

AN INDEPENDENT POLICY REPORT ON UK STROKE AFTERCARE

The Discharge Gap

Scope: England. Health is a devolved matter in Scotland, Wales, and Northern Ireland

"The NHS built one of the world's best acute stroke pathways. Then it stopped."

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Every year I see four or five hundred people with long-term problems after stroke, most of them through the Queen Square Upper Limb neurorehabilitation programme. Their stories differ, but many arrive bewildered, a year or so on from the stroke that turned their lives upside down. Often, they have been told that they are now on the recovery plateau, that no further recovery is likely and that no further treatment is available for them just as they feel they are getting going. Almost all use the same word: abandoned. I do not think they are exaggerating.

The science does not support this abandonment. It is true that remarkable improvements can be seen in the first few weeks and months after stroke. This is attributed to the process of spontaneous biological recovery – a series of changes in the stroke brain that can lead to some degree of brain repair that supports recovery. Although it is also true that this process is time limited, what continues indefinitely in many stroke survivors is the capacity to learn through normal brain plasticity. Recovery beyond the first few months is often about learning. Anyone who has tried to learn the piano knows that the key ingredient is good quality teaching aligned with practice, practice, practice. We know that many people don't get back to where they were before the stroke, but we also know that many people are not being helped to achieve their full recovery potential.

So why does the idea persist that recovery ends at six months? "Window of opportunity" is a phrase that is used a lot, but what do we do with open windows? We close them! Many people are told there is no plasticity to support recovery after this time, which is just not true. The idea of a recovery plateau is most prominent in the field of recovery of movement but those who study recovery of language and cognition have long believed recovery can continue for years. Despite this, the idea of a plateau appears to have influenced our provision of care - you have reached a plateau, so you will not improve, so there is no point treating you. The 2023 national guidelines explicitly reject this idea, stating that people with stroke should be considered to have the potential to benefit from rehabilitation at any point after their stroke, and that the provision of appropriate rehabilitation should be needs-led not time-limited (ISWP, 2023).

I think we already have rehabilitation treatments that work; what we are rarely permitted to do is deliver them at the dose and intensity required for them to work. The Upper Limb rehabilitation programme at Queen Square provides an opportunity to see what happens when we provide high-dose high-intensity rehabilitation to people with stroke many years after the event. Not surprisingly, we see big improvements. However, in most cases, rehabilitation is low-dose low-intensity. If rehabilitation was a tablet, we are underdosing our stroke survivors dramatically.

It's not just dose though. What you actually do matters and this depends on each individual's combination of impairments – there is not a single treatment for recovery of the arm, the leg, speaking, or thinking. The point here is that stroke rehabilitation is complex, requiring several complementary treatment approaches depending on whether this person has weakness, sensory loss, spasticity, apraxia, aphasia, cognitive impairment, low mood, fatigue and so on, because each is a target for treatment. This is something health care professionals working in rehabilitation have always known.

Why are we in this situation? I think rehabilitation is suffering from a lack of good quality evidence to support the inclusion of available treatments in national guidelines. I think clinical trials often test one thing (a tablet, a device, one form of exercise), rather than the complex intervention in its entirety. But I also think there is a view that rehabilitation must be expensive and that we don't really have the resources to deliver best quality rehabilitation as recommended in the national clinical guidelines. Stroke is the commonest cause of neurological disability - there are 1.4 million people in the United Kingdom living with the consequences of stroke (Stroke Association, n.d.), with a total annual economic cost to the UK of £25.71 billion in 2025 (Stroke Association, 2026). Can we afford not to treat them, to reduce their carer burden, to allow them or their partners the opportunity to get back to work? We know how to help these people but lack the opportunity to implement these effective treatment strategies. The NHS has lots of money – where we spend it is a choice.

Recovery is achieved, in the end, by the survivor doing the work, but the role of the expert coach is crucial. The commonest thing people tell me is "I don't know what I'm supposed to be doing." Stroke survivors need expert assessment ('diagnostics') to understand what their combination of impairments is, and then expert coaching to help them achieve their personal goals and achieve the best recovery possible – however long that takes. How do our stroke survivors get access to this expert knowledge? The report's proposals for a named coordinator, a route back into services and a community service commissioned against the guideline will help greatly.

The authors have both had a stroke, and both came to this subject from careers in business and technology, where they learned to look for the place at which a complex system fails the people it is built for. They do not offer testimony in place of evidence. They set out the clinical data, say carefully what it does and does not show, and ground it in lived experience of the pathway. The science has been available for some time.

What remains is the will to act on it.

A NOTE ON POSITION

We are both stroke survivors and patient leaders, and we came to stroke policy from business. Between us we have worked in multiple sectors including, in Paul's case, thirty years in financial services, information technology, manufacturing, logistics, and strategic consulting as a business owner, investor, board member and senior management and, in Maya's case, twenty years in digital strategy and operations at high-growth companies in energy and financial services, including at executive board level. These are industries where complex, legacy systems consistently underserve the people they are built for, and where the distance between policy intent and operational reality is the whole problem. We know what that gap looks like from the inside.

Maya had her stroke in 2021; Paul had two in quick succession in 2023. What we met in the years that followed confirmed something we already understood professionally: systems don't fail randomly. They fail in predictable places, at the point of handover, at the edge of the commissioning boundary, wherever accountability becomes diffuse enough that nobody is clearly responsible. Stroke rehabilitation fails in exactly those places.

This report is not patient testimony. The clinical evidence is cited throughout and stands independently of our experience. But we want to be transparent about why we wrote it: we have both lived the gap this report describes and spent our careers identifying where systems break down and why. We also both advocate for commissioned, paid lived-experience roles in stroke care, and we have set out our interests in the Disclaimer.

A note on scope. This paper addresses stroke rehabilitation and discharge in England. Health is devolved, so Scotland, Wales and Northern Ireland each run their own health services, set their own stroke strategies and make their own commissioning and funding decisions. The funding figures, commissioning arrangements and recommendations here relate to England, including the role of NHS England and Integrated Care Boards, and should not be read as applying to the other three nations. The SSNAP ask touches other nations' funders. Where evidence comes from UK-wide or multi-nation sources, the text says so. The lived experience and clinical evidence cited may well resonate beyond England, and we would welcome conversations with colleagues in the devolved nations about what a comparable approach could look like there.

The argument here is precise. This is not a funding mystery. The evidence for what good community rehabilitation looks like is unambiguous, internationally demonstrated, and largely unimplemented in England. That is a commissioning and systems failure, and it is the kind of failure that is fixable, if the people with the authority to fix it can be persuaded to look at it clearly.

That is what this report is for.

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This report is a structural analysis. It was written independently, without commission or sponsor, by two stroke survivors who have spent between three and five years navigating what comes after the NHS pathway ends. The authors are not writing as clinicians or researchers but from the position that the people who live with the consequences of a policy gap are the people who should be writing about it. This is that report.

That position is structural as well as personal. Stroke care in England moves through three distinct phases — acute care, community rehabilitation, and life after stroke — each commissioned separately, delivered by different clinical teams, and measured, where measured at all, by different frameworks. No clinician works across all three. Acute and community rehabilitation are both NHS-commissioned but sit under separate contracts and budgets; life after stroke, the longest phase, increasingly depends on means-tested social care, unpaid family carers, or charities rather than guaranteed NHS provision. No audit follows a patient through all three either — SSNAP, the national stroke audit, stops measuring at six months, just as life after stroke is only beginning. The one person in England's stroke pathway who experiences every phase — in sequence, in their own body — is the stroke survivor. That is not just a perspective. It is the only vantage point from which the full pathway is visible. And the disparity, seen from that vantage point, is stark: in hospital, physiotherapy is delivered on 70% of recommended days; in community rehabilitation, that drops to 15%; in life after stroke, guidance recommends annual review, but no national audit tracks whether survivors receive it (Chartered Society of Physiotherapy & Association of Chartered Physiotherapists in Neurology, 2026).

England has one of the world's best acute stroke pathways. As people leave hospital, the intensity of therapy steps down and time-limited community rehabilitation takes over. The cliff comes at six months, where provision and measurement stop altogether. Below it is the gap: for many survivors no commissioned service, no national measurement and no way back in. Not because stroke stops at six months — it does not — but because the structures that govern stroke care were built around that point. The Sentinel Stroke National Audit Programme (SSNAP, 2025) stops measuring at six months. The National Institute for Health and Care Excellence (NICE, 2023) published Stroke rehabilitation in adults (NG236) in October 2023, a guideline recommending needs-led rehabilitation that continues for as long as it helps people meet their rehabilitation goals (NICE, 2023). Many Integrated Care Boards (ICBs) are not commissioning against it; SSNAP provides no measurement beyond six months to hold them to account. Each decision was structural in origin. In combination, they have built and maintained the six-month cliff. In this report, "discharge" means leaving NHS stroke support, not only leaving hospital. For many survivors support ends before six months. The six-month review is the last point at which anyone is meant to look, which is why measurement matters.

The six-month cliff was not an accident. It was built in by three decisions nobody reviewed together.

The cost is first human. Nearly half of stroke survivors with paresis have increased muscle tone within three months (Zorowitz et al., 2026), and in one US claims study fewer than one in a hundred first-stroke patients received botulinum toxin A (Hull et al., 2025). Around one in three stroke survivors experience depression (Naghedi et al., 2025) and one in five has anxiety (Knapp et al., 2020). Fewer than half of working-age survivors are back at work a year after stroke (Sen et al., 2019), though rates are higher in trial populations with milder strokes (Radford et al., 2026). Carers absorb the support the system no longer provides, until they cannot. The cost is also financial. Stroke is estimated to cost the UK £25.7 billion a year, rising to £35.9 billion by 2035 without action (2025 prices), and 87% of NHS and social care costs arise after the first year (Stroke Association, 2026). Yet the system that looks after survivors stops measuring its own outcomes at six months (SSNAP, 2025).

Three decisions built the cliff, and four actions would close the gap. SSNAP's measurement window should extend to twelve months. This is the cheapest step, because it can be made as a variation to a contract that already exists, subject to its extension terms. Measurement alone is not enough: SSNAP already records inpatient therapy minutes, and in 2013 to 2015 delivery was well below the guideline standard (Gittins et al., 2020). So NHS England should attach a consequence to it, such as a twelve-month stroke metric in the NHS Oversight Framework or a payment component for community stroke provision. NICE should then publish benchmarkable standards for the community components of NG236, with an outcome measure suited to rehabilitation, not the modified Rankin Scale alone, so that ICBs face benchmarks, not aspirations. The guideline is advisory, and a standard needs data to benchmark against. ICBs, with local authorities, should commission community stroke rehabilitation against NG236, which already covers community stroke services at any point, based on clinical need. And survivors and carers should be co-designers with paid roles and decision-making authority, present before the model is set, not consulted once it is fixed.

None of this needs a new national budget line. The first action sits inside an existing contract. The pilot is funded by redirecting community rehabilitation spend and pooling it with local authorities, a direction the 10 Year Health Plan supports through outcome-linked budgets and a reformed Better Care Fund that jointly funds rehabilitation (Department of Health and Social Care [DHSC], 2025). Any additional posts are requested only after the pilot reports. The pathway should be shaped by the people who have lived it from beginning to end.

£25.7 billion per year

estimated UK economic cost of stroke for people aged 16 and over, in 2025 prices

(Stroke Association, 2026)

35.1%

share of eligible stroke survivors receiving the recommended six-month review

(SSNAP, 2025)

SECTION 1

The Cliff



The pathway, and where it ends



ACUTE CARE	EARLY SUPPORTED DISCHARGE	SIX-MONTH REVIEW	CLIFF EDGE	NATIONAL MODELS*
Commissioned by ICBs. Measured by SSNAP from admission.	NICE NG236-specified. Community, short-term.	Current SSNAP endpoint. The last point at which the system looks. Reached by 35.1% of eligible survivors (SSNAP, 2025).	Some ICBs fund services beyond six months, many do not. No national measurement. No re-entry pathway.	Not commissioned to specification, not measured, and no consequence for non-delivery (authors' interpretation).

*NATIONAL MODELS

Integrated Stroke Delivery Network (ISDN)
The regional network that joins up the whole stroke pathway, from prevention and emergency care to rehab and life after stroke, so that care is consistent wherever you live (NHS England, 2021).

Integrated Community Stroke Service (ICSS)
One joined-up community team that provides stroke rehabilitation after hospital, from early supported discharge through to longer-term rehab, at the intensity each person needs (NHS England, 2022).

Integrated Life After Stroke Support (ILASS)
The practical, emotional and social support, including the six-month review, that helps survivors and carers rebuild their lives and reduce the risk of another stroke. It runs alongside rehab, not after it (NHS England & Stroke Association, 2023).

A stroke happens in the UK roughly every five minutes, around 100,000 people a year (Stroke Association, n.d.). For the minority who receive clot-busting treatment, the acute response is fast: the median time from arrival to thrombolysis in 2024/25 was 56 minutes (SSNAP, 2025). Six months later, only 35.1% of eligible patients received a follow-up review (SSNAP, 2025), and after that the national audit stops counting. There are now 1.4 million stroke survivors in the UK (Stroke Association, n.d.).

SURVIVOR VOICES

"I don't think I got anything via the hospital in terms of emotional support...I don't remember anybody talking to me about what those options are. A lot of people don't have that – they will be struggling with the emotional intensity of the experience and the trauma, and left to work it out yourself."

JONATHAN LEDGER
STROKE SURVIVOR
(personal communication, 11 September 2026)

SECTION 2

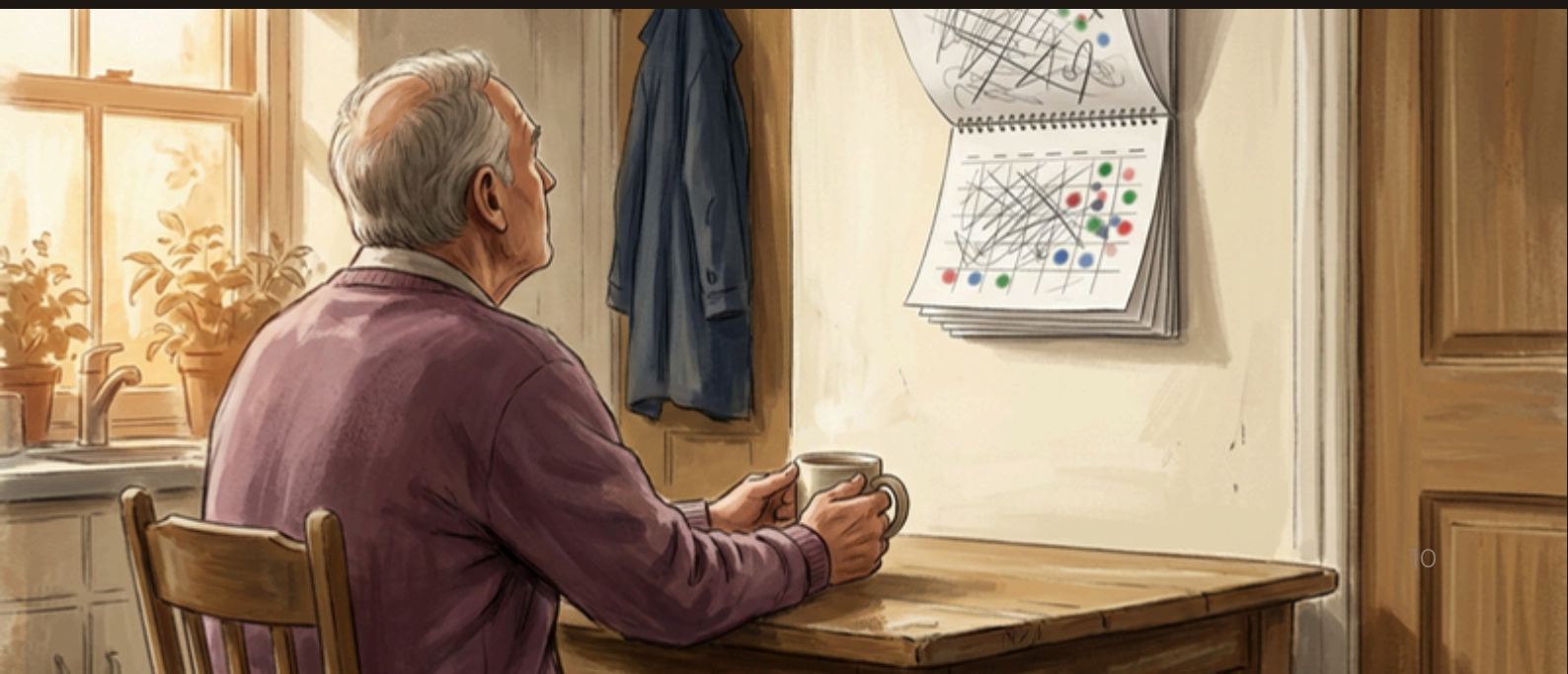
Why the Cliff Exists

The gap in stroke care was not designed to harm anyone. It emerged from three structural decisions made independently, in three different rooms — each defensible on its own terms, devastating in combination. The one person who lived through all three phases of care in sequence, in their own body, was the stroke survivor.

2.1
SSNAP's measurement window ends at six months

2.2
NICE's guideline, NG236, is advisory, not a mandate - and many ICBs are not commissioning against it

2.3
Why the disparity exists: a structural analysis



Three decisions built the cliff. SSNAP's measurement window was set around acute care and ends at six months (2.1). NICE and the Intercollegiate Stroke Working Party published guidance that rejects the plateau, but it is advisory, not a mandate (2.2). And many ICBs have not commissioned community rehabilitation against it, because nothing in their funding, contracts or performance measures requires them to (2.2 and 2.3). None was designed to harm anyone. Each is defensible on its own terms. Together they leave a gap that no single organisation owns.

2.1 SSNAP stops measuring

SSNAP is the closest thing England, Wales, and Northern Ireland have to a national quality framework for stroke care. It audits every stroke admission, tracks what happens in hospital, follows up at six months. Then it stops.

This was not a design flaw. When SSNAP was established in 2012, the focus was acute care — getting patients to the right ward within four hours, administering thrombolysis within sixty minutes, reducing in-hospital mortality. Those are achievable targets with measurable endpoints, and SSNAP has driven significant improvements across all of them. The six-month follow-up was added as a later extension, intended to capture whether the gains made in hospital were holding in the community.

What it cannot capture is what happens after that point. There is no national data point at twelve months. No national data point at two years. No national data point at five. Once a patient exits the SSNAP window, they are, in a data sense, recovered. The system has stopped asking.

The consequence is structural. Commissioners cannot be held accountable for outcomes they are not measuring. Clinicians cannot be resourced to address needs that are not quantified. And the case that post-discharge stroke support is inadequate cannot be sustained with national data, because the national data does not exist. 35.1% of eligible patients received a six-month review in 2024/25 (SSNAP, 2025). This is the limit of the system's understanding.

PHYSIOTHERAPY DELIVERED ON RECOMMENDED DAYS, BY PHASE



CSP/ACPIN WORKFORCE REVIEW, FEBRUARY, 2026; SSNAP STATE OF THE NATION 2025

SECTION 2.2

2.2 NG236 exists - but many commissioners are not acting on it

In October 2023, the National Institute for Health and Care Excellence (NICE, 2023) updated its stroke rehabilitation guidance with Stroke rehabilitation in adults (NG236), which covers rehabilitation from inpatient care through to long-term community support. It followed the Intercollegiate Stroke Working Party's (ISWP, 2023) national clinical guideline, published about six months earlier. Both set out a needs-led approach to rehabilitation that is not tied to a fixed period.

Both guidelines formally repudiate the six-month plateau. They state, explicitly, that stroke survivors should be considered to have the potential to benefit from rehabilitation at any point after their stroke, and that access to community rehabilitation should be based on clinical need and individual goals — not on time elapsed since stroke onset. NG236 sets out what good stroke rehabilitation looks like, including the 6-month and annual reviews. It is guidance rather than a mandate, but it is the standard ICBs are expected to commission against, and the one their performance can be measured against.

The 2023 national guideline recommends that people with motor recovery goals receive a minimum of 3 hours of multidisciplinary therapy a day (ISWP, 2023, p. 65). A national analysis of SSNAP data from July 2013 to July 2015 found that, against a guideline recommendation of at least 45 minutes of each appropriate therapy daily, median therapy delivered was 13.8 minutes of physiotherapy, 12.9 of occupational therapy, 6.7 of speech and language therapy and 1.9 of psychology per day of inpatient stay (Gittins et al., 2020). The strength of England’s acute pathway is emergency treatment; inpatient therapy was already below the guideline standard. After discharge the safety net is thinner still. In 2024/25 only 35.1% of eligible patients received a six-month review, down from 38.8% the year before and part of a decline since 2019/20 (SSNAP, 2025). SSNAP reports that two-thirds of discharges (66.6%) now go to a stroke-specific community rehabilitation service (SSNAP, 2025). That is progress, but it makes the falling review rate more striking, not less.

This is no longer a failure of guidance. NICE guideline NG236 is comprehensive, but it is advisory: it sets the standard commissioners are expected to take into account, not one they are legally bound to meet. What is missing is a way of measuring performance beyond the point where SSNAP stops, at six months. Where no data exists, services cannot be benchmarked and no commissioner can be held to account. Without a measurement framework that extends beyond six months, the standard NG236 sets cannot be monitored.

Integrated Care Boards (ICBs) hold the commissioning budget for community stroke rehabilitation in England. They make funding decisions based on clinical standards, population need, and financial pressure — usually in that order. NG236 specifies post-discharge stroke support. ICBs have a standard to commission against — and many are not commissioning against it.

The result is variation in the most consequential sense. Some ICBs fund community stroke specialist services beyond six months; many do not. SSNAP (2026) documents significant disparity in community rehabilitation provision across English ICBs, but cannot quantify it precisely — because the data required to do so falls outside the SSNAP measurement window.

45 min

median daily therapy time in inpatient stroke units (Gittins et al., 2020)

180 min

minimum multidisciplinary therapy offered per day, for at least five days (NICE, 2023)

35.1%

received their six-month review — down from 38.8%, and falling since 2019/20

SURVIVOR VOICES

"When I got home from hospital, they put in place all this physio, which was great... they used to come three times a week... Having spoken to other survivors, I know I was very lucky."

BETHAN DAVIES
STROKE SURVIVOR
(personal communication, 10 September 2026)

SECTION 2.3

2.3 Why the disparity exists: a structural analysis

2.3.1 How We Got Here: Two Decades of Acute Investment

The concentration of resource, research and clinical attention in acute stroke care is not arbitrary. It reflects a period of genuine and transformative progress. From the early 1990s, thrombolysis and later mechanical thrombectomy offered what stroke care had never previously had: interventions capable of reducing brain injury when delivered rapidly. Research, workforce development and service organisation consequently focused heavily on the acute phase. The London HASU reorganisation, for example, was estimated to save approximately 96 lives annually (Marshall et al., 2022). These demonstrable and measurable improvements inevitably shaped what the system came to recognise as successful stroke care.

However, the success of acute stroke care has not been matched by equivalent investment in what happens after people leave hospital. As the evidence has developed, it has become increasingly clear that survival and neurological recovery are only part of the story. People may return home with cognitive, emotional, physical, vocational and social difficulties that are not always apparent during the acute admission and may only become evident once they resume their lives in the community.

From the frontline, this can be seen in the nature of post-stroke follow-up. Dr Jennifer Crow, a clinical specialist occupational therapist at the National Hospital for Neurology and Neurosurgery and stroke researcher at Imperial College London, argues that the challenge is not that individual professionals do not recognise the importance of rehabilitation, but that different professionals have different roles and expertise, and the current model of follow-up does not always bring those areas of expertise together (J. Crow, personal communication, 28 August 2026).

Medical follow-up appointments are often brief and necessarily focus on medical priorities, including medication, secondary prevention, investigations and neurological status. They are not designed to explore the full range of difficulties that someone may encounter after stroke. Yet people may arrive at these appointments with months of questions about fatigue, cognition, mood, returning to work, relationships, driving, community participation or rehabilitation needs.

The difficulty is what happens when those questions emerge. Few stroke follow-up clinics are genuinely multidisciplinary, and fewer still bring together professionals from acute and

community services. The issue is therefore not about asking one professional group to do more, but about ensuring that the different professionals involved in stroke care can contribute their respective expertise at the appropriate point in a person's recovery.

As Crow puts it: “The guidelines are saying the right thing, but it hasn't translated into who delivers that.” (J. Crow, personal communication, 28 August 2026). The funding and workforce required to deliver personalised and holistic follow-up is currently not in place.

The 2023 National Clinical Guideline (ISWP, 2023) has moved towards a needs-led, time-unlimited model of community rehabilitation. The challenge is translating that ambition into the workforce, funding, commissioning structures and integrated pathways required to deliver it consistently.

What emerges from Crow's account, therefore, is not a story of individual professional failure. It is a structural gap between what people may need after stroke and the way follow-up services are currently organised. Acute stroke care has benefited from sustained investment in interventions, infrastructure and specialist expertise. The next challenge is ensuring that equivalent attention is given to the longer trajectory of recovery, with multidisciplinary services designed around the questions and needs that emerge when people return to their lives in the community.

2.3.2 The Commissioning Mismatch: Why Community Services Remain Under-Resourced

The structural problem in commissioning is one of metrics. NHS commissioning is configured to measure what is measurable in the short term, and community rehabilitation does not fit that template. Its goals are return to work, functional independence and taking part in community life. They show up months or years after the intervention, and much of the benefit lands outside the budget that paid for it (see 2.3.4). A commissioner working to a short-term, single-budget test will always find an acute pot easier to defend than a community one.

This is not a case for abandoning measurement. It is a case for measuring the right things. A twelve-month outcome point covering return to work, functional independence and community participation (see Section 5, The measurement framework) would give commissioners the evidence base rehabilitation currently lacks, in terms they can fund against.

Community services are also paid differently from the rest of the pathway. Acute care runs on a blended payment model — a fixed baseline plus elective activity paid at 100% of national tariff, with Best Practice Tariffs layered on top for defined quality standards — and GP practices receive a substantial share of income through the Quality and Outcomes Framework (QOF), a genuine

pay-for-performance mechanism. Community health services, where stroke rehabilitation is actually delivered, are paid almost entirely through block contracts: a fixed sum "irrespective of how many patients are seen or the quality of care" (Healthcare Financial Management Association [HFMA], 2026). This is not only an underfunding problem but a visibility problem. NHS England's 2025 baseline data-collection exercise found that "the data collected for non-acute services was very limited" (HFMA, 2026), so commissioners often cannot see community activity, let alone outcomes, in the way acute activity is made visible through national tariff data.

HFMA's guidance now points towards moving community and mental health services onto activity- and outcome-linked "currency" models, with reform signalled for 2027/28 onwards (HFMA, 2026). If that transition proceeds, the ask is not to invent a new payment mechanism for community stroke rehabilitation, but to ensure stroke is not left out of it. Because most community rehabilitation is bought through block contracts, closing the gap is a decision about how existing money is commissioned as much as a request for new money. Moving money between services involves real trade-offs for providers, so it is not simple. But it is a solvable administrative and political process, and Section 4 sets out what the evidence does and does not show to guide it.

2.3.3 The Plateau Myth in Practice: Time-Based Commissioning vs. Non-Linear Recovery

The most operationally damaging belief embedded in the NHS stroke pathway is also the most straightforwardly disproved by the science: that meaningful recovery from stroke is essentially complete by six months, and that further intervention is clinically unwarranted.

The 2023 National Clinical Guideline explicitly rejected this. It states clearly that people with stroke should be considered to have the potential to benefit from rehabilitation at any point after their stroke (ISWP, 2023, p. 63), a formal repudiation of the historic six-month horizon. But a guideline and a commissioning contract are different things, and in much of England, the contracts have not followed the science.

Crow identifies the structural root of this disconnect: "The commissioning is time based. And the reality of recovery after stroke is that it doesn't follow a specific timeline, and it really varies for people. Some people can't engage in anything for quite a while, and by the time they can, all the windows have closed and they've got nowhere to go." (J. Crow, personal communication, 28 August 2026).

This is not a problem unique to England. The American stroke rehabilitation guidelines, revised in 2026, also moved toward longer periods of rehabilitation and away from time-bounded models

(Richards et al., 2026). Clinical understanding has shifted too, but Crow suggests that the shift has not yet reached the workforce configurations that determine what patients can actually access.

Fixed-episode models build the same assumption into service design. A service commissioned to offer a set number of sessions, or to review at a set point, treats recovery as something that follows the calendar. The 2023 guideline points the other way: rehabilitation should be led by need, not by time (ISWP, 2023). Crow's account shows what the calendar costs. People who cannot engage early may only be ready once the windows have closed. What the guideline describes, and what Section 5 proposes to commission, is care that can be reopened when a person is ready, without starting again from a fresh referral.

The neuroscience does not support a six-month cut-off for recovery after stroke. Ward sets out what actually changes. Early after stroke there is a period of spontaneous biological recovery, broadly the first few weeks and months, in which people can regain movement or language without being trained at all. That period is real, but it fades. What does not fade is "ordinary" plasticity. After the repair period, recovery depends on learning, which itself depends on plasticity. This requires training that is intensive and task-specific, supervised by someone who knows what to teach, and it can take a person as far as their surviving nervous system allows. Treat the six-month mark as the end of recovery, Ward says, and the system is left with "a kind of illogical circle of ideas": you are on a plateau, so you cannot recover, so why would we treat you? (N. Ward, personal communication, 7 September 2026). His explanation of why rehabilitation sits outside medicine's frame of reference is blunt: "because it's not a tablet and it's not an operation, it's not considered a treatment." That, he says, is why he now deliberately calls what he does treatment rather than therapy (N. Ward, personal communication, 7 September 2026).

The paper reporting the Queen Square programme opens by naming the problem: "There is a nihilistic view about what clinically relevant changes are possible after the early post-stroke phase" (Ward et al., 2019, p. 498). The programme is a single-centre clinical service available to people at any time after their stroke. It delivers 90 hours of timetabled upper limb treatment over three weeks, six hours a day, five days a week, with one member of staff for each patient, and the authors describe it as high-quality, high-dose and high-intensity. Between January 2015 and December 2017, 238 people with stroke were admitted, and 224 of them completed assessments six weeks and six months after the programme. They were a median of 18 months from their stroke on admission (Ward et al., 2019). Ward says patients usually arrive having received no rehabilitation since discharge from the NHS, and often having been told that no further change was possible (N. Ward, personal communication, 19 October 2026). Scores for upper limb impairment and activity, and the patients' own reports, improved by clinically important amounts and continued to improve over the following six months. The median change in the Fugl-Meyer upper limb score was 6 points at discharge and 9 points at six months, and by

by six months 68.3% of patients had gained more than the minimum clinically important difference on that measure (Ward et al., 2019).

The authors are explicit about the limits. This is a report from a clinical service, with no randomisation and no control group, and the assessments were not blinded. The patients were generally younger (median age 52) and more independent than the average person with stroke, and they were not admitted if, for example, they had absent movement throughout the limb, although the authors say the programme has no strict inclusion or exclusion criteria. The programme addresses the upper limb specifically. The authors expect that people this far from their stroke would be unlikely to change across this range of scores without treatment, but say that this requires empirical confirmation. Their conclusion is that the results provide strong justification for trials of much higher doses than stroke survivors are currently offered, even years after their stroke. Current services are not set up to deliver this dose and intensity. Ward argues that positive trials could prompt services to reorganise, much as the advent of thrombolysis led to the formation of hyper-acute stroke centres (N. Ward, personal communication, 19 October 2026). The authors compare the idea behind the programme, that high dose and intensity can lead to large clinical improvements, with what thrombolysis did for acute care: "Post-stroke neurorehabilitation must adopt the same aspirational approach" (Ward et al., 2019, p. 504).

Ward's team is now trying to replicate these results in a randomised controlled trial (N. Ward, personal communication, 12 October 2026). Rehabilitation can be specified, dosed and measured in the terms medicine uses for any other treatment. This programme does not settle what a randomised comparison would find, and its authors say that is the next step. But the barrier to going further is not that rehabilitation cannot be described this way. It is that commissioning has not yet been asked to read it that way.

2.3.4 The Double Standard: Different Rules for Rehabilitation

A final structural barrier lies in the rules by which treatments access funding. New drugs are appraised against a published threshold of £25,000 to £35,000 per QALY (NICE, n.d.-a), and commissioners must fund a positive recommendation within 90 days (NICE, n.d.-b). The test is value for money, and a treatment does not have to save the NHS money to pass it. Stroke thrombolysis entered the NHS this way, and NICE's appraisal found that within three hours of stroke it cost less than standard care as well as improving outcomes (NICE, 2012). Thrombectomy was funded nationally through an NHS England clinical commissioning policy rather than left to local discretion.

Treatments that do not save money are judged on the same terms. New drugs for Alzheimer's disease will not save money, and NICE did not approve lecanemab or donanemab in 2025 because the benefit was too modest to justify the cost. However, manufacturers successfully appealed the rejections, and hearings in January 2026 ultimately sent both drugs back to the appraisal committee for formal reconsideration. While the medications remain under active re-evaluation, they continue to be assessed through a national process with a clear test.

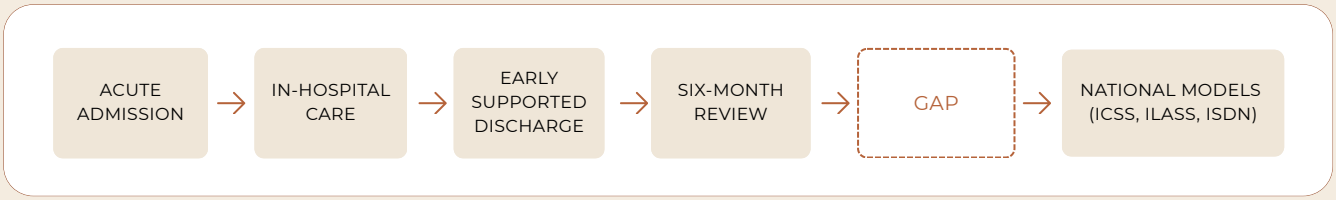
Rehabilitation has no equivalent route. NG236 sets out current evidence for rehabilitation, but it provides guidance rather than a funding mandate, so services depend on local commissioning decisions. They compete for cash-limited local budgets with no national threshold to be appraised against and no deadline by which a positive recommendation must be funded. Ward makes the same comparison with new drugs for Alzheimer's disease, which he says may not save money, and asks: "So why is rehabilitation held to a different account?" (N. Ward, personal communication, 7 September 2026).

Five features of the system make that test hard for rehabilitation to pass.

- **The savings land elsewhere.** About 79% of the modelled cost of stroke sits outside the NHS healthcare budget, derived from Stroke Association (2026). A commissioner who pays for rehabilitation may see the benefit, such as fewer care home placements and smaller social care packages, in a council's budget, not their own. Action 03 pools funding with local authorities for this reason.
- **Acute care wins the competition for funds.** Boards facing immediate pressure on emergency and elective targets fund the visible acute service first, and the returns on rehabilitation arrive over months or years (see 2.3.1) (HFMA, 2026).
- **The staff are not there.** In community stroke services, there are 26% fewer registered physiotherapists and 36% fewer physiotherapy support workers than the guidance requires (Chartered Society of Physiotherapy & Association of Chartered Physiotherapists in Neurology, 2026; survey of 159 services, December 2024 to January 2025). A commissioner cannot buy a service that cannot be staffed.
- **Commissioning is fragmented.** Since responsibility moved to Integrated Care Boards, what gets funded varies by area (see 2.2). For smaller commissioning bodies, managing the specialised expertise and risk-pooling required for complex neurological care can present distinct structural challenges.
- **The returns cannot be shown.** It is easy to track the cost and discharge date of an acute inpatient. It is much harder to track a survivor's progress across six-month reviews and community visits, so community teams struggle to evidence the return on investment commissioners ask for. SSNAP stops at six months and holds no national data beyond it (HQIP, 2022/2023). This is why SSNAP should collect longer-term recovery outcome data, and why Action 01 extends follow-up to 12 months.

The cost of stroke is already large, and most of it falls outside the NHS budget that would pay to reduce it. The Stroke Association's 2026 economic model puts it at £25.71 billion in 2025 for people aged 16 and over, in 2025 prices (Stroke Association, 2026). But the model prices current provision, not need, so the cost of failing to rehabilitate survivors, in lost employment, care dependency and worsening mental health, is rarely modelled for the commissioners deciding what to fund (Lane Clark & Peacock, 2026). Acute care ensures survivors live. Rehabilitation determines how they live. The system funds the first through a national mechanism and leaves the second to local discretion.

What SSNAP measures — and when it stops



WHAT NG236 RECOMMENDS

NG236 recommends needs-based, multidisciplinary rehabilitation totalling at least 3 hours a day, on at least 5 days a week (up from the 45 minutes of each therapy used as the benchmark in Gittins et al. (2020)).

It also recommends early supported discharge, and care and rehabilitation continuing after hospital for as long as they help people meet their goals. NG236 also refers to a six-month stroke review, at which fatigue should be assessed.

(NICE, 2023)

WHAT THE NATIONAL AUDIT SHOWS

35.1% of eligible patients received a six-month review, down from 38.8%

2 in 3 of discharges went to a stroke- or neurology-specific community rehabilitation service.

6 mo SSNAP's follow-up ends. No national data beyond this point.

(SSNAP, 2025)

INPATIENT THERAPY DELIVERED

Median minutes of therapy per inpatient day (SSNAP inpatient data from 2013 to 2015)

13.8	12.9	6.7	1.9
PHYSIOTHERAPY	OCCUPATIONAL THERAPY	SPEECH AND LANGUAGE THERAPY	PSYCHOLOGY

(Gittins et al., 2020)

WHAT 20 STROKE SURVIVORS TOLD US

Survey conducted August - September 2026. Non-probability convenience sample of 20 stroke survivors - see Methodology.

12 in 20 received no discharge or care plan from the NHS



14 in 20 described post-discharge support as 'little' or 'nothing'



18 in 20 sought additional support from charities, private providers, or personal networks after NHS services ended



9 in 19 either paid out-of-pocket for care they needed, or went without it entirely



TOP ONGOING NEEDS REPORTED

% of 20 survey participants

55%	50%	40%	35%
PHYSIOTHERAPY	MENTAL HEALTH SUPPORT	INFORMATION & GUIDANCE	FATIGUE MANAGEMENT

SURVIVOR VOICES

"My memory of it is that basically when you discharge, you just get pushed off a cliff and left to get on with things. It might have been a minor stroke in someone's opinion, but to me it was massive."

STEPHEN RIMMER
STROKE SURVIVOR
(personal communication, 10 September 2026)

"I felt dropped – discharged off the books to meet timelines."

MARK A.
STROKE SURVIVOR
(Kuzalti, 2026)

"Once that timeline was reached all NHS OT and physio was withdrawn, it was up to me on how to find and resource ongoing physio. Patchy post stroke support from local stroke nurse, she visited once — she left a pamphlet and I never saw her again."

ADRIAN D.
STROKE SURVIVOR
(Kuzalti, 2026)

SECTION 3

What the Six-Month Cliff Costs

"The six-month cliff is not only a clinical failure. It is a fiscal one. Stroke already costs the UK £25.7 billion a year, and most of that falls outside the NHS budget that would pay to reduce it."

UK COST OF STROKE
(Stroke Association, 2026)

£25.7 billion
2025, modelled

£35.9 billion
2035, projected



SECTION 3

3.1 Where the costs sit

UK 2025 modelled costs (billions)

Aged 16 and over, 2025 prices

£25.71



(Stroke Association, 2026)

01 — SOCIAL CARE

£13.72 The largest cost. £13.22 billion arises after the first year. It is not an NHS cost.

02 — UNPAID CARE AND PRODUCTION

£5.69 Lost household, children, and caring time (£5.07 billion) plus informal care (£0.62 billion). Outside every NHS budget.

03 — NHS HEALTHCARE

£5.34 The only component that falls on the NHS budgets. £3.41 billion of it arises after the first year.

04 — LOST PRODUCTIVITY

£0.95 The smallest modelled component. About 1 in 4 strokes occurs in working-age adults (Stroke Association, 2025).

05 — NOT CAPTURED fiscal cost, outside the total

£2.36 Welfare and lost tax (£2.36 billion) are reported separately. Not costed: what rehabilitation would save, and who pays for the social care (Lane Clark & Peacock, 2026)

SURVIVOR VOICES

"The NHS feel like there's a plateau after six months... but the DWP believe you get better because they want to stop your benefits. The system wants to have its cake and eat it too."

STEPHEN RIMMER
STROKE SURVIVOR
(personal communication, 10 September 2026)

SECTION 3.2

3.2 What the model shows

The Stroke Association commissioned Lane Clark & Peacock LLP (LCP) to model the economic cost of stroke in the UK. It puts the cost at £25.71 billion in 2025, rising to £35.86 billion by 2035, for people aged 16 and over, in 2025 prices (Stroke Association, 2026; Lane Clark & Peacock, 2026). Of the 2025 total, £19.06 billion is NHS and social care cost and £6.65 billion is wider societal cost. Welfare payments and lost tax, a further £2.36 billion, are reported separately and are not in the total. These are modelled estimates, not official statistics. The model replaces earlier projections by King et al. (2020), which put the cost at £42.6 billion for 2025 and £75.2 billion for 2035 in 2015 prices. The new estimate is lower partly because observed incidence in 2025 (105,490 strokes) was well below King's projection (148,700 for people aged 45 and over), partly because the model holds unit costs constant in real terms instead of raising them 2% a year, and partly because it values unpaid care differently. The 2035 figure assumes no change in treatment, policy or investment. Because it is in 2025 prices, it can be set against today's budgets.

Social care is the largest cost, and most cost arises after the first year

Social care accounts for £13.72 billion of the £25.71 billion in 2025, about 53%. Unpaid production and informal care come to £5.69 billion (22%), NHS healthcare to £5.34 billion (21%) and lost paid productivity to £0.95 billion (4%) (Stroke Association, 2026). Most of the NHS and social care cost arises after the first year: £2.43 billion falls in the first year after a stroke, against £16.63 billion a year for the 1.4 million people living with its effects, which is 87% of NHS and social care cost (Stroke Association, 2026). Social care alone is 72% of NHS and social care cost (calculated as 13.72 / 19.06). The unpaid component is a value, not money spent. It is the modelled loss of time spent on household work, childcare and caring, measured against a no-stroke baseline and valued at the average net wage, so the cost sits with families before it reaches any budget. Estimates of unpaid care depend heavily on method: King et al. (2020) valued it at £15.6 billion in 2015. Only £5.34 billion of the £25.71 billion falls on NHS healthcare budgets, so about 79% of the modelled cost sits outside them (calculated as 1 − 5.34 / 25.71).

The model does not trace where cost moves when a family can no longer sustain the load. It is reasonable to expect that it moves to councils as social care, to DWP as benefits and to GP practices as unplanned demand, but no source in this report shows that. The household end is better documented. In a survey of 1,251 survivors one to five years after stroke, 52% reported reduced or lost work activity, 18% a loss of income and 31% increased expenses (McKevitt et al., 2011).

Among the 20 survivors who completed this report's survey, 18 sought support from charities, private providers or personal networks after NHS services ended. Of those who said how they paid for it, 9 of 19 paid out of pocket or went without. The sample is self-selected, so this shows that the cost is reaching households, not how often (Kuzalti, 2026).

SURVIVOR VOICES

"That was the only way I was going to get any result out of this was to pay for it."

MARTYN HOROBIN
STROKE SURVIVOR
(personal communication, 14 September 2026)

"I needed to find support from a private speech therapist for at least six additional months...therapy was rationed. I did not find any support for acalculia and had to work out my own recovery independently."

COLIN JENKINSON
STROKE SURVIVOR
(personal communication, 10 September 2026)

3.3 Work, recurrence, and what the model cannot show

About one in four strokes occurs in working-age adults (Stroke Association, 2025). Lost paid productivity is the smallest modelled component, £0.95 billion in 2025. Welfare payments and lost tax and National Insurance, £2.36 billion, are reported separately (Stroke Association, 2026). Whether rehabilitation improves return to work is not settled: the largest UK trial found no significant difference at 12 months (64.2% v 59.4%; Radford et al., 2025), as Section 4.3 explains.

Stroke recurrence adds to the bill. A meta-analysis found cumulative recurrence of 11.1% at one year and 26.4% at five years, falling to 16.2% in more recent studies (Mohan et al., 2011). Yet only 35.1% of eligible survivors received the recommended six-month review in 2024/25, down from 38.8% the year before (SSNAP, 2025). The long-term costs of spasticity and cognitive impairment, which a six-month review can miss, are covered in Section 4. They are not itemised in the 2026 model, so this report does not put a figure on them.

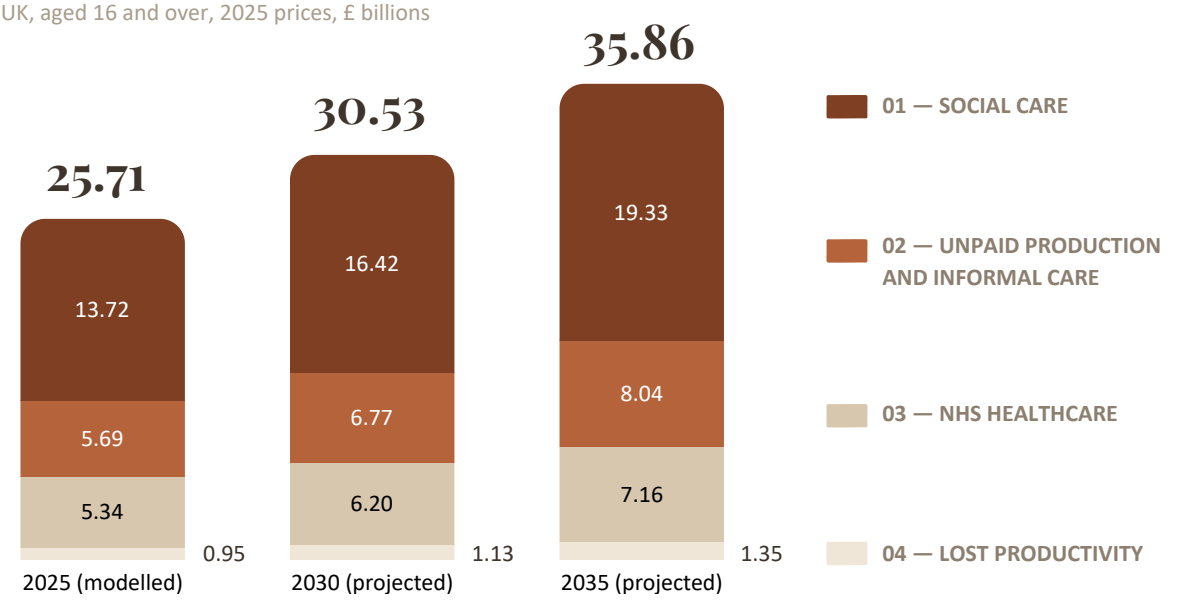
The model estimates cost in aggregate. It prices current provision, not need, and assumes that after the first year people use the same services as in the first year, so it cannot show what the six-month cliff costs or what better rehabilitation would save (Lane Clark & Peacock, 2026). The Stroke Association calls £25.7 billion "the lowest defensible estimate" (Stroke Association, 2026, p. 4). The model could not identify how much social care is self-funded, reflects depression only through quality of life, excludes children, and tests uncertainty one input at a time, without a range around the total. That is why Section 5 proposes a bounded pilot that measures these costs, and does not claim a saving.

3.4 The structural problem

The estimate exists. The difficulty is that about 79% sits outside the NHS healthcare budget that would pay for the fix. You cannot commission against costs you do not count, and the costs that are counted fall mostly on families and councils, not on the budget holder. Section 5 starts from redirected money, not new money, and pools it so that social care and carer savings count in the same business case.

What the 2026 Stroke Association model includes

UK, aged 16 and over, 2025 prices, £ billions



(Stroke Association, 2026)

Fiscal costs (welfare payments and lost tax) are reported separately and are not included: £2.36 billion in 2025 and £2.88 billion in 2035. Unpaid production and informal care are combined. Figures may not sum because of rounding (Stroke Association, 2026; Lane Clark & Peacock, 2026, Table 27)

What the model does not fully capture:

- **Mental health:** depression is reflected only through quality of life, not costed separately
- Recurrent stroke after the first year, and the return on rehabilitation and life after stroke support
- **Who pays for social care:** self-funded care and out-of-pocket spending are not separated or counted
- **Carer's own costs:** informal care is valued as hours of care at net pay, estimated from the survivor's quality of life. The carer's own lost earnings, health, and wellbeing are not separately costed

SECTION 4

The evidence already exists

“The evidence for what to measure and what to test already exists. What does not exist is a commissioned pathway to act on it.”

4.1
Cognition: the six-month review cannot see what it does not measure (IC3)

4.2
Spasticity: a common condition with a large treatment gap (EPITOME and related data)

4.3
Vocational rehabilitation: what RETAKE does and does not show

4.4
International evidence: a time-limited episode, a guaranteed way back, and a named contact



SECTION 4.1

4.1 Cognition: the six-month review cannot see what it does not measure (IC3)

IC3 is a remote digital cognitive battery of 22 tasks developed at Imperial College Healthcare NHS Trust. It was validated against 6,364 healthy UK adults and published in peer-reviewed form (Gruia et al., 2025). The author is a Lay Research Stakeholder on the programme and cites it here as a tool stalled inside the NHS, not as personal testimony.

The Montreal Cognitive Assessment (MoCA) is the most widely used cognitive screen in NHS stroke pathways. In the validation data, patients scoring as unimpaired on the MoCA (26 or above out of 30) were still found to be impaired on a subset of IC3 tasks, at a mean rate of 30.2% (range 4%–54%), and IC3's global score correlated more strongly with everyday function (r = 0.51) than the MoCA did (r = 0.38) (Gruia et al., 2025). In other words, some of the people discharged as cognitively recovered are not, and the current pathway has no routine way to find out.

What this shows:

a measurement gap that a six-month review could close.

What this does not show:

that cognitive rehabilitation after six months improves outcomes. The validation sample of stroke patients was small (90), and most were assessed in the acute phase, so IC3 is evidence about detection, not about treatment effect. The barrier is adoption, not evidence. No NICE guideline references IC3, no SSNAP metric uses it, and no ICB has a framework to commission it. The structural reasons are not mysterious. They are the same ones this report was written to address.

4.2 Spasticity: a common condition with a large treatment gap (EPITOME and related data)

Interim analysis from EPITOME, an international observational study sponsored by Ipsen, found that 45.7% (69 of 151) of survivors with paresis had clinically confirmed spasticity within three months of stroke (Zorowitz et al., 2026, study protocol in Zorowitz et al., 2025). "Confirmed" here means any increase in muscle tone on the Modified Ashworth Scale, not necessarily problematic spasticity needing treatment.

Two points matter for the six-month argument. First, spasticity is already present at the point the pathway steps back, so a six-month review is the last natural checkpoint to find it, not an early one. Second, it persists: a meta-analysis of 23 cohort studies (6,956 participants) put prevalence at 24.2% beyond six months, and 39.5% in first-ever stroke with paresis (Zeng et al., 2021).

The treatment gap is documented in registry and claims data, not in EPITOME. In French national data covering 287,370 survivors, 13.1% were coded with spasticity and only 2.8% of those received botulinum toxin A (Bensmail et al., 2025). A US claims study found 0.8% of all first-stroke patients received it (Hull et al., 2025). The aforementioned studies and EPITOME all involve Ipsen, the manufacturer of botulinum toxin A. There is no equivalent England figure, which is itself a finding.

What this shows:

a common, persistent, treatable condition that a time-limited pathway is not designed to catch.

What this does not show:

England treatment rates, or the effect of earlier detection on outcomes. An England audit linked to SSNAP would close the first gap.

4.3 Vocational rehabilitation: what RETAKE does and does not show

The case that rehabilitation remains worthwhile beyond six months does not rest on RETAKE. The ISWP (2023) national guideline states that people with stroke "should be considered to have the potential to benefit from rehabilitation at any point after their stroke", a position that is difficult to reconcile with a fixed six-month cut-off.

RETAKE tested something different: early specialist vocational rehabilitation. This pragmatic, multicentre trial randomised 583 adults who were in work at the time of their stroke, within 12 weeks of onset (median 28 days), to early stroke specialist vocational rehabilitation or usual care. The intervention was delivered by specialist occupational therapists for up to 12 months, and participants attended a median of seven sessions. At 12 months, 64.2% (165/257) of the intervention group had returned to work, against 59.4% (117/197) of the usual-care group (adjusted odds ratio 1.12, 95% CI 0.75–1.68; Radford et al., 2025). Usual-care participants reported better functional ability on one measure (NEADL, mean difference −3.37, 95% CI −6.26 to −0.48; Radford et al., 2025).

What this shows:

in this trial, early specialist vocational rehabilitation did not significantly improve return to work at 12 months. The confidence interval is wide, so the result does not rule out a modest benefit, and it should be cited as a null finding, not as proof of ineffectiveness.

What this does not show:

anything about rehabilitation beyond six months, because participants were recruited early. RETAKE also did not test whether vocational support offered later, or alongside rehabilitation aimed at impairments such as cognition, language and movement, would perform differently.

RETAKE is not evidence that rehabilitation fails. The implication is for the design of the next trial, not against rehabilitation. A bounded pilot could test vocational support offered later and alongside impairment-focused rehabilitation, with return to work at twelve months as the outcome.

4.4 International evidence

No comparator country has solved the problem this report describes. Canada's own guidance acknowledges it: publicly funded Canadian systems "tend to allow for stroke rehabilitation within the first six months following stroke onset, even though many individuals with stroke will require some of these services beyond that arbitrary time frame" (Heart & Stroke Foundation of Canada, 2025, p. 7). What the comparators offer is specific mechanisms, each of which can be examined on its own terms.

Ontario: a time-limited episode, a guaranteed way back, and a named contact

CorHealth Ontario (2022) model of care specifies:

- first contact within 48 hours of discharge from acute care and within 72 hours of discharge from inpatient rehabilitation;
- a core team that includes a dedicated stroke care coordinator or navigator;
- programmes of about 8–12 weeks on average, at a frequency set by the person's needs and goals;
- re-entry to the programme for people who meet eligibility criteria up to one year after discharge from it, with referrals accepted from primary care;
- follow-up at 6 months and 1 year, to be considered where the person consents in advance.

The outcome evidence is a retrospective cohort of 794 clients of Ontario community stroke rehabilitation teams (Allen et al., 2014). Clients showed statistically significant improvement in functional independence, in Stroke Impact Scale domains including communication, activities of daily living and social participation, and in anxiety, community reintegration and caregiver outcomes, assessed up to six months after discharge. There was no control group.

What this shows:

three mechanisms that this report argues are not commissioned as standard in the English pathway (a named contact, a defined way back in, and scheduled contact after discharge) exist in publicly funded systems, and outcomes in that system are consistent with benefit.

What this does not show:

causation, or an unlimited time ceiling. Ontario's programmes are time-limited, and the principle that rehabilitation can benefit people at any point rests on the UK guideline quoted in Section 4.3 not on Ontario's model.

Sweden: a longer measurement window

Sweden's national stroke register, Riksstroke, collects follow-up data at three months and again at twelve months after stroke (Riksstroke, 2025). In England, SSNAP's final routine checkpoint is the six-month review, which only 35.1% of eligible survivors received in 2024/25 (SSNAP, 2025). No national measurement point exists beyond six months.

What this shows:

a comparable national register can carry a twelve-month follow-up point as routine. Whether SSNAP could do the same is a design question for its owners, and the Swedish example shows it is not an unusual one.

What this does not show:

that the twelve-month data have improved outcomes or changed commissioning decisions in Sweden. This report has not examined Swedish outcomes.

Singapore: recent national guidance and pilot of coordinated care

Singapore published its Stroke Rehabilitation Guideline in April 2026, developed by the Agency for Care Effectiveness as an adaptation of the Australian and New Zealand living clinical guidelines for stroke management (Agency for Care Effectiveness, 2026). The SLS CHARTER model, evaluated in a prospective, non-randomised case-control study at a single hospital (206 intervention and 55 control participants, six-month follow-up), used two care coordinators to support early engagement and a self-monitoring checklist. Checklist use rose from 50.5% at one month to 86.9% at six months, and the intervention group made fewer day-care visits. There was no difference in emergency visits or readmissions, and return-to-work rates were similar between groups (about 58% and 54%) (Wei et al., 2025).

What this shows:

a high-income health system has recently moved to national rehabilitation guidance and has piloted a named-coordinator model, which is directional evidence of where other systems are heading.

What this does not show:

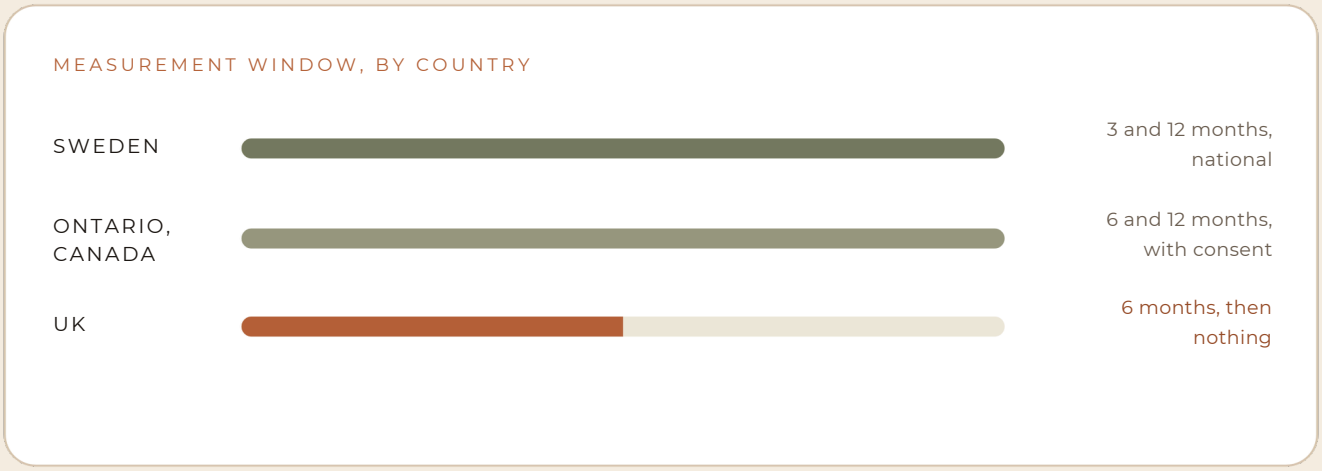
that coordination improves clinical or employment outcomes. The study was small, non-randomised and single-site, and the outcomes that did not differ include return to work.

Europe: guideline evidence for rehabilitation after six months

At European level, the ESO motor rehabilitation guideline (Alt Murphy et al., 2025) recommends high-intensity walking training in the chronic stage of stroke. The guideline gives a strong recommendation, based on moderate-certainty evidence, for high-intensity walking training in the chronic stage, which in the included trials meant more than six months after stroke. People trained this way walked 39 metres further on the six-minute walk test (95% CI 20 to 58; Alt Murphy et al., 2025). What this does not show: that every survivor benefits, since participants walked unassisted and had stable cardiovascular status, or what upper-limb dose works in the chronic stage, which the guideline calls "less clear".

What the international comparators add up to

These comparators do not show one country that has closed the gap. They show three separate design choices that England's pathway currently lacks or does not measure: a named contact and a defined way back in (Ontario), a longer measurement window (Sweden), and a piloted named-coordinator model (Singapore). None is evidence of causation, and none removes the need for an England test. They are the basis for the bounded pilot proposed in the recommendations.



EVIDENCE INVENTORY

What exists, where it stands, and what blocks it

STUDY	WHAT IT SHOWS	WHAT IT DOES NOT SHOW	ENGLAND STATUS	BARRIERS TO ADOPTION
(Gruia et al., 2025)	Remote digital cognitive battery validated against 6,364 healthy adults. Patients scoring as unimpaired on MoCA (26 or above) were still impaired on some IC3 tasks. The global score correlated more strongly with everyday function than MoCA did (r = 0.51 v 0.38)	Treatment effect. Performance beyond the acute phase (90 stroke patients, most assessed acutely)	Published (2025); not adopted into NHS pathways	No NICE reference, SSNAP metric or ICB commissioning framework
(Zorowitz et al., 2026; Zeng et al., 2021)	45.7% (69/151) of survivors with paresis had confirmed spasticity within 3 months. Prevalence was 24.2% beyond 6 months (meta-analysis of 23 cohorts, 6,956 participants)	England treatment rates. Treatment effect. EPITOME is interim and Ipsen-sponsored.	EPITOME ongoing; England included in the protocol	No post-discharge step to screen or refer
(Bensmail et al., 2025; Hull et al., 2025)	France: of 287,370 survivors, 13.1% were coded with spasticity and 2.8% of those received at least one injection. US claims: 0.8% of all first-stroke patients received it	England data. Both studies are Ipsen-funded or Ipsen-linked, and both use administrative data	No England equivalent figure identified	No England audit or SSNAP-linked data
(Radford et al., 2025)	Return to work 64.2% v 59.4% at 12 months, not significant (adjusted OR 1.12, 95% CI 0.75–1.68). Usual care scored better on one functional measure	Anything about rehabilitation beyond six months (recruited within 12 weeks). Whether later or bundled vocational support differs	Published 2025; null result	Open question for trial or pilot design, not a commissioning barrier
(Alt Murphy et al., 2025)	Strong recommendation (moderate evidence) for high-intensity walking training in the chronic stage (more than 6 months in the included trials). 39 metres further on the six-minute walk test (95% CI 20–58)	That every survivor benefits (participants walked unassisted, with stable cardiovascular status). Upper-limb dose in the chronic stage ("less clear")	European guideline; UK adoption not examined	Guideline notes cardiovascular testing can be a barrier

EVIDENCE INVENTORY: CONTINUED

STUDY	WHAT IT SHOWS	WHAT IT DOES NOT SHOW	ENGLAND STATUS	BARRIERS TO ADOPTION
(ISWP, 2023)	"Potential to benefit from rehabilitation at any point after their stroke." Needs-led community rehabilitation; re-access when needs arise; reviews at 6 and 12 months, then annually	Delivery or funding. It is guidance, not a funded standard	Published 2023; not commissioned against by many ICBs	No SSNAP accountability beyond six months; 35.1% six-month review rate in 2024/25
(CorHealth Ontario, 2022); (Allen et al., 2014)	48/72-hour first contact; dedicated coordinator; programmes of 8–12 weeks; re-entry up to one year after discharge; optional 6- and 12-month follow-up. Cohort of 794 improved significantly (uncontrolled)	Causation. An unlimited time ceiling	No equivalent defined re-entry or coordinator role in the commissioned pathway	Needs a commissioning standard and a named role
(Heart & Stroke Foundation of Canada, 2025)	Acknowledges that Canadian systems "tend to allow" rehabilitation in the first six months, though many need more	A time-unlimited standard (no such recommendation found)	Not applicable	Not applicable
(Riksstroke, 2025)	National register collects follow-up at 3 and 12 months	Effect of the 12-month data on outcomes or commissioning	SSNAP's final routine checkpoint is 6 months	No national measurement point beyond six months
(ACE guideline, Apr 2026; SLS CHARTER, 2025)	National guidance adapted from the Australian and New Zealand living guidelines. Coordinator pilot (261 participants, non-randomised, single site): checklist use rose and day-care visits fell	Improved in emergency visits, readmissions or return to work (no difference)	Directional evidence only	None claimed

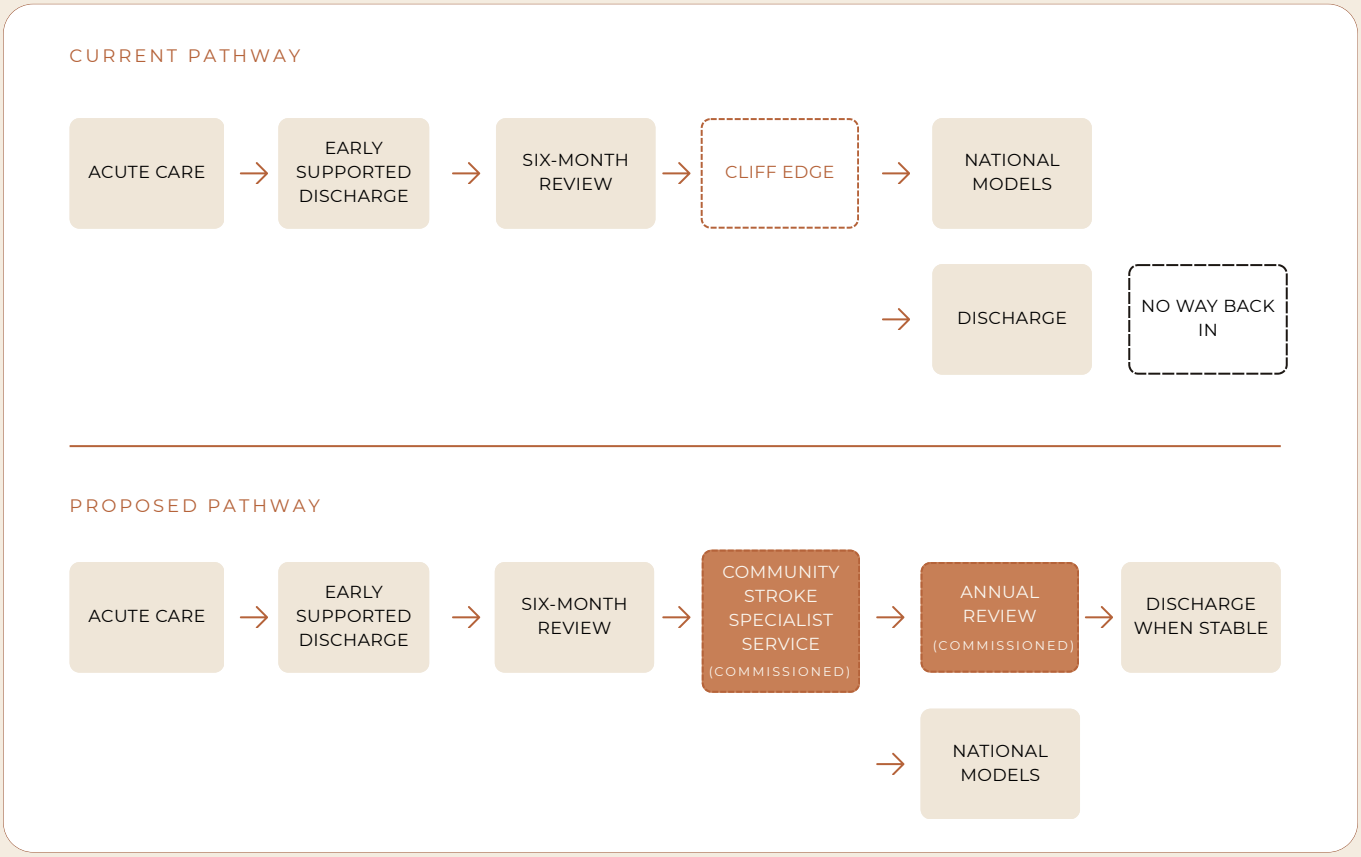
SECTION 5

What a second pathway looks like

“England does not need to invent a second stroke pathway. It needs to commission the one that already exists, with the carer and a way back in, built in.”



5.1 The six-month review becomes a gateway, not an exit



ACUTE CARE

Commissioned by ICBs. SSNAP-measured. Delivered in hospital. No change required.

EARLY SUPPORTED DISCHARGE

Commissioned. NICE NG236-specific. Extend, don't replace.

SIX-MONTH REVIEW

The current SSNAP endpoint, reached today by 35.1% of eligible survivors (SSNAP, 2025). In the second pathway it is offered to every survivor and, separately, to their carer. It becomes the gateway to the second pathway, not the exit from it, and it can reopen rehabilitation, not only record decline.

COMMUNITY STROKE SPECIALIST SERVICE (COMMISSIONED)

Interprofessional team: physiotherapy, occupational therapy, speech and language therapy, psychology access and a stroke coordinator. Referral from GP, acute team or self. Goal-based rehabilitation in time-limited blocks; carers get training, information and peer support; one named coordinator throughout, with a planned, announced handover if they change. Measured by patient-reported outcomes, readmissions, return to work and caregiver strain.

ANNUAL REVIEW (COMMISSIONED)

Recommended in guidance, but not commissioned or measured today. Extended SSNAP window. Flags deterioration, spasticity emergence, cognitive decline, secondary prevention gaps.

DISCHARGE WHEN STABLE

Clinical decision, not a calendar. Explicit re-entry pathway retained.

SECTION 5.2

5.2 Borrowing the architecture

The NHS does not have to invent the second pathway. It has built its components before: twice in stroke and adjacent care, and once in another country's stroke system.

Early Supported Discharge (ESD) is specified in the 2023 national guideline and shows that intensive, interprofessional stroke rehabilitation, at inpatient standard but at home, can be delivered in the NHS (NICE, 2023). ESD is time-limited and often falls short of the intensity it is designed for (SSNAP, 2025). So what ESD proves is not that it should run longer. It proves that this standard of care is achievable in the community at all. The second pathway asks for needs-led rehabilitation that continues for as long as the person is still improving, at the intensity ESD shows is possible, and ends when progress levels off, not after a set number of weeks.

Cancer survivorship is the second precedent. NHS England and NHS Improvement's (2020) Personalised Stratified Follow Up (PSFU) pathways move people from routine clinical review to supported self-management after treatment. Under this model, "a person is not 'discharged' and can still access care from their hospital team" and can "call their cancer team with any concerns, and immediately be recalled to clinic depending on the situation" (NHS England and NHS Improvement, 2020, p. 13). Every patient is offered personalised care and support planning, and the GP is told how to contact the cancer team. That model is not unlimited care. It is structured, proportionate and clinically governed, with each trust responsible for the safety of its protocols (NHS England and NHS Improvement, 2020). The stroke pathway borrows the same logic: not everyone needs the same support beyond six months, but everyone needs an assessed plan, a named contact and a route back in.

Ontario supplies the feature England lacks: a defined way back in. Its programmes run for roughly 8 to 12 weeks, accept referrals from primary care as well as hospital, and allow re-entry for up to one year after programme discharge for people who still meet eligibility criteria (CorHealth Ontario, 2022). Section 4 sets out what that evidence does and does not show. The 12-month window is a starting point for the pilot to test, not a proven interval.

SECTION 5.3

5.3 The commissioning trigger

The principle is already accepted. The 2023 national guideline says people with stroke should be considered to have the potential to benefit from rehabilitation at any point after their stroke (ISWP, 2023), and NICE NG236 sets out what community rehabilitation should include. But NICE guidance is advisory. What does not yet exist is a mechanism that makes it count. There are three asks plus co-design (action 4), each with an owner. SSNAP moves first, NICE's work runs alongside it, and the ICB pilot builds on both.

1. **SSNAP, first.** Extend the audit's follow-up to 12 months. This is a decision for the Healthcare Quality Improvement Partnership and NHS England as SSNAP's commissioners, working with the team at King's College London that runs the audit. It is the smallest of the three steps, a variation to an existing contract rather than a new programme, and it gives the first national data on what happens after the six-month review.
2. **NICE, alongside.** Start now on updating NICE Quality Standard QS2 (NICE, 2016) to cover the community components, so ICBs can be benchmarked rather than encouraged, and test benchmarks against SSNAP's 12-month data when they exist. Those benchmarks will need an outcome measure suited to rehabilitation: the modified Rankin Scale alone, which grades outcome from no symptoms to death, is too coarse.
3. **ICBs, next.** Commission community stroke rehabilitation as the guideline describes it, report on it, and run the bounded pilot set out below. Without SSNAP data, ICBs have nothing to be held to.

5.4 The measurement framework

Two decisions, on two timescales, kept separate.

Near term: extend SSNAP's follow-up from six to twelve months. This is a data-collection and reporting change, and it should be costed and owned as an extension of SSNAP's existing commissioning, with NHS England and HQIP as owners, not left as an unattributed cost. SSNAP is commissioned by HQIP and delivered by King's College London, under a contract won in competitive tender in March 2023. The base contract is worth £2.28m over three years from April 2023, about £760,000 a year, with an option to extend by up to two years at the same annual rate. On those dates the three-year base term ended in April 2026, so a change of scope would be made under the extension option, which runs to April 2028 at most. Whether the specification can be varied within that option depends on the contract's terms, which this report has not seen. HQIP would need to confirm that. The tender also reserved up to £1m for changes of scope, such as new data sources (Healthcare Quality Improvement Partnership [HQIP], 2022, 2023). A 12-month data point could be handled as a variation of that kind. Its price is not published and is to be agreed with the SSNAP team and HQIP. It matters because commissioning tends to follow what is measured, and services that fall outside the audit's window are easier to deprioritise. Riksstroke, Sweden's national register, follows survivors at three and twelve months, so time-based national follow-up is workable. It is a precedent for this step only.

A second dependency is data capture. SSNAP's six-month data come from a review that only 35.1% of eligible survivors received in 2024/25. A twelve-month field collected through the same route would at first describe mostly the same minority, and would say least about the survivors this report is most concerned with. The extension therefore needs a way to record the twelve-month position for people who were not reviewed at six months, for example a short patient-reported outcome collected online. How to do that is a design question for HQIP and the SSNAP team. The first twelve-month dataset should also report how many survivors it could not reach, so that coverage is measured as well as outcome.

A separate question is whether the twelve-month data point triggers a clinical contact (someone sees the survivor) or is only a reporting field (someone records that a review took place). A clinical contact is a workforce and funding decision distinct from the audit extension. It should be named and costed as its own decision, not bundled into the first.

Destination: readiness, not a calendar. The long-term position of this report is that re-access and continued rehabilitation should depend on whether a person is still making functional gains, not on whether a date has passed. In the pathway, readiness means goals met, or a functional reassessment showing no further gain. This model rests on the principle in the 2023 national guideline that people can benefit from rehabilitation at any point after stroke, and on the accounts of clinicians and survivors in this report. No international audit, Riksstroke included, tests it, and no England trial yet does. That is why it is proposed as a bounded pilot first.

What the pilot measures. The pilot should report survivors and carers separately, and distinguish process from outcome.

Process: time to first contact (target 72 hours), time to re-entry once requested, and whether each handover of coordinator was announced in advance.

Outcome: goals met, patient-reported outcomes, return to work, readmissions, and caregiver strain at 12 months, measured with a validated carer-strain tool and the carer assessment the Care Act 2014 already provides.

5.5 The workforce

The second pathway does not need a new clinical profession. It needs a new role within the existing workforce: the stroke care coordinator. This is one named person who stays with the survivor and carer across the transitions between hospital, home and community, runs the reviews, keeps the route back in open, and coordinates between the GP, community therapy and specialist services. The architecture is familiar. Ontario's model of care includes a dedicated stroke care coordinator or navigator (CorHealth Ontario, 2022). England's ESD teams already have key workers, and cancer pathways have clinical nurse specialists (CNS). What the role needs is to be specified, funded and protected.

A coordinator is one named person at every stage. If the coordinator changes, the survivor and carer are told in advance and introduced to the new coordinator.

Where the coordinator comes from. Three routes could supply the role, and the pilot should name the one it uses and cost it. The first two use existing workforce. The third is untested.

- **Extend the early supported discharge key-worker role.** Early supported discharge is specified in NG236 (NICE, 2023). Extending its key-worker post beyond the early discharge period would mean the same type of post follows the survivor into the community.
- **Give a community therapist protected coordination time.** The time would be backfilled so that coordination does not displace treatment. This mirrors the dedicated coordinator or navigator in Ontario's community stroke model (CorHealth Ontario, 2022).
- **Test a primary care network (PCN) hosting the role.** Where the commissioner agrees, a PCN could employ or host a stroke-focused care coordinator through the Additional Roles Reimbursement Scheme (ARRS). NHS England (2026b) says PCNs can recruit a broader range of ARRS roles where agreed with the commissioner, and the contract specification allows additional roles to be employed by another body such as a Trust, local authority or voluntary sector provider (NHS England, 2026a). The role must be additional to existing staff and is paid from the PCN's capped allocation (NHS England, 2026a). Whether a stroke-focused coordinator qualifies as a care coordinator is untested, so the pilot should establish this before relying on it.

Two ideas to test, not assume. Two options for shaping capacity around the coordinator emerged during development of this proposal. The first would bundle cognitive, language, motor and vocational support into a single explicit service. Its logic is that one defined offer is easier to commission and deliver, but it risks leaving some needs outside the bundle, and those needs would then cost the NHS money elsewhere. The second would contract private therapists to serve unmet need further down the pathway. Neither is cost-neutral. The first redirects effort around an outcome that commissioners already pay for. The second adds capacity beside NHS staff. Neither removes the funding question, which is why the pilot must cost its chosen route.

5.6 Why carers are in the pathway

Carers are not a footnote to survivor outcomes. Families carry a large part of the cost of stroke: the Stroke Association's 2026 model values unpaid production and informal care at £5.69 billion a year, about 22% of the £25.71 billion total, borne by families rather than the NHS (Stroke Association, 2026). Estimates of carer cost depend heavily on method; King et al. (2020) valued unpaid care at £15.6 billion in 2015. The Care Act 2014 already entitles carers to an assessment, but nothing in the stroke pathway triggers one, repeats it, or lets a carer ask for help on the survivor's behalf. The second pathway therefore does four things: it identifies the carer before discharge; it offers a carer assessment at discharge and at the six-month review; it lets a carer start a re-entry request, with the

survivor's consent; and it asks the carer, separately, at the annual review what has changed. NHS England's Integrated Life after Stroke Support (ILASS) delivered with the Stroke Association, already names peer and carer support, so this is an extension of an existing national model. In the one uncontrolled Ontario evaluation, caregiver outcome scores improved (Allen et al., 2014); that suggests a signal worth measuring, not proof.

5.7 The co-designers

The second pathway will only work if it is shaped by the people who have lived it. Survivors and their carers are among the few who have experienced every stage in sequence. They felt the gap between what the guideline specifies and what was delivered, and they know what the move from acute care to community rehabilitation to life after stroke actually requires. They are not just end-users of the pathway.

Co-design from the start means something specific:

- **Seats before the model is set.** Survivors and carers with experience of the post-discharge pathway sit on ICB commissioning groups before the service model is fixed, shaping its terms rather than reviewing a finished draft.
- **Paid roles with authority.** These are paid roles with real decision-making authority, not voluntary ambassador positions. The pilot budget should fund them.
- **Evaluation with a route back.** Survivors and carers help evaluate the pathway in practice, with a formal mechanism to report to commissioners when it does not work.

The survey points the same way. A self-selected non-representative panel of survivors who completed the Discharge Gap survey were asked what would have made the move from hospital to home more manageable. 12 in 20 wanted longer rehabilitation support, 11 in 20 a named clinical contact, and 10 in 20 a scheduled review (Kuzalti, 2026). These are not expressions of dissatisfaction. They are an indicative design specification, and they match what the pathway builds in. Carers were not surveyed separately. That is a limit of this report, and the pilot should co-design the carer elements with carers from the start.

SURVIVOR VOICES

"You read all your textbooks. You have degrees in speech and language therapy. But the difference is: you have not had a stroke. That is why you need us. And that is why we need you. It is a partnership."

COLIN JENKINSON
STROKE SURVIVOR
(personal communication, 10 September 2026)

SECTION 5.8

5.8 Start with redirected money, not new money.

Stroke is already costing the country. In 2025 it cost about £25.71 billion: £5.34 billion to the NHS, £13.72 billion to social care, £5.69 billion in unpaid production and informal care and £0.95 billion in lost paid productivity (Stroke Association, 2026). Roughly 79% of that sits outside the NHS healthcare budget (derived from those components), and 87% of NHS and social care cost arises after the first year (Stroke Association, 2026). It is paid in carer hours, in avoidable readmissions, in lost working years, and in council social care costs when NHS support ends too soon.

The second pathway needs two sequenced funding decisions, and neither depends on a new national budget line.

DECISION 1, YEAR 1

Extend SSNAP to 12 months. This is a decision for the Healthcare Quality Improvement Partnership (HQIP) and NHS England as SSNAP's commissioners, working with the King's College London team that runs the audit and the funding governments in Wales, Northern Ireland, Jersey and Guernsey. SSNAP's central running cost is about £760,000 a year, and the extension would be a variation to that existing contract, not a new programme (HQIP, 2022, 2023). While the exact price is not published, the base term ended in April 2026, so any change would be made under the contract's extension option, which HQIP would need to confirm.

DECISION 2, YEARS 2 and 3

A bounded pilot of the readiness-based model in two or three ICBs. Care continues while a person is still making functional gains, and steps down or reopens on outcome, not date. Fund the pilot by redirecting part of the existing community rehabilitation allocation. Pool it with the local authority under a Section 75 agreement or the Better Care Fund, so that social care and carer savings count in the same business case. Pooling matters because most of the savings from fewer carer breakdowns and fewer care packages accrue to councils and households, not to the budget that pays for therapy. The pilot may carry some double-running cost in year 1, while existing services continue.

If the pilot cannot show a 12-month benefit for survivors or a reduction in caregiver strain, it stops, and the cost to commissioners is limited to the pilot itself.

The case is not that this is affordable. The case is that the current arrangement is not.

RECOMMENDATIONS BY STAKEHOLDER

Three decisions built the cliff. Four actions would close the gap. Each action has one lead owner, so that none becomes everyone's job and therefore no one's. For each, the card below sets out who moves first, what is known about the cost of starting, and how a commissioner would know it was working.

> These are not separate faults. They are links in one chain. SSNAP moves first because the change sits inside a contract that already exists: a published standard gives measurement and commissioning something to point at. NICE's work can start in parallel. The ICB ask then becomes something to commission against, not something to invent. Survivors and carers sit alongside all three from the start.

01 SSNAP'S OWNERS: HQIP (LEAD AND COMMISSIONER), WITH NHS ENGLAND (FUNDER), AND SSNAP TEAM AT KING'S

Extend the measurement window to twelve months as a minimum.

Phase 1, measurement (no new clinical workforce unless the twelve-month point is made a clinical contact, which is a separate decision): *(months 0 to 12)* HQIP varies the SSNAP specification to add a 12-month data point, built from fields SSNAP already collects, and records how many survivors the point reached. King's develops the case-mix adjustment so providers can be compared fairly.

Gate: first 12-month dataset published with case-mix adjustment

Phase 2, scoring: *(months 12-24, after the gate)* HQIP and NHS England consider adding a twelve-month stroke metric to the NHS Oversight Framework, or re-pointing part of the SSNAP-linked Best Practice Tariff incentive from process compliance towards outcome trajectory, within the existing tariff envelope. Research funders back a longitudinal PROMs study to validate outcome measures beyond the acute phase, informing the Phase 2 design.

02 NICE

Publish commissionable, auditable quality standards for the community rehabilitation components of NG236

Develop the quality standard; define measures ICBs can report against; set explicit re-entry criteria beyond the six-month review *(6-12 months, starts now)*

03 NHS COMMISSIONERS / ICBS, WITH LOCAL AUTHORITIES

Commission community stroke specialist services beyond the six-month review, against the NICE standard and SSNAP data.

Phase 1, pilot (live within 12-18 months) in two or three ICBs or network footprints, funded by reallocating existing community stroke spend.

- **Re-entry:** vary the community stroke contract so GPs can refer back in up to 12 months post-discharge.
- **Coordinator:** name and cost the route (Section 5). Default to existing staff: extend the early supported discharge key-worker role, or give a community therapist protected, backfilled coordination time.
- **Funding:** pool with the local authority (Section 75 or Better Care Fund) so social care and carer savings count.
- **Carers:** identify the carer before discharge, offer an assessment at discharge and at six months, and let a carer start a re-entry request with the survivor's consent.
- **Reporting:** survivor and carer outcomes separately, including caregiver strain at 12 months, against the NICE measures and SSNAP 12-month data when available.

Gate: a year of pilot data on re-entry volumes, coordinator caseload and outcomes, with a year-1 net position.

Phase 2, scale (from about 24-30 months, subject to the gate and the NICE standard) write the model into ICB commissioning intentions and the community payment design, so stroke is included. Extra coordinator posts are requested here only, as invest-to-save with a payback window.

04 STROKE SURVIVORS AND CARERS AS CO-DESIGNERS

Co-design the second pathway from the outset, with survivors and carers present before the commissioning model is set.

Establish paid lived-experience representation (survivors and carers) on ICB commissioning groups for stroke; survivor-led evaluation of post-discharge pathways; formal feedback mechanism to commissioners when pathways do not work as designed; survivor input into SSNAP measurement frameworks before next revision. Carers were not surveyed for this report, so the pilot should co-design the carer elements with the carers from the start.

Immediate - begin before commissioning models are set.

How this report was written

The Discharge Gap is an independent policy report. It was researched and written by Maya Kuzalti and Paul Quinn between July 2026 and October 2026, without institutional commission, sponsor, or funder. The independence is deliberate: this report makes specific asks of NHS commissioners, NICE, and the stroke research community. It cannot make those asks with credibility if it is funded by any of them.

The research process had three components. The first was a structured review of published evidence, covering national audit data (SSNAP, 2025); clinical guidelines (ISWP, 2023; NICE, 2023); published cost models (Stroke Association, 2026; Lane Clark & Peacock, 2026; King et al., 2020; Patel et al., 2020); peer-reviewed trials and observational studies (Gruia et al., 2025; Radford et al., 2025; Zorowitz et al., 2025, 2026); and international comparators (CorHealth Ontario, 2022; Heart & Stroke Foundation of Canada, 2025). Full citations are listed below.

The second component was a structured interview programme. Between 28 August 2026 and 20 October 2026, fourteen individuals were interviewed: stroke survivors, NHS clinicians, stroke charities, and patient leaders. Interviewees were offered the choice of being named or remaining anonymous.

The third component was a survivor survey (Kuzalti, 2026). Twenty stroke survivors completed the online questionnaire hosted at discharge-gap-questionnaire.netlify.app between 8 August 2026 and 1 September 2026. (A further three submissions were identified as test entries and excluded from analysis.) The survey is a non-probability convenience sample, self-selected and recruited primarily through the authors' personal network and the Imperial College Healthcare NHS Trust Patient and Public Involvement group. Percentages and proportions reported are indicative only and should not be treated as statistically representative of England's stroke survivor population. Qualitative responses are reported as illustrative testimony, not as findings generalisable beyond this sample. Survey data is used in aggregate; individual responses are anonymised unless the respondent gave explicit consent to be named.

Acknowledgements

The stroke survivors who completed the questionnaire and the survivors who gave their time to speak: this report exists because of what you shared.

About the authors

Maya Kuzalti spent twenty years in digital strategy and operations at high-growth companies in energy and financial services, including at executive board level. Her career was built on identifying where complex systems break down between policy intent and operational delivery — and on making the case for change to the people with the authority to act on it.

In 2021 she had a stroke. In the years that followed, she retrained. She is currently completing a Master's in Applied Neuroscience at King's College London and has conducted primary research for this report through structured interviews with leading stroke clinicians, researchers, frontline workers and stroke survivors in England.

She also writes and publishes essays on Substack covering stroke rehabilitation, health system governance, and lived experience in health policy, and is developing The Discharge Gap as a podcast and public platform. She lives in London, and can be contacted at hello@thedischargegap.com.

Paul moved from his native Liverpool to work for a large US investment house in the City of London before pursuing his dream of creating and running his own businesses ultimately across multiple sectors and jurisdictions.

In the summer of 2023, Paul had two strokes in quick succession, the second initially creating significant cognitive issues plus a significant emotional and psychological impact driven by the loss of agency and purpose that a stroke can cause. Thankfully his recovery enabled him to rediscover much of his determination and drive, in setting up peer to peer support groups among stroke survivors and their loved ones plus becoming a very vocal advocate for the recognition of, and professionalisation of lived experience. Paul lives and works in Central London and can be contacted at paul@cwte.uk

Disclaimer

The Discharge Gap is an independent publication. It has no institutional sponsor, no funder, and no commercial relationship with any of the organisations, studies, or interventions referenced within it. For transparency: the authors hold voluntary roles in the sector — Lay Research Stakeholder at Imperial College Healthcare NHS Trust, and Ambassadors for UK Stroke Charities. Maya is a student at King's College London. The foreword is by the lead of the Queen Square programme described in section 2.3.3, and is his own view. None of these organisations has reviewed, approved or endorsed this report.

Named studies and technologies are cited as evidence, not as endorsements. Where interim or unpublished data is cited (EPITOME), this is noted explicitly.

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The Discharge Gap

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INDEPENDENCE

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THIS REPORT CALLS FOR

Extend SSNAP measurement to twelve months. Publish a NICE standard for the community components of NG236. Commission community stroke rehabilitation against it, with a named coordinator, a way back in and support for carers. Involve stroke survivors and carers as co-designers, from the start, with paid roles, before the model is fixed.

JOIN THE CONVERSATION

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