Not just a funny turn

The real impact of TIA

Get involved at:

stroke.org.uk/tia

or #ministroke
<table>
<thead>
<tr>
<th>Contents</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>About the data in this briefing</td>
<td>4</td>
</tr>
<tr>
<td>Foreword</td>
<td>5</td>
</tr>
<tr>
<td>Chapter 1 TIA: the basics</td>
<td>6</td>
</tr>
<tr>
<td>The condition, its symptoms and significance</td>
<td></td>
</tr>
<tr>
<td>Anthony: ‘I’d never heard of TIA’</td>
<td>8</td>
</tr>
<tr>
<td>Chapter 2 Spotting symptoms and taking action</td>
<td>10</td>
</tr>
<tr>
<td>The reasons people do, and do not, seek help</td>
<td></td>
</tr>
<tr>
<td>Simon: ‘There should be more information on TIA’</td>
<td>14</td>
</tr>
<tr>
<td>Chapter 3 Health and care professionals and TIA</td>
<td>16</td>
</tr>
<tr>
<td>Addressing inequalities in services and care</td>
<td></td>
</tr>
<tr>
<td>Susan: ‘My stroke should never have happened’</td>
<td>20</td>
</tr>
<tr>
<td>Chapter 4 Information, advice and support after TIA</td>
<td>22</td>
</tr>
<tr>
<td>What is needed to help people make their best recovery</td>
<td></td>
</tr>
<tr>
<td>Janet: ‘No one explained TIA’</td>
<td>26</td>
</tr>
<tr>
<td>Chapter 5 Long-term impact</td>
<td>28</td>
</tr>
<tr>
<td>How TIA has affected people’s lives</td>
<td></td>
</tr>
<tr>
<td>Peter: ‘I had severe panic attacks’</td>
<td>30</td>
</tr>
<tr>
<td>Chapter 6 A wake-up call – life after TIA</td>
<td>32</td>
</tr>
<tr>
<td>Lifestyle support and missed opportunities</td>
<td></td>
</tr>
<tr>
<td>Margaret: ‘I feel much healthier now’</td>
<td>34</td>
</tr>
<tr>
<td>Our calls to action</td>
<td>36</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>38</td>
</tr>
</tbody>
</table>
About the data in this briefing

This briefing is based on evidence obtained from a UK-wide survey of 670 people who have experienced a TIA or transient ischaemic attack (also known as a mini-stroke) within the past five years. National breakdowns can be found at stroke.org.uk/tia

Purpose
Its aim was to capture the experiences of people who have had a TIA, the treatment and care they received and how TIA has affected their lives.

Method
The survey, which ran from October to December 2013, was conducted both online (via Survey Monkey) and on paper. It included questions about symptoms; the action people took following their TIA; the treatment, information and support they received from the NHS; and how TIA has affected them in the long term. Interviews also took place with 18 respondents and two NHS professionals.
Not just a funny turn is based on the experiences of 670 people who have experienced a TIA or transient ischaemic attack (also known as a mini-stroke) during the past five years.

A TIA is a warning sign that a person is at risk of a stroke that could cause them considerable harm. That risk is greatest in the first few days – within a week more than one in 12 people who have had a TIA go on to have a stroke. By spotting the symptoms early and having swift access to specialist services, thousands of people a year could avoid the serious consequences of stroke.

This survey shows that too many people write off TIA symptoms as ‘just a funny turn’ and are unaware of the need to seek urgent medical attention, which can prevent future strokes.

Although most people believed their symptoms were taken seriously, a third felt that health and care professionals were too quick to dismiss TIA, and a number of people reported examples of poor care. In some cases, people felt that this had contributed to them going on to have a stroke.

We also heard, in people’s own words, about what they believe to be the long-term impact of TIA. There is some debate as to whether or not TIA causes any long-term damage. Perhaps this misses the point. People told us about memory loss, muscle weakness, poor mobility and confusion. They also told us about the emotional impact of TIA. Whatever the cause of these long-term effects, they and their families need support in adjusting to the unexpected changes that have come about and must not be left to cope on their own.

Some people viewed their TIA as a wake-up call – a chance to make positive lifestyle changes, improving their overall health and fitness. Yet, apart from being prescribed medication, most were offered little practical support to achieve this. This is a missed opportunity.

We are launching this campaign in order to prevent more people from going on to have a stroke after TIA. Everyone has a role to play here. Whether you work in health, social care or research, in hospitals, care homes or the community, we hope you will join us in ensuring that people who have a TIA are supported and helped to make their best possible recovery.

Jon Barrick
Chief Executive
Stroke Association

Each year, 46,000 people in the UK have a TIA for the first time – a warning that they are at risk of stroke. Yet too many people are unaware of the link between TIA and stroke and are not getting the services and support they need.

Not just a funny turn is based on the experiences of 670 people who have experienced a TIA or transient ischaemic attack (also known as a mini-stroke) during the past five years.

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TIA: the basics

The symptoms of TIA are often short and can easily be mistaken for tiredness or other conditions, delaying or even stopping people receiving the urgent medical treatment that could prevent stroke. That is why it is vital that public awareness of TIA is improved.

A TIA or transient ischaemic attack (also known as a mini–stroke) is the same as a stroke, except that the symptoms last for a short amount of time and no longer than 24 hours. Most strokes are caused by a blockage cutting off the blood supply to part of the brain. The only difference when a person has a TIA is that the blockage is temporary – it either dissolves on its own or moves, so that the blood supply returns to normal and symptoms disappear.

Every year, at least 46,000 people in the UK have a TIA for the first time \(^1\) and although the symptoms may not last long, a TIA is still very serious. It’s a sign that a person is at risk of going on to have a stroke. Because of this, it is often called a warning stroke. More than one in 12 people will have a stroke within a week of having a TIA \(^2\).

Stroke is the third single largest cause of death in the UK, accounting for around one in 10 deaths \(^3\). It’s also the largest cause of complex disability in the UK \(^4\), with half of all stroke survivors affected \(^5\).

Key messages for the general public

There is no way to tell whether a person is having a TIA or a stroke when the symptoms first start.

Stroke is a medical emergency. The quicker the person gets access to specialist assessment, investigation and treatment, the more likely they are to make a better recovery. Therefore the message to the general public is:

**If you, or someone else, show any of the signs of stroke, you must call 999.**

Research has suggested that approximately 10,000 strokes could be prevented every year in the UK if all TIAs and minor strokes were treated urgently \(^6\). The symptoms of TIA often pass very quickly so the public – and some health and care staff – may mistake them for tiredness, migraine or just a ‘funny turn’. Rapid access to specialist assessment, investigation and treatment is still important even if the symptoms have stopped as it can reduce the risk of a person having another TIA or stroke, so the other crucial message for the public is:

**If you think you have had a TIA and have not sought medical attention, see your GP urgently.**

Urgently investigating and treating people who have a TIA or minor stroke could reduce their risk of having another stroke by 80% \(^6\).

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Know the signs of stroke and TIA

The FAST test can help you to recognise the symptoms of a stroke or TIA. Look out for:

- **Facial weakness**
  - Can the person smile?
  - Has their mouth or eye drooped?

- **Arm weakness**
  - Can the person raise both arms?

- **Speech problems**
  - Can the person speak clearly and understand what you say?

- **Time to call 999**
  - If you see any one of these signs, seek immediate medical attention.

The symptoms of a stroke or TIA usually come on suddenly. Others that are sometimes associated with TIA can include:

- weakness or numbness on one side of your body
- loss of vision or blurred vision in one or both eyes
- memory loss or confusion
- dizziness, unsteadiness or a sudden fall, especially with any of the other symptoms.

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**Risk factors for stroke and TIA**

- **Age**
  - A person’s arteries become harder and narrower with age, raising risk of stroke and TIA.

- **Gender**
  - Men are at higher risk than women, and at an earlier age too.

- **Ethnic background**
  - South Asian and black people in the UK are more likely to have a stroke and TIA than white people.

- **Family history**
  - Someone with a close relative who has experienced stroke or TIA is likely to have an increased risk.

- **Certain medical conditions**
  - A number of conditions including high blood pressure, high cholesterol, atrial fibrillation and diabetes can increase the chances of stroke and TIA.

- **Lifestyle factors**
  - Having an unhealthy diet, drinking too much alcohol, taking recreational drugs, smoking and a lack of exercise can also increase likelihood of stroke and TIA.
Anthony delayed getting help when he first experienced TIA, believing his symptoms were caused by sciatica.

When his left arm and leg went weak one evening in October 2013, Anthony, 62, thought it was his old sciatic nerve problem troubling him again.

“I have occasional problems due to a prolapsed disc at the base of my spine so put it down to my sciatic nerve. It didn’t feel like an emergency but the next morning, when I couldn’t put any weight on to my leg, I was worried,” he says.

Unsure of what to do, Anthony’s partner, Zena, called 111 (an NHS non-emergency medical helpline in England) and an ambulance arrived within five minutes.

“The paramedic recognised that I’d had a TIA, which I’d never heard of before. He explained that it was connected to stroke but I was surprised because I hadn’t had any of the facial drooping or slurred speech I’d seen before in the advertisements,” he explains.

After arriving at hospital, Anthony saw a specialist who sent him for tests, which confirmed the diagnosis.

“Six weeks later, I had a check-up at the TIA clinic with the same doctor. He was fantastic and I couldn’t have paid for better care. I’m now about to go back to the clinic for my six-month check-up,” he says.

Anthony was given written information on TIA and how it increases risk of stroke, plus advice on diet and lifestyle, including material from the Stroke Association. As a result, he has now joined a weekly exercise class and has made several improvements to his diet.

“My left arm and leg are still slightly weak, but medication is helping. I’ve been very lucky; the TIA was a wake-up call,” he says.

Anthony feels that there should be more publicity about TIA and its risks: “I’d never heard of TIA and it makes you wonder how many people may have had one without realising it, unaware that they are at increased risk of a stroke.”

“It makes you wonder how many people have had a TIA without realising it.”
Despite campaigns, public awareness of TIA is low, which means people often do not seek urgent medical help. Our survey examined why people did – and did not – take action after TIA.

Raising public awareness of stroke symptoms and the need for an emergency response has been the focus of national and local awareness campaigns. Such campaigns have promoted awareness of the FAST test (see page 7), designed to allow the public and health professionals to quickly identify potential stroke and TIA symptoms.

However, despite these efforts, public awareness of TIA is low. In 2012, a Stroke Association opinion poll of more than 2,000 members of the public found a very poor awareness of TIA, its symptoms and its significance.

This is reflected in our more recent *Not just a funny turn* survey. Respondents told us that their awareness of TIA had been low before they experienced one.

- Almost half (44%) had never heard of TIA.
- 27% had heard of it but did not know a lot about it.
- 61% did not know that a TIA is a warning sign of a possible future stroke.

Subsequently, half of respondents said that when they experienced TIA symptoms, they didn’t know what was happening to them. Many mistook their symptoms for a range of other conditions, including problems with their eyes, a migraine or a trapped nerve. For others, the symptoms seemed vague and difficult to pinpoint with over a third putting them down to just a ‘funny turn’.

People told us:
“I was worried about the symptoms plus I didn’t feel right, but I didn’t know it could be potentially serious.”

“Didn’t know what it was. Wasn’t as familiar with all symptoms as I am now.”

“Had a funny turn for a few minutes on a couple of occasions. Had a sit down. Did not get medical help.”

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**Successful stroke campaign**

According to Public Health England, the Stroke: ActFAST campaign, which has aired on TV screens across England, has been one of their most successful public awareness campaigns, significantly improving recognition of the signs and symptoms of stroke and prompting people to take the right action.

Following the campaign, 94% of adults over 55 were able to identify at least one of the FAST stroke symptoms and 74% knew to call 999 should anyone display a stroke symptom.
Delayed response
This lack of awareness of TIA, along with a range of other factors, appears to have delayed people seeking medical attention, either while they were experiencing symptoms or afterwards.

Although most people reported taking action while they were experiencing TIA symptoms, around a third didn’t. However, almost a quarter said that their symptoms lasted for fewer than 10 minutes, meaning there was a very short window of opportunity for them to do so. Yet others described their symptoms as lasting for hours, with some delaying seeking medical attention for up to 24 hours.

For those who waited for their symptoms to stop, the time taken to seek medical attention was even longer, with a third waiting for more than 24 hours.

As many as 14% of people reported taking no action at all. Some people said that they experienced the symptoms on a number of occasions before they sought medical attention. For others, it was only following a stroke that they realised they had had TIA symptoms in the past.

Why people did not seek help
Most people who didn’t take action immediately said that this was because it didn’t feel like an emergency. Worryingly, we also found that almost a quarter of people had experienced the symptoms more than once and not taken action.

About 10% of people said that they delayed taking action because they didn’t know who to contact, while others said that they didn’t seek medical attention as they felt there was nothing that the NHS could do to help people who were having a TIA. People also reported delaying taking action as they didn’t want to waste the time of NHS staff.

“At first I didn’t know what a TIA was and didn’t go to the hospital as I didn’t want to take up the staff’s time as they are always busy.”

Despite public awareness campaigns playing a part in some people recognising their symptoms, a number of people said that they put off seeking help because they were not experiencing all of the FAST key symptoms.

“Never had the facial symptoms that people look out for and never lost the strength in my arms and legs.”

Some people felt that awareness campaigns around stroke should also include more information about TIA.

“I feel most people, including myself, have never heard of TIA before and surely it needs to be more widely publicised. It seems a stroke is publicised well on TV adverts but there’s no mention of TIA.”

Even when people did recognise the symptoms as being potentially related to TIA or stroke, many said that they were in denial about what was happening to them.

“I was in denial and told myself it wasn’t a TIA very stupidly, but in the back of my mind I knew.”

1 ICM Research survey on a random sample of 2,009 adults in GB online (October 2012).
2 Cardiovascular Disease Outcomes Strategy, Department of Health (2013)
Martin, 73, first knew something was wrong one morning in September last year when he couldn’t press the right keys on his computer keyboard.

“My wife, Merle, noticed that my left eye and mouth were sagging and asked if I was okay, but I couldn’t speak properly. We both immediately thought of stroke because the symptoms are so well publicised. Merle dialled 999 and the ambulance arrived in five minutes,” he says.

Martin saw a consultant within the hour then, after several tests, was diagnosed with TIA and put on anti-platelet medication to reduce the risk of clots, and a statin to reduce cholesterol. He has taken blood pressure medication for some years.

Impressed with the care and information he received, Martin says: “I was given plenty of information about TIA, which I hadn’t heard of before, plus advice on diet and lifestyle.”
Calls to action for planners and providers of health and social care

- Continue to run public health initiatives including stroke-awareness campaigns to ensure that as many people as possible recognise the symptoms of stroke and seek emergency help.
- Ensure that more prominent and tailored messages on TIA feature in national and local stroke-awareness campaigns.

Why people sought help
Of those who did recognise that the symptoms were those of a TIA or stroke, around half (53%) said that this was because either they or a relative had experienced a TIA or stroke in the past.

Awareness campaigns were also influential, with around 40% saying that they or someone they were with recognised the symptoms as a result of such a campaign – 31% specifically referring to FAST campaign messaging.

Only a small number of people (15%) said that they recognised their symptoms as a result of being told about TIA or stroke by a health professional such as their GP.

**Reasons people recognised the symptoms**

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<th>Reason</th>
<th>Percentage</th>
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<tr>
<td>I had had a stroke or TIA before</td>
<td>33%</td>
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<tr>
<td>A relative or friend had had a stroke or TIA before</td>
<td>20%</td>
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<tr>
<td>I/someone else recognised the symptoms from the FAST campaign</td>
<td>31%</td>
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<tr>
<td>I/someone else recognised the symptoms from a different campaign</td>
<td>9%</td>
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<tr>
<td>I/someone else had been told about stroke/TIA by a health professional</td>
<td>15%</td>
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<tr>
<td>I/someone else had been told about stroke/TIA by a voluntary organisation</td>
<td>5%</td>
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No. of respondents = 347
Initially Simon thought his TIA may have been a stroke but because his symptoms were brief, and he had never heard of TIA, he almost dismissed it as a ‘funny turn’.

Simon was a fit and healthy 53-year-old when he had a TIA one evening in October 2011.

“I was clearing the dishes away after having dinner with my wife, Tricia, when I felt a sudden numbness in my left arm and couldn’t get my words out. I had to sit down. I’d seen the FAST ads and it immediately came into my mind that I was having a stroke, which was frightening.

“But it was over within about 30 seconds. Tricia and I talked about whether we should do anything or just put it down to a ‘funny turn’,“ he says.

In the end Tricia called a doctor friend. She advised them to call their out-of-hours GP who dialled 999.

“The emergency response was amazing. Within 20 minutes we had a first responder – two paramedics in a car and an ambulance,” remembers Simon.

“When we arrived at A&E, medical staff were waiting and I was seen within the hour. Some tests were carried out and I returned for more the next day.”

The specialist confirmed a TIA, which was a huge shock to Simon, considering his age and healthy lifestyle. “I’d lost weight, my diet was good and I was in training for a 100km cycle ride,” he says.

However, follow-up appointments revealed that the TIA was caused by atrial fibrillation, a condition that affects heart rhythm and increases risk of blood clots, which in turn increases stroke and TIA risk.

“I was given a folder with information about TIA and how to reduce risk of stroke through diet and lifestyle. It was quite sketchy and not very professional-looking but the consultant was great at explaining everything. I now take medication to control my blood pressure and a drug called warfarin to help prevent my blood clotting.”

Simon hadn’t heard of TIA or its link to stroke risk, which is why he hesitated in getting help.

“There should be more information about TIA. If I’d known about it, I would have called 999 right away. I dread to think what could have happened if I had ignored it and just put it down to a ‘funny turn’,“ he says.

“I dread to think what could have happened if I had ignored it.”
Urgent medical treatment for TIA can significantly reduce the risk of stroke, yet awareness among health and care staff and quality of services vary throughout the UK.

The evidence for treating TIA has developed significantly in recent years, and the need for an urgent response by health and care professionals is now recognised.

Research suggests that urgently investigating and treating people who have a TIA or a minor stroke could reduce their risk of another stroke by 80%, preventing approximately 10,000 strokes a year. The annual cost of stroke to the UK, including direct costs to the NHS and wider costs such as informal care, lost productivity and benefits paid is around £9 billion. Therefore greater provision of rapid treatment for TIA could also result in considerable savings to the NHS and wider economy through stroke prevention.

The development of specialist services for the rapid assessment, investigation and treatment of people with suspected TIA in dedicated settings such as TIA clinics has become a priority in some parts of the UK. However, access to these services is still variable and much more needs to be done to address this.

Recognising symptoms
If people are to fully benefit from advances in TIA treatment, their symptoms must be recognised and they must be considered for urgent referral to specialist services. As we have seen, part of the problem with ensuring access to the best services and treatments is that people experiencing TIA don’t always recognise the symptoms, often delay seeking medical attention or even take no action at all.

Our survey also suggests that there may be some problems with recognition of TIA symptoms and the need for urgent action among health and care professionals. This could also be leading to delays in vital treatment that could help avoid further TIAs or stroke, potentially saving lives and preventing long-term impairment.

Seeking medical attention
Due to the lack of public awareness around TIA, people who sought medical attention did so in a variety of ways:

- 29% made an appointment with their GP
- 25% went to A&E
- 23% rang 999
- 8% rang an NHS helpline.

Others mistook symptoms for an unrelated condition, so took other action such as visiting an optician.

Professional response
Many people commented positively about the initial response they received when they first reported their symptoms. They praised health and care staff who had listened to them, taken the time to understand their symptoms and dealt with their TIA seriously. Here are some of our respondents’ comments:

“I was frightened but all the medical personnel, the fast response, the ambulance, the A&E were fantastic. I couldn’t have been treated any better if I were royalty.”

“From GP to hospital, I had excellent care.”
However, 16% of respondents felt that they were not taken seriously when they described their symptoms and 25% reported that health professionals did not initially recognise that they had had a TIA. In addition, 31% agreed with the statement that health professionals are too quick to dismiss TIA as ‘just a funny turn’.

People commented very strongly on the problems they had experienced with misdiagnosis or the feeling that their symptoms may have been initially dismissed. In some cases, people believe that this had contributed to subsequent strokes:

“I had facial drooping, slurred speech, my entire left side was paralysed and I went to A&E in an ambulance. They admitted me with migraine. I went on to have a stroke the next day.”

“Our GP has told us not to bother to attend GP surgery or A&E as it is not worth it for TIAs.”

“When I mention TIAs, doctor’s response is ‘it’s just a TIA’.”

“I had numerous TIAs that were misdiagnosed as migraine. Sadly my symptoms progressed to strokes, which I believe could have been avoided had the TIAs been correctly diagnosed.”

“Looking back, not sure why GP’s receptionist didn’t tell me to go straight to A&E.”

“The procedure for TIA is wrong. My stroke shouldn’t have happened. Medical staff don’t have enough knowledge of TIA – there should be more awareness.”

**Diagnosis challenges**

We know from speaking to people working in health services that it isn’t always easy to spot if someone has had a TIA. Symptoms have often resolved by the time the healthcare professional sees the patient.

Healthcare professionals often have to rely on reported symptoms, which can be vague. In addition, TIA is a condition with many mimics (conditions with similar symptoms), including migraine, cognitive impairment, visual problems and epilepsy, which means that it can be difficult to diagnose.

However, our survey suggests that more could be done to ensure that all health and care staff can recognise TIA symptoms and understand the need for urgent action.

Training programmes around TIA have been developed for ambulance personnel, staff in GP surgeries and others who may be the first point of contact. Staff in TIA clinics are often keen to help provide training and raise awareness. People who plan and deliver health and social care should consider improving training and increasing awareness of TIA among relevant staff.

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Urgent referral
Besides improving TIA awareness among health and care staff, it’s important that systems are in place at all access points to enable rapid referral of people with suspected TIA for specialist assessment. This will allow any secondary prevention plans that are required to be put in place.

In many parts of the UK, people with suspected TIA will be referred to a TIA clinic where specialists will be able to investigate symptoms, diagnose TIA and decide on the treatment required to reduce the risk of future TIA or stroke.

Current guidelines and best practice for the management and diagnosis of TIA recommend that patients considered to be at higher risk of stroke are referred for specialist assessment, investigation and treatment within 24 hours while those at lower risk should be seen within seven days.


Direct referral pathway
As part of the development of the English National Stroke Strategy, the South Western Ambulance NHS Foundation Trust piloted the direct referral of suspected TIA patients to a specialist TIA clinic, which is now considered to be an example of best practice.

The system attempts to reduce unnecessary delays in assessment, investigation and treatment by identifying patients who are at high and low risk of stroke.

For patients whose symptoms have resolved by the time the ambulance arrives, ambulance clinicians use a set of criteria to assess stroke risk. High-risk patients are taken straight to A&E, while low-risk patients are left at home, referred directly to the TIA clinic and provided with aspirin.

Every ambulance has information about TIA and the referral pathway as well as patient information packs, which they can leave with those who have been referred.

Efforts to educate and train staff to recognise TIA symptoms and take appropriate action are a priority. All ambulance clinicians in the Trust receive training on stroke/TIA recognition, assessment and management. Online education and training in stroke/TIA care is also available. Email James.Wenman@swast.nhs.uk for more information.

Of the survey respondents who were referred to a TIA clinic, nearly a quarter (22%) said they had to wait for more than a week before their first appointment. This suggests that improvements are needed to speed up the process.

Innovative approach
In some parts of the UK, innovative methods are being introduced to achieve this. This has included better training for health professionals on patient referral; the development of streamlined referral routes, including the use of online tools; the utilisation of telemedicine for remote specialist TIA assessment and the redesign of pathways to allow more rapid direct referral by a range of healthcare professionals, including paramedics.

There is also scope to improve access to specialist TIA clinics in many parts of the UK. This includes developing new services in areas where provision isn’t currently available and making the services that already exist available seven days a week.
**TIA service redesign**

Staff at Southend University Hospital have developed an innovative referral system and improved access to specialist services to ensure the rapid assessment, investigation and treatment of TIA patients.

Prior to recent changes, the TIA clinic at Southend University Hospital was only open Monday to Friday and could only see three patients a day. In addition, half of the patients seen who were at high risk of stroke were already outside of the 24-hour period recommended for assessment, and the same number had been given the wrong risk score by their GP.

In September 2012, a rapid-access, hyper-acute online referral system (HOT-TIA) was set up for GPs and other services, which automatically assesses the patient’s risk of stroke and sends the information direct to the TIA clinic team or mobile. The system also instantly provides GPs with a checklist regarding immediate treatment and advice that should be provided, and information for the patient to take away.

Access to the TIA clinic was extended to seven days a week and designed around patient needs. All tests, including magnetic resonance imaging (MRI) scans and carotid ultrasound, can be carried out and treatment started on the same day. This was achieved by training more clinic staff to carry out ultrasound tests and changing MRI scan protocols so that patients can be seen seven days a week and fitted in between the routine list.

All high-risk TIA patients are now treated within 24 hours and all low-risk patients are seen within a week, meeting current guidelines. There have been improvements in the information given to patients at the clinic and at point-of-referral, plus people can be referred to the stroke team clinical psychologist if required.

The new HOT-TIA system has won several national awards and the team believes it has great potential to be rolled out. For more information, email TIA@southend.nhs.uk

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**Calls to action for planners and providers of health and social care**

- Put in place training and communication activities to ensure that all staff who are the first points of contact for patients are able to recognise TIA symptoms and understand the need for urgent action.
- Ensure that systems are in place to enable rapid referral of people with a suspected TIA for specialist assessment, investigation and treatment.
- Ensure that access to specialist TIA assessment, investigation and treatment services such as those provided by TIA clinics are available seven days a week, across the UK.
When Susan, 47, went dizzy and couldn’t see out of her right eye, she didn’t hesitate in seeking help. At the time – July 2012 – she worked for the NHS, implementing treatment plans for stroke survivors, so recognised the potential symptoms.

“A colleague took me to A&E, where I waited most of the afternoon for a CT scan but nothing showed up. I was diagnosed with a migraine, referred to an ophthalmologist and sent home,” she says.

However, the next day her sight had still not returned. “I saw the ophthalmologist who referred me to the TIA clinic and told me I’d be seen very quickly but by the following day I’d heard nothing.”

Susan called the clinic but was told the next available appointment was in a week’s time. “I insisted it was urgent and managed to get an appointment for 2pm that afternoon but by 12.30 it was too late – I was having a stroke,” she says.

Susan was with her mother and a friend, both healthcare support workers, when she suddenly experienced weakness down one side and a loud ringing in her ear. Her mother dialled 999 but the ambulance took 30 minutes to arrive.

“After I told the A&E doctor about my appointment at the TIA clinic, he insisted that I had to go, despite the fact that I was clearly unwell. Perhaps because I didn’t have the classic face-drooping, he didn’t believe I was having a stroke,” she says.

“During the appointment my eyesight deteriorated, I was nauseous, my balance went and I couldn’t sit upright in the wheelchair. I was taken back to A&E.”

Tests finally confirmed that Susan had had a stroke. “I can’t stop thinking I should have gone to A&E after seeing the ophthalmologist – I knew it was urgent from my experiences with stroke survivors,” she recalls.

Susan can no longer work after the loss of vision on the right side of both eyes, a condition called hemianopia.

“I’ve lost some of my sight, I can’t work or drive and I suffer from dizziness, headaches and low confidence. I’m lucky that I can still be there for my son, nine, and daughter, four, but I worked for the NHS for 29 years and know my stroke shouldn’t have happened. Staff don’t have enough knowledge of TIA. They need to be supported to understand TIA so a stroke like mine can be prevented,” she says.
“Staff...should be supported to understand TIA so a stroke like mine can be prevented.”
The right information and support is vital to help people make their best recovery, yet our survey revealed that many are not receiving this. We asked people what would have helped them most.

The lack of awareness of TIA and its link to stroke means that diagnosis comes as a complete shock to most people who have one. Our survey shows that many people who have a TIA could be helped to respond to their diagnosis by better access to quality information, advice and support.

For many people, such help is currently lacking. Having access to information helps people understand what has happened to them and explains ways in which they could reduce their risk of further TIAs or strokes. Our survey respondents say:

“After TIA I had no support or advice or information...I didn’t know about risk of stroke – was not told this by anyone.”

“GP told me I had a TIA but never told me it was a mini/warning stroke.”

**Poor information**

Our survey revealed that:

- Nearly 40% of people had been given little or no information on what a TIA is.
- Nearly 40% had been given little or no information about what a stroke is.
- More than half (51%) had been given little or no information about the link between stroke and TIA.
- 56% had had little or no information about treatments available related to TIA.
- Around 50% had received little or no information and advice about the changes they could make to their lifestyle to reduce their risk of further TIAs or strokes.
- Over 70% said they had been given little or no information about other organisations that may be able to help with advice or support such as the voluntary sector.

**What is needed**

Information provision must start with helping people to understand what has happened, develop a basic understanding of TIA and stroke, how the two are linked and how future TIAs or strokes can be prevented. When people are equipped with the right information, it allows them to make clear decisions and understand the range of options open to them. To fill this information gap, people used a variety of research tools:

- internet research (45%)
- the Stroke Association website (41%)
- NHS websites (38%)
- Stroke Association leaflets or factsheets (33%).

In comparison, very few used NHS or voluntary sector helplines.

“In my NHS experience, I was not given information or advice on either stroke or TIA. I had to be self-informed and I was so grateful to find the Stroke Association website.”
What people want

People had many ideas about what information, advice and support would have been useful to them. Information must be accessible, appropriate and delivered at the right time. Here are some of their comments:

“On the whole, I was given plenty of very helpful information. My main problem was that, having just had the TIA, I wasn’t really with it. Much of the information passed me by.”

“Information would have been useful from day one, not on the day I left hospital.”

“Plain speak by doctors and less jargon. Need to explain clearly to the patient what is happening to them.”

Written information was helpful but many people would also like someone to talk to:

“I would have liked to have known who I could call for advice during my recovery time at home.”

“Perhaps a visit from someone who had suffered TIA or stroke as I found the situation a very lonely experience.”

We were told that people would welcome hearing about others’ experience of TIA:

“I think more case studies would be useful ie, what happened to me, the effect it is having and how I am coping.”

“Referral to a stroke support group or to a buddy to explain what was going on and the after-effects. I was left in limbo by the NHS.”

People would like to be directed to other organisations that may be able to offer them information, advice and support:

“The Stroke Association information is really good but I wasn’t made aware of it at the time I had my TIA.”

“The TIA clinic putting me in touch with organisations such as yourselves may have helped...”
“There were no local aftercare services for emotional wellbeing.”

‘I felt vulnerable afterwards’

It’s nearly three years since Yvonne, 56, was diagnosed with a stroke. Tests also revealed she’d had four TIA’s. She’d first gone to her GP after becoming dizzy in the swimming pool but strength, balance and blood pressure tests proved normal.

However when she couldn’t lift her left leg fully walking up the stairs the following day, she knew something was wrong. “I called my GP and this time he told me to go to A&E,” she says.

“Finding out about the TIA’s was a shock as I hadn’t noticed anything out of the ordinary until the day in the pool. I had heard of TIA’s before but I didn’t expect to have one, or a stroke, in my mid-50s.” Now, Yvonne still has a weakness down her left side and has taken ill-health retirement from her job as a secretary.

“The stroke unit gave me plenty of information about TIA and strokes and they referred me to the community stroke team, which sent someone to visit regularly. I was also given information about diet and lifestyle, which I’ve tried to incorporate.”

However, one area in which Yvonne would have liked more support was the emotional side.

“I felt vulnerable afterwards and at the time there were no local aftercare services for emotional wellbeing, such as counselling, which I feel I would have benefited from.

“I’m now about to get involved in a befriending service, set up by the Stroke Association, to help others who have recently been through similar experiences.”
Stroke Association TIA support service

Through the work carried out at the Stroke Association’s Community Groups in Bridgend County, Wales, we are supporting people who have had TIAs, including some who have gone on to have strokes.

We are currently running a course entitled *Eat Healthily* to ensure that people are aware of what constitutes a healthy diet. This can be vital for promoting weight loss, reducing TIA and stroke risk factors such as high blood pressure and high cholesterol.

However, the main benefit of attending our community groups is that people can talk to and support each other. There is little or no psychological support for stroke survivors in Bridgend County, so the community groups are lifelines.

We also have exercise classes running in partnership with our local leisure centre and as part of the GP referral scheme. People can take part in the classes at our group then access a stroke-specific hydrotherapy session at the leisure centre and a stroke-specific falls-prevention class.

We also have a share in an allotment, and encourage our service users to grow vegetables, which they can then take home to eat.

In Bridgend, we ensure we hold regular community events so that we can promote the FAST message. The majority of the people who attend and/or support our community groups are now very aware that TIA needs urgent intervention. For information, visit stroke.org.uk/cymru

How the Stroke Association can help

**Online information**
People can be directed to our website, which provides expert information on all aspects of stroke, including TIA. Visit stroke.org.uk

**Stroke helpline and information service**
Call our stroke helpline (0303 3033 100) or email us at info@stroke.org.uk for information and guidance on all aspects of stroke including TIA. Visit stroke.org.uk/support/helpline

**Publications and leaflets**
We provide an extensive range of publications about stroke, including a factsheet and information leaflet on TIA. Download for free from stroke.org.uk/eshop or order hard copies.

**Online discussion forum**
This tool enables people who have been affected by TIA to share their stories and experiences. Visit stroke.org.uk/talkstroke

**Prevention and support services**
In some areas, we already provide services to help prevent stroke or support those who have experienced TIA. We can also assist in the development of those services. Call 020 7566 0310 or visit stroke.org.uk/contact/professional

**Calls to action for planners and providers of health and social care**

- Ensure that people who have been diagnosed with TIA are provided with the information, advice and support they need in an accessible and timely manner.
- Improve signposting of people diagnosed with TIA to NHS and other sources of information, advice and support, such as the Stroke Association and other national and local patient organisations.
In July 2013, Janet, 77, woke in the early hours of one morning in a hot flush.

“I tried to throw the bed covers off but I couldn’t use my left arm and leg. I thought I must have slept in the same position for too long and went back to sleep. Then I woke again and tried to go to the bathroom, but fell to the floor several times because I couldn’t move my left leg,” she remembers.

“My face had also dropped on the left side, but I only realised this when my husband, Mart, saw it. I’d seen the FAST adverts on TV and recognised the symptoms. We went straight to A&E.”

When the couple reached the hospital, Janet fell to the floor while speaking to the nurse. This turned out to be her third TIA.

“I was extremely fortunate because we recognised the signs and acted straight away,” she says.

Janet was discharged the next day with blood pressure medication, a statin to lower cholesterol, and aspirin, which was changed two weeks later to another anti-clotting medication. However, apart from a visit by a physiotherapist, she received no further advice or support.

“I’d never heard of TIA and assumed I’d had a stroke until I saw ‘TIA’ written on the discharge letter I was given. No one mentioned it to me, never mind explaining what it was, or that it increased my stroke risk.

“I was told that someone who could give me lifestyle advice would get in contact but it never happened.

“I was given no information about diet or other ways to reduce my risk and I’ve since taken it upon myself to switch to low-fat milk and olive oil spread instead of butter. When healthcare staff promise to follow up, they should get in contact,” she says.

Janet felt weak for a long time afterwards and still gets tired more easily.

Janet only learned she had had a TIA when she looked at her hospital discharge letter. She received no explanation about the condition and its risks and no follow-up support or health and lifestyle advice.

“I was told that someone who could give me lifestyle advice would get in contact but it never happened.”
It is often assumed that TIA has no long-lasting effects, yet people told us that they experienced problems ranging from muscle weakness, poor memory and fatigue to anxiety and panic attacks.

The current understanding of TIA is that symptoms are short-lived and there are no long-lasting effects. However, this wasn’t reflected in our survey, with the majority of respondents feeling that the TIA had affected their lives.

Our results support the findings of the limited research that has been done into the impact of TIA, which indicates that people may experience long-term physical or clinical problems, functional impairments, cognitive problems and reduced quality of life.

Physical or clinical problems
In our survey, around 70% of people reported that their TIA had long-term effects. They described a range of effects, including memory loss (41%), muscle weakness (38%), poor mobility (25%), confusion (26%), problems with speech (21%) and difficulty in understanding (18%).

People also mentioned tiredness and fatigue, ongoing visual problems, loss of balance and continuing numbness or loss of feeling in an arm or leg. Some people reported just one long-term effect, while others noted several.

“Twelve months later my mouth is still slightly drooped and I struggle with putting on jackets. However, I’ve been told by my doctor that it was a TIA and not a stroke.”

Survey respondent

Emotional fallout
Over 60% of people stated that their TIA had affected them emotionally. People recounted that they felt vulnerable following their TIA and experienced a loss of confidence, particularly when leaving the house. People told us they experienced a wide range of emotions, which often caused considerable distress.

Anxiety
Respondents mentioned anxiety, panic attacks and depression.

“It has affected me mentally. Shock to everyone because I look so healthy. Years later, still feel anxious it might happen again.”

“Overall this has had a huge impact as it has affected my work, confidence and mentality.”

Shock
Almost all of the people in our survey described how the diagnosis of TIA came as a shock to them.

“Could not believe the diagnosis and found it hard to come to terms with this.”

Guilt
Some people had regrets or felt guilty because they had not taken action earlier.

“I should have reacted to first symptoms.”

Specific worries
Most people were worried that they would have another TIA (73%) or a stroke (70%) in the future.

“Immense impact, each day I am still aware I could suffer a further TIA.”
People were also worried that the TIA would affect their job, with 58% of those of working age expressing concern about this. Subsequent restrictions on driving were mentioned as problematic. Others were anxious that it could impact on their relationship with a partner (35%), possibly because of the emotional strain the experience had put them under.

**Need for support**
Although some people said they were offered emotional support such as counselling after their TIA, others weren’t and felt this could have benefited them.

“Almost felt like a near-death experience – keep thinking what might have happened and can’t forget...I couldn’t talk to anyone about it, offered no counselling. The doctor and family just said think yourself lucky, you had a lucky escape, now get on with your life – but you can’t just forget about it, it never gets out of your mind.”

The long-term impacts of stroke are well known. Although there is still much work to be done, improvements in long-term aftercare for stroke survivors, including treatment of physical, psychological and emotional needs, are an increasing priority for health and social care providers throughout the UK.

In contrast, current TIA treatment in the UK focuses on prevention of future stroke. Little consideration is given to psychological or cognitive impacts of TIA and patients are not routinely offered rehabilitative support. However, untreated fatigue and psychological or cognitive impairment will result in reduced quality of life and affect people’s abilities to return to work and social activities.

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**Calls to action for planners and providers of health and social care**
- Consider the possible longer-term impacts of TIA and assess if current treatment options, particularly with regard to emotional support, help people to make their best possible recovery.
- Make sure there is a clear route to access reassessment, advice and support for people who report long-term effects of TIA such as fatigue, mobility problems and confusion.

**Call to action for the research community and research funders**
- Conduct further research into the long-term effects of TIA and the most effective management strategies to address them.

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‘I had severe panic attacks’

Anxiety after his TIA meant that Peter virtually stopped going out until counselling helped him to deal with his fears.

Peter Tugwell was a healthy, active 24-year-old when a TIA changed his life one day in August 2013.

“I’d just come in from the garden and was talking to my mum. The first thing I noticed was pins and needles in my right arm, then I couldn’t move my arm or grip with my hand. My speech was slurred but I managed to say, ‘I think I’m having a stroke.’ Then I slid down the wall and ended up in a heap on the floor,” he recalls.

“Mum rang for an ambulance. The rapid response paramedic arrived very quickly but the ambulance took an hour. Finally, I was taken to A&E. I’d recognised the stroke symptoms from the FAST campaign but the paramedics and some of the nursing staff said I was too young.”

Peter was sent for tests, which confirmed a TIA. “I’d never heard of TIA before but the team at the TIA clinic gave me information on what it is, how it’s linked with stroke and how your stroke risk is higher in the first few weeks. I was also given diet and lifestyle advice,” he explains.

Peter was prescribed medication to help prevent blood clots and has cut down on processed meats like bacon and ham and joined a gym.

However, despite extensive tests, no physical cause of the TIA has been found. “The staff said that although I should try to lose weight, being overweight was not the cause. My heart rhythm, blood pressure and cholesterol are fine, I don’t smoke and I have a fairly active job as a residential cleaner, which involves going up and down stairs,” says Peter.

For several months, the fear of another TIA triggered severe panic attacks. “About a week afterwards, I felt pins and needles in my arm, thought I was having another TIA, and ended up in hospital. What I didn’t realise is that a panic attack can also cause pins and needles and numbness.

“After the diagnosis, the seriousness had sunk in. I was worried that if I had another TIA when I was out and I was slurring and stumbling around, people would assume because of my age that I was drunk. I virtually stopped going out, apart from to work,” he remembers.

Peter’s panic attacks became more frequent, up to a couple of times a day. He says: “I began to feel suicidal and my GP referred me for counselling. This has really helped and I’ve now got my life back on track.”

“I began to feel suicidal and my GP referred me for counselling.”
After a TIA, many people want to make positive lifestyle changes, yet our survey found that support to help them do this is limited, with potential costs to individuals’ health and the NHS.

For 68% of respondents, having a TIA acted as a ‘wake-up call’, with the shock of diagnosis motivating nearly two-thirds of people to make lifestyle changes to reduce their risk of further TIAs or stroke. However, support to make such changes appears to be limited, and as a result, opportunities to help prevent future strokes are being missed.

After the event
Following diagnosis of a TIA, it’s important that immediate steps are taken to reduce the risk of stroke – for instance through medication or surgery – and that an individualised and comprehensive strategy for preventing future events is maintained throughout a person’s life. For this to happen, the necessary information, advice and support must be made available to people who have been diagnosed with TIA.

Lifestyle changes
Stopping smoking, eating more healthily and cutting down on, or cutting out, alcohol were changes people were motivated to make after their TIA. Some also changed their working patterns or gave up stressful elements of their lives, while others talked about taking part in more physical exercise and adhering more fully to their medication regimen. Here are comments from two survey respondents:

“It made me think more carefully about my lifestyle. I eat more sensibly – less fat and more fruit and veg. I also try to get more exercise. I have lost just over a stone in weight.”

“Completely changed my life. I am trying everything I can to prevent future episodes.”

Missed opportunity
Despite the post-diagnosis period being a time when people are clearly motivated to make lifestyle changes, our health services seem to be missing an opportunity to build on this.

Although the vast majority of people reported having their condition managed with medication, only 23% said that they’d received support to help them make lifestyle changes as part of their treatment.

As highlighted earlier in this report, people described the information they’d received about TIA and stroke as inadequate, and around half told us that they had received little or no advice about making lifestyle changes to reduce their future risk.

Some people also reported struggling with lifestyle adjustments that had been recommended to them and said they would welcome more personalised and individual support to help them reduce their risk. Here are two examples:

“Support in losing weight and stopping smoking rather than just telling me and then expecting me to do it.”

“Formal in-depth classes on how to eat and exercise to reduce the risk of this happening again, or worse.”
Positive outlook

Despite the emotional turmoil of TIA, some people were able to draw positives from the experience:

“Learned to relax and try not to stress out. Live life at a more steady pace. Realised that my family and friends are really important.”

“1 Surprise. 2 I learnt more about strokes and TIAs. 3 I carried on enjoying life as much as before.”

Others used their experience to help spread awareness of TIA:

“I’m now a great advocate for passing on the FAST message and advising on blood pressure – too late for me but hopefully not for others.”

Those who plan and provide health services would do well to engage with people who have had TIAs or strokes and support them to share their stories.

Structured support

In parts of the UK, there are structured cardiac rehabilitation programmes that provide exercise and information sessions for heart patients. The aim is to help them make lifestyle changes and get back to everyday life as successfully as possible.

Some early pilot studies have suggested that TIA patients may benefit from participation in ‘cardiac-style rehabilitation programmes’ and some services do now exist that provide such support for TIA patients.

However, currently the use of such an approach for people who have had a TIA is limited, despite the fact that both conditions share similar risk factors, age profiles, incidence levels and increased risk of future vascular events.

 Calls to action for planners and providers of health and social care

- Ensure information, advice and support is available to those who have had a TIA to enable them to make lifestyle changes and so reduce their risk of future TIA and stroke.
- Consider adapting existing structured rehabilitation programmes for other conditions to meet the needs of people after TIA.
- Engage people with personal experience in spreading awareness of TIA and the importance of preventative action.

Call to action for the research community and research funders

- Conduct further research into establishing the best possible model of rehabilitative support specifically for people who have experienced TIAs.

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1 Hillsdon K M, Kerston P, Kirk JS H, A qualitative study exploring patients’ experiences of standard care or cardiac rehabilitation post minor stroke and transient ischaemic attack, Clinical Rehabilitation, 27 (9) 845–853, October 11, 2013, doi: 10.177/0269215513478956
In 2013, Margaret, 70, began to experience TIA symptoms while walking down the stairs at home.

“My right arm and leg and the right side of my mouth all started to go numb and I began to feel dizzy. I tried to call upstairs to my husband, Sandy, but no words came out. I couldn’t communicate and I was terrified. Sandy came downstairs and found me. He called our GP right away,” she remembers.

The doctor arrived quickly and, suspecting a stroke, she called an ambulance.

“In retrospect, we should have called an ambulance straight away but because we live in rural Scotland, we felt it would be quicker to see the GP,” explains Margaret.

The whole experience came out of the blue. “The only time I’d gone to the doctor in the past year was for a flu jab,” she says.

Margaret had a scan and was given medication to stop further damage. She reacted well to her treatment, her symptoms disappeared and she hasn’t had any long-term effects, although she says, “I was a bit wary at first of being at home on my own.”

Margaret is now taking a statin, a blood-thinning drug and medication to control her blood pressure. She describes the information and support she received after her six days in hospital as “tremendous”.

“A stroke nurse visited and explained about the link between stroke and TIA and gave me lots of advice about exercise and losing weight. She also told me about a local exercise class, specially for people recovering from strokes, and now I go every week. I have an exercise bike at home, do more walking and have cut down on fatty, sugary foods. I feel much healthier now – the whole thing has been a wake-up call,” she says.

Impressed with the information and support she received after her TIA, Margaret has taken up exercise and improved her diet and lifestyle.
Our calls to action

Everyone who experiences a TIA deserves the highest standard of treatment and support to help them make their best possible recovery and reduce their risk of the devastating effects of stroke.

For planners and providers of health and social care

1. Continue to run public health initiatives including stroke awareness campaigns to ensure that as many people as possible recognise the symptoms of stroke and seek emergency action.

2. Ensure more prominent and tailored messages on TIA feature in national and local stroke-awareness campaigns.

3. Put in place training and communication activities to ensure that all staff who are the first points of contact for patients are able to recognise TIA symptoms and understand the need for urgent action.

4. Ensure that systems are in place to enable rapid referral of people with a suspected TIA for specialist assessment, investigation and treatment.

5. Make sure that access to specialist TIA assessment, investigation and treatment services, such as those provided by TIA clinics, are available seven days a week, across the UK.

6. Ensure that people who have been diagnosed with TIA are provided with the information, advice and support they need in an accessible and timely manner.

7. Improve signposting of people diagnosed with TIA to NHS and other sources of information, advice and support, such as the Stroke Association and other national and local patient organisations.

8. Consider the possible longer-term impacts of TIA and assess whether current treatment options, particularly with regard to emotional support, help people to make their best possible recovery.

9. Make sure there is a clear route to access reassessment, advice and support for people who report long-term effects of TIA such as fatigue, mobility problems, memory loss and confusion.

10. Ensure information, advice and support is available to those who have had a TIA to enable them to make lifestyle changes and so reduce their risk of future TIA and stroke.

11. Consider adapting existing structured rehabilitation programmes for other conditions to meet the needs of people after they have experienced TIA.

12. Engage people with personal experience in spreading awareness of TIA and the importance of preventative action.

13. If you are involved in activity to help raise awareness of TIA among the public, health or care staff or have examples of TIA service improvement work, please get in touch via campaigns@stroke.org.uk or #ministroke.

Not just a funny turn
For the research community and research funders

1. Conduct further research into the long-term effects of TIA and the most effective management strategies to address them.

2. Conduct further research into establishing the best possible model of rehabilitative support specifically for people who have experienced TIA.
Acknowledgements

**Not just a funny turn**

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We are the Stroke Association

We believe in life after stroke. That’s why we support stroke survivors to make the best recovery they can. It’s why we campaign for better stroke care. And it’s why we fund research into finding new treatments and ways of preventing stroke.

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