

# Stroke Alliance for Europe: needs of stroke survivors and carers scoping review

## Objectives and methods summary

### Objectives and methods for this scoping review

#### Objectives

We aimed to scope the available and accessible literature to:

1. describe the longer-term needs, and unmet needs, of adult stroke survivors living in the community in Europe.
2. describe the longer-term needs, and unmet needs, of caregivers of stroke survivors.
3. briefly describe the current state of the evidence for interventions which aim to address the identified needs.

#### Conceptual framework

The topics in this review were selected by a combination of availability of research evidence, the International Classification of Functioning, Disability and Health (ICF) core data set for stroke<sup>1</sup> and our eight-level socio-ecological model, as described below. This framework served as a guide for synthesising the literature and determining how needs can be classified.

#### The 8 levels of the socio-ecological model

See Figure 1.

##### **1. Individual**

The first level identifies characteristics of individuals and components of health involved in creating need, including: health (physical, emotional, occupational, etc); lifestyle (e.g. tobacco use) and health behaviours (e.g. injuries); body functions impairments (physical, cognitive, emotional); secondary conditions; functional status (i.e., activities and participation); and self-transformation (goals that a person with stroke wants to achieve to improve their self-perceived wellbeing)

##### **2. Relationships with people affected by the stroke event**

This level examines the close relationships with partners, children, other family members, friends and colleagues that may be affected by stroke. It includes sexuality and sex life.

##### **3. Systems of care**

The third level explores the availability, accessibility, acceptability, and quality of systems of care, that is any coordinated networks of community-based services (including health and social services and third sector organisations) and supports (such as peer support groups) that are organised to meet the changing needs and challenges

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<sup>1</sup> ICF Research Branch. ICF Core Set for Stroke. 2017 [cited 2021 16 November]; Available from: <https://www.icf-research-branch.org/icf-core-sets-projects2/cardiovascular-and-respiratory-conditions/icf-core-set-for-stroke>.

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of people with stroke and their families. We include needs related to health and social services of any type, whether they form part of a coordinated system of care.

### ***4. Community and social context***

The fourth level explores the social and community setting. Factors relevant to people with stroke include those related to safety and security and social networks, given that these may have a significant effect on their health and wellbeing.

### ***5. The built environment***

The fifth level explores the built environment, including the buildings that people live in, neighbourhood/ community conditions and transportation routes and systems. The built environment may impact on the behaviours of people with stroke such as physical activity (e.g. how 'walkable' an area is), healthy eating, or alcohol use.

### ***6. Laws, policies and regulations***

The sixth level relates to policy, which includes laws, regulations, procedures, administrative acts or decisions which might affect people with stroke and their families. Relevant areas include health, social and economic policies.

### ***7. Science, research, and society***

The seventh level looks at science, research, and society. People with stroke and their families may use research-generated knowledge to help make decisions about different aspects of life (such as health care, vaccinations, climate change) and engage in setting the stroke research agenda.

### ***8. The social environment***

The eighth level looks at the broad societal factors that help create an environment in which needs for security, education, work, health, and wellbeing are met (or not). Components of the social environment include labour markets; social and economic processes; power relations; social inequalities; cultural practices; etc.

## **How this review was designed and undertaken**

Methods for this study were developed based on Arksey and O'Malley's [31] scoping review methodology. Four stages of the process are described below.

### **Stage 1: Identifying the research question**

#### ***Specific topic questions***

1. How many adults living with long-term stroke are affected by stroke-related problems/conditions (incidence or prevalence)
2. What are the 'needs' or 'unmet needs' of adults living with long-term stroke or their caregivers, and how many people have each need? There are various ways need may be defined: by healthcare professionals; by someone's ability to benefit from healthcare provision; by comparing one group's access to provision

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with another group; and by the stroke survivor/carer themselves. In this scoping review we were interested in all definitions of need, but have emphasized need as perceived and reported by people with stroke/carers themselves.

3. The effects of health or social care interventions, with emphasis on outcomes that matter to adults living with long-term stroke.

### ***Population***

Our main aim was to draw on studies that recruited people living in Europe one or more years after stroke onset. However, because our initial searches indicated that this would retrieve few items of literature, we did not use country or time since stroke onset as an exclusion criterion.

## **Stage 2: Identifying relevant studies**

### ***Types of evidence***

We were interested in the following types of evidence:

1. Analysis of any large data sets (such as Global Burden of Diseases, Injuries, and Risk Factors Study (GBD)) with the purpose of quantifying the impact of stroke on functioning, disability and health in the longer term in Europe and exploring international variations in functioning, disability, health, access to health and/or social care services, social or environmental factors influencing functioning, disability, health and others
2. Peer-reviewed reviews of non-experimental/observational studies reporting measures of occurrence (i.e., incidence, prevalence) of stroke-related problems/conditions
3. Peer-reviewed reviews of quantitative or qualitative studies of
  - a. the unmet care needs of people living with long-term stroke.
  - b. the needs and unmet needs of people living with long-term stroke
  - c. the needs and unmet needs of informal caregivers of people living with long-term stroke
4. Non-peer reviewed survey/other research which reports stroke survivors' perceived needs (identified via SAFE member organisations).
5. Peer-reviewed reviews of the effects of health or social care interventions, with emphasis on outcomes that matter to adults living with long-term stroke.

### ***Search strategies***

We used multiple search strategies to approach the various research questions and types of evidence of interest. These included:

- Systematic searches of peer-reviewed journals via databases such as Ovid Medline and EBSCOhost

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- Search of the Cochrane Library (reviews of health or social care interventions)
- Using Google Scholar
- Asking SAFE member organisations if they were aware of relevant non-peer reviewed research

We included studies using any language. We excluded hospital-based studies.

### Stage 3: Study selection

We used citation manager software and a screening and data extraction tool to support the article/item selection process. Two authors screened abstracts and, if applicable, full text articles/items.

### Stage 4: Charting the data/ data extraction

One author extracted information from selected articles/items into a template devised by the research team. We did not critically appraise any of the retrieved literature because of time limitations.

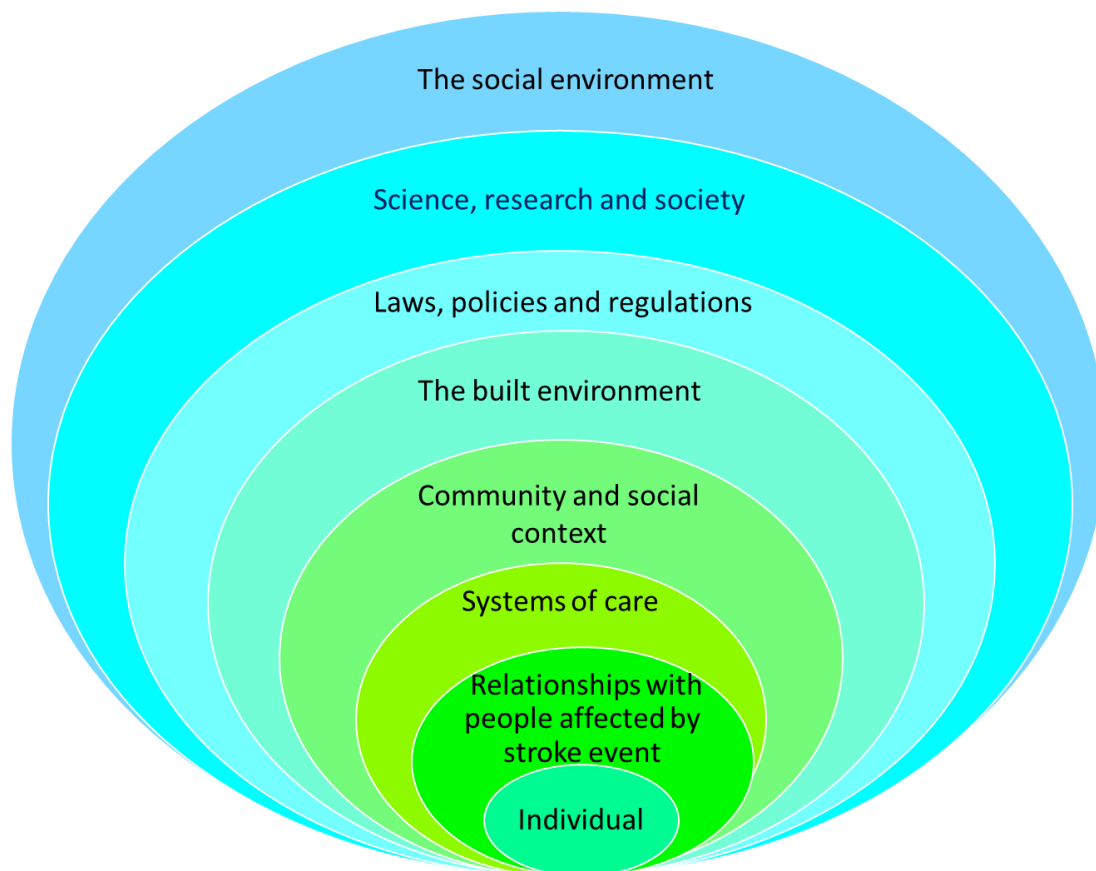


Figure 1. Socio-ecological model of elements relevant to the needs of adults living with long-term stroke.