Help us select this year’s research priorities

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Stroke Association

stroke.org.uk
This workshop

• Our Research Strategy
• Why we’re here
• Time for questions
• Potential priorities for research
  • What are they?
  • What are the issues?
• Over to you
• Feedback
• Which topics are most important?
The research we fund is driven by our strategy
Research Strategy 2019-2024

1. Establish the next generation of stroke research leaders

2. Fund research that will bring the greatest benefit to people affected by stroke
   • Emergency care and treatment
   • Rehabilitation and long-term support
   • Secondary prevention

3. Work with other organisations to raise the profile of, and bring more money into, stroke research
   • Address issues that commonly affect stroke survivors
Future priorities for research

• While developing our new Research Strategy we consulted with:
  • Over 50 research experts
  • Over 30 people affected by stroke
  • Other research funders

Some of the top priorities for research
• Fatigue
• Continence
• Frailty
• Carers
Current/future priorities for research

• Psychological consequences of stroke
• Haemorrhagic stroke
• Vascular Dementia
  • Co-funding research with the British Heart Foundation and Alzheimer’s Society
• Vision after stroke
  • Will co-fund research with Fight for Sight
• End of Life Care
  • Will co-fund research with Marie Curie
We want your help!

We want to know which of these areas are most important to you:

• Frailty
• Fatigue
• Carers
• Continence

Which of these areas should we encourage more research in?
Any questions?
Frailty
So, what is frailty?

Frailty is a reduced ability to recover from a stressor event such as an illness.
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Is frailty seen in stroke?

All stroke admissions assessed for frailty in a UK hospital:

- **Frail**: 28% (151)
- **Not frail**: 21% (115)
- **Pre-frail**: 51% (276)
  (at immediate risk of becoming frail)
Frailty is a ‘hot topic’

• Last year, 1458 scientific studies on frailty were published
• Last year, 4 studies on frailty and stroke were published

• Frailty assessment being introduced in NHS
• But not for stroke

• UK Government has policy on frailty in older age
• Stroke not mentioned

• New treatments for frailty being tested
• People living with stroke are excluded
Lots of questions on frailty & stroke

• What is the best way to assess frailty in people with stroke?

• What are the implications of frailty in stroke?

• Can treating frailty prevent stroke or stroke problems?

• Can we treat frailty in people living with stroke?
Fatigue
What is fatigue?

‘Feeling of weariness, unrelated to previous exertion, which is not ameliorated by rest’

Characteristics:

• Chronic lack of energy, aversion to effort
• Unrelated to previous exertion levels
• Doesn’t improve after rest
What are the issues?

• **Common**, but unclear how common
  • 87% of stroke survivors have experienced fatigue
• Fatigue affects rehabilitation and outcomes
• One of the most **distressing symptoms** after stroke
• One of the **top research priorities** for life after stroke
  • For people affected by stroke and healthcare professionals
I never felt this tired. Never felt tired like this before.

It cramps your lifestyle, ’cause it cuts out a chunk of the useable day and that’s annoying and frustrating.

I got this leaflet about fatigue after stroke. It made me realise that it’s going to last longer than I thought...

It’s just a general lack of how I was, how I think I used to be.
“There was insufficient evidence on the efficacy of any intervention to treat or prevent fatigue after stroke”
Lots of questions around fatigue

• How should we **define** post-stroke fatigue?
• **How common** is fatigue after stroke?
• Which factors may **predict** a stroke survivor developing fatigue?
• **What causes fatigue** after stroke?
• How should we **assess** stroke survivors for fatigue?
• What are the **best ways to treat** fatigue after stroke?
Carers
Background

- Stroke survivors often rely on family members and friends for help day-to-day
- Informal (unpaid) care for stroke survivors was worth £15.8 billion in 2015
- Caring can come at a great personal cost to caregivers:
  - Affects identity, emotional well-being, physical health, social participation
Experiences of informal caregivers

How are you?

Caregiver Training

Support Networks

FEEDBACK
Carer needs
Looking after themselves -> Supporting caring role
Carer needs

But needs change over time – no ‘one size fits all’ approach
Background

- Identified as an area of unmet need by:
  - Patients, carers and family
  - Health and social care professionals

- 2014: 14,934 active research projects in the UK worth £2 billion
  - Only 33 projects into ‘continence’

- 64% of stroke survivors report their stroke impacted their continence
What are the issues?

• Stigma

• Lack of public understanding

• 2016 survey: 60% of people would be embarrassed to speak about continence issues

• Waiting to get help can reduce the number of treatment options

• Drug treatments have side effects

• Treatment can be affected by other conditions
My bladder and bowel own my life 24/7. They are a dictator and tyrant lying in wait to cause trouble and embarrassment and social isolation.

The indignity of incontinence is often worse than the illness that has caused it, the devices are not practical or well designed, and care for people with incontinence can become a burden.
Lots of questions around continence

• What is the **patient experience** of continence issues?

• What is the **cost of continence issues**?

• What are the most effective **self-management techniques**?

• What are the **side effects** of continence medication?

• How effective are **non-surgical interventions**?
Over to you
Questions for you

On tables spend 15 minutes talking about:

• Which areas are important to you? Why?

• What do you think the needs are in these areas?

• What would make the biggest difference to you?
Feedback
Your priorities
Summary
Stroke Association

Rebuilding lives after stroke