

Joint Stroke Strategy 2011-2016

A Summary of Submissions received in response to Consultation

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1. Introduction

Public consultation on Enfield's Joint Stroke Strategy (2011-2016) took place from 1 March 2011 to 20 May 2011. 148 responses were received from a wide range of people and groups, including people who have had a stroke, families and carers, voluntary sector organisations and health and social care bodies.

This report highlights the findings from the consultation which include the importance of training, awareness raising and increased provision of community rehabilitation and support services. This report then sets out the joint response from the Council and NHS Enfield and summarises how responses to the consultation have influenced the final strategy.

2. Consultation process

Formal public consultation on the draft stroke strategy was undertaken over a 3 month period from 1 March to 20 May 2011. Whilst all members of the general public were invited to respond to the consultation, the engagement process specifically targeted the following groups:

- Service users of health and adult social care services
- Patients of NHS services
- Carers of people with a disability, or who are frail
- Stroke survivors
- People with a family history of stroke or Transient Ischaemic Attack (TIA)
- People of African or Caribbean ethnicity
- People aged over 55 years and over
- Edmonton Green Ward.

Stakeholder and public views on the strategy were sought through the following means:

- The Enfield Council website:
 - People were invited to comment on the draft strategy by answering a questionnaire, which was available on the Enfield Council website, or completing a hard copy version on request.

- Live consultation events were held with:
 - Health and Social Care Partnership Boards
 - Health and Social Care Scrutiny Panels
 - Older People’s Conference
 - Ebony People’s Association
 - Age Concern exercise classes
 - Enfield Stroke Survivor and Family group
 - Nursing Homes and Care Homes
 - Total Healthcare
 - Enfield Carers UK
 - Different Strokes
 - Acute Stroke Unit at North Middlesex Hospital and Barnet Hospital
 - Two events organised by Enfield Council – Pymmes Park Visitors Centre, Edmonton and Trinity-at-Bowes Community Centre, Palmers Green.

The consultation was publicised through the following means:

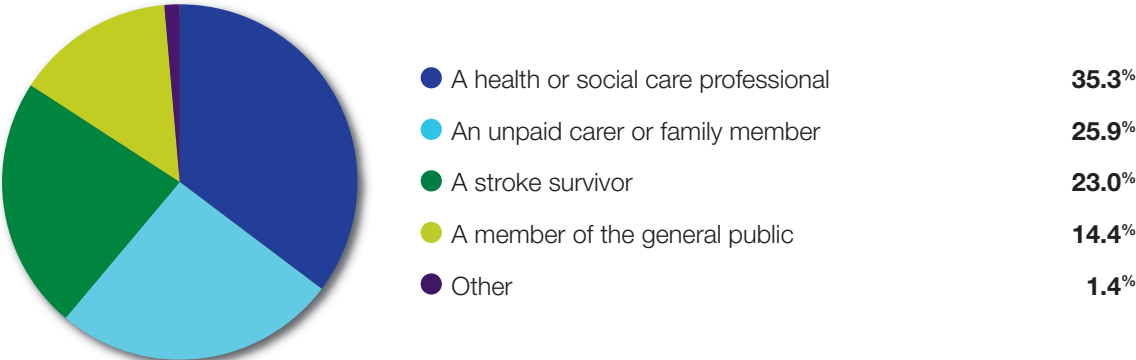
- A poster was distributed to hospital wards, GP surgeries, Council receptions, community and voluntary organisations. The poster was designed with stroke survivor and carer input.
- The consultation was also publicised through professional and public newsletters and websites. These included:
 - Staff Matters
 - Team Brief
 - Enfield Community Empowerment Network (ECEN)
 - Enfield Voluntary Action (EVA)
 - NHS London website
 - Enfield Council website
 - North Middlesex Hospital website
 - Attend website
 - Enfield Over 50s Forum
 - Different Strokes website
 - Enfield Independent newspaper
 - Enfield LINK.

3. Participation Statistics

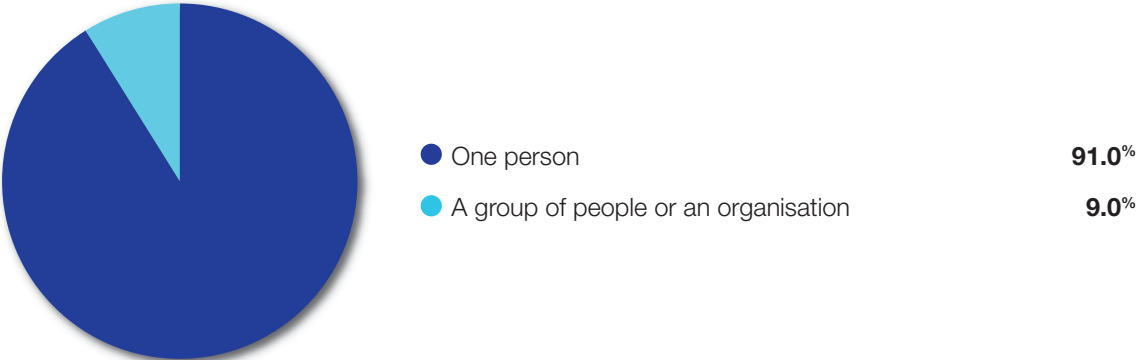
148 responses to the consultation were received. Respondents were asked a series of personal and organisational questions and this section displays the results of these questions.

Please note, figures have been rounded to the nearest whole number and in some cases the total percentage may not add up to 100%.

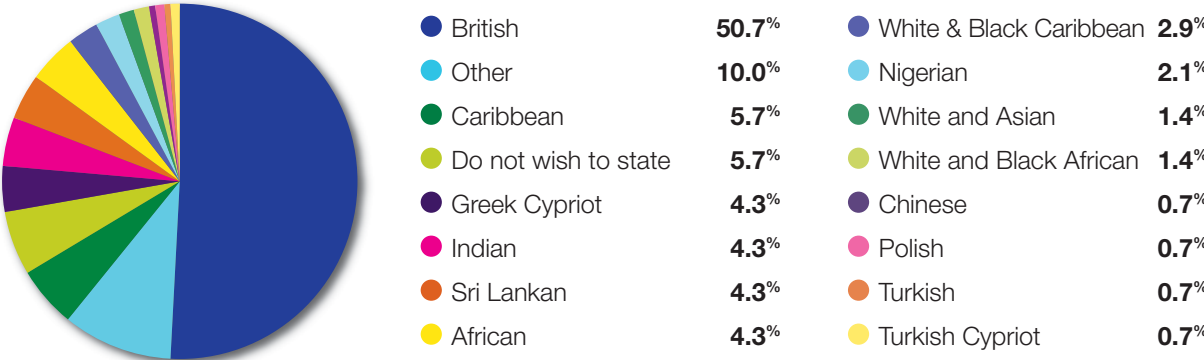
3.1. Who are you?



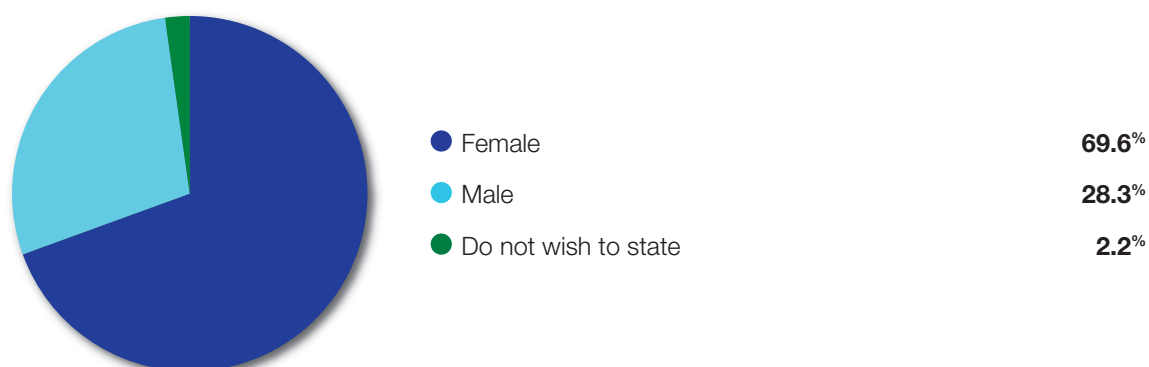
3.2. Is your response from one person or a group of people?



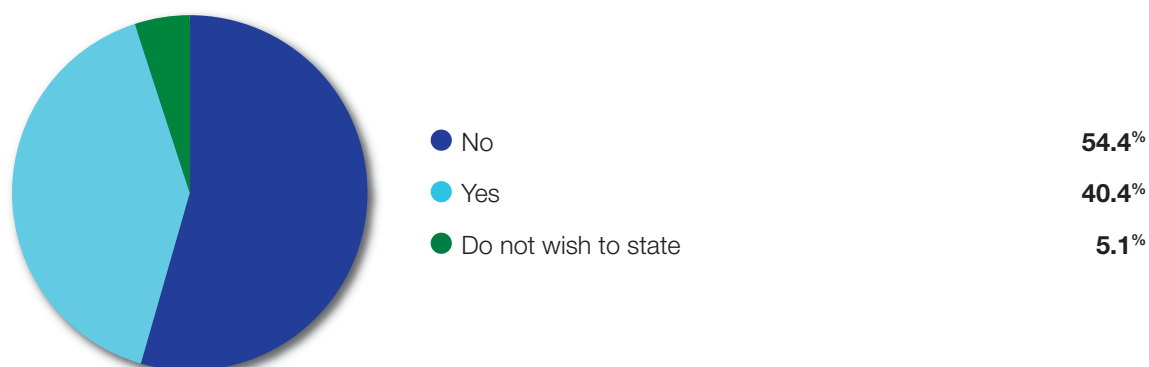
3.3. What is your ethnicity?



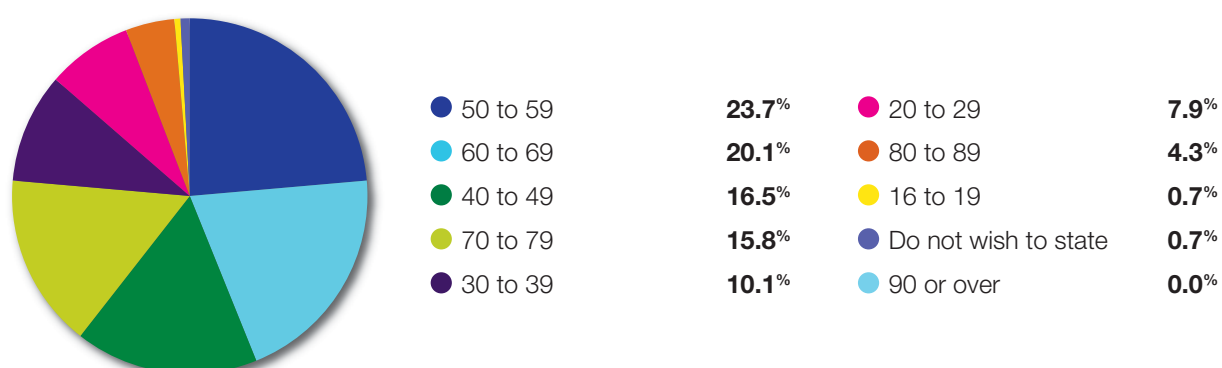
3.4. What is your gender?



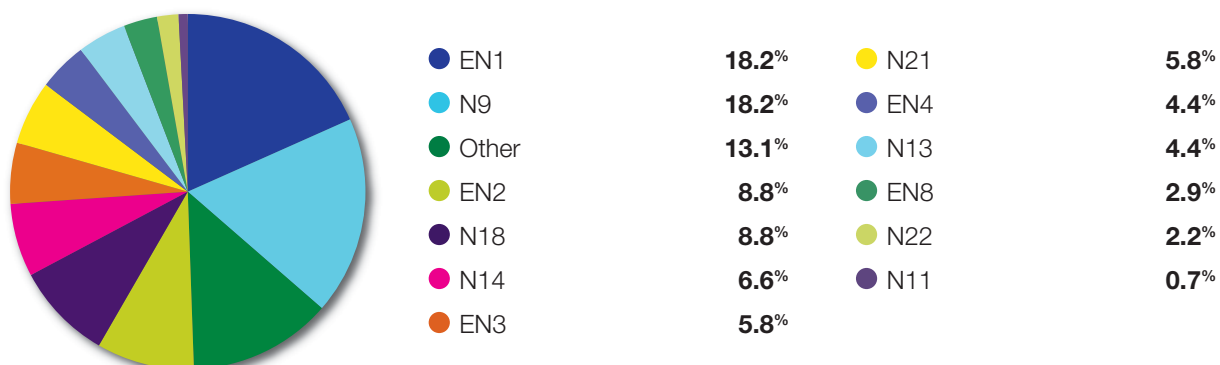
3.5. Do you consider yourself to have a disability or long-term illness?



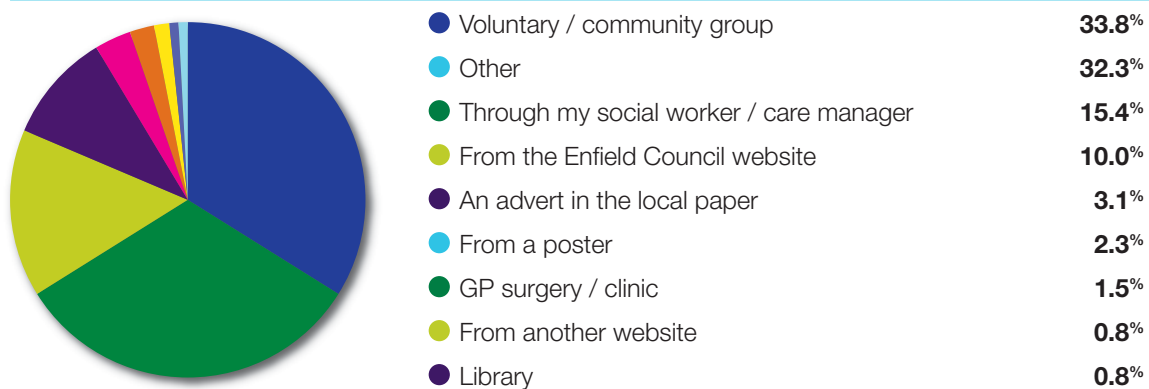
3.6. How old are you?



3.7. Where do you live?



3.8. How did you find out about this questionnaire?

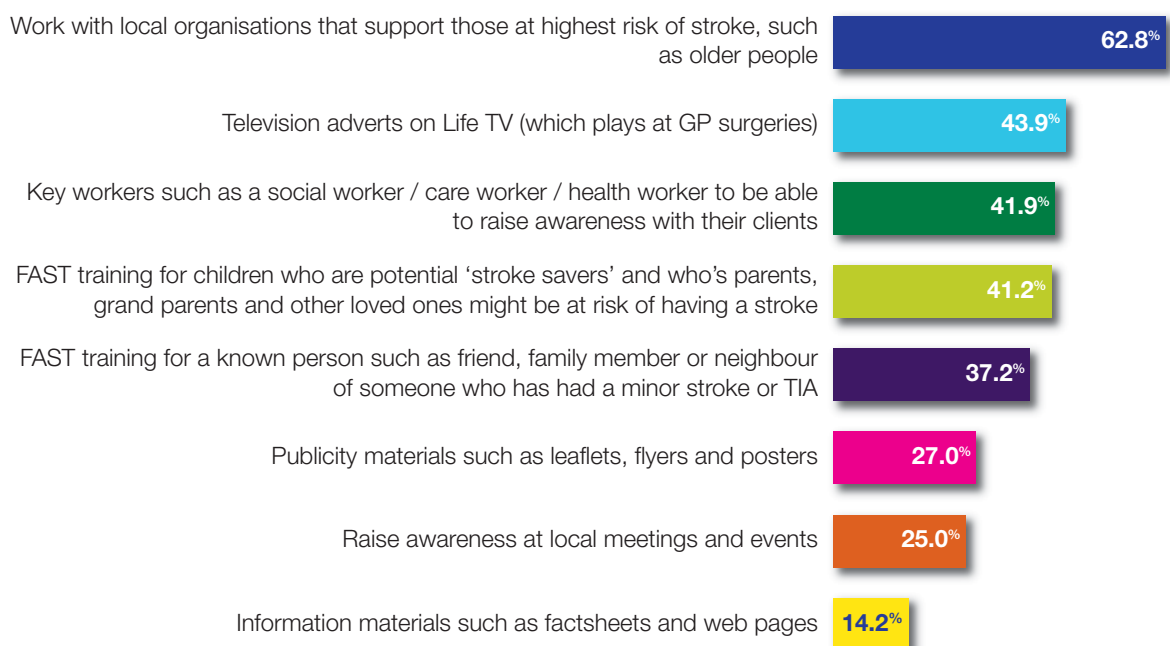


4. Summary of Submissions

The first nine questions that participants were asked gave people a number of choices to respond to. The results are summarised below:

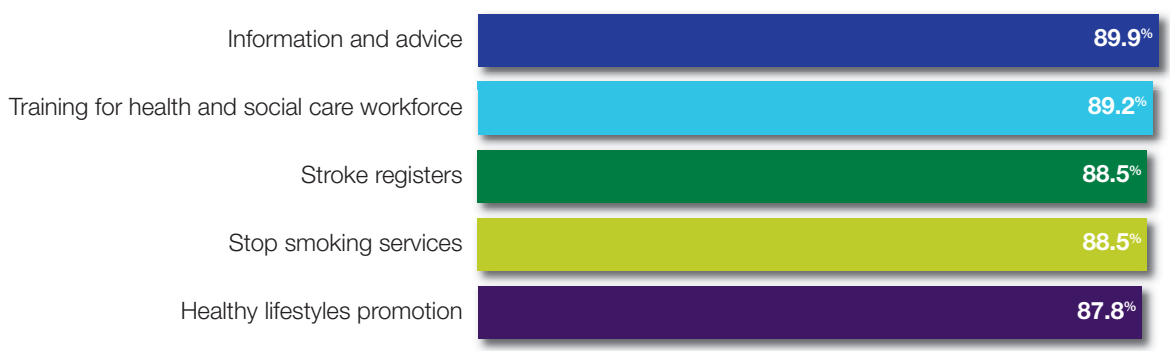
1. The sooner somebody who is having a stroke gets urgent medical attention, the better their chances of a good recovery. We will be running local awareness campaigns, initially targeting those at highest risk of stroke.

Please select those you feel would be the best way to raise awareness about stroke especially with those at highest risk.



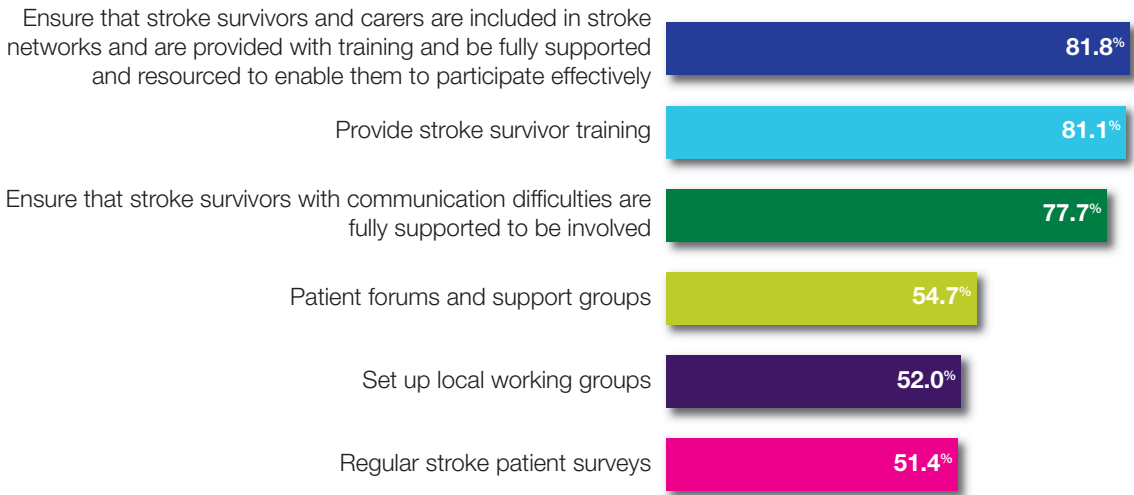
2. To reduce the chance of strokes and minor strokes in people who have a TIA (Transient Ischaemic Attack) or a minor stroke, we will ensure that there are local prevention systems in place.

From the options below please rank these prevention services in order of importance (with 1 being low and 5 being high level of importance).



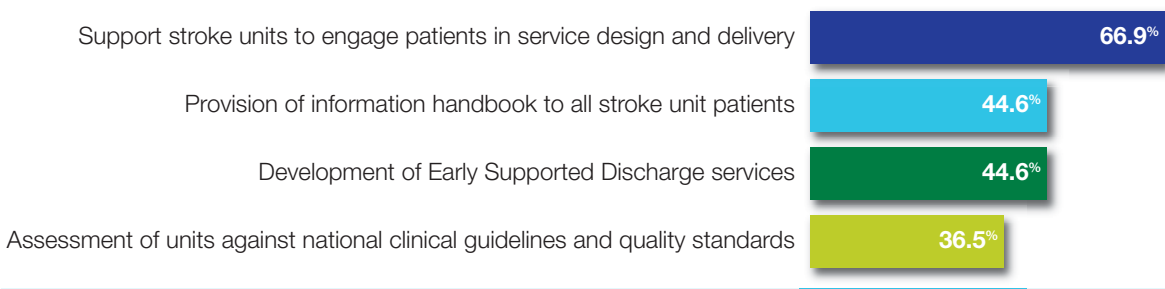
3. We will be creating more opportunities to involve service users and carers in the planning, development and delivery of services. This will improve the quality of current services and lead to better outcomes.

From the options below, please select the best ways we should involve service users and carers in the planning, development and delivery of services.



4. We will be working with patients, family members and carers to improve the quality of local acute stroke units to provide care and meet their needs.

From the options below please select the two you feel would most contribute to improving Enfield acute stroke units.



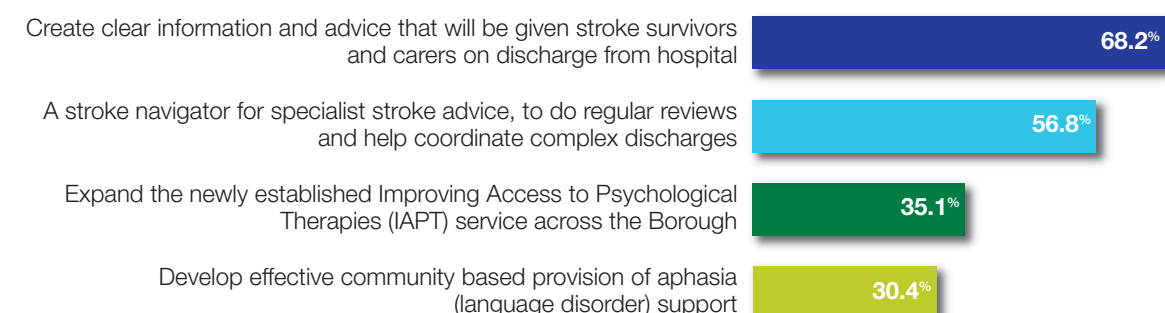
5. One of the ways we are planning to improve Enfield services for stroke survivors is by improving access to rehabilitation and community services.

From the options below please select the two that you feel are the most important to you.



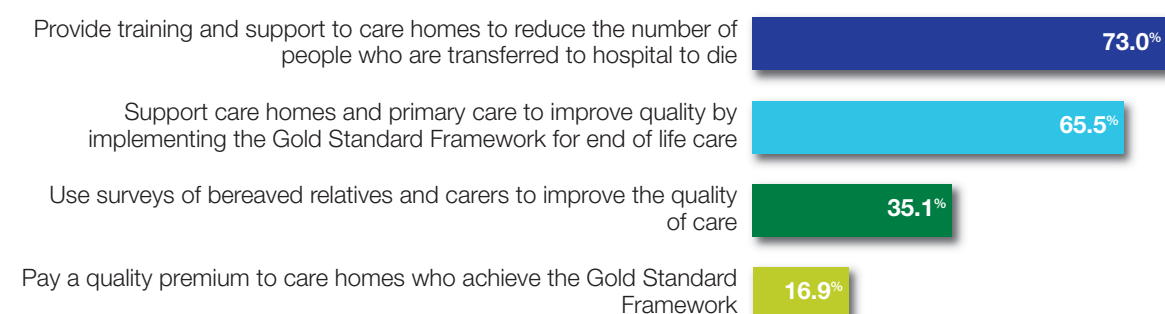
6. We will be developing services to support stroke survivors to overcome physical, communication and psychological barriers to take part in community activities and move on after a stroke.

From the options below please select the two that you feel are the most important to you.



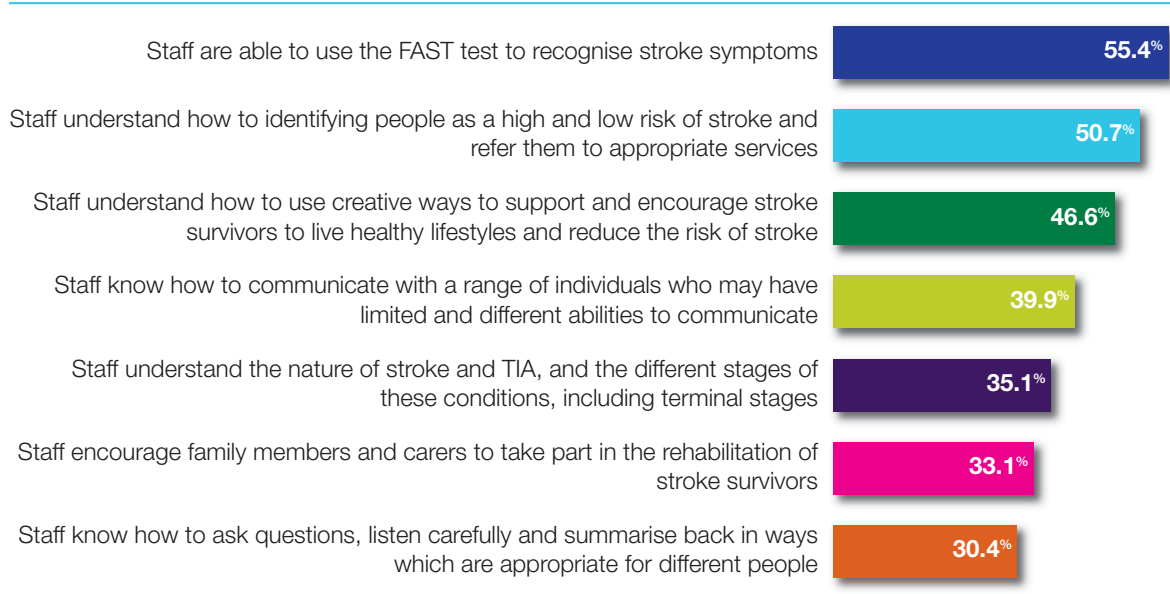
7. We will be working to improve end of life care to ensure that people are treated with dignity and respect and are able to die free of pain in their preferred place of care.

From the options below please select the two that you feel will most improve the quality of end of life care.



8. We will be undertaking a review of the current local stroke workforce to develop a plan and training for staff. This is to ensure that stroke survivors receive care from staff with the skills, competence and experience appropriate to their needs.

From the options below please select the three that you feel are the most important skills local stroke staff should have.



9. We have developed a local stroke implementation team that will continue working to improve local services. This team is made up of staff from Enfield Council, NHS Enfield other partner organisations, stroke survivors and carers (a full membership list is available on page 99 of the draft Enfield Joint Stroke Strategy). We will ensure that this network has a key role in the implementation and monitoring of the Enfield Joint Stroke Strategy.

From the options below please select the three that you feel are most important for the stroke implementation team to focus on.



Question 10 asked for other comments, concerns and suggestions people may have about how to improve the range and quality of adult health and social care services for people who have suffered a stroke and their carers. Some 36% of respondents took the opportunity to provide comment.

The collation process involved reading each of the narrative responses that were received. On reading the responses, a number of key themes emerged and comments were allocated to one or more theme headings. A lengthy and wide ranging response will have been allocated to a number of theme headings while shorter responses and comments have been allocated to just one or two theme headings. The groupings are useful indicators of where there is common ground with the following themes being most prominent in the responses received:

- Early Diagnosis / Admission to Hospital
- Raising Awareness / Prevention
- Support for Carers
- Discharge from Hospital
- Ongoing Support
- User Groups / Patient Engagement.

What follows is a summary of responses collated under each theme heading, followed by a response from the Council and NHS Enfield.

4.1. Early Diagnosis / Admission to Hospital

There was general support within the responses for basic awareness of stroke symptoms to be increased, including making diagnosis at initial point of contact (by General Practitioners), coupled with more understanding needed at Accident and Emergency units when stroke patients or suspected stroke sufferers are admitted.

One respondent was concerned about levels of staff on duty at the Acute Stroke Unit at Chase Farm Hospital and the extent at which staff are trained in order to respond to the needs of its patients.

Response:

The strategy makes a commitment to ensuring that all staff have appropriate skills, competence and experience. A commitment has been made to undertaking a review of the current local workforce (formal and informal) and producing a development and training plan in order to create a stroke skilled workforce. The plan will encompass all health and social care staff, including GPs, Accident and Emergency and acute unit staff.

The strategy also makes a commitment to improving stroke unit quality and developing a local performance management and monitoring framework for assessing local stroke units against national clinical guidelines and quality standards.

4.2. Raising Awareness / Prevention

A significant number of respondents expressed concern at the current level of awareness raising; both amongst professionals from within health and social care arenas to the general public, this includes increasing the understanding on the differences between physical and neurological problems that stroke sufferers have. Information and awareness of Transient Ischaemic Attacks (TIA) or mini-strokes was also highlighted as a gap in information provision.

Respondents stated that awareness is the key to stroke prevention and with more suitable signposting to advice on prevention and good practices, accurate and appropriate information can be provided, both to individuals and to support groups / voluntary organisations. Likewise, links to information on what not to do would equally be as important and welcomed.

It was noted that voluntary and community sector organisations can play a large part in raising awareness within the communities they support, especially in partnership with local health and social care authorities.

Further comments recommended that both Primary and Secondary stroke prevention be given equal attention and information on preventative measures and awareness campaigns be more accessible to disabled people.

Response:

The need to increase public and professional awareness of stroke symptoms is recognised as a key priority within the strategy. Information and awareness of Transient Ischaemic Attacks (TIA), or mini stroke, was not explicitly mentioned in the draft strategy. In response to consultation we have amended the final strategy to ensure that it is now explicitly referenced.

Since publication of the draft strategy, we have made the following progress towards improving information and awareness raising:

- A stroke information handbook has been developed with input from services users and carers. This is available in a variety of accessible formats and will be given to all stroke survivors on discharge from hospital.
- A stroke navigator has been commissioned from the voluntary sector. The navigator will play a key role in improving signposting, co-ordination and personalisation of services.

We are committed to improving access to the provision of information, advice and guidance, through both this strategy and through a wider programme of work within the Council that is transforming the way that services are provided.

A new information and advice module has been developed for the Enfield website. It is simple to use and covers all aspects of adult social care. In addition, a new Health and Adult Social Care Access Team has been established. This will provide a single point of access for people who want to speak to someone to get information, advice and guidance.

Further to this, the Council is also reviewing the role of the voluntary and community sector and plans to develop a greater role for the sector in terms of information, advice and guidance.

4.3. Support for Carers

Key issues articulated by respondents included:

- More support to be provided to family members and carers throughout all stages, including actual stroke, hospital admission, rehabilitation, discharge from hospital to support when at home.
- Support to relatives/carers in dealing with caring for someone with a long term condition and the effect this has on their own lives.
- Specific information and an access number to contact for support.
- Training.

Response:

We recognise the crucial role that carers play and are committed to providing them with better support and information. The strategy sets out our intentions to develop and support a wide range of local community-based and peer-delivered activities for people who have had strokes and their carers, involving the local voluntary and community sector, for example peer-led conversation groups and peer-support or befriending schemes. This will include:

- Development of a stroke service user and carer group
- Development of a carer befriending scheme
- Development of a stroke carer support group
- Development of monthly carer drop-in sessions to facilitate access to general advice and support services, counselling, befriending, and carer support groups.

In addition we have developed an overarching strategy for carers which sets out our commitment to improved support for all carers.

4.4. Discharge from Hospital

Many respondents stated that the discharge procedure from hospital needs improving, from the actual physical discharge arrangements to the provision of information (for example, on how to exercise and self-manage their programmes) to both the stroke survivor and / or family members / carers.

Respondents highlighted concerns over the lack of accurate information regarding the individuals' support needs were not always provided at the point of discharge and can lead to misunderstandings. It was stated that access to therapy specialists who can advise on day to day issues stroke victims experience would also be beneficial.

It was suggested that the initial support services are improved at the patients home and when a stroke patient is discharged from hospital, a 6 month follow up appointment is made to evaluate progress / provide additional support.

Response:

These comments reinforce the findings of the 2010 Care Quality Commission review and we have begun work to improve local processes for discharge and transfer home from hospital.

Since publication of the draft stroke strategy, we have developed a stroke information handbook with input from services users and carers. This will be given to all stroke survivors on discharge from hospital.

In addition, we have developed a 'transfer home' protocol for stroke patients which includes:

- A dedicated key worker for each patient
- Involvement of patient and carers in discharge planning and agreed goals included in discharge plan
- Involvement of the community stroke team
- Follow up by stroke rehabilitation services within 72 hours of discharge.

A newly appointed stroke navigator will also work to improve patients' experience of the transition from hospital to home by visiting them in hospital and at home.

Following transfer home, we have made additional funding available to the voluntary sector to pilot a new review process that will include a 6 week and a 6 month review. General Practitioners will be responsible for undertaking annual reviews for all of their patients.

4.5. Ongoing Support (Physiotherapy, Occupational Therapy, Alternative Solutions etc.)

Another clear message from the responses centred on the provision of ongoing support, from more and varied rehabilitation therapies (for example, physiotherapy, occupational therapy and speech and language therapy) to stroke survivors having increased access to a range of support services throughout the different stages of recovery. This includes accessing alternative therapies, for example, music, art and animal assisted therapies.

It is generally perceived that support is often minimal at best following discharge and if received, only for short periods of time. One respondent stated categorically that the great work undertaken by hospital based stroke units is often let down by inadequate aftercare and support services.

It was also suggested that whilst still in hospital, patients are provided with increased opportunities for therapy (for example, access to everyday objects to help increase fine motor skills).

Response:

Through development of the draft stroke strategy, the lack of community rehabilitation services for stroke survivors was recognised as a key gap; addressing this gap is given high priority within the strategy.

Since publication of the draft strategy, a specialist stroke community rehabilitation team has been established. The team will provide:

- Physiotherapy
- Occupational Therapy
- Speech and Language therapy
- Rehabilitation Assistants
- Social Workers
- Early Supported Discharge

The team will also provide vocational rehabilitation and support to people to return to driving. They will also be able to access clinical psychology, neuropsychology, district nursing, counselling, and spasticity clinics.

Through implementation of the strategy, we will continue to develop community rehabilitation services and ensure that they are providing high quality, effective services to enable people to maximise their independence.

4.6. User Groups / Patient Engagement

A large number of respondents expressed concerns regarding the lack of community based services available, with further alarm noted at those that are often established only to be removed (or closed) in quick succession.

It was recommended that these services are increased with stroke social clubs or open forums established where stroke survivors can:

- Learn about healthy living options
- Participate in exercise sessions (with therapists on hand to assist individuals with their personalised programmes)
- Attend walk in sessions to gain confidence in going out and socialising
- Learn how to relax and reduce stress.

Networking with others was seen as crucial in order to feel supported and reduce the risk of becoming isolated and the development of community based services plays a significant and positive part in the lives of those accessing the service at varying levels. This includes the views of carers and family members who often see these services as their 'lifelines'.

Response:

The strategy makes a commitment to continue to invest in healthy lifestyles promotion and support to people to change behaviour.

The strategy sets out our intentions to develop and support a wide range of local community-based and peer-delivered activities for people who have had strokes and their carers, involving the local voluntary and community sector, for example peer-led conversation groups and peer-support or befriending schemes. These groups would provide an ideal forum for learning about healthy lifestyles, reduction of stress, exercise and building confidence.

We are committed to increasing the involvement of service users and carers in the planning, development and delivery of services in order to improve outcomes. The planning and commissioning of new local support services will be developed in partnership with service users to ensure that they meet the expressed needs of stroke survivors and their carers.

We will ensure that stroke survivors benefit from the personalisation agenda by working closely with service users, voluntary, private and third sector organisations to develop flexible, accessible, responsive services across sectors including transport, leisure and accommodation services.

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