3549. <https://doi.org/10.1016/j.sapharm.2022.01.007>.
56. Kam JE, Choo PL. Feeling lonely and dissatisfied - understanding social network functioning in stroke survivors. *BMC Psychol*. 2024;12(1):558. <https://doi.org/10.1186/s40359-024-01986-1>.
57. Puhan MA, Ahuja A, Van Natta ML, Ackatz LE, Meinert C. Studies of Ocular Complications of AIDS Research Group. Interviewer versus self-administered health-related quality of life questionnaires - does it matter? *Health Qual Life Outcomes*. 2011;9(1):30. <https://doi.org/10.1186/1477-7525-9-30>.
58. Durant LE, Carey MP. *Archives Sex Behav*. 2000;29(4):309–22. <https://doi.org/10.1023/a:1001930202526>.
59. Sharma H. How short or long should be a questionnaire for any research? Researchers dilemma in deciding the appropriate questionnaire length. *Saudi J Anaesth*. 2022;16(1):65. https://doi.org/10.4103/sja.sja_163_21.
60. Dolnicar S, Grün B, Leisch F. Quick, simple and reliable: forced binary survey questions. *Int J Market Res*. 2011;53(2):231–52. <https://doi.org/10.2501/ijmr-53-2-231-252>.
61. Vegi VK, Sudhakar PV, Bhimarasetty D, Pamarthi K, Edara L, Kutikuppala LVS, Suvvari T, Anand S. Multiple-choice questions in assessment: perceptions of medical students from low-resource setting. *J Educ Health Promotion*. 2022;11(1):103. https://doi.org/10.4103/jehp.jehp_621_21.
62. Melovitz Vasan CA, DeFouw DO, Holland BK, Vasan NS. Analysis of testing with multiple choice versus open-ended questions: Outcome-based observations in an anatomy course. *Anat Sci Educ*. 2018;11(3):254–61. <https://doi.org/10.1002/ase.1739>.
63. Little JL, Bjork EL. Multiple-choice pretesting potentiates learning of related information. *Mem Cognit*. 2016;44(7):1085–101. <https://doi.org/10.3758/s13421-016-0621-z>.
64. Badarudeen S, Sabharwal S. Assessing readability of patient education materials: current role in orthopaedics. *Clin Orthop Relat Res*. 2010;468(10):2572–80. <https://doi.org/10.1007/s11999-010-1380-y>.
65. Hoffmann T, McKenna K. Analysis of stroke patients' and carers' reading ability and the content and design of written materials: recommendations for improving written stroke information. *Patient Educ Couns*. 2006;60(3):286–93. <https://doi.org/10.1016/j.pec.2005.06.020>.
66. Paz SH, Liu H, Fongwa MN, Morales LS, Hays RD. Readability estimates for commonly used health-related quality of life surveys. *Qual Life Res*. 2009;18(7):889–900. <https://doi.org/10.1007/s11136-009-9506-y>.
67. Hillis AE, Tippet DC. Stroke recovery: surprising influences and residual consequences. *Adv Med*. 2014;2014:1–10. <https://doi.org/10.1155/2014/378263>.
68. Kelava A, Rohrmann S, Hodapp V. Regression discontinuity designs. *International encyclopedia of education*. Elsevier; 2010. pp. 134–41.
69. Hassan ZA, Schattner P, Mazza D. Doing a pilot study: why is it essential? *Malaysian Family Physician*. 2006;1(2–3):70–3. <https://pubmed.ncbi.nlm.nih.gov/27570591/>.
70. In J. Introduction of a pilot study. *Korean J Anesthesiology*. 2017;70(6):601. <https://doi.org/10.4097/kjae.2017.70.6.601>.
71. Zajacova A, Lawrence EM. The relationship between education and health: reducing disparities through a contextual approach. *Annu Rev Public Health*. 2018;39:273–89. <https://doi.org/10.1146/annurev-publhealth-031816-044628>.
72. Reeves MJ, Prager M, Fang J, Stamplecoski M, Kapral MK. Impact of living alone on the care and outcomes of patients with acute stroke. *Stroke*. 2014;45(10):3083–5. <https://doi.org/10.1161/STROKEAHA.114.006520>.
73. DeVoe JE, Wallace LS, Fryer GE Jr. Patient age influences perceptions about health care communication. *Fam Med*. 2009;41(2):126–33.
74. Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Rep*. 2014;129(Suppl 2):19–31. <https://doi.org/10.1177/003335491412915206>.
75. Roos E, Lahelma E, Saastamoinen P, Elstad J-I. The association of employment status and family status with health among women and men in four nordic countries. *Scand J Public Health*. 2005;33(4):250–60. <https://doi.org/10.1080/14034940510005680>.
76. Heizomi H, Iraj Z, Vaezi R, Bhalla D, Morisky DE, Nadrian H. Gender differences in the associations between health literacy and medication adherence in hypertension: A population-based survey in heris county, Iran. *Vasc Health Risk Manag*. 2020;16:157–66. <https://doi.org/10.2147/VHRM.S245052>.
77. Roddis JK, Holloway I, Bond C, Galvin KT. Living with a long-term condition: Understanding well-being for individuals with thrombophilia or asthma. *Int J Qualitative Stud Health Well-Being*. 2016;11(1):31530. <https://doi.org/10.3402/qhw.v11.31530>.
78. Mehawej J, Mishra A, Saczynski JS, Waring ME, Lessard D, Abu HO, La V, Tisminezky M, Tran K-V, Hariri E, Filippaios A, Paul T, Soni A, Wang W, Ding EY, Bamgbade BA, Mathew J, Kiefe C, Goldberg RJ, McManus DD. Online health information seeking, low atrial fibrillation-related quality of life, and high perceived efficacy in patient-physician interactions in older adults with atrial fibrillation. *Cardiovasc Digit Health J*. 2022;3(3):118–25. <https://doi.org/10.1016/j.cvdh.2022.03.001>.
79. Fawns-Ritchie C, Starr JM, Deary IJ. Health literacy, cognitive ability and smoking: A cross-sectional analysis of the english longitudinal study of ageing. *BMJ Open*. 2018;8(10):e023929. <https://doi.org/10.1136/bmjopen-2018-023929>.
80. Lim ML, van Schooten KS, Radford KA, Delbaere K. Association between health literacy and physical activity in older people: A systematic review and meta-analysis. *Health Promot Int*. 2021;36(5):1482–97. <https://doi.org/10.1093/heapro/daaa072>.
81. Nasmith L, Kupka S, Ballem P, Creede C. (2013). Achieving care goals for people with chronic health conditions. *Can Fam Physician*, 59(1). <https://pubmed.ncbi.nlm.nih.gov/23341646/>.
82. Liu C, Wang D, Liu C, Jiang J, Wang X, Chen H, Ju X, Zhang X. What is the meaning of health literacy? A systematic review and qualitative synthesis. *Family Med Community Health*. 2020;8(2):e000351. <https://doi.org/10.1136/fmch-2020-000351>.
83. Van de Velde D, De Zutter F, Satink T, Costa U, Janquart S, Senn D, De Vriendt P. Delineating the concept of self-management in chronic conditions: A concept analysis. *BMJ Open*. 2019;9(7):e027775. <https://doi.org/10.1136/bmjopen-2018-027775>.
84. Muhammed S, Doll WJ, Deng X. Developing individual level outcome measures in the context of knowledge management success. *Strategies for knowledge management success*. IGI Global; 2010. pp. 106–27.
85. Weir CR, Staggers N, Doing-Harris K, Dunlea R, McCormick T, Barrus R. (2012). A taxonomy for contextual information in electronic health records. *NI 2012: 11th International Congress on Nursing Informatics*, June 23–27, 2012, Montreal, Canada. *International Congress in Nursing Informatics* (11th: 2012: Montreal, Quebec), 2012. <https://pubmed.ncbi.nlm.nih.gov/24199138/>.

Publisher's note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.