Sentinel Stroke National Audit Programme SDM
03 03 22

Kim Rezel
Head of Patient and Carer Engagement

- Stroke survivors

- Different Strokes

- Stroke Association

Stroke Association perspective on SSNAP

Dr Rubina Ahmed, Associate Director for Systems Engagement

SSNAP Specification Development Meeting, 3 March 2022

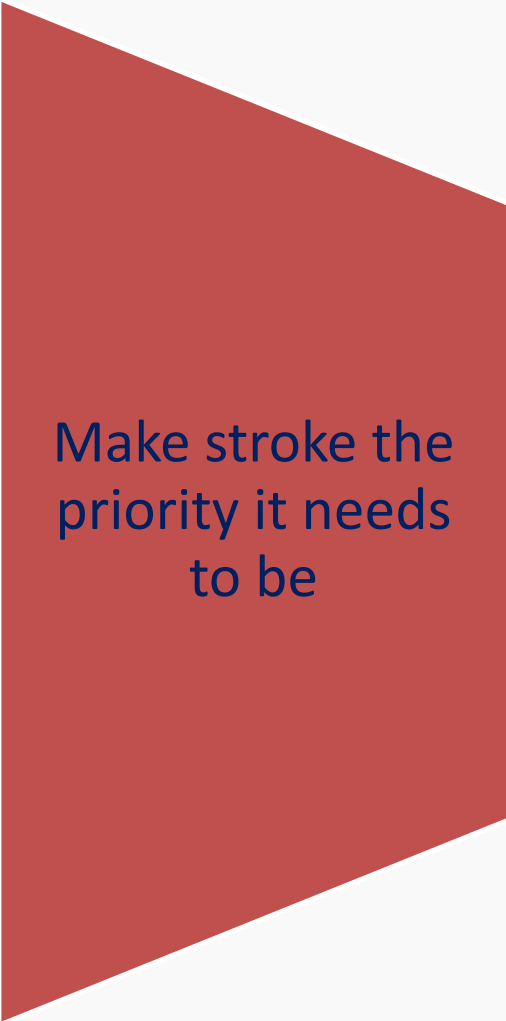Cymdeithas
Strôc | **Stroke**
Association

Our Vision

Our vision is for there to be fewer strokes, and for people affected by stroke to get the help they need to live the best life they can.

Our Goals

Make stroke the priority it needs to be

Ensure that everyone affected by stroke has access to the rehabilitation and lifelong support they need

Partner with people and communities to help them take action on stroke

Service Delivery	Research
Influencing	**Community Engagement**

Our work with SSNAP

- Post stroke review teams input data into SSNAP

- Use SSNAP (and Scottish Audit) for own data analysis and statistics that are reported externally.

- Juliet Bouverie is co-chair of the SDB and Rubina Ahmed is a member. Both are also members of the ICSWP.

- Local teams work with ISDNs

- National teams work closely with NHS England CPU and NHS Wales.

Main methods of patient involvement

- Insight and surveys

- Influencing and campaigning – national and local

- Design of our products and services

- Fundraising and Volunteering

- Research

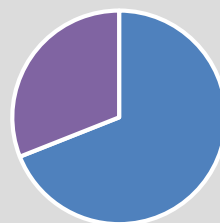# What we are hearing from people affected by stroke

2018 Lived experience of stroke survey
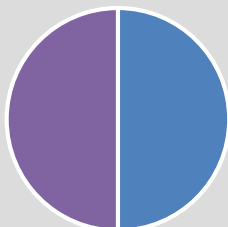
Hidden effects of stroke

¾ experience a change in their mental health.
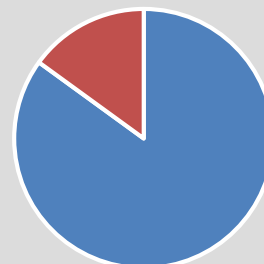
Practical impacts of stroke

For **69%** of people, stroke impacts independence

Rehabilitation and recovery

A **half** of stroke survivors felt they needed support for longer or more frequently.
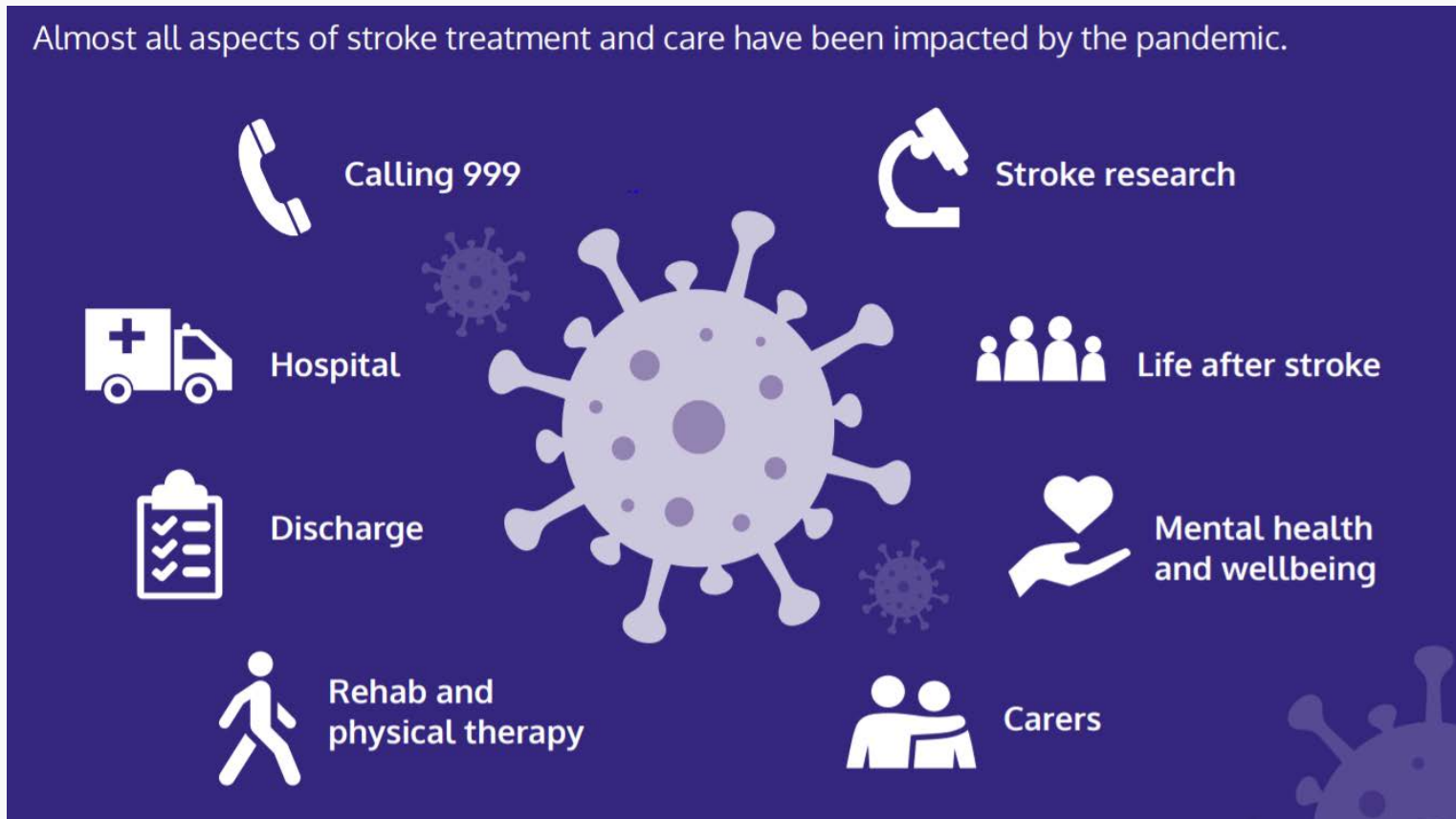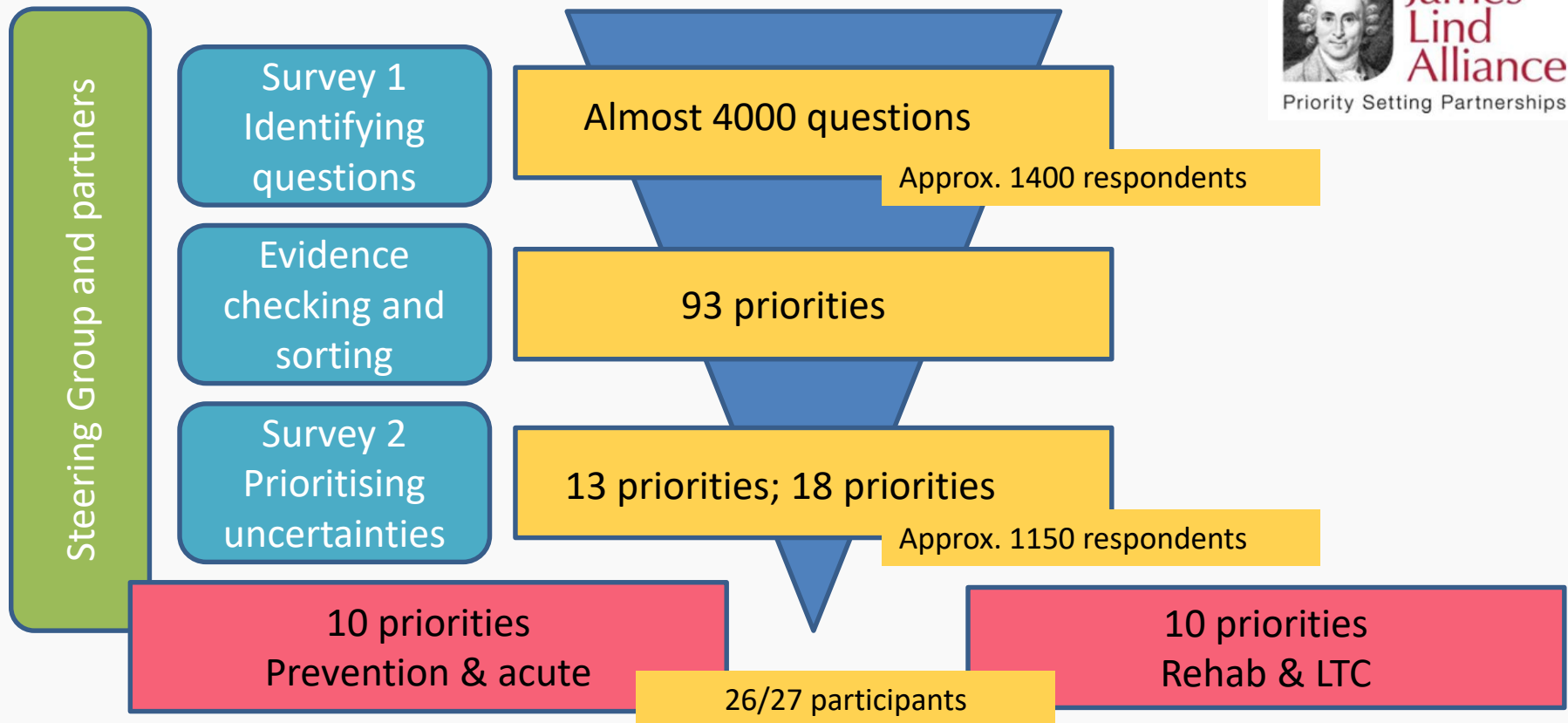
Caring for a stroke survivor

85% don't get the support and information they need.

2020 Covid - Stroke Recoveries at Risk report

Almost all aspects of stroke treatment and care have been impacted by the pandemic.

Calling 999

Hospital

Discharge

Rehab and physical therapy

Stroke research

Life after stroke

Mental health and wellbeing

Carers

Establishing research priority areas

Steering Group and partners

- Survey 1
  Identifying questions
- Evidence checking and sorting
- Survey 2
  Prioritising uncertainties

Almost 4000 questions

Approx. 1400 respondents

93 priorities

13 priorities; 18 priorities

Approx. 1150 respondents

10 priorities
Prevention & acute

26/27 participants

10 priorities
Rehab & LTC

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James Lind Alliance
Priority Setting Partnerships

The Top 10 priorities: Stroke prevention, diagnosis, pre-hospital, and hospital care

The priorities are areas of evidence **uncertainty in stroke policy and practice**. This means there are no up-to-date, reliable reviews of research evidence to guide treatment and care, or that up-to-date reviews show that uncertainty exists (James Lind Alliance, 2021). The priorities must guide research investment to address the issues that matter most to people affected by stroke.

1. What are the **best interventions** to **stop stroke happening** for the first time (i.e. primary prevention)?

2. How can the public, paramedics and other health care professionals **recognise and respond** to stroke or TIA better and more quickly?

3. What are the **benefits and risks of acute treatments for intracerebral haemorrhage** (e.g. surgery and medications)?

4. What are the **benefits and risks of new therapies** for stroke (e.g. stem cell therapy) and those that work to protect the brain from damage (i.e. neuroprotection)?

5. What is the **risk of recurrent stroke**, how does this risk change over time, and what can stroke survivors do to **reduce the likelihood** of having another stroke (i.e. secondary prevention)?

6. How can the proportion of patients with **ischaemic stroke who get clot retrieval** (thrombectomy) **be increased** either by using new ways to identify more patients that are eligible, or by increasing the number of specialist healthcare professionals who can carry out thrombectomy?

7. What are the processes that **cause delayed changes in brain function** (neurological deficit) **after subarachnoid haemorrhage caused by an aneurysm?**

8. How can complications of stroke be reduced (e.g. pneumonia)?

9. What are the **risks and benefits of using blood-thinning treatments** (antiplatelet and anticoagulants) to stop stroke happening after TIA or haemorrhagic or ischaemic stroke? Is **personalised decision-making** possible for the timing and types of antiplatelet and anticoagulant therapy used?

10. Do patients' **other health conditions, and characteristics** such as age, ethnicity and frailty, affect stroke symptoms, outcomes, interventions and care pathways?

All submitted questions will be available at **jla.nihr.ac.uk/priority-setting-partnerships/Stroke**

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The Top 10 priorities: Stroke rehabilitation and long-term care

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The list below summarises the priority areas. The full descriptions can be found at **stroke.org.uk/psp**.

1. Impact of psychological problems and how to reduce them...

2. Understanding cognitive problems and how to reduce them...

3. Effects of communication problems, how to assess and reduce them...

4. Understanding fatigue and how to reduce it...

5. Organising community stroke services to meet all survivor needs...

6. Long term impacts on everyday abilities and availability of interventions...

7. Time, place and amount of therapy for best outcome...

8. Working with the stroke care team and support for carers...

9. Strength and fitness for recovery and stroke prevention...

10. Stroke survivor and carer experience of stroke pathway...

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Views on SSNAP

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What works well

- Good completion rate from stroke units which demonstrates engagement

- Acute data – very robust and captures key data

- Recent introduction of demographic data points and PROMs.

Areas for improvement

- Doesn't capture ALL stroke patients. Excludes TIA, SAH and childhood stroke patients.

- More data required on the post-acute and community pathway

- PREMs data – want to see equal parity of patient experience as well as outcomes

- Data collected but not fully driving quality improvement

- Opportunities for data to be used for research and innovation in a trusted research environment

- Integration of stroke data with other NHS clinical audits

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Rebuilding lives after stroke

Resources

- Clearly laid out
- Good overview
- Easy read options

Improvements

- Quite technical

- More appropriate for clinicians

- How does it support stroke survivors in their care

- More focus on PPI

- Useful links from charity websites

Conclusions

- Life after stroke

- Patient reported measure – post acute care

- Emotional and psychological support

- Covid impact

- Healthcare inequalities – post code data