

Engagement report: New early supported discharge
service for stroke patients in Suffolk

6th November 2013

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1.0 INTRODUCTION

- 1.1 The NHS Ipswich and East Suffolk Clinical Commissioning Group (IESCCG) and the NHS West Suffolk Clinical Commissioning Group (WSCCG) have planned to commission an Early Support Discharge (ESD) service for patients who have a stroke.
- 1.2 A local engagement exercise was carried out, and the public was invited to give their views through surveys and focus groups, on how the ESD service can provide the best level of care
- 1.3 As the independent champion for health and social care, Healthwatch Suffolk has independently collected and analysed people's feedback and opinions on behalf of the local health and social system.
- 1.4 This report summarises the findings of the ESD engagement exercise, and its contents are to be used by the Suffolk Stroke Project Board to shape the new service.
- 1.5 This is not intended to be public document, and a modified version will need to be prepared before communicating and sharing findings of the engagement exercise with the public and other stakeholders.

2.0 BACKGROUND

- 2.1 NHS Midlands and East (now a defunct organisation) carried out a review of the stroke services in 2012/13. The aim was to identify how the region could achieve a step change improvement in service quality and clinical outcomes.
- 2.2 In December 2012, the IESCCG and WSCCG considered the evidence available for stroke care provision. A Statement of intent was agreed by both CCG Governing bodies, setting out the plan to:
 - commission Hyper Acute and Acute Stroke services from both Ipswich Hospital and West Suffolk Hospital
 - commission a patient centred Early Supported Discharge (ESD) service based on a Stroke Multidisciplinary Team (MDT) approach
- 2.3 The NHS Midlands and East Stroke Review had made recommendations on service reconfigurations. As stroke is a CCG commissioned service, the final

decision is the responsibility of the CCGs.

- 2.4 In May 2013, a Suffolk Stroke Project Board has been established by the IECCG and WSCCG to lead and oversee the development of stroke services in their areas. Please see appendix 1 for the terms of reference.
- 2.5 The two CCGs agreed to commission a Hyper Acute Stroke Unit (HASU) across Ipswich and West Suffolk hospitals. There will be one clinical team operating across both hospital sites and the service is due to commence in autumn 2013.
- 2.6 To improve the after care service for patients with stroke, an Early Supported Discharge (ESD) will also be put in place in 2014. This new service aims to complement the HASU, and give patients access to physiotherapists, occupational therapists, speech and language therapy, clinical neuropsychologists and dietician as appropriate.
- 2.7 To inform the commissioning requirements of the ESD service, an engagement exercise was carried out from 25th September 2013 to 5th November 2013. The engagement is in line with legal requirements for NHS bodies to consult their local communities on health plans. Patients and public were asked to give their views on how the new service should operate to ensure the best level of support and care for stroke patients and their families.
- 2.8 Healthwatch Suffolk have collected and analysed the results of the engagement independently. The findings are to be used by the Suffolk Stroke Project Board to refine and modify the service specification, ready for the procurement process in 2014.

3.0 EARLY SUPPORTED DISCHARGE (ESD) SERVICE

- 3.1 The National Stroke Strategy (2007) sets out 10 quality markers to improve stroke services in England, from prevention through to support for those who have experienced a stroke.
- 3.2 While there had been significant developments in stroke services in the region, the NHS Midlands and East Stroke Review highlighted a scope for further improvement. The Review presented a best practice specification covering seven stages of the pathway from primary prevention to end of life, including Early Supported Discharge (ESD).

- 3.3 An ESD workstream has been set up under the IECCG & WSCCG Stroke Review Project Board, and amongst other responsibilities, the workstream was tasked to develop a service specification for the new service.
- 3.4 The new ESD service aims to support patients and their carers during the recovery stage of the condition in their home. The service will be available seven days a week and will provide access to physiotherapists, occupational therapists, speech and language therapists, clinical neuropsychologists and dieticians as appropriate.
- 3.5 The final service specification was presented to the Stroke Project Review Board in September for approval. Please see appendix 2 for a copy of the draft document. This is then followed by a community engagement exercise to seek the views of the public before service procurement.

4.0 PUBLIC ENGAGEMENT

Preparation

- 4.1 The ownership of the public engagement of the ESD rests with the IECCG and WSCCG. As members of the Stroke Review Project Board, Healthwatch Suffolk and the Stroke Association had the opportunity to influence the process and provide input into the documentation.
- 4.2 An Engagement Plan was developed by the Head of Communication of the CCGs, setting out the approach of the exercise. Please see appendix 3 for a copy.
- 4.3 An invitation letter from the Project Director of the ESD and a briefing document have also been developed by the CCGs to support the public engagement. Please see appendix 4 for more details.
- 4.4 The public engagement consists of two components:
- Questionnaire survey
 - Face to face focus groups facilitated by members of the CCGs

Survey

- 4.5 The survey (see appendix 5) was designed by the CCGs with inputs from the Stroke Association. It sought to obtain both qualitative (comments on the

service proposals) and quantitative data. Participants were asked several types of question including 'rating', 'multiple choice' and 'open response'.

- 4.6 The survey was created and uploaded to www.surveymonkey.com, which is an online survey creation service. It allows Healthwatch Suffolk to gather responses with one URL by including a link on emails, websites, Twitter and Facebook. Hard copies of the questionnaire were also made available on request from Healthwatch Suffolk.
- 4.7 Healthwatch Suffolk circulated the survey using various communication channels including emails and newsletter features to 2,276 members, posting on website, regular social media updates (Twitter and Facebook) and direct communication with members of the public by the Healthwatch Suffolk staff team.
- 4.8 The questionnaire link was also circulated directly by the two CCGs to 91 stakeholders / organisations for information and wider circulation. Please see appendix 6 for the distribution list.
- 4.9 A summary of responses was downloaded by Healthwatch Suffolk staff and sent to the CCGs for information weekly. This meant that CCG staff could address any issues that might require immediate attention, for example, the indication of a problem with the engagement materials that required corrective action.

Focus Groups

- 4.10 The CCGs had also offered face to face meetings with service users to receive feedback on the draft service specification and general comments. 25 organisations had been contacted and seven meetings took place between 1/10/13 to 5/11/13. Please see appendix 6 for the direct engagement request list.
- 4.11 Notes of the focus groups were typed up by the CCG staff and forwarded to Healthwatch Suffolk for analysis.

Participants

- 4.12 There were no specific eligibility criteria for the public engagement exercise, and respondents were self-selected. People were not obliged to take part, although it must be recognised that some participants were invited to complete the survey.

- 4.13 The self-selected nature of the sample may result in a self-selection bias that limits the external validity of the results. This bias arises because it might be considered that some members of the target population may be more likely to respond than others when a choice to respond is available.
- 4.14 As a consequence of this bias, it will be important to recognise that the results cannot be generalised to the population of Suffolk.
- 4.15 The invitees of the engagement exercise represent a range of stakeholders with an interest in stroke services in Suffolk. Some have specific expertise to contribute whilst others are experts by experience. They include:
- Patients/Service users
 - Carers of patients/service users
 - Organisations with a specific interest in stroke care
 - Organisations with an interest in health, social care and wellbeing
 - NHS staff
 - The public

Age profile

- 4.16 As might be expected, the greatest proportion of our respondents belong to the 60 - 69 age group (32.20%), which is the point at which people are most likely to be affected by a stroke. As figure one shows below, the total number of people with a reported age group that is younger than 60 or older than 69 steadily decreases with each age grouping thereafter.

Disability

- 4.17 60.36% of our sample that responded to this question reported that they do not consider themselves to have a disability whilst 35.14% said that they do. These proportions are presented visually in figure two. 4.50% of respondents to the question said that they would rather not say.
- 4.18 Of those that answered the above question, a further 38 respondents chose to give further information about their impairment. From this we are able to report that 23 respondents have a physical impairment, five have a sensory impairment, one individual has a learning disability, three respondents have a long term mental health condition and six have other health conditions.

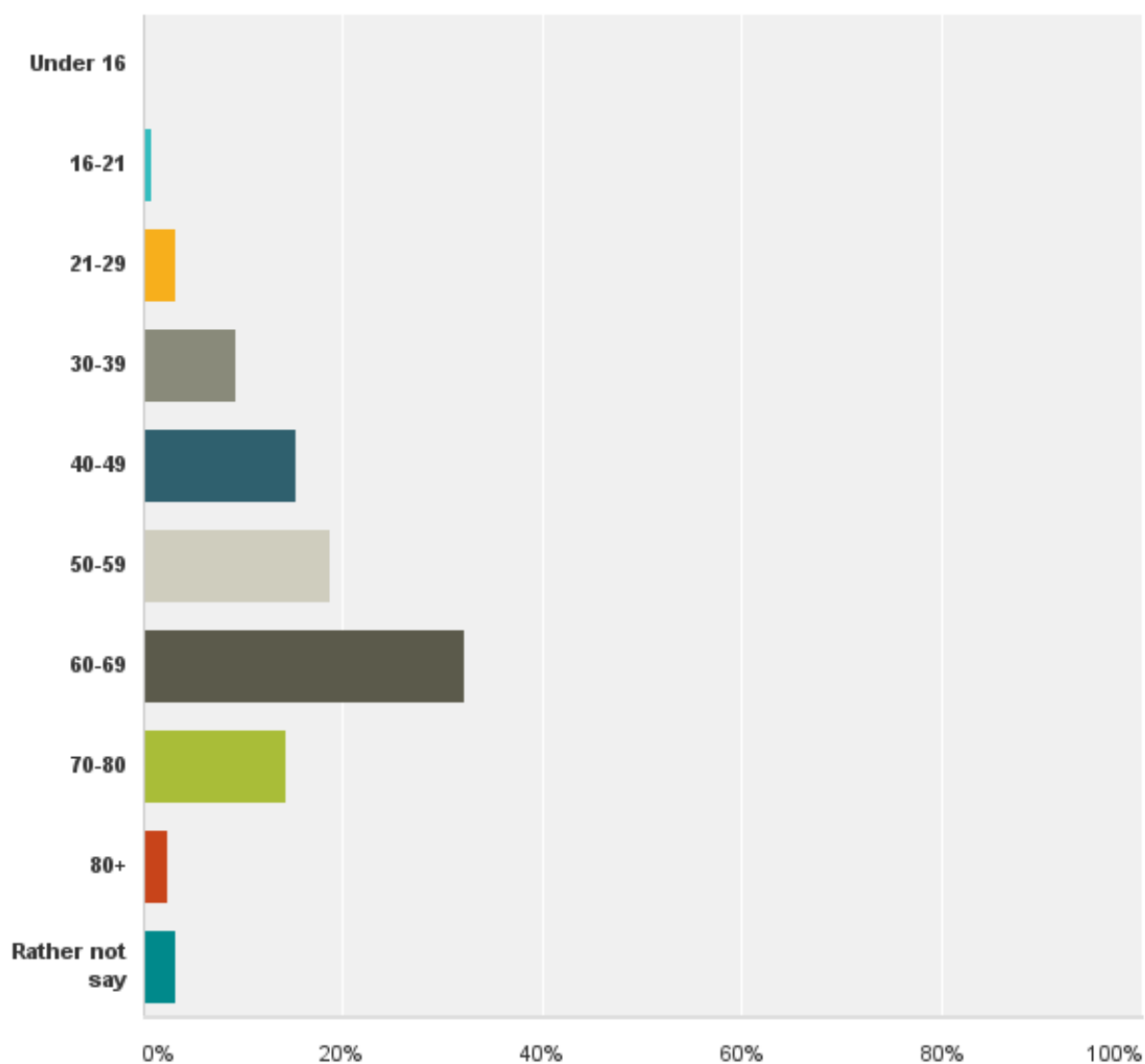


Figure 1: Bar chart - The age profile of our respondents.

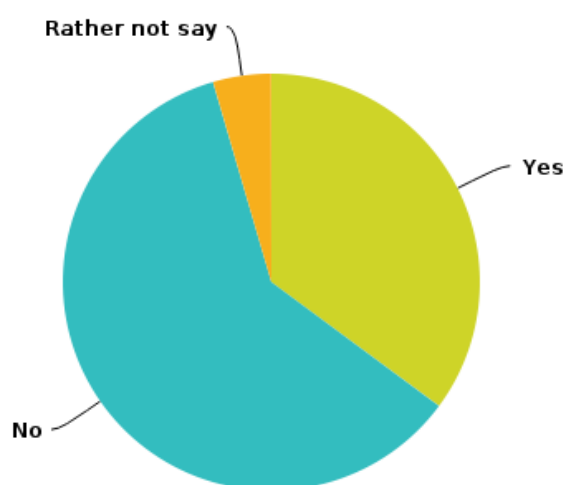


Figure 2: Pie chart - Proportion of respondents who have a disability to those who do not or would rather not say

Ethnicity

4.19 The table below summarises the reported ethnicity of our respondents. 13 individuals chose not to answer the question.

Asian or Asian British				
Bangladeshi 1 (1%)	Indian 0	Pakistani 0	Any Other Asian Background 0	
Black and Black British				
African 0	Caribbean 0	Any other Black Background 1 (1%)		
Mixed				
White and Asian 0	White and Black African 0	White and Black Caribbean 1 (1%)	Any Other Mixed Background 0	
White				
White British 103 (92%)	White Irish 0	Gypsy or Irish Traveller 1 (1%)	Polish 0	Any Other White Background 2 (2%)
Other Ethnic Group				
Chinese 0	Kurdish 0	Any Other Ethnic Group 2 (2%)		

Gender

4.20 The ratio of men to women is 38:76. No participants identified themselves as being transgendered and three said that they would rather not say. Seven respondents chose not to answer the question.

Religion/Belief

- 4.21 Figure three indicates that our survey was completed by a variety of respondents. The greatest proportion (53.77%) of our sample belong to the Christian religion or have no religion or belief (32.08%). 18 individuals chose not to answer this question.

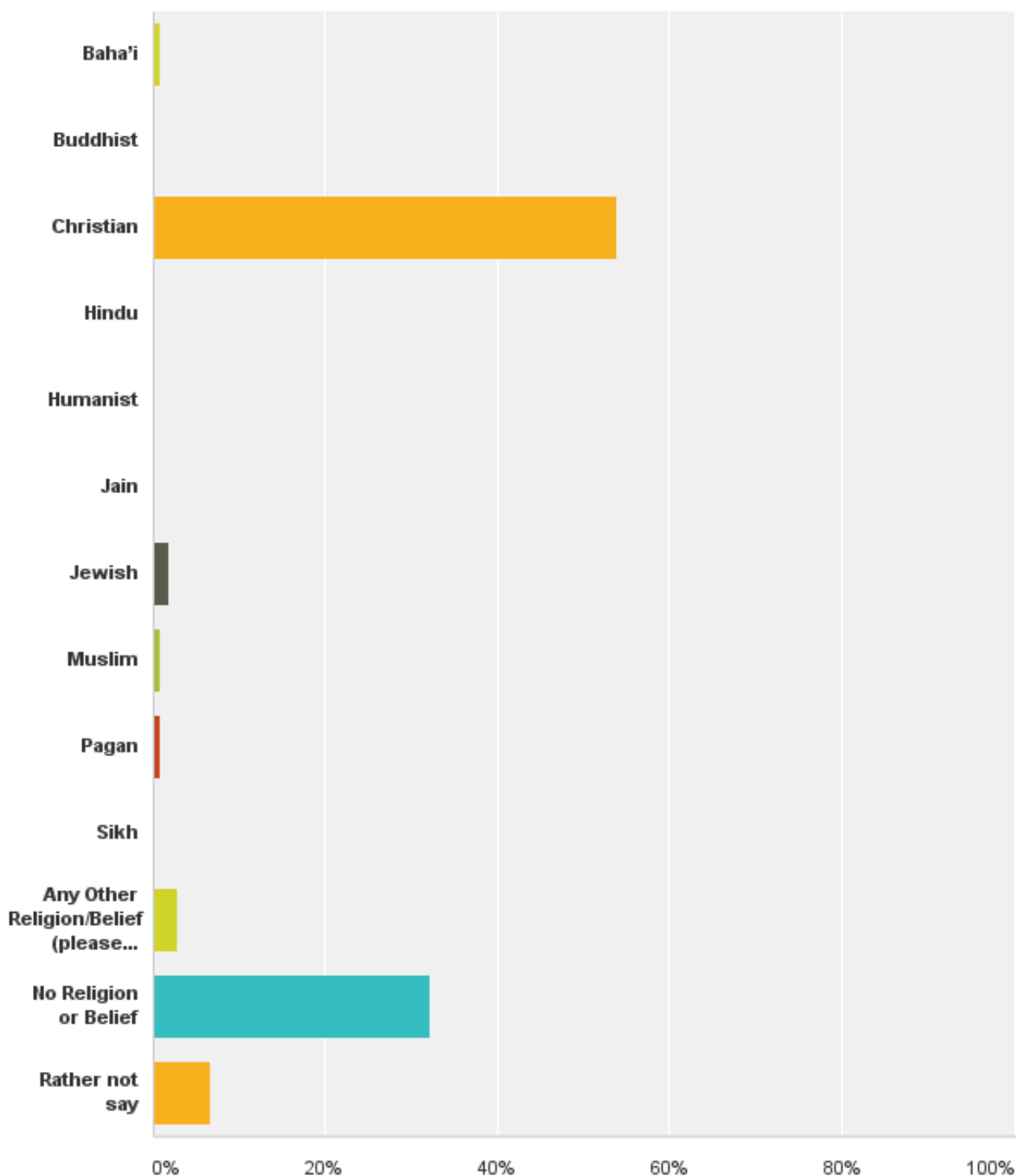


Figure 3: Bar chart - Proportion of respondents by religion/belief.

Sexual orientation

- 4.22 Figure four shows that a clear majority (88.24%) of our sample reported their sexual orientation as being heterosexual. This was followed by those who would rather not say (7.84%), are bisexual (2.94%) or have identified themselves as a gay man (0.98%). 22 respondents chose not to answer this question.

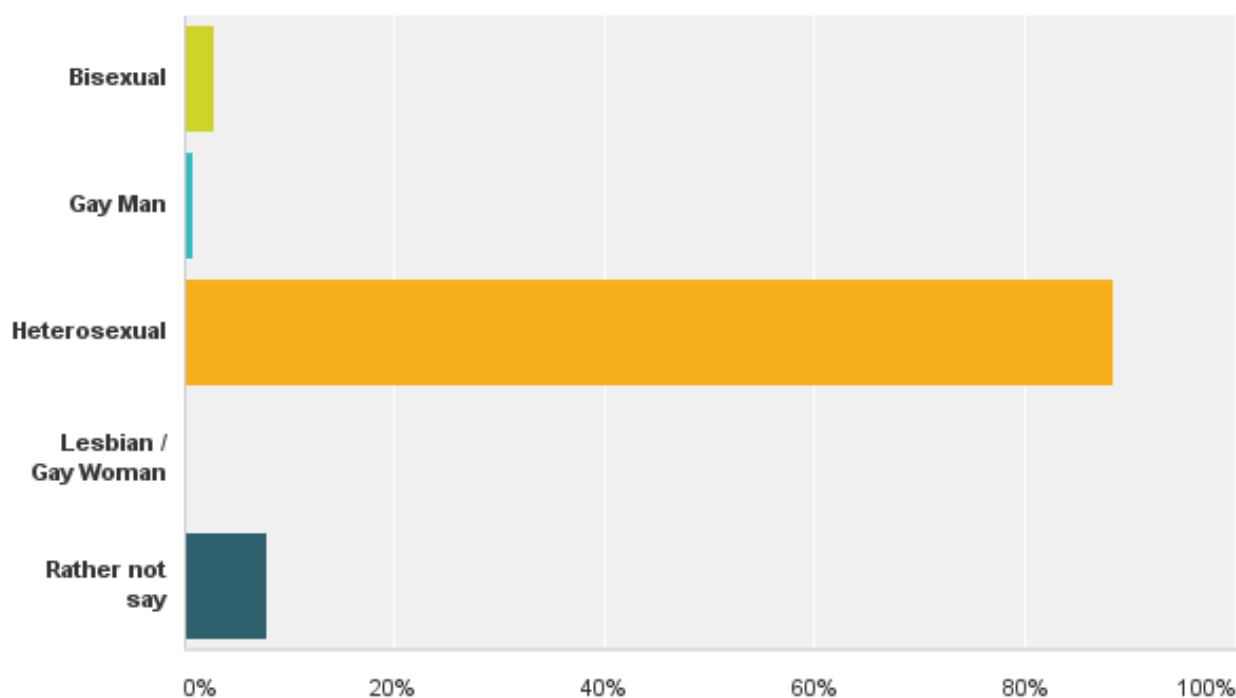


Figure 4: Bar chart - Proportion of respondents by sexual orientation.

Analysis & Reporting

- 4.23 All responses to the questionnaire and focus groups had been analysed independently by Healthwatch Suffolk. This has strengthened the credibility of findings and avoided potential bias in the engagement process.

5.0 SURVEY FINDINGS

Respondents

- 5.1 As indicated in figure five below, the survey was completed by a variety of respondents that featured, amongst their number, carers and family members; NHS staff; heart, diabetes and vascular patients; and members of

the general public. A total of 124 people had responded. Almost half of all respondents were members of the latter category (44.71%), with a further 55.29% being carers, family and NHS (including clinical and transport) staff.

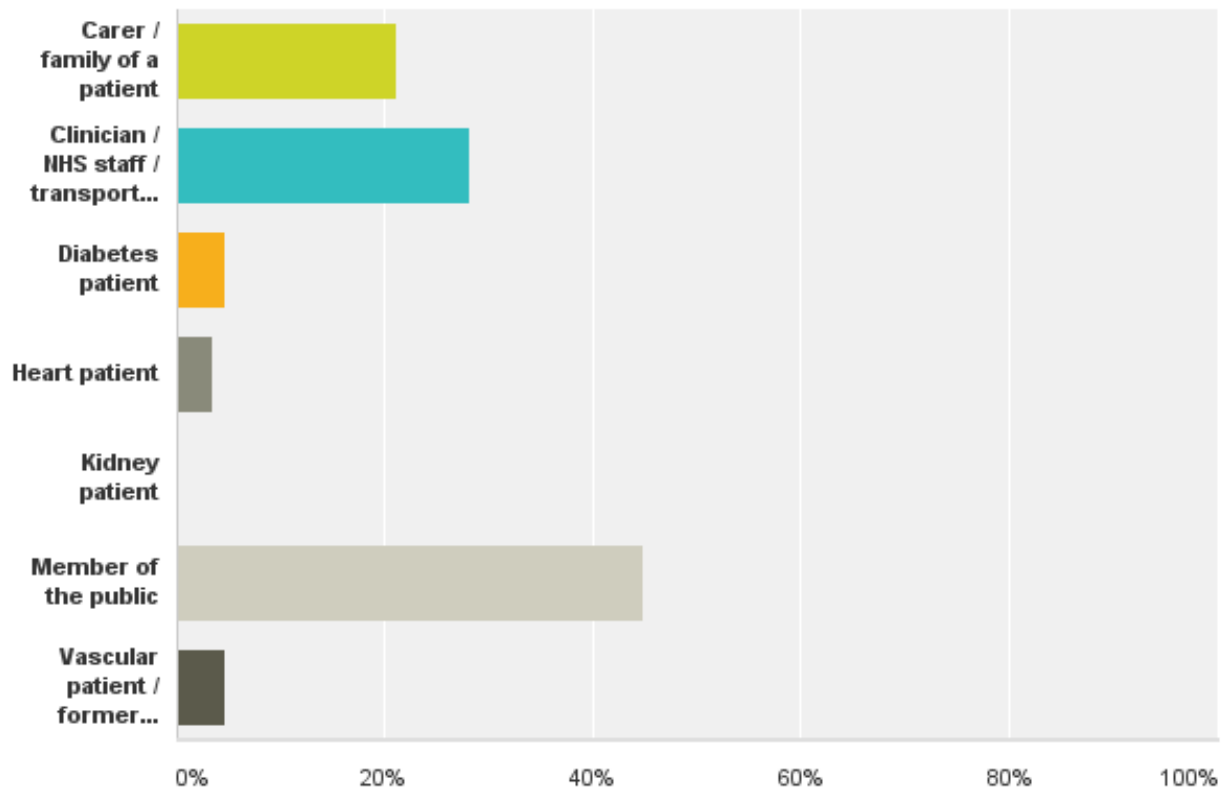


Figure 5: Bar chart - Participant capacity.

- 5.2 In addition, the number of respondents who had suffered strokes was significantly high but uncalculated.
- 5.3 The sample had a demographic that also included a significant physical impairment (60.53%), sensory impairment (13.16%) and long-term health condition (15.79%). 'Disability' amongst respondents was 35.14% and the number of respondents delivering 'support' to a significant other (i.e. partner, child, friend etc.) was 17.70%.

- 5.4 As figure 6 shows below, a majority of participants chose not to respond to indicate when they received care for a stroke. Out of those who did respond, 31 people stated that they experienced their stroke between 2011 and 2013 and a further 10 said that they had received treatment between 1996 and 2010.

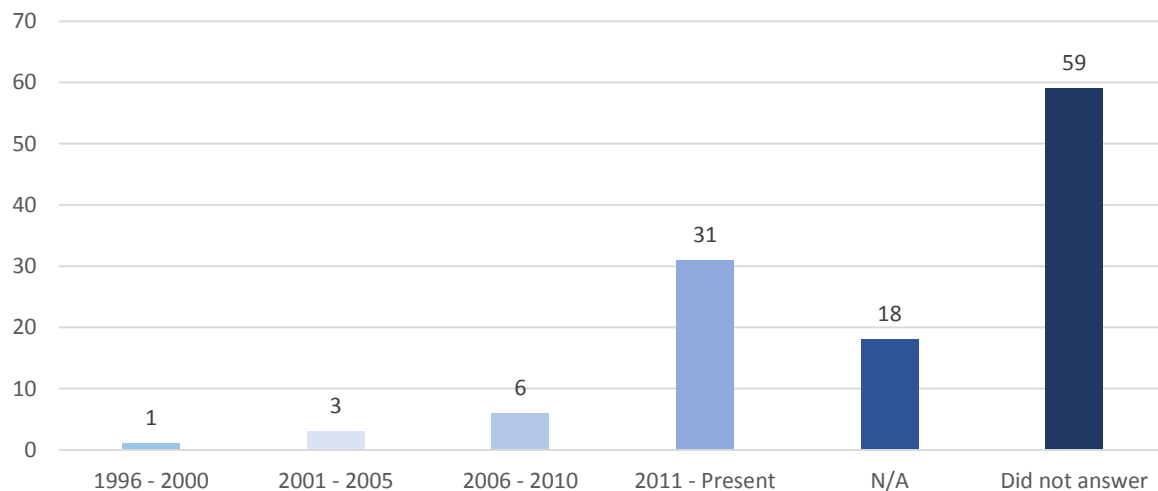


Figure 6: Year of stroke treatment.

- 5.5 Participants were asked to state the hospital at which they were treated for their stroke. The majority of respondents to this particular question (48.48%) reported attending Ipswich Hospital. 22.72% attended West Suffolk Hospital. The final 28.78% of our sample either stated that the question did not apply to them or attended other hospitals outside of Suffolk as summarised in figure seven below. 54 individuals chose not to answer the question.

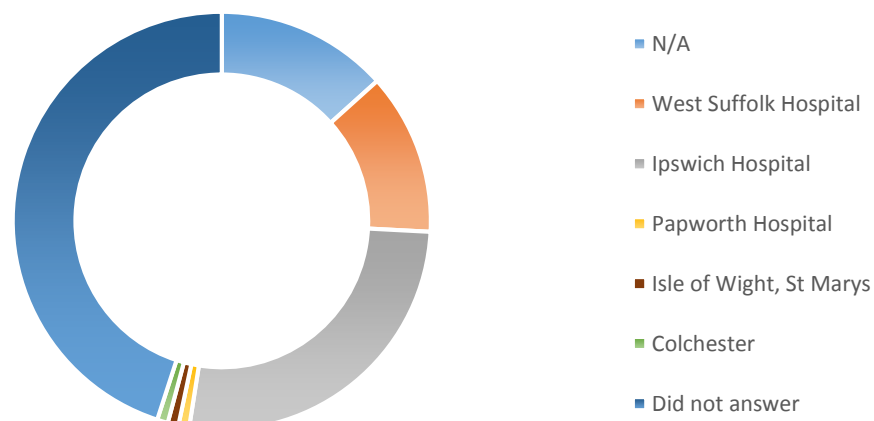


Figure 7: Hospital at which participants received treatment for their stroke.

Specifications of the Service

- 5.6 Respondents were asked to grade how they felt about certain specifications of the service, including seven day supported discharge; referrals between teams; equity of access to early supported discharge; action to reduce the likelihood of mental health problems in carers and patients; improving satisfaction levels; assisting eligible patients to be discharged in a timely way; reduction of the number overstay; improving uptake of early discharge for suitable patients; and reduction in readmissions. It probably comes as no surprise that respondents were strongly in favour of the overarching proposals and aims of the service presented to them, with particular emphasis being placed on:
- the aim that all patient referrals between teams should be managed in a person-centred (and timely) way; and
 - the aim to ensure that all eligible stroke patients are discharged from hospital in a timely fashion and when fit for discharge.
- 5.7 It should be noted, however, that the issue of referrals between teams also attracted the second highest 'disagree' response and that all of the measures mentioned tended to achieve 80-90% agree/approve mark when 'strongly agree' and 'partially agree' responses were collated. The greatest disapproval ratios tended to centre on the 'seven day a week early supported discharge service' and the emphasis on reducing mental health problems in carers and patients coupled with focus on patient satisfaction.
- 5.8 Respondents, when given the opportunity, added that particular attention should be given to:
- Providing more space on wards
 - Training support workers and improving ward staffing
 - Improvement of motivation
 - Communication channels for carers and information for survivors
 - Improving standards in community care
- 5.9 There is also a special emphasis highlighted on not requiring people to feel that they *must go home*. There is a worry that emerges from the data that vulnerability may be exposed by lack of adequate care external to the hospital setting. As one respondent put it, 'You do not say for how long this service applies. In our case we got no help yet my wife is still unable to walk. I would not be interested in a service that drops the survivor for lack of resource'. In addition, one telling point also emerges from a comment

that requires consideration. In modern times, with greater numbers of the population living alone, a respondent draws attention to this conundrum - namely, discharge always seems to assume that there are significant others available to deal with the requirements of informal or formal, home-based care for the recovering patient. There is also a deep sense that respondents believe that changes are driven by financial austerity and not by a desire to improve the service.

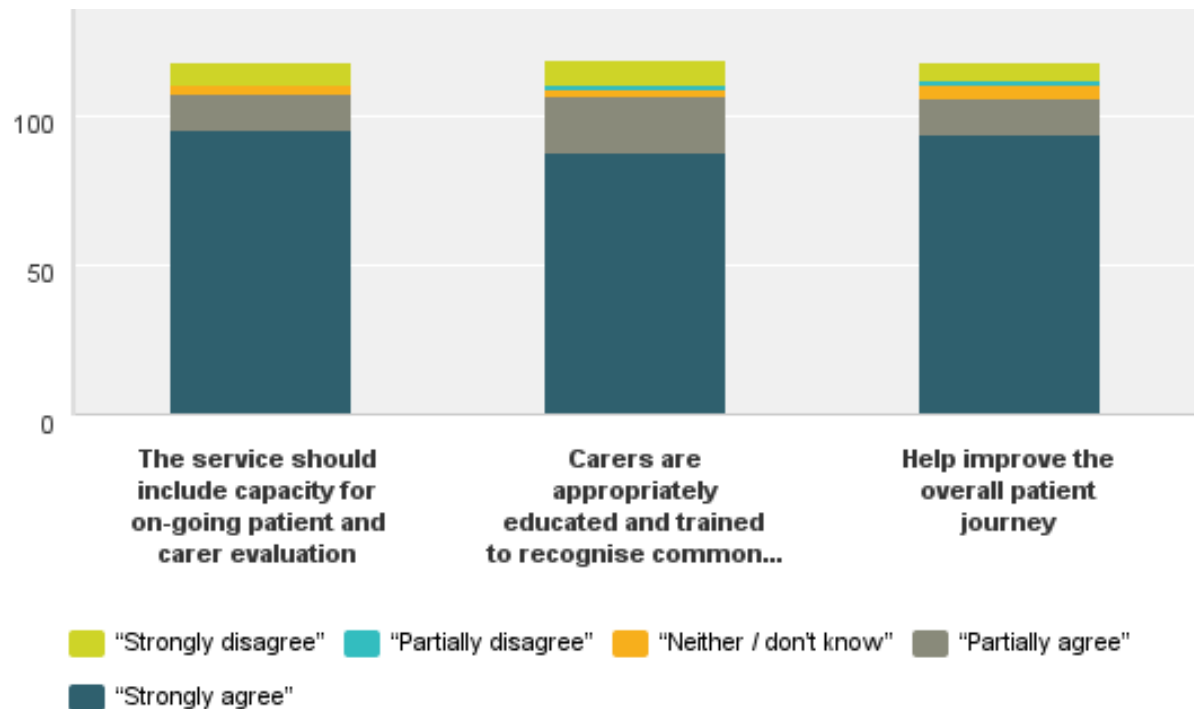


Figure 8: Bar chart - Indication of agreement with specifications for carers.

Continued Service Evaluation, Training and Patient Journey

5.10 As indicated in figure eight above, there is strong agreement amongst the sample that the service should include a capacity for patient and carer evaluations, ongoing education and training provision for carers (as a preventative measure against readmission) and measures to improve the 'patient journey'.

5.11 Approval ratings for each subject/question foci are circa 90% agreement that these are affirmative measures, even if the use of the terminology of 'patient journey' often caused mild scorn and derision due to its probable evocation of a service that appears to be driven by jargon and targets.

- 5.12 Respondents, commenting on the suggestions, emphasize that focus should be placed on these areas with particular concern being voiced relating to:
- Empathy and understanding of carer sacrifice on early discharge (and additional training for family carers)
 - Information on the benefits of the programme for patients
 - Recognition of capacity of hospital provision and responsiveness of service under constraints of finite resources
 - Development of support to capture shortfall in caring provision and proficiency
- 5.13 There is, again, a suspended belief that such measures could be afforded ('sounds wonderful, but I can't really see how it could work: who foots the bill?' and 'looks wonderful on paper'). However, perhaps the biggest indicator of uncertainty comes via the repeated suggestion that only staff with authoritative status should be treating patients ('patients should be treated by medically qualified staff and not generic staff' and the requirement for 'backup of support [being] needed, as not all carers have the same ability' and are often 'informal'), calling into discussion the impression that there is, at least, potential for a level of 'outsourcing' of expertise from medics to 'others' in the responsibility *for*, and care *of*, stroke patients. This is augmented by a conciliatory factor, illustrated by the overall faith in caring staff but the concern that such staff might be underpaid, driven too hard to meet targets or burdened with disproportionate responsibility.
- 5.14 The essence of responses can, perhaps, be summarised by the words of one respondent who chooses to focus on the overarching requirements of such service improvements, centering on practicality, emotional (augmented by educational) support and the reflexivity of each, individual case:

Respondent: Carers will have a long-term perspective and they need long-term support and assistance with the ways in which they can assist their relative. The emotional impact upon the carer can be significant, as the nature of their relationship with the person who has had a stroke can have changed significantly. The danger of readmission to hospital is significantly increased if the carer's needs and wishes are not taken account of.

Accessing Community Rehab and Joined-up Health and Social Care

- 5.15 When prompted to score the intention to maintain appropriate access to community rehabilitation services and long-term care (if needed) and the intention to improve interaction between health and social care teams, the respondents considered that both priorities were of a high importance, especially the requirement for access to community rehab. This is clear in figure nine below. It seems that, while the joining-up of services is deemed important, *access* to services is considered more imperative than how they work.

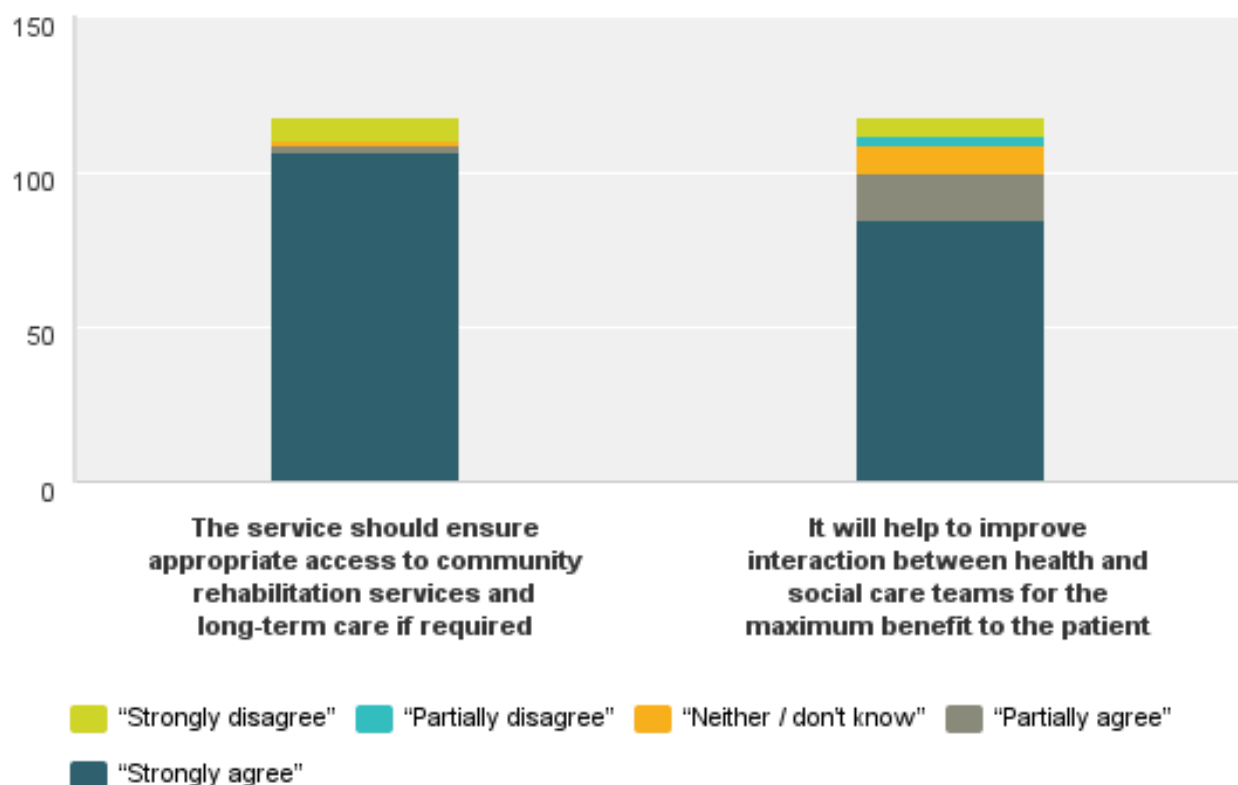


Figure 9: Bar chart - Indication of agreement with specifications.

- 5.16 The respondents were asked to comment on the benefits of community rehab and the eradication of potential 'silo working' of health and social care, and the rejoinders were indicative of the need for access over function. Community rehab and long-term care is a positive progression in service provision - and that improved interaction between healthcare and social care teams would benefit the individual. Therefore, Respondents suggested that:

- There are clear, generic benefits from the access and joined-up service (works better/more robust) with a sense that joining up

services would be a *challenge*, but ultimately rewarding on many levels (human/emotional; financial; logistically etc.)

- Access needs to be universal and have sufficient longevity
- It has a joint positive effect of relieving the patient of hospital and ensuring that isolation does not occur - home is best for recovery
- The provision needs to be 'cross county' and accessible to both patient and carer

- 5.17 However, there was also an underlying, tenacious sense that services should be operating to a high standard at all times and that people should not need to consider such matters unless they are *ready* for discharge regardless. There was also a strong sense that finance needs to be made available additionally to existing funding streams, rather than drawing on a (perceived) diminishing resource. There is a sense that 'capacity for recovery of stroke patients should not be underestimated [and if] everyone works together for the good of the patient [...] better outcomes for the patient could then [...] be achieved'. Ending 'silo' practices and opening up access to community-based resources are therefore compliant with a philosophy of holistic care and patient responsiveness.

Views on Clinician Criteria of Patient Discharge

- 5.18 When asked to comment on the criteria that clinicians would utilize to discharge patients, the responses reflected the essence of the criteria and the perceived strengths and weaknesses. Criteria include patient-carer collusion and unit assessments of case; patient stability (including mobility); Barthel rating; unmet needs and everyday capabilities (including assurance on patient feeding themselves etc.); connectivity with additional professions - including physiotherapy; liaison with early supported discharge services. While a long list, respondents were able to comment on the suitability of criteria. Among the recommendations were:

- Comprehensive, but must be flexible and applied in a bespoke, case-by-case manner (but needs to be meticulously followed at source each time for effect)
- Encourages communication between significant actors: patient (if appropriate), specialists, service providers and so on.
- Needs to also involve source communication with involved parties prior to discharge (not after)
- Needs to be observed over a longer period of time for maximum effect

- Represents good practice
- A home assessment needs to be included to ensure suitable environmental capacities for the patient on discharge

5.19 Additionally, some concerns arose that duly focused on the pressure that may be placed on already stretched services as well as the implication that carers are present and willing at the source of the discharge. There also needs to be a check and balance approach, ensuring uniformity of practice and implementation for a maximum effect and, of course, accountability and review. Some Respondents also suggested that the input of family would be an appropriate and positive addition to the criteria.

Views on ESD service impact in West and East Suffolk and Ipswich

5.20 Respondents were asked, by way of a conclusion, what they considered the impact and implications of the new ESD would be and how the ideas presented to them could be improved and what additional suggestions they may have on the service.

Impact of the New EDS on citizens

5.21 Impact was measured via positive and (potentially) negative, discursive observations. There was a strong suggestion, throughout the process, that people considered home care to be preferable to hospital-based care if conditions of care and provision were met to the satisfaction of all parties. Of course, as we have seen, there was also a strong support for joining-up services and placing the patient at the centre of (possible) bespoke discharge. Affirmative impacts of the new ESD include:

- Better recovery
- More spaces on wards that may be already close to capacity
- Greater staff satisfaction (arguably often overlooked as a component of successful delivery of services)
- Maintenance of independence and wellbeing for the patient
- May assist in the decrease or prevention of readmissions
- Empowering for patients
- Possibly focus specialism in the area of stroke recovery care
- Add value to the perception and reality of care in stroke recovery

5.22 As we can see, there is a strong focus on both resources and the dynamism of both patient and staff self-efficacy. Negative considerations, however, were voiced and include:

- Potential ‘invisibility’ of patients external to hospital; and
- People being left without any help at all (possibly as a result of the former)
- Untrained carers may carry a disproportionate amount of pressure
- While people tend to want to go home earlier, no pressure should be asserted on patients to feel compelled to do so

5.23 Neither a negative or positive critique, but helpful nevertheless, was the suggestion that a focus should be placed on the equal distribution of resources on the ESD throughout/across the county as a whole. The essence of the discussion, however, is perhaps best summarised by one Respondent who said:

Respondent: I have seen many people who never make a good recovery for whatever reason. All too often help is given for a short while and then the patient is left to cope by themselves. Some [who] can afford it get private physiotherapy but what about those who cannot afford this? Much is said about an aging population and how we need to keep fit in order to help prevent diseases. It is therefore important to ensure that a person gets as fit as possible after having a stroke and good care and treatment is therefore essential.

5.24 In short, the perceived impact/effect of the new service tends to rest on the assumptions that improved service tends to equate to improved care and improved conditions for patients. There is also a belief that the public perception of such care will be boosted. Concerns are largely based on the efforts that must be made to deter an ‘out of sight, out of mind’ slip in provision that can affect patients and their carers significantly, leading to the risk of a fall in standards and sufficient pressures made on those involved in care.

Additional implications

5.25 Additional implications of the new service include a combination of foci involving family, location, familiarity (and mental health in both patient and carer), and the positive aspects of freeing up capacity in hospital care. Some points raised involved impact being measured in terms of:

- Family (critical, without them there is a problem)

- Feeling of abandonment without it could occur
- Familiarity assists in care and contributes towards defeating isolation
- Less travelling required, but greater strain on services that travel to people
- Concerns over the 'correct' and functional running of the service - things must be done 'correctly'
- A greater sense of support and involvement
- Better recovery (arguably certainly considered better conditions for such)
- Awareness on the risks of early discharge should be upheld and considered by both the service providers and the patients and families

5.26 However, some are quick to warn of the unseen impacts beyond the 'promise' of the service, and this invisible (or, *overlooked*) context is well summarised in the following quotation from a respondent.

Respondent: "You need to ensure that the family are fully aware of the impact of having a potentially very dependent person home earlier will have on their relationship and both of their health. We have seen a real shift towards getting people home earlier which has positives but there are also negatives if there is only a four times a day care package going in that is a lot of time that the family have to care for the individual / night time needs will need to be very carefully explained to the family, also you need to consider hospital transport and whether the people are eligible for this, also issues with home access these take weeks if not months to sort but can significantly delay rehab starting at the gym if the patient can't get out of the house. You need to think about how rehab will be conducted in the home if the person can't get out as this can prove difficult with manual handling / space."

Improvements

5.27 Respondents suggested that the ideas presented can be improved by further involvement of actors in the provision of service, creating a largely progressive momentum as long as the building blocks for successful functioning of the service are in place and maintained. Joined-up thinking/communication is a central key to success on a provision-side approach, coupled with sufficient interaction with patient and carers through information and participation. Of course, greater public awareness of the condition and its effects assists in the overall recovery and progress of affected individuals and families and carers. Respondents suggest that,

alongside the ubiquitous calls for more staff and investment, transport provision between hospital and home should be improved along with other facilities (such as gyms etc.) designed to assist in recovery

Additional Observations

- 5.28 Finally, Respondents make clear that the service is positive, progressive and useful and could be enhanced only by subtle improvements in patient understanding. Additional observations include:
- Setting up of a halfway house service for patients - not ward or home, but somewhere in-between
 - Better communication facilities (such as helplines)
 - An emphasis on 'choice' assists in bespoke care pathways (including no compulsion)
 - Bespoke community action teams might add further value by, effectively, understanding the 'back yard' in which they operate and the needs of citizens
 - Training and further awareness assists everyone involved - patients, staff, families and so on.
- 5.29 The scheme offers 'care, compassion and continuity' and some final survey materials presented valuable data to further underpin the information presented above.
- 5.30 One final comment summarises the generic spirit of the data gathered. The project is full of promise and it is potentially liberating and, as we have seen, offers the potential for joined-up service and thinking. However, we must tread carefully. Things require comprehensive planning, the encompassing involvement of many specialists and careful consideration must be given to those at the caring frontline. It should be a starting zone, flexible and able to be continued seamlessly if required:

Respondent: "If it works well, it should benefit patients by giving intensive specialised rehabilitation in the familiar surroundings of the patient's own home. The role of the carer is extremely important and greater emphasis should be placed in the specification on carer education and support. For the service to *work properly*, it needs to be delivered by physiotherapists, occupational therapists, speech and language therapists, and psychologists who are neurological specialists. ESD must not be launched until a full team of appropriately qualified therapists is in place. When the service is up and

running, individual patients should not be discharged unless those delivering the service are able to meet their needs. The service specification states that the ESD service can continue for up to 6 weeks. Although this may be an aim, there should be the flexibility to treat patients for longer if required.” [emphasis added]

A Vote of Confidence in ESD?

- 5.31 As one would expect and as indicated in figure 10, there is an overall positivity relating to the development of an Early Supported Discharge service in West and East Suffolk and Ipswich. Of those questioned, 84.12% stated that they were strongly or partially in favor of the establishment of such a service. This reflects the overarching levels of (guarded) positivity relating to the ideas of provision and reflections on impact stated above.

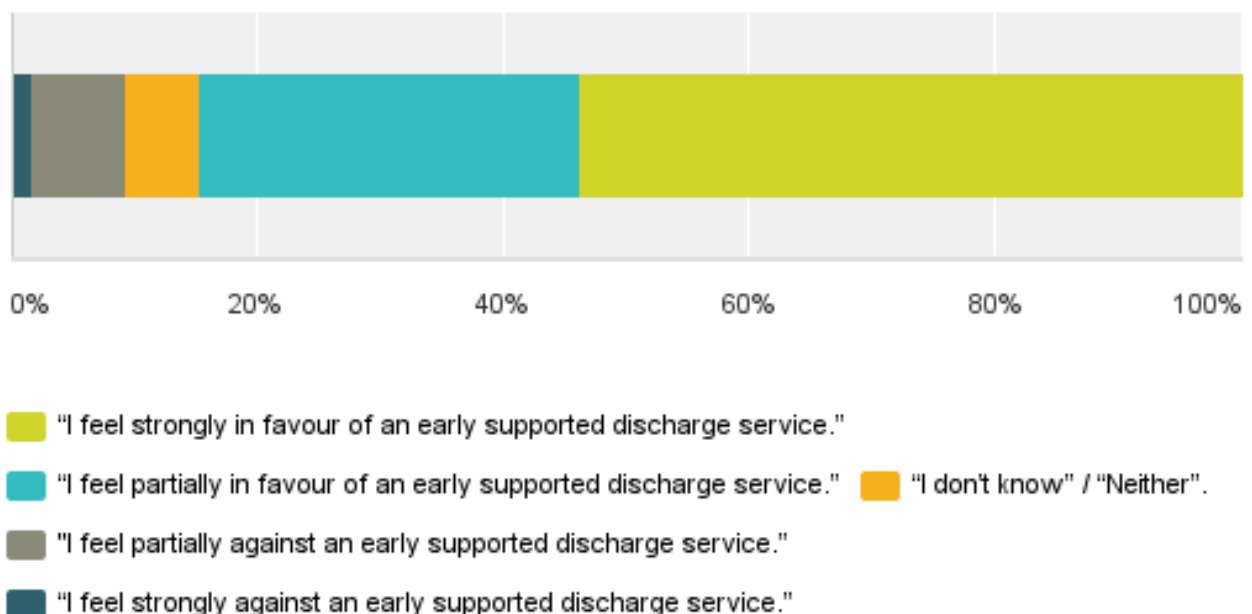


Figure 10: Strength of support for an Early Supported Discharge Service in Suffolk.

Some Additional Responses

- 5.32 In addition to the mainstream Respondents input, additional feedback has been gathered to add richness and essence to the discourse here. Representations were made to the CCGs relating to the service provision in ESD that illustrated the following:
- Lack of training for carers and associative frustrations are evident, but are partially assuaged by the development of the ESD

- Lack of depth of alternatives can be frustrating for those who care - namely a lack of alternatives to the given pathway
- Survivors are often not in an ideal position to make calculated and informed decisions on their circumstances
- Time frames for recovery are often open-ended
- Carer vulnerability is often overlooked as well as the variability of effect of the stroke - adding a robustness to calls for the system to be more reflexive and bespoke where possible
- Information is generic
- A pilot scheme would pay dividends

5.33 Additional evidence gathered individually on the subject of robustness and fallibility of the scheme suggested that awareness should be considered relating to:

- The short-term (6 week) post-stroke span of the care
- The requirement to segue the end of the six week period with the launch into further support required
- Continued monitoring of 'what good looks like'
- Greater empathy with the needs of the carer and understanding of socio-geographic challenges in the wider county.

5.34 It is also prudent to mention that concerns over PPP's (especially with the considered 'risk' of private sector involvement in a predominantly public sector provision) have also been raised, along with the important juxtaposition of both home carer and GP/practice community team involvement (namely, where and when?).

6.0 FOCUS GROUPS FINDINGS

6.1 In addition to information gathered via our surveys and written responses, supplementary evidence was gathered via a variety of consultations with organisations throughout the county of Suffolk dedicated to post-stroke care. The primary purpose of these sessions was to enhance feedback.

6.2 Themes that ran particularly strongly within the consultations tended to evolve from the issues set about above relating to:

- Preparation of patient and carer for challenges
- Assessment of capability of carer, patient and suitability of home
- The provision of comprehensive information and advice services

- 6.3 The above three criteria augment the spirit of the ESD with robust, every day and crucial aspects of practicability required to make the scheme viable holistically. Support Groups recommended key worker provision in the absence of twenty four hour service provision; understanding of, and action to resolve, the perceived vulnerability of many carers (both on a personal, physical level and via training on coping with the challenges of associative physical work, safety and safe patient handling and the omnipresent realities and risks that aphasia - should it be circumstantially present - can cause in prediction, understanding and control of situations faced).
- 6.4 The CCGs have also been gathering opinions and suggestions from organisations connected to stroke aftercare and prevention. The themes that emerged from these sessions included:
- General affirmative responses to the promise of ESD
 - Recognition that there are many ‘agents’ at work in assessment: O.T.; physiotherapy; speech therapists et al and that the ‘variety’ of strokes differs (perhaps additionally sequela orientated) demanding bespoke responses to assist carers (no need is the same). Subarachnoid haemorrhages and subdural haematomas - and their effects - are examples of such oscillations in definition.
 - Quality control in discharge must be tightly regulated and the provision of aftercare must be homely and well informed
 - Segue into additional aftercare services after the ‘6 week period’ must be seamless
 - Psychosocial contagion must also be recognised within the overall sphere of total care - carer’s are affected too
 - Disadvantageous geographical locations must be carefully considered and recognised as challenging for both carer, patient and service connectivity
 - Recognition of condition longevity is paramount

7.0 CONCLUSION

- 7.1 With the approval rating so high on the development of ESD in West Suffolk, East Suffolk and Ipswich, the responses of the sample have plainly concluded that the following matters are of importance when addressing the development/improvement of service provision in this area:

- The development of a person-centred programme, used as a structure to involve and innovate, couched in a sturdy, financially maintained framework of care.
- The development of a training and information stream, focusing on bespoke care capacity over broad universalism approaches and the structuring of care to provide something of a safety harness of provision from qualified experts acting in auxiliary roles to the main, designated carer.
- Reassurance that service improvements will not mean stealth diminishing of service provision in practice
- The critical importance of joined up health and social care that maintains and improves high standards within a philosophy of holistic care and patient responsiveness
- The development of individual, bespoke care plans based on enhanced discharge criteria involving patients (where possible), carer, specialist and auxiliary service providers (where needed)
- That the ESD was a policy and practice of progressive essence, delivering important improvements in patient and staff satisfaction, wellbeing and empowerment and the progress of stroke recovery
- Gentle improvements could add tiers of recovery - such as halfway house care - better choice (but no compulsion) on participation and enhanced training for carers.

7.2 In conclusion, the development of the new ESD service is considered practical, achievable, affirmative and progressive and has enthused a largely optimistic cohort on its virtues.

APPENDICES

Appendix 1 Suffolk Stroke Project Board Terms of Reference	 Appendix 1 - Stroke Review Governance
Appendix 2 The service specification	 Appendix 2 - DRAFT ESD Service Specifica
Appendix 3 Action plan for engagement and communications	 Appendix 3 - 2013_SEPT_ESD_eng
Appendix 4 Invitation letter from the Project Director of the ESD and briefing document	 Appendix 4 - Stroke ESD letter.pdf  Appendix 4 - Stroke - ESD briefing.pdf
Appendix 5 The survey	 Appendix 5 - 2013_aug_stroke_qu
Appendix 6 CCG direct engagement distribution lists	 Appendix 6 - Copy of Stroke survey dist