

# Perspectives from support organisations – German Stroke Foundation

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**European Life After Stroke Forum 2024**

**Dr. Michael Brinkmeier  
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# Disclosure Statement

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**There are no conflicts of interests to declare.**

# A stroke survivors voice

- Ulla had her stroke in May 2020
- Ischemic stroke that turned into a hemorrhagic stroke under thrombolysis
- Fragmented German healthcare system → transfer to a specialist clinic
- Stroke consequences: Walking disability, hemiplegia of the arm, severely impaired speech right after the stroke
- Focus on walking in initial rehabilitation
- Inadequate inpatient and outpatient logotherapy
- Her second rehabilitation helped her a lot more in terms of speech



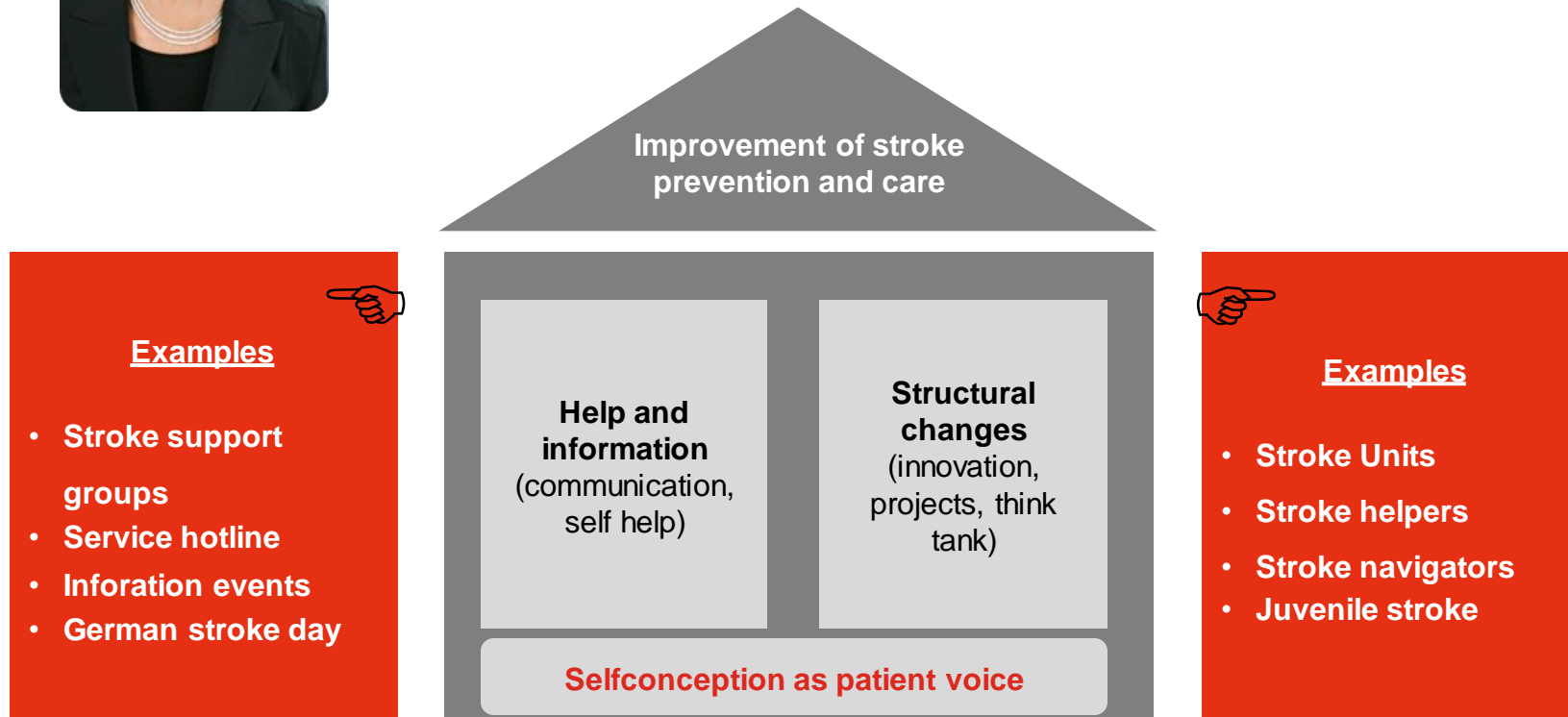
# Short portrait of the German Stroke Foundation

## What we do – who we are



Founder Liz Mohn

- Independent non profit organisation
- 40 employees
- 5 Mio. € annual budget



# Advise, help, motivate

*380 german support groups with more than 18,000 participants*

## Hilfe zur Selbsthilfe

Mehr als 16.000 Schlaganfall-Betroffene, Angehörige und teilweise auch Fachleute engagieren sich in den bundesweit rund 380 Schlaganfall-Selbsthilfegruppe. Die Stiftung Deutsche Schlaganfall-Hilfe unterstützt diesen ehrenamtlichen Einsatz.

*Service hotline at the German Stroke Foundation to answer all questions and uncertainties concerning strokes*

## Orientierung in schwierigen Zeiten

Unser Service für Sie - Das Beratungsteam der Stiftung Deutsche Schlaganfall-Hilfe hilft Ihnen gerne.

*More than 600 voluntary stroke helpers*

Start > Das tun wir > Aktivitäten >

## Schlaganfall-Helfer

In der Nachsorge fühlen sich viele Betroffene und Angehörige überfordert. Schlaganfall-Helfer sind in dieser Phase für die Betroffenen und ihre Angehörige da. Sie motivieren, helfen und leisten Gesellschaft.

*Health care supply stores: Improve the advice for the provision of aids*

Start > Das tun wir > Aktivitäten >

## Bessere Beratung in Sanitätshäusern

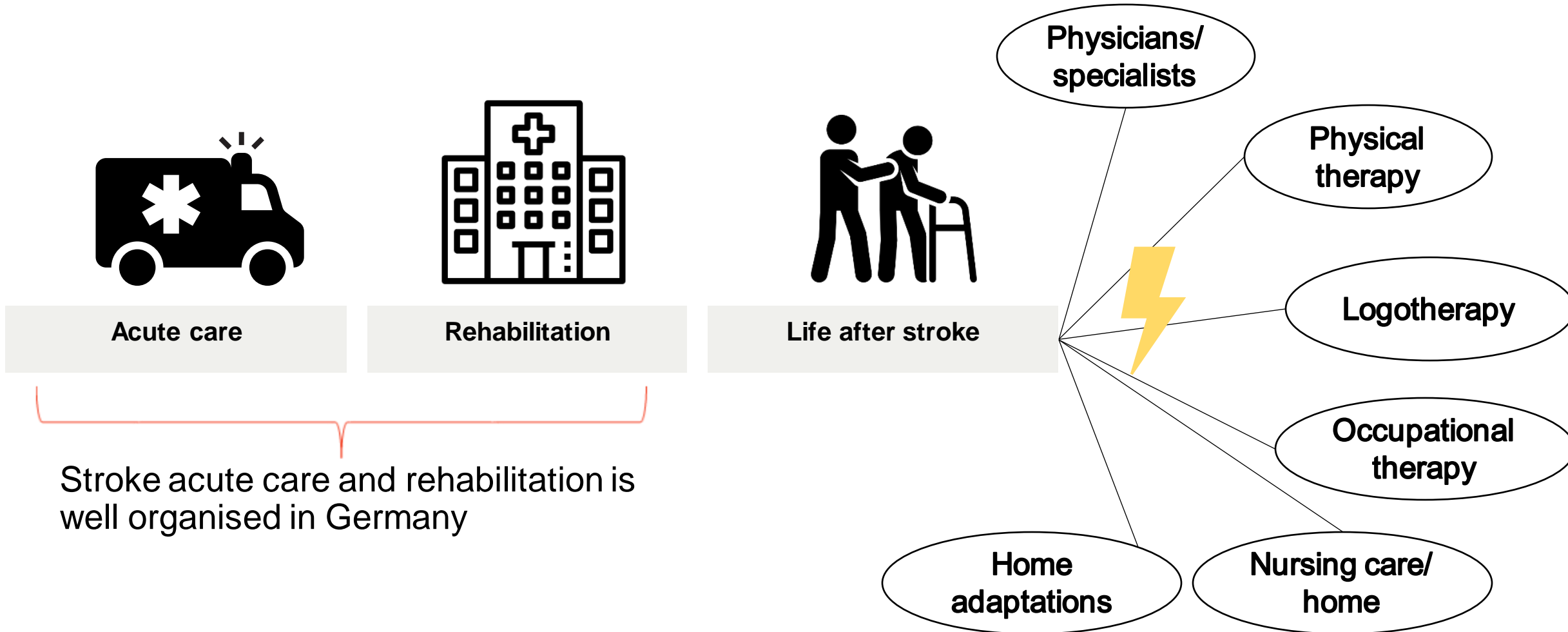
Die Stiftung Deutsche Schlaganfall-Hilfe will die Hilfsmittelversorgung verbessern. Dafür schult sie Mitarbeitende von Sanitätshäusern in der Beratung von Schlaganfall-Betroffenen.

# Germany – an overview



- Total population: 83 million
- More than 300,000 strokes per year
- More than 50,000 death per year
- 1,9 million people living with stroke
  
- 340 certified stroke units
- 2,800 beds in stroke units
- 77% of patients are treated in a certified Stroke Unit
- Total cost: 17,6 billion €

# The German Health Care System



# Patient involvement

## Challenges along the care way

### UNMET NEEDS IN STROKE AFTERCARE A SURVEY OF STROKE SURVIVORS IN GERMANY

Christina Franzisket, Christian Voigt, Dr. Markus Wagner, Dr. Michael Brinkmeier, Rebecca Pries, German Stroke Foundation, Gütersloh, Germany

#### Introduction and Purpose

Stroke is a severe illness with different long-term impairments [1]. Little information is available regarding the unmet needs of stroke survivors in Germany in the long-term. This survey tried to close information gaps in this area.

#### Methods

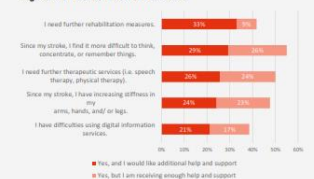
The German Stroke Foundation has developed an unmet needs questionnaire in German based on three different stroke assessment tools: The Greater Manchester Stroke Self-Assessment Questionnaire (GM-SAT) [2], Longer-term Unmet Needs after Stroke (LUNS Tool) [3], Post-Stroke Checklist (PSC) [4]. The questionnaire covered different domains of life after stroke (i.e., physical and mental health needs).

It was tested and finalized including stroke survivors' expertise (focus groups). The questionnaire was sent out in May 2021 to 3,375 stroke survivors included in the database of the German Stroke Foundation.

#### Results

29% people responded. The majority was male (56%) and on average 56 years old at the time of their stroke. 73% of the respondents had one and 27% more than one previous stroke. The self-assessed stroke severity was moderate in 40% and heavy in 26% of the respondents. The average time period since the last stroke was 9.2 years (SD=8.4). With the stroke five or more years ago more stroke survivors reported a care dependency or a disability degree. Approximately 70% of the respondents had at least one unmet need.

#### Figure 1: 5 most common unmet needs



#### Literature

- [1] Chen, T., Zhang, B., Deng, Y., et al. (2019). Long-term unmet needs after stroke: systematic review of evidence from survey studies. *BMJ open*, 9 (5).
- [2] National Institute for Health Research (2010). GM-SAT Greater Manchester Stroke Assessment Tool. Assessing the long term needs of stroke patients and their carers. Salford Royal NHS Foundation Trust (Hrag).
- [3] LoTS care LUNS study team (2013). Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multicentre study. *In: Clinical rehabilitation* 27 (11), S. 1020-1028. DOI: 10.1177/0269215513487082.
- [4] Philip, Ian; Braamin, Michael; Walker, Marion F., et al. (2013). Development of a poststroke checklist to standardize follow-up care for stroke survivors. *In: Journal of stroke and cerebrovascular diseases: the official journal of National Stroke Association* 22 (7), e173-80. DOI: 10.1016/j.jstrokecerebrovasdis.2012.10.016.

Unmet needs were primary found in the following topics: further rehabilitation measures, remembering and concentrating and further therapeutic measures (figure 1).

Regarding unmet physical and mental health needs, eight items of our questionnaire assessed physical (i.e., pain, speech or swallowing problems) and five items mental health needs (i.e., anxiety, sadness or depression). 51% of respondents reported unmet physical and 33% reported unmet mental health needs (figure 2). Women were more often affected in both categories. Additionally, an increasing stroke severity led to a higher burden of unmet physical and mental health needs. Older stroke survivors (>65 years old) reported slightly less unmet needs in both categories.

Figure 2: Unmet physical and mental health needs



#### Conclusions:

The survey gave a first non representative overview of unmet needs of nearly 1,000 stroke survivors in Germany. Reported unmet needs were manifold comprising the variety of challenges stroke survivors are confronted within their daily life after stroke. Via focusing on the stroke survivor's perspective, the German Stroke Foundation tries to improve the process of establishing patient-oriented aftercare stroke services. To support its use on a broader level, our survey instrument needs further validation and shortening.

More outcome research including the patients' perspective on stroke aftercare is needed in Germany, as structured follow up data collection after acute and rehabilitation phase as demanded in the Stroke Action Plan for Europe (SAP-E) are missing.

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## Challenges in Life after stroke in Germany

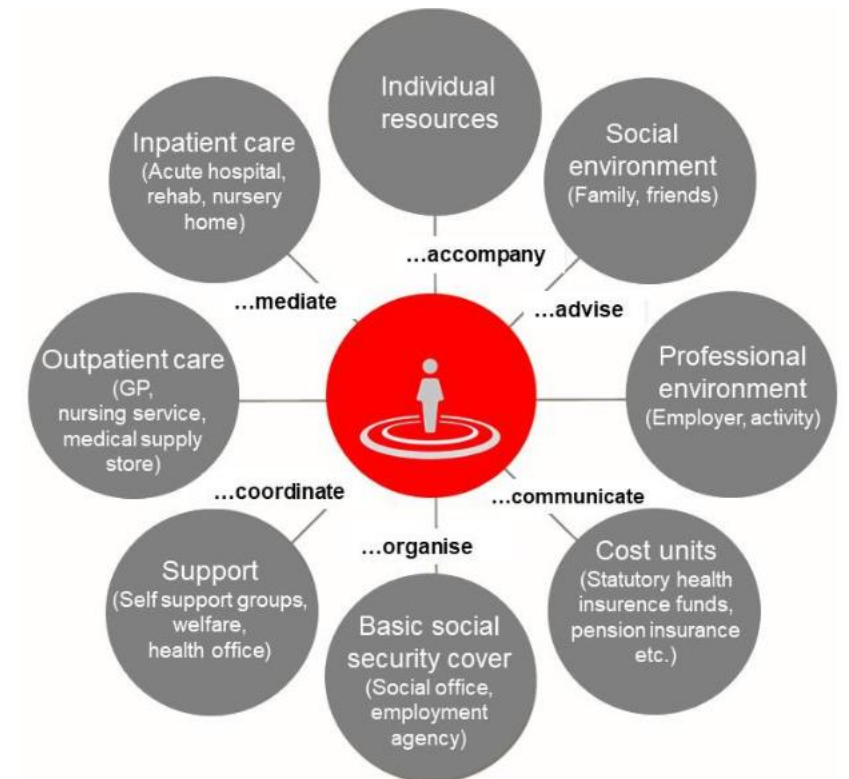
- Complex care system with many health care providers
- Unmet information needs
- Individual care needs
- Patients have to be advocates for their health
- Patients have to navigate through the health care system by themselves
- Different health care sectors which do not communicate with each other



# The stroke Case Manager intervention

## Support across the continuum of care

- 12 months of support throughout the whole patient journey provided by a professional case manager (nursing/ therapeutic background)
- Improvement of quality of care for stroke survivors
- Increase quality of life (patient related outcomes)
- Care and medication plans supervised by medics
- Individual targets for secondary prevention, motivation to change lifestyle
- Regular telephone contacts
- Support of caregivers and family members



# The stroke Case Manager intervention

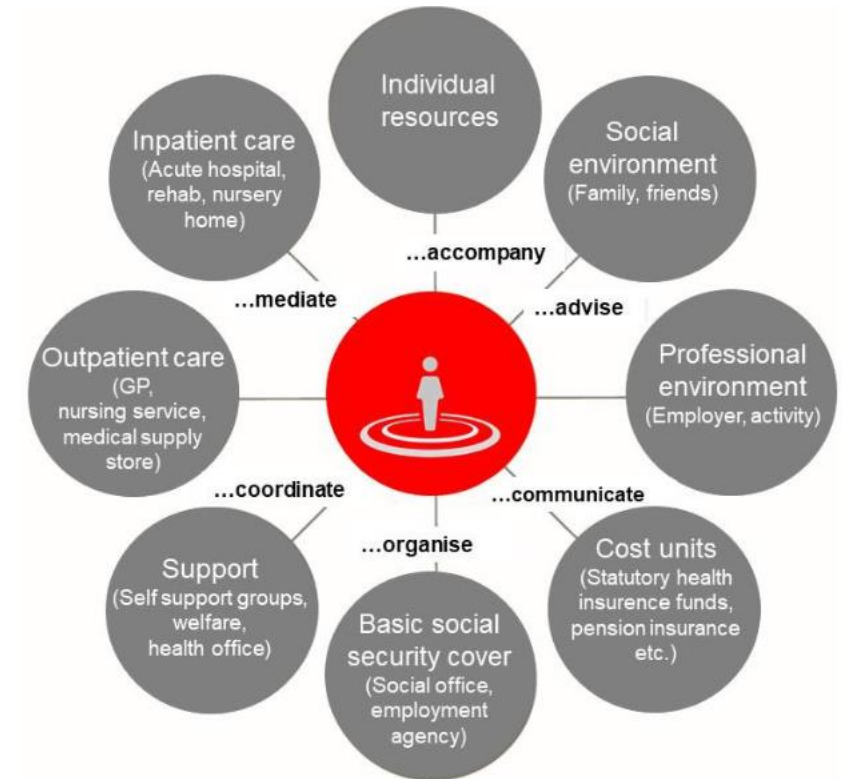
## Support across the continuum of care

- 12 months of support throughout the whole patient journey provided by a professional case manager (nursing/therapeutic background)

***Reintegration into worklife and participation into the community. Support of social life, improving self-management***

***Stroke navigator as an advocate for the patient***

- to change lifestyle
- Regular telephone contacts
- Support of caregivers and family members



# Results of STROKE OWL

## Innovation funds project of stroke navigators 10/2017-09/2021

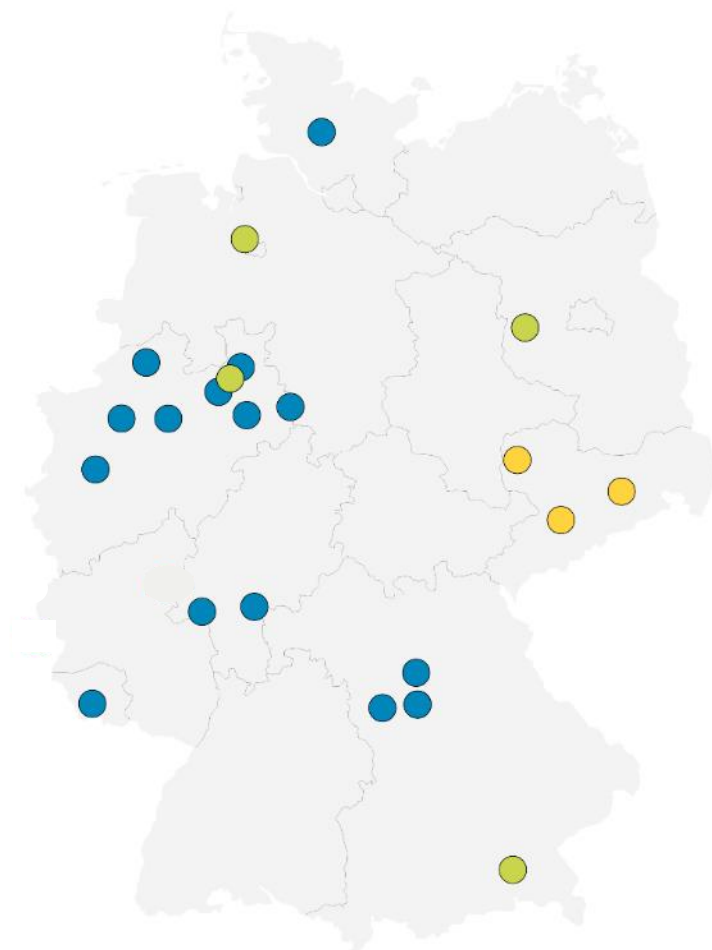
- The stroke navigator intervention is running
- Regional networks in East Westphalia Lippe (OWL) are established
- Expansion to other regions and indications is in progress
- Secondary prophylaxis seemed to work better with stroke navigators
- Patient perspective confirms benefit of intervention

**Cave: In the study, the stroke navigators have not yet achieved a significant positive health effect in terms of hard medical outcomes (i.e. mortality, rehospitalisation).**

**Reason: The one year follow-up was too short to see significant changes that quickly**

# Stroke navigators in 8 german federal states

Summer 2023



## Stroke navigators established as in the STROKE OWL project

- Bielefeld
- Gütersloh
- Herford
- Höxter
- Lippe
- Paderborn
- Ansbach
- Düsseldorf
- Erlangen
- Hanau
- Recklinghausen/Marl
- Püttlingen
- Sulzbach
- Wiesbaden
- Steinfurt
- Schwabach
- Schleswig

## Cooperating stroke navigator projects

- Leipzig (PostStrokeManager)
- Dresden (SOS-Care)
- Chemnitz

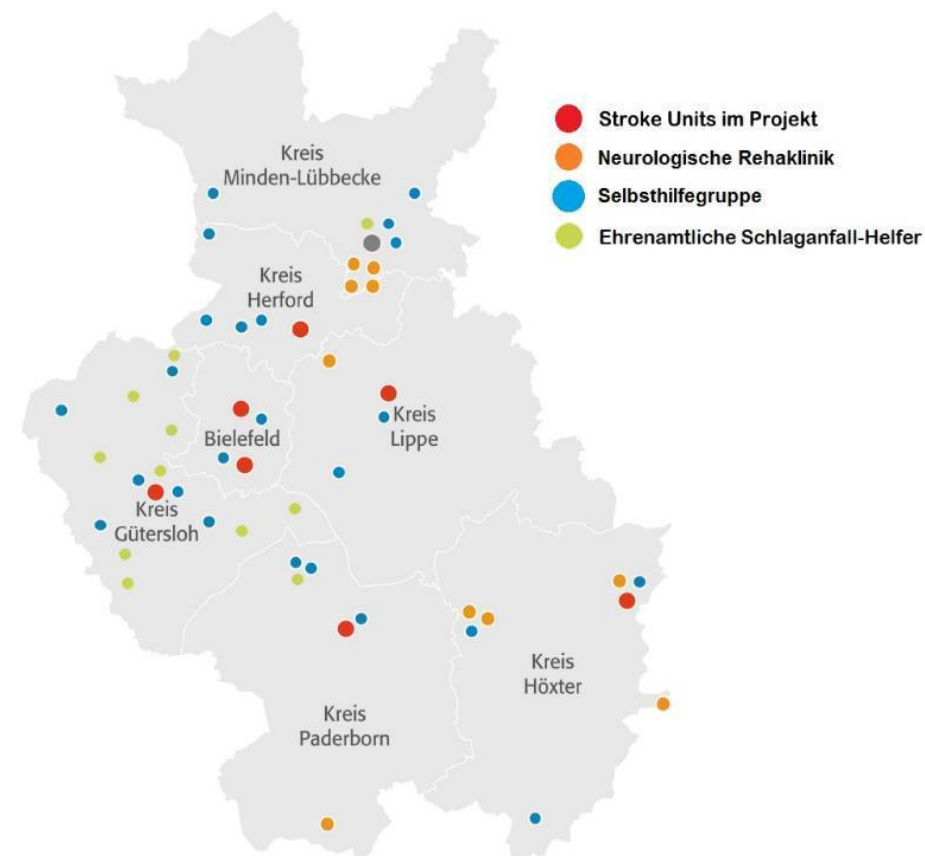
## Stroke navigators for children

- Bielefeld (West)
- Bremen (Nord)
- Hohenstücken (Ost)
- Vogtareuth (Süd)

# Project LEX LOTSEN OWL

## The general framework

- Project period: 01/01/2024 – 31/12/2026
- Funding: 7 million €
- Project in the German innovation funds
- Implementation of patient navigators (stroke and cardiologic diseases) in a randomised controlled trial
  - Proof efficacy of patient navigators (PROMs)
  - Combine different programs for different indications
- **Establish a governance structure to integrate navigators in the health care system**



# Our goal

Everybody in need  
gets support by a  
stroke navigator.



STIFTUNG  
DEUTSCHE  
SCHLAGANFALL  
HILFE



# Thank you!

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**Dr. Michael Brinkmeier**

*Chairman German Stroke Foundation*

michael.brinkmeier@schlaganfall-hilfe.de

+49 5241 9770-61

**Contact details:**

Web:	<a href="https://schlaganfall-hilfe.de">schlaganfall-hilfe.de</a>
Facebook:	<a href="https://facebook.com/schlaganfallhilfe">facebook.com/schlaganfallhilfe</a>
Twitter:	<a href="https://twitter.com/schlaganfall_dt">twitter.com/schlaganfall_dt</a>
Instagram:	<a href="https://instagram.com/schlaganfallhilfe">instagram.com/schlaganfallhilfe</a>