Cholesterol Related Information on the World-Wide-Web: Qualitative
Study Highlighting the Information-Seeking Behavior of South Asian
Indian Males in America.

By

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CERTIFICATE OF APPROVAL
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Cholesterol Related Information on the World-Wide-Web: Qualitative Study Highlighting the Information-Seeking Behavior of South Asian Indian Males in America
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Abstract

Purpose: This study will describe information seeking behavior of South Asian Indian males searching the web for retrieval of cholesterol related health information.

Methods: Qualitative study using naturalistic observation of a purposive sample of ten South Asian Indian males searching the web in their home environment for cholesterol related information, followed by semi-structured interviews.

Results: The analysis and interpretation of naturalistic observation and interview notes provided major themes like criteria for trustworthiness that explained my participant's search preferences for cholesterol related information.

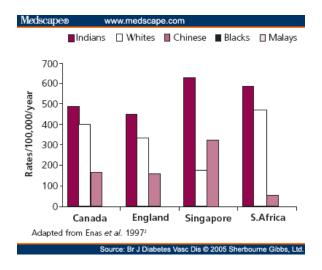
Conclusion: Further observational studies are needed to enhance the major themes which will be used to evaluate the quality of health information on the web.

Recommendation: Health information on the Internet will be advanced by the needs of consumers who are hungry for information about their health and for control over the health services they receive.

Introduction and Background

The term "South Asian Indians" will be used in this review to denote people originating from the Indian subcontinent and to distinguish them from American Indians (Native Americans).

South Asian Indians have the highest rates of coronary artery disease (CAD) the world over. The incidence, prevalence, and mortality from CAD among overseas Indians have been 50% to 300% higher than the Europeans, Americans, and other Asians. Graph 1 below shows the CAD mortality rates among different ethnicities living in different countries.



Graph 1 shows the mortality rates of Asian Indians compared to other ethnicities for CAD.

Source: British Journal Diabetes Vascular Disease, 2005 Sherbourne Gibbs, Ltd. Reproduced from Medscape.com

The CAD rates among first generation immigrants are usually intermediate between those of the country of origin and the country of immigration.² In virtually all populations, the CAD rates blend with those of the adopted country in two to three successive

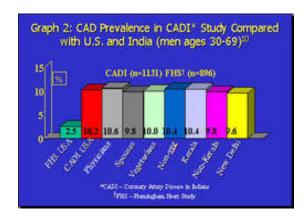
generations, depending upon the degree and speed of acculturation, as well as the prevailing rates in the respective countries.³ Asian Indians have been a singular exception in having higher rates of CAD than the native population of the adopted country.⁴ South Asian Indians residing in different countries have higher rates of incidence, hospitalization, prevalence, morbidity, mortality, and case fatality from CAD than people of other ethnicity.⁵,⁶ The CAD rates in urban India over the past 40 years have increased dramatically and are now similar to that of overseas Indians and several times higher than in other Asian countries.⁷,⁸ This review initially discusses the magnitude of CAD among South Asian Indians in various countries.

Overview of CAD among Overseas South Asian Indians

Prevalence:

In the U.K, which has one of the highest mortality rates of CAD, the prevalence of symptomatic CAD in Asian Indians is similar to Whites (8.5% versus 8.2%), but the asymptomatic or silent CAD is higher. In the US, the prevalence of CAD in Asian Indians is 4-fold higher than Whites (10% versus 2.5%) as shown in **Graph 2**. In the US, the prevalence of CAD in Asian Indians is 4-fold higher than Whites (10% versus 2.5%) as shown in **Graph 2**. In the US, the prevalence of CAD in Asian Indians is 4-fold higher than Whites (10% versus 2.5%) as shown in **Graph 2**. In the US, the prevalence of CAD in Asian Indians is 4-fold higher than Whites (10% versus 2.5%) as shown in **Graph 2**.

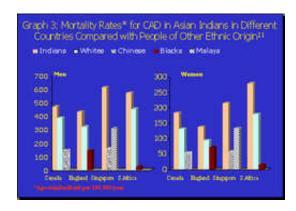
The prevalence data underestimate the incidence when case fatality rates are higher, as is the case in the U.K. Therefore, the burden of CAD in Asian Indians is much higher than that reflected by the prevalence data.



Graph 2: CAD Prevalence in CADI* Study Compared with US and India (men ages 30 – 69) ¹⁰. Source: Coronary Artery Disease in Indians, Framingham Heart Study, reproduced from IPSUB.com

Mortality Rate:

The relative risk (RR) of CAD mortality in Asian Indians is 20% to 50% higher than Whites in Canada, South Africa, and U.K., 300% to 400% higher than Chinese in Canada and Singapore, and 20 times higher than Blacks in South Africa (**Graph 3**). Other countries, which have reported substantially higher CAD mortality among Asian Indians, include Fiji, Mauritius, Trinidad, Uganda, Malaysia, and Qatar. In the U.S., only the state of California has reported CAD mortality data among Asian Indians. This report showed that CAD mortality among Asian Indians is 3-fold higher in men <45 years of age.



Graph 3: Mortality Rates* for CAD in South Asian Indians in different countries compared with people of other ethnic origin¹¹. Source: Coronary Artery Disease in Indians, Framingham Heart Study, reproduced from IPSUB.com (* standardized for 100,000 deaths)

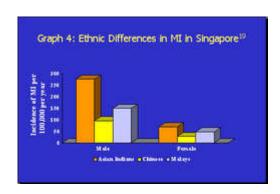
The excess CAD mortality among Asian Indians is greater in women than in men (**Graph** 3).

In the U.S., CAD mortality rates are 2-fold higher in Asian Indian women 45-64 years of age than in Whites. ¹² In Singapore, CAD mortality among Asian Indian women 30-39 years of age is 8-fold higher than Chinese women of the same age. ¹³ The excess burden of CAD among Asian Indian women has been recently reviewed. ¹⁴

Incidence:

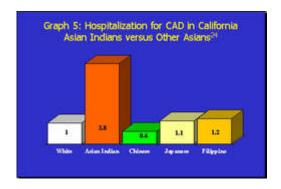
Data for incidence of CAD in Asian Indians is sparse except for the St. James Survey¹⁵ and the Singapore MI Registry.¹⁶ In the 10-year prospective follow-up of the St. James Survey in Trinidad, the age-standardized RR of CAD incidence in Asian Indians was 2-fold higher than Whites and 7-fold higher than Blacks.18 In Singapore, where all MI in the country are systematically entered in the registry, the incidence of MI has been 3-fold

higher among Asian Indians than Chinese men and women (**Graph 4**) ¹⁷, ¹⁸, ¹⁹. This difference is maintained in 2001. Even developed countries including the U.S. have limited data on the incidence of CAD, since it is very difficult and expensive to collect detailed morbidity and mortality figures over an extended period of time. ²⁰



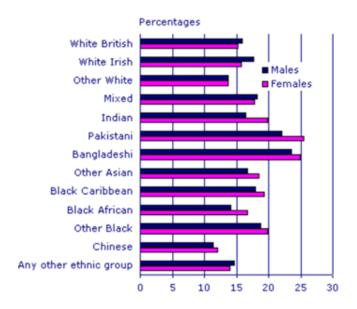
Graph 4: Ethnic Differences in MI in Singapore, reproduced from IPSUB.com

Hospitalization: In the U.S. (California), hospitalization for CAD among Asian Indians is 4-fold higher than in Whites, Japanese, and Filipinos and 6-fold higher than Chinese (**Graph 5**). In many countries, hospitalization for MI in Asian Indians compared to other ethnic groups is 2 to 4-fold higher overall and 5 to 10-fold higher in those under 40 years of age. ²²



Graph 5: Hospitalization for CAD in California South Asian Indians versus Other Asians, reproduced from IPSUB.com

South Asian migrants in foreign countries have higher death rates from CAD even at younger ages compared to local ethnicities of that country²³. The (**Graph 6**) is again a good example of health inequalities among minorities in England and Wales. People from South Asian populations (Indian, Pakistani, Bangladeshi) have a higher incidence of coronary heart disease (50% higher) than the general population in the UK and a 300% higher incidence between the age 30 to 40.



Graph 6 shows the mortality rates of South Asians in UK compared to other ethnicities for CAD, reproduced from Journal of Nutrition website jn.nutrition.org

The above references, data points and graphs have established the severity of CAD among South Asian Indian Males in various countries. According to World Health Organization estimates, by 2010, South Asian Indians will represent 60% of world's cardiac patients ²⁴. An epidemic of CAD is currently underway among South Asian Indian Males worldwide²⁵.

Conventional Risk Factors in CAD, Cholesterol Prominent Risk among South Asian Indian Males:

All conventional risk factors are significantly associated with the risk of CAD in South Asian Indians, as in all other populations. However, compared with Whites, South Asian Indians have a lower prevalence of hypertension, hypercholesterolemia, obesity, and smoking, but a higher prevalence of high triglycerides (TG), low high density lipoprotein

(HDL), glucose intolerance, and central obesity. Although the conventional risk factors do not fully explain the excess burden of CAD, these risk factors appear to be doubly important in South Asian Indians, and remain the principal targets for prevention and treatment ²⁶. While each of the risk factors above merit a discussion, but for the purpose of this study, we will focus on bad cholesterol, as the most significant risk factor in CAD among South Asian Indian Males.

An elevated level of total cholesterol (TC) is the strongest risk factor for CAD.²⁷ Enas et al²⁸ were the first to report high levels of Lp(a) in South Asian Indians. Elevated Lp(a) level was the most common risk factor in the CADI Framingham Study. Subsequent studies have reported elevated Lp(a) levels in Asian Indians in the U.S.,²⁹ Canada,³⁰ Singapore,³¹ U.K.,³² and India.³³,³⁴ Numerous case control and angiographic studies have shown Lp(a) to be a powerful risk factor for CAD among Asian Indians.³⁵

In the U.K, Lp(a) levels in Asian Indians are significantly higher than Whites but identical to their siblings living in India. Also, Asian Indians with CAD and their offspring in the U.K. had higher Lp(a) levels than White CAD patients and their offspring. More than 10 angiographic and case-control studies in India have shown elevated Lp(a) levels to be a powerful risk factor for premature CAD, especially under the age of 40.

A recent case control study involving South Asian Indians in India and the U.S. showed similar results. The South Asian Indian control subjects in the U.S. and India had similar levels of Lp(a). These data suggest that elevated levels of Lp(a) confer genetic

predisposition to CAD in Asian Indians. However, U.S. controls had higher levels of LDL and apo B, and lower levels of HDL, than their counterparts in India. This suggests that nutritional and environmental factors (affluence, urbanization and/or immigration) can further increase the risk of CAD by virtue of acquired dyslipidemia in these genetically predisposed individuals ³⁸.

We have established direct correlation that bad cholesterol is the single most significant risk factor for the onset of CAD among South Asian Indian Males. This situation is compounded by lifestyle factors too.

The high rates of CAD in South Asian Indians are due to a combination of nature (genetic predisposition) and nurture (lifestyle factors). The nature is attributed predominantly to elevated levels of Lp(a), a common but often ignored risk factor in South Asian Indians. With a prevalence >40%, elevated Lp(a) appears to be the most common risk factor in this population. Given this genetic predisposition, the harmful effects of lifestyle factors are magnified exponentially. The lifestyle factors include those associated with affluence and urbanization as well as immigration and acculturation. Urbanization is accompanied by decreased physical activity and increased consumption of fat and calorie dense food, resulting in abdominal obesity, insulin resistance, and a therogenic dyslipidemia. These acquired metabolic abnormalities appear to have a synergistic effect on the development of CAD in genetically susceptible individuals such as those with elevated levels of Lp(a), which are South Asian in origin ³⁹.

Infodemiology⁴⁰

Infodemiology can be defined as the science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy⁴⁰. The Internet has become an important mass medium for consumers seeking health information and health care services online 41. On Feb 19, 2009, a paper published in the journal "Nature" by scientists associated with Google made worldwide headlines: Ginsberg and colleagues discussed how monitoring search queries on Google can be used to predict influenza outbreaks in the United States⁴². Data from this study was used to develop the Google Flutrends application. What was frequently missed in lay media reports was the fact that this was not an entirely novel idea. In fact, exactly the same methods have been employed and evaluated at the Centre for Global eHealth Innovation since 2002, under the label "infodemiology". An award-winning paper published in 2006 by Eysenbach was the first to show a correlation between influenza-related searches on Google and influenza cases occurring in the following week in Canada⁴³. As Google did not share search data with external researchers, a "trick" was used to obtain these data: A keywordtriggered ad on Google was purchased, allowing access to statistics reflecting search and click behavior of Google users. This pioneering study also showed the Internet searches preceded doctors' visits to sentinel physicians by 1 week (a fact which was later also confirmed by the Ginsberg study), pointing to the circumstance that often people first consult the Internet before going to a doctor. As early as 2003, a similar methodology was employed to evaluate whether search behavior changed before the SARS outbreak;

however, at that time "in our search term experiment it did not seem to be sensitive enough [to detect] SARS"⁴⁴. These early studies have inspired and motivated others to explore correlations between search behavior, information on the Internet, and public health relevant events. Wilson and Brownstein published a paper suggesting that chatter on the Internet preceded official announcement of a Listeriosis outbreak⁴⁵. A number of other studies have replicated findings from the Eysenbach study on the relationship between the Internet search behavior and influenza incidence^{42,46,47} A seminal paper published by Cooper and colleagues in this journal explored the relationship between search behavior for cancer (information demand), cancer incidence, cancer mortality, and news coverage (information supply)⁴⁸.

In the context of this study, Infodemiology concepts are best suited in analyzing how South Asian Indian Males will search and navigate the Internet for cholesterol-related information, as well as how they communicate and share this information, can provide valuable insights into health-related behavior of South Asian Indian populations. For example, the level of understanding of health issues, knowledge about cholesterol-related conditions, risk to CAD epidemic and so on.

Qualitative methods provides honest data on health information seeking behavior, free from recall or social desirability biases, conducted in real time, and executed relatively cheaply. The Internet may be a valuable resource for researchers desiring to understand people and the social and cultural contexts within which they live outside of experimental settings, with due emphasis on the interpretations, experiences, and views of `real world' people. However, "very" few content providers have explored the relationships between

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information supply and/or demand, on one hand, and population health, on the other hand, and have experimented with infodemiology metrics⁴⁹.

There is an unmet need, little is known on how South Asian Indian Males search for, and appraise health information on the web. South Asian Indians may seek cholesterol related information on the web because of the condition of self or loved ones. Additionally, the consumer may want to search about the condition because of what they heard on radio or from friends or a family history of high blood cholesterol. Information seeking step becomes personal for them. In either case their perspective on the quality of health information available on the web is important and should be studied for future guidance in the development of online content.

Methods

The participants were recruited from among South Asian Indian males living in San Francisco Bay Area, CA. The recruitment was accomplished through two-part process. In part 1, respondents between the ages of 25 years to 65 years were distributed a survey questionnaire at selected local sites within San Francisco Bay Area. The sites included a Hindu temple in Sunnyvale CA, at Indian Community Center in Milpitas CA, at local Indian grocery stores in Foster City and Belmont CA and participants' within the network of friends and families. An initial survey was used to recruit 10 willing participants to this study. Potential participants were provided with the consent and authorization form for their review, voluntary participation and consensual signature. Once consent and authorization was obtained, the initial survey questionnaire was distributed across the chosen locations in San Francisco Bay Area.

In returning initial surveys, email address and / or telephone number were collected to arrange for further participation in this study.

OHSU's Research Integrity Office, IRB has approved this study for 10 subjects. This study met the criteria for EXPEDITED IRB review based on Expedited Category #7. It states "Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies."

1st survey questionnaire

What ethnicity best describes you?

- > Caucasian
- ➤ Black
- > Hispanic
- Pacific Islander / Asian
- South Asian (Indian, Pakistani, Bangladesh, Sri Lanka, Nepal and Bhutan)
- > Others

Do you live in San Francisco Bay Area?

- > Yes
- > No

What age group best defines you?

- **>** 18 − 24
- **>** 25 − 34
- **>** 35 − 44
- **>** 45 − 54
- **>** 55 − 64

What is your highest education level?

- ➤ High School
- > Undergraduate
- ➤ Graduate

Masters or higher

Your level is to read / write the English language?

- Beginner
- > Intermediate
- > Expert

Do you own a personal computer?

- > Yes
- > No

Do you have the Internet connection at home?

- > Yes
- > No

If willing and selected based on qualifying criteria, what is the best way to contact you for further observation?

- **➤** Email
- > Phone

Please provide your email and / or telephone number for future observation:

We may contact you for further observation. What is the best time for us to observe you in your home environment?

- ➤ Weekdays Morning
- Weekdays Afternoon
- Weekdays Evening

- ➤ Weekends Morning
- ➤ Weekends Afternoon
- ➤ Weekends Evening

In part 2, respondents to initial questionnaire were shortlisted and observed in their home environment searching for cholesterol related information on the web. Survey interviews of participants included questions seeking answers to demonstrate their behavior during search. After each observation session and answering survey questions, the study aimed to validate its purpose to look for recurring patterns and themes which would allow online content providers to customize their content based on participant's expressed preference and need.

In-house observation (semi-structured questions)

- ➤ Do you know someone, either yourself or your loved ones who has high cholesterol?
- ➤ How frequently do you search for cholesterol related health information on the Internet?
- ➤ What is your source of health information on the Internet?
- ➤ Do you have a preference to use a particular search engine over others? Why?
- ➤ How do you rate cholesterol related health information on the Internet? Is the information usable to you?

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➤ What criteria will you use to judge the credibility of cholesterol related content online? What are the important measures of quality to you when you assess cholesterol information on the web?

- ➤ Would currency of information matter to you?
- ➤ Would credibility of information source be of importance to you? Would it matter if the content is sponsored by pharmaceutical company, medical device company or anyone entity with commercial interests?
- ➤ What changes would you like to see in online content? What would be your advice to online providers?
- ➤ Would you use your findings from the Internet to augment your doctors' diagnosis and treatment? Will the information build trust with your doctor?

Essentially, this will be a qualitative study that uses *grounded theory* to generate research subject from analysis and interpretation of the major themes. Naturalistic observations (in their own homes) of the participants—searching the web for cholesterol related information will be conducted and the participants instructed to think aloud during their searches. No specific search engine or method will be recommended and they may start with an empty browser screen. Immediately following naturalistic observations, semi-structured interviews / questionnaire with all the participants will be conducted. The transcripts from field notes and interview notes, data, will then be analyzed using the *grounded theory* approach.

The data will be divided into segments and then scrutinized for commonalities that reflect categories, sub-categories or themes while searching for cholesterol related information on the web. Possible interconnections between themes will be made. There will be common sets of search patterns emerging across users. Eventually, we may be able to generate hypotheses on how consumers might search for and appraise cholesterol related health information on the web.

Results

Quality is defined as "the totality of characteristics of an entity that bear on its ability to satisfy stated and implied needs. *50" For quality to be evaluated, these needs have to be defined and translated into a set of qualitatively stated requirements for the characteristics of an entity that reflect the stated and implied needs. This study aims to do that.

Participants' profile

The participants' are South Asian Indian Males originally from the country of India living in San Francisco Bay Area. They are three engineers and two business managers from the high-tech industry, two small business owners, one security guard, a teller, and an insurance agent. They are recruited from varying education and socio-economic class. They all own a computer with the Internet access. They can read, write and speak English language. They are willing participants' in this study. The study was set in participant's home environment.

The transcripts of interviews from participants' are analyzed for major themes and patterns which are used to evaluate the quality of health information on the Internet and general statements about the use of the Internet to obtain cholesterol related health information.

Major themes emerged from the observation and interviews

<u>Prior knowledge about cholesterol</u> – Nine out of ten participants' were familiar with cholesterol and had searched for cholesterol related information on the Internet. Seven out of ten participants' had high cholesterol some time in their life. A 25 year old participant had no familiarity with cholesterol information on the Internet. None of the participants had known that CAD has become an epidemic among South Asian Indian males.

"I started my health search about 2 years (in year 2006) ago when I was diagnosed with having high blood cholesterol. I went for a routine physical and the blood test results showed high cholesterol"

"I know that cholesterol is the main risk to heart attack"

"It is sobering data on epidemic of CAD among South Asians living in US. The Internet as a medium is so underutilized in this aspect. I wish there is more awareness, perhaps a market solution to alleviate, promote better communication between doctors and patients"

<u>Preference for a particular search engine</u> – All participants' preference was in using search engines over health websites to look for cholesterol related information. All of them preferred using Google over Yahoo or MSN search. All remarked that they trusted Google's ranking for displaying the search results. None of the participants used health

websites like WebMd as a starting point. Rather they used search engines in an attempt to find relevant pages.

"With the new technology in the search engines, search results from any search engine are the same but I personally prefer Google over the others because of its simplicity in layout and design. It is an intelligent search engine which tries to guess the consumer's needs and context. Hope there was an equally smart health search engine out there"

"I personally prefer Google because of its ranking capability. I totally trust Google ranking rather than my own gut feeling. If I had to search computers related information, I would go with my gut feeling but since this is a health related search, I would stick to Google's ranking. They (Google) give a very refined search"

"Searching is an art which one needs to master or go to Google"

"WebMD is a medically heavy website, too much information"

"Yahoo has the best dashboard on the Internet"

<u>Search strategy</u> —The search strategy used by the participants was sub-optimal. My subjects read only the first five results displayed by the search engine and if they did not find what they were looking for, they rephrased their query rather than turning to the next page and exploring further results.

One of the subjects' tweaked his search query to be more specific (for example "cholesterol LDL 200") and it resulted in information which was useful to him.

<u>Increased numbers of health websites now compared to previous years</u> - my subjects were consistent in their opinion that there was significant increase in the number of health websites now compared to the previous years when they had first searched for health information on the Internet.

<u>Simplicity preferred for layout and appearance</u> - my participants wanted the health website to look simple, usable and professional. None of them wanted advertisements or pop-ups on their results page.

"Simplicity on information including lay out, design, readability (no medical jargon), no ads, no banners, no eye catchy things- are very important to me"

"As you can see, I am not a big fan of advertisements and pop-ups. I would say that simplicity of information without medical jargon is what I want out of my health related searches on the Internet"

"Appearance and layout of the website is important. I do not like excessive hyperlinks or bullets on the pages. On most of the web sites, you have to click on tabs which will take you to the next/new page –for example, there will be bullets on causes, treatments, risk factors etc and you will have to click on each to read the material"

"I will trust anyone, be it Doctor or the Internet or even Drugs companies as long as they explain my condition in simple terms, the US uses too much medical jargon"

<u>Credibility of source was very important</u> - the authority and credibility of the sources was very important to my participants. Seven of the ten participants remarked that they would trust the content from Government websites like NIH and CDC over studies and content sponsored by the pharmaceutical companies. Accurate health information became synonymous with trust. This was the major theme among my participants.

"I would like to know the authenticity of the source producing the material, the qualifications of the person who wrote the content and also the date when the content was written"

"By trusted source, I mean reliable and updated information- Is the information coming from a government body like the NIH/NLM, or a public institution like the Mayo clinic or some organization like the American Heart Association (AHA)"

"By authenticity I mean, where is the content from? Which institution is providing the content? The source has to be a respectable one. I will trust government websites or associations over corporations like pharmaceutical companies which always have vested interests"

"The appearance of website, terminology, updated content, educational qualifications of the content providers should be made available for consumer to gain trust"

"I trust content posted by online support groups because they are in same boat as me"

"I trust NIH website to have trustworthy content, accurate content and non-biased content"

"For me, accuracy of information is synonymous with trust"

<u>Drug companies were singled out</u> – Nine out of ten participants viewed information put out by drug companies to be less trust-worthy. Only one participant was complimentary of drug companies.

"Drug companies have hijacked our health. The Internet can play a significant role in exposing the drug companies, medical devices companies, and insurance companies"

"Drug companies don't want people to be healthy. They are interested in pushing their drugs and making money."

"I trust the Pharmaceutical companies. They have invested billions of dollars in making drugs and saving lives. I don't agree that they would like to harm us. The information on their website is accurate and scientifically wetted"

<u>Updating of content</u>- more than half of my participants were conscious in checking the date of when the content was written/updated. They wanted the content on the health website to be current.

"The date when the content is updated is important to me. What's the point in showing old information?"

Opportunity to cross-reference search results and seek a second opinion - participants agreed the Internet was a very resourceful tool to cross reference health information across search results. It allowed them access to multiple opinions on a particular subject with little or no cost.

"The Internet is a resourceful tool to cross reference health results across different mediums"

The Internet acts as a communication tool with doctors – Two of my participants agreed that there is value in sharing the search results from the Internet with their doctors to validate their line of treatment. The participants were skeptical whether the doctor would accept the search results to be deterministic.

"Doctors in US have no regards for patients' choice of alternative medicines to cure diabetes and high blood cholesterol"

"Yes, I certainly would like to hear doctor's opinion on my findings from the Internet.

Every clinician has a style of practicing and no two styles can be same. I always discuss my findings from the Internet with my clinicians, the response to my input is mixes, some clinicians are receptive, and most are not"

"I feel the Internet is just a tool to provide health (or any other) information, it is not the authority on the subject. I will still trust my doctor's knowledge and will not question them on their domain expertise"

The Internet will promote alternative treatments – All respondents agreed the Internet will promote alternative systems of medicine like Ayurveda and Homeopathy and provide choices to American consumers in making their health decisions. With the rising cost of healthcare in America, more consumers will seek cost effective and affordable health solutions on the Internet.

"Being an immigrant from India, I am always interested in knowing the alternative methods of treating a disease if there is any. Like in India, there is Ayurveda (Indian system of medicine), which has mastered the art of curing chronic diseases like arthritis and asthma for which in Allopathic (Western) medicine there are only steroid drugs. The Internet will change the perception of American people towards healthcare"

"The cost of healthcare is rising. Doctors have no time to spend with their patients, the visits are becoming shorter day by day, and most insurance companies do not cover alternative therapies like Ayurveda, Homeopathy and Acupressure. With all this background and the advent of access to the Internet, more and more people will rely on the Internet for their health related information. They will look for cheaper and alternative therapies for their chronic conditions. I believe the Internet will provide choices to American consumers to find solutions for their health problems"

<u>Dissatisfaction with the search results</u> – Eight of the ten participants' agreed that health information on the Internet will take time to mature and display relevant search results. Their overall concern was that much of the health information currently available is written at a level that exceeds the reading recognition and comprehension skills of many non-medical readers.

Participants' were personally not too happy with the search results for cholesterol related information.

"I will trust a site which focuses on environmental issues to cholesterol in Indians. I know the genetic part but I want website to tell me about diet, exercise for Indians. There is no such website available"

<u>In future content will be delivered through micro sites, self-help groups and social</u>

<u>networking sites</u> – four of my subjects envisioned the growing role of Twitter in future to deliver customized health content. All but one saw the emerging role of self-help groups and social networking sites in health education and awareness.

"Twitter will play an important role in sharing health information during epidemics and pandemics"

"In Twitter, no one can censor tweet, the flip side is accuracy of what is promoted"

"I grew up on the motto of prevention is better than cure. In this country prevention requires more effort"

"Self help groups and social networking sites like "patients like me" and "Facebook" will provide voice to patient view"

"Information in future will delivered and stored on hand held devices"

"Innovation is missing in health information delivery and care. I wish, my cholesterol readings could go to my Doctor in real-time"

Discussion

The results from this study indicate that consumers search for and appraise health information for trustworthiness of the content and simplicity of layout^{51,52}. Several criteria to assess credibility emerged from the interviews. Websites from Government authorities, understandable and professional writing laid out in a simple manner were the most often mentioned criteria for trustworthiness⁵¹.

The Internet users explore only the first few links on general search engines when seeking health information and do not check out the "about us" sections of websites or read disclaimer or disclosure statements. Often they don't remember the site they got their health information from⁵².

Participants were generally successful in getting the desired search results by rephrasing their search query. They looked at the first five search results and fine tuned their search strategy for better results.

This study had several limitations. The overall information-seeking behavior of a specific population is far too broad and general a topic to investigate adequately in the context of a single study, and thus cholesterol related health information was chosen as a situational focus. Participants were professionals with high levels of information literacy and education. Also, results from a small sample size (n=10) may not be generalized to the whole South Asian Indian male population.

The future of the Internet in Health Care

Several developments will influence consumer access to information on the Internet in the future⁵⁵.

Because much diverse, inconsistent, and incoherent information is now available on the Web, opportunities exist for new approaches to collect and combine information for easier use⁵⁵.

Consumers need help in sorting through the extensive "noise" on health care Web sites.

Search engines with a stronger editorial voice – specialized health "portals" that compile and index health information rather than simply accumulate information from the Internet – will be the choice of the majority of Web searchers⁵⁵.

A small number of trusted services that rate the quality of information on health care sites will emerge from efforts such as Health On The Net (www.hon.ch). Mainstream sites will comply with the raters' guidelines to get their coveted seals of approval. At the same time, the multitude of sites that don't care about ratings will continue to thrive.

New forms of health care information on the Internet will proliferate. With the growing

availability of inexpensive data and storage, more images, animation, video clips, and interactive learning systems will be put in place. Few consumers, however, will have wide enough bandwidth connections to the Internet to be able to take advantage of that rich content⁵⁵.

Patients, especially those with chronic diseases, will begin to use personalized health records services to track their health status. These systems will allow patients to perform health risk assessments online and to track their adherence to diet, exercise, or medication regimens⁵⁵.

Conclusion

The Internet may be a valuable resource for researchers to identify health beliefs, common topics, motives, information, and emotional needs of patients, and point to areas where research is needed⁵³.

The South Asian Indians may seek cholesterol related information on the web because of the condition of self or loved ones. Their perspective on the quality of health information and other characteristics available on the web is important and should be studied for future guidance in the development of patient centric online content⁵⁴.

Sample size of ten participants' is too small to conclusively assess the search trends of large South Asian Indian population. Therefore further observational studies will be needed to elicit the perceptions of South Asian Indian population which can then be utilized to design and evaluate educational and technological innovations for guiding this population to search for high quality health information on the web⁵¹.

References

- 1. Enas EA. Coronary artery disease epidemic in Indians: A cause for alarm and call for action. J Indian Med Assoc 2000:98:694-5, 697-702.
- Enas EA. Cardiovascular diseases in Asian Americans and Pacific Islanders. Asian Am
 Pac Islander J Health 1996;1:163 175.
- 3. Enas EA, Yusuf S, Mehta J. Prevalence of coronary artery disease in Asian Indians. Am J Cardiol 1992;70:945 - 949.
- 4. Jha P, Enas EA, Yusuf S. Coronary artery disease in Asian Indians: prevalence and risk factors. Asian Am & Pac Islander J Health 1993;1:161-175.
- 5. Enas EA, Yusuf S, Mehta J. Meeting of International Working Group on coronary artery disease in South Asians. Indian Heart J 1996;48:727-732.
- 6. Enas EA, Dhawan J, Petkar S. Coronary artery disease in Asian Indians: Lessons learned so far and the role of Lp(a). Indian Heart J 1997;49:25-34.
- 7. Yusuf S, Ounpuu S, Anand S. Global burden of cardiovascular disease: A review of evidence. In: Sethi KK, ed. Coronary Artery Disease in Indians: A Global Perspective. Mumbai: Cardiological Society of India, 1998:11-25.
- 8. Mohan V, Deepa R, Shanthi Rani S, Premalatha G. Prevalence of coronary artery disease and its relationship to lipids in a selected population in South India. The Chennai Urban Population Study (CUPS No. 5). J Am Coll Cardiol 2001;38:682-687.

- 9. McKeigue PM, Ferrie J, Pierpoint T, Marmot M. Association of early-onset coronary heart disease in South Asian men with glucose intolerance and hyperinsulinemia. Circulation 1993;87:161-165.
- 10. Enas EA, Garg A, Davidson M, Nair V, Huet B, Yusuf S. Coronary heart disease and its risk factors in first-generation immigrant Asian Indians to the United States of America. Indian Heart J 1996;48:343-353.
- 11. Steinberg WJ, Balfe D, Kustner H. Decline in the ischemic heart disease mortality rates of South Africans, 1968-1985. S Afr Med J 1988;74:547-550.
- 12. Wild SH, Laws A, Fortmann S, Byrne C. Mortality from coronary heart disease and stroke for six ethnic groups in California, 1985-1990. Ann Epidemiol 1995;5:432-439.
- 13. Hughes K, Lun K, Yeo P. Cardiovascular disease in Chinese, Malays and Indians in Singapore: 1. Differences in mortality. J Epidemiol Community Health 1990;44:24-28.
- 14. Enas EA, Senthilkumar A, Juturu V, Gupta R. Coronary artery disease in women. Indian Heart J 2001;53:282-292.
- 15. Miller GJ, Beckles GL, Maude GH, Carson DC, Alexis SD, Price SG, Byam NT. Ethnicity and other characteristics predictive of coronary heart disease in a developing community: Principal results of the St James Survey, Trinidad. Int J Epidemiol 1989;18:808-817.

- 16. Bee KS. The Health of Singaporeans. Singapore: Research and evaluation department, Ministry of Health, 1993.
- 17. Hughes K. Coronary artery disease in Indians in Singapore. In: Sethi K, ed. Coronary artery disease in Indians A Global perspective. Mumbai: Cardiological Society of India, 1998:56-62.
- 18. Lee J, Heng D, Chia KS, Chew SK, Tan BY, Hughes K. Risk factors and incident coronary heart disease in Chinese, Malay and Asian Indian males: the Singapore Cardiovascular Cohort Study. Int J Epidemiol 2001;30:983-988.
- 19. Heng DM, Lee J, Chew SK, Tan BY, Hughes K, Chia KS. Incidence of ischaemic heart disease and stroke in Chinese, Malays and Indians in Singapore: Singapore Cardiovascular Cohort Study. Ann Acad Med Singapore 2000;29:231-236.
- 20. Enas EA, Yusuf S, Sharma S. Coronary artery disease in South Asians; second meeting of the International Working Group, 16 March 1997, Anaheim, California. Indian Heart J 1998;50:105-113.
- 21. Klatsky AL, Tekawa I, Armstrong MA, Sidney S. The risk of hospitalization for ischemic heart disease among Asian Americans in northern California. Am J Public Health 1994;84:1672-1675.
- 22. Enas EA. Why is there an epidemic of malignant CAD in young Indians? Asian J Clin Cardiol 1998;1:43-59.

- 23. Balrajan R. Ethic differences in mortality from ischaemic heart disease and cerebrovascular disease in England and Wales. BMJ 1991:302:560-4
- 24. American Heart Association. Heart Disease and Stroke Statistics 2003 Update. Dallas, Tex.: American Heart Association; 2002.
- 25. Prayaga S. Asian Indians and coronary artery disease risk. SUNY upstate medical university. The American J Med, Vol. 120, Issue 3, March 7 2007, pge15 e16.
- 26. Enas EA. Cooking oil, cholesterol and coronary artery disease. Indian Heart J 1996;48:423-428.
- 27. Brown MS, Goldstein JL. Heart attacks: Gone with the century? Science 1996;272:629.
- 28. Enas EA, Yusuf S, Garg A, Davidson L, Thomas J, Pearson T. Lipoprotein (a) levels in Indian physicians: Comparison with Black and White physicians in the U.S.A. Indian Heart J 1994;46 suppl:185(abstract).
- 29. Chuang C Z, Subramaniam PN, LeGardeur BY, Lopez A. Risk factors for coronary artery disease and levels of lipoprotein(a) and fat-soluble antioxidant vitamins in Asian Indians of USA. Indian Heart J 1998;50:285-91.
- 30. Anand S, Enas EA, Pogue J, Haffner S, Pearson T, Yusuf S. Elevated lipoprotein(a) levels in South Asians in North America. Metabolism 1998;47:182-184.

- 31. Hughes K, Aw TC, Kuperan P, Choo M. Central obesity, insulin resistance, syndrome X, lipoprotein(a), and cardiovascular risk in Indians, Malays, and Chinese in Singapore. J Epidemiol Community Health 1997;51:394-399.
- 32. Shaukat M, de Bono D. Are Indo-origin especially susceptible to coronary artery disease? Postgrad Med 1994;70:315 318.
- 33. Gupta R, Kastia S, Rastogi S, Kaul V, Nagar R, Enas EA. Lipoprotein(a) in coronary heart disease: A case-control study. Indian Heart J 2000;52:407-410.
- 34. Gambhir JK, Kaur H, Gambhir DS, Prabhu KM. Lipoprotein(a) as an independent risk factor for coronary artery disease in patients below 40 years of age. Indian Heart J 2000;52:411-415.
- 35. Gupta R, Vasisht S, Bahl V, Wasir H. Correlation of lipoprotein (a) to angiographically defined coronary artery disease in Indians. Int J Cardiol 1996;57:265-270.
- 36. Bhatnagar D, Anand IS, Durrington PN, Patel DJ, Wander GS, Mackness MI, Creed F, Tomenson B, Chandrashekhar Y, Winterbotham M, et al. Coronary risk factors in people from the Indian subcontinent living in west London and their siblings in India. Lancet 1995;345:405-409.
- 37. Shaukat N, de Bono DP, Jones DR. Like father like son? Sons of patients of European or Indian origin with coronary artery disease reflect their parents' risk factor patterns. Br Heart J 1995;74:318-323.

- 38. Superko HR, Enas EA, Kotha P, Bhat N. Impaired cholesterol transport in Asian Indians. J Am Coll Cardiol 2001;37:300A.
- 39. E. A. Enas & A. Senthilkumar : Coronary Artery Disease In Asian Indians: An Update And Review . The Internet Journal of Cardiology. 2002 Volume 1 Number 2
- 40. Eysenbach G. Infodemiology and Infoveillance: Framework for an Emerging Set of Public Health Informatics Methods to Analyze Search, Communication and Publication Behavior on the Internet. J Med Internet Res 2009;11(1):e11
- 41. Eysenbach, G., Powell, J., Kuss, O., Sa, E.-R. (2002). Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web: A Systematic Review. *JAMA* 287: 2691-2700
- 42. Ginsberg J, Mohebbi MH, Patel RS, Brammer L, Smolinski MS, Brilliant L. Detecting influenza epidemics using search engine query data. Nature 2009 Feb 19;457(7232):1012-1014.
- 43. Eysenbach G. Infodemiology: tracking flu-related searches on the web for syndromic surveillance. AMIA Annu Symp Proc 2006:244-248
- 44. Eysenbach G. SARS and population health technology. J Med Internet Res 2003 Jun 30;5(2):e14
- 45. Wilson K, Brownstein JS. Early detection of disease outbreaks using the Internet. CMAJ 2009 Mar 12

- 46. Polgreen PM, Chen Y, Pennock DM, Nelson FD. Using the Internet searches for influenza surveillance. Clin Infect Dis 2008 Dec 1;47(11):1443-1448.
- 47. Hulth A, Rydevik G, Linde A. Web queries as a source for syndromic surveillance. PLoS ONE 2009 Feb 6;4(2):e4378
- 48. Cooper CP, Mallon KP, Leadbetter S, Pollack LA, Peipins LA. Cancer Internet search activity on a major search engine, United States 2001-2003. J Med Internet Res 2005 Jul 1;7(3):e36
- 49. Gibbons MC. A historical overview of health disparities and the potential of eHealth solutions. J Med Internet Res 2005;7(5):e50
- 50. International Organization for Standardization, Technical Committee ISO/TC 176. ISO 8402: Quality management and quality assurance—Vocabulary. 2nd ed. Geneva: International Organization for Standardization, 1994(1994-04-01.)
- 51. Eysenbach G, Kohler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. BMJ 2002; 324:573-577 (9 March)
- 52. Eysenbach G. Consumer health informatics. BMJ 2000; 320: 1713-1716
- 53. Eysenbach G, Wyatt J, Using the Internet for Surveys and Health Research J Med Internet Res 2002;4(2):e13,

URL: http://www.jmir.org/2002/2/e13

- 54. Quintana Y, Feightner JW, Wathen CN, Sangster LM, Marshall JN. Preventive health information on the Internet. Qualitative study of consumers' perspectives. Can Fam Physician 2001; 47: 1759-1762
- 55. Cain M, Mittman R. The Future of the Internet in Health Care Five Year Forecast.

 Written for California Health Care Foundation on the web @

 http://www.chcf.org/documents/healthit/forecast.pdf, 1999