

# INPLASY

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## To what extent do stroke survivors want to know about the risk of dementia after stroke? And do healthcare professionals currently inform patients; if not should they and to what extent? A systematic review

James, M<sup>1</sup>; Dozier, M<sup>2</sup>; Kruuse, CR<sup>3</sup>; Sunnerhagen, KS<sup>4</sup>; Tang, EYH<sup>5</sup>; Mead, GE<sup>6</sup>.**ADMINISTRATIVE INFORMATION****Support** - No financial support or sponsor.**Review Stage at time of this submission** - Piloting of the study selection process.**Conflicts of interest** - None declared.**INPLASY registration number:** INPLASY202420058**Amendments** - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 13 February 2024 and was last updated on 13 February 2024.**INTRODUCTION**

**Review question / Objective** To evaluate the attitudes of both stroke patients and healthcare professionals about the extent to which patients are, or should be, informed of the risk of dementia after stroke.

**Rationale** Around 40% of patients who have a stroke go on to develop dementia within the first year (Dichgans et al, 2024). Hence, there is an argument that stroke survivors should be routinely informed about the risks of dementia, in the same way that they are informed about the risks of recurrent stroke and how to reduce such risk. However, to the best of our knowledge there are no systematic reviews exploring healthcare professionals' or patients attitudes towards informing stroke survivors of their potential future risks. Such information could be important for establishing an effective post-stroke management strategy and could have significant clinical applications for information provision after stroke.

There is information material about vascular dementia after stroke produced by charities, aimed at stroke survivors with vascular dementia and those who think they might have it ([https://www.stroke.org.uk/sites/default/files/Vascular\\_dementia.pdf](https://www.stroke.org.uk/sites/default/files/Vascular_dementia.pdf)). However, this information is not provided routinely to all stroke survivors soon after their stroke.

**Condition being studied** This review will be studying strokes; "an episode of acute neurological dysfunction presumed to be caused by ischemia or hemorrhage, persisting  $\geq$  24 hours or until death" (Sacco et al, 2013). This will include all subcategories (except subarachnoid haemorrhage) and all patients regardless of prognosis.

**METHODS**

**Search strategy** Search strategy established in MEDLINE and adapted for Embase, Pysclnfo, Cinahl, & Web of Science.

1. stroke/ or apoplexy/ or cerebrovascular accident/ or cerebral accident/ or embolic stroke/ or hemorrhagic stroke/ or ischemic stroke/ or thrombotic stroke/ or Paralytic stroke/ or Cardioembolic stroke/ or Cerebellar stroke/ or Completed stroke/ or Thromboembolic stroke/ or Nonparalytic stroke/ or Occlusive stroke/ or Recurrent stroke/ or Stroke; sequelae/ or cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or brain ischemia/ or exp brain infarction/ or transient ischemic attack/ or vertebrobasilar insufficiency/ or exp carotid artery diseases/ or cerebral small vessel diseases/ or cerebral amyloid angiopathy/ or lacunar stroke/ or cerebrovascular trauma/ or vertebral artery dissection/ or intracranial arterial diseases/ or cerebral arterial diseases/ or infarction, anterior cerebral artery/ or infarction, middle cerebral artery/ or infarction, posterior cerebral artery/ or moyamoya disease/ or intracranial aneurysm/ or intracranial arteriosclerosis/ or exp intracranial arteriovenous malformations/ or exp "intracranial embolism and thrombosis"/ or intracranial h?emorrhages/ or exp \*cerebral h?emorrhage/ or intracranial h?emorrhage, hypertensive/ or exp subarachnoid h?emorrhage/ or vasospasm, intracranial/ or blunt traumatic cerebrovascular injury/ or intracranial atherosclerotic disease/

2. (stroke or poststroke or post-stroke or cerebrovasc\* or (cerebr\* adj3 vasc\*) or CVA\* or apoplectic or apoplexy\* or (transient adj3 isch?emic adj3 attack) or tia\* or SAH or AVM or ESUS or ICH or (cerebral small vessel adj3 disease\*)) or ((cerebr\* or cerebell\* or arteriovenous or vertebrobasil\* or interhemispheric or hemisphere\* or intracran\* or intracerebral or infratentorial or supratentorial or MCA\* or ((anterior or posterior) adj3 circulat\*) or lenticulostriate or ((basilar or brachial or vertebr\*) adj3 arter\*) adj3 ((blood adj3 clot\*) or disease\* or damage\* or disorder\* or disturbance or dissection or lesion or syndrome or arrest or accident or lesion or vasculopathy or insult or attack or injury or insufficiency or malformation or obstruct\* or anomal\*)) or ((cerebr\* or cerebell\* or arteriovenous or vertebrobasil\* or interhemispheric or hemisphere\* or intracran\* or corpus callosum or intracerebral or intracortical or intraventricular or periventricular or posterior fossa or infratentorial or supratentorial or MCA\* or ((anterior or posterior) adj3 circulation) or basal ganglia or ((basilar or brachial or vertebr\*) adj3 arter\*) or space-occupying or brain ventricle\* or lacunar or cortical or ocular) adj3 (isch?emi\* or infarct\* or thrombo\* or emboli\* or occlus\* or hypoxi\* or vasospasm or obstruct\* or vasoconstrict\*)) or ((cerebr\* or cerebell\* or vertebrobasil\* or interhemispheric or hemisphere\*

or intracran\* or corpus callosum or intracerebral or intracortical or intraventricular or periventricular or posterior fossa or infratentorial or supratentorial or MCA\* or ((anterior or posterior) adj3 circulation) or basal ganglia or ((basilar or brachial or vertebr\*) adj3 arter\*) or space-occupying or brain ventricle\* or subarachnoid\* or arachnoid\*) adj3 (h?emorrhag\* or h?ematom\* or bleed\*) or (isch?emic adj3 encephalopathy) or ((carotid or cerebr\* or cerebell\* or intracranial or ((basilar or brachial or vertebr\*) adj3 arter\*)) adj3 (aneurysm or malformation\* or block\* or dysplasia or disease\* or bruit or injur\* or narrow\* or obstruct\* or occlusion or constriction or presclerosis or scleros\* or stenosis\* or atherosclero\* or arteriosclero\* or plaque\* or thromb\* or embol\* or arteriopathy)) or ((moyamoya or moya moya) adj3 (disease or syndrome)).tw.

3. or/ 1-2

4. exp Access to information/ or Consumer health information/ or Health information exchange/ or Health information management/ or Information management/ or Information services/ or Knowledge/ or Health Knowledge, Attitudes, Practice/ or Informing/ or Discussion/ or View/ or exp Patient Education as Topic

5. Knowled\* or inform\* or discuss\* or view\* or "patient educat\*" or guid\* or instruct\* or counsel\* or detail\*.tw.

6. or/ 4-5

7. exp dementia/ or cognitive disorder/ or neurocognitive disorder/ or post-stroke dementia/ or cognitive problems/ or dementia, vascular/ or frontotemporal dementia/ or dementia, multi-infarct

8. dementia or ((cogni\* or neurocogni\*) adj3 (disorder or decline or impair\* or incapac\* or debilit\* or problem\*)) or ((stroke or poststroke or post-stroke) adj3 dementia).tw.

9. or/ 7-8

10. exp risk/ or risk adjustment/ or risk assessment/ or exp risk factors/ or risk management/ or health risk behaviours

11. risk\* or (risk adj3 (adjust\* or assess\* or fact\* or manag\* or behav\*)) or ((long term or long-term) adj3 (effect\* or risk\*)).tw.

12. or/ 10-11

13. patients/ or humans/ or survivors/ or caregivers

14. patient\* or case\* or human\* or adult\* or suffer\* or surviv\* or care\*.tw.

15. or/ 13-14

16. doctors/ or physicians/ or "Attitude of Health Personnel"/ or "Surveys and Questionnaires"/ or "qualitative research"/ or "randomized controlled trials"

17. doctor\* or physician\* or (health adj3 (personnel or professional\*)) or (healthcare adj3 (professional\* or personnel)).tw.

18. or/ 16-17

19. 3 and 6 and 9 and 12 and 15 and 18.

**Participant or population** Healthcare professionals involved in post-stroke management and stroke patients/their carers will be eligible for this review, with no exclusions based on stroke type/cause, prognosis etc.

**Intervention** If we find randomised controlled trials, then the intervention would be 'Being informed of stroke's long-term risk of dementia'.

**Comparator** Not expected to be applicable as randomised trials are not expected to be found, however, if so, the comparator would be usual care.

**Study designs to be included** Any study design will be included, including observational (e.g. qualitative, quantitative, care series, cohort studies) and experimental (e.g. randomised trials), the only exclusion will be case studies.

**Eligibility criteria** Due to the limited volume of relevant literary material that we expect to find, no studies will be excluded based on time frame, country, publication status, setting or other factors. There is more literature reporting research on the perspectives of healthcare professionals and patients separately, however resource constraints require a more focussed review. Eligible studies will be those explicitly mentioning stroke, excluding individual case studies; this was decided post initial screening.

**Information sources** MEDLINE, EMBASE, CINAHL, PsycInfo, & Web of Science Core Collection.

**Main outcome(s)** Opinions of both patients and healthcare professionals as to the extent to which stroke survivors should be informed of dementia

risk. The basis of these opinions; whether they are founded in quality of life, mental health, personal beliefs, etc; as well as any interventions implemented as an element of the study (e.g. information leaflets regarding future risks of dementia) and the impact on knowledge, health behaviour and anxiety outcomes.

**Additional outcome(s)** Opinions of both patients and healthcare professionals as to when and how patients should be informed, any improvements to post-stroke management and any therapeutic effects.

**Data management** Study selection;  
- Search results will be imported into Covidence, deduplicating any returned studies and recording the selection process.

- Both titles and abstracts will be screened first; then potentially eligible full texts will be obtained. For the initial 200 titles/abstracts two reviewers will be applying the eligibility criteria and selecting studies for inclusion, completing this blind to the others selection. The level of agreement between selections will determine whether the remaining citations can be screened by one person or whether a further 200 should be screened etc.

Data extraction;  
- Data will be extracted, managed and recorded in Covidence using a custom data extraction template alongside a PRISMA flow diagram. The template will allow for extraction of information about the article (authors, year of publication, title, DOI), information about the study (study type, theoretical framework, data collection method, study quality, role of researcher/any potential bias) and the outcomes/results.

- This will be done primarily by a single reviewer, with a secondary quality checking 10% of the extraction

- Study investigators will be contacted by email for unreported data or additional details, with one reminder two weeks later.

**Quality assessment / Risk of bias analysis** Risk of bias and quality assessment will be conducted by one reviewer and overseen by a blinded secondary, assessment will be done at study level assessing methods of data collection and scope of populations involved, with quality assessment criteria being taken from PRISMA 2020 Checklist and performed using Covidence's Quality Assessment and Risk of Bias Template tool.

**Strategy of data synthesis** Data to be synthesised will include attitudes of both patients and healthcare professionals towards the extent to

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which survivors should be informed of dementia risk. Data from individual studies will be combined using a narrative synthesis. If any suitable randomised controlled trials are found a meta-analysis will be completed.

**Subgroup analysis** Stroke is an umbrella term covering multiple different stroke types/causes. Different types of stroke vary in their impact on the chances of dementia development. All types of study and individual will be included and the data synthesis (likely narrative synthesis) will take into account different stroke types.

**Sensitivity analysis** Not applicable.

**Language restriction** Only studies published in languages known to the authors will be considered for inclusion.

**Country(ies) involved** United Kingdom, Denmark, Sweden.

#### **Protocol References:**

- Dichgans, M., Georgakis, MK. & Filler, J. (2024) Risk factors for cognitive impairment and dementia after stroke: a systematic review and meta-analysis. *The Lancet Health Longevity*. 5(1), e31-e44

- Sacco, RL., Kasner, SE., Broderick, JP., Caplan, LR., Connors, JJ., Culebras, A., Elkind, MSV., George, MG., Hamdan, AD., Higashida, RT., Hoh, BL., Janis, LS., Kase, CS., Kleindorfer, DO., Lee, JM., Moseley, ME., Peterson, ED., Turan, TN., Valderrama, AM. & Vinters, HV. (2013) An Updated Definition of Stroke for the 21st Century. *AHA Journals*. 44 (7), 2064-2089.

**Keywords** Stroke, Information, Dementia, Patients, Risk, Healthcare professionals.

**Dissemination plans** Presentation at a conference, and paper in journal.

#### **Contributions of each author**

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