

# **A life saved is a life worth living**

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# Life After Stroke

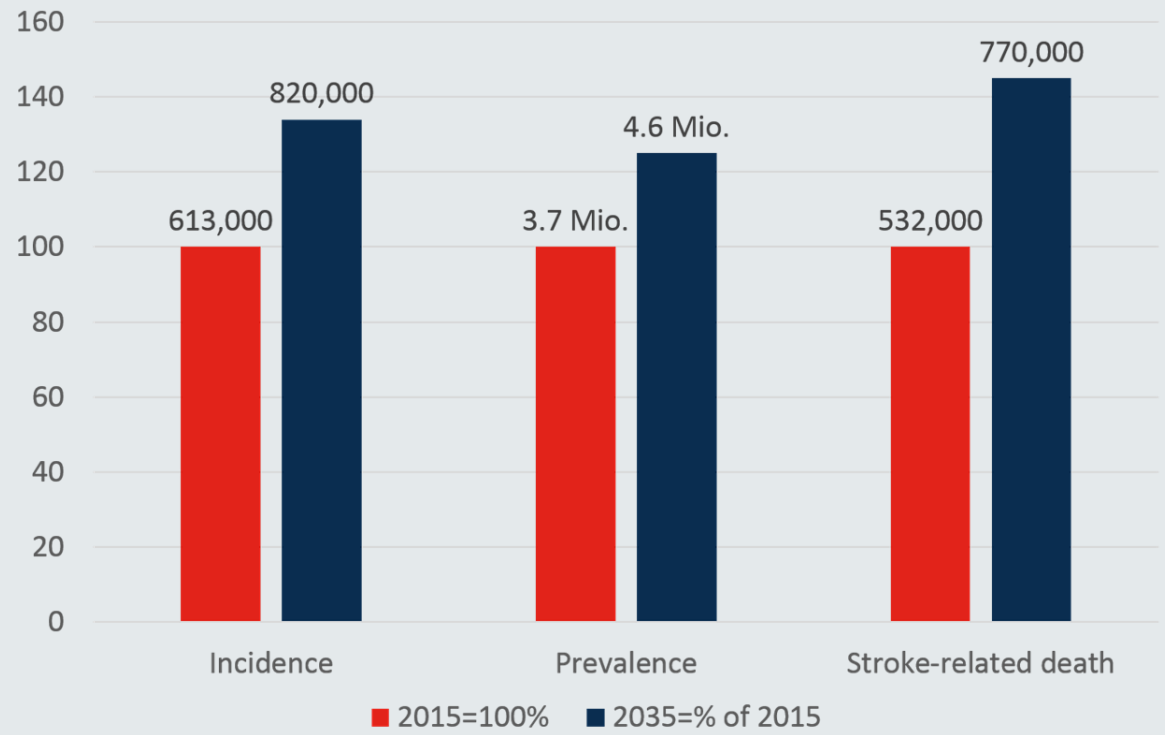
## **This presentation will cover:**

- Context – Burden of Stroke report; key work on long-term unmet needs
- Key findings from unmet needs literature review
- Recommendations for future research
- SAFE's Call to Action

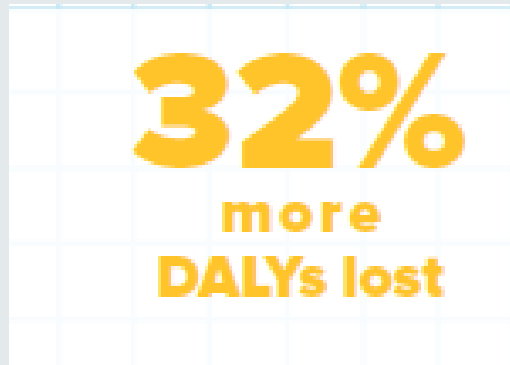
# Number of stroke survivors in Europe is increasing (Projection 2015-2035, Burden of Stroke report)



Number of people living with stroke as a chronic condition from 3,718,785 in 2015 to 4,631,050 in 2035 an increase of almost **25%** or **1 million** across the EU



# Number of stroke survivors in Europe is increasing (Projection 2015-2035, Burden of Stroke report)



**DALYs; Disability  
Adjusted Life years  
The sum of years lost  
due to premature  
disability**

**Consequences of stroke** include family stresses and breakdowns, access to work difficulties, financial problems, depression and social reintegration issues.

# Life After Stroke – findings from Burden of Stroke report

- Many countries **did not have a specific strategy for dealing with stroke**, or offer support for adjusting to life after stroke.
- **No pathway** for survivors - who often find themselves on parallel paths for other conditions (e.g. depression, diabetes).
- **No model** of what best care looks like **following discharge** from specialist services.

 **Stroke ACTION Plan for Europe**

## Past work on long term unmet needs

- 49% reported **1+ unmet needs** up to **5 years** after stroke

*McKevitt C et al. Self reported long term needs after stroke*  
**Stroke 2011;42:1398-1403**



## Unmet health needs (McKevitt *et al.* 2011)

	N reporting problem (weighted %)	<b>Need unmet (%)</b>	Need met to some extent (%)
<b>Mobility</b>	321 (58.4)	<b>25</b>	43
<b>Falls</b>	265 (43.9)	<b>21</b>	47
<b>Incontinence</b>	217 (37.2)	<b>21</b>	40
<b>Pain</b>	249 (39.5)	<b>15</b>	51
<b>Emotional</b>	244 (38.4)	<b>39</b>	34
<b>Speech</b>	194 (34.3)	<b>28</b>	33
<b>Sight</b>	212 (37.2)	<b>26</b>	39

# Other unmet needs (McKevitt *et al.* 2011)

	N reporting problem (weighted %)	<b>Need unmet (%)</b>	Need met to some extent (%)
<b>Fatigue</b>	301 (51.7)	<b>43</b>	36
<b>Concentration</b>	260 (44.7)	<b>43</b>	41
<b>Memory</b>	260 (42.8)	<b>59</b>	25
<b>Reading</b>	148 (23.2)	<b>34</b>	43



# The unmet needs of stroke survivors and carers

## Key findings

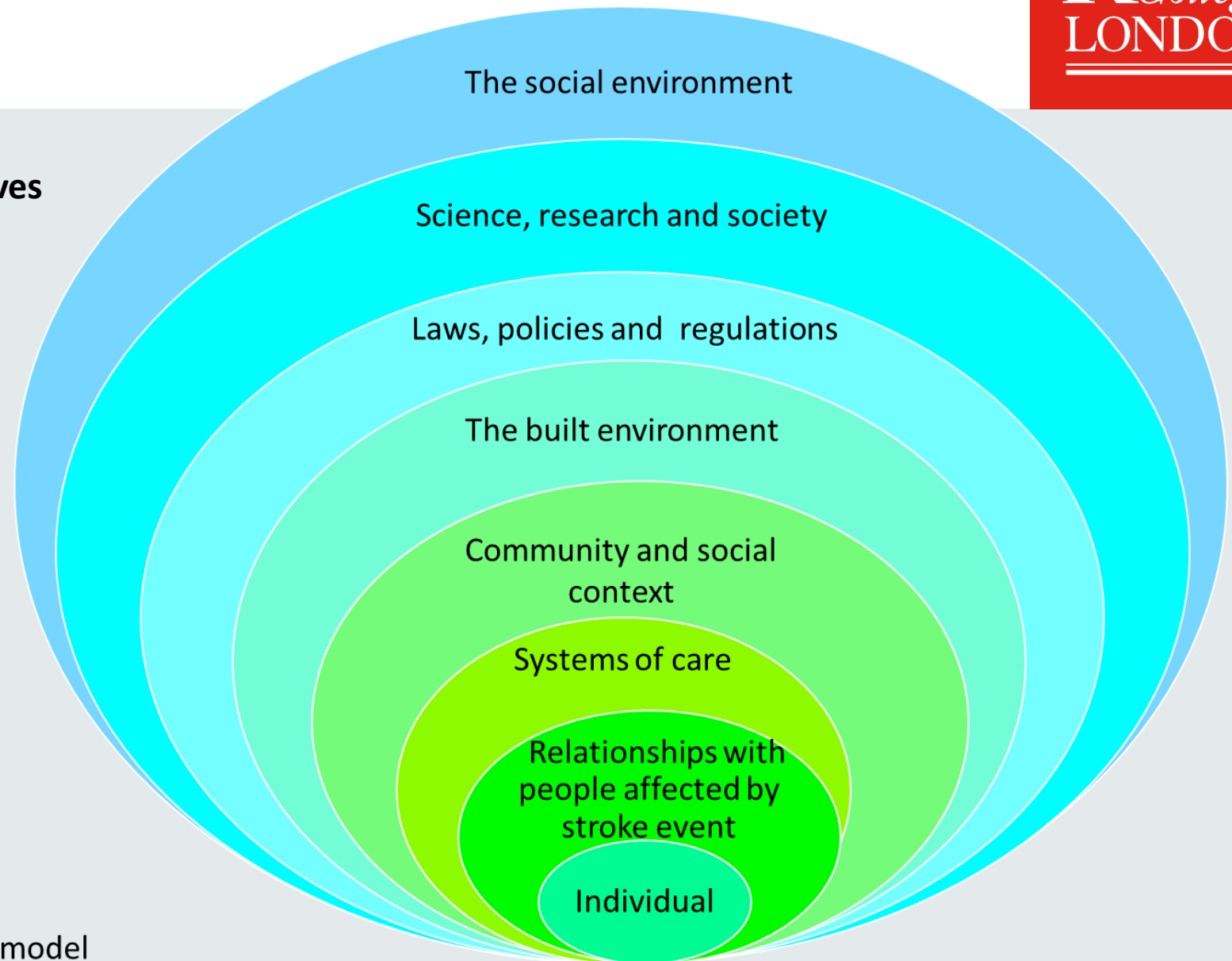
**Literature review** to reveal types & extent of unmet needs, and gaps in our knowledge

- **Too little research** into the *long-term needs* of stroke survivors and their carers (e.g. beyond 3 months)
- Lack of common ways of **understanding and measuring needs** – rarely possible to compare studies/countries/regions
- **Gaps** in evidence-based **interventions** (treatment, support) around some needs
- Stroke survivors left with a range of often **very debilitating unmet needs**:
  - **two-thirds** of stroke survivors have **at least 1 type of unmet care need** within 6 months after stroke
  - prevalence of **unmet care needs continually increases** up to **81%** at 2 years after stroke (Lin, B.-L., et al., *Unmet care needs of community-dwelling stroke survivors: a systematic review of quantitative studies*. BMJ open, 2021. **11**(4): p. e045560.)

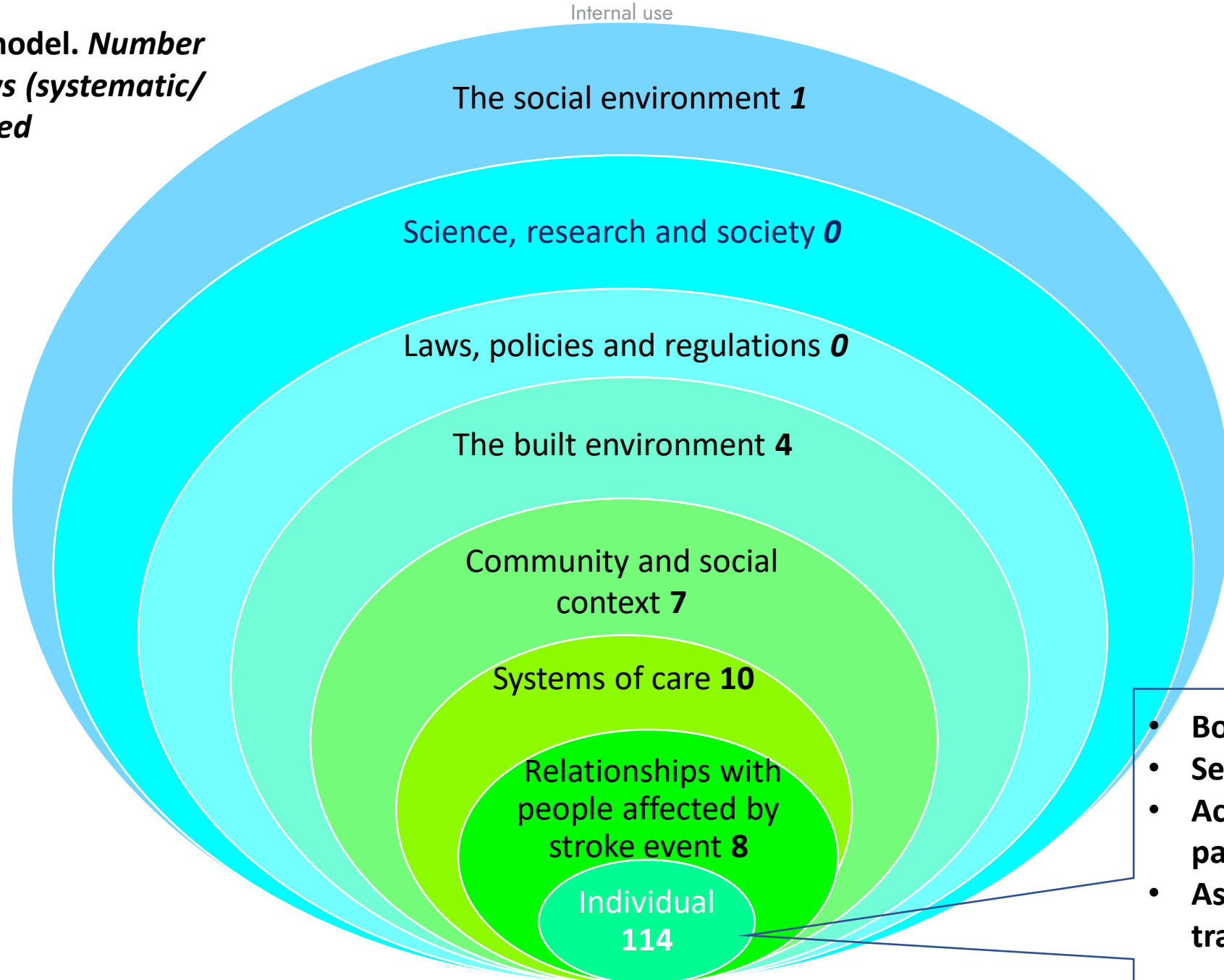
# Domains of needs

- Interested in **need from all perspectives** (survivor, carer, professional)
- **Individual** needs (ICF Core Set for Stroke)
- Needs related to **interactions with others/environment/society** (socio-ecological model)

Socio-ecological model



**Socio-ecological model. *Number of relevant reviews (systematic/narrative) identified***



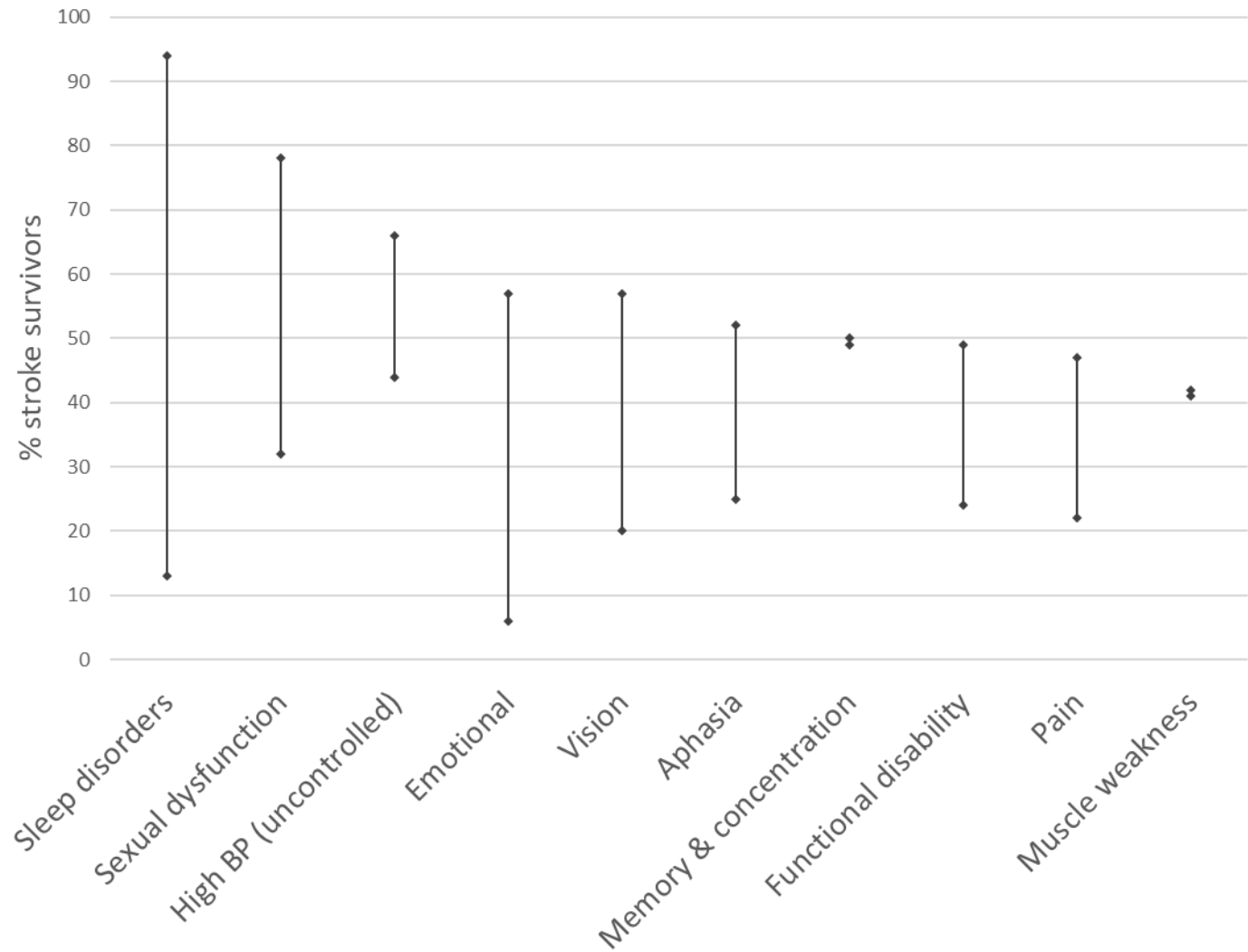
- **Body functions 64**
- **Secondary conditions 8**
- **Activities & participation 37**
- **Aspirational & transformative 5**

# Most common problems

Data from (usually) multiple observational studies

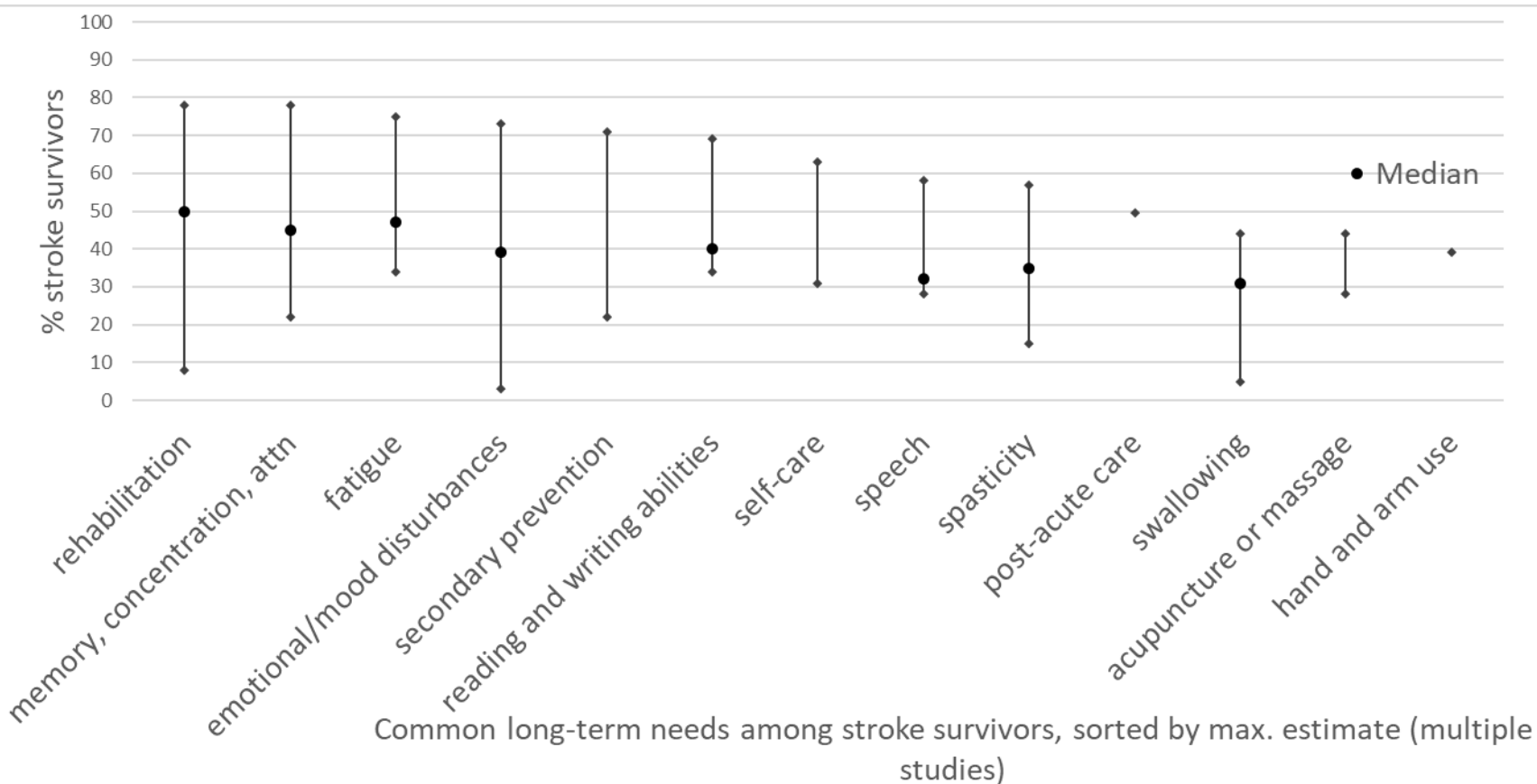
Surprising ranking of problems?

**Difficult to compare without 'averages'** - study differences make comparisons inappropriate



Common longer-term problems among stroke survivors, sorted by max. estimate (multiple studies)

# Most common unmet needs



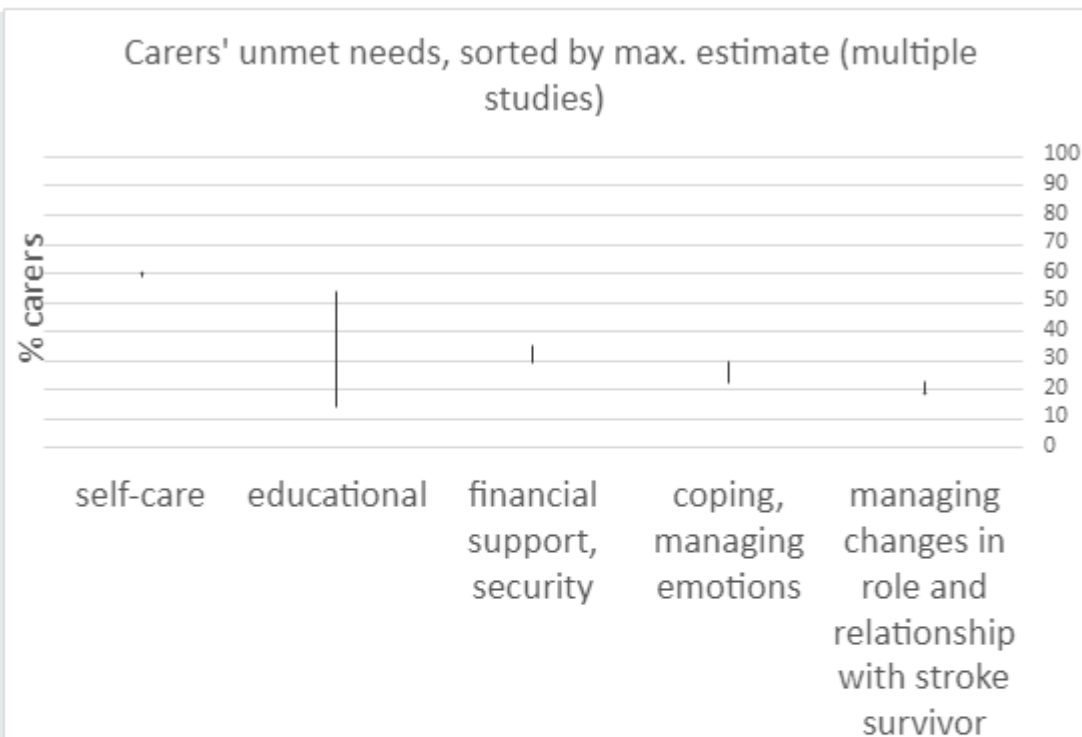
Apparent **mismatch between the top observed problems and top reported 'needs'**.

For some problems, is the need being met?

Or an artefact of different studies: when were survivors asked, which groups of survivors were included

It **took some time** to get familiarised with my disability **and develop ways of adapting**, coping and solving problems. Alexia, Cyprus

# Carers' unmet needs



- self-care
- educational
- financial support, security
- coping, managing emotions
- managing changes in role and relationship with stroke survivor

**Carers [need] more comprehensive information** about a range of topics...**adaptations** to property, **benefits** advice, appropriate **exercise**...*Alexia, Cyprus*

# Interventions

Often, reviews of **interventions** for longer-term needs conclude '**insufficient evidence for effect**'.

Existing interventions are **not flexible enough to meet varied needs** of stroke survivors in longer term.

## **Gaps include:**

- cognitive function
- fatigue
- bowel and bladder function
- sleep problems
- participating in family or community roles (e.g. employment)
- post-stroke pain
- proprioception (awareness of position of body/limbs)
- psychological/emotional health e.g. **anxiety, depression, suicidal ideation**, loss of social filters, involuntary behaviour
- sexual functions and problems
- vision e.g. visual field, eye movement.

## In summary

- Continuing **large increase in stroke survivor numbers** across Europe
- Many stroke survivors find **shortcomings in community-based rehabilitation therapies, and secondary prevention** advice/treatment
- Stroke survivors left with a range of often **very debilitating unmet needs**
- **Stroke survivors and carers want more consistent information/support/training** to help them manage long-term needs
- Current research evidence base **dominated by biomedical studies**
  - Funding/publication bias?
  - Mismatch with stroke survivor and carer priorities?



# Recommendations for future research

- **Needs assessments: Tools** used should enable stroke survivors and carers to **identify all needs**, not only those which align with interests of professionals managing their care or conducting research
- Research to **understand changes** in stroke survivor and carer **needs/priorities over time** into the long term
- **Data gap** on needs and unmet needs in **Non-Western European countries**: important to address
- Deciding **priorities for research** into interventions for **carers** (similar to James Lind/Stroke Association research priority-setting)

**Research gaps** (socio-ecological model) include the **built environment, legal concerns, and the social environment.**

- For example: Public perceptions of stroke-related disability - What works to improve attitudes/behaviour so stroke survivors are treated with dignity and feel respected?
- **Wide range** of academic/professional **disciplines valuable to stroke research**

To **interact socially** with others...I need my interlocutors to **give me the space and time** to let me **express myself**. [Even **professionals**] can't help but **finish my sentences** despite knowing of my **aphasia**... *Jurg, Switzerland*

## SAFE - a call to action (1/2)

1. Governments and research bodies should provide **funding to investigate** the **medium and long-term needs** of stroke survivors and the **improvements in service provision** to meet those needs.
2. **Health and social care systems** should be designed to provide **high-quality information and support** for stroke survivors and their carers that is **easily accessible** over the long-term.
3. All stroke survivors should be **followed up, at least annually**, by a stroke specialist to have their physical, mental and societal **needs assessed** and to be **referred to relevant services**.
4. National and local **health and social care systems** must **improve access to rehabilitation** therapies for stroke survivors for as long as they continue to show benefit.
5. National and local **health and social care systems** must **improve** the provision of and access to **secondary prevention** services and support.

There needs to be **funding** through the **national stroke plan** for **specialist therapies** for stroke survivors, and proper **information for care-givers** about how to get training, help and relevant advice. *Dorina, Georgia*

## SAFE - a call to action (2/2)

6. More **specialist support** is needed post stroke to help stroke survivors cope with ongoing issues such as **chronic fatigue, concentration problems and mental health** support.
7. **People supporting and caring** for stroke survivors should have timely **access to information and support**, including meeting their needs to self-care.
8. **Stroke specialists and health planners** should develop a **European-wide model of care** or set of principles (with an agreed definition of un-met need) to **guide the provision of services** to meet the long-term needs of stroke survivors.

# Thank you

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