

# High-quality Health Information Provision for Stroke Patients

Hong-Sheng Du, Jing-Jian Ma, Mu Li

Department of Neurosurgery, Tianjin First Central Hospital, Tianjin 300192, China

## Abstract

**Objective:** High-quality information provision can allow stroke patients to effectively participate in healthcare decision-making, better manage the stroke, and make a good recovery. In this study, we reviewed information needs of stroke patients, methods for providing information to patients, and considerations needed by the information providers.

**Data Sources:** The literature concerning or including information provision for patients with stroke in English was collected from PubMed published from 1990 to 2015.

**Study Selection:** We included all the relevant articles on information provision for stroke patients in English, with no limitation of study design.

**Results:** Stroke is a major public health concern worldwide. High-quality and effective health information provision plays an essential role in helping patients to actively take part in decision-making and healthcare, and empowering them to effectively self-manage their long-standing chronic conditions. Different methods for providing information to patients have their relative merits and suitability, and as a result, the effective strategies taken by health professionals may include providing high-quality information, meeting patients' individual needs, using suitable methods in providing information, and maintaining active involvement of patients.

**Conclusions:** It is suggested that to enable stroke patients to access high-quality health information, greater efforts need to be made to ensure patients to receive accurate and current evidence-based information which meets their individual needs. Health professionals should use suitable information delivery methods, and actively involve stroke patients in information provision.

**Key words:** Health Information; Information Provision; Stroke Patient

## INTRODUCTION

The concept of information need was coined by an American Researcher Taylor<sup>[1]</sup> and is defined as people's "awareness or recognition of not knowing or existence of uncertainty".<sup>[2]</sup> Thus, people "require some form of knowledge for resolution"<sup>[3]</sup> and have "a desire to locate and obtain information to satisfy their requirements".<sup>[4]</sup> In this review, "information need" is related primarily to stroke patients who want to understand their health problems and use healthcare services.

The idea that patients should receive sufficient information is not new. The initiative to provide health information to patients was pioneered in the US.<sup>[5]</sup> Similar efforts have been undertaken in other countries, such as Australia, Canada, New Zealand, and the UK.<sup>[6-9]</sup> These efforts have increased patients' awareness as well as access to health information.<sup>[5]</sup>

Meanwhile, government policy has also been encouraging the provision of quality health information to patients.<sup>[5]</sup> For

example, the Department of Health in the UK has advised health professionals to put information at the center of people's health, improve access to quality information, and enable the public to make better healthcare decisions.<sup>[10]</sup> The government has developed and launched the information prescriptions service. More importantly, patients have a legal right to be adequately informed before receiving healthcare services to participate in healthcare decision-making, as specified and regulated in the policy and legislation document.<sup>[11]</sup>

Tailored and high-quality information provision can allow patients to take more responsibility for their health and respond

**Address for correspondence:** Dr. Hong-Sheng Du,  
Department of Neurosurgery, Tianjin First Central Hospital,  
Tianjin 300192, China  
E-Mail: hongshengdu1@163.com

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

**For reprints contact:** reprints@medknow.com

© 2016 Chinese Medical Journal | Produced by Wolters Kluwer - Medknow

**Received:** 15-05-2016 **Edited by:** Qiang Shi  
**How to cite this article:** Du HS, Ma JJ, Li M. High-quality Health Information Provision for Stroke Patients. Chin Med J 2016;129:2115-22.

### Access this article online

#### Quick Response Code:



**Website:**  
www.cmj.org

**DOI:**  
10.4103/0366-6999.189065

better and more quickly to health problems,<sup>[12]</sup> feel more in control,<sup>[13]</sup> create positive attitudes toward their disease, and effectively participate in the decision-making concerning healthcare and life.<sup>[14]</sup> Inadequate information may increase the patients' distress, anxiety, and dissatisfaction, which may negatively affect the patients' decision-making and quality of life.<sup>[15]</sup> However, the quality of health information provided to patients has been generating increasing concern. Thus, health professionals are exerting extensive efforts to ensure that patients can have access to high-quality and evidence-based information resources.<sup>[5]</sup>

Stroke is a major public health concern in China and worldwide because of its significant mortality and long-term morbidity.<sup>[16]</sup> Following an acute stroke, both older people and their family carers have to make major life decisions in a relatively short period, often without an adequate understanding about stroke and its consequences.<sup>[17]</sup> To improve the situation, it is suggested that professionals need to actively work with patients and empower them to make informed decisions to better manage the stroke and make a good recovery.<sup>[18]</sup>

The aim of this study was to review the research literature on information needs of patients with stroke, methods for providing information to patients, and considerations needed by the information providers. The literature review method used was a comprehensive search of relevant literature and thematic analysis of the research findings.<sup>[19,20]</sup> The literature search was conducted using online electronic database, i.e., PubMed for English-language articles published from 1990 to 2015 to consider the latest research and to gain an in-depth understanding or knowledge of relevant areas. The items cited in the reference list of the published articles which appeared to be particularly relevant to the topic were also retrieved from the electronic database and examined. The key words used for searching were as follows: stroke, brain infarction, cerebral infarction, transient ischemic attack, cerebral hemorrhage, patients, health information, information need, and information provision. The search and inclusion of studies were not restricted to those which reported the exploration of information provision for patients with stroke as their main objective. Thus, the studies that provided useful data and findings for understanding of the above topic were included, with no limitation of study design. Thematic analysis of the research findings was used.<sup>[20]</sup> Similar findings were extracted, grouped into respective themes, and summarized to reflect the main ideas across a body of evidence, and develop insights on the current knowledge in the area of information provision for stroke patients.

## INFORMATION NEEDS OF STROKE PATIENTS IN ALL STAGES OF PATIENT JOURNEY

Patients need access to good-quality information to actively participate in healthcare.<sup>[5]</sup> Many studies have suggested that stroke patients should be informed on all aspects of their disease and care.<sup>[12,17]</sup> Although information is necessary in

all stages of patient journey, patients' information needs or areas of concern vary at different stages of stroke and may change over time.<sup>[18]</sup> Hanger *et al.*<sup>[18]</sup> showed that patients often continue to have unanswered questions throughout the whole process of the disease.

### Before the onset of stroke

Information provision to the general public at this stage is primarily aimed to reduce risk, increase early recognition, and decrease treatment delay. Therefore, the following information should be provided: stroke risk factors, affected organ or body part, warning signs or symptoms, emergency nature of stroke, physiological processes, functional consequences, medication or medical interventions used to control risk factors, actions needed to respond to a potential stroke and treatment strategies.<sup>[21]</sup>

### During the acute period of stroke

Patients may visit a doctor to get early medical help when they recognize that they are having a stroke. At this moment, patients may desire expert information and explanations from doctors to comprehend their diagnosis and treatment to accept treatment. Patients may refuse doctors' prescriptions or referral without clear and detailed information.<sup>[22]</sup>

Patients may need detailed information after admission to the hospital and during their hospitalization in an acute care setting. Patients need to understand the process of stroke, meaning of symptoms, nature of their current disease condition, and influence of the disease on their health. Patients should also be aware of the treatment being applied, the results of examinations, such as their scans or X-rays, and the meaning of diagnosis. Patients need to understand the treatment that can manage their symptoms, treatment options, the effectiveness and potential side effects of these treatments, possible treatment outcome, and future recovery. Patients may also seek advice on the purpose or importance of walking or moving and how to eliminate bad habits, such as smoking, during their hospital stay.<sup>[23]</sup>

### At discharge

Patients may still increasingly desire sufficient information on their condition at the time of discharge from the hospital when the acute stage has passed. Patients may inquire on the course of their illness or disease process and the evaluation of their symptoms and treatment effects. However, patients may begin to be concerned of long-term issues at this point.<sup>[23]</sup> Thus, patients may desire information on the prognosis and possible life situation postdischarge, continuing treatment after discharge, follow-up schedules, and prevention of stroke recurrence. Patients may also need information about their goals or needs for continued daily care and rehabilitation services. Patients may need assistance in the management of their limitations caused by physical and psychological impairments. Patients may require guidance on how to cope at home and overcome difficulties in issues in their daily life, such as driving or resuming sexual activity, availability of local voluntary support group, or organization and contact details of health professionals.<sup>[24,25]</sup>

Keeping patients with stroke well-informed is essential to their well-being.<sup>[25]</sup> Studies have repeatedly indicated that stroke patients' information needs continue to exist and change over time during all stages of the stroke journey. However, the information disseminated by health professionals often fails to well address all these concerns or uncertainties, and the needs of patients are not satisfied adequately.<sup>[26,27]</sup> Therefore, health professionals should clearly identify the patients' information needs during the different stages of stroke and provide high-quality and individualized information to the patients.<sup>[28]</sup>

## **METHODS FOR PROVIDING INFORMATION TO PATIENTS WITH STROKE**

Different methods of information delivery to patients with stroke are adopted in the practice of stroke care. Information is primarily disseminated using the following approaches: (1) verbal information given by health professionals to patients with stroke; (2) printed materials, such as patient information leaflets or booklets, magazines and newspapers, medical books, and professional journals; (3) audio/visual materials, such as TV, radio or video/audio tapes; and (4) electronic format, for example, web-based Internet resources or first-hand information from expert patients.<sup>[17,23,29]</sup> This section discusses the relative merits of each format and its suitability in disseminating information to patients with stroke [Table 1].

Thus, each method used to provide information for patients with stroke presents its own specific effectiveness, weaknesses, and suitability. Health professionals need to consider all these important issues when providing information to patients.<sup>[17,63]</sup> Meanwhile, stroke patients prefer information to be delivered using different approaches,<sup>[18]</sup> and their preferences of structuring the information in different media may also vary.<sup>[28]</sup> Information providers need to be conscientious to consider patients' preferences and improve information provision to stroke patients in practice.

## **CONSIDERATIONS NEEDED BY THE INFORMATION PROVIDER**

Providing high-quality health information to patients with stroke throughout the whole patient journey is important to assist patients understand their disease and healthcare received, make fully informed decisions, have good recovery, and prevent another stroke. The following factors should be considered by health professionals to ensure the provision of high-quality information.

### **Providing high-quality information**

Stroke patients need health professionals to use simple and understandable language when providing information, especially when patients have communication difficulties.<sup>[30]</sup> Information providers should avoid the mismatch between the readability and suitability of written materials and the reading ability of stroke patients by conducting a readability

assessment during the development and structuring of information.<sup>[31]</sup>

Health information should include high-quality and evidence-based data to effectively support patients' participation in healthcare.<sup>[27]</sup> Quality monitoring and assessment of information provision for stroke should be a standard practice,<sup>[31,64]</sup> in which health professionals need to assess the health information for accuracy, completeness, consistency, reliability, and comprehensibility, regardless of the format, whether as printed materials, audio/visual programs, or online information.<sup>[65-67]</sup> Therefore, health professionals play a valuable role in guiding stroke patients in obtaining high-quality and evidence-based information.<sup>[68]</sup>

### **Meeting patients' individual needs**

Stroke patients' individual needs and preferences for information vary or differ individually and may change over time. Information provision should be individualized rather than standardized to meet each patient's personal needs and maximize its relevance to each patient.<sup>[46]</sup> Specific information adapted to the patient's personal needs could also inspire and facilitate behavioral changes following stroke.<sup>[69]</sup> In addition, health professionals should be aware of the behavior of information avoidance among stroke patients who may not always need to know disease-related information, particularly if the information constitutes bad news.<sup>[70]</sup>

Thus, health professionals should actively involve patients, consider their preferences, and address all their personal concerns when developing, structuring, and recommending information materials. Meanwhile, health professionals should continually assess patients' needs, as well as evaluate and revise information accordingly.<sup>[17,71]</sup> Sometimes, patients may also need to revisit information because of their poor memory, older age, and impaired cognitive function. Thus, health professionals need to repeatedly provide information to facilitate the understanding of patients.<sup>[72]</sup>

### **Using suitable method(s) in providing information**

No approach has been considered as the best method of information delivery to patients with stroke.<sup>[31]</sup> Health professionals should recognize and consider the different values, weaknesses, and suitability of different approaches to health information delivery to provide information appropriately.<sup>[17,73]</sup> However, health professionals should also accept that stroke patients may also have different preferences for the method of information delivery. Thus, the required information should be provided in suitable formats which are adapted to patients' individual preferences.<sup>[23]</sup>

### **Maintaining active involvement of patients**

According to Thomas and Parry,<sup>[74]</sup> information is often provided according to the health professionals' perceptions of stroke patients' needs. However, compared with providing information passively, actively involving patients in learning and problem-solving during information provision has been proved more effective in improving patients' knowledge

**Table 1: Relative merits and suitability of different methods for getting information to patients with stroke**

Methods of information delivery	Strengths	Weaknesses	Suitability
Giving information verbally By health professionals By patients with stroke	<p>Professional consultation or advice is essential in effective health information provision for stroke patients<sup>[30]</sup></p> <p>Health professionals are considered by patients as a good and knowledgeable source of information<sup>[25]</sup></p> <p>Patients prefer and strongly desire the one-on-one verbal discussion with health professionals<sup>[31-33]</sup></p> <p>Patients can receive the tailored and detailed information when their individual needs or concerns are taken into consideration<sup>[31,33]</sup></p> <p>Patients can receive personalized support and practical help when their individual needs or concerns are taken into consideration<sup>[31,33]</sup></p> <p>Through face to face communication between patients in group learning or local stroke support groups, stroke patients can share their stories with each other and hear about their experiences at first hand. In particular, the “expert patient” can provide the valuable information about effective coping strategies for managing their everyday lives poststroke<sup>[34]</sup></p>	<p>Verbal information given by health professionals may be very expensive and time-consuming due to the fact that it happens in person and on an individual basis<sup>[36]</sup></p> <p>It is easy for patients to forget the verbally delivered information<sup>[45]</sup></p> <p>Health professional-related barriers which may hinder stroke patients’ getting information include lack of knowledge, lack of time, or poor communication skills<sup>[46]</sup></p>	<p>The suitability may be limited to stroke patients without cognitive impairments</p> <p>It is not suitable for stroke patients who have problems with speaking or language, understanding, memory, and concentration<sup>[30]</sup></p>
Printed materials Patient information leaflets or booklets Magazines or newspapers Medical books or professional journals	<p>It mainly provides written information or explanations and is viewed by patients as a valuable resource<sup>[31]</sup></p> <p>Receiving information in written form is very helpful, especially for patients to use for reference when required during the future recovery process<sup>[23]</sup></p> <p>Information in printed materials can be consistent and help recall<sup>[35]</sup></p> <p>Medical books or professional journals have a higher level of accuracy and reliability than written information in other formats<sup>[36]</sup></p>	<p>It mainly presents general and uniform information but cannot provide the targeted information to meet each patient’s individual needs and to best fit his or her particular situation<sup>[47]</sup></p> <p>The acceptability and readability of the information may not have been ensured and examined<sup>[17]</sup></p> <p>Their level of readability, especially that of medical books or professional journals, can be too high, and therefore the information can be considered as nonunderstandable, unacceptable and unsuitable for patients<sup>[48]</sup></p> <p>Patients may misunderstand the content written in professional books or journals, and so develop false interpretations or expectations about their own disease or treatment<sup>[49]</sup></p> <p>The accessibility of academic publications is questionable<sup>[36]</sup></p> <p>The accuracy and reliability of the information from magazines or newspapers are questionable<sup>[36]</sup></p> <p>Patients’ disease condition may have been changed since they are given the information, so they may no longer consider the information to be useful and helpful<sup>[50]</sup></p> <p>The written information may be in danger of getting out of date quickly so that it is important to ensure that it includes current information consistent with present and the latest state of the art evidence in the field of stroke care<sup>[51]</sup></p>	<p>Patient information leaflets or booklets, and magazines or newspapers are useful mainly for patients who have the ability to read and understand</p> <p>It is unfeasible for patients to get written information if they have cognitive impairments, such as problems with concentration, perception, and understanding, as well as age-related vision loss.<sup>[30]</sup> It is important that the materials are in an appropriate format with large text, suitable colors, and shorter and “easy to read” language<sup>[61,62]</sup></p> <p>Medical books or professional journals are more suitable for health professionals to seek information than for patients with stroke<sup>[36]</sup></p>
Audio/visual materials	<p>They have the wider acceptability by stroke patients than other information delivery methods no matter whether or not patients can read</p>	<p>The content and quality of information delivered in audio/visual format have not been sufficiently evaluated<sup>[17]</sup></p>	<p>Audio/visual information is particularly beneficial for stroke patients who are not able to read and is similarly suitable for patients who have the ability to read</p>

Contd...

**Table 1: Contd...**

Methods of information delivery	Strengths	Weaknesses	Suitability
Electronic information	Stroke patients can easily listen to or watch the recorded audio/visual materials at their own speed and convenience <sup>[37]</sup>		
	The information presented in visual materials, such as television programs, is usually very vivid <sup>[36]</sup>		
	The information presented in visual materials, such as television programs can easily peak the interests and curiosities of the audience <sup>[36]</sup>		
	The television program is considered as the favorite information resource by stroke patients <sup>[38]</sup>		
	The use of videos may help explain the information <sup>[23]</sup>		
	The use of videos may help facilitate understanding, for example, it is easy for patients to understand complicated anatomical knowledge through watching three-dimensional images <sup>[23]</sup>		
	Maintaining active participation	The lack of accuracy and reliability	Using Internet to provide information can particular cater patients' needs after discharge when they are difficult to access other resources <sup>[30]</sup>
	Patients with stroke can search information by themselves <sup>[28]</sup>	The content, accuracy, and reliability of information posted on the Internet have not been sufficiently evaluated <sup>[23]</sup>	It may not be an ideal information source for stroke patients with disabilities, such as aphasia, in which patients often have particular problems with cognitive processing of information, memory, attention and understanding <sup>[54]</sup>
	Providing support through on-line discussion and self-help groups can facilitate patients' participation in decision-making and healthcare <sup>[39,40]</sup>	The inaccurate and misleading information may be spread through the Internet due to the lack of quality control and restrictions on online information publication <sup>[32,52]</sup>	It is not suitable for patients without access to computer <sup>[54]</sup>
	Presenting information in different ways	It is usually more difficult for lay people to make an accurate judgment on the quality of Internet information <sup>[32,52]</sup>	It is not suitable for patients without access to Internet <sup>[54]</sup>
	The Internet can present various types of information, such as texts, audios, or videos, to meet the particular needs of stroke patients who prefer the information to be given in different format <sup>[18]</sup>	The inappropriate readability level	It is not suitable for patients without any previous experiences of using Internet <sup>[54]</sup>
	Relative ease of access	The level of readability of some stroke information websites is unsuitably higher than patients' level of understanding <sup>[53,54]</sup>	
	The Internet is a convenient and beneficial information resource <sup>[32]</sup>	The incorrect or even dangerous information	
	Anybody who has a computer connected to the Internet and some technical skills can seek information on the web <sup>[41]</sup>	Health information is not scrutinized or peer-reviewed before being presented on the website, <sup>[55]</sup> so incorrect and potentially dangerous information can be found on websites <sup>[56]</sup>	
	Anybody who has a computer connected to the Internet and some technical skills can share information on the web <sup>[41]</sup>	The barriers to computer access and the use of Internet	
Meeting individual patient's specific learning needs	Patients with disability, poor financial condition or low education level often encounter barriers to computer access and the use of Internet <sup>[57,58]</sup>		
Patients are allowed the opportunity to access information on their own pace <sup>[42]</sup>	The difficulties of accessing electronic information encountered by the vulnerable group of older patients aged 75 years and above also deserve careful consideration by information providers to reduce their higher risk of social exclusion <sup>[59,60]</sup>		
Patients are allowed the opportunity to access information at their preferred time <sup>[42]</sup>	The problems with ease of navigation, currency of information, design and esthetics, organization and presentation of information <sup>[54]</sup>		
Patients are allowed the opportunity to access information at their preferred place <sup>[42]</sup>	Patients are easy to get lost, confused or overwhelmed, or to receive misleading or out-dated information <sup>[55]</sup>		
Patients are allowed the opportunity to access information when they are actually ready to learn <sup>[42]</sup>			
Getting first-hand information from expert patients			
The use of Internet has the potential for peer information giving, sharing and co-learning from and with each other, through electronic forums or other forms of group, community and peer learning activities or programs <sup>[43]</sup>			
The Internet and video-conferencing communication in particular can help novice patients get expert patients' first-hand information about coping strategies, and empower them to self-manage their chronic long-standing disease, as highlighted by the government policies <sup>[44]</sup>			

of stroke, facilitating recovery, and increasing satisfaction. The effective strategies may include providing patients with opportunities to ask questions, express their needs or raise concerns, or establishing a dynamic online discussion and communication if the Internet is used in information delivery.<sup>[75]</sup>

However, service user involvement is important in the design, development, evaluation, and improvement of information materials in whatever format.<sup>[17,76]</sup> For health information to be effective, it needs to be meaningful and comprehensive to the consumers. Thus, health professionals need to develop useful and understandable information materials together with stroke survivors themselves. If stroke patients are involved and they voice their views, needs, or preferences, the information will be much more likely to be relevant, acceptable, and understandable to stroke patients.<sup>[77]</sup> For example, involving the end users or patients in the design and evaluation of the content and the “look and feel” of websites and other modern forms of communication is crucial when information and communication technology is used in delivering health information to patients.<sup>[78]</sup>

## CONCLUSIONS

Patients with stroke need access to health information, which can help them respond more quickly to health problems, comprehend their disease and treatment interventions, obtain good recovery, and reduce the chance of a new stroke. Ensuring that patients’ information needs are satisfied is an important component in practice. This can promote informed choice and shared decision-making as well as enable patients with stroke to actively take part in healthcare.<sup>[31]</sup>

As the patient journey evolves, patients’ needs or preferences for health information at different stages of stroke vary individually, consistently exist, and change over time. Healthcare workers should also be aware of the relative merits and suitability of different methods for providing information to patients with stroke and the patients’ different preferences for the format of information delivery. Thus, greater efforts need to be made to actively involve stroke patients in information provision, and use the most suitable method(s) to provide health information which is sensitive to the patients’ individual needs.<sup>[17]</sup>

The discussion is expected to be useful in raising awareness on the importance of providing high-quality health information to stroke patients among health professionals. The quality of health information for patients with stroke is vital to ensure good recovery and improve quality of life. Health professionals have the responsibility to provide high-quality and evidence-based information, that is accurate, reliable, and comprehensive to patients. To make progress in this aspect, some principles should be followed,<sup>[10,79]</sup> and effective strategies should be undertaken to monitor and evaluate the quality of information from various resources.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

## REFERENCES

1. Taylor RS. Process of asking questions. *Am Doc* 1962;13:391-6. doi: 10.1002/asi.5090130405.
2. Ford N. Relating information needs to learner characteristics in higher education. *J Doc* 1980;36:99-114. doi: 10.1108/eb026692.
3. Chen C, Herson P. *Information Seeking: Assessing and Anticipating User Needs*. London: Neal-Schuman Publisher;1982.
4. Information Needs. Wikipedia; 2011. Available from: [http://www.en.wikipedia.org/wiki/Information\\_needs](http://www.en.wikipedia.org/wiki/Information_needs). [Last accessed on 2016 May 12].
5. Shepperd S, Charnock D, Gann B. Helping patients access high quality health information. *BMJ* 1999;319:764-6. doi: 10.1136/bmj.319.7212.764.
6. Dunning M, AbiAad G, Gilbert D, Hutton H, Brown C. *Turning Evidence Into Everyday Practice*. London: King’s Fund; 1999.
7. Coulter A, Entwistle VA, Gilbert D. *Informing Patients: An Assessment of the Quality of Patient Information Materials*. London: King’s Fund; 1998.
8. NHS Executive. *Patient Partnership: Building a Collaborative Strategy*. Leeds: NHS Executive; 1996.
9. Rees AM. Medical consumerism: Library roles and initiatives. In: Rees AM, editor. *Managing Consumer Health Information Services*. Phoenix: Oryx Press; 1991. p.23-36.
10. Better Information, Better Choices, Better Health: Putting Information at the Centre of Health. DoH; 2004. Available from: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4098599.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4098599.pdf). [Last accessed on 2016 May 12].
11. NHS Constitution. DoH; 2009. Available from: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_093442.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093442.pdf). [Last accessed on 2016 May 12].
12. Heinemann AW, Magasi S, Hammel J, Carlozzi NE, Garcia SF, Hahn EA, *et al*. Environmental factors item development for persons with stroke, traumatic brain injury, and spinal cord injury. *Arch Phys Med Rehabil* 2015;96:589-95. doi: 10.1016/j.apmr.2013.11.024.
13. Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: A systematic review. *Ann Oncol* 2011;22:761-72. doi: 10.1093/annonc/mdq413.
14. Martins JC. Patients’ satisfaction with information on disease and morbidity. *Rev Lat Am Enfermagem* 2009;17:335-40. doi: 10.1590/S0104-11692009000300009.
15. Mossman J, Boudioni M, Slevin ML. Cancer information: A cost-effective intervention. *Eur J Cancer* 1999;35:1587-91. doi: 10.1016/S0959-8049(99)00195-1.
16. Kahraman A, Jones F. Factors Influencing and Shaping the Lived Experience after Stroke: A Systematic Review of Qualitative Studies; 2009. Available from: <http://www.joannabriggs.edu.au/protocols/Protocol237.pdf>. [Last accessed on 2016 May 12].
17. Rodgers H, Bond S, Curless R. Inadequacies in the provision of information to stroke patients and their families. *Age Ageing* 2001;30:129-33. doi: 10.1093/ageing/30.2.129.
18. Hanger HC, Walker G, Paterson LA, McBride S, Sainsbury R. What do patients and their carers want to know about stroke? A two-year follow-up study. *Clin Rehabil* 1998;12:45-52. doi: 10.1191/026921598668677675.
19. Aveyard H. *Doing a Literature Review in Health and Social Care: A Practical Guide*. 2<sup>nd</sup> ed. Maidenhead: Open University Press; 2010.
20. Mays N, Pope C, Popay J. Details of Approaches to Synthesis. A Methodological Appendix to the Paper: Systematically Reviewing Qualitative and Quantitative Evidence to Inform Management and Policy Making in the Health Field; 2005. Available from: <http://>

- www.citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.113.2530&rep=rep1&type=pdf. [Last accessed on 2016 May 12].
21. Sug Yoon S, Heller RF, Levi C, Wiggers J, Fitzgerald PE. Knowledge of stroke risk factors, warning symptoms, and treatment among an Australian urban population. *Stroke* 2001;32:1926-30. doi: 10.1161/01.STR.32.8.1926.
  22. Hjelmblink F, Holmström I, Kjeldmand D. Stroke patients' delay of emergency treatment. *Scand J Caring Sci* 2010;24:307-11. doi: 10.1111/j.1471-6712.2009.00721.x.
  23. Garrett D, Cowdell F. Information needs of patients and carers following stroke. *Nurs Older People* 2005;17:14-6. doi: 10.7748/nop2005.09.17.6.14.c2386.
  24. Almborg AH, Ulander K, Thulin A, Berg S. Patients' perceptions of their participation in discharge planning after acute stroke. *J Clin Nurs* 2008;18:199-209. doi: 10.1111/j.1365-2702.2008.02321.x.
  25. The Royal College of Physicians National Stroke Guidelines. Royal College of Physicians Intercollegiate Working Party for Stroke; 2008. Available from: <http://www.bookshop.rcplondon.ac.uk/content/6ad05aab-8400-494c-8cf4-9772d1d5301b.pdf>. [Last accessed on 2016 May 12].
  26. Gallacher K, Morrison D, Jani B, Macdonald S, May CR, Montori VM, *et al*. Uncovering treatment burden as a key concept for stroke care: A systematic review of qualitative research. *PLoS Med* 2013;10:1-7. doi: 10.1371/journal.pmed.1001473.
  27. Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: Is the information good enough? *BMJ* 1999;318:318-22. doi: 10.1136/bmj.318.7179.318.
  28. Kerr J, Hilari K, Litosseliti L. Information needs after stroke: What to include and how to structure it on a website. A qualitative study using focus groups and card sorting. *Aphasiology* 2010;24:1170-96. doi: 10.1080/02687030903383738.
  29. De Simoni A, Shanks A, Balasooriya-Smeekens C, Mant J. Stroke survivors and their families receive information and support on an individual basis from an online forum: Descriptive analysis of a population of 2348 patients and qualitative study of a sample of participants. *BMJ Open* 2016;6:e010501. doi: 10.1136/bmjopen-2015-010501.
  30. Edwards G. Good Practice for Keeping Stroke Patients and Carers Informed; 2003. Available from: <http://www.nursingtimes.net/nursing-practice-clinical-research/good-practice-for-keeping-stroke-patients-and-carers-informed/199466>. article. [Last accessed on 2016 May 12].
  31. Hoffmann T, Cochrane T. What education do stroke patients receive in Australian hospitals? *Patient Educ Couns* 2009;77:187-91. doi: 10.1016/j.pec.2009.03.009.
  32. Hunter BG, Bridger MW. An out-patient study into the suitability of providing ear, nose and throat patients with internet based information. *Internet J Med Inform* 2008;3:1-5. Available from: <http://www.ispub.com/ostia/index.php?xmlFilePath=journals/ijmi/vol3n2/info.xml>. [Last accessed on 2016 May 12].
  33. Dowswell G, Lawler J, Young J, Forster A, Hearn J. A qualitative study of specialist nurse support for stroke patients and care-givers at home. *Clin Rehabil* 1997;11:293-301. doi: 10.1177/026921559701100405.
  34. Recovering after a Stroke: A Patient and Family Guide. US Agency for Health Care Research and Quality; 1995. Available from: <http://www.strokecenter.org/patients/ras.pdf>. [Last accessed on 2016 May 12].
  35. Eames S, McKenna K, Worrall L, Read S. The suitability of written education materials for stroke survivors and their carers. *Top Stroke Rehabil* 2003;10:70-83. doi: 10.1310/KQ70-P8UD-QKYT-DMG4.
  36. Huang Q. Information needs of the patients with cervical cancer. *Glob J Health Sci* 2009;1:54-9. doi: 10.5539/gjhs.v1n1p54.
  37. Warlow CP, Dennis MS, Van Gijn JC, Hankey GJ, Sandercock PA, Bamford JM, *et al*. *Stroke: A Practical Guide to Management*. Oxford: Blackwell Science;2001.
  38. Yoon SS, Byles J. Perceptions of stroke in the general public and patients with stroke: A qualitative study. *BMJ* 2002;324:1065-8. doi: 10.1136/bmj.324.7345.1065.
  39. Pierce LL. www. Information resources for stroke. *Rehabil Nurs* 2002;27:134-41. doi: 10.1002/j.2048-7940.2002.tb02221.x.
  40. Towards a Common Language for Functioning, Disability and Health. World Health Organisation; 2002. Available from: <http://www.who.int/classifications/icf/site/beginners/bg.pdf>. [Last accessed on 2016 May 12].
  41. Pallen M. Guide to the Internet. The world wide web. *BMJ* 1995;311:1552-6. doi: 10.1136/bmj.311.7019.1552.
  42. Lewis D. The Internet as a resource for healthcare information. *Diabetes Educ* 1998;24:627-30, 632. doi: 10.1177/014572179802400508.
  43. Rigby M, Ashman D. Service innovation: A virtual informal network of care to support a 'lean' therapeutic community in a new rural personality disorder service. *Psychiatr Bull* 2008;32:64-7. doi: 10.1192/pb.bp.107.015628.
  44. Goodwin N. Will telehealth and telecare thrive or perish in a cold financial climate? *J Care Serv Manag* 2009;3:116-8. doi: 10.1179/csm.2009.3.2.116.
  45. Kitching JB. Patient information leaflets – The state of the art. *J R Soc Med* 1990;83:298-300.
  46. Wiles R, Pain H, Buckland S, McLellan L. Providing appropriate information to patients and carers following a stroke. *J Adv Nurs* 1998;28:794-801. doi: 10.1046/j.1365-2648.1998.00709.x.
  47. Wellwood I, Dennis MS, Warlow CP. Perceptions and knowledge of stroke among surviving patients with stroke and their carers. *Age Ageing* 1994;23:293-8. doi: 10.1093/ageing/23.4.293.
  48. Hoffmann T, McKenna K. Analysis of stroke patients' and carers' reading ability and the content and design of written materials: Recommendations for improving written stroke information. *Patient Educ Couns* 2006;60:286-93. doi: 10.1016/j.pec.2005.06.020.
  49. Helft PR, Eckles RE, Johnson-Calley CS, Daugherty CK. Use of the internet to obtain cancer information among cancer patients at an urban county hospital. *J Clin Oncol* 2005;23:4954-62. doi: 10.1200/JCO.2005.09.621.
  50. Pain HS, McLellan DL. The use of individualised booklets after a stroke. *Clin Rehabil* 1990;4:265-72. doi: 10.1177/026921559000400403.
  51. Lindsay MP, Gubitz G, Bayley M, Hill MD, Davies-Schinke C, Singh S, *et al*. Canadian Best Practice Recommendations for Stroke Care. On Behalf of the Canadian Stroke Strategy Best Practices and Standards Writing Group; 2010. Available from: [http://www.strokebestpractices.ca/wp-content/uploads/2011/04/2010BPR\\_ENG.pdf](http://www.strokebestpractices.ca/wp-content/uploads/2011/04/2010BPR_ENG.pdf). [Last accessed on 2016 May 12].
  52. Ziebland S, Chapple A, Dumelow C, Evans J, Prinjha S, Rozmovits L. How the internet affects patients' experience of cancer: A qualitative study. *BMJ* 2004;328:564. doi: 10.1136/bmj.328.7439.564.
  53. Walsh TM, Volsko TA. Readability assessment of internet-based consumer health information. *Respir Care* 2008;53:1310-5.
  54. Griffin E, McKenna K, Worrall L. Stroke education materials on the World Wide Web: An evaluation of their quality and suitability. *Top Stroke Rehabil* 2004;11:29-40. doi: 10.1310/JKJK-N2MP-9LQ1-FF2N.
  55. Zun LS, Blume DN, Lester J, Simpson G, Downey L. Accuracy of emergency medical information on the web. *Am J Emerg Med* 2004;22:94-7. doi: 10.1016/j.ajem.2003.12.009.
  56. Kane E. Stroke; 2011. Available from: <http://www.healthy.net/Health/Article/Stroke/853/1>. [Last accessed on 2016 May 12].
  57. Internet Access 2008: Households and Individuals. National Statistics; 2008. Available from: <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5672>. [Last accessed on 2016 May 12].
  58. Dutton W, Helsper EJ. *The Internet in Britain*. Oxford: University of Oxford, Oxford Internet Institute; 2007.
  59. Hoff A. Tackling Poverty and Social Exclusion of Older People-Lessons from Europe; 2008. Available from: <http://www.ageing.ox.ac.uk/system/files/Working%20Paper%20308.pdf>. [Last accessed on 2016 May 12].
  60. Fight Against Poverty and Social Exclusion: Definition of Appropriate Objectives Strategy. Commission of the European Communities; 2000. Available from: [http://www.ec.europa.eu/employment\\_social/social\\_inclusion/docs/approb\\_en.pdf](http://www.ec.europa.eu/employment_social/social_inclusion/docs/approb_en.pdf). [Last accessed on 2016 May 12].
  61. Blanck AW, Marshall C. Patient education materials from the layperson's perspective: The importance of readability. *J Nurses Staff Dev* 2011;27:E8-10. doi: 10.1097/NND.0b013e31820e0eff6.
  62. Management of Patients with Stroke: Rehabilitation, Prevention and Management of Complications, and Discharge Planning;

- A National Clinical Guideline. Scottish Intercollegiate Guidelines Network; 2010. Available from: <http://www.guidelines.gov/content.aspx?id=23849>. [Last accessed on 2016 May 12].
63. Flynn D, Ford GA, Stobbart L, Rodgers H, Murtagh MJ, Thomson RG. A review of decision support, risk communication and patient information tools for thrombolytic treatment in acute stroke: Lessons for tool developers. *BMC Health Serv Res* 2013;13:225. doi: 10.1186/1472-6963-13-225.
  64. Gattellari M, Leung DY, Ukoumunne OC, Zwar N, Grimshaw J, Worthington JM. Study protocol: The DESPATCH study: Delivering stroke prevention for patients with atrial fibrillation – A cluster randomised controlled trial in primary healthcare. *Implement Sci* 2011;6:48. doi: 10.1186/1748-5908-6-48.
  65. Lee KW, Choi SJ, Kim SB, Lee JH, Lee SJ. A survey of caregivers' knowledge about caring for stroke patients. *Ann Rehabil Med* 2015;39:800-15. doi: 10.5535/arm.2015.39.5.800.
  66. Rothwell K, Boaden R, Bamford D, Tyrrell PJ. Feasibility of assessing the needs of stroke patients after six months using the GM-SAT. *Clin Rehabil* 2012;27:264-71. doi: 10.1177/0269215512457403.
  67. Coulter A. Evidence based patient information. Is important, so there needs to be a national strategy to ensure it. *BMJ* 1998;317:225-6. doi: org/10.1136/bmj.317.7153.225.
  68. Dubey D, Amritphale A, Sawhney A, Amritphale N, Dubey P, Pandey A. Smart phone applications as a source of information on stroke. *J Stroke* 2014;16:86-90. doi: 10.5853/jos.2014.16.2.86.
  69. Walsh D, Shaw DG. The design of written information for cardiac patients: A review of the literature. *J Clin Nurs* 2000;19:658-67. doi: 10.1046/j.1365-2702.2000.00383.x.
  70. Case DO, Andrews JE, Johnson JD, Allard SL. Avoiding versus seeking: The relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *J Med Libr Assoc* 2005;93:353-62.
  71. Sureshkumar K, Murthy GV, Kinra S, Goenka S, Kuper H. Development and evaluation of a Smartphone-enabled, caregiver-supported educational intervention for management of physical disabilities following stroke in India: Protocol for a formative research study. *BMJ Innov* 2015;1:117-126. doi: 10.1136/bmjinnov-2015-000042.
  72. Rowntree D. *Teaching through Self-Instruction*. London: Kogan Page; 1990.
  73. Kamal AK, Shaikh QN, Pasha O, Azam I, Islam M, Memon AA, *et al*. Improving medication adherence in stroke patients through Short Text Messages (SMS4Stroke)-study protocol for a randomized, controlled trial. *BMC Neurol* 2015;15:157. doi: 10.1186/s12883-015-0413-2.
  74. Thomas C, Parry A. Research on users' views about stroke services: Towards an empowerment research paradigm or more of the same? *Physiotherapy* 1996;82:6-12. doi: 10.1016/S0031-9406(05)66991-X.
  75. Smith J, Forster A, House A, Knapp P, Wright J, Young J. Information provision for stroke patients and their caregivers. *Cochrane Database Syst Rev* 2008;11:CD001919. doi: 10.1002/14651858.CD001919.pub3.
  76. Flynn D, Nesbitt DJ, Ford GA, McMeekin P, Rodgers H, Price C, *et al*. Development of a computerised decision aid for thrombolysis in acute stroke care. *BMC Med Inform Decis Mak* 2015;15:6. doi: 10.1186/s12911-014-0127-1.
  77. Groene O, Sunol R, Klazinga NS, Wang A, Dersarkissian M, Thompson CA, *et al*. Involvement of patients or their representatives in quality management functions in EU hospitals: Implementation and impact on patient-centred care strategies. *Int J Qual Health Care* 2014;26 Suppl 1:81-91. doi: 10.1093/intqhc/mzu022.
  78. McNamara K. *Improving Health, Connecting People: The Role of ICTs in the Health Sector of Developing Countries: A Framework Paper*; 2007. Available from: <http://www.search.asksource.info/cf/search/search.cfm?search=framework%20paper&db=biball>. [Last accessed on 2016 April 12].
  79. Good Medical Practice. General Medical Council; 2006. Available from: [http://www.gmc-uk.org/static/documents/content/GMP\\_0910.pdf](http://www.gmc-uk.org/static/documents/content/GMP_0910.pdf). [Last accessed on 2016 May 12].