

PRIORITY BRIEFING

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days.

Would an e-health guide help stroke survivors and carers to access on-line information and support for self care more easily and with more confidence, improving their quality of life and ability to self care?

Question ID: 2

Question type: Intervention

Question: Would an e-health guide help stroke survivors and carers to access on-line information and support for self care more easily and with more confidence, improving their quality of life and ability to self care?

Population: Stroke survivors and carers, living in the community, sampled via GP registers. We want to recruit a wide range of people with experience of stroke. We would aim to include people at all stages post-stroke, of different ages, backgrounds and ethnicities, with different types and levels of impairment, including people with aphasia) and their carers. We would exclude people under 18 or living in long term care. The earliest time to recruit post-stroke is difficult to determine. Preliminary feedback from stroke survivors indicates that it would depend on stroke severity. Carers however might welcome a chance to maximise their access to additional information in the first 6 months.

Intervention: We want to develop a practical e-health guide which will help people living with stroke to access reliable guidance and support for self care.

It is envisaged that the evaluation of the effectiveness of this e-health guide will take place as a process involving several stages. It is aimed that the first stage will be to define the framework for a future definitive trial of the clinical and cost effectiveness of an e-health guide in post-stroke patients.

In order to define this framework, we need to establish (i) whether the internet currently meets the self care needs of people with stroke and their carers, (ii) whether an e-health guide would be useful and acceptable, and (iii) the feasibility of integrating such a guide into existing primary care systems.

This first stage would have four interconnected components, combining quantitative and qualitative approaches:

- 1) A postal survey to establish how stroke survivors and carers currently use the internet, what helps or hinders in using it and their level of confidence/expertise
- 2) Working jointly with stroke service users to identify websites relating to stroke and other long term conditions; using validated quality measures to assess user views of the accessibility and usefulness of these sites in supporting

self care.

3) Using both quantitative and qualitative findings to undertake a user-driven iterative development of a prototype e-health guide.

4) Carrying out a small scale evaluation of its feasibility and acceptability in rural and urban practices.

Control: post stroke patients and carers (representative of urban and rural areas) who will be provided with standard post-stroke care, but without the e-health guide.

Outcome: Outcomes are likely to focus on knowledge, attitudes and behaviour. They could include improved confidence in using the internet for self care, achieving self-set goals, increased preventive activity or reduced social isolation. Specific measures will depend on the goals identified by participants as relevant and achievable. We will seek advice on appropriate, validated measures for people with aphasia.

*Please note that the details included in the box are from the original submission and have been edited where necessary for clarity and precision

Stroke: Stroke occurs when the blood supply to part of the brain is cut off. Brain cells in that part of the brain may be damaged or die. Depending on which parts of the brain are affected, and for how long, this can lead to death or a wide range of movement, sensory and other problems. Strokes usually affect one side of the brain, leading to their impacts being predominantly on one side of the body. A stroke lasting less than 24 hours is called a transient ischemic attack (TIA).

E-health guide: electronic health guides are health education and support material for patients (in written, visual and/or verbal form), available either as

- i) software based in computers or other devices which may be in a health care facility or in the patient's home;
- ii) a dedicated intranet based in health facility servers;
- iii) a website on the internet (world wide web).

The Health Problem:

Stroke:

Stroke is a major public health problem in the UK. It has a major impact on individuals and their families, the NHS, and society.

The Office of National Statistics Health Statistics Quarterly in 2005, reports that over 130,000 people have a stroke each year in England and Wales. Of these, about 87,700 are first strokes and 53,700 recurrences. The Stroke Association reports that stroke is the largest cause of disability in the UK (300,000 people live with a moderate to severe disability as a result of a stroke), and the third commonest cause of death after heart disease and cancer (over 40,000 deaths in England and Wales

in 2009, representing 11% of all deaths). Most cases occur in people aged over 65. Each year about 1 in 100 people over the age of 75 have a stroke, but stroke can occur at any age.

The prevalence of stroke is around one million people in the UK i.e about 1.61% of the population (2006). About 80% of survivors experience motor impairments requiring rehabilitation, and half of those following stroke will need help with everyday activities. It is estimated that 75% of those who survive stroke suffer disability severe enough to affect employment. In addition, about a third of individuals who have had a stroke develop depression and a third of individuals experience communication difficulties. However, only around half the people who have had a stroke receive sufficient rehabilitation to meet their needs in the first six months following discharge from hospital. This falls to around a fifth in the following six months.

In the South West, according to the NHS Quality and Outcomes Framework (QOF) database, of the 1.7 million people registered with a general practice in the South West SHA region in 2010, there were over 36,000 people with experience of stroke (approximate prevalence of 2%).

There is evidence that the level of care provided in the South West for stroke is amongst the best in England. The Care Quality Commission's review of services for people who have had a stroke (Supporting Life After Stroke, 2011), reports that the proportion of PCTs achieving best scores across the 15 indicators for stroke care is higher in the South West than all other English regions.

In terms of the trend of the burden of stroke over time, the National Audit Office and the Department of Health's 2005 publication 'Reducing Brain Damage' reports that the incidence of, and mortality from stroke have declined in recent years. Between 1992 and 2002 stroke death rates in those aged under 75 declined by 30 per cent. However, the decline mortality from stroke in England is offset by increasing prevalence due to improved survival after stroke.

According to the National Audit Office, in 2005, stroke was estimated to cost the economy around £7 billion per year. This comprised direct costs to the NHS of £2.8 billion, costs of informal care of £2.4 billion and costs because of lost productivity and disability of £1.8 billion.

Information needs of people with stroke and their carers:

It is estimated that between 30 and 50% of stroke survivors lack the necessary information to support their long term needs. These needs may be related to physical, psychological and social difficulties. The Stroke Association's report 'UK Stroke Survivor Needs Survey' in 2010 also found that about half of stroke survivors and their carers had unmet information needs. Higher levels of need were associated with minority ethnicities and with more severe disability. Areas of reported information need were in relation to diet, holidays for people with a disability, advice about benefits entitlements and access, aids and adaptations for the home, advice about driving, and advice on employment.

Work with service users by the Stroke Research Network in the South West indicates that this type of information is also lacking when stroke survivors or their carers access primary care. The internet may promote self management and reduce social isolation, as well as providing information. However, in addition to the important issue of availability of the internet, stroke survivors and carers may also be hindered in accessing the internet by difficulties with confidence, communication or co-ordination. There are numerous stroke-related websites, but a small local survey in South Devon indicates that people with stroke may need additional help to benefit from on-line information and support for self care.

Guidelines:

NICE, through commissioning the National Collaborating Centre for Chronic Conditions, produced a guideline in 2008 on the diagnosis and initial management of stroke and transient ischemic attack. This guideline did not comment on the long term care of those who have had a stroke.

A guideline for stroke rehabilitation after the stroke event is currently being developed by NICE.

The National Stroke Strategy (2007) recommends clinical and social management strategies for acute stroke as well as for the period after stroke. The National Stroke Strategy recommends that good information needs to be tailored to individual requirements, and flexible enough to meet the different requirements of different people. It suggests that it is important to provide information in a variety of ways, for example by supporting verbal information with written information or diagrammatic material. The National Stroke Strategy document however does not describe how to develop these 'good information'.

These documents do not comment specifically on electronic health guides, online or otherwise.

NHS Priority:

Regional

Stroke features prominently in two ambitions in the South West SHA Priorities Framework 2008-11. 'Staying Healthy' and 'Acute Care' relate to the acute management of stroke (e.g. thrombolysis - drugs to break up blood clots, and brain imaging). Self care and rehabilitative care was a target for the ambition of 'Long Term Conditions' in general, but was not described specifically for stroke as such.

The South West SHA has also committed to the introduction of self care plans for everyone with a long term condition and NHS Devon has joined with Devon County Council to support a joint Self Care Commissioning Strategy.

Local

Devon and Cornwall and Island of Scilly PCTs have adopted the reduction of the number and impact of strokes as a priority area.

Existing Research:

Published research

We found several studies on electronic health guides to support people who have had stroke and their carers. These studies generally found no statistically significant differences in patients' knowledge of their condition, quality of life, clinical and other outcomes, between the groups who received online health guides and the groups that did not.

Pierce and colleagues in 2009 conducted a randomised controlled trial of the effectiveness of a web based intervention called Caring-Web, to support carers of people who have had a stroke^{1,2}. They randomised 103 carers into a group that received this online health guide accessible from their home internet and a control group that did not. They found that there were no statistical differences in the well being of carers or in the visits carers made to stroke survivors. However, the number of emergency department visits ($p = 0.001$) and the number of hospital re-admissions ($p = 0.0005$) were significantly less in the intervention group compared to the control group.

Rochette and colleagues developed a website in 2008 called StrokEngine-Family based on their findings of websites providing information for patients with stroke and their carers, and assessed the usability of this website among seven respondents³. They found that six of the seven respondents responded favourably and that requests for improvement included specific information regarding emotional support and how to access this support, greater use of short phrases, bulleted notations, and the addition of a depression module.

Maasland and colleagues conducted a trial of a non web-based computer programme in 2007⁴. This provided health education that was customised to the educational level, risk profile and symptoms of individual patients. Transient ischemic attack or minor stroke patients were allocated to health education by a physician ($n = 32$) or to a combination of education by a physician and the computer program ($n = 33$). Their knowledge was tested by means of a questionnaire at one and 12 weeks after inclusion. They found that there was no statistically significant difference in knowledge between the groups, but that the level of knowledge was low in both groups at both time points.

A cross sectional comparative study conducted in 2011 by Kim and Park⁵ examined the relationship between patient education carried out via a web group, a booklet group and a control group on a range of outcomes (level of knowledge, self reported level of family support, and health behaviour compliance). They found that there was no statistically significant difference in outcomes between the web and booklet groups.

We did not find any systematic reviews of online e-health guide interventions for improving quality of life and health outcomes and ability to self care, for patients with stroke and their carers.

Ongoing research

We did not identify any ongoing studies of the effectiveness of online information and support on the quality of life and rehabilitation of people with stroke or their carers.

Feasibility:

This question receives support from a range of organisations. A member of the South West NHS Research Design Service is a member of the group developing this research question. The South West Stroke Research Network has provided advice and support throughout and have offered help with recruitment via primary care provider groups, as and when needed. The Primary Care Research Network Lead has also offered support.

References:

1. Pierce, L.S., V. Govoni, AL, In-home online support for caregivers of survivors of stroke: a feasibility study. CIN: Computers, Informatics, Nursing, 2002. 20(4): p. 157-64.

The primary aim of this feasibility study was to determine if caregivers (n = 5) were willing and able to use Caring-Web, a Web-based intervention for support, from their home Internet connection for 3 months. The caregivers' perceived health and satisfaction with caring, as well as the care recipients' use of healthcare services, were recorded. The experience of caring (problems and successes) was examined. Data were collected via weekly online surveys and e-mail discussions. Descriptive analyses revealed that the 3 caregivers who completed the study were satisfied with Caring-Web. Caregivers rated their health as average to excellent and their satisfaction with caring as good. Care recipients averaged 6 calls/visits to a medical office with one emergency room visit and subsequent hospitalization. Major problems for the caregivers included dealing with medical conditions about which they lacked knowledge. Content analysis of the e-mail discussions revealed that subjects sought information about medical conditions related to caring for the survivor of the stroke. Major successes for the caregivers involved communicating effectively with the care recipient and returning to everyday life with family and friends.

2. Pierce, L., The effect of a Web-based stroke intervention on carers' well-being and survivors' use of healthcare services. Disability and rehabilitation, 2009. 31(20): p. 1676-84.

PURPOSE: We hypothesised that carers of stroke survivors who participate in the Web-based intervention, Caring approximately Web, would have higher well-being than non-Web users. We also postulated that those survivors whose carers participated in Caring approximately Web would use fewer healthcare services. **METHOD:** A randomised, two-group, repeated measures design was used. Subjects were recruited from four rehabilitation centres from which first-time stroke survivors were discharged to home in two Midwestern states. Of 144 carers screened, 103 carers of these survivors who were novice Internet users were assigned to a Web or non-Web user group. Seventy-three subjects completed the study. **INTERVENTION:** Caring approximately Web was a Web-based intervention of education and support provided to the Web user group for 1 year. A bi-monthly telephone survey collected data on all carers well-being (perceived depression, life satisfaction) and survivors healthcare service use (self-reported provider and emergency department visits, hospital re-admissions, nursing home placement). **RESULTS:** No statistical differences were found between the groups in carers well-being or in the number of provider visits for survivors. There were significant differences in emergency department visits ($p = 0.001$) and hospital re-admissions ($p = 0.0005$) related to the

health of survivors. CONCLUSIONS: This Web-based intervention helped new carers make informed decisions about healthcare needs of stroke survivors, thus reducing service use.

3. Rochette, A., N. Korner-Bitensky, V. Tremblay, and L. Kloda, Stroke rehabilitation information for clients and families: assessing the quality of the StrokEngine-Family website. *Disability & Rehabilitation*, 2008. 30(19): p. 1506-12.

PURPOSE: This study: (i) Identified the availability of scientifically-based information on the internet regarding stroke rehabilitation intended for those who have experienced a stroke and their families; and, (ii) assessed the usability of a newly created website on stroke rehabilitation for laypersons, StrokEngine-Family. METHOD: First, an extensive systematic search was undertaken to identify and appraise existing stroke rehabilitation websites. Seventeen websites met specific inclusion/exclusion criteria. Although some addressed stroke rehabilitation interventions in layperson language, none discussed the numerous treatment options based on scientifically based information. Thus, StrokEngine-Family was developed and its usability assessed with individuals who had experienced a stroke and family members. RESULTS: Seven respondents aged 43-68 years participated in the pilot testing of the newly developed StrokEngine-Family. All except one indicated overall satisfaction with the website: The one respondent rated it as somewhat user-friendly mainly for aesthetic reasons including the need for darker colors and larger font. In addition, respondents requested specific information regarding emotional support and local community referrals to this type of support. Based on the feedback, minor changes were made including a greater use of short phrases, bulleted notations and the addition of a depression module. CONCLUSIONS: The systematic review provided support for the development of StrokEngine-Family. In pilot testing, StrokEngine-Family was easy to use and valuable in content.

4. Maasland, E.K., P.J. Habbema, J.D. Dippel, D.W. , Effects of an individualized multimedia computer program for health education in patients with a recent minor stroke or transient ischemic attack - a randomized controlled trial. . *Acta Neurologica Scandinavica*, 2007. 115(1): p. 41-8.

BACKGROUND: Transient ischemic attack (TIA) and stroke patients often show a striking lack of knowledge about their disease. We developed a computer program that provided health education fitting the educational level, risk profile and symptoms of patients and evaluated it in a randomized controlled trial. METHODS: Transient ischemic attack or minor stroke patients were allocated to health education by a physician (n = 32) or to a combination of education by a physician and the computer program (n = 33). Knowledge was tested by means of a questionnaire at 1 and 12 weeks after inclusion. The maximum possible score was 71 points. RESULTS: Overall knowledge was low - the mean score was 43.6 at 1 week and 42.0 points at 12 weeks for both the groups. The intervention group had slightly better scores at 1 week after using the computer program, 45.4 vs 41.5 (P = 0.09), with the difference increasing to 4.3 points after (post-hoc) adjustment for age and level of education (P = 0.06). After 12 weeks, the score in the intervention group dropped significantly to 42.0 points (P = 0.05), and was no longer different from the standard group. CONCLUSION: This study did not show a lasting effect of health education by an individualized computer program on the knowledge of TIA and minor stroke patients.

5. Kim, C.G. and H.A. Park, Development and Evaluation of a Web-based

Education Program to Prevent Secondary Stroke. , in J Korean Acad Nurs. 2011. p. 47-60.

PURPOSE: This study was conducted to develop and evaluate a web-based education program for secondary stroke prevention. **METHODS:** A web-based secondary stroke prevention education program was developed using the system's life cycle methods and evaluated by comparing the effects of education among three groups, a web group, a booklet group and a control group. **RESULTS:** Knowledge level of both patients and family, as well as some health behavior compliance in the web-based and booklet education groups were significantly higher than those of the control group. Family support in the web-based and booklet education groups was significantly higher than that of the control group after 12 weeks. The urine cotinine level in the web-based education group was significantly lower than that of the control group after 12 weeks. Medication adherence, blood pressure and perceived health status were not statistically different among the three groups at any time. **CONCLUSION:** Web-based and booklet education programs were equally effective regarding the level of knowledge of patients and their families, family support, health behavior compliance, and urine cotinine level. These results demonstrate the potential use of a web-based education program for secondary stroke prevention.