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Assessing the quality of websites providing information on multiple sclerosis; evaluating tools and comparing sites

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The quality of health information available on the Internet has proved difficult to assess objectively. The Internet's growing popularity as a source of health information, accompanied by the lack of regulation of websites, has resulted in research that has developed and tested tools to evaluate health website quality. However, only a few studies have tested the validity and reliability of these tools. There is a lack of consensus about appropriate indicators with which to operationalise the concept of quality health information. This study aimed to contribute to this research by testing the validity and reliability of existing tools, through their application to websites that provided information about multiple sclerosis. Furthermore, a specific tool for evaluating multiple sclerosis information was developed, contributing to the debate about suitable criteria for measuring the 'quality' of health information on the web.

Keywords
Multiple sclerosis, world-wide web, evaluation

1. Introduction

Multiple sclerosis (MS) is a chronic disease of the central nervous system. It has an unpredictable course and there is no known cure. Although not normally fatal, the disease progressively worsens and quality of life may deteriorate as a result of increasing disabilities. Multiple sclerosis causes damage to the protective myelin sheath around the nerve cells, resulting in a wide variety of physical and psychological symptoms, including visual disturbances, spasticity, fatigue, bowel and bladder problems, numbness, cognitive impairment and depression. Given the diversity of symptoms and the long-term trajectory of the disease it is likely that people with MS and their family members will have needs for information at various stages of the disease.

Hepworth and Harrison surveyed the information needs of 2030 people with multiple sclerosis in the UK [1]. They reported that although information had been shown to help people with the condition, their information needs were not adequately met by professional health services, particularly in relation to practical aspects of everyday life and coping strategies. As multiple sclerosis is characterised by phases of remission and changes in the symptoms exhibited, it was also reported that information needs are likely to vary over time, depending on the stage of the illness and length of time since diagnosis. They also found that a high proportion of the

respondents were dissatisfied with the level of information provision [1]; 43% reported they had received no information since diagnosis. Other research has demonstrated that people with multiple sclerosis need to make informed decisions about their long-term healthcare [2]. One possible source of information is the world-wide web.

Hepworth and Harrison assessed the sources of information for people with multiple sclerosis and found that only around 5% of their sample wanted to access information from the Internet [1]. This may indicate that the quality or relevance of the information currently provided is inadequate, or that people with multiple sclerosis may not be aware of resources that are available on the Internet and may need to be directed to the best websites by professionals. There is a clear need for information, and the Internet has the potential be a useful source of information. In this paper we describe a study to evaluate the content of websites providing information on multiple sclerosis.

2. Background

2.1 Health Information on the Web

The benefits of being able to access health information on the Internet have been described by a number of researchers. For example, Croft and Peterson suggested that it is an inexpensive means of information dissemination that can reach millions of people across geographic boundaries with relative ease and at times when they need it [3]. Bedell et al. highlighted that information can be sought anonymously, without the patient feeling inhibited or embarrassed, as they may do in person [4]. Nguyen, et al. argued that it has the potential to be an interactive medium, engaging the user with both the information and other people with similar conditions [5].

Rozmotis and Ziebland undertook a qualitative study to interview cancer patients about their use of the Internet [6]. They found that patients believed having access to websites that provided relevant health information was likely to make them assume a more active role in medical decisions, to question medical staff and to be more assertive when they felt that their needs were not being met. It was recognised that this can have positive implications for health care, helping the cultural shift from the traditional paternalistic approach of "doctor knows best" to the patient making informed decisions [7]. As Seidman et al. suggested [8]:

"The web can bridge the chasm between doctor and patient and elevate the level of dialogue, allowing them to discuss diagnostic and treatment choices in a more sophisticated and timely manner" (p.3).

Schmidt and Ernst summarised research suggesting that between 36% and 55% of Internet users access medical information on the web [9]. However, research by Eysenbach and Kohler suggested that consumers do not often examine the source of health information they find on the web, and while they may look for signs of credibility, such as a professional design, they rarely look for information about authorship or disclosure notices [10]. This body of research suggests that it is important to evaluate the quality of health information available on the Internet.

2.2 Generic Evaluation Tools

With an increasing amount of health information freely available on the web, and concerns that some of the information is of questionable quality due to the lack of quality control over information published on the web, a number of evaluation tools have been designed to direct consumers to good sources of information. These evaluation tools are usually generic, so that they can be applied to websites providing

a wide range of health information covering a variety of different conditions. Furthermore, they may not be specifically designed for use with websites, but may be applicable to other sources of health information, e.g., patient information sheets. However, while the proliferation of tools to evaluate the quality of information on websites means that a wide choice of tools is available for people to assess the quality of health information on the web, concerns have been expressed that this may actually cause harm to patients and the public [11]. Tools used by patients and the public to assess the quality of information which have not been validated may lead to their misplacing trust in websites and the information the sites contain. Eysenbach recommended that tools should be validated to ensure their suitability for assessing web-based health information [12].

The criteria used to operationalise the concept of quality health information on the web have been examined. Kim et al. conducted a comprehensive review of the rating tools and evaluation instruments found on the Internet or in peer-reviewed journals [13]. In their review of 29 evaluation tools, they identified 165 explicit criteria for rating websites. They found that evaluation tools most often used aspects of information accuracy, website design and aesthetics, disclosure of authorship and sponsorship, authority of the source and currency of the information, as proxy measures of quality. The authors concluded that although it may be difficult to develop a single tool suitable for evaluating all health information, effort should be made to reach a consensus about the key criteria. A recent review paper by Childs suggested that agreement over criteria had still not been reached [14].

A limited number of studies have examined the validity and reliability of a selection of evaluation tools, in an attempt to assess their suitability for assessing website quality. Ademiluyi et al. conducted research to test the validity and reliability of three evaluation tools for use by health professional and patients, each of which had a rating scale allowing scores to be directly compared [15]. The authors evaluated 89 websites, containing information about smoking cessation, with the information quality (IQ) tool, the quality scale and the DISCERN tool. Only the internal consistency of the DISCERN tool was adequate (Cronbach's alpha= 0.777). The IQ tool was Cronbach's alpha =0.634 and the quality scale was Cronbach's alpha = 0.413. This suggested that the items in each of these scales might not be adequately related and so not suitable for measuring a single concept of quality. For 22 of the websites, two researchers assessed their quality to test for inter-rater reliability. For the IQ tool they found that agreement between each item on the scale ranged from moderate to perfect, with only average agreement between the overall scores. This demonstrated that some items in the scale were subjective and open to interpretation by the rater, such as the ease with which the website could be navigated. The inter-rater reliability of the quality scale was found to be better. Overall it was rated as satisfactory, with perfect agreement found for more objective items. The agreement between raters for the DISCERN tool was again rated as satisfactory, with differences found between the more subjective measures, such as the relevancy of the information. These results suggested that a number of the items in each of the tools employed both objective and subjective measures to assess information quality. However, the correlation between the tools, except for IQ tool and DISCERN, in terms of the overall scores awarded was found to be good. The authors contended that this convergent validity indicated that the evaluation tools were measuring a similar concept of quality. However, they argued that further testing of evaluation tools, on different samples of websites, was necessary.

Bouchier and Bath tested the concordance of four evaluation tools, Jones, eAccess Health, the Health Summit Working Group (also known as the IQ tool) and the Health on the Net (HON) code, on a sample of 15 websites providing information about Alzheimer's disease [16]. Only the IQ tool had a rating system, so the responses from the other tools were converted in to a percentage score, and the websites were ranked according to each tool. The correlation between rankings was then assessed

for each pair of evaluation tools, and only two pairs of tools (the IQ tool and eAccess Health, and Jones and eAccess Health) did not show a significant correlation between them. The HON Code showed a correlation most consistently with the other three tools, with correlations of between 0.45 and 0.50. This was similar to the findings of the Ademiluyi et al. and suggested that most of the tools were measuring a similar concept of quality, even though they employed different proxy measures [15]. However, correlation coefficients of 0.50 or less only show a modest correlation and while there may be some overlap in how they rate quality, different tools appeared to be incorporating different quality measures or domains of quality.

2.3 Disease-Specific Evaluation Tools

The apparent subjectivity of some measures used in generic evaluation tools, as well as their use of proxy measures to judge health information quality has caused some researchers to suggest that only disease-specific tools should be used to evaluate websites that contain information on specific diseases. Eysenbach et al. presented a systematic review of the characteristics of 79 studies that evaluated the quality of health information available on the web [17]. They found that 70% of these studies concluded that quality of information was a problem on the Internet, 21% were neutral and 9% reported more positive findings. However, they contended that the more positive results came from studies that used a less rigorous search and evaluation strategy. For example, they reported that when examining the accuracy of the information provided, studies that judged accuracy against criterion standards or personal opinion found, on average, 15.4% of websites were inaccurate, compared with 33.3% of sites found to be providing inaccurate health information when judged against textbooks or expert consensus and 38.3% inaccurate when compared with clinical guidelines.

Seidman et al. argued that existing generic tools for evaluating health information on websites contained too many subjective measures and that a more rigorous and scientific approach to identifying good quality information was required [18]. To assess the quality of information about diabetes on the web they developed a measure that was based on clinical guidelines about diabetes, concerning both the comprehensiveness and accuracy of information. They found that the websites scored significantly higher on the comprehensiveness scale compared to the accuracy scale but that the means of both scores were relatively low, 59% and 44% respectively. This, they suggested, indicated that although good quality information was available, consumers would need guidance to be able to retrieve it from the web effectively.

However, judging information against clinical guidelines means that only medical experts can evaluate information quality; it is not appropriate for use by patients or voluntary organisations. Furthermore, it promotes a bio-medical agenda, as suggested by Dixon-Woods' in her review of research on patient information leaflets [7], which privileges the medical profession's view of quality information rather than focusing on the patient's needs. As Coleman and Childs reported [19][14], there is growing recognition that patients' views and experiences should be considered in order to meet their information needs . Furthermore, Childs highlighted that websites that provide message boards and chat rooms, facilitating communication between people so that they can share experiences and advice, meet the needs of their users, although they may not be deemed to provide high quality information when compared against clinical guidelines [14].

Bath and Bouchier found that the diversity of the websites available on Alzheimer's disease meant that some of the generic tools were difficult to apply, not least because of ambiguous questions [20]. They developed a tool that adopted criteria based on the information needs of carers to assess websites about Alzheimer's disease. This was designed for use by carers rather than health professionals. While

a variation in the quality of information was still found within the sample of websites, it was felt that the new tool provided a more user-centred method of evaluation.

This aim of this study was to evaluate the quality of information about multiple sclerosis available on the web and to measure the validity and reliability of existing generic evaluation tools. It also compared the results from these tools with that of an instrument specifically designed to evaluate multiple sclerosis information according to the information needs of people with multiple sclerosis.

3. Methods

3.1. Identification and Sampling of Websites

In July 2004, the search engines Google and Yahoo were used to search the World Wide Web using the terms "multiple sclerosis, or "ms" or "neurological disorder" to identify websites that contained information about multiple sclerosis. Over 100 separate websites that contained substantial amounts of information about the condition were identified. A purposive sampling strategy was used to select 40 websites for evaluation and a snapshot of each was taken on a single day using Catch the Web. Inclusion was based primarily on their popularity, according to their ranking in the list of search results. Ideally, a review of all websites would have been conducted; however, it was not possible for one researcher to review all the websites with four different evaluation tools in a limited time.

The majority of the websites (n=17) were produced by not-for-profit organisations, including many of the national multiple sclerosis societies from English speaking countries, including Canada, the USA, Australia, New Zealand, the UK and South Africa. Websites created by commercial organisations (n=11) were also included, comprising all the major drug companies involved in the production of drug therapies for people with multiple sclerosis. Research websites (n=6), mainly produced by universities, and the highest ranked websites produced by individuals (n=6) were also included. There were many more personal websites, however, their low ranking on the Google and Yahoo lists of results, and the low number of websites that linked to them, suggested they would not be frequently accessed by a typical web searcher.

3.2 Evaluation Tools

Wilson classified tools for rating health information on the Internet into five categories [21], of which, only three were suitable for application by consumers. These were 'code of conduct', 'quality label', and 'user guide'. One tool was selected from each of these categories. All were freely accessible on the Internet in July 2004. The Health Summit Working Group developed the Information Quality (IQ) tool [22]. It consisted of 21 questions concerning disclosure of authorship and sponsorship, currency and neutrality. The questions were weighted and a no response to any of three specific questions, concerning disclosure of authorship, ability to contact the author and a subjective assessment of the quality of medical information provided, automatically resulted in a total score of zero. The Centre for Health Information Quality developed the Health Information (HI) Quality Guidelines, which could be applied to all types of written health information [23]. This tool contained 29 indicators concerned with the consistency and currency of the information, as well as disclosure of authorship and sponsorship. It also suggested criteria for the presentation and design of written information, which could be applied to websites. The Health On the Net Foundation established the HON Code as a self-certification scheme to which authors could subscribe if their websites accorded to eight principles, including disclosure of authorship, sponsorship and currency of

information and evidence to support medical claims [24]. These eight principles were adapted to nine 'yes/no' questions for the purpose of this evaluation.

One researcher (JH) assumed the role of a 'typical' user and applied each evaluation tool to the sample of 40 websites at least once. The IQ tool was applied twice, with a three-week gap between assessments, to test for intra-rater reliability. The responses for each question were coded and input into SPSS version 12.1. The results from the IQ tool were also entered in to the interactive scoring system on the IQ tool website. This automatically computed a score for the site out of 100. As the other tools did not have a scoring system, websites were awarded a percentage score based on the number of positive answers from the total number of questions. The 40 sites were then ranked according to these scores to allow comparison of the relative quality of the websites.

3.3 Development of a Multiple Sclerosis Evaluation Tool

A new tool, designed to assess the comprehensiveness of information provided about multiple sclerosis, was developed. This was based on the self-reported information needs of people with multiple sclerosis [1]. Reference was made to the Alzheimer's disease tool, developed by Bath and Bouchier [20], however, unlike their tool, it did not incorporate proxy ratings of quality taken from existing evaluation tools, but examined the quality of the website in terms of how well the content and style matched the self-reported information needs of people with multiple sclerosis.

The tool is shown in Appendix 1 and consisted of 48 questions, divided into four separate sections, partly because the literature suggested that information needs would change over the course of the disease, but also because family and carers are likely to have different needs to people with multiple sclerosis. The first section contained 11 items relating to information needed by people who have been newly diagnosed with multiple sclerosis: basic information about the disease, its prognosis and treatment. The second section concentrated specifically on the information needs of those who had a diagnosis of the disease confirmed for some time. The third section assessed if the information needs of families and carers were catered for and the fourth section examined general qualities of the website and the extent to which it met the specific needs of people with multiple sclerosis in terms of content, presentation and tone.

3.4 Psychometric testing of the reliability of the evaluation tools

Using SPSS, the internal reliability of the evaluation tools was assessed using Cronbach's alpha. The correlation between the rankings for pairs of tools was measured using Kendall's rank-order correlation coefficient. The same researcher applied the IQ tool to the sample of 40 websites twice, with a three-week gap to test for intra-rater reliability.

4. Results

4.1 Quality of Information about Multiple Sclerosis available on the Internet

IQ Tool

One quarter of the websites scored zero according to the IQ tool because they either did not disclose authorship or provide contact details for the author. No website scored perfect marks of 100, but two websites, Boston Cure and All About Multiple Sclerosis, were just one 'yes' response short, with both only failing to score top

marks because one of the questions, about the security of personal information, was not applicable. The rest of the scores ranged from 40.2%- 88.4%.

HI-Quality Guidelines

Using the HI-Quality Guidelines, the scores ranged from 96% for the MS Society UK, which was judged to have only answered one question negatively, to 38% for the CLAMS (Computer Literate Advocates for Multiple Sclerosis) website, which only obtained ten 'yes' responses   Most websites scored at least 50%, however all websites had at least one question that was judged to be not applicable.

HON Code

Unlike the other two tools, top marks were achieved by some websites, with five, including MS Society UK and National MS Society, scoring 100%. The lowest score achieved however, 33% by the MS Resource Centre, was below that of the lowest score from the Hi-Quality tool. All but three websites obtained scores of over 50%.

MS Tool

No website achieved a perfect score, but the MS Society of Canada, the National MS Society and MS Gateway all obtained scores above 80%. The MS Society Canada, which was ranked first, achieved high scores in all parts of the evaluation tool. The MS Gateway website, which is a commercially sponsored website provided by a pharmaceutical company, obtained very high scores for all but one section concerning information for families and carers, where it only achieved 14%, lowering its total score considerably. The lowest overall score achieved was 11% for the MS National Research Institute website, which scored low marks in all four sections. There were four other websites that also were given less than 20% and over half of the websites achieved a score of less than 50%. However, considerable variation was seen between the four sections of the tool, with much higher scores being achieved when websites were assessed for information required by people who are newly diagnosed with MS, compared with information for family and friends.

4.2 Correlation

Table 1 illustrates the ranking of the 40 websites according to each evaluation tool. It can be seen from Table 1 there was considerable variation among the evaluation tools in their assessment of the relative quality of the websites. However, there was some agreement about the best websites, with the MS Society UK and the National MS Society ranked in the top five by all evaluation tools. There was less agreement about the worse websites, although the personal website provided by T H Juland and the commercial websites, MS Central Support and the Chiltern's MS centre, both of which promoted products, were ranked amongst the lowest. The high number of tied ranks in the generic tools, especially the HON Code, might indicate that the ability of these tools to discriminate between websites was limited.

Table 1 Rankings of website by each evaluation tool

Website	Rank according to evaluation tool			
	IQ tool	HI-Quality	HON code	MS tool
Action MS [25]	17=	32=	34	8
All about MS [26]	2	2=	9=	25=
Betaseron [27]	22=	27=	28=	34
Boston Cure [28]	1	8	6=	10=
Chilterns MS Centre [29]	31=	39	16=	38
CLAMS [30]	31=	40	31	39
Direct MS [31]	31=	22	38	37
Friends with MS [32]	31=	37	24	19=
James S Huggins [33]	5	2=	1=	24
Jean Sumption [34]	11=	14=	20=	16
Jooly's Joint [35]	11=	7	16=	14
Mayo Clinic [36]	17=	5	1=	30
MS Active Source [37]	22=	25=	9=	6
MS Awareness Foundation [38]	31=	27=	34=	36
MS Central Support [39]	31=	36	26=	15
MS Gateway [40]	17=	12=	9=	3
MS International Federation [41]	9=	10=	28=	12
MS Lifelines [42]	28	21	32=	28
MSNational Research Institute [43]	25=	29	39	40
MS Net [44]	28	30	9=	22
MS Network [45]	14=	12	9=	31=
MS Only [46]	25=	18	6=	27
MS Outreach [47]	30	34	30	33
MS Resource Centre [48]	6=	14=	40	10=
MS Society Australia [49]	9=	18=	9=	9
MS Society Canada [50]	22=	17	6=	1
MS Society UK [51]	3	1	1=	5
MS Society USA [52]	14=	9	9=	13
MS South Africa [53]	31=	32=	16=	17
MS Sucks [54]	25=	24	19	31=
MS Watch [55]	6=	25=	20	23
Multiple Sclerosis.com [56]	6=	6	20=	4
Multiple Sclerosis Foundation [57]	14=	18=	34=	7
National MS Society [58]	4	2=	1=	2
NINDS [59]	17=	16	1=	19=
Pennsylvania Neurologic [60]	17=	35	24	19
ThJuland's MS Pages [61]	31=	38	35	25=
Understanding MS [62]	11=	10=	32=	28
Utah University [63]	31=	23	34=	18
Vernon Society [64]	31=	30=	26=	35

Table 2 shows the level of agreement between each pair of tools in their assessment of website quality.

Table 2 Kendall's rank correlation coefficient for each pair of evaluation tools

	IQ tool	HI-Quality	HON code	MS tool
IQ Tool	1.000	0.647	0.312	0.368
HI-Quality	0.647	1.000	0.370	0.301
HON Code	0.312	0.370	1.000	0.249
MS Tool	0.368	0.301	0.249	1.000

Although all of the correlations were statistically significant, the only strong correlation was between the IQ tool and the HI Quality tool (0.647), suggesting that they were measuring a similar concept of quality. The weakest correlation was between the HON Code and the MS tool (0.249). However, both tools only demonstrated weak correlations with the other two tools, raising the possibility that they are each measuring a different concept of quality. This is not unexpected for the MS tool, as it was designed to assess comprehensiveness of information provided, rather than using proxy measures to evaluate quality. The low level of concordance of the HON code is more surprising, although could be related to the fact that it consisted of fewer indicators.

4.3 Reliability

The internal reliability for three of the four tools was very high. The IQ tool had a Cronbach's alpha of 0.842, the HI Quality guidelines had a Cronbach's alpha of 0.746, and the MS tool had a Cronbach's alpha of 0.930. This suggests that the indicators with in each tool were measuring the same concept. However, the HON code had a Cronbach's alpha of 0.537, which suggests only moderate internal reliability and well below the level of 0.8 that Bland and Altman recommended for multi-item scales that seek to measure a single concept, such as quality [65]. When the IQ tool was evaluated for test-retest reliability, there was almost perfect agreement (0.986) between the first and second application of the instrument, indicating good reliability when assessed by the same reviewer.

5. Discussion

The quality of information provided on websites about multiple sclerosis was found to be variable. However, there was evidence of some very good sources of information. Furthermore, the MS tool suggested that some websites would meet nearly all of the information needs of people with multiple sclerosis, presenting information in a positive way and encouraging communication with other people affected by multiple sclerosis. However, the best websites, as assessed by the generic tools, did not always match the best websites as evaluated by the MS tool. This suggests that when reviewing websites against generic quality criteria, existing measures may be limited in the extent to which they are able to direct consumers to those websites that will satisfy their needs. For example, people with multiple sclerosis value finding out about the experience of others, however websites produced by individuals often score poorly when assessed against generic evaluation criteria.

Currency is an important facet of health information, as medical opinion and research evidence can change as new treatments become available. It is important that people with multiple sclerosis are kept up to date, especially as there is still much that is not known about the condition. Furthermore, people may automatically assume that information on the web is current. However, many of the websites did not satisfy the currency criteria. Croft and Petersen also reported similar findings about currency of information on websites providing information about asthma [3].

Results of the psychometric tests differed from those previously reported, although not all of the same evaluation tools were applied and a different group of websites was sampled. The internal consistency of three out of the four evaluation instruments was found to meet the acceptable standard [25]. Although the HI-Quality guidelines were not designed specifically for the evaluation of websites, they achieved a satisfactory internal reliability, suggesting that they contained criteria that assess website quality in a consistent way. However, further research with different and larger samples of websites is still needed to confirm these findings, especially as the Ademiluyi et al. found that the IQ tool did not achieve an acceptable level of internal consistency in their study [15]. Furthermore, although the IQ tool achieved a satisfactory level of intra-rater reliability, Ademiluyi et al. reported only a moderate degree of inter-rater reliability. Some of the criteria used in the generic evaluation tools are inherently subjective and it is not possible to exclude researcher bias when applying the tools. Due to time limitations, it was only possible for one researcher to apply all the evaluation tools; however, future research should address inter-rater reliability to ascertain if they meet acceptable levels of objectivity.

Agreement between tools, demonstrated by the correlation between the relative rankings of the websites, was weaker than in previous studies. Bouchier and Bath found that the HON code was the most consistent with other generic evaluation tools [16]. However, in this study it demonstrated the weakest relationships. Furthermore, the limited number of questions reduced its ability to discriminate between websites, as evidenced by the high number of tied ranks. Evaluation with the MS tool produced the lowest number of tied ranks, probably because it consisted of the most indicators. Although this made it more laborious to apply, it may mean that it the most suitable for directing people with multiple sclerosis to useful websites that best meet their information needs.

6. Conclusions

Some generic evaluation tools, employing an index of proxy measures of quality, are useful instruments to evaluate health information on the web. However, it must be remembered that they are only giving an approximation of one facet of information quality, and certain rating items are inherently subjective. The low internal reliability, poor correlation with other tools, and high number of tied ranks of the HON Code suggests that further research is needed to evaluate the items used, especially as the presence of the HON Code on a website is supposed to assure consumers of its quality. Due to limitations of this study, including the relatively small number of websites sampled and the fact that all websites were assessed by just one reviewer, it is not possible to draw definite conclusions about its suitability as a quality assurance tool.

The MS tool allowed evaluation of the websites in terms of their content and presentation according to the needs of people with multiple sclerosis. The results showed only a low level of agreement with those obtained with the generic evaluation tools, suggesting that the best websites for people with multiple sclerosis can only be assessed through a combination of generic and disease-specific tools. However, the disease specific tool did have the advantage of consisting of more objective measures, and unlike tools based on clinical guidelines could more easily be used by non-medics.

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Appendix 1

Multiple Sclerosis Evaluation Tool

This tool is used to assess the comprehensiveness of the information provided on a web site in relation to the reported needs of MS sufferers and their families. Sites will be given an overall score and individual scores for how well they meet the needs of:

1. Newly diagnosed or currently being diagnosed

2. Post-diagnosis

3. Family and carers.

They are also awarded a score for the way in which they present information in relation to the preferences reported in the literature.

Web site address:

Name of the person or organisation that produced the web site:

Date web site accessed:

Section 1: Information for newly diagnosed PWMS
1. Is information given about the physiology of the disease?
2. Is there a section of the web site specifically for people who are being, or who have just been, diagnosed with MS?
3. Is there information about how MS is diagnosed?

Are the following topics discussed:
4. Course of the disease?
5. Physical symptoms?
6. Symptom management?
7. Drug treatments?
8. Exercise?
9. Diet?
10. Role of a MS specialist nurse?
11. How to tell family and friends?

Section 2: Post-diagnosis phase
12. Does the web site have separate sections on medical information about MS and practical information about how to live with the disease?
13. Does the website allow users to make contact with fellow MS sufferers, e.g. through a bulletin board?

Does the site contain information about:
14. Balance and walking problems?
15. Bowel and bladder disturbances?
16. Emotional changes, including depression?
17. Memory problems?
18. Fatigue?
19. Visual disturbances?
20. Spasticity?

Does the site provide balanced advice and information about:
21. Different drug treatments available and how they compare?
22. Complementary medicines?

23. Nutrition?
24. Research in to MS?
25. Physiotherapy?
26. Pregnancy and MS?
27. Sex and MS?

Does the web site provide practical information on:
28. Access and transport?
29. Aids and appliances?
30. Benefits and entitlements?
31. Home modifications?
32. Leisure activities and holidays?
33. Occupational therapy?
34. Working and MS?

Section 3: Information for family or carers of PWMS
35. Is there a section specifically for families or carers of PWMS?
36. Is there general advice on caring?

Does the site provide information on how to cope with:
37. Emotional challenges?
38. Practical challenges?

39. Does the site report the personal experiences of carers/ family members of PWMS?
40. Is information provided on support groups or useful contacts for the family and carers of PWMS?
41. Is there a means to contact other carers/ family members of people with MS (e.g. specific bulletin board for carers/family)?

Section 4: Overall content/ presentation of information on the site.
42. Are there any sections written by people with MS?
43. Is the information presented in a positive manner?
44. Does the information help to inspire or motivate PWMS?
45. Is the information presented in a succinct manner (e.g. long paragraphs are summarised with bullet points)?
46. Can the web page be adjusted to allow it to be more easily read by disabled users (e.g. can text size be increased)?
47. Are contact addresses and telephone numbers provided for people to get in touch with organisations that support PWMS?
48. Would you recommend this web site for people wanting to find out more about multiple sclerosis?