

PAIN TREATMENT TOPICS

Education, Information, Research & News for Better Pain Management

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Pain-Topics.org Ratings Survey Results – 2010

Overall, we consider this latest survey, conducted throughout June 2010, as a great success. We thank the **212** persons who took the time to respond. This was only our second site-rating survey; the first was conducted during December 2008.

Responses came from 109 (51.4%) healthcare professionals, 89 (42.0%) patients, and 14 (6.6%) persons who classified themselves as “other.” The survey software was set to allow only one set of entries from any single computer (IP address), thereby preventing the same person from responding multiple times.

Overall, 91% percent of respondents said that they would recommend Pain-Topics.org to others, the remaining 9% said “maybe.” The other 5 questions of the survey were scored from 1 to 5 by respondents — with 1 being the lowest (most negative) response, 2 = below average, 3 = average, 4 = above average, and 5 being the highest (most affirmative) for each question. None of the questions received any responses at the “1” level; in contrast, there were many “5” ratings for each question.

The global, or overall, average score for the entire 2010 survey was 4.41 out of 5.0. Response details for each of questions are in **Appendix 1**, and may be summarized as follows:

- **93%** believe we offer trustworthy information and education; 64% give us the very highest rating (average rating = 4.56 out of 5).
- **92%** consider Pain-Topics.org as ‘useful’ or ‘very useful’ (average rating 4.52 out of 5).
- **88%** said they find our UPDATES weblog above average in interest and helpfulness (average rating 4.43 out of 5).
- **86%** rate Pain-Topics.org as better than other pain management websites they’ve visited (average favorable rating = 4.26 out of 5)
- **78%** say it is ‘easy’ or ‘very easy’ to find what they are looking for at the site (average rating 4.18 out of 5).

Further Observations on 2010 Survey

It is surprising that nearly half of all responses came from patients/others as Pain-Topics.org was designed to appeal mainly to and be of most use for healthcare professionals. This could be due to a selection bias (eg, patients/others have more time to complete surveys) but all other trends seem to indicate that Pain-Topics.org is increasingly garnering visits from patients. Patients/others scored Pain-Topics.org slightly higher on trustworthiness and in comparison with other websites than healthcare professionals; however, these and other differences across groups were minor and not statistically significant.

Question number 3 regarding our UPDATES weblog, asking if respondents found it of interest and helpful, was newly added to the 2010 survey, since this blog-based offering had existed for only 11

months at the time of the survey. Respondents were instructed to skip the question if they were unfamiliar with the blog and 31% did so. We are not certain if this means that nearly a third of Pain-Topics.org visitors have no experience with our UPDATES weblog offering or if they were confused by the question, since the UPDATES are seamlessly integrated with the main website and respondents might not have even realized it is a weblog.

The lowest-scoring area appears to be site navigation; although, this still scored high (4.18 on average) and nearly 8 of 10 persons said it is “easy” or “very easy” to find what they are looking for. It may be unavoidable that some persons, perhaps less experienced in navigating educational websites, may have some difficulties; nobody scored this question “very difficult” and 7 of the 10 who scored this below average were patients/others.

Commentary on Survey Comments

There were 74 write-in comments to the survey; 33 from healthcare providers and 41 from patients/others. These are of great interest and are provided unedited but with personally identifying information removed in **Appendix 2** and **Appendix 3**. Item numbers below refer to listings in the appendices.

Among the earliest comments to be submitted were a couple criticizing our “e-Notifications” format (eg, items #16 and #55). For example, “I like the e-notification system and have found this useful, however it could benefit from reformatting and the layout standardizing. The use of large amounts of color, stars **** and different fonts doesn't make it an easy read.” In response, we immediately changed the “e-Notifications” format to make it more contemporary and easier to follow. Shortly thereafter, a respondent indicated we had succeeded (item #12).

Other respondents suggested that we need a search feature [#2], and more evidence base and guidelines [#20]. This was confusing, since we already do have a search feature at the top of every page at the website and we feature only evidence-based resources including probably the most extensive listings of pain-related guidelines anywhere on the Internet. A patient suggested that we “offer a physician referral resource... noting specialties and subspecialties” [#35], which is a useful notion but beyond our mission and already handled adequately at more consumer-oriented websites.

There were some complaints that Pain-Topics.org places too much favorable emphasis on opioid therapy [#5, #23, #70], while healthcare professionals wrote, “I appreciate the NON-NARCOTIC as well as non-medicinal options” [#21] and “I especially appreciate the complementary and alternative [medicine] information” [#24]. In a balanced perspective, one person wrote:

Pain Treatment Topics has been for several years and continues to be the "go-to" web site for pain information. The "big reports" (e.g., methadone, Vitamin D) are invaluable resources. Whenever a colleague asks me for a web resource on pain and related issues (especially if the subtext of the question is opioid treatment), Pain Treatment Topics is the one site I can refer to with enthusiasm and without hesitation.” [#33]

Other criticisms noted that some of the links go to outside documents that must be purchased [#28], or “It is very difficult getting the source articles or data that is discussed in this website” [#47]. This has been a great source of frustration for us as well. While we do our best to link only to documents that are openly accessible without cost, in many cases we find that we cannot completely ignore certain journal articles, guidelines, or other vital documents that require subscription or purchase from outside sources. Unfortunately, not everyone shares our open-access philosophy, and we would be remiss if we did not list these resources for that reason.

It is interesting to note that many patients/others seem to use Pain-Topics as a source of information that they can take with them to their healthcare providers [#36, #62, #64]. One wrote, “You provide documented information that I can provide my doctor who has now come to trust and study your site” [#74]. This is, indeed, an appropriate and important way in which a resource like Pain-Topics.org can serve the needs of patients and their healthcare providers.

Finally, one patient complained that the site is overly loaded with information, requiring scrolling down long pages to find items of interest [item 48]. “Also, the site is so drab and boring,” he/she writes, “A little face lift [would help] to make it more appealing [sic].” Well... we do appreciate and respect these opinions but this is somewhat akin to saying that our beloved child is ugly! Others have suggested in the past that we use *too much* color at the site (anything but drab). So, for now, it seems best that we put aside thoughts of a face lifting for Pain-Topics.org.

Comparisons with 2008 Survey

In December 2008 there were only 78 responses to the survey, which included the exact same questions as in 2010 (but without the UPDATES weblog question). In 2008, the vast majority of respondents were healthcare professionals (66.7%), with the remaining being patients (26.9%) and others (6.4%). So, there was a shift in 2010 not only toward a 2.7-fold greater number of respondents but in greater participation by patients. There was a nonsignificant uptick in the overall average rating between 2008 and 2010 (4.25 to 4.26). As noted above, however, there were no significant changes in average ratings for each of the 4 questions asked in both 2008 and 2010; the rating scores in 2008 were quite high and remained so — which is a quite favorable outcome.

How does Pain-Topics.org compare with other pain management education websites? Unfortunately, based on surveys, there is no real way to know how we might compare with competing Internet-based projects, since they do not conduct such surveys or, if they do, they do not make the results public.

We hope you have found these data of some interest and we are grateful for your continued interest in *Pain Treatment Topics*.



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Please see the pages following.

APPENDIX 1: Response Summary Details

1. In general, do you find Pain-Topics.org to be useful?							
	Not Useful		Average		Very Useful	Rating Average	Response Count
Select Rating	0.0% (0)	0.9% (2)	7.5% (16)	29.7% (63)	61.8% (131)	4.52	212
answered question							212
skipped question							0

2. Is it easy to find what you are looking for at Pain-Topics.org?							
	Very Difficult		Average		Very Easy	Rating Average	Response Count
Select Rating	0.0% (0)	4.7% (10)	17.0% (36)	33.5% (71)	44.8% (95)	4.18	212
answered question							212
skipped question							0

3. Do you find our News/Research UPDATES blog to be of interest and helpful? (If you are unfamiliar with the blog, leave blank.)							
	Not at All		Average		Yes, Definitely	Rating Average	Response Count
Select Rating	0.0% (0)	0.0% (0)	12.3% (18)	32.2% (47)	55.5% (81)	4.43	146
answered question							146
skipped question							66

4. Do you feel that Pain-Topics.org offers trustworthy information and education?							
	Not at All		Average		Yes, Definitely	Rating Average	Response Count
Select Rating	0.0% (0)	0.9% (2)	6.1% (13)	28.8% (61)	64.2% (136)	4.56	212
answered question							212
skipped question							0

5. Overall, how does Pain-Topics.org compare with other pain management websites that you've visited?							
	Much Worse		Average		Far Better	Rating Average	Response Count
Select Rating	0.0% (0)	1.4% (3)	12.9% (27)	43.8% (92)	41.9% (88)	4.26	210
answered question							210
skipped question							2

APPENDIX 2: Comments from Healthcare Professionals

1. I've already recommended [Pain-Topics.org] to other psychologists, physicians, and nurses.
2. [You need] a search feature.
3. Pain Topics is very good and suits its purpose for quick updates but different from City of Hope eg which gives more depth. Therefore no 5 is difficult to answer as by comparing it is difficult to score.
4. More evidence base, more guidelines.
5. Your pro opiate leanings make you sound like a lobbyist for the drug companies, but then if you read the fine print I see you are underwritten by Purdue Pharma. If your goal is helping pain patients and health pros then show the other side of the coin more often in the research...., If your goal is to sell more opiates don't change a thing. Bottom line -- I do find the site informative, and helpful as a pain patient and surgical 1st assistant.
6. Links to other evidence-based blogs discussing pain-related material would be helpful (those that don't have advertising and conform to HONcode ethics etc).
7. More needed on pain and addiction/pain and addiction recovery.
8. It is so well organized, and up to date. I don't know what I'd do without it. I have already sent the link to many other providers. thank you thank you thank you!
9. The medical-legal updates are especially appreciated.
10. There are no models to teach pain and palliative care to students, trainers or nurses.
11. I'm anesthesiologist specialized in pain control and palliative medicine. I teach in several places and is really useful. Thank you
12. I like the new e-mail format.
13. I am a health practitioner and a sufferer of chronic pain and have only found help after years of worsening pain and then job loss. Right now, I am in grad school and studying for pain mgr certification through ANCC. I look forward to receiving the weekly update even though I am on many newsletter lists.
14. Brings many key topics under one roof - really a great service!
15. I am both a health professional, retired for one year now, and a pain patient. I have been reading your information for a few years and have found it very helpful and ahead of other medical information sites very often. I have often brought information from your site to the attention of my care providers, as well as to the providers I worked with before my retirement.
16. I like the e-notification system and have found this useful, however it could benefit from reformatting and the layout standardizing. The use of large amounts of color, stars **** and different fonts doesn't make it an easy read.
17. I think there needs to be much more recognition of the role government and lack of education have to do with poor pain care than anything else in this country. My contention is if we all stood together against these two things, we'd get more done. Whining and talking more about deterrence (the tyranny of the minority) versus solid pain care, active listening, and opioid use for the majority of patients. The 'in your face' acknowledgment that the police, DEA, and boards have much more influence than science or logic in the field of pain care cannot be overstated. This must change, and it starts with the so-called experts (supposedly us). <truncated due to extreme length>

18. In the area of palliative care and chronic pain management it has been very useful to suggest to the doctors of patients what is new. So thank you.
19. I'm a Palliative specialist & appreciate your viewpoints. Think you're doing a good job!
20. More Specific inservice information on Pain issues.
21. I appreciate the format, that it's easy to find articles (from reliable sources, such as MEDSCAPE) to compare many different treatment options — and in terminology that is understandable to most interested lay people as well as to health care professionals like me. I appreciate the NON-NARCOTIC as well as non-medicinal options as well.
22. I continually update my "pain 101" program with information from pain topics — I teach continually and need up to date information. Thanks!
23. Dr. L's views seem clearly biased toward opioid use for chronic pain with little recognition of public problem of Rx opioid abuse, so this content is viewed through that filter.
24. Especially appreciate the complementary and alternative information. Would also like more palliative/hospice pain issues addressed from time to time.
25. I feel Pain-Topics and the e-newsletter one of the most interesting tools to the Health Professional who want to be updated in Pain Management related issues (papers and so on). You may count on me!
26. I currently work with methadone maintained patients who have been in treatment for at the most thirty years and the least five. They have become a "geriatric" population and have moved into significant medical issues. Your site has been a valuable source of information for them in managing pain with or without narcotics. It would be beneficial for them if more information were made available in addressing the medical needs of these long term patients in Pain-Topics.
27. Send update less often. Thank you for the excellent material you provide.
28. Some of the links take you to information that you have to purchase.
29. Great job - I utilize the short summaries of pain topics the most and find them very helpful for keeping lectures up to date.
30. I like how up-to-date your reviews are and how they are balanced with results from other studies.
31. I'm the pain coordinator at an ambulatory surgery center which does pain procedures 3 days a week. Would love to see more info that is pertinent to interventional pain.
32. I find the links to guidelines and pertinent evidence particularly helpful.
33. Pain Treatment Topics has been for several years and continues to be the "go-to" web site for pain information. The "big reports" (e.g., methadone, Vit D) are invaluable resources. Whenever a colleague asks me for a web resource on pain and related issues (especially if the subtext of the question is opioid treatment), Pain Treatment Topics is the one site I can refer with enthusiasm and without hesitation.

APPENDIX 3: Comments from Patients/Others

34. Your newsletters are informative, the links impressive and easy to navigate. something I would like to see are more condition specific articles. At times, seems as though the news is geared more towards a "one size fits all" type of article. I must tease out and find specific info . Overall, I like the site. Have not learned too much, if anything from the blog/comment section, although I do read them. Thanks for the information . It is appreciated by many of us who suffer from chronic pain-no matter the (non) diagnosis.
35. Offer a physician referral resource.....noting specialties and subspecialties.
36. I came upon this website by accident, but sooo glad I did. I found it very interesting and far more informative than others I have reached online. Thanks for the important info.!!! I have bookmarked many pages and plan to take them to my next Doctor appt. with me. I hope they find it as great as I did.
37. I do appreciate this mailing as a person who works with the Cochrane Pain group, it's also good to see a couple of our Cochrane reviews referenced every now and then and know they're getting there too.
38. Thank you.
39. Need more info on no cancer related pain.
40. The reason I like pain topics is because you cut through the BS and get to the matter at hand. You tell the truth and give the pain community (patients/caregivers/medical professionals) a chance to be heard.
41. I believe you are doing a good job...your site has good information that is useful...I have reflex sympathetic dystrophy in my hands....thanks for all you do.
42. Ability to personalize topics.
43. Include links to best articles in any given area.
44. You cover a very wide spectrum of subjects as it relates to pain.
45. I'm fairly new to the site and have found many, useful articles and have passed the info on the site along to others in a chronic pain support group. Thanks for making this info available!
46. I really appreciate that, as a patient, I am able to read validated and properly researched data.
47. It is very difficult getting the source articles or data that is discussed in this website. I cannot pass along any information that I cannot verify and therefore the information is "useless" because of this.
48. The site is full of information but you have to scroll and scroll while quickly reading all the way down to see if anything interest you. Sometimes it is just not inviting to do it. Would like to see categories maybe or another way to organize all of the info. Also, the site is so drab and boring. A little face lift to make it more appealing.
49. As a patient, it good to read validated data and not newspaper hearsay. I value this site.
50. This site seems geared more for the professional. But I do find things that interest me on it. Thank you for keeping us informed, it is very helpful when we have a hard time getting our doctors to do the same!!
51. I believe that it is a very valuable site , the information is timely and to the point. I work for a major healthcare distributor as well as suffering from chronic pain for the past 5 years and a opiate using patient. Keep up the great work, your site makes me feel that someone is interested in helping inform

people about current issues rather than a site that is interested in selling memberships or products. This is very important to people in the same position as I am in. Thank you!

52. I love Pain-Topics! The topics interest me, as a 20+ yr pain patient, and what I usually find is biased, and based mostly on the social environment, versus the facts. Keep up the great work!
53. There is really nothing more you can do. All I need is for my doctor to increase my dose.
54. It is easy for a patient to understand. It also covers many areas.
55. the newsletter needs some serious redesigning! it's hard to read and the giant colored fonts could be dispensed with... other than that i have no complaints. I like the information that is presented.
56. While very scientific the information is presented in an easy to follow and understand format. I do appreciate links to more in depth information for topics I want to learn more about. I consider it a very reliable and critical source.
57. Your topics have been very realistic, to the point, and about what it's really like for chronic pain sufferers. As a caretaker to my brother, I have learned a lot about chronic pain and the medications and other treatments for it. I feel like I'm getting up to date news about new discoveries related to pain management, which is so important to me because I'm always searching for something that will help my brother.
58. The information that is intended for health care professionals is helpful to me, as their patient. I was most informed recently by all the news about opioids and the government's attitude towards doctors who prescribe them and patients who use them. As a person with fibromyalgia, with moderately severe pain, as well as neuropathy from the fibro and diabetes, I am always interested and have a lot of concern about whether or not I will lose even the mild relief I get from these medications. You also bring up many points the doctors never mention, such as the constipation connected with opioid use. And you bring me the opportunity to express my views on some subjects and to read what others have written. It is most obvious to me that whoever is behind this newsletter is determined to do the best job possible and I thank you. <truncated due to length>
59. I am both a Patient, Healthcare Professional. I appreciate the info and ease with which your website gives me! thanks!
60. In general, I appreciate the fact that you present information, or rather links to information, and then you don't try to push a certain agenda or viewpoint. You make the information available and then allow the reader to make of it what they will. Thank You.
61. The currency of research projects cited by Pain-Topics make the site very valuable to me, my family and my primary physician. As you and your readers know, living with intractable pain is a constant struggle and having a conduit to the latest research can only improve our ability to cope. Thank you for all of your efforts.
62. Pain-Topics.org is my best online resource for new information. I print paragraphs or make notes for myself to bring to my monthly pain doctor appointment for discussion. Right now we are evaluating, for a few months, something I read about on your site. Knowledge I get from you makes me a well-informed patient with a better handle on my treatment options and more information at hand about alternatives and safety concerns. Thank you.
63. As a patient with fibromyalgia, I really appreciate the topics that you cover relating to pain. I find them all to be very helpful for me to gain more understanding on what is going on in the medical world regarding issues on pain, as well as topics that I can discuss more knowledgeably with my healthcare practitioner, family and friends. Keep up the good work! Thank you.

64. Very well written, well documented articles that are far more trust worthy than many of the other sites I have visited and that is several. Please keep up the good work as many of your articles I have taken to my pain specialist who was most appreciative. Thanks to many of your articles I am now getting some of the best pain care I have gotten in over 15 years. Thank You and God Bless.
65. I would like to see more info that can be shared with the medical doctors to counteract those wanting to treat pain by removing oral pain medication. Specifically, there is a new program being used on intractable pain patients called "Blending Initiative" being pushed by the NIDA. My husband is a Veteran where total milligrams are being used as a reason to remove all oral meds. Sudden withdrawals are not considered as reason to taper or consider diseases that cause Intractable Pain. I fear for all Disabled and the Elderly who are non TAX producing Americans.
66. You always post the most up-to-date and concise information. I always share your information with my pain groups. I always let people know they can subscribe for free updates.
67. I was born with central canal stenosis. My first disc herniation (L5-S1) was just after my 17th birthday. I've had three disc herniations and four failed (lumbar) spine surgeries, including multilevel fusion. Now, I also have a cervical disc herniation (C 5-6). I research physical and pharmacological treatment paradigms continuously. I have been through two comprehensive pain management programs. For every potential treatment, I've "been there and done that." I understand the advantages of fellowship-trained spine surgeons. I also value detailed and comprehensive pharmacological research for chronic pain. I thank you for your research reporting. It is vital, appropriate, robust and authoritative. Your sources are impeccable. Thanks for the great work. Keep it up. There are thousands of people like me who rely upon your efforts to locate and deliver essential research related to chronic pain management. Let me know how I can help.
68. FINALLY my pain is taken seriously! Thanks for this site!!!
69. I think you do a very good job and you do a good service for the pain community.
70. I think there is too much emphasis opioids.
71. I as an RN enjoy reading new findings in health. I also suffer from fibromyalgia and after several years am finding it is pretty much ruling my life. I get very frustrated with doctors. They still have this "all in your head" frame of mind. I find some very interesting things to help me learn more about my and others problems due to fibro and chronic pain. When I find a doctor who will look "outside the box" then either insurance will not pay or only a VERY small portion. Then you go to your regular MD and he tells you why you should not be doing this or that and you need something like your site to try and figure some of these things for yourself or to have some education on them so you feel comfortable asking and questioning things more. Thank you for your info!
72. As a researcher in the addiction field I find that your service helps me keep up with the various issues associated with pain management.
73. I always appreciate the commentary and opinions about articles that can often appear one-sided. The insight is always helpful and the topics ALWAYS relevant!
74. You provide documented information that I can provide my doctor who has now come to trust and study your site. I feel if not for your web-site I would not be getting the pain treatment I am getting. We are not where I want to be yet but hopefully between your website and my documentation it won't be long until that care arrives. Please keep up the good work and the articles that are documented by so many professionals.