

# Monitoring life after stroke in Sweden



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# Disclosure Statement

- Mia von Euler is the Chair of the Swedish Stroke Registry, has been a member of the Swedish Stroke task force (now called the national working group for Stroke) for over a decade, and has been an active party in writing the Swedish National Guidelines for Stroke Care and the Swedish National Care Pathway for Stroke.
- Annlie Torsfeldt Heikenborn is part of the steering committee of the Swedish Stroke Registry.





## Together for better stroke care in Sweden

- Board of Health and Welfare
- National system for knowledge-driven management within Swedish healthcare
- National quality registries
- Professional organisations
- Patient organisations



# The chain of care for stroke in Sweden - what to do

- National guidelines for stroke care
- National care pathway for stroke

the Board of Health and Welfare

the National Program Area for diseases of the nervous system and the National Working Group for Stroke both part of the National system for knowledge-driven management within Swedish healthcare

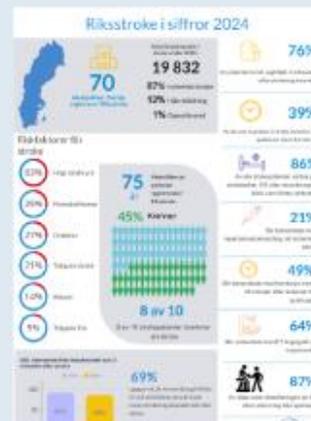
- Emergency care
- Life after stroke



# The chain of care for stroke in Sweden - what is done

- National quality register, Riksstroke
  - Emergency care Hospital reported
  - Outcome 3 months Patient reported Outcomes and Experiences
  - Outcome 1 year Patient reported Outcomes and Experiences

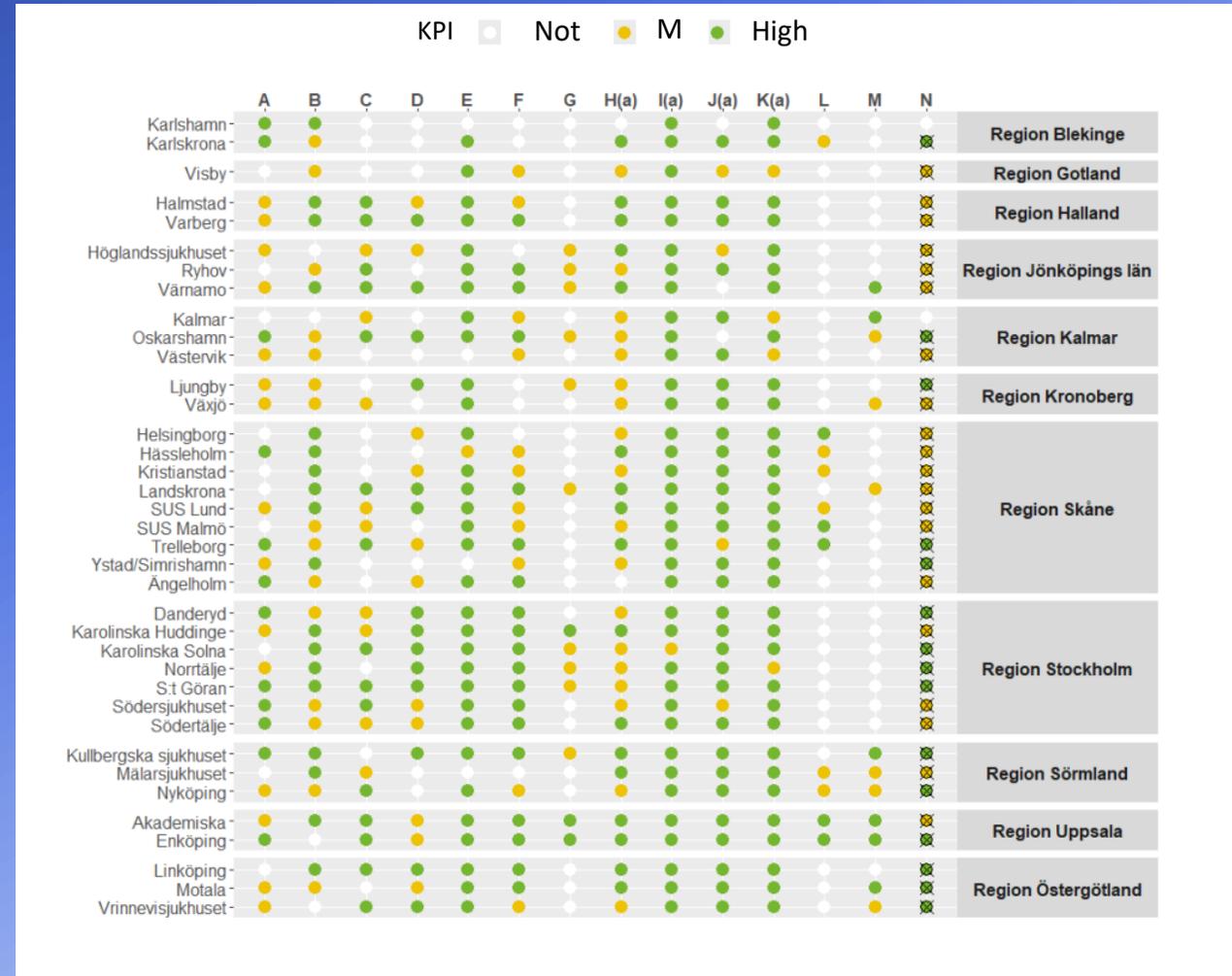
[Brief summary of data for the full year 2024 |](#)



Riksstroke i vården i siffror

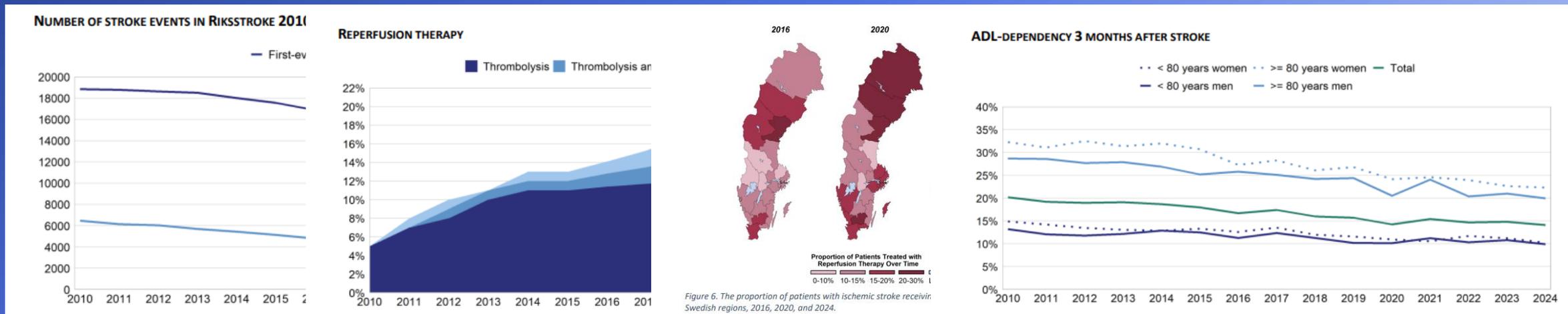
# Benchmarking is effective

- Comparing hospitals and regions
  - Offered services
  - Access to care
  - Patient outcomes
  - Patient satisfaction
- Follow up in regional and local groups
- Sharing good examples
- Patient organisations



# Monitoring and benchmarking

- Swedish stroke care has improved over time



BUT



## Equal access to good quality health care

- The regions deliver and are responsible for health care
- 21 regions
- The largest Norrbotten: 97 239 km<sup>2</sup> and 0.28 mil inhab
- Most people in Stockholm: 6 512 km<sup>2</sup> and 2.5 mi inhab
- Different resources, possibilities, challenges

## Acute care is relatively "easy" to monitor



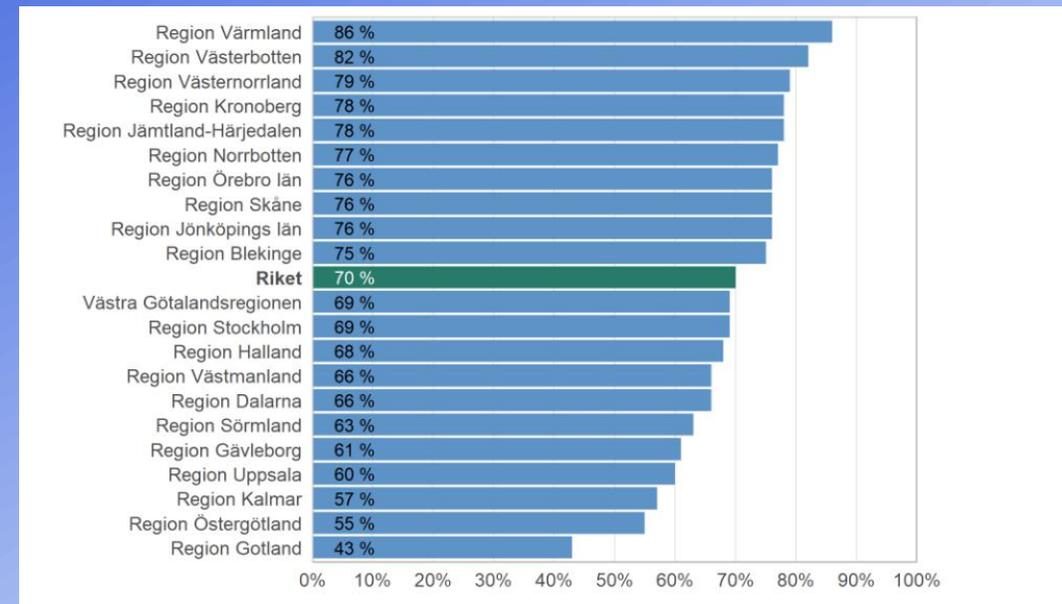
*Annelie at the time of the stroke*

- 71 hospitals with 70 Stroke Units involved
- Dedicated personal with stroke focus

# Challenging to follow up long term

- What is done – difficult to capture in registries
  - Different organisations in different regions
  - Primary care – specialized care
- PROMs and PREMs: response rate
- Digital questionnaires
  - Easier
  - Cheaper
  - GDPR
  - Digital literacy vary

*Met needs of home health care  
3 years after stroke*





## What we want to capture

- Quality measures ensuring stroke survivors get the care they need to be able to live their lives to the fullest

*Annelie, a number of years after the stroke  
– a stroke survivor living her life*

Thank you!



**RIKSSTROKE**  
The Swedish Stroke Register

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