Welcome and introduction

David Weller

James Mackenzie Professor of General Practice

Session One

Chair:

Michaela Gilarova

James Beeston

Juliet Bouverie OBE
Chief Executive of the Stroke Association

Alex Todhunter-Brown
Glasgow Caledonian University and The University of Edinburgh

Susan Shenkin
The University of Edinburgh

Frederike van Wijck
Glasgow Caledonian University and Research Centre for Health

Priorities for Life after Stroke Research: A Stroke Association perspective

Juliet Bouverie, OBE
Chief Executive of the Stroke Association

Stroke Association

Make May Purple

This Stroke Awareness Month we are asking people to Make May Purple to raise vital funds and awareness.

We have over 1300 people registered to take part.

My pledge was to dye my hair purple.

You can donate using the QR code or this link: https://www.justgiving.com/fundraising/Juliet1777489754892

Beyond survival – why life after stroke research matters

100,000

There are more than 100,000 strokes in the UK each year.

1.4 million

There over 1.4 million stroke survivors in the UK.

£26 billion

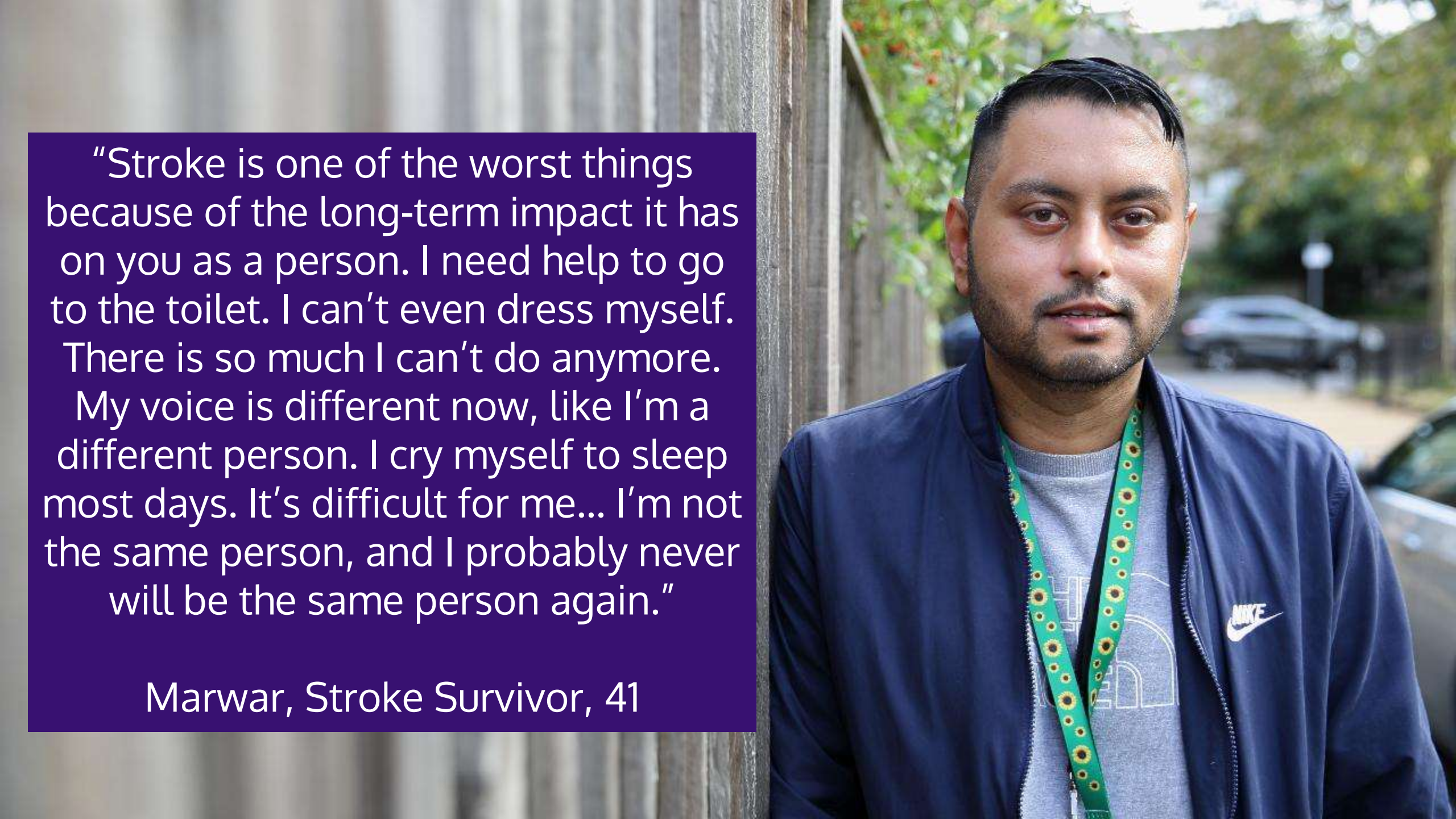
The cost of stroke to society is around £26 billion a year.

4th

Stroke is the 4th biggest killer in England and Wales, and the 3rd biggest killer in Scotland and Northern Ireland.

2 out of 3

Around 2 out of 3 stroke survivors leave hospital with a disability.



"Stroke is one of the worst things because of the long-term impact it has on you as a person. I need help to go to the toilet. I can't even dress myself. There is so much I can't do anymore. My voice is different now, like I'm a different person. I cry myself to sleep most days. It's difficult for me... I'm not the same person, and I probably never will be the same person again."

Marwar, Stroke Survivor, 41

Stroke impacts on all aspects of daily life

Stroke PREMs

91% felt they were treated with dignity and respect

Only 28% felt supported with return to work, and 19% with returning to hobbies/activities

39% left hospital without a clear understanding of their medication

23% didn't receive help with emotions/mood but would have liked it

25% wanted support to monitor their BP but didn't receive it

PROMs (SSNAP Spotlight report)

Pre stroke: 15% working full time and 4.2% part time. Post stroke: 6% and 4.8%.

66% report slight to extreme problems with returning to previous activities

44% report slight to extreme problems with anxiety and depression

44% report slight to extreme problems with self-care

Stroke Association data – Top 10 needs

Reassurance

Understanding of stroke

Emotional wellbeing and health

Fatigue

Benefits and finance

Home and daily living

Support networks

Mobility

Needs of carer/family

Independence

Stroke impacts on all aspects of daily life

50% are impacted by depression

66% state their relationships have been impacted

71% report an impact on their social life

Work has been impacted for 54%

1 in 10 have had suicidal thoughts

Finances are impacted for 3 in 5 stroke survivors

45% report that they've experienced anxiety

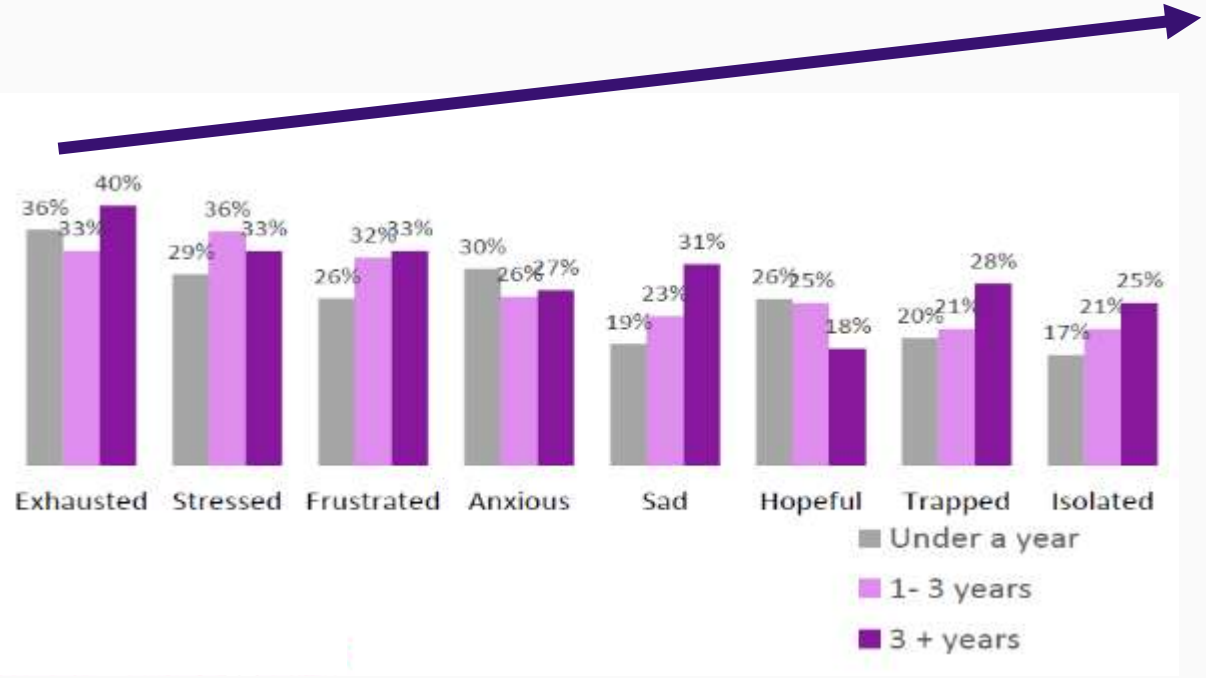
80% say stroke has impacted on their overall happiness

Lived experience of stroke report | Stroke Association, 2019

And the impacts of stroke can intensify long after the event itself.

Example:

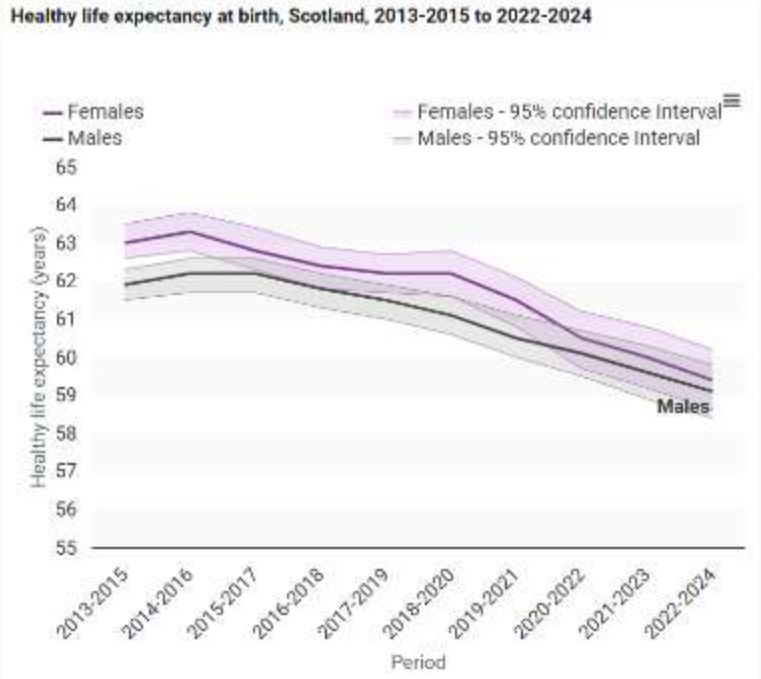
Carers' negative emotions don't diminish over time but instead show signs of growing stronger.



Lived experience of stroke report | Stroke Association, 2019

Scotland has the highest stroke mortality of the four UK nations and the largest proportion of people living with disability because of stroke

- People in the **most deprived areas** of Scotland are 62% more likely to die from a stroke than those in the least deprived areas.
- **Healthy life expectancy** has also been falling since mid 2010s, despite small increases in life expectancy.
- Since the 2014-16 survey period, women have lost almost four years of healthy life expectancy and men have lost three years.

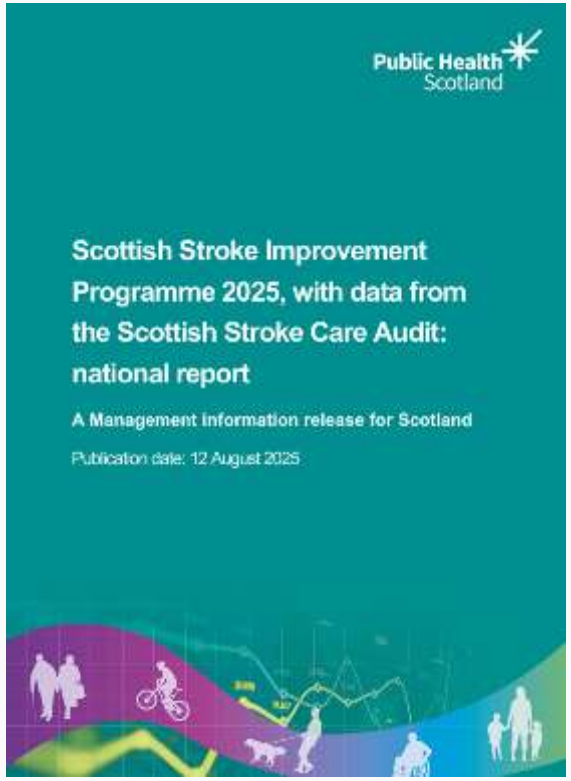


Healthy Life Expectancy, 2022-2024 - National Records of Scotland (NRS)

And advances in long term care and support lag behind those in the acute space.

- Across England, Wales and NI, only 35% (of those eligible) have a **six-month follow-up** completed. In Scotland, only 4/12 Health Boards rate themselves 'green' for six month review provision (Scottish Stroke Care Audit).
- The proportion of patients receiving a 6-month review after stroke has been in steady decline since 2019/20, despite patients continuing to report significant levels of physical and psychological morbidity.

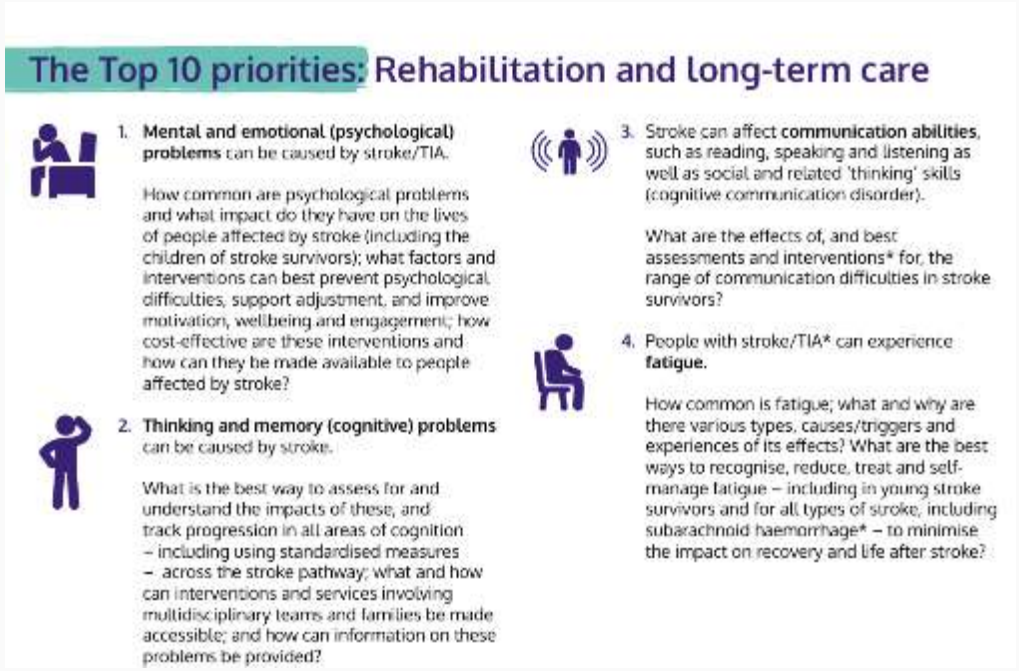
Not one Scottish Health Board received a green RAG rating for psychological care in the most recent audit period.



Ayrshire and Arran	
Borders	
Dumfries and Galloway	
Fife	
Forth Valley	
Grampian	
Greater Glasgow and Clyde	
Highland	
Lanarkshire	
Lothian	
Orkney	
Shetland	
Tayside	
Western Isles	

Life after Stroke research – what are the priorities?

The James Lind Alliance Priority Setting Partnership has already described the life after stroke research questions that matter most to people affected by stroke.



The Top 10 priorities: Rehabilitation and long-term care

1. **Mental and emotional (psychological) problems** can be caused by stroke/TIA.

   How common are psychological problems and what impact do they have on the lives of people affected by stroke (including the children of stroke survivors); what factors and interventions can best prevent psychological difficulties, support adjustment, and improve motivation, wellbeing and engagement; how cost-effective are these interventions and how can they be made available to people affected by stroke?

2. **Thinking and memory (cognitive) problems** can be caused by stroke.

   What is the best way to assess for and understand the impacts of these, and track progression in all areas of cognition – including using standardised measures – across the stroke pathway; what and how can interventions and services involving multidisciplinary teams and families be made accessible; and how can information on these problems be provided?

3. Stroke can affect **communication abilities**, such as reading, speaking and listening as well as social and related 'thinking' skills (cognitive communication disorder).

   What are the effects of, and best assessments and interventions* for, the range of communication difficulties in stroke survivors?

4. People with stroke/TIA* can experience **fatigue.**

   How common is fatigue; what and why are there various types, causes/triggers and experiences of its effects? What are the best ways to recognise, reduce, treat and self-manage fatigue – including in young stroke survivors and for all types of stroke, including subarachnoid haemorrhage* – to minimise the impact on recovery and life after stroke?

5. How can **community stroke services** best be resourced and organised in all regions to provide effective home/community-based rehabilitation that meets the needs of all groups of stroke survivors such as ethnic groups, young people, stroke severities and those with multiple health conditions?

6. What and how common are the **long-term impacts of stroke on abilities necessary for everyday life**; what interventions* can be made available to facilitate these abilities, and how? For example, impact on and interventions including education, assessment, treatment and support for return to work, driving, relationships and financial wellbeing.

7. What is the best **time, place and amount of therapy** (eg speech and language therapy, physiotherapy, occupational therapy) to get the best outcomes* for stroke survivors, and is this different than advised in the Stroke Guidelines (5 times a week for 45 minutes)?

8. How can **people supporting stroke survivors work best with the stroke care team,** and what personalised training and support is available for carers to enable them to support stroke survivors and their recovery, including those with communication, cognitive and engagement difficulties? For example, the roles of family members, volunteers, stroke liaison workers and young carers.

9. What are the best interventions* including exercise to **improve strength and fitness, promote recovery and prevent further stroke** in stroke survivors?

10. What do stroke survivors think and feel works well, or needs improvement as they move through the stroke pathway, including the intensity of rehabilitation*? What can be done to improve the **stroke survivor and carer experiences**?

The priority now is clear: accelerate progress on answering these questions and delivering real world impact.

Doing this in a way that:

1. Centres lived experience

When people affected by stroke play an active role in shaping research, its relevance, quality and impact increase dramatically.

Meaningful involvement needs to be the norm, not the exception, across the entire research system.

2. Embraces multidisciplinary expertise and collaboration

Stroke Association is developing a Stroke Research Academy to connect, grow and amplify multidisciplinary stroke research

- Connect the community: Bring clinicians, AHPs, researchers and lived experience partners together.
- Grow research capability: Support more multidisciplinary teams to take part in research.
- Shape strategic direction: Create the shared conversations needed to grow stroke research around survivor priorities.

3. Considers multimorbidity and chronic stroke

- “People with stroke should be considered to have the potential to benefit from rehabilitation at any point after their stroke (National Clinical Guideline for Stroke 2023)

- Yet there is a dearth of evidence investigating **long-term** therapy-based rehabilitation interventions for patients with stroke

- We must see progress in the testing of interventions for people 1+ year post-stroke.

Therapy-based rehabilitation services for patients living at home more than one year after stroke - Aziz, NA - 2008 | Cochrane Library

Example of studies benefiting those 1+ years post-stroke

We have recently funded a PhD as part of the TRICEPS vagal nerve stimulation study.

The study **offers hope for better arm function**, particularly for stroke survivors many months or years after stroke who might have plateaued in their recovery.

4. Actively addresses inequalities

- Focusing on people and communities who are disproportionately affected by stroke.
- But also, making strides towards better inclusion of those commonly underrepresented in clinical trials and research studies, such as older people.

5 and 6. Responds to historic methodological challenges AND has a clear pathway to real world impact

- Life after stroke research questions don't always lend themselves to traditional clinical research methods and AHPs don't yet have the support they need to be truly research active.
- A clear pathway to impact is essential if research is to lead to meaningful change. In the life after stroke space, this can be particularly complex, as effective support frequently extends beyond traditional NHS structures, demanding creative approaches to implementation and sustainability.

Accelerating progress together – the role of the Stroke Association

Our purpose is to tackle the devastation of stroke

Support
Help stroke survivors and their loved ones live their best lives after stroke

Influence
Catalyse action with decision-makers to drive improvement in stroke.

Contribute
Help and inspire supporters to make their best contribution.

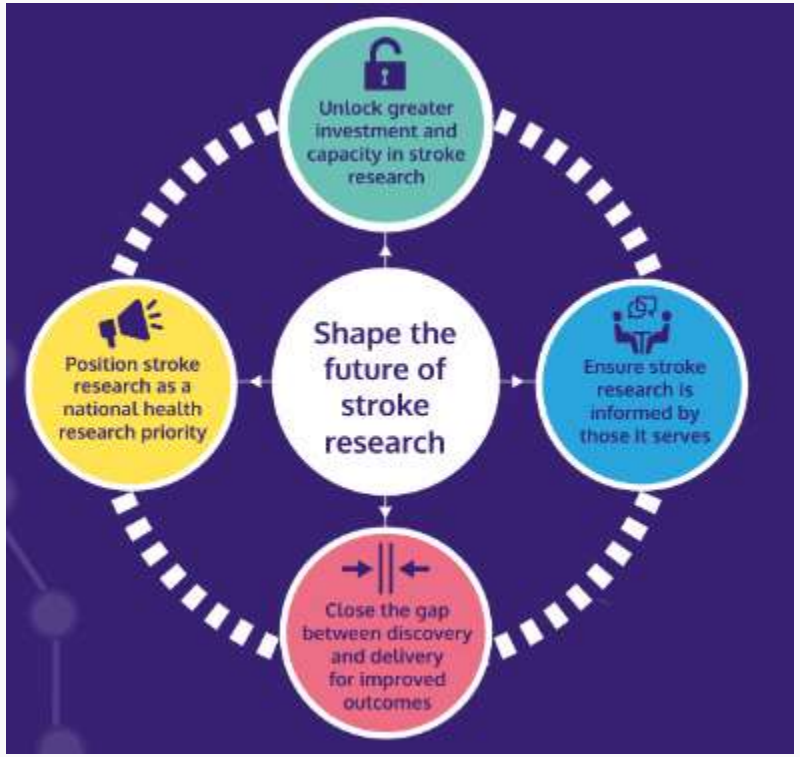
Underpin
Help our people to work safely, legally, ethically, sustainably and continuously.

Our medium-term strategic focus

- We exist to tackle the devastation of stroke.
- Too many stroke survivors in the UK feel abandoned after leaving hospital and without the rehabilitation they need.
- We want to see **every stroke survivor having access to high-quality rehabilitation** for as long as they need it.
- Over the next two years we'll **expand emotional support** to help stroke survivors engage with their recovery, influence the health system to **improve access to quality rehabilitation,** and **inspire partners and supporters** to help drive change.

Influencing: Our new Research Strategy outlines an evolution in our research role

From primarily a funder **to a system leader** (including funder), working with the clinical and research community to shape the stroke research landscape



Influencing: We're demanding stroke be made a greater priority in Scotland

For this month's Scottish Parliament elections, we worked with the stroke community to co-produce five key policy calls for change.

- Deliver equitable 24/7 national thrombectomy service
- Increase inpatient and outpatient rehabilitation capacity
- Give acute stroke care the same hospital status as other specialist units
- Produce innovative long-term stroke specific workforce plan
- Ongoing failure to meet stroke standards to be escalated to Health Improvement Scotland

Influencing: We continue to engage internationally to drive the life after stroke agenda

Stroke Action Plan for Europe
Life after Stroke domain

Global Stroke Action Coalition
Advocating
for rehabilitation

Stroke support organisations
Facilitating involvement of SSOs in Africa in life after stroke research

Support: We're exploring how to expand emotional support and how to test new research interventions & models of care

WAterS
Wellbeing after stroke

COMMITS
Confirming the mechanism of motivational interviewing therapy after stroke

Contribute: Inspiring our supporters to give their time, voice and money

We're improving our data and digital infrastructure to give our supporters a more personalised experience so they feel valued and appreciated.

With a focus on brilliant stewardship.

Take home messages

Take home messages

- Life after stroke research is about people. It's about building a future where everyone affected by stroke has the chance to live their best lives after stroke.
- We already know the life after stroke research questions that matter most to people affected by stroke.
- The priority is therefore clear – **accelerate discovery and deliver real-world impact for life after stroke at pace and scale.**
- The Stroke Association is committed to shaping the UK and global stroke research landscape, strengthening collaboration, and helping build an ecosystem where innovation and lived experience are at the heart of discovery.

Stroke Association

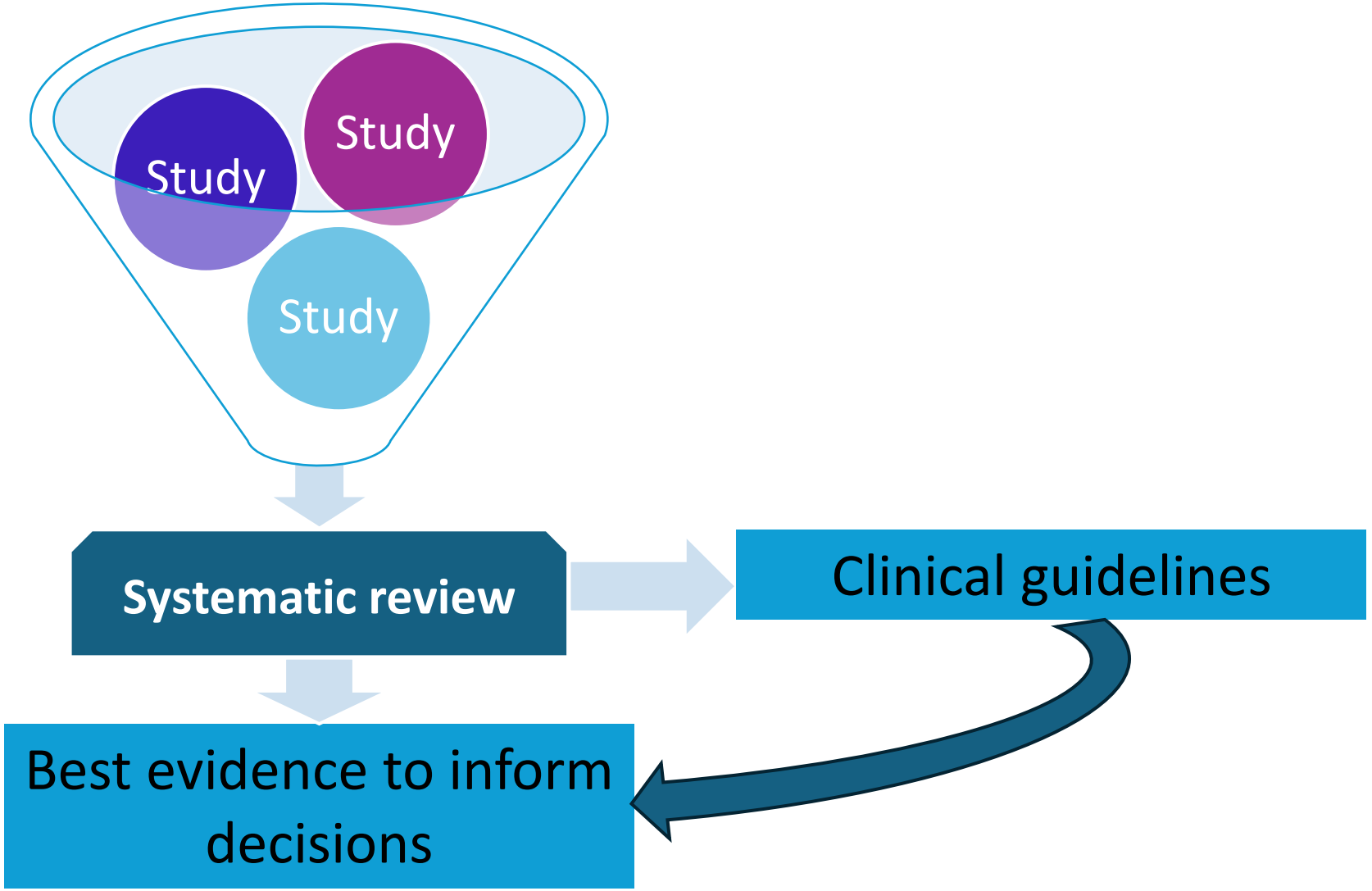
Finding **strength** through **support**

Systematic reviews and their crucial underpinning role in life after stroke research

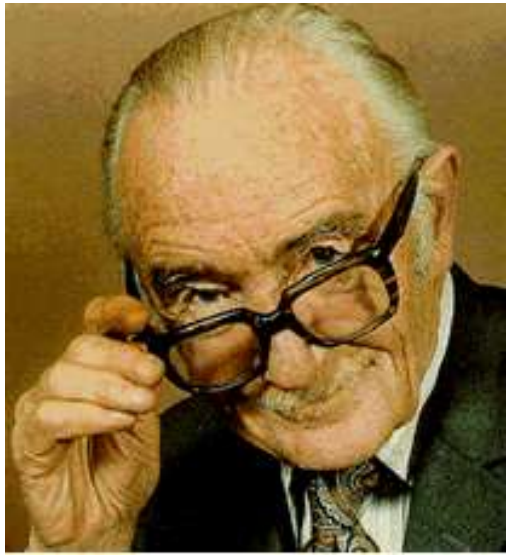
Alex Todhunter-Brown

What is a systematic review (evidence synthesis)?

A type of research that brings together the findings of primary research studies to answer a clinical question



Cochrane systematic reviews



THE COCHRANE COLLABORATION®

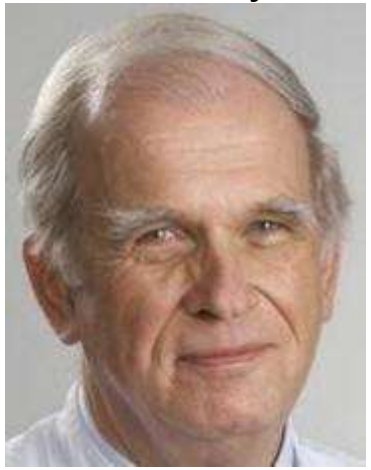
1993

Cochrane Stroke

Founded by:

Charles Warlow

Jan van Gijn



Peter Sandercock

"It is surely a great criticism of our profession that we have not organised a critical summary, by specialty or subspecialty, adapted periodically, of all relevant randomised controlled trials."
Archie Cochrane, 1979

Cochrane review of Stroke Units

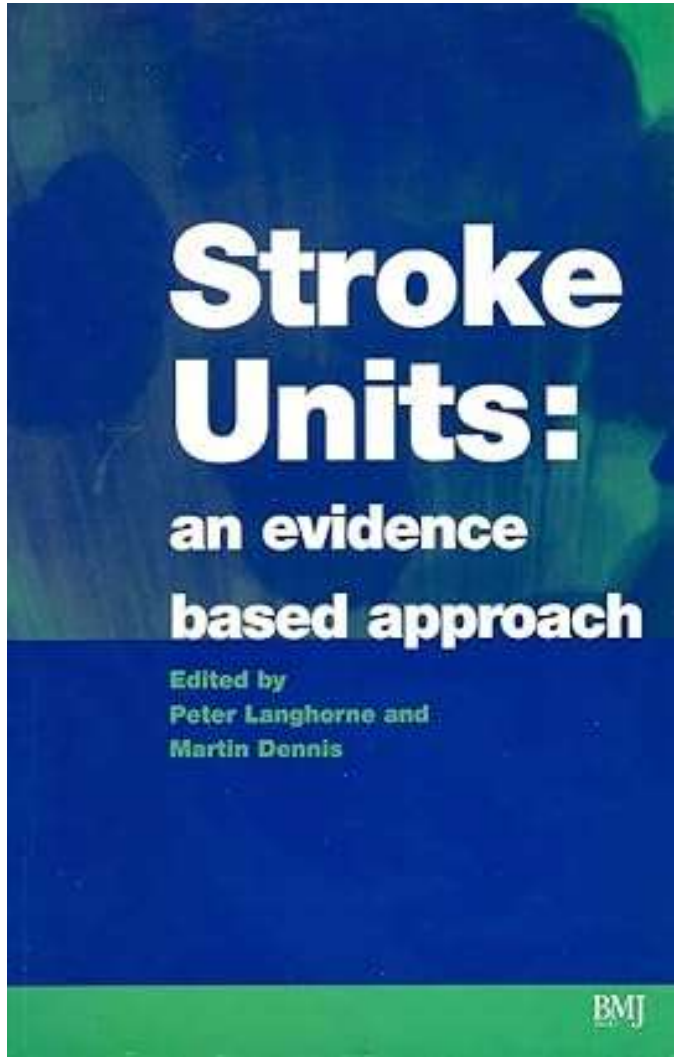
Cochrane Stroke

Multidisciplinary stroke unit care for stroke in-patients

Collaboration Stroke Unit Trialists, Peter Langhorne

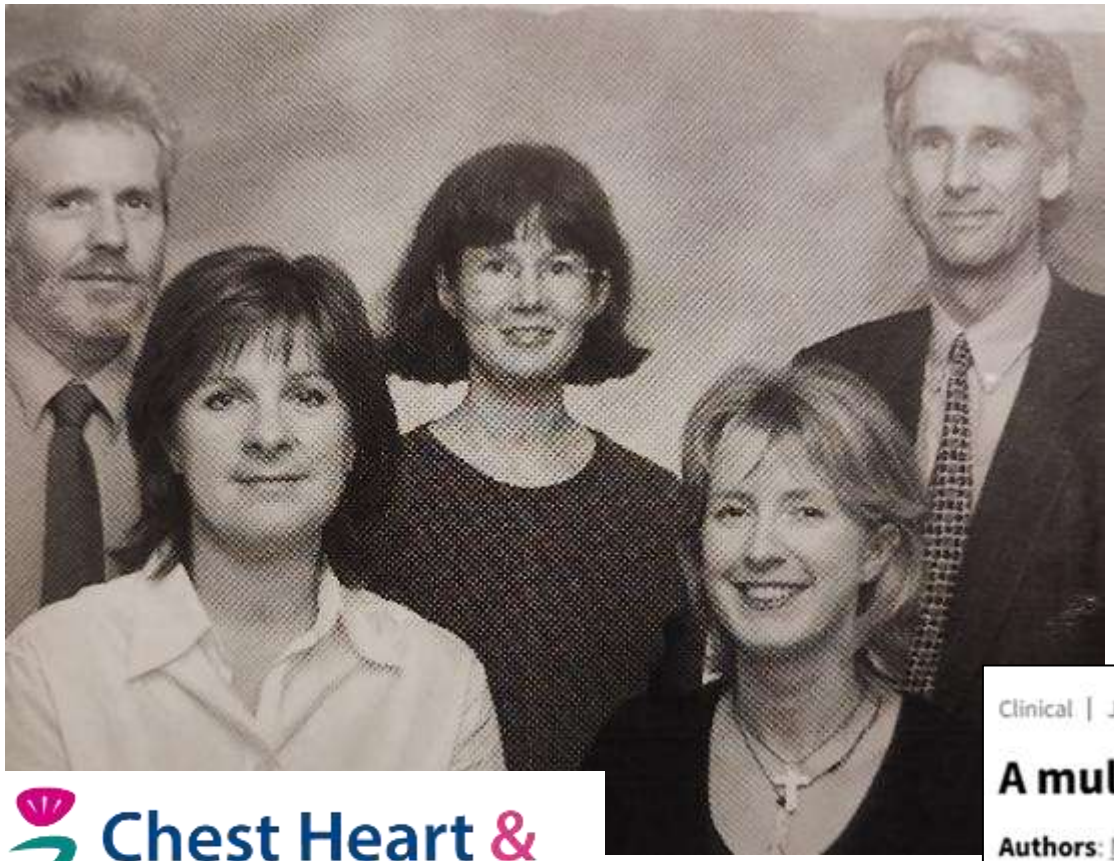
Cochrane Database of Systematic Reviews; Disk Issue 1, 1995

*"**Conclusions:** Organised **stroke unit care resulted in long term reductions in death, dependency, and the need for institutional care**. The observed benefits were not restricted to any particular subgroup of patients or model of stroke unit care. No systematic increase in the use of resources (in terms of length of stay) was apparent."*



Cochrane reviews of stroke rehabilitation

Stroke Therapy Evaluation Programme (STEP)



Chest Heart & Stroke Scotland

JOURNAL ARTICLE

What are the components of effective stroke unit care?

Peter Langhorne, Alex Pollock in Conjunction with The Stroke Unit Trialists' Collaboration

Age and Ageing, Volume 31, Issue 5, September 2002, Pages 365–371,
https://doi.org/10.1093/ageing/31.5.365

Published: 01 September 2002 **Article history**

Does Bobath therapy work?

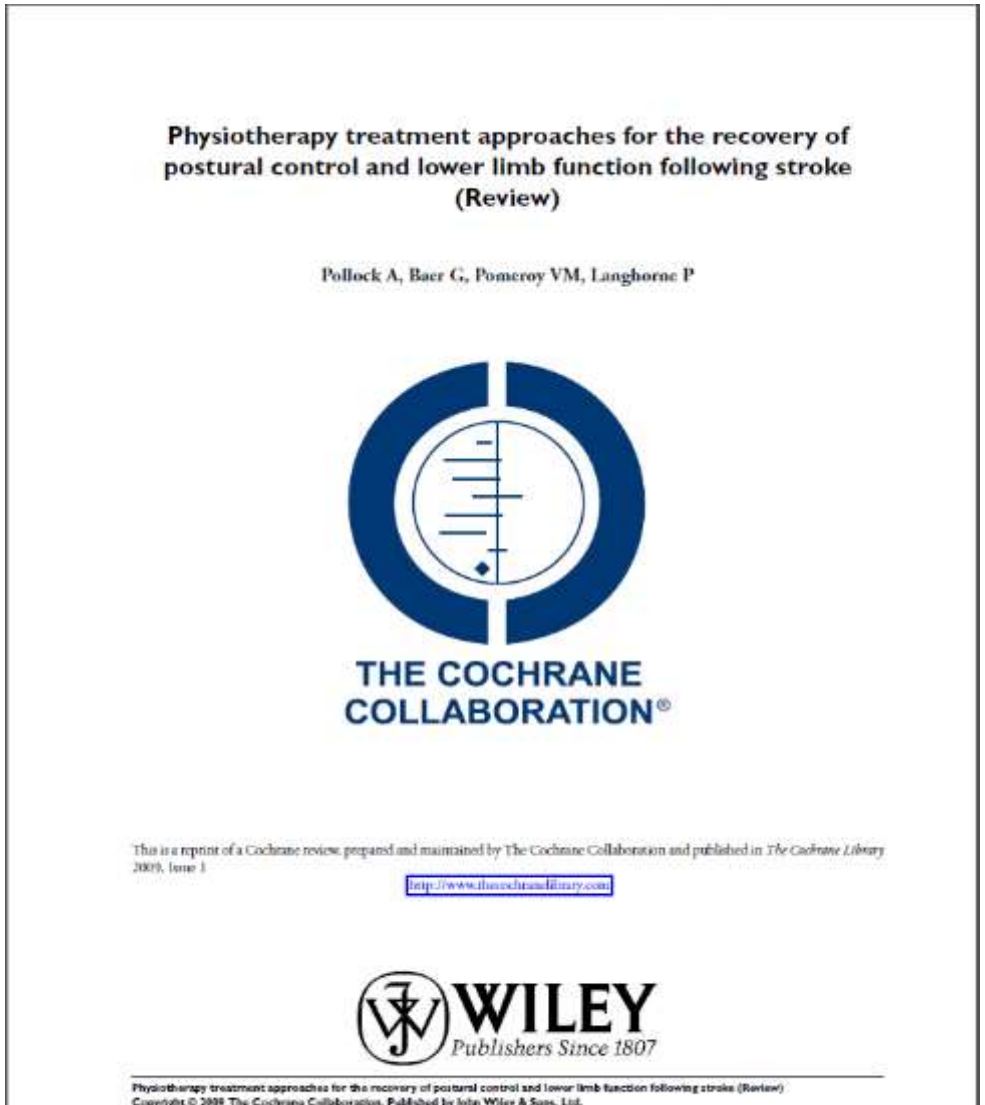
Clinical | July 2000

A multidisciplinary research agenda for stroke rehabilitation

Authors: Ms Lynn Legg, Dr Alex Pollock, Dr Peter Langhorne, and Mr Cameron Sellars | AUTHORS INFO & AFFILIATIONS

Publication: British Journal of Therapy and Rehabilitation • Volume 7, Number 7 • https://doi.org/10.12968/bjtr.2000.7.7.13869

Cochrane review of physiotherapy treatment approaches



Physiotherapy treatment approaches for the recovery of postural control and lower limb function following stroke (Review)

Pollock A, Baer G, Pomeroy VM, Langhorne P

THE COCHRANE COLLABORATION®

This is a reprint of a Cochrane review, prepared and maintained by The Cochrane Collaboration and published in *The Cochrane Library* 2009, Issue 1

http://www.thecochranelibrary.com

WILEY Publishers Since 1807

Physiotherapy treatment approaches for the recovery of postural control and lower limb function following stroke (Review)

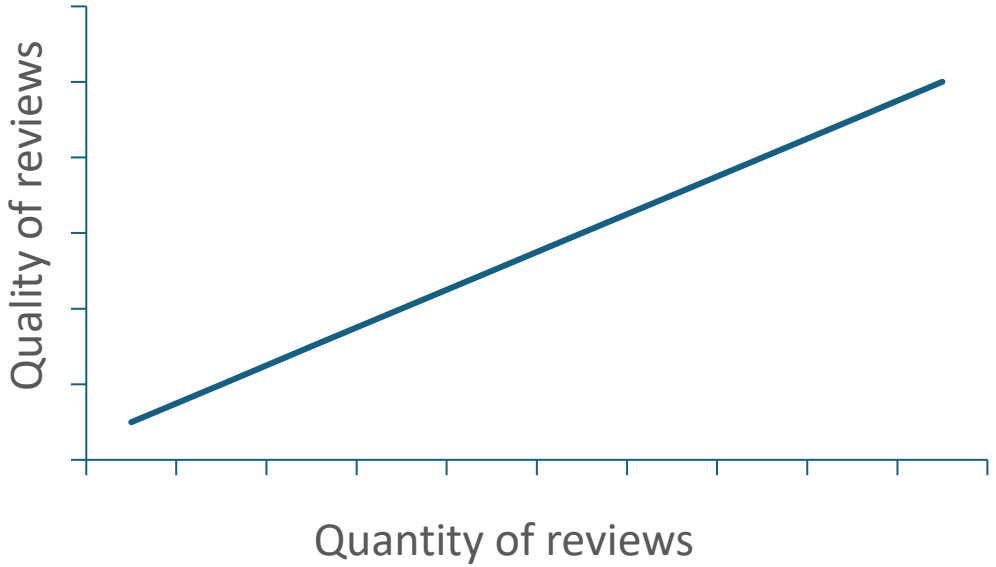
2002	2007	2014	2025
11 RCTs (n=267)	21 RCTs (n=1087)	96 RCTs (n=10401)	267 RCTs (n=21838)

*"……physical rehabilitation that focused on **functional task training may improve the ability to carry out activities of daily living**……..*

***…….Neurophysiological approaches……..may be less effective** than other approaches at improving daily activities"*

Cochrane reviews of stroke rehabilitation

Methodological quality improved over time



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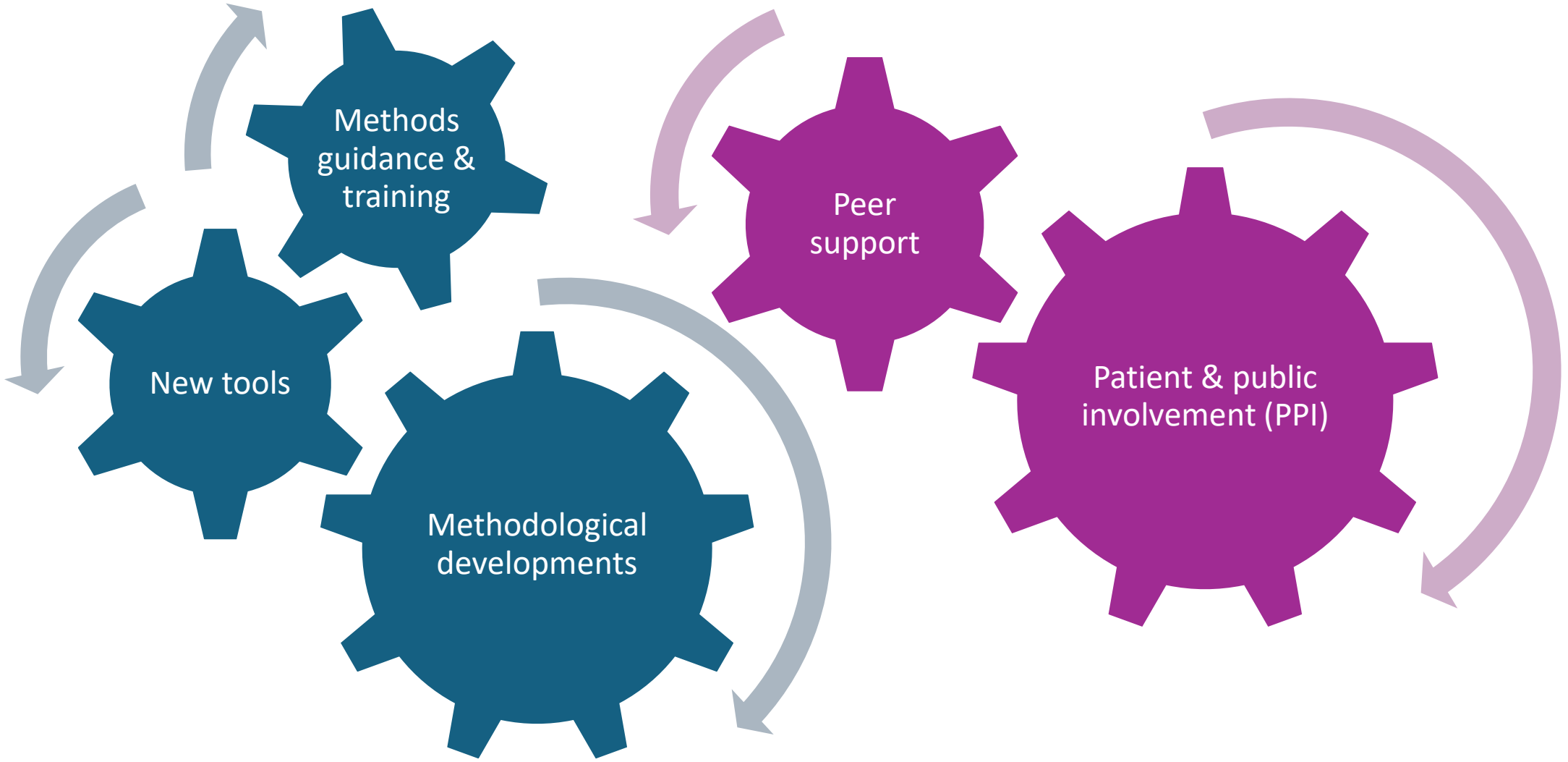
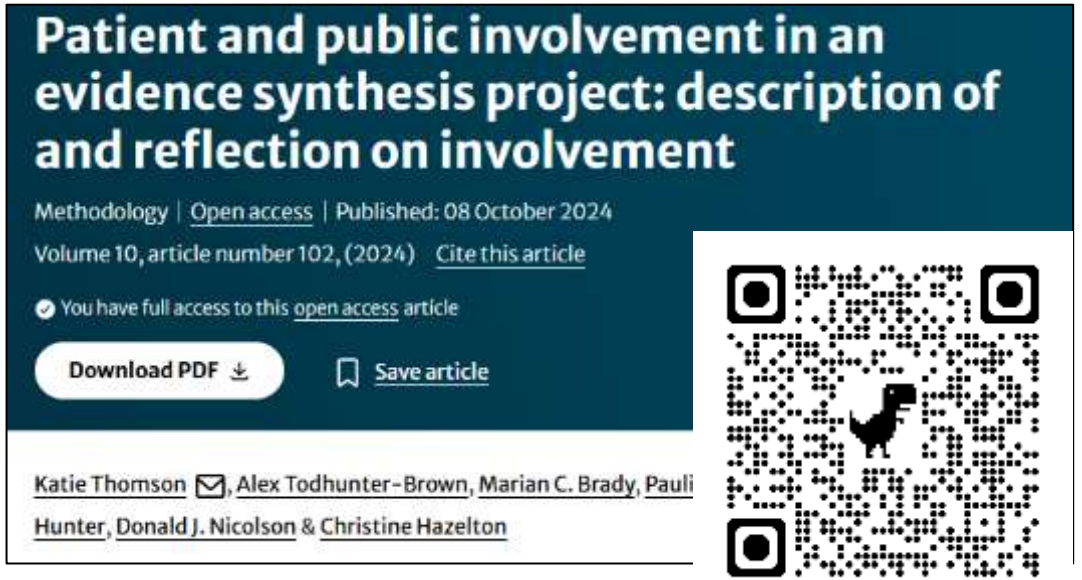


Patient & public involvement in stroke reviews



Cochrane Stroke rehabilitation reviews and their crucial underpinning role in life after stroke research

- High quality reviews provide best evidence about stroke rehabilitation
- Stroke rehabilitation reviews impact clinical guidelines worldwide
- Volume of evidence & certainty of evidence has increased over time
- Patient & public involvement (PPI) established as core method within stroke rehabilitation reviews

Challenges & opportunities

Challenges / risks

Strengths

High-quality stroke rehabilitation reviews – cited in guidelines

Community of experts

Patient & public involvement

Weaknesses

Complexity of reviews, e.g.

- Multimorbidity

- Outcome measures

- Application of evidence to individual stroke survivors

Opportunities

?

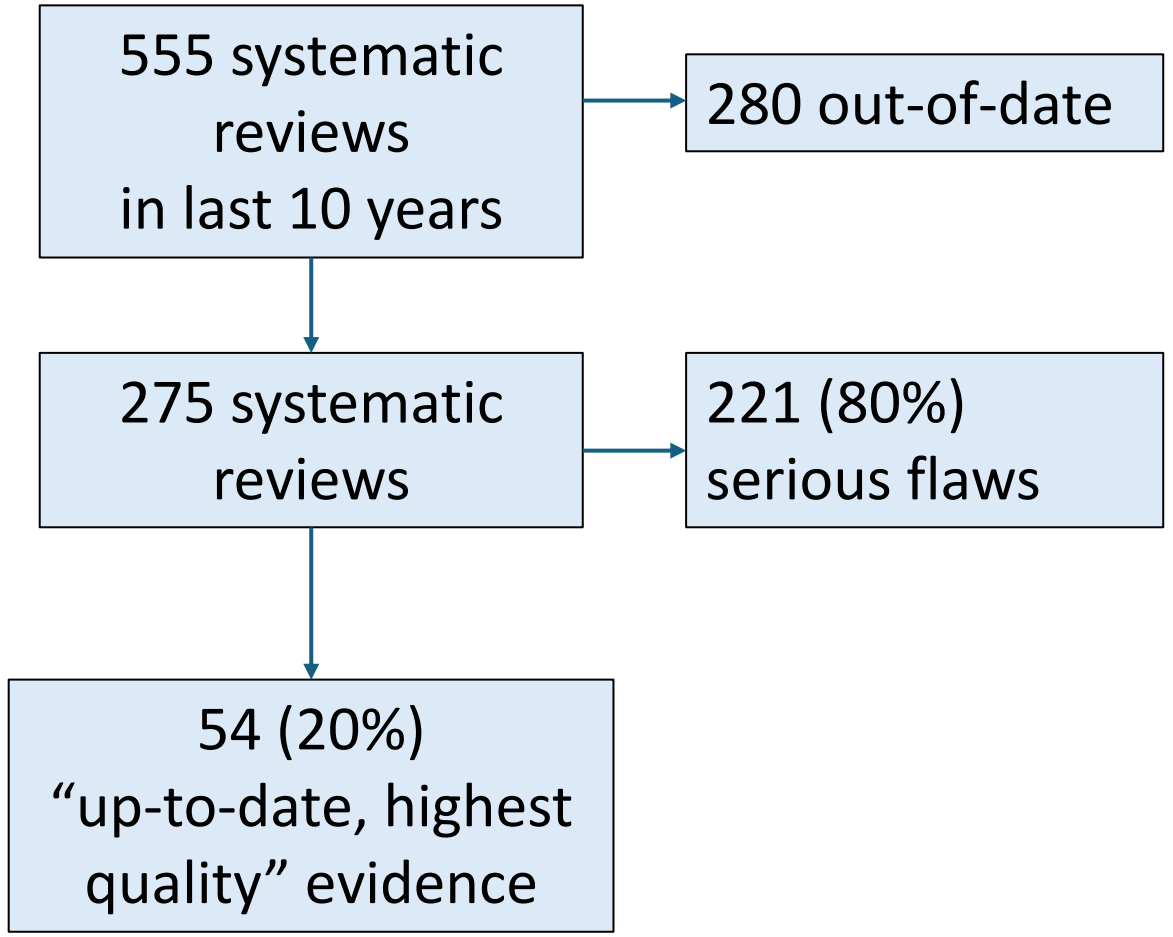
Threats

Recent loss of infrastructure support

Reduction in quality

Move to non-Cochrane publications

Evidence of threat to high quality stroke reviews



Challenges / risks

Strengths

High-quality stroke rehabilitation reviews – cited in guidelines

Community of experts

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Weaknesses

Complexity of reviews, e.g.

- Multimorbidity

- Outcome measures

- Application of evidence to individual stroke survivors

Opportunities

Education, collaboration & peer support to ensure quality

PPI

Align systematic reviews with priority questions (& guidelines)

Strategies to support early career researchers

Threats

Recent loss of infrastructure support

Reduction in quality

Move to non-Cochrane publications

Thank you!

Alex.TodhunterBrown@gcu.ac.uk

Life after stroke: more than just about the stroke, a geriatrician's perspective

Prof Susan D. Shenkin

Professor of Healthcare for Older People
Ageing and Health & Advanced Care Research Centre
Usher Institute, University of Edinburgh

Better health, better futures

THE UNIVERSITY of EDINBURGH | usher institute

ACRC Advanced Care Research Centre

Susan.Shenkin@ed.ac.uk

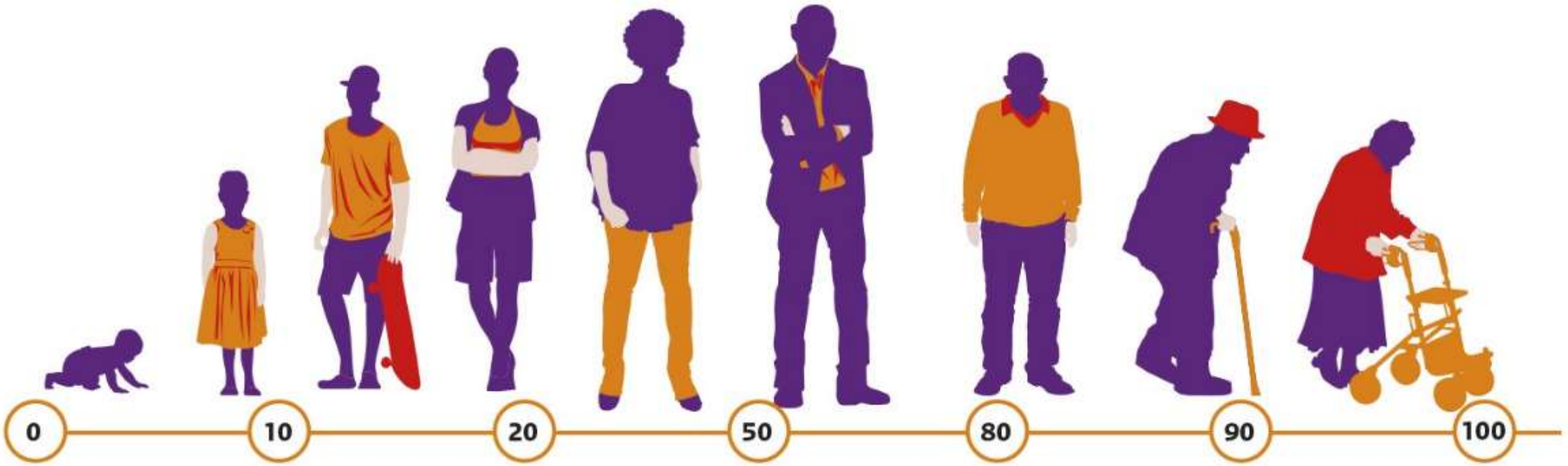
Outline

- Stroke
  - Sudden; health and functional impact
  - Life before stroke, and life after stroke

- Often co-exists with other conditions
  - Co-morbidity & Multiple long term conditions
  - Frailty
  - ‘Geriatric giants’

- How do we ensure (life after) stroke research includes everyone?
  - Data linkage, pre-existing consent, biobanks
  - Research in hospitals, homes, care homes…

Life after stroke…life before stroke



Not just about the stroke

- How many people with stroke have at least one other condition?
  ("co-morbidity")

~25% ~50% ~75% ~100%

94.2%....in a cross-sectional survey in primary care

It depends where you look….

High blood pressure ~61%
Heart disease ~30%
Painful condition ~22%
Depression ~21%
Diabetes ~19%
Kidney Disease ~14%
Constipation ~14%
Atrial fibrillation ~13%
Thyroid disorders ~12%
COPD ~12%

Gallacher et al, 2014 DOI: 10.1186/s12916-014-0151-0: 1,424,378 patients in Scotland (GP data)
Gruneir et al 2016 DOI: 10.1212/WNL.0000000000000332 29,6773 patients in Canada (community dwelling)

How many people in hospital with first stroke have another condition?

- ~25%
- ~50%
- ~75%
- ~100%

42.7%

Atrial fibrillation ~11%
Cancer ~11%
Diabetes ~9%
Heart failure ~8%
COPD ~8%

What you see depends on where you look…

Community / Primary Care

Hospital

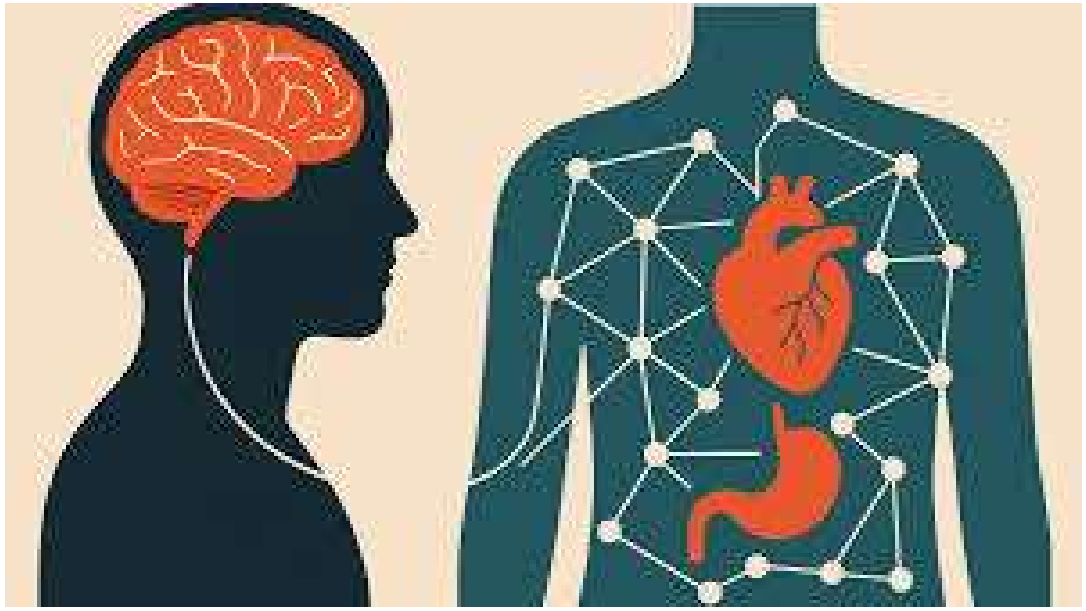
Care home

What you see depends on how you look…

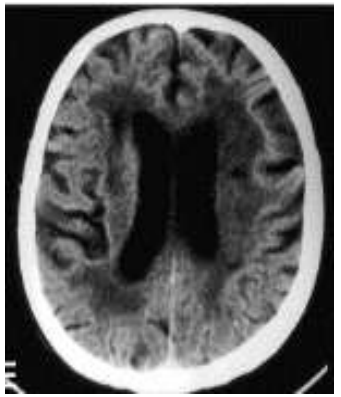
Healthcare data

Surveys (self-report)

What you see depends on what you look for…



Psychiatric and mental health issues
including cognitive decline and dementia
(also fatigue etc) undercoded and understudied

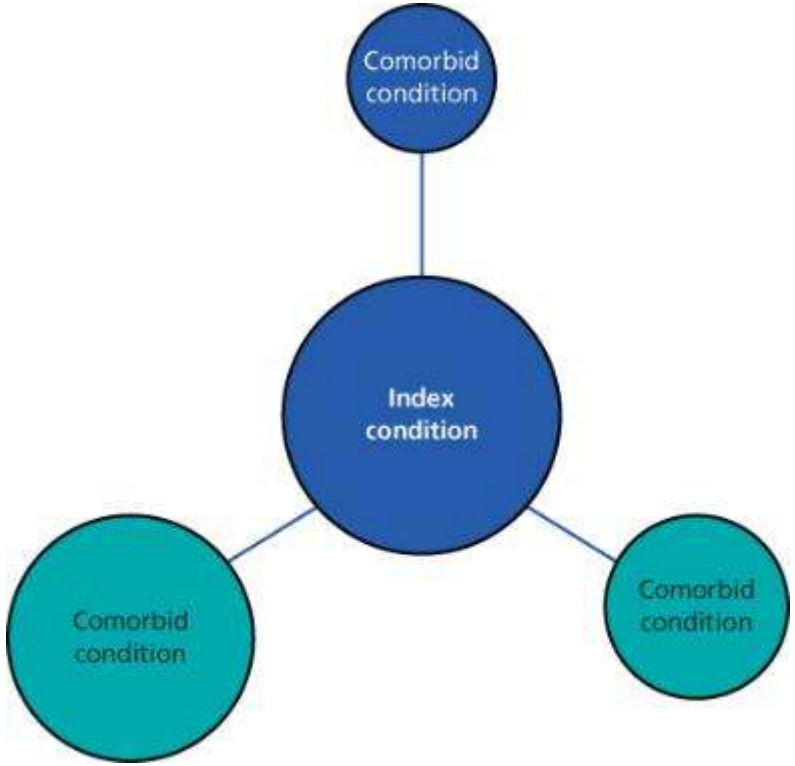


Stroke…or cerebrovascular disease
(History, scan or report)

Stirland et al. 2020 DOI: 10.1136/bmj.m160; Stirland et al 2024 DOI:10.1002/alz.70546

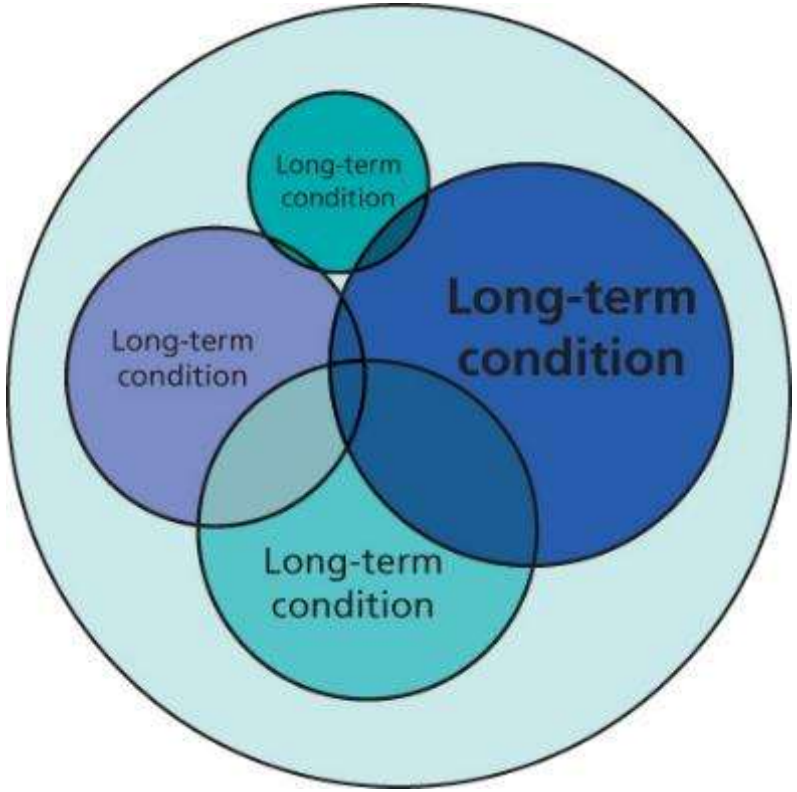
Terminology

Comorbidity



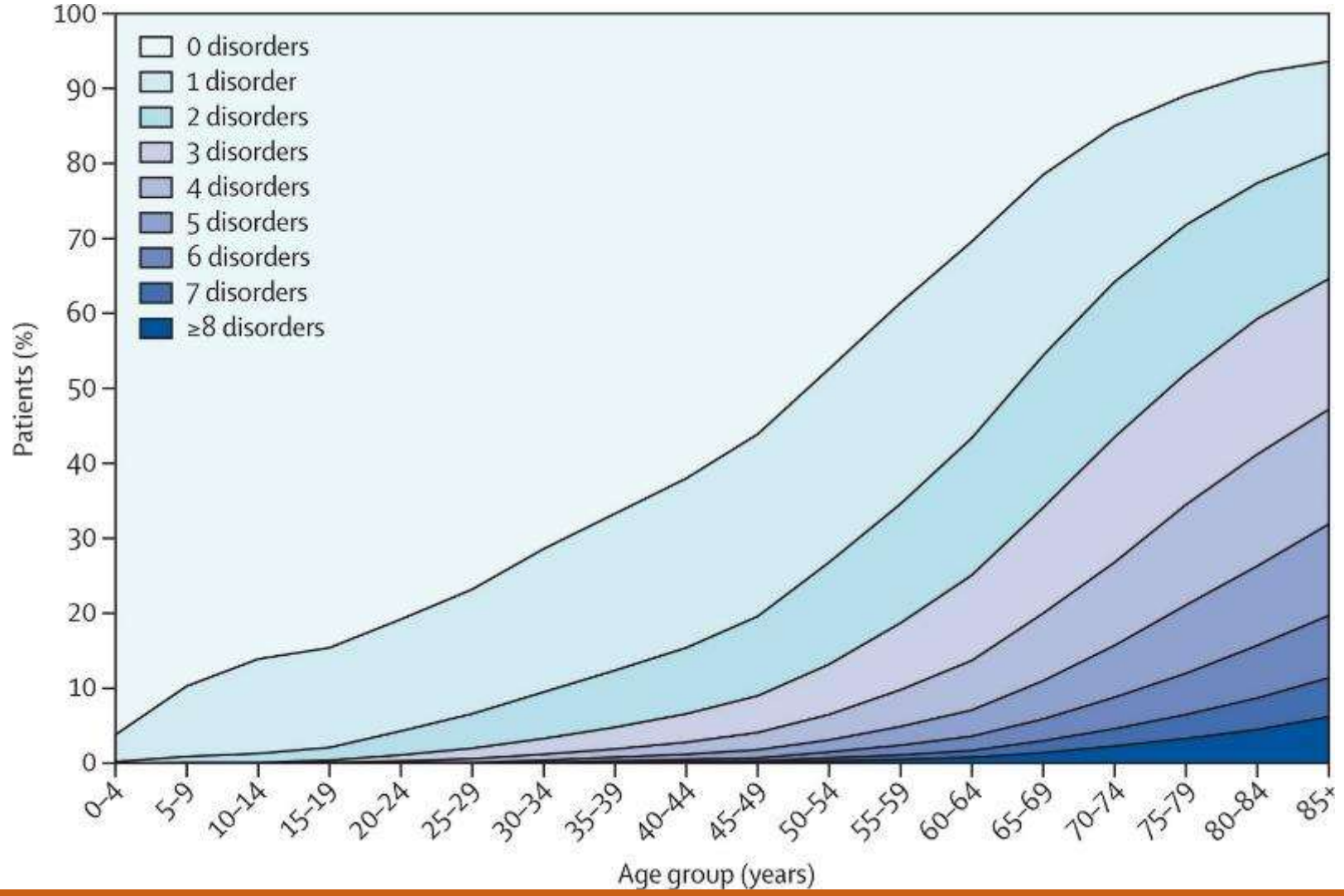
vs

Multimorbidity (2+ long term health conditions)



…. or “MLTC” (Multiple Long Term Conditions)

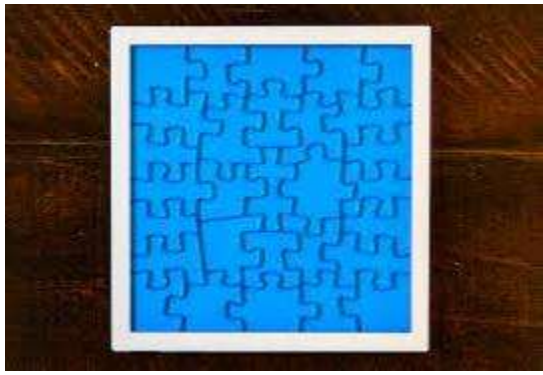
How common are MLTC?



'normal' in older people

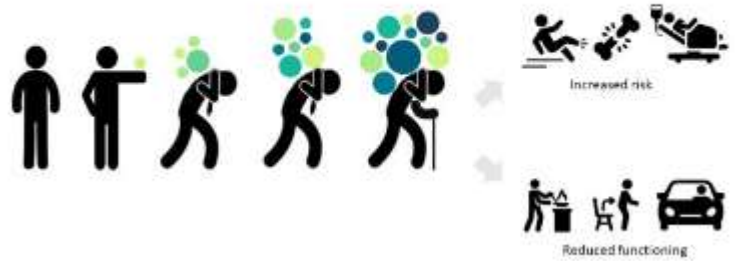
Barnett et al. 2012; **Ho et al. 2021**

MLTC (Multiple Long Term Conditions) – seeing the whole picture in life after (and before) stroke



- Increasingly common
- Significant impact on individuals, poorer outcomes
- Healthcare services & research projects, typically designed around single diseases
  - need new ways of working and researching
  - is stroke an ‘index condition’ or ‘another condition’
- Trials often don’t report ‘co-morbidities’ esp cognitive/psychiatric
- Overlap with ‘frailty’ and ‘geriatric syndromes’ (but distinct)

Frailty



- The ability to ‘bounce back’ after a stressor
- Very common in patients with acute stroke

- It depends where and when you look!
  - Post stroke 66.8% (95% CI 49.9 to 83.7%)
  - Pre-stroke 24.6% (95% CI 16.2 to 33.1%)

  - Associated with poorer outcomes

Frailty and MLTC (including stroke) are related to the ‘Geriatric giants’

Immobility

Instability

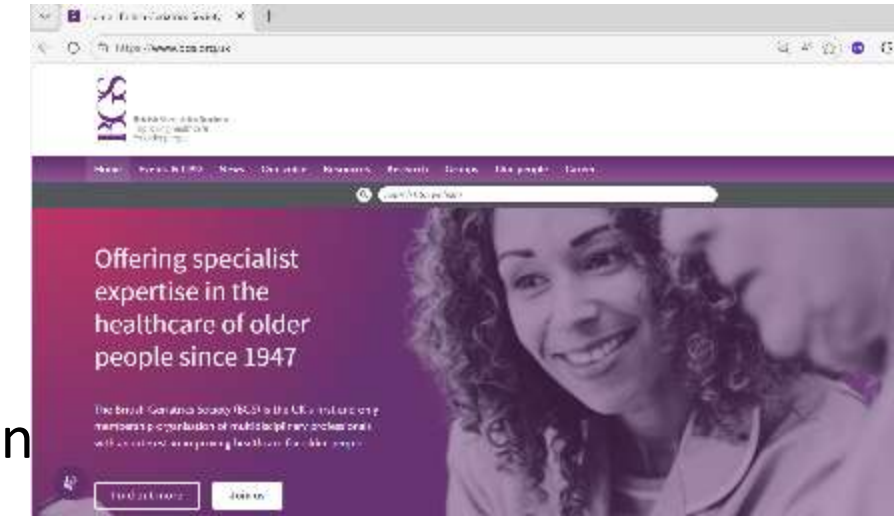
+Polypharmacy

Incontinence

Impaired intellect/memory

Geriatricians

- Essential part of care for older people with stroke, before stroke and after stroke
- Part of Multidisciplinary Team
- “Doctors of small things”
- Comprehensive Geriatric Assessment
  - Can ‘slay’ geriatric giants, reverse frailty, improve function



Stroke research and older people

- Older people underrepresented in stroke research
  - 75% of strokes in people >65
- ‘Excluded by design’
  - No co-existing conditions, no disabilities, need to access research centres
  - Need capacity to consent and to participate
  - Fear of complications
  - Recruitment sites – hospital, home, care home





Google search of ‘stroke research patient’

Gaynor et al 2014 DOI: 10.1093/ageing/afu026
; Nelson et al 2023 doi: 10.1177/26335565231211668

Moving to a care home after a stroke

- What % of stroke survivors move directly to a care home?
  - Declining (24% in 1990s to 5% 2018)
  - More likely if older, higher disability

- Need to ensure a move to a care home is ‘right place at the right time’
  - And can provide the right care
    - Positioning, eating/drinking, continence, cognition, recognition of further stroke/secondary prevention, palliative care

- Equitable access to research

Clery et al 2019 DOI: 10.1161/STROKEAHA.119.026618; Care homes unable to meet needs of stroke survivors;
Harrison et al 20022 DOI 10.1016/j.jamda.2022.05.003

Enabling Research In Care Homes (ENRICH Scotland)

>40% of care homes 'Research Ready'

- Supporting care homes to participate in research
- Study design & delivery
- Ethics and governance
- Trials

Conclusion

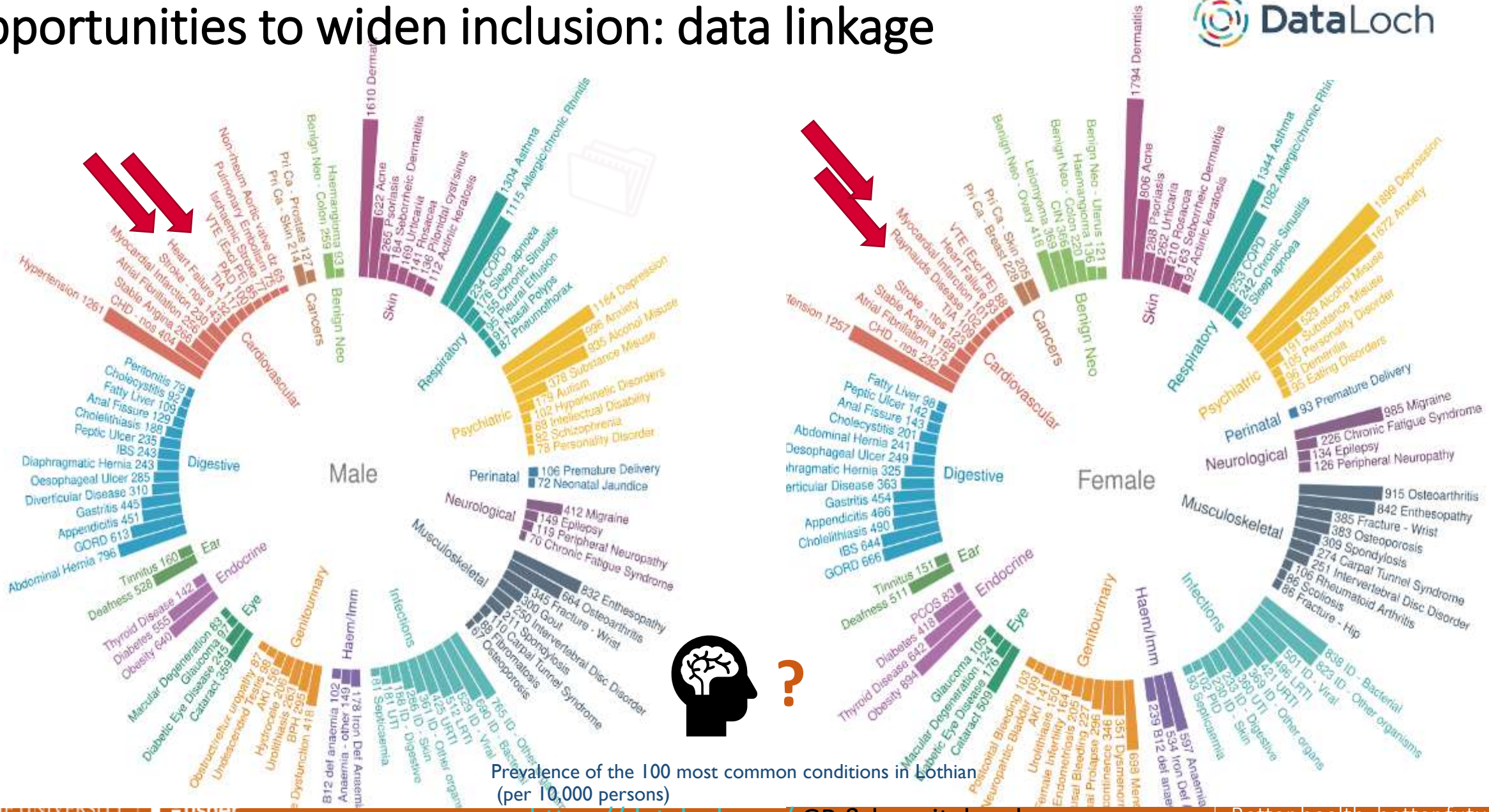
- Stroke…but not just about the stroke, or vascular risk factors
  - Consider life before stroke and life after stroke

- Role of MLTC, frailty…and the geriatrician

- Power of data and data linkage
  - Need multiple methods to answer important questions
- Need accurate coding of clinical encounters in primary and secondary care
  - Diagnoses, functional impairment, cognitive/psychiatric/psychological issues

- Research has to include everyone
  - age, gender, ethnicity, residence, country, cognition

Opportunities to widen inclusion: data linkage



Prevalence of the 100 most common conditions in Lothian (per 10,000 persons)

https://dataloch.org/ GP & hospital codes

Conclusion

- Stroke…but not just about the stroke, or vascular risk factors
  - Consider life before stroke and life after stroke

- Role of MLTC, frailty…and the geriatrician

- Power of data and data linkage
  - Need multiple methods to answer important questions
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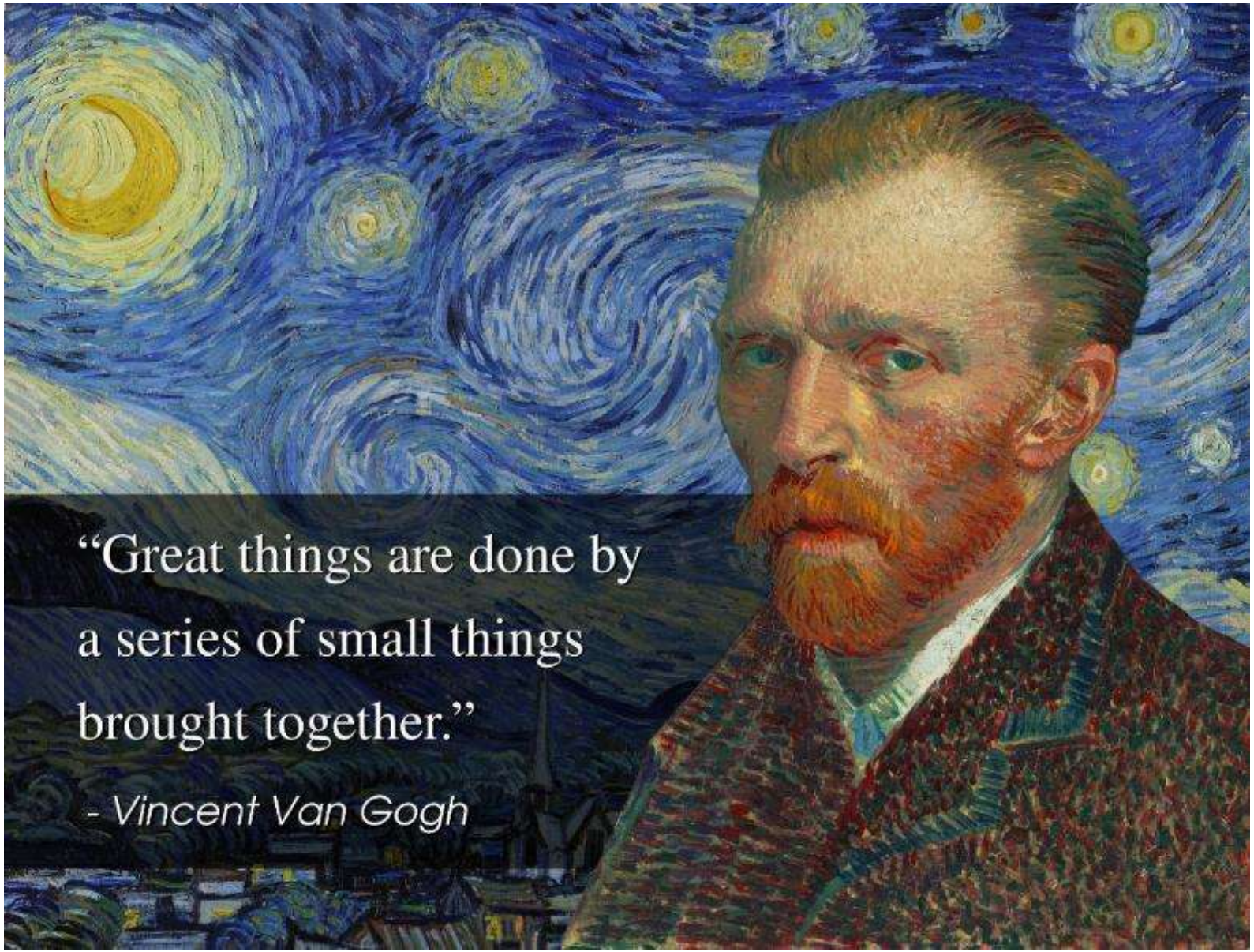
  - age, gender, ethnicity, residence, country, cognition


"Great things are done by
a series of small things
brought together."
- Vincent Van Gogh



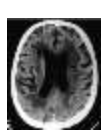







Google search of ‘stroke patient’

Linking research datasets to electronic healthcare records: role of brain scans in predicting risk of dementia after stroke



Acute stroke patients

Data linkage

Diagnosis of dementia

Post-stroke dementia ⬆

with ⬆ white matter hyperintensities

and ⬆ atrophy on CT

Rebuilding life after stroke through physical activity: translating evidence into 'real life'

Edinburgh, 11 May 2026

Frederike van Wijck

Research Centre for Health

Glasgow Caledonian University

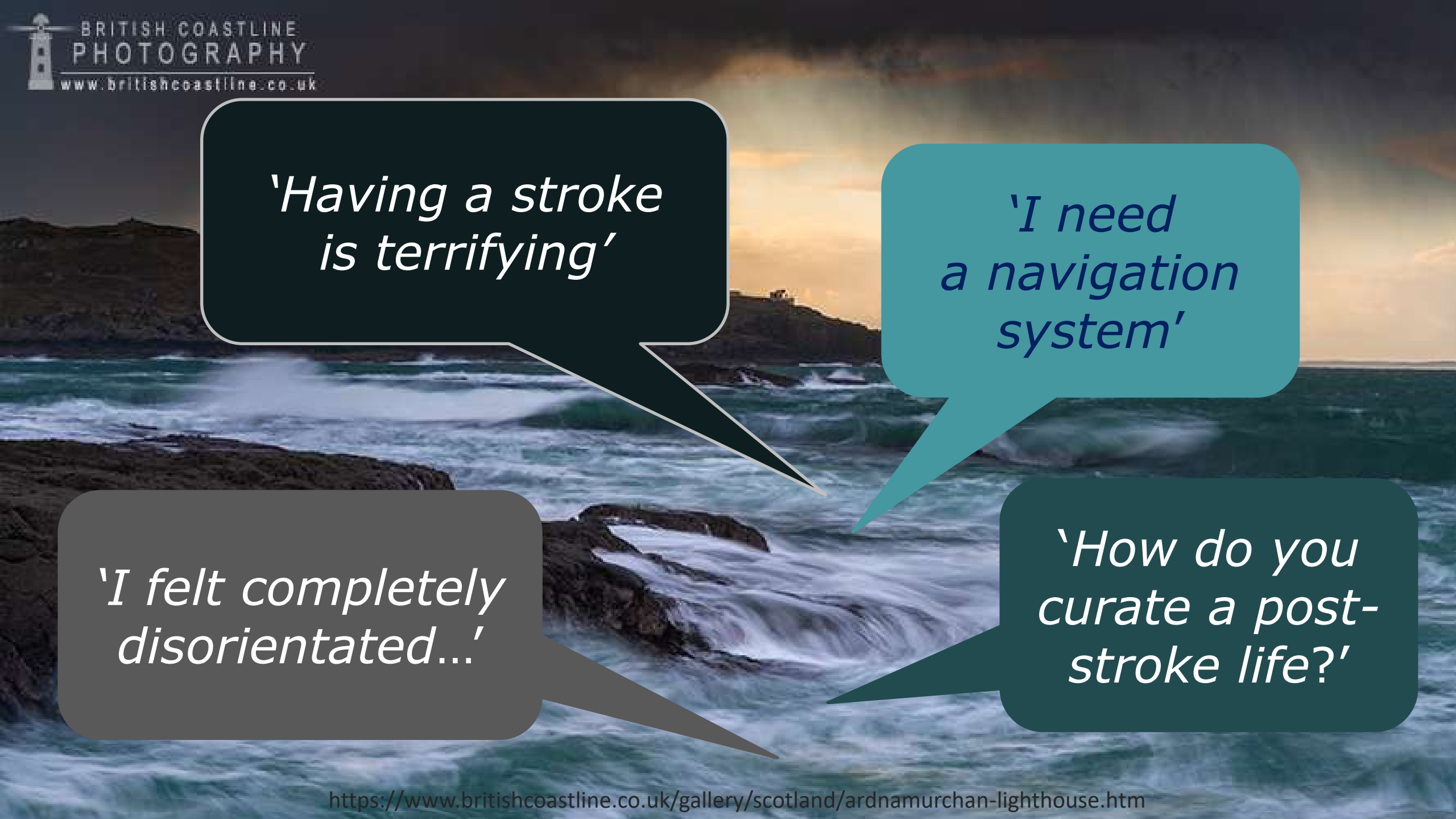
University for the Common Good

Disclosures

Receiving royalties for a textbook on exercise and fitness training after stroke (Elsevier)

Overview

1. Introduction
2. Rebuilding life after stroke –
   the role of physical activity
3. Translating evidence into guidelines
4. Implementing guidelines into ‘real life’
5. Where to next?


BRITISH COASTLINE
PHOTOGRAPHY
www.britishcoastline.co.uk
'Having a stroke is terrifying'
'I need a navigation system'
'I felt completely disorientated…'
'How do you curate a post-stroke life?'
https://www.britishcoastline.co.uk/gallery/scotland/ardnamurchan-lighthouse.htm

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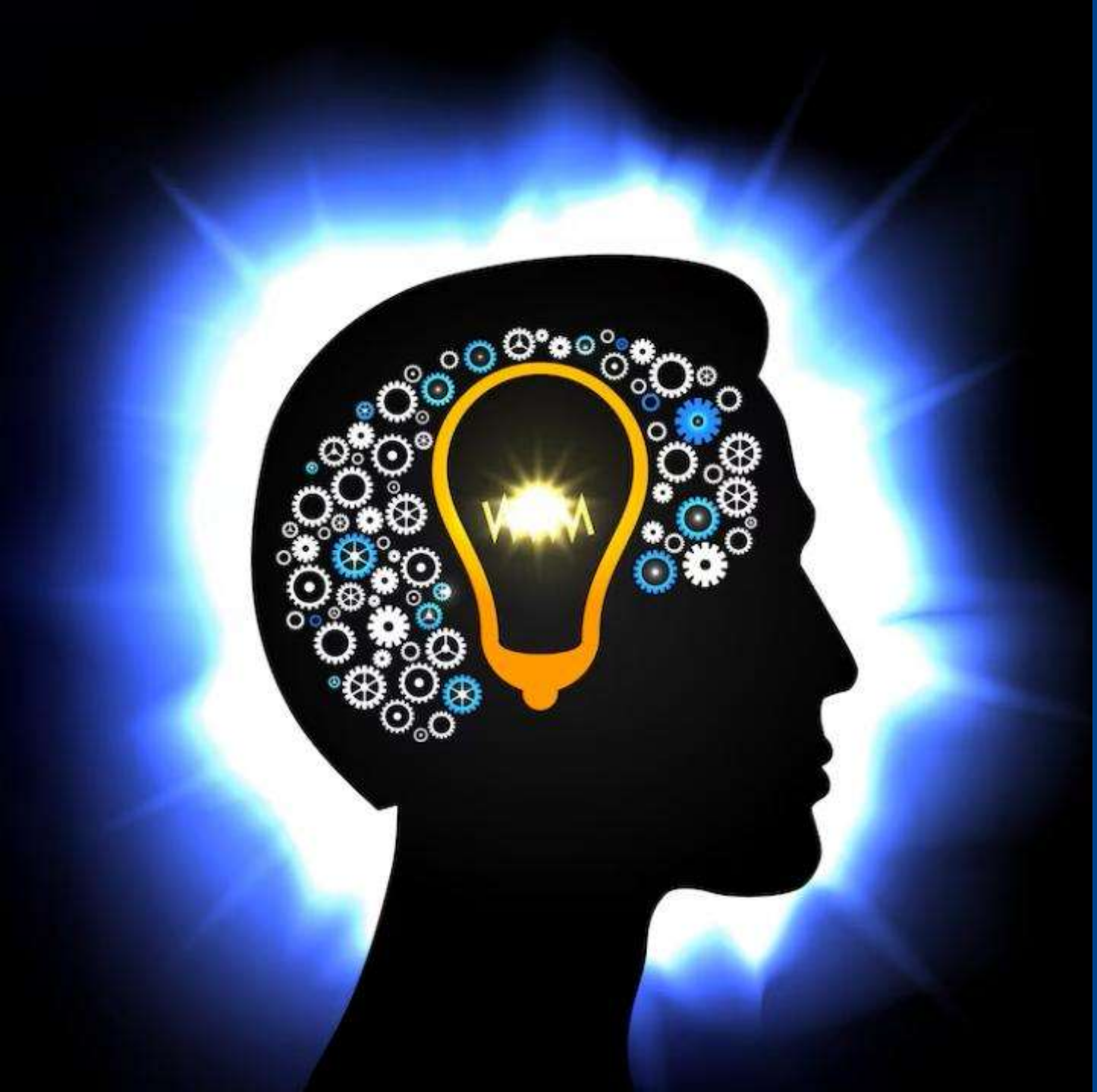

Douglas Horn:

'Physical activity is not just an objective…

It is a catalyst'

Evidence-qualitative

DISABILITY AND REHABILITATION

Taylor & Francis

RESEARCH PAPER

Examining daily physical activity in community-dwelling adults with stroke using social cognitive theory: an exploratory, qualitative study

Ryan Bailey

Brown School, Washington University in St. Louis, St. Louis, MO, USA

RESEARCH ARTICLE

NursingOpen WILEY

Stroke survivors' experiences with rebuilding life in the community and exercising at home: A qualitative study

Lisa van Dongen[1] | Thóra B. Hafsteinsdóttir[1,2] | Ethna Parker[2] | Ingibjörg Bjartmarz[3] | Ingibjörg Hjaltadóttir[2,3] | Helga Jónsdóttir[2,3]

Disability and Rehabilitation

informa healthcare

RESEARCH PAPER

From physical and functional to continuity with pre-stroke self and participation in valued activities: A qualitative exploration of stroke survivors', carers' and physiotherapists' perceptions of physical activity after stroke

Jacqui H. Morris, Tracey Oliver, Thilo Kroll, Sara Joice, and Brian Williams

http://www.ukhost4u.com

BMC Neurology

RESEARCH Open Access

Between commitment and avoidance – working age stroke survivors' perceptions of physical activity and sedentary behaviour: a qualitative study

Kirsti S. Roaldsen, Charlotte Walter, Johan Gäverth and Ing-Mari Dohrn

healthcare MDPI

Article

Understanding the Experiences of People Living with Stroke Engaging in a Community-Based Physical-Activity Programme

Matthew Smith, Andrew Scott, Serena Mellish and James Faulkner

Taylor & Francis

RESEARCH ARTICLE

OPEN ACCESS

"More than effort, it's dedicating time and perseverance." experiences of physical activity and physical exercise in stroke survivor with high functional capacity: a qualitative study

Cristina de Diego-Alonso, Almudena Buesa-Estéllez, Patricia Roldán-Pérez, Pablo Bellosta-López and Javier Gómez-Rodríguez

Evidence-quantitative

Cochrane Library

Cochrane Database of Systematic Reviews

Resistance training for people with stroke (Review)

Saunders DH, Baker G, Cheyne JD, Cooper K, Fini NA, Kilgour AHM, Swinton PA, Williams G, Mead GE

Cochrane Library

Cochrane Database of Systematic Reviews

Combined cardiorespiratory and resistance training for people with stroke (Review)

Saunders DH, Carstairs SA, Cheyne JD, Fileman M, Morris J, Morton S, Wylie G, Mead GE

http://www.ukhost4u.com

Original research article

CLINICAL REHABILITATION

High-intensity interval training after stroke: A mixed-methods systematic review and meta-analysis of safety, feasibility and acceptability

Sage

Hugo Blatgé, Lorna Paul and Frederike van Wijck

REVIEW

WILEY Brain and Behavior

Physical fitness interventions for nonambulatory stroke survivors: A mixed-methods systematic review and meta-analysis

Megan Lloyd[1] | Dawn A. Skelton[1] | Gillian E. Mead[2] | Brian Williams[3] | Frederike van Wijck[1]

Articles

The effects of exercise on secondary prevention and health-related quality of life in people with existing vascular disease: systematic review and meta-analysis of randomised controlled trials

oa

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Evidence-based Guidelines


Guidelines

Journal of Stroke WSO

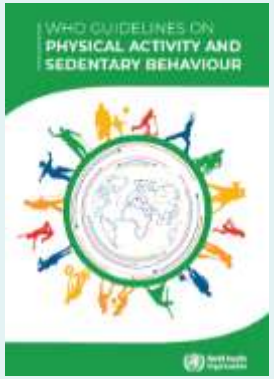
A systematic review and synthesis of global stroke guidelines on behalf of the World Stroke Organization

Gillian E Mead, Luciano A Sposato, Gisele Sampaio Silva, Laetitia Yperzeele, Simiao Wu, Mansur Kutlubaev, Joshua Cheyne, Kolawole Wahab, Victor C Urrutia, Vijay K Sharma, PN Sylaja, Kelvin Hill, Thorsten Steiner, David S Liebeskind and Alejandro A Rabinstein

SAGE

American Heart Association guidelines
(Billinger et al. 2014)

WHO Guidelines
(2020)



National Stroke Foundation
(Living)

AEROBICS
Aerobic exercise recommendations to optimise best practices in care after stroke
(2019)

UK Chief Medical Officers' recommendations

https://www.stroke.org/en/life-after-stroke/stroke-rehab/post-stroke-exercise-videos

http://www.chss.org.uk/chss-campaigns-projects-patient-involvement/parcs-project/

https://www.kumc.edu/about/news/news-archive/jama-study.html

" If physical activity were a drug, we would refer to it as a miracle cure, due to the great many illnesses it can prevent and help treat."

CMOs England, Wales, Northern Ireland and Scotland

Physical activity guidelines: UK Chief Medical Officers' report (2019). p. 3.

GCU Glasgow Caledonian University

Scottish Government
National Advisory Committee for Stroke (2022)

https://www.gov.scot/publications/progressive-stroke-pathway/source

‘Physical activity, exercise and fitness training should be provided through **partnerships** between health and exercise professionals, the third sector and local authority services.
Exercise and fitness training should begin, as appropriate, in hospital and **continue** in the community.’

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Stepping stones to implementation

BRIEF REPORTS

Stroke: A Randomized Trial of Exercise or Relaxation

Gillian E. Mead, MD, Carolyn A. Greig, PhD,* Irene Cunningham,* Susan J. Lewis, PhD,* Suste Dinan, PGDip,† David H. Saunders, M Phil,† Claire Fitzsimons, PhD,* and Archie Young, MD**

laterLife training

Disability and Rehabilitation — informa healthcare

A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity

Systematic review

A systematic review of perceived barriers and motivators to physical activity after stroke

LEVEL 4 REPs SKILLSACTIVE APPROVED

QM0045 UK Forum for Stroke Training

Exercise and Fitness Training After Stroke

A handbook for evidence-based practice

Edited by Gillian Mead and Frederike van Wijk

Foreword by Peter Langhorne

Health and Social Care in the Community

Health and Social Care in the Community (2012) 20(4), 400–411 doi: 10.1111/j.1365-2524.2011.01043.x

A survey of community exercise programmes for stroke survivors in Scotland

C. Best PhD BSc[1], F. van Wijck PhD MSc BSc MCSP FHEA[2], J. Dennis BSc MCSP[3], M. Smith MPhil BSc MCSP[4], M. Donaghy BA PhD FCSP FHEA[5], H. Fraser RGN[6], S. Dinan-Young PhD BEd[7] and G. Mead MB B Chir MA MD FRCP[8]
[1]University of Stirling, [2]Institute of Applied Health Research and School of Health, Glasgow Caledonian University, Glasgow, UK, [3]NHS Greater Glasgow and Clyde, Glasgow, UK, [4]NHS Lothian, Edinburgh, UK, [5]School of Health Sciences, Queen Margaret University, Edinburgh, UK, [6]NHS Fife, Dunfermline, UK, [7]Primary Care & Population Health, Division of Population Health, Faculty of Population Health Sciences, University College London, London, UK and [8]Geriatric Medicine, University of Edinburgh, Edinburgh, UK

Accepted for publication 29 September 2011

Best Practice Guidance for the Development of **Exercise after Stroke Services** in Community Settings

Catherine Best, Frederike van Wijck, Susie Dinan-Young, John Dennis, Mark Smith, Haze Fraser, Marie Donaghy, Gillian Mead

THE UNIVERSITY of EDINBURGH

November 2010

Stroke Scotland — Chest Heart & Stroke Scotland — CMS

EXERCISE AFTER STROKE

Welcome

Best Practice Guidance for the Development of Exercise after Stroke Services in Community Settings November 2010

Best Practice Guidelines

뇌졸중 후의 운동과 체력 훈련

Exercise and Fitness Training After Stroke

Dundee Stroke Exercise Club

Margaret Mitchell MBE and team

https://dsec-org-uk

Dundee Stroke Exercise Club

Photographs courtesy of Margaret Mitchell MBE

More Information

Physical Activity Routines
After Stroke

Welcome | Ward Training | Home & Community Training | Tailoring PARAS | Delivery Resources | Background & Publications | FAQ | Self Evaluation | Contact Us

Welcome Video

https://paras-strokerehab.org/

Welcome video

In this video, Associate Professor Sarah Moore provides an overview of PARAS. Sarah describes that PARAS is a supported self management programme to enable stroke survivors to move more and sit less.

Resources

Ward Training & Resources
Home & Community Training & Resources
Tailoring PARAS
Delivery Resources
Background & Publications

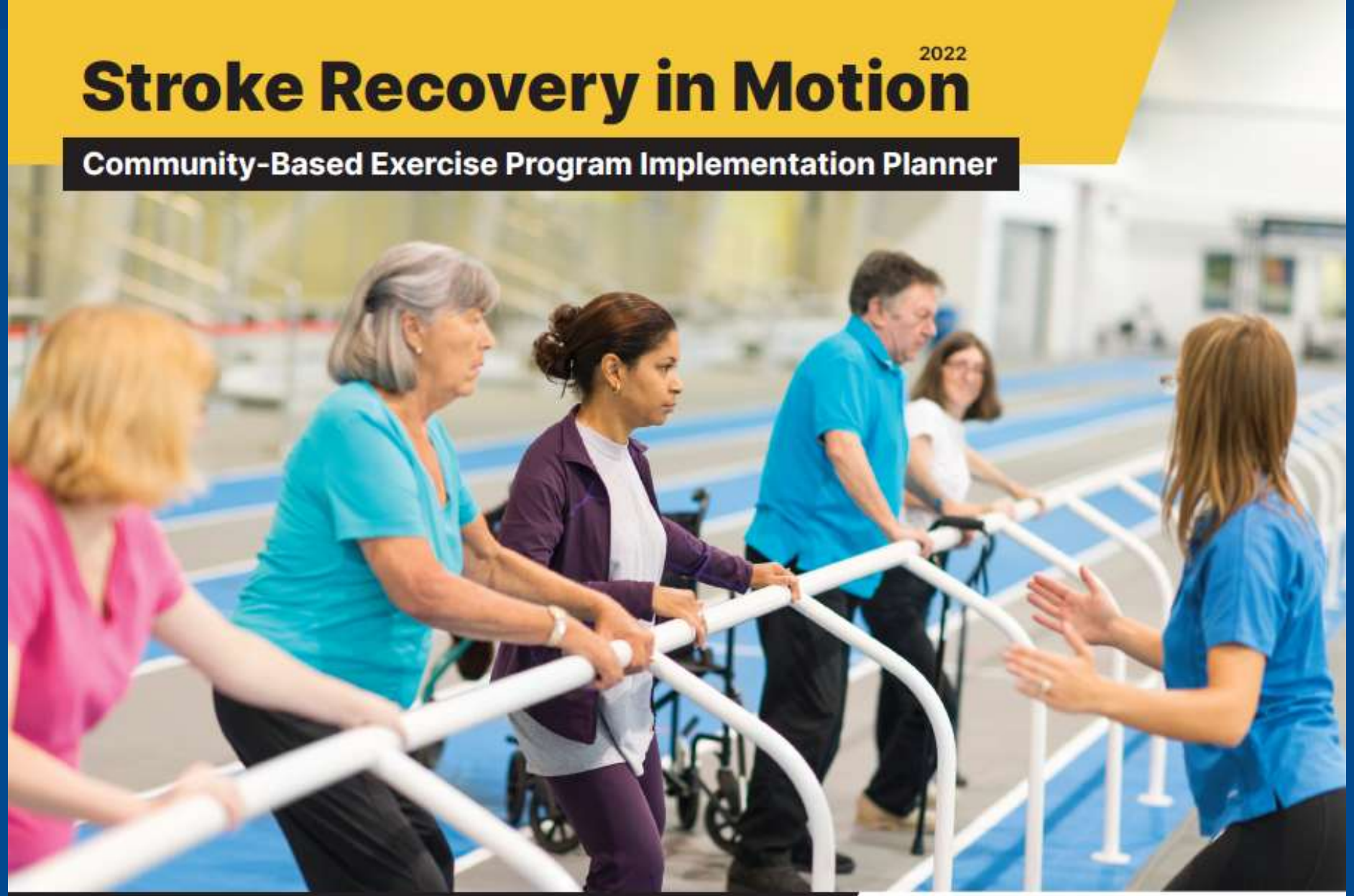
Contact Us

Department of Sport, Exercise and Rehabilitation, Northumbria University, NE7 7XA
@PARAStroke

https://fameexercise.com/

Stroke Recovery in Motion 2022

Community-Based Exercise Program Implementation Planner



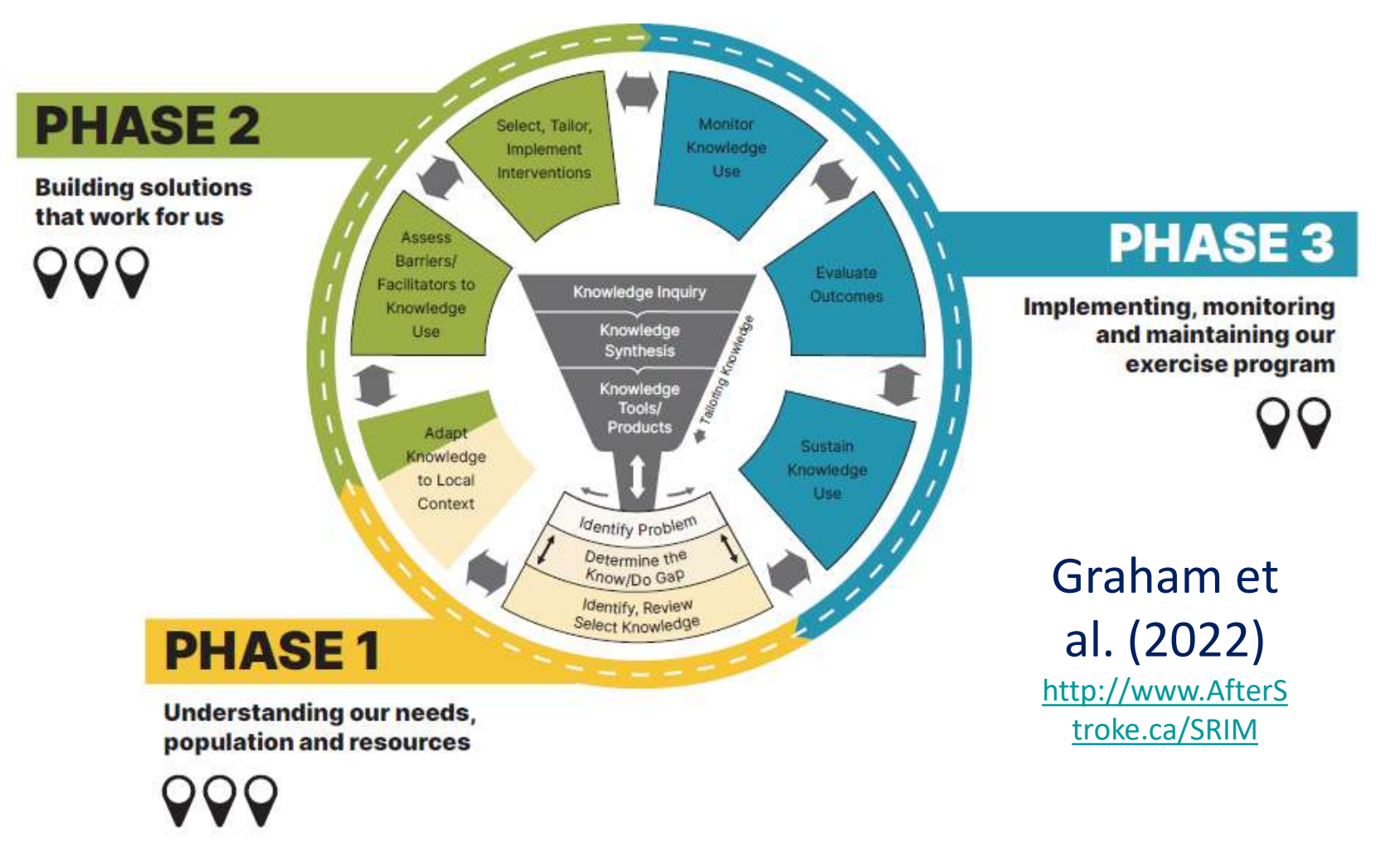
A roadmap for starting and maintaining a community-based exercise program for people with stroke

https://www.afterstroke.ca/resource/srimp

GCU Glasgow Caledonian University

MARCH OF DIMES CANADA | After Stroke

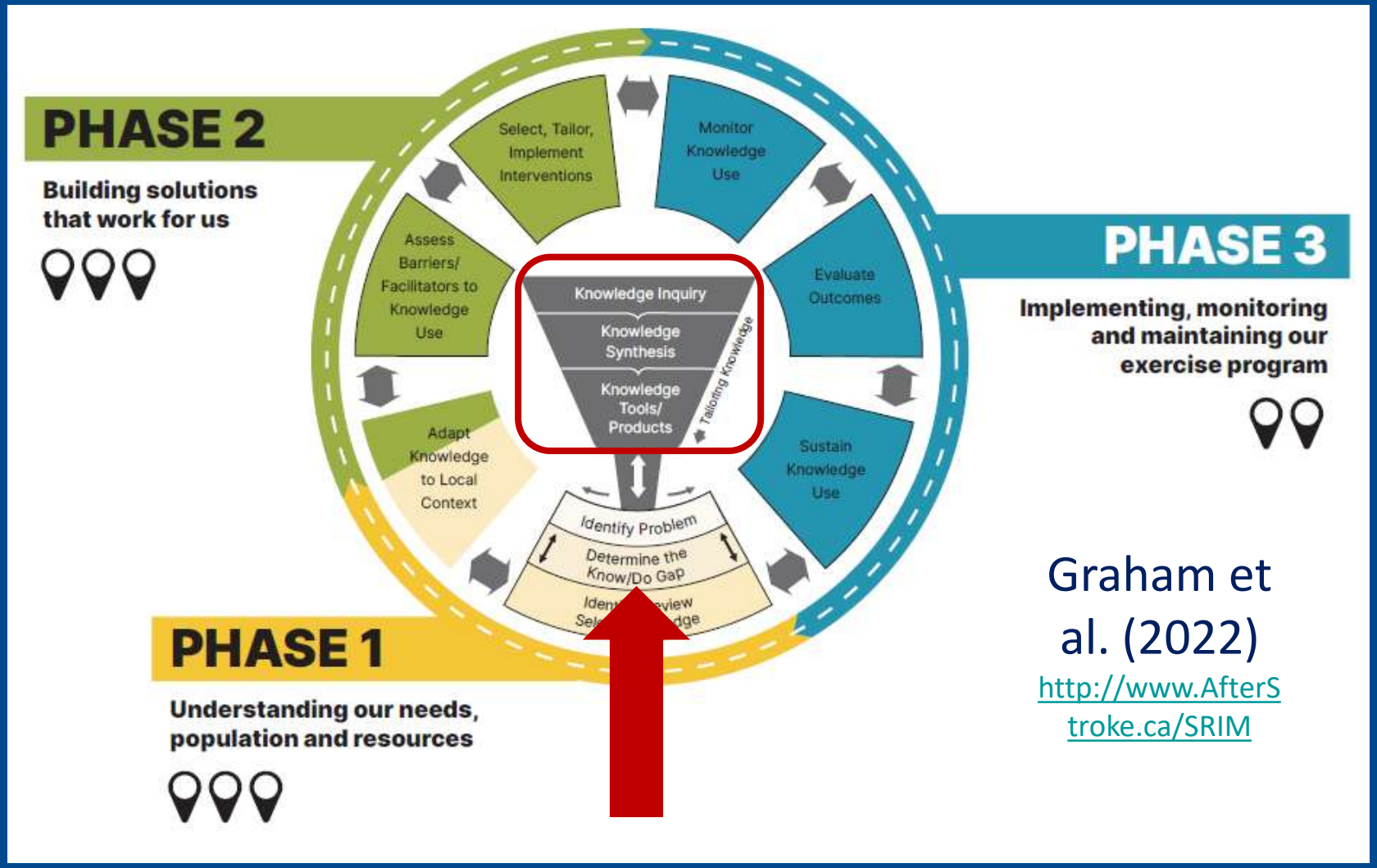
Stroke Recovery in Motion planner for the implementation of community-based exercise programs for people with stroke



Graham et al. (2022)
http://www.AfterStroke.ca/SRIM

GCU Glasgow Caledonian University

Stroke Recovery in Motion planner for the implementation of community-based exercise programs for people with stroke



Graham et al. (2022)
http://www.AfterStroke.ca/SRIM

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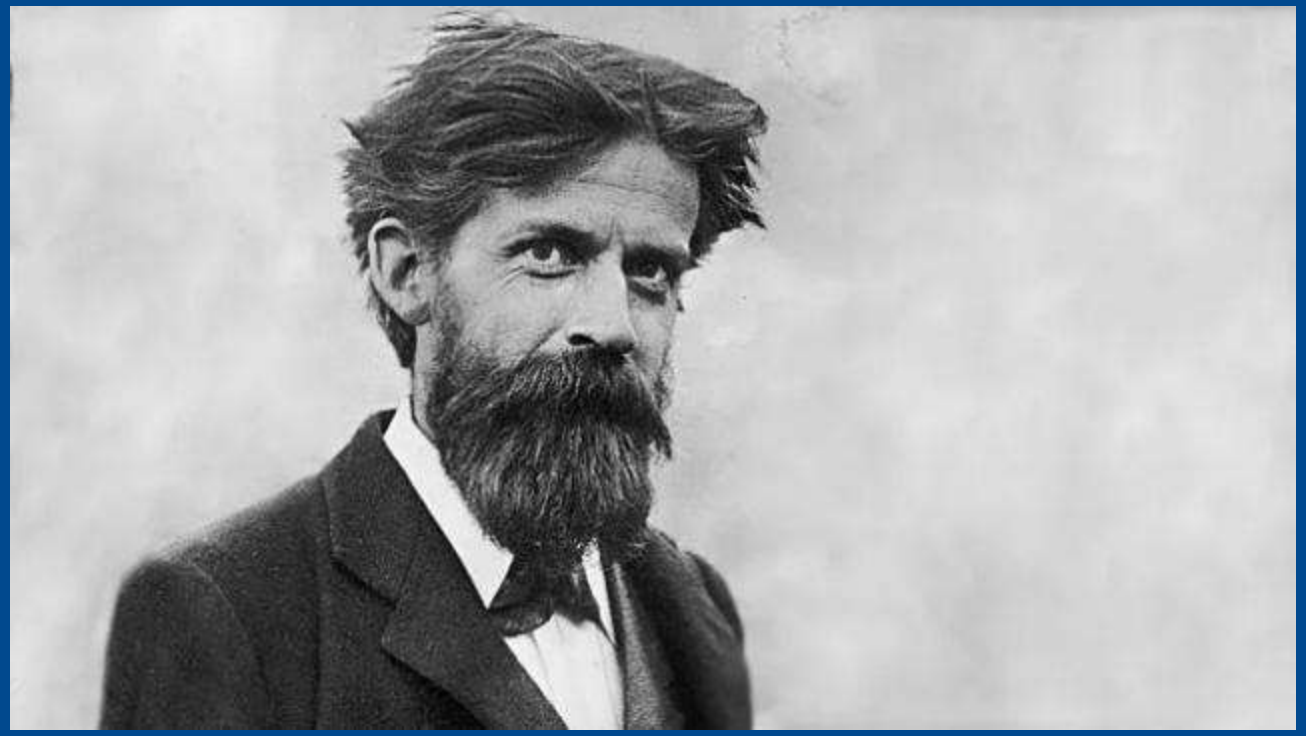
‘*Think globally, act locally*’



https://www.shbt.org.uk/the-patrick-geddes-centre/

Sir Patrick Geddes

(1854-1932)

GCU Glasgow Caledonian University

Where to next?

Multi-morbidity

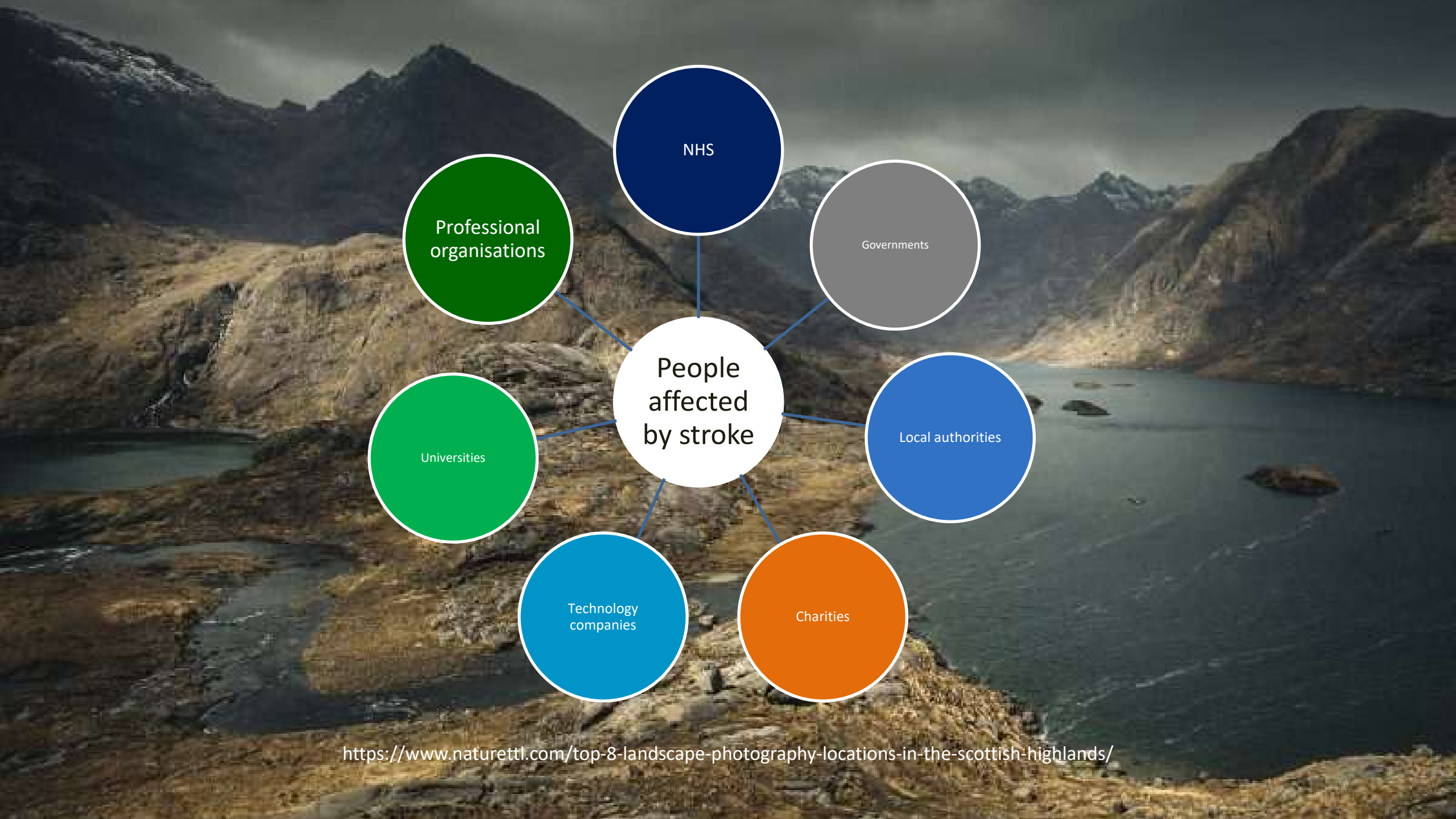
Resource limitations

Sedentary lifestyle

Air pollution

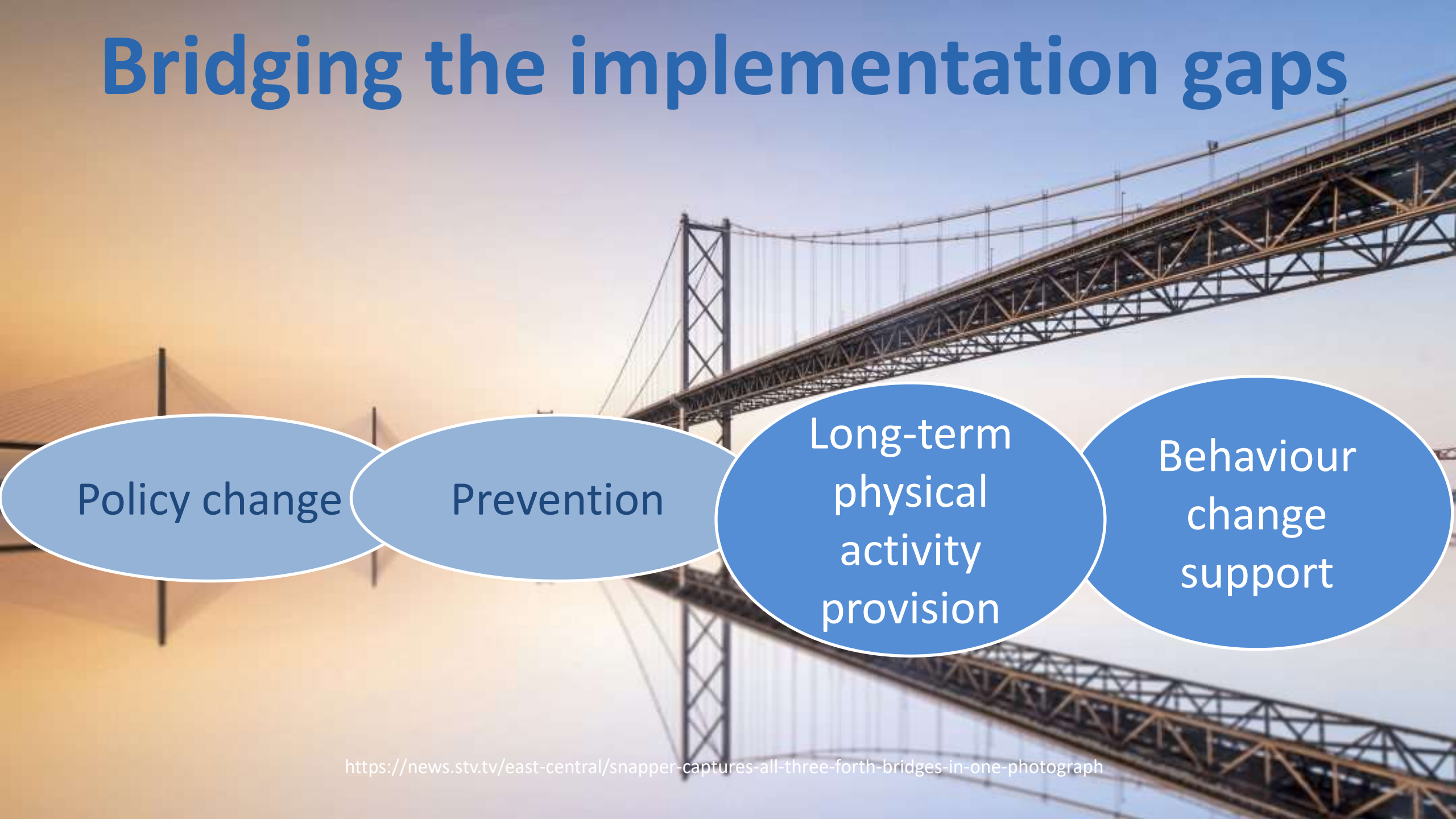
Inequalities

https://www.naturettl.com/top-8-landscape-photography-locations-in-the-scottish-highlands/



https://www.naturettl.com/top-8-landscape-photography-locations-in-the-scottish-highlands/

Bridging the implementation gaps



https://news.stv.tv/east-central/snapper-captures-all-three-forth-bridges-in-one-photograph

Acknowledgements

All stroke survivors, carers and clinician representatives and all study participants

GCU Stroke & Neurological Rehabilitation Research Group (SYNERGY) members

All research collaborators, book co-editors and co-authors

Research partner and professional organisations

Research funders

Supporting organisations

Thank You

Frederike.vanWijck@gcu.ac.uk

GCU
Glasgow Caledonian
University

University for the Common Good

Chair:

David Weller

Panel

To submit a question, scan this QR code or go to **slido.com** and enter **# Usher1105**

Juliet Bouverie OBE
Chief Executive of the Stroke Association

Alex Todhunter-Brown
Glasgow Caledonian University and The University of Edinburgh

Susan Shenkin
The University of Edinburgh

Frederike van Wijck
Glasgow Caledonian University and Research Centre for Health

Session two

Chairs:

Amanda Barugh

James Beeston

Jiban Karaki
Liverpool School of Tropical Medicine and PHASE Nepal

Amanda Farrin
The University of Edinburgh

Ayeesha Kamran Karmal
Aga Khan University Hospital, Pakistan

Craig Anderson
University of New South Wales, Australia

Life after stroke research in Nepal: Developing international research partnership

Dr Jiban Karki

Senior Research Associate, Liverpool School of Tropical Medicine

Executive Director, PHASE Nepal

Presentation outline

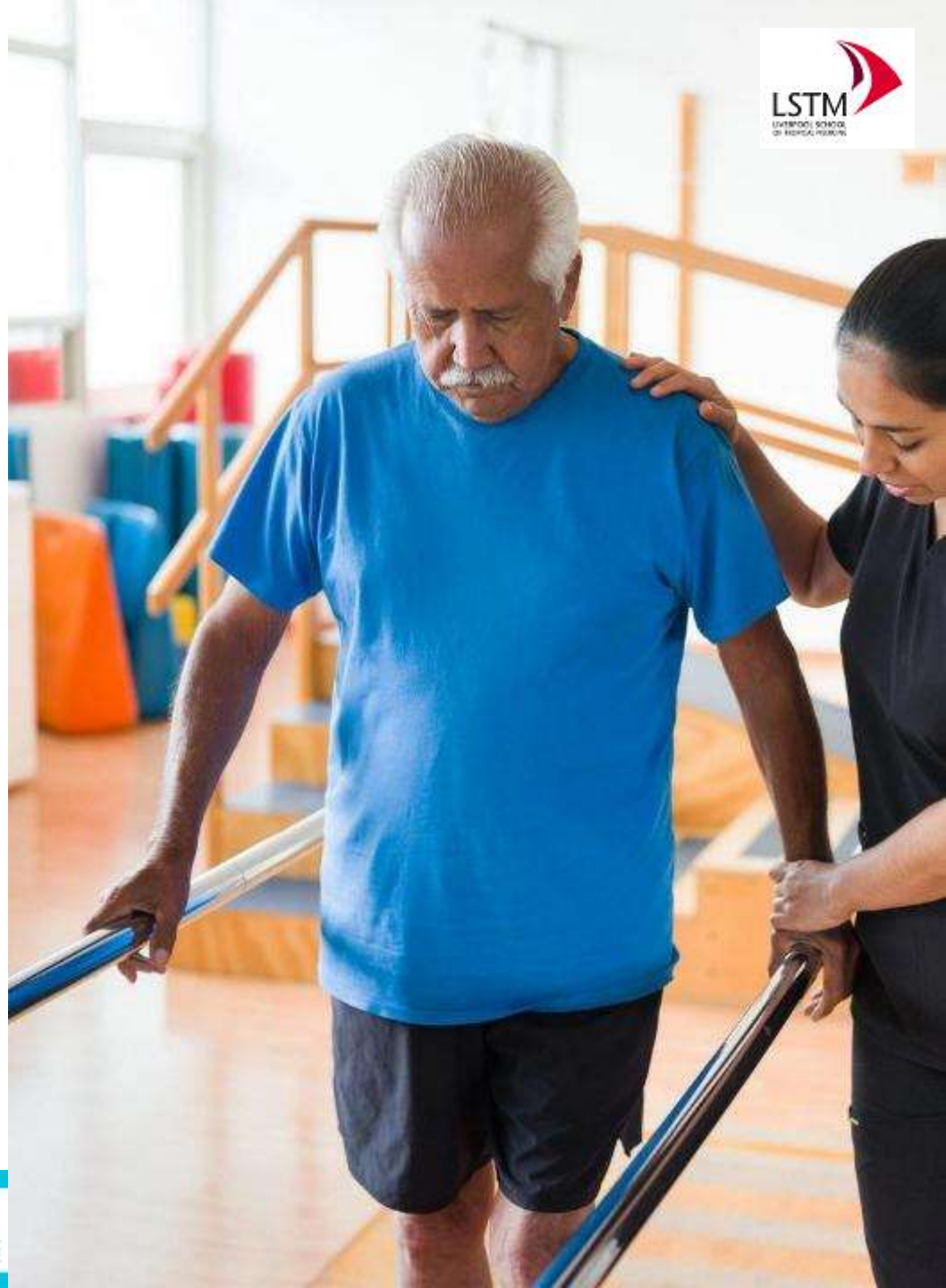
- Background: Global Burden of Stroke
- Stroke in Low- and Middle-Income Countries
- Stroke in Nepal: Current Status and Initiatives
- Emerging Challenges and Research Gaps
- Current “Life After Stroke” Research Project
- Study Objectives
- Methodology and Study Design
- Data Analysis Approach
- PHASE Nepal as a Research Partner
- Projects, Locations, and Implementation Context
- References

Why stroke matters globally?

- Stroke has become a major global public health challenge, with an estimated 12.2 million new cases, 101 million prevalent cases, and 6.55 million stroke related deaths [1]
- The global burden of stroke continues to rise, with a 70% rise in stroke incidence and a 43% rise in stroke related deaths over recent decades [1]
- Stroke remains the third leading cause of death and disability worldwide [1]
- More than half of stroke survivors are left with permanent disability and less than half regain their pre-stroke level of functionality [2]

Stroke in low- and middle-income countries

- People living in low- and middle- income countries (LMICs) are largely affected, which is further exacerbated by limited access to healthcare and inadequate stroke care resources [3]
- Acute stroke care is provided to less than a third of all stroke patients [4]
- Availability of rehabilitation services are limited in inadequate in required quantity and quality in LMICs compared to high-income countries [4]
- The reported incidence of stroke in Asia ranges from 116 to 483 per 100,000 per year [5,6]
- South Asians have a twofold higher risk of getting a stroke than Europeans due to the higher prevalence of dyslipidemia, diabetes mellitus, and central obesity [7,8]



Stroke in Nepal- what has been done?

Nepal has reported a relatively high crude and age-standardized prevalence of stroke in the southwestern region in 2018, with rates of 2368 and 2967 per 100,000 population [9]

Stroke care services have been provided by limited tertiary hospitals across Nepal

Stroke research in Nepal has increased over the past decades, although it is still largely limited to hospital-based studies conducted in a few urban centers

In terms of treatment, existing studies showed that thrombolysis for acute ischemic stroke was both feasible and effective in the Nepalese context, marking an important step forward (6)

Mechanical thrombectomy services were later introduced in 2019, representing another milestone in the development of stroke care in Nepal (7)

Stroke care initiatives in Nepal

- The Nepal Stroke Association (NSA) is the leading national organization working to improve stroke care in Nepal supported by the World Stroke Association
- A nationwide initiative, in collaboration with the university of Heidelberg conducted 26 stroke related training workshop for over 1000 healthcare professionals
- The Registry of Stroke Care Quality (RES-Q) has been introduced to strengthen stroke care monitoring and quality improvement
- National stroke awareness campaigns have also been implemented to improve public knowledge and early recognition of stroke

Stroke in Nepal- Emerging public health challenge

Lack of specialized healthcare personnel remains a major barrier to stroke care, with approximately one neurologist per one million people [10]

Less awareness about stroke symptoms and treatment contributes to delayed health care seeking and under utilization of available services [11]

Dedicated stroke care units and specialist rehabilitation centres remains limited in Nepal

Lack of stroke registry in Nepal is one of the major challenge

- Long-term care for the stroke survivors is largely provided by family members. Many stroke survivors are discharged home without family members or caregivers being adequately prepared or supported to provide care for stroke survivors with complex care needs [11]

- Community or home-based care has the potential for positive impacts; however, post-stroke services remain poorly structured, with substantial regional inequalities in service availability and access [12]

- Most existing stroke studies are urban centered and conducted in tertiary hospitals, while evidence from rural and remote settings remains limited

- Areas such as rehabilitation, long-term outcomes, and community-based prevention strategies remain largely unexplored in the Nepalese context

Current ‘Life after stroke’ Research Project in Nepal

Title: Mixed methods study of the ‘life after stroke’ needs of stroke survivors in the Nepal

Principal Investigators: Prof Gillian Mead and Dr Jiban Karki

Donor: University of Edinburgh, Internal funding from G Mead’s donation account

Collaborations: University of Edinburgh, PHASE Nepal, Gurkha Welfare Trust Nepal and Manipal Teaching Hospital Nepal

Duration: 18 months (April 2026-September 2027)

Objectives

General Objectives:

To identify long-term problems after stroke and unmet care needs among ex-servicemen and their families cared for by the GWT, and community stroke survivors not cared for by the GWT support

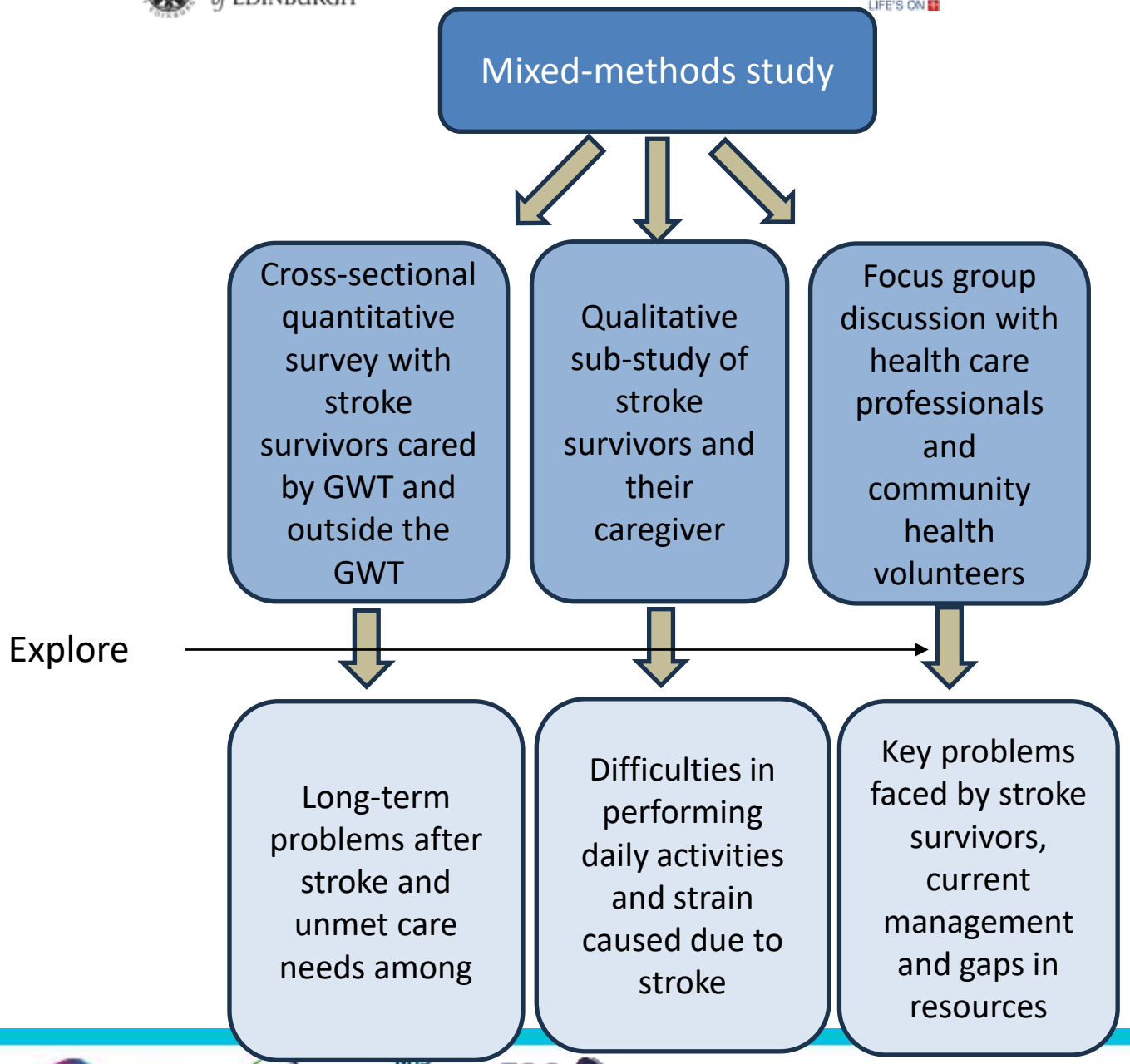
Specific Objectives

To assess the prevalence and types of long-term problems among stroke survivors receiving Gurkha Welfare Trust (GWT) care

To identify the prevalence and types of long-term problems among community stroke survivors without GWT care

To compare long-term stroke-related issues between GWT-supported and community-based survivors

To explore factors (e.g. age, gender, stroke severity) associated with long-term stroke related problems in both groups


Mixed-methods study
Cross-sectional quantitative survey with stroke survivors cared by GWT and outside the GWT
Qualitative sub-study of stroke survivors and their caregiver
Focus group discussion with health care professionals and community health volunteers
Explore
Long-term problems after stroke and unmet care needs among
Difficulties in performing daily activities and strain caused due to stroke
Key problems faced by stroke survivors, current management and gaps in resources

Methodology

Study Location →

Study Population →

Stroke survivors in Nepal receiving care and support from Gurkha Welfare Trust (GWT) and not receiving the GWT support

Patient Recruitment →

Patient recruitment will be done from GWT, Manipal hospital and through consultation with local female community health volunteers during home visit of stroke survivors residing in Kaski and Gorkha districts

Methodology

Methods	Quantitative survey	Qualitative interview	Focus group discussion
Sample size	A total of 422 participants for the quantitative survey, calculated using Cochrane's formula of calculating sample size, with additional 10% non-response rate. Of 422, 211 patients from GWT and 211 from non-GWT	In-depth interviews will be conducted with a purposive subset of 40-60 participants, including approximately 30-35 stroke patients and 20-25 caregivers of stroke patients	About 12-15 health care professionals will be included in focus group discussion including stroke physician, physiotherapists, nurses from GWT and Manipal hospitals, and FCHVs will be included

Data analysis

Continuous variables with a normal distribution will be summarized using means and standard deviation, while, for the non normally distributed variables will be presented as median and interquartile range

Categorical variables will be summarized using frequency and percentage

Appropriate parametric and non-parametric tests will be used to compare the long-term outcomes between GWT supported and non-GWT patients

Regression analysis will be conducted to examine the association between long term problems and sociodemographic factors, adjusting for potential confounders

Quantitative data will be analyzed using statistical software SPSS 25

Qualitative data will be coded using Nvivo and analyzed thematically

PHASE Nepal

is

open for collaboration

in stroke research in low-resource context

PHASE Nepal's strength as Local Research & Implementation Partner

- Field research coordination
- Strong local partnerships in remote and underserved areas
- Community engagement embedded within primary health care
- Experience in data collection in remote rural settings and urban settings
- Expertise in qualitative and mixed-method research
- Use of participatory research approaches
- Translating evidence to policy implications

PHASE Nepal

- A non-governmental and not for profit organization
- Established in 2006 with a vision, “A self-empowered and self-sustained society where all kinds of discrimination are absent”
- We work across health, education, livelihoods, climate and disaster risk reduction, and research, with a cross-cutting focus on inclusion (gender, social equity, and disability) at all levels, and a commit to strong partnership, collaboration, continuity, and sustainability.

The team 2006 - 2026


2006


2019


2026

Key achievements 2006 - 2025

- Delivered primary healthcare services to 1,078,012 people
- Supported 4,498 safe deliveries
- Trained 200+ health professionals (ANMs, nurses, CMAs, health assistants)
- Supported 13,103 children with learning materials
- Constructed 5 schools
- Trained 2,002 teachers
- Reintegrated 100+ out-of-school children through catch-up education
- Delivered adult literacy programmes to 2,846 women
- Trained 6,069 adolescent girls in empowerment programmes
- Built 11 health posts
- Constructed 509 houses for vulnerable populations post-earthquake
- Established 95 gravity-flow water supply systems
- Humanitarian Response (2015 Earthquake)
- Provided emergency food, hygiene, and shelter support to 13,034 families
- Conducted 19 research studies
- Published 23 peer-reviewed journal articles
- Trained 100+ community members in participatory video across South Asia
- Mobilised over NRs 219 million (~USD 20 million) since inception
- Sustains approximately USD 1 million annual funding

Why partner with PHASE

Karnali Province (Mugu, Humla,Jajarkot)

- Health: GoPhil, Healing Buddha Foundation, PWW, PA-ADA,EKFS
- Livelihoods: PWW, PA, USAID, SFS
- Education: PA, CoV,USAID
- Emergency: GoPhil, Global giving, PWW,ADA
- Disability: USAID, CoV (PA)
- Research: HSRI (Mugu)
- **Health support project: ASIA**

Sudurpaschim Province (Bajura)

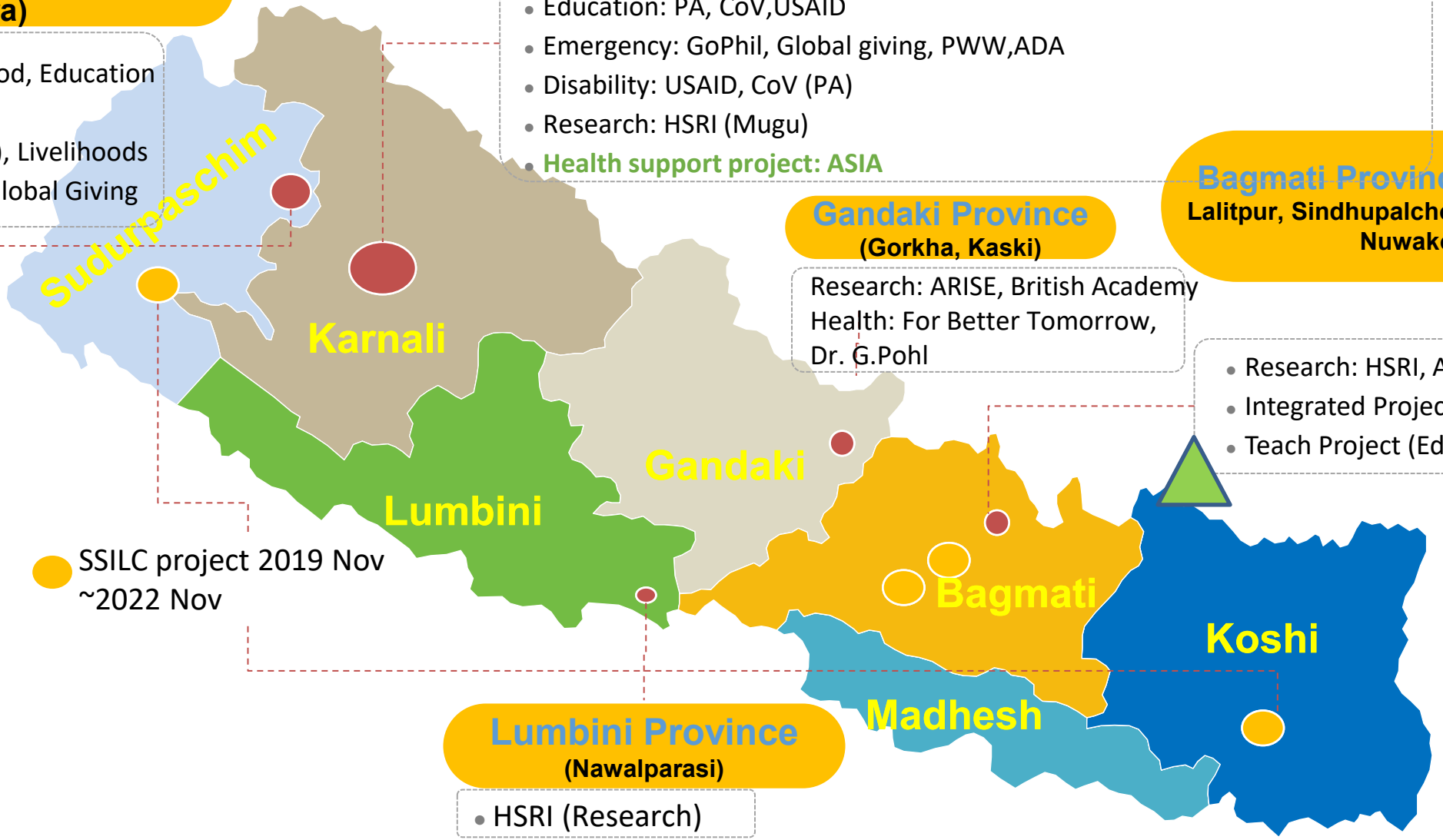
- ADA: Health, Livelihood, Education
- Global Giving: Health
- PWW(UkAid): Health), Livelihoods
- Emergency: GoPhil, Global Giving

Gandaki Province (Gorkha, Kaski)

Research: ARISE, British Academy
Health: For Better Tomorrow, Dr. G.Pohl

Bagmati Province (Kathmandu, Lalitpur, Sindhupalchowk, Makwanpur, Nuwakot)

- Research: HSRI, ARISE, NHRC, BA
- Integrated Project: HDFA
- Teach Project (Education): Rotary



SSILC project 2019 Nov ~2022 Nov

Lumbini Province (Nawalparasi)

- HSRI (Research)

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Innovations in trial methodology for global Life after Stroke Research, including adaptive platform and decentralised trials

Amanda Farrin

Professor of Clinical Trials and Complex Intervention Evaluation

Director for the Edinburgh Clinical Trials Unit, Usher Institute

Better health, better futures

Innovations in trial methodology for global Life after Stroke research

- including adaptive platform and decentralised trials

Professor Amanda Farrin

Professor of Clinical Trials and Complex Intervention Evaluation

Director of Edinburgh Clinical Trials Unit

Amanda.Farrin@ed.ac.uk

Evidence gap in ‘life after stroke’ pathway

Stroke remains a significant global health challenge

Better survival, rising incidence: **more survive but do not thrive**

Stroke survivors live for years with life-changing disabilities

- Psychological & emotional problems, cognition, communication, fatigue, mobility, pain, participation in everyday & social activities …

BUT lack of interventions that work for life after stroke problems

Global need for more efficient life after stroke research

- Slow, inefficient evidence generation
- Better understand multiple treatments
- Answer multiple questions in same study


SAGE journals

Guidelines

A stroke recovery trial development framework: Consensus-based core recommendations from the Second Stroke Recovery and Rehabilitation Roundtable

Julie Bernhardt[1], Kathryn S Hayward[1], Numa Dancause[2], Natasha A Lannin[3], Nick S Ward[4], Randolph J Nudo[5], Amanda Farrin[6], Leonid Churilov[7], Lara A Boyd[8], Theresa A Jones[9], S Thomas Carmichael[10], Dale Corbett[11], and Steven C Cramer[12]

Smarter Trials

Improve trial speed, efficiency, productivity

Enable faster, simpler, more equitable access to safe, effective healthcare innovations

Smarter design

- ✓ More promising interventions trialled
- ✓ Fewer, larger trials … but more efficient
- ✓ Adaptive trials
- ✓ Master protocols and platform trials

Smarter conduct

- ✓ Decentralised trials
- ✓ Evidenced-based trial conduct

Smarter use of data & technology

- ✓ Tech-enabled conduct
- ✓ Data enabled or e-trials

Adaptive trials

Designed to increase trial efficiency & utility

Use accumulating data to modify during trial

Trial changes made at pre-specified intervals:

- ✓ Add new promising interventions
- ✓ Drop interventions of no benefit
- ✓ Stop trial early: efficacy / futility
- ✓ Re-estimate sample size
- ✓ Alter allocation ratio
- ✓ Adaptive randomisation (bias towards more promising treatment)

Adaptations MUST be pre-planned

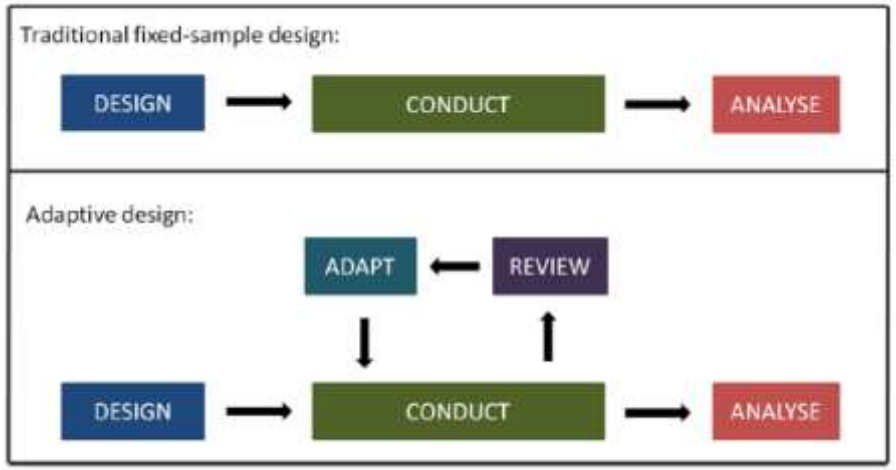
Fallmann et al. BMC Medicine (2018) 16:29
https://doi.org/10.1186/s12916-018-1017-7

BMC Medicine

CORRESPONDENCE Open Access

Adaptive designs in clinical trials: why use them, and how to run and report them

Philip Fallmann[1*], Alun W. Bedding[2], Babak Choodari-Oskooei[3], Munyaradzi Dimairo[4], Laura Flight[5], Lisa V. Hampson[1,6], Jane Holmes[7], Adrian P. Mander[8], Lang'o Odondi[9], Matthew R. Sydes[3], Sofia S. Villar[8], James M. S. Wason[8,9], Christopher J. Weir[10], Graham M. Wheeler[8,11], Christina Yap[12] and Thomas Jaki[1]



RESEARCH METHODS IN NEUROLOGY

Adaptive Trials in Stroke

Current Use and Future Directions

Hayward et al *Neurology* 2024

Master Protocols

Large trials answering multiple research questions

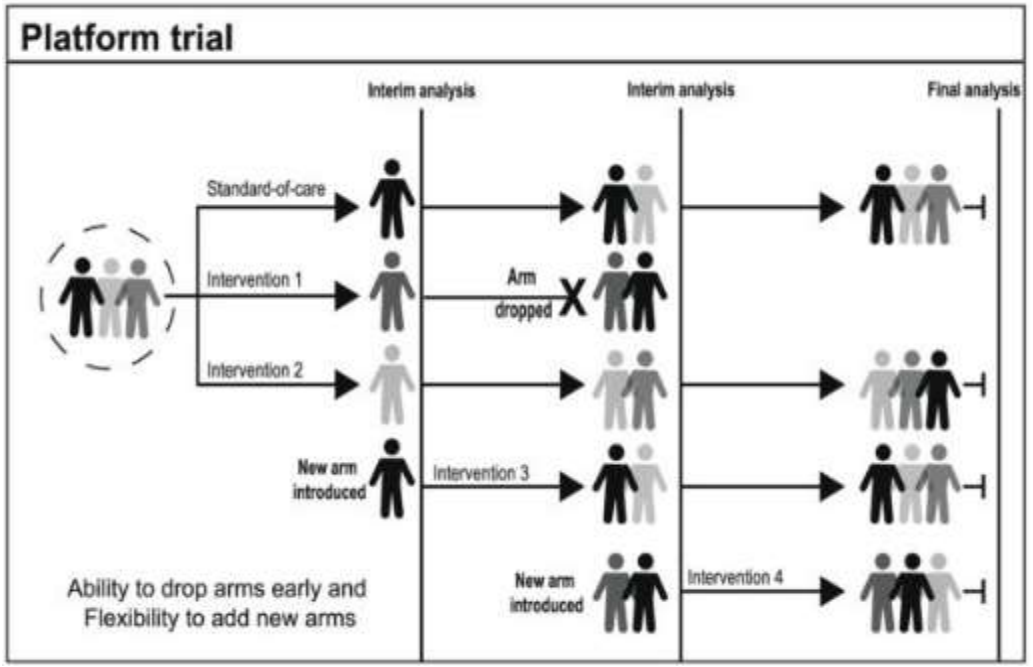
Test multiple treatments across multiple patient subgroups or diseases under a single protocol

Basket trials test a single treatment across multiple diseases (or patient subgroups)

Umbrella trials test multiple treatments on stratified patient subgroups within a single disease

Platform trials test multiple treatments, treatments added or dropped throughout trial

Multi-arm, multi-stage (MAMS)



Park et al. *Trials* 2019

The way forward

Efficient research through platform trial approach

- ✓ Flexible, inclusive, popular with patients
- ✓ Minimise burden to stroke services & survivors
- ✓ Make best use of (scarce) research funding
- ✓ Reduce research waste
- ✓ Speed up generation of evidence
- ✓ Accelerate translation of research into clinical practice

But much more complex to design and deliver (vs 2-arm RCTs)

Design considerations for life after stroke platform trials

P

Should the platform & interventions target different post-stroke problems? **Umbrella**

Will patients be included based on a subgroup definition? **Umbrella**

I

Can we deliver interventions in combination? Feasible for sites or stroke survivors? **Factorial**

How / when will patients be assigned to intervention? **Time post-stroke**

Do we need to limit the number of interventions? **Deliverability / funding**

C

Is a common / shared control group possible? **MAMS**

O

Linking outcome measures to mechanism of action for each intervention

Choice of intermediate outcomes for interim analyses

S

When & how often to perform interim analyses? **Recruitment rates & length of follow-up**

Which stopping rule / decision criteria? **Efficacy, futility, non-inferiority**

All promising, pick the winner, drop the loser

(Remote) Decentralised Trials

Move trial activities closer to home

https://trialsathome.com/

Potential for efficiencies

- ✓Accessibility
- ✓Choice
- ✓Engagement
- ✓Improved recruitment
- ✓Greater retention
- ✓Reduce burden

Taken from *https://**trialsathome.com**/wp-content/uploads/2020/09/Trials@Home_D1.1-First-set-of-recommendations-f-RDCTs-to-be-implemented-in-the-pan-EU-pilot-RDCT.pdf*

Spectrum of ‘remoteness’ -- decentralised processes

Population

Identification e.g. via HSD, online, registries

Recruitment – postal, online …

e-consent

Digital endpoints and trial data

Healthcare systems data - ‘routine data’

e-PROs, postal, phone, apps, SMS

e-CRFs

Home visits / home test kits

Wearables / sensors

Google analytics

RECREATE
Reducing sedentary behaviour after stroke

Interventions

Direct to patient interventions

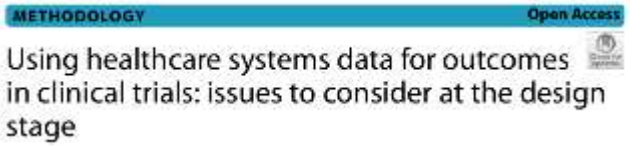
Digital health interventions

Tele-rehabilitation

Wearables / sensors / apps

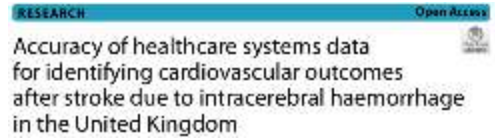
VR / AI

Toader et al *Trials* 2024


METHODOLOGY Open Access

Using healthcare systems data for outcomes in clinical trials: issues to consider at the design stage

Hosking et al *Trials* 2024


RESEARCH Open Access

Accuracy of healthcare systems data for identifying cardiovascular outcomes after stroke due to intracerebral haemorrhage in the United Kingdom

Efficient ‘tech-enabled’ trial conduct

Intelligent use of wide range of ‘technology’

Videos	Smartphone apps	Registries
Podcasts	Text messaging	Telehealth
Social media	Wearable devices	Virtual reality
Web portals	Electronic records	Artificial Intelligence

Benefits?

- ✓ Minimise workload / time at site
- ✓ Enhance outreach, inclusivity, accessibility
- ✓ Greener trials

Trial processes / conduct

- Identification, recruitment & consent
- Outcome assessment & data management
- Intervention delivery
- Monitoring
- Communication, publicity & dissemination

Think about

- Ethics, regulatory, privacy, data standards
- Population: Digital poverty / familiarity with technology
- Hybrid approaches: Not ‘one-size fits all’
- Multi-format materials: tailored to needs

Evidence for trial efficiency: SWATs

Self-contained research study embedded in a host trial to **systematically test** ways of delivering or organising trial processes

Test alternative ways of recruiting, following-up, intervention delivery, inclusivity, dissemination …

Original Research Article

A new opportunity for enhancing trial efficiency: Can we investigate intervention implementation processes within trials using SWAT (study within a trial) methodology?

Ahmed et al Res Meth Med & Health Sci 2022

SWAT 142: Use of a video animation to improve participant understanding, engagement and compliance with an intervention in a cluster randomised trial of stroke survivors

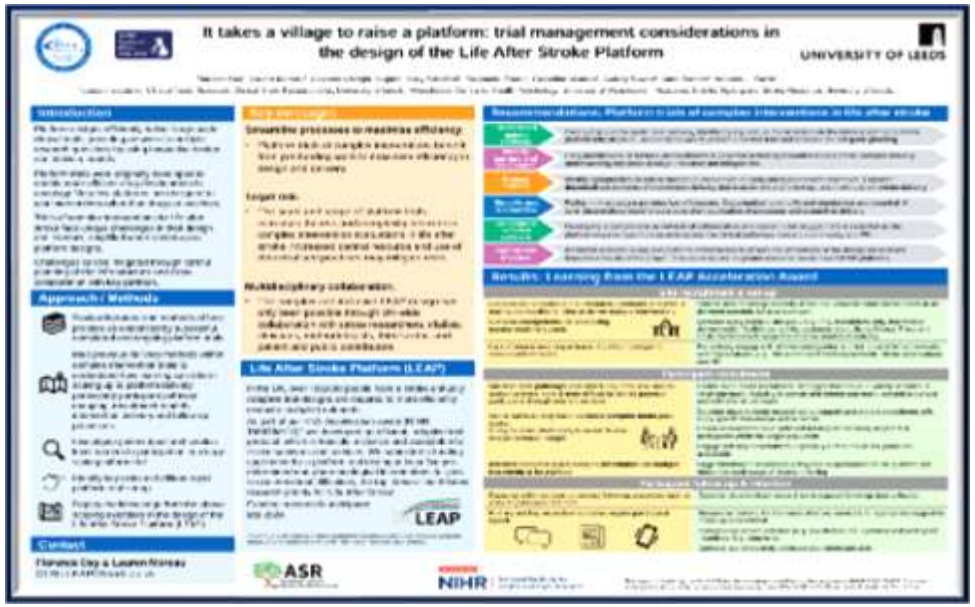
SWAT 233: Behavioural nudges to increase responses from residents in England to a postal invitation from NHS England to take part in the Antiplatelet Secondary Prevention International Randomised study after INtracerebral haemorrhaGe (ASPIRING)

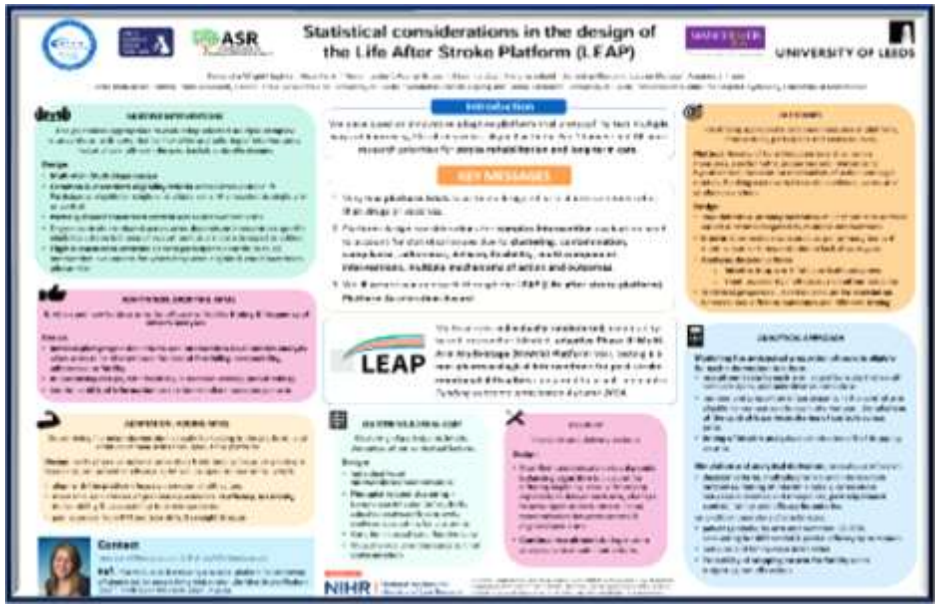
Lessons from developing the LEAP master protocol

FUNDED BY NIHR | National Institute for Health and Care Research

LEAP Life after Stroke Platform

Farrin AJ et al *NIHR Open Res* 2025, 5:25
(https://doi.org/10.3310/nihropenres.13611.1)





RESEARCH ARTICLE

Check for updates

Developing a national platform for delivering efficient trials for people living with stroke: the Life after Stroke Platform (LEAP)

[version 1; peer review: 1 approved]

Amanda Farrin [1], Alexandra Wright-Hughes[1], Lauren Moreau[1], Holly Schofield [1], Florence Day[1], Geraldine Murden[1], John Green[2], Audrey Bowen [3], Lisa Kidd[4], Chris Bojke[5], Anne Forster[2], LEAP (Life After Stroke Platform) Collaborative

Patient, Carer & Public Involvement

FUNDED BY NIHR | National Institute for Health and Care Research
LEAP Life after Stroke Platform

Partnership working was key

Perspectives of people with lived experience vital to platform trial development

PPI input to developing the platform trial

- ✓ Selecting platform focus, interventions and outcomes
- ✓ Developing criteria for assessing if an intervention is ready for testing
- ✓ Integrating PPI into the process for prioritising future interventions
- ✓ Identifying participation barriers and developing strategies to address
- ✓ Drafting, reviewing and testing patient-facing (multi-media) materials

"I feel I have been listened to and had a real impact"

"The research is flexible in approach and will, I think, get some positive, practical results to make a real difference."

Why don't you do all your trials this way?

Developing inclusive PPI approaches together

Exploring how clinical communication strategies & visual aids can be adapted for PPI to facilitate diverse inclusion

Developing the LEAP collaborative

FUNDED BY NIHR | National Institute for Health and Care Research

LEAP Life after Stroke Platform

How? Winning hearts & minds

Outreach & education: Webinars, conference talks, workshops

Relationship building & decision-making: 2-day Stakeholder meeting, Intervention Roundtables, regular team video calls

Wider networking, stakeholder involvement: Referrals, discussion forums, network meetings, 1-1s, dissemination meetings

Clear roles: co-applicants, intervention leads & delivery, advisory

Who? Iterative / gap filling / international

Stroke specialists: physicians, AHPs, GPs, nurses

Mental health specialists: psychologists, psychiatrists

Original developers of the platform interventions

NHS England: Stroke Programme

Third sector: Stroke Association, Stroke Foundation

Data providers & stroke research infrastructure

What? Clinical input to developing the platform

- ✓ Platform focus, adaptation features, interventions, outcomes
- ✓ Criteria for assessing if an intervention is ready for testing
- ✓ Clinical review into process for prioritising future interventions
- ✓ Opportunities for standardisation across platform
- ✓ Reviewing intervention deliverability & capacity
- ✓ Identify sites, site-level barriers, potential solutions
- ✓ Design of inclusive platform processes
- ✓ Feedback on platform governance

Reflections

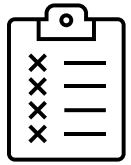
Platforms are complex to design: complex intervention platforms even more so

Take your time

- Educate / upskill the community
- Identify and involve the 'right' people
- Develop a strong, collegiate, multi-disciplinary collaborative - with shared aspirations & goals

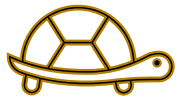
Streamline platform processes & resources

- Additional resource for platform infrastructure: different / greater than CTIMP platforms?
- Consider remote delivery, decentralised elements … effect on inclusivity?
- Internal pilot



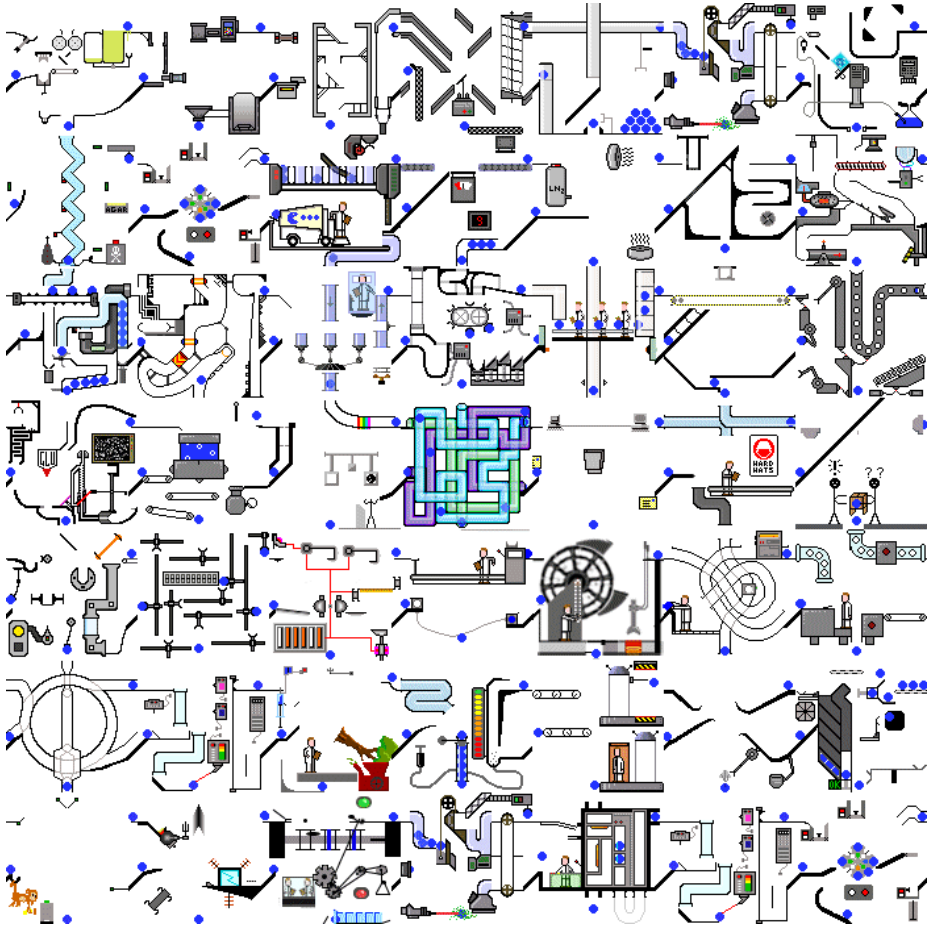
Consider many statistical issues common to stroke rehab trials

- Clustering: by site, by therapists, heterogeneity across interventions
- Contamination / compliance / adherence / intervention tailoring / mutually exclusive therapists?
- Content of usual care comparator / proof of concept for interventions



Cultivate resilience: it's a marathon not a sprint

To raise a platform … it takes a village



LEAP
Life after Stroke Platform

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Academic Collaborators: Audrey Bowen, Penny Bee, Emma Patchwood (Manchester); Rebecca Bestwick, Chris Bojke, Bethan Copsey, Else Guthrie, Jess Johannsson (Leeds); Jen Airlie, Louisa Burton, Tom Crocker, Faye Wray (Bradford); Duncan Edwards, Jonathan Mant, Pavel Mozgunov (Cambridge); Gillian Mead, Yvonne Chun (Edinburgh); Satu Baylan, Jon Evans, Lisa Kidd, Maggie Lawrence, Terry Quinn (Glasgow); Chris Price, Lisa Shaw (Newcastle); Avril Drummond, Kate Radford, Cath Sackley, Shirley Thomas (Nottingham); Rebecca Palmer (Sheffield); Harry McNaughton (New Zealand)
The Stroke Association: Juliet Bouverie, Richard Francis, Emily Griffin, Maeva May
Clinical & Methodological Advisory Group: Rustam Al-Shani Salman, Martin Dennis, Richard Emsley, Allan House, Martin James, Matthew Sydes, Will Whiteley
Clinical Reference Group: Aoife Bennett, Lauren Crutchley, Anne Eisenthal, Kirstin Guy, Alwyn Sproul.

International Collaborators: Richard Lindley, Sabine Allida, Osvaldo Almeida, Dominique Cadilhac, Angela dos Santos, Caleb Ferguson, Erin Godecke, Maree Hackett, Graeme Hankey, Ian Kneebone, Adrian O'Malley, Rene Stolwyk, Vincent Thijs, Dana Wong, Kam Wong, Anna Balabanski, Brenda Booth, Rebecca El-Helou, Anna Holwell, Melissa Kang, Tarren Leon, Brooke Ryan, Simone Russell. **The Stroke Foundation** (Australia)

More details: Farrin A, Wright-Hughes A, Moreau L *et al.* Developing a national platform for delivering efficient trials for people living with stroke: the Life after Stroke Platform (LEAP): [version 1; peer review: 1 approved]. *NIHR Open Res* 2025, **5**:25 https://doi.org/10.3310/nihropenres.13611.1

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The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care

FUNDED BY NIHR | National Institute for Health and Care Research

ctru University of Leeds

ASR Academic Unit for Ageing and Stroke Research

Geoffrey Jefferson Brain Research Centre

MCHP Manchester Centre for Health Psychology

INNOVATION AND TRANSLATION IN STROKE TRIALS

LEAP Life after Stroke Platform

Thank you

Amanda.Farrin@ed.ac.uk

ECTU-new.proposals@ed.ac.uk

Implementation research and digital interventions for stroke in low-and-middle income countries

Ayeesha Kamran Karmal

Professor of Neurology and Director of Stroke Services

Aga Khan University Hospital, Pakistan

World Stroke Organization

Life after stroke research: WHO perspective

Craig Anderson - *President-elect*

A global voice for stroke

Global Stroke Action Coalition

GLOBAL STROKE ACTION COALITION

Officially launched in 2025, the Global Stroke Action Coalition (GSAC) is a multi-stakeholder platform convened by WSO to unite civil society, clinicians, industry, and policymakers behind a shared goal: accelerated action on stroke across the full care pathway. As co-Chairs of the Coalition, WSO past-Presidents Bo Norrving and Sheila Martins bring their extensive stroke policy influence, expertise and implementation insight to the partnership.

The Global Stroke Action Coalition has:

- Provided a coordinated multi-sectoral global advocacy platform, aligning diverse stakeholders behind 5 key policy recommendations to increase impact
- Increased visibility of stroke within major global health discussions, particularly in the lead-up to the UN High-Level Meeting on NCDs
- Positioned action on stroke as essential to achieving SDG3 and Universal Health Coverage (UHC)
- Secured a draft WHO resolution on stroke that, when adopted in 2026, will drive government action and accountability on stroke

Deliver proactive and collaborative advocacy

WSO will drive global political commitment and supporting regional and national advocacy in collaboration with our members towards delivering positive outcomes.

Deliver accessible, engaging and applicable training and education

WSO will provide world class training and education for stroke-care professionals

Change perceptions of stroke

WSO will lead the global conversation on stroke focused on changing perceptions of stroke to underpin multi-level action on stroke prevention, treatment, rehabilitation and long-term management.

Capacity Strengthening

WSO will work with health care professionals, civil society, and people with lived experience to identify and increase understanding of the importance of quality stroke care across the continuum.

Deliver impact through partnerships and collaboration

WSO will collaborate with global, regional and national partners to identify and facilitate achievement of shared goals.

World Stroke Organization

Align Life after stroke – a WSO strategic priority

Priority 1: Deliver proactive, collaborative & impactful advocacy

Advocacy for WHO Stroke Resolution which includes calls for early supported discharge, palliative + end of life care, community-based rehabilitation & social support.

Priority 2: Deliver accessible, engaging and applicable training and education

To improve the quality of care and psychosocial support available globally, the WSO and WSA have developed education materials focused on Life After Stroke.

Priority 3: Change perceptions of stroke

World Stroke Campaign resources highlight the unmet needs of stroke survivors and the actions that we can all take to help optimize recovery.

Priority 4: Capacity strengthening

In collaboration with Stroke Support Organizations (SSOs) globally, WSO emphasizes life after stroke as an equal part of the stroke care pathway

Operationalizing these strategic priorities

SSO capacity strengthening

The SSO Committee promotes the work of SSOs across the stroke pathway and supports collaborative initiatives between SSOs, health professionals and industry. Through engagement in community, we champion the voice of lived experience and facilitate the meaningful involvement of people with lived experience across WSO activities. Our activities in 2025 included:

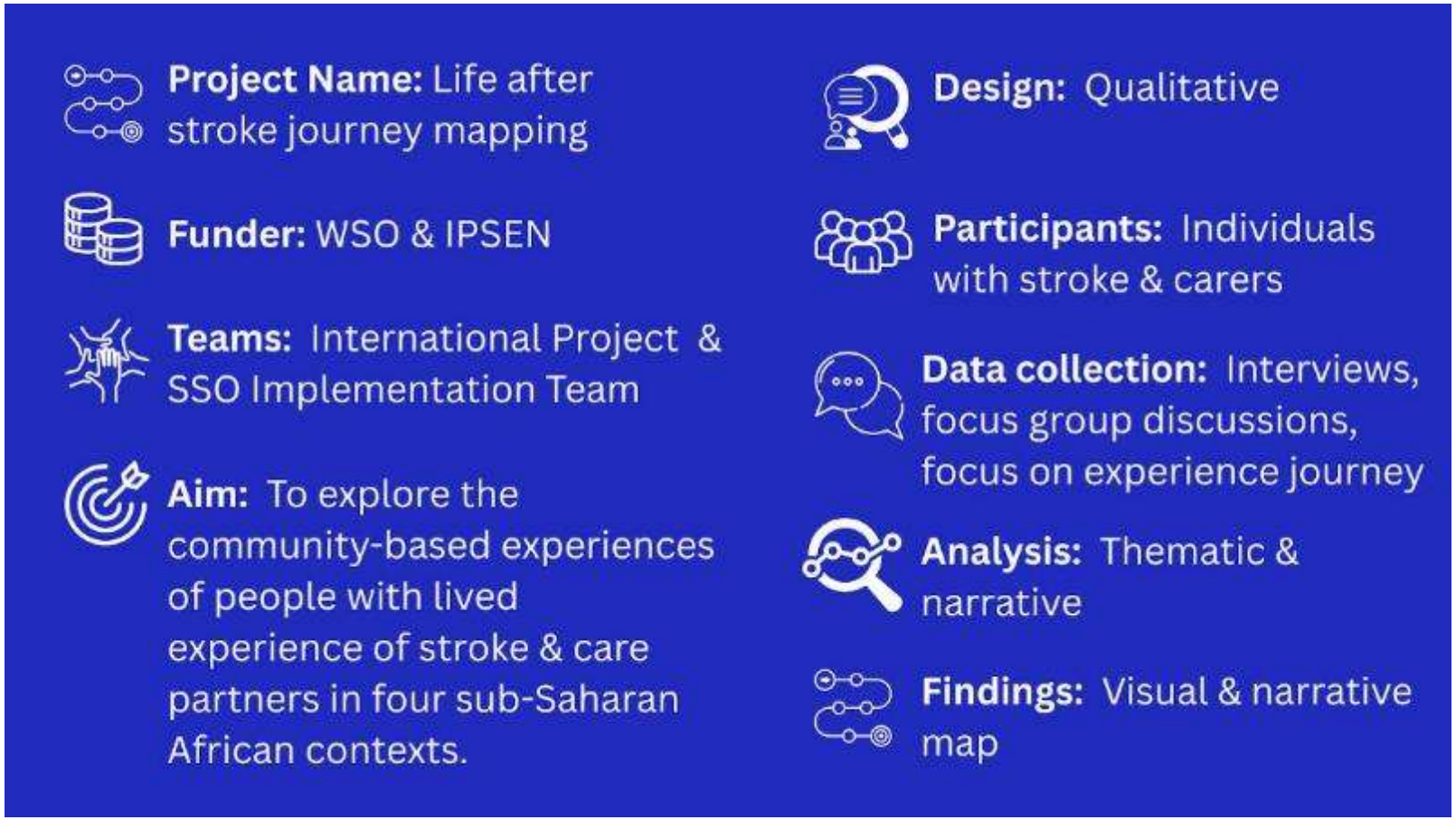
What will this mean in practice going forward?

Going forward, this work can help create a more thoughtful and consistent approach to lived experience storytelling across stroke organizations. In practice, that means clearer processes around consent, storage and reuse, stronger stewardship of people's stories, and a better understanding of how lived experience can inform education and policy. In the short term, it is already helping shape discussions around good practice and where more structure and support are needed.

Life After Stroke Research: 2025 - 2026

World Stroke Organization

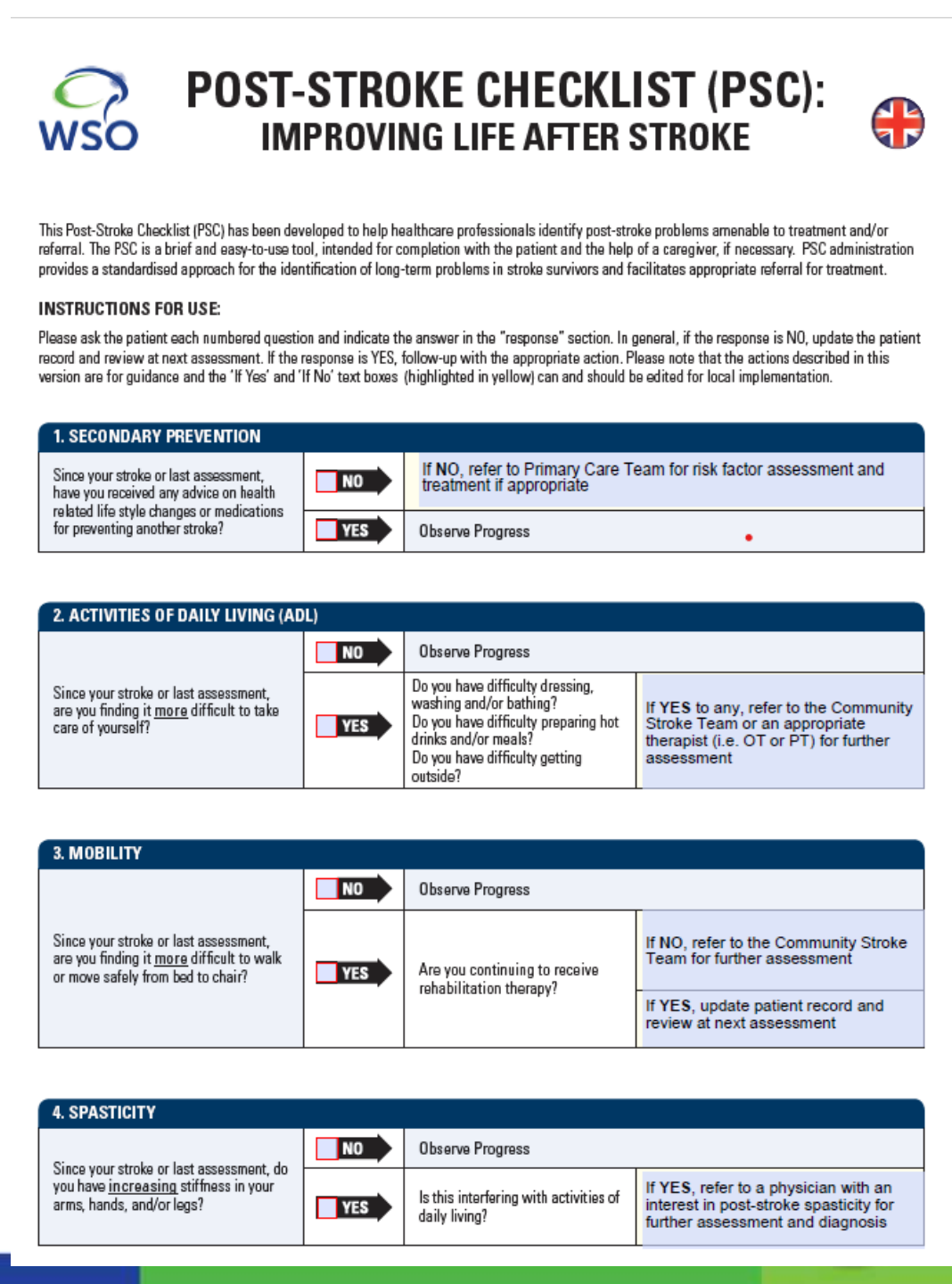
Life After Stroke Journey Mapping – with SSOs in Malawi, Rwanda, Nigeria and Rwanda



Life After Stroke Research: 2025 - 2026

Review of the post-stroke checklist

- To understand adoption and adaptation globally.
- Survey of global stroke experts and health professionals to identify where the post-stroke checklist has been adopted into national stroke plans and where and how it is implemented (including modifications) in health settings.



WSO

POST-STROKE CHECKLIST (PSC):
IMPROVING LIFE AFTER STROKE

This Post-Stroke Checklist (PSC) has been developed to help healthcare professionals identify post-stroke problems amenable to treatment and/or referral. The PSC is a brief and easy-to-use tool, intended for completion with the patient and the help of a caregiver, if necessary. PSC administration provides a standardised approach for the identification of long-term problems in stroke survivors and facilitates appropriate referral for treatment.

INSTRUCTIONS FOR USE:

Please ask the patient each numbered question and indicate the answer in the "response" section. In general, if the response is NO, update the patient record and review at next assessment. If the response is YES, follow-up with the appropriate action. Please note that the actions described in this version are for guidance and the 'If Yes' and 'If No' text boxes (highlighted in yellow) can and should be edited for local implementation.

1. SECONDARY PREVENTION

Since your stroke or last assessment, have you received any advice on health related life style changes or medications for preventing another stroke?	NO	If **NO**, refer to Primary Care Team for risk factor assessment and treatment if appropriate
	YES	Observe Progress

2. ACTIVITIES OF DAILY LIVING (ADL)

Since your stroke or last assessment, are you finding it more difficult to take care of yourself?	NO	Observe Progress	
	YES	Do you have difficulty dressing, washing and/or bathing? Do you have difficulty preparing hot drinks and/or meals? Do you have difficulty getting outside?	If **YES** to any, refer to the Community Stroke Team or an appropriate therapist (i.e. OT or PT) for further assessment

3. MOBILITY

Since your stroke or last assessment, are you finding it more difficult to walk or move safely from bed to chair?	NO	Observe Progress	
	YES	Are you continuing to receive rehabilitation therapy?	If **NO**, refer to the Community Stroke Team for further assessment
			If **YES**, update patient record and review at next assessment

4. SPASTICITY

Since your stroke or last assessment, do you have increasing stiffness in your arms, hands, and/or legs?	NO	Observe Progress	
	YES	Is this interfering with activities of daily living?	If **YES**, refer to a physician with an interest in post-stroke spasticity for further assessment and diagnosis

Life After Stroke Research: 2025 - 2026

Mapping the Global Stroke Support Organization Landscape: A 2025 World Stroke Organization Survey

- Insights into the contributions SSOs are making to reduce the global burden of stroke across the stroke care pathway, including life after stroke

Survey sent

to **155** SSOs from **76** countries

Survey completed

by **108** SSOs from **63** countries

Response rate

69.67%

Life After Stroke Research: 2025 - 2026

Publications:

- **Beyond the Clinic:** The Impact of SSOs on Patient Experience and Outcomes (Nelson et al., 2026) – engaged SSO Committee members
    - A rapid review to define the role & scope of SSOs in the stroke care pathway and identify strategies to optimize their engagement across the continuum of care.
    - SSOs function across the stroke care pathway. SSOs bridge gaps between formal healthcare and community-based care, particularly when clinical rehabilitation services end.
- SSOs as Essential Implementation Partners for the WSO-Lancet Neurology Commission Recommendations: A Scientific Statement (publication pending) – SSO Committee led
    - Explores how SSOs provide essential infrastructure to operationalize the integral role of community stakeholders as recognized in the 2023 WSO-Lancet Neurology Commission's pragmatic solutions for reducing the global burden of stroke.

Our priority was to close the evidence-to-implementation gap through interactive, outcome-oriented learning, with expanded multilingual and regionally adapted content, particularly for low- and middle-income countries, where stroke burden is greatest. Growth in learners, traffic, and global reach confirmed the urgency of this need.

Assoc. Professor Octávio Marques Pontes-Neto

Editor in Chief
World Stroke Academy

World Stroke Academy

9,500 registered learners

+280% vs. 2024

60% from LMICs

90% would recommend to a colleague

186 countries reached

Very interesting webinar, my clinical practice will change according to next regulatory agency steps for factors XI inhibitors, thank you!

25 live webinars

+14 vs. 2024

80% likely to change clinical practice

Our global community of stroke leaders

85	20	24	9
Participants from diverse disciplines	Countries across six global regions	Abstracts submitted to WSC 2025	Alumni on the ISJ editorial board

World Stroke Organization Future Leaders

Strengthening stroke care capacity in Africa

Chairs:

Rustam Al-Shahi Salman

Panel

To submit a question, scan this QR code or go to **slido.com** and enter **# Usher1105**

Craig Anderson
University of New South Wales, Australia

Amanda Farrin
The University of Edinburgh

Ayeesha Kamran Karmal
Aga Khan University Hospital, Pakistan

Jiban Karaki
Liverpool School of Tropical Medicine and PHASE Nepal

Closing remarks

Gillian Mead

Professor of Stroke and Elderly Care Medicine