

How can we harness data to improve the lives of stroke survivors?

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Policy Brief

This report details the findings from a Policy Lab that considered the different types and flows of data involved in stroke care, with a view to understanding how best to harness that data in order to improve the lives of stroke survivors.

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Who is this report for?

This report is designed for policymakers, clinicians, healthcare workers, stroke survivors and others, to quickly grasp an understanding of the stroke data landscape and its potential.

How can I use this report?

This report can be used to provide a foundational understanding of how data operates and flows in stroke care and related health systems, which can often be extremely complex. The aim is to support stakeholders to harness and use stroke data in more effective ways. For example, the report offers ideas for new and impactful ways that stroke data might be used to improve care.

Developed with experts attending the Policy Lab and in the wider research team, the ideas in this report can provide direction to future care provision, service organisation and research, as well as being used to raise awareness and influence decisionmakers in health policy and beyond.

Acknowledgements

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Contents

Summary	04
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Stroke in the UK	05
-------------------------	-----------

The stroke data landscape	06
----------------------------------	-----------

The Policy Lab	09
-----------------------	-----------

A vision for stroke care	10
---------------------------------	-----------

Harnessing data to improve the lives of stroke survivors	12
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Next steps	17
-------------------	-----------

References	19
-------------------	-----------



Summary

This work, led by the Stroke Programme at King's College London in collaboration with the Policy Institute, aims to harness data to improve long-term outcomes for stroke survivors, focusing on the range and quality of data collected, its relevance and accessibility to different stakeholders, how it can inform and improve research, and how it can be used most effectively in decision making and care.

As a leading cause of death and disability in the UK, stroke care is a clinical priority for the National Health Service (NHS). Considerable data exists on stroke in the UK to inform care. The South London Stroke Register, managed by the project team, is a notable registry which collects key outcomes for stroke, and has begun to collect long-term patient outcomes following survivors up to 15 years post-stroke. However, there is significant scope to harness these data and data from other sources better, as many challenges remain which can make the data fragmented or inaccessible.

'Policy Labs' are one approach which can help identify ways to address these challenges. Developed by the Policy Institute, a Policy Lab is a collaborative workshop bringing together diverse stakeholders with research, policy, practitioner and experiential expertise to deliberate evidence, understand barriers and constraints to change, and use this to inform policy and practice. In June 2023, a Policy Lab was convened to address the question:

How can we harness data to improve the lives of stroke survivors?

Key Findings

1. There is scope to harness stroke data better at the levels of the individual stroke survivor, health organisation (e.g., NHS Trust), the integrated care system (ICS), and the nation.
2. At each of these levels, there are a variety of feasible ways that collection, storage, access and use of stroke data can have a positive impact on the lives of stroke survivors. Some specific proposals include collecting patient-generated longitudinal data; disseminating data and research through stories that are accessible, timely and compelling; promoting collaboration between integrated care systems on low-volume interventions; and developing risk profiles for stroke survivors.
3. Given that a wealth of stroke-specific and broader health data are already collected, the most promising way currently to harness data to improve the lives of stroke survivors is by making better use of this existing data, and connecting data across health and social care systems.



Stroke in the UK

Stroke is a leading cause of death and disability in the UK

Every five minutes someone in the UK has a stroke, resulting in around 85,000 stroke patients per year¹. Stroke occurs when the blood supply to part of the brain is disrupted, which can impair functioning¹. Stroke survivors may suffer from disabling health conditions, such as communication problems (aphasia), mental health issues including depression and anxiety, and impaired movement and physical activity, such as limb weakness, limb paralysis, difficulty walking and difficulty gripping objects^{2,3}. In the UK, 30,000 people die from stroke each year¹.

A haemorrhagic stroke involves bleeding in or around the brain while an ischaemic stroke results from any blockage that disrupts blood supply to the brain. A transient ischaemic attack (TIA), also known as ‘mini-stroke’, occurs when the blockage of the blood supply is temporary, with the symptoms lasting only a short amount of time. However, 17% of people with TIA will experience a stroke within three months¹.

The trend in recent years has been that strokes are occurring at earlier ages and many people with stroke are surviving longer, but often with complex needs and multiple morbidities. People from lower socioeconomic backgrounds are significantly more likely to experience a stroke, meaning that neglecting stroke care threatens to widen health inequalities.^{1,4}

Stroke care is a clinical priority for the NHS

Stroke is a clinical priority in the NHS long-term plan, which commits to saving 150,000 lives from cardiovascular disease over the next decade¹. By 2035, the number of first-in-a-lifetime strokes in England is expected to reach 118,000 per year, with stroke care totalling up to £75bn.¹

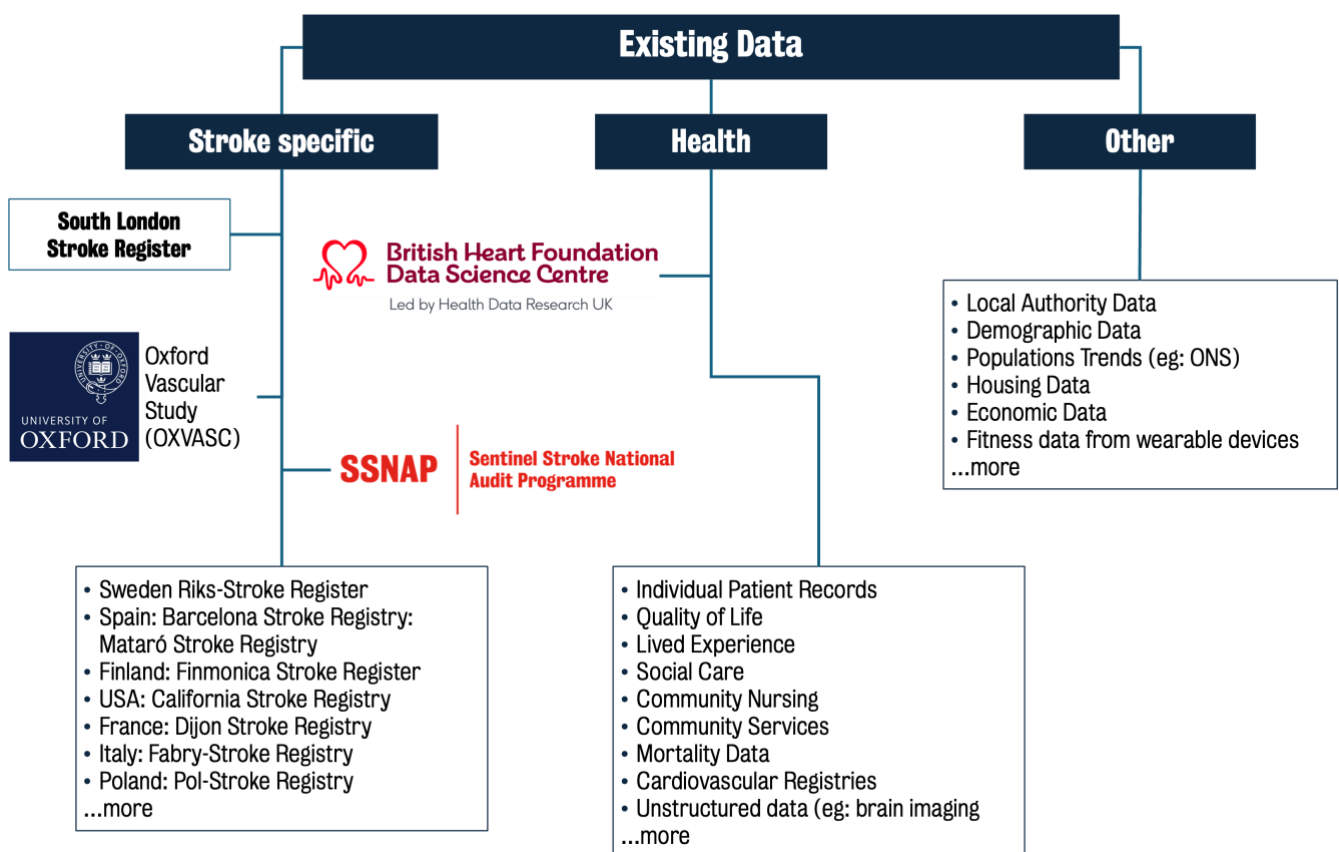
Acute stroke care has improved significantly in recent years, with the establishment of dedicated Hyper-Acute Stroke Units (HASU) in some hospitals and advancement of evidence around reperfusion therapies. However, there are challenges with implementing and delivering sufficient rehabilitation for stroke survivors in the community in the long-term. Effective care requires a personalised, multi-disciplinary approach, with care that may be provided across a range of disciplines, such as by stroke specialists, speech and language therapists, physiotherapists, mental health practitioners, carers, charities and family members.

The stroke data landscape

Considerable data on stroke outcomes already exists

Stroke survivors, clinicians and policymakers have consistently called for better quality data on the long-term consequences of stroke, to better inform decision-making with regards to care and rehabilitation. There is a considerable amount of clinical stroke data available, which we began to map to guide the Policy Lab.

What data is currently collected?





Stroke specific data sets

South London Stroke Register (SLSR)

Managed by the team at King's College London, the SLSR⁵ is an ongoing register following stroke survivors across South London up to 15 years after first stroke. It aims to better understand stroke epidemiology, including stroke survivors' experience and long-term care.

Some examples of the data collected include a detailed description of the nature of the stroke, functional outcomes, disability, quality of life, cognitive function, mental health measures, and personal and demographic data. Data are collected prospectively from general practitioners (GPs), accident and emergency departments, hospital wards, brain imaging, coroners, and more.

The SLSR data is used to improve service delivery, inform research and inform policy, including informing the European Parliament on the burden of stroke in Europe⁶.

Sentinel Stroke National Audit Programme (SSNAP)

The SSNAP audit⁷, active since 2013, is a national healthcare quality improvement programme based at King's College London. It collects data on outcomes for recovery and rehabilitation of stroke across all acute hospitals in the UK, following stroke survivors up to six months post hospital admission. SSNAP aims to benchmark national stroke services, to improve service delivery.

Data from around 90,000 stroke survivors are collected each year, representing more than 90% of stroke hospital admissions in the NHS. SSNAP measures the process of care against clinical standards and outcomes, such as how quickly stroke survivors are treated, hospital discharge and mortality.

SSNAP uses data to improve service delivery, inform research, inform guidelines (e.g., NICE quality standards for stroke) and inform stroke-based metrics.

Oxford Vascular Study (OXVASC)

The OXVASC registry⁸ collects vascular data from stroke survivors across eight GP sites in Oxfordshire, with the aim to better understand vascular disease and how to treat it. It follows survivors up to 10 years after the initial stroke event to see how they recover.

Examples of the data collected include brain imaging, blood pressure, heart tests (e.g., ECG), blood tests and cognitive testing. The data are used to track changes in healthcare over time and to compare and validate other registers.



There is scope to use the data better

Despite a wealth of available data, there are many challenges limiting its utility.

- **Most data reports short-term outcomes**

Much of the existing data focuses on short-term outcomes around the occurrence of stroke. The South London Stroke Register seeks to address this challenge by collecting long-term recovery data for up to 15 years post-stroke.

- **Data systems lack interoperability**

This can make it extremely difficult to connect different data sources to provide a complete understanding of a person's outcomes. For example, secondary and tertiary health records are often collected through a different electronic system to primary care.

- **Data repositories are often fragmented**

Data are collected, stored and connected inconsistently across different NHS trusts and services. For example, primary care data can sometimes be connected at the local level, but not across the NHS.

- **Lack of coordination between services**

Different services use data differently and inconsistently for service design, e.g., social care versus community care.

- **Limited capacity for recording data**

Healthcare staff can be extremely busy, meaning that data collection may not be a priority. This can result in incomplete or inconsistent records.

- **Variable engagement with existing data**

Different clinicians, healthcare staff and stroke survivors have different levels of familiarity with and understanding of the data. They may also not have the particular skillsets needed for effective data analysis and communication, which can moderate how well they engage with existing data.

- **Concerns about data security**

The healthcare workforce and stroke survivors have concerns about the security, ownership and protection of data, including the need for consent for its collection, storage and use for different purposes.

The Policy Lab



Policy Labs

A method developed by the Policy Institute at King's College London, Policy Labs are collaborative workshops which convene diverse stakeholders with research, policy, practitioner and experiential expertise to assess the evidence regarding an issue, understand barriers and constraints to change, and use this understanding to inform policy options that can help improve outcomes.

Through exploring a range of perspectives and co-producing practical ideas, Policy Labs also create a highly invested group who can become powerful advocates for the subsequent application of a Lab's conclusions.

The research team hosted a Policy Lab⁹ in June 2023, to discuss the following question, with a focus on improving care and outcomes for stroke survivors:

How can we harness data to improve the lives of stroke survivors?

The Policy Lab brought together 18 stakeholders with diverse expertise, including stroke survivors and carers, stroke researchers, population health scientists, clinicians (e.g., stroke consultant physicians), charities, data scientists and health system leadership.

The aim was to think as broadly as possible about how data can be better collected, accessed, connected and used, to improve the lives of stroke survivors. A range of activities were facilitated to realise this, including envisioning the future of stroke care at different levels and backcasting how to get there; brainstorming proposals for better harnessing data; prioritising such proposals based on how feasible, acceptable and impactful they are; and developing specific proposals in greater detail. Noting that a wide range of data already exists, participants focused mainly on the use of this data – rather than extensive collection of new data – as the most valuable, impactful and feasible way to improve stroke care.



A vision for stroke care

Envisioning the future of stroke care

Participants discussed a vision of what they would like stroke care to look like, in five years and beyond, at the individual, organisational, system and national levels. Better or new uses of existing data at these levels were generally seen as having greater potential impact because they were considered more feasible than collecting new data or linking data.

It is important to recognise that these levels do not operate in isolation, but instead form part of a highly interconnected system, through which data flows in different directions and at different levels of aggregation. As such, changes at one level will have consequences elsewhere. For example, data collected in relation to an individual patient at a specific point in time may be aggregated over time and across populations for use in service design or needs-based planning. Similarly, use of large-scale data at a national level to develop risk profiles might then be used to inform the availability or organisation of local services.

At the individual patient level, participants wanted stroke survivors to be able to access their own data regarding their condition and care (e.g., through an online portal), have a better understanding of treatment options that were personalised to them (e.g., personalised care plans), have better signposting to services, and play a more active role in shared decision making with clinicians, including having a say in which data is most useful for patients.

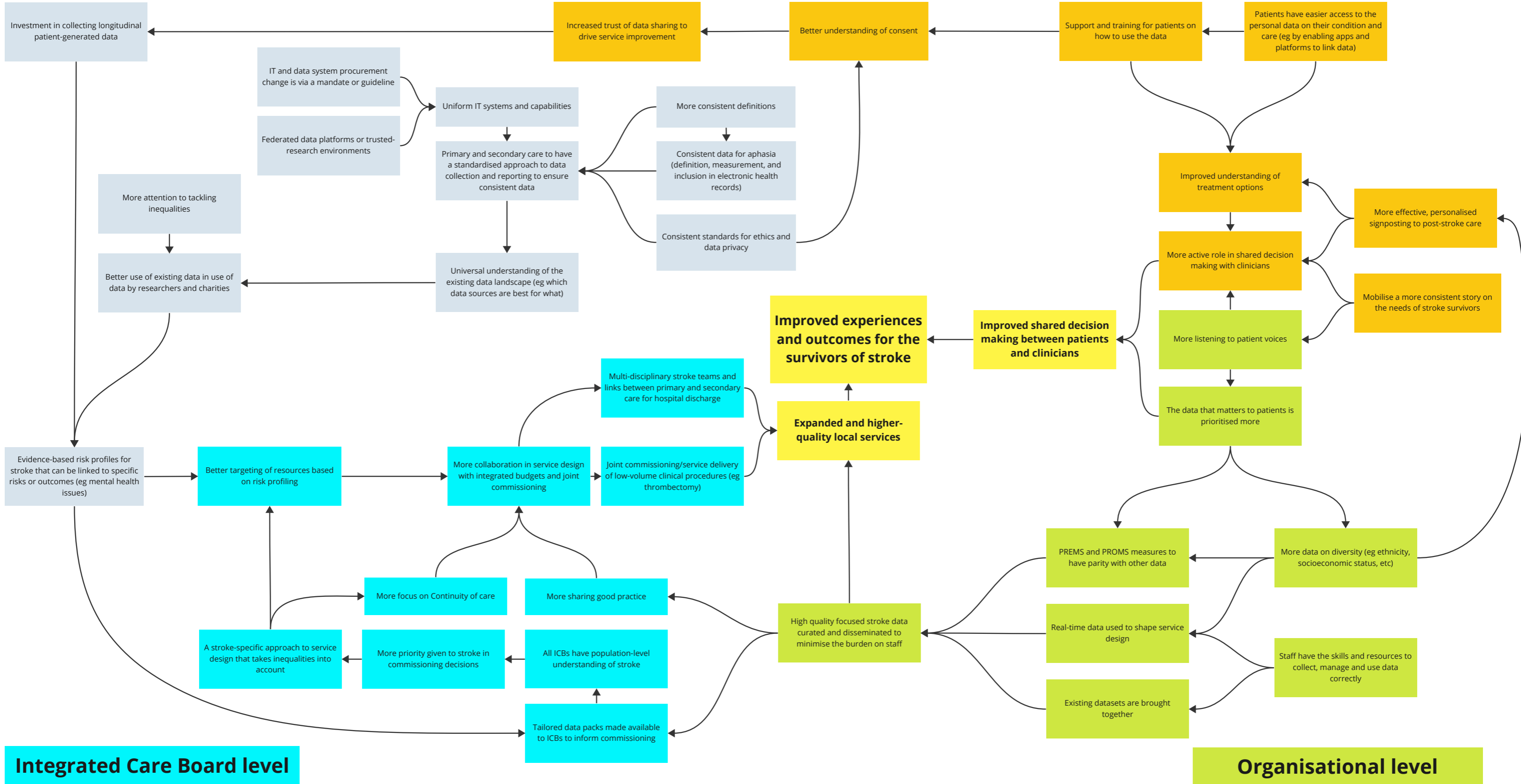
At the organisational level, participants emphasised the importance of staff having the skills and resources to collect, manage and use data correctly, for example, through training and careful selection of impactful evidence to disseminate. They also wanted to see real-time data used to shape service design, and for patient-reported experience and outcome measures to have a parity with other data.

At the integrated care system level, participants particularly wanted to see sharing of good practice and collaboration between integrated care systems, particularly on low-volume clinical procedures such as thrombectomy. Participants also indicated that commissioning decisions across the health service should give more priority to stroke, enabling a stroke-specific approach to service design and adoption of an inequalities lens in considering access and outcomes. A population-level understanding of stroke and continuity of care in stroke were also seen as important. As integrated care systems are relatively new entities, it was noted that it is an opportune time to act at this level.

At the national level, participants prioritised the development of evidence-based risk profiles for stroke that can be linked to specific outcomes such as mental health issues, better use in general of existing data by researchers and charities, and more consistency in definitions of aphasia (language impairment). More aspirational ideas included uniform IT systems and capabilities, and default data capture and sharing (e.g., standardisation across health systems, public debate on the balance between data security and use).

National level

Individual patient level



Harnessing data to improve stroke care

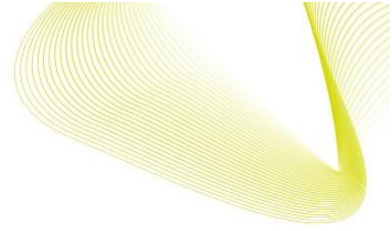
The pathway of data flow

After developing a vision for the future of stroke care, Policy Lab participants considered what needs to change at each level to achieve this and the role of data in getting us there.

We can think of effective harnessing of data as a pathway, flowing from data collection, through storage and access, to use.



This schema can be applied to each element of the vision for stroke care, to produce a pathway to impact. Within each pathway to impact, we can identify if changes can be made to data collection, access or use, to improve outcomes.

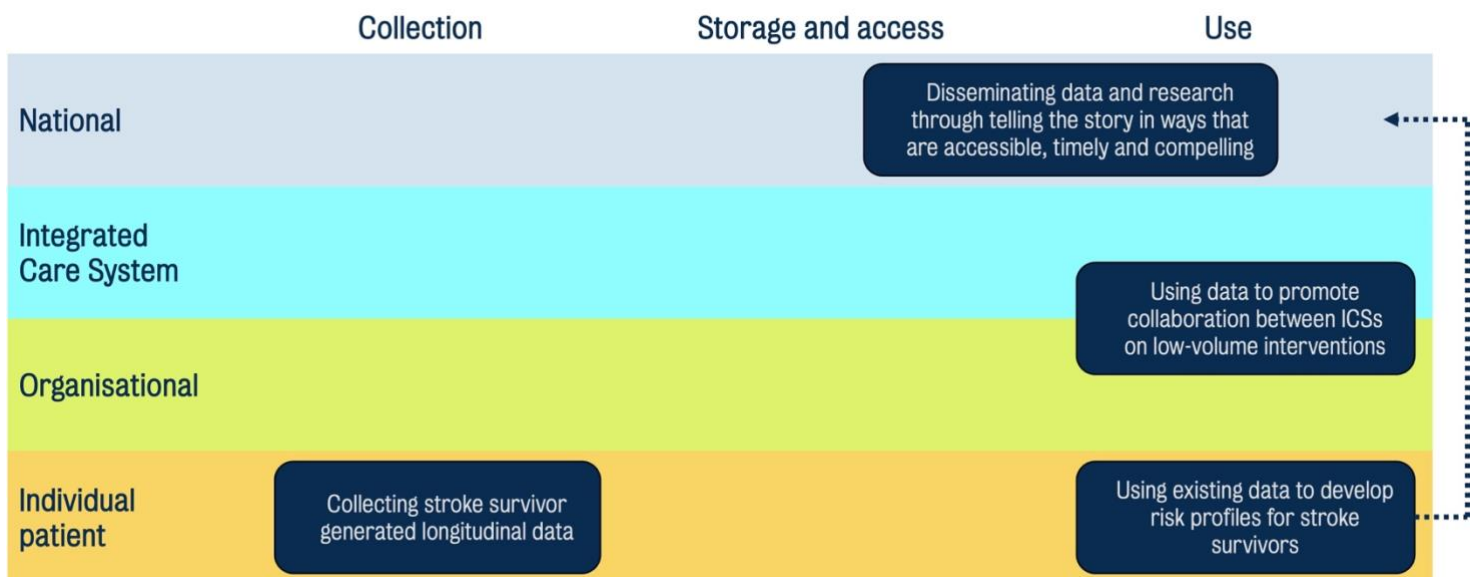


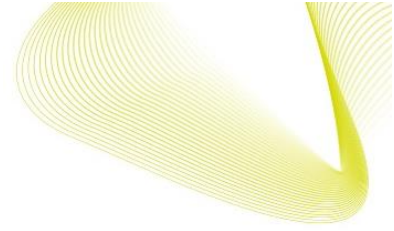
Proposals to harness stroke data

Policy Lab participants brainstormed a list of proposals to harness stroke data – either through collection, access, or use – to move towards the vision for stroke care (see technical appendix for full list). Here, we detail four proposals that participants prioritised as most valuable, feasible and acceptable: collecting stroke survivor-generated longitudinal data; disseminating data and research through telling the story in ways that are accessible, timely and compelling; promoting collaboration between ICSs on low-volume interventions; and developing risk profiles for stroke survivors.

There are clear trade-offs in such prioritisation. For example, while there was a recognition that collecting new data (e.g., on social care) might be very valuable, challenges in setting up comprehensive and universal data collection systems make this difficult to achieve. Similarly, issues around what is acceptable to clinicians and stroke survivors in terms of data collection, storage and sharing are important in considering where there is scope for the most impact.

It is also important not to think about changes to the data landscape in isolation. These proposals can work together to be more impactful. For example, stroke survivor-generated data can inform the development of risk profiles, and disseminating research through compelling stories could encourage ICSs to prioritise stroke care.





1. Collect stroke survivor-generated longitudinal data

Data collection at the patient-level

The PPI group supporting the stroke data programme has been advising on how some form of patient portal could assist stroke survivors through the dissemination of information and advice derived from existing and new stroke data. This thinking has pointed to a big opportunity in tracking the long-term progress or decline amongst stroke survivors through a broad set of measures that capture experiences and outcomes in a holistic way.

This data, reported by stroke survivors themselves, could include vitals like blood pressure, mobility assessments, mental health, other long-term conditions, lifestyle changes, and treatments. Stroke survivors could be able to access their own data, and there could be potential for aggregated data to be stored anonymously in a secure, centralised database for research. Health professionals and those involved in service design and delivery could advise on what data is helpful to capture and how it can best be measured consistently.

This approach could bring benefits for stroke survivors and clinicians, such as an improved understanding of individuals' conditions to make personalised care decisions, as well as for clinicians and commissioners in service design and delivery. Some potential risks include self-report biases, data security including GDPR, costs, ensuring that reporting is not too burdensome, and exclusion of important demographics, e.g., those with limited access to technology or limited computer literacy if the data is collected online only.



2. Disseminate data and research through telling the story in ways that are accessible, timely and compelling

Data access and use at the national level

With many different types of fragmented data and very diverse audiences (e.g., clinicians, policymakers, researchers, charities, the public), it is important that each audience receives the right messages in the right way. Participants suggested that it would be beneficial to create a consistent story of stroke survivors' experiences and needs, that can be told to different audiences in ways that resonate with them and mobilise them to take actions to improve stroke care. For example, with increasing incidence of stroke in younger people, there is a need to target communication to younger age groups. However, there is a trade-off to consider between developing strong, consistent messaging, and tailoring different messages to specific audiences.

To advance this proposal, a working group could be convened to develop messages that are most valuable and instrumental in improving stroke care, and to identify existing evidence to support such messages. A toolbox of resources (e.g., handouts, videos, campaigns) could subsequently be developed to support stakeholders (e.g., charities) to produce audience-led messages. This could be done in collaboration wider communication specialists.

The benefits of a consistent narrative include raising awareness amongst policymakers of the key priorities for stroke survivors and helping to make the case for improving care.

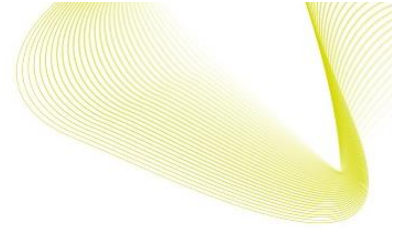
3. Promote collaborations between ICSs on low-volume interventions

Data use at the organisational and ICS level

Another way in which existing data can be better used is to promote collaboration at the ICS level, particularly by sharing good practice to improve service design. Data can inform stroke integrated service delivery networks (ISDNs), which are each responsible for contributing to the design and co-ordination of stroke services across ICSs.

ICSs could be encouraged to work together on low-volume interventions in stroke, such as mechanical thrombectomy. Approximately 10 – 15% of stroke survivors undergo this procedure and there is significant geographical inequity in access.

The potential benefits of collaboration across ICSs include improving health equity, particularly in access to services, and sharing best practice across organisations. The main risk is that other clinical priorities prevent organisations from focusing on stroke.



4. Develop risk profiles for stroke survivors

Data use at the patient and national levels

Existing data could be used to develop risk profiles for stroke survivors that provide indications on various outcomes and risks that different demographics may be more or less disposed to. The risk profiles could contain information and guidance pertaining to quality of life, recovery and rehabilitation, mental health outcomes, long-term sequelae of stroke, risks of recurrent stroke and risks of other cardiovascular events.

The profiles could be based on routinely collected data (e.g., from the South London Stroke Register), electronic health records, public surveys and patient-reported data. Co-developing risk profiles with stroke survivors would help to identify the outcomes that are important to them (e.g., mobility, communication, mental health outcomes). The associated risks and outcomes could be presented graphically so that they are easy to understand and compare to one another, alongside patient guidance (e.g., through videos) to help stroke survivors understand and interpret the profile. The risk profiles could be available on an online platform or portal.

The potential benefits of developing risk profiles include reducing uncertainty for stroke survivors and carers, informing people of potential triggers or signs to look out for, helping to manage expectations for recovery, and empowering stroke survivors in their own care. For the NHS and clinicians, it could provide a useful resource to signpost stroke survivors to, it could support workforce planning through providing the basis of projections for care needs, and it could help to identify priorities for funding. If machine-based learning is used in developing the risk profiles, this could also reveal unexpected results (e.g., a possible focus on mental health rather than hypertension). Potential risks could include inability to secure funds or permission to develop the profiles, as well as not disseminating the profiles efficiently, or stroke survivors over-relying on the profiles as a clinical tool.

In addition, it may be difficult to communicate risk honestly and transparently in a way that is empowering. For example, the risk information, such as the likelihood of common mental health problems, may need to be communicated sensitively and carefully with appropriate support in place, such as the ability to ask questions and discuss implications with a clinician.



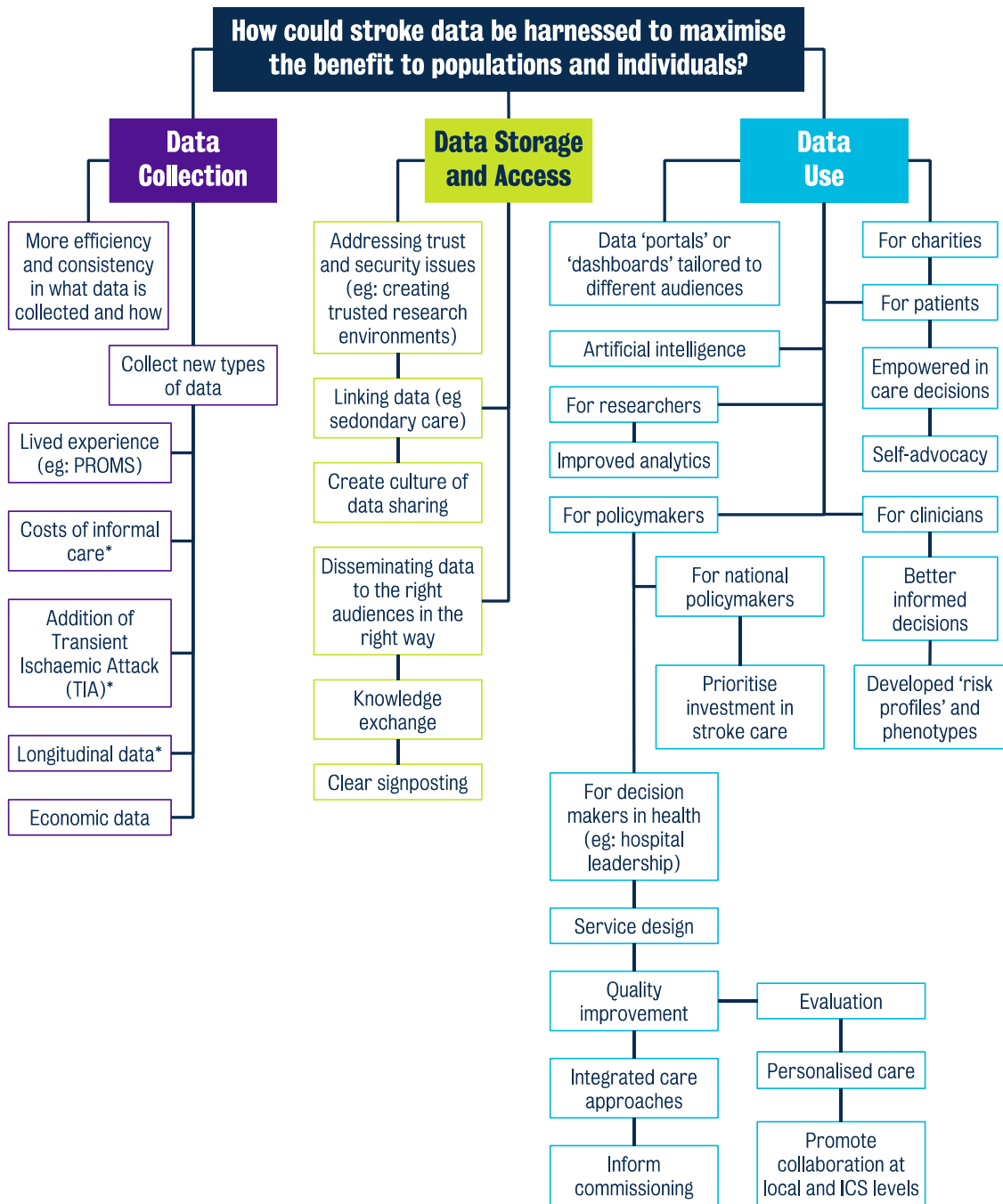
Next Steps

There is significant scope to harness stroke data better to improve the lives of stroke survivors, which is supported by Policy Lab attendees who represent a powerful coalition of stakeholders willing to mobilise and drive stroke care forward.

The first in a series of Policy Labs, this exercise has provided a useful mapping of the stroke data landscape, as well as the foundation for thinking about how to take this work forward. In building on this and further developing data practices in line with the vision set out, there will be several important aspects to consider. Some of these have been touched on in the more detailed proposals set out in this report, but include careful consideration of the needs and priorities of different stakeholders – for example, the format of data that can best support discussions between a patient and clinician about individual care may be quite different to that which commissioners require for planning. If the stroke care community is to move effectively and efficiently towards the ideals described by our Policy Lab participants, a collaborative approach to planning data collection and use is thus critical in identifying both common goals and potential conflicts or trade-offs.

Future Policy Labs can help us navigate some of these issues and develop ways to address specific concerns relating to data collection, data storage and access, or data use from different perspectives, including stroke survivors, clinicians and policy makers. We hope that these - alongside further work instigated by others with an interest in stroke - can then establish practical ways forward in implementing changes that result in improved care for stroke survivors.

As participants felt that data use offered the most potential, future labs could address the most impactful uses of data for these different groups. For example, a future lab could explore how online portals could best be designed to gather and present information to different audiences. At the ICS level, this could be a platform for data sharing to feed into workforce planning, at the patient level it might allow stroke survivors to track and monitor their own data, whilst at the clinician level it could provide a tool to compare individual data to different stroke risk profiles.



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