Decision Making In Online Health Communities:
What Can We Learn From Member Choice Inquiries

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Abstract

By 2015, 30.3 million American people or 9.4% of the US population had diabetes. Diabetes management can be challenging as patients experience evolving information needs around complex lifestyle and medical decisions. As patients' condition progress, they make decisions by identifying or evaluating choices. These choice inquiries along the decision-making process present a valuable research opportunity to uncover and support their information needs. As an increasing number of patients visit online health communities (OHCs) to fulfill their information needs, we conducted a qualitative content analysis of 1000 diabetes community posts with a goal to identify choice inquiries and analyze their contents. We found choice inquiries occurred in approximately 20% of member initiated posts. Medication and treatment, blood sugar control, and food was the most popular topics members make decisions upon. The top list of triggers that make members post choice inquiries included having blood sugar problems, desiring for more information and forming specific goals. We present direction to better support decisional needs in online health communities.

Introduction

Chronic illnesses are characterized by their lack of cure when patients must constantly manage and receive care throughout their lifetime. Upon diagnosis, patients with diabetes must absorb information, change habits, and adopt new behaviors[1]. As their condition progresses, they make decisions that affect their health on a day-to-day basis[2], such as food and exercise choices. Even as patients achieve control of their diabetes, new issues come up and they need to readjust their routines and behavior[3]. Prior research showed inadequate information was provided to patients after their initial diagnosis[4–7]. Patients are left with questions regarding lifestyle modifications and other required changes[6], and express high desires for gaining medical knowledge[4]. One critical source of information for patients is Online health communities (OHCs) because of the vast amount of anecdotal information available[8,9].

We call the moments of decision making process where alternatives are developed and evaluated c*hoice inquiries*. Since OHCs are filled with collective knowledge (e.g., members often review new diabetes-related products in OHC[10]) and the potential to support patients in their chronic illness management, we conducted a qualitative study on an online diabetes community. We uncovered decisional needs of members and the context surrounding these needs. In the end, we present insight on how to better support decision making for patients with chronic conditions.

Background

Diabetes management

In the US alone, in 2015, 30.3 million people were diagnosed with diabetes[11]. Most people with chronic illnesses such as diabetes do not receive appropriate or effective chronic illness management from primary care providers[12]. The day-to-day management of diabetes falls on patients themselves[2]. As diabetes has a substantial and increasing impact on quality of life, patients need to become more educated partners in their care[13].

Chronic conditions such as diabetes progresses over time, resulting in evolving information needs from patients. Corbin and Strauss proposed the chronic illness trajectory framework to explain the evolving nature of patients' and families' needs, with "trajectory" referring to the course of a chronic disease in its different stages and phases[14]. As patients transition through phases, they inquire about their choices to decide on the next course of action[2]. Consequently, their inquiries present an opportunity to provide informational support to aid informed decision-making, a process that involves various resources and understanding pros and cons of different choices.

Patient decision-making

The decision-making process is a complex construct, where the level of rationality involved in the process is still being debated. For example, normative theories of decision-making (e.g., subjective expected utility theory[15]) assumes patients consider decisions rationally and evaluate the risks and benefits of all available interventions[16]. Descriptive theories of decision-making (e.g., prospect theory[17]) on the other hand describes how cognitive biases can cause people to deviate from the rational ideal[18]. The Dual-Process Theory of decision-making states people make decisions either intuitively or rationally where the latter results in less cognitive bias[18].

While decision-making theories highlight the various factors that influence people's decision-making behavior, the decision-making process models[19,20] share in common the steps leading to making a decision: establishing

objectives, gathering information, and developing and evaluating alternatives. We call the moments of decision making process where alternatives are developed and evaluated *choice inquiries*. This type of inquiry provides a critical opportunity to support patient decision-making by informing them about the risks, benefits, and consequences of the choices[16], through which the quality of patients' decisions can be improved.

Though daily decision-making in diabetes can have immediate impact and result in potentially life-threatening complications[21], we know little about how patients seek information from OHC to aid decision making. Mamykina et al. showed much of diabetes self-management involves the need to make quick decisions under uncertain conditions. More research is underway to make use of OHC content, such as text classification methods[26,27], and visual decision-making techniques[28]. However there is lack of research on understanding diabetes patients self-care decision-making in everyday settings[21]. To this end, we investigate how people make decisions through choice inquiries, and the context surround decision making. As a result of this, we propose solutions to support their decision making in chronic disease management in online health communities.

Methods
We chose an active, publicly available online diabetes community as a data source to conduct our research. We focused on diabetes because it is prevalent and that diabetes management relies heavily on self-care[2]. We anonymize the identity of the community due to privacy concerns of the posters. The Institutional Review Board at our university's Human Research Protections Program determined this project to be exempt.

We extracted 71,177 community posts between 2007 and 2014 and saved them to a local database program. We were interested in identifying thread initiating posts members posted with the purpose of choice inquiries. Thus, we excluded replies and thread initiating posts posted by moderators or health professionals. In our dataset, we had 8690 thread initiating posts by members. We then randomly sampled 1000 posts (~11.5%) for content analysis (Figure 1). The content analysis was guided by a codebook developed from prior research. The codebook provides instruction on extracting posts relevant to analysis, and from there, posts that involve identifying and evaluating choices as suggested in the decision making literature[19,20].

To refine the codebook, coder 1 and coder 2 reviewed 50 posts together and incorporated changes to codebook. Following that, two coders coded 50 posts independently to assess inter-rater agreement. After good agreement was established (k >=0.8), coder 1 and coder 2 each coded the 450 posts. Both coders reviewed the final results to ensure accuracy. The coders also identified contextual factors surrounding decision making, such as how (inquiry type), what (topics), who (subjects), and why (triggers).
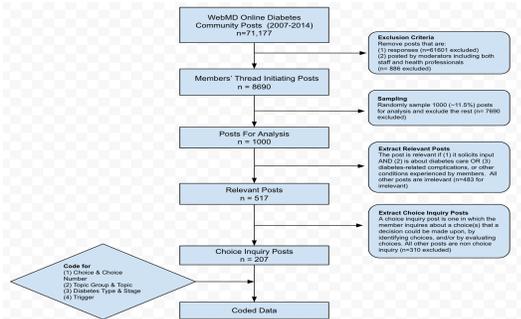

Figure 1. Qualitative content analysis process
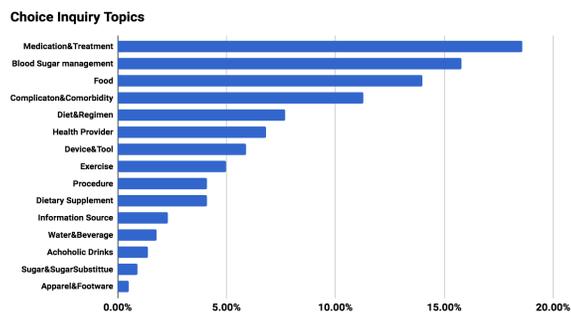

Figure 2. The popular topics of choice inquiries

Results
The prevalence of choice inquiries
Slightly over half of sampled 1000 posts are relevant to our analysis (51.7%). By "relevant" it meant these posts solicit input and are about diabetes care or its complication. Decision making in the form of choice inquiries takes place in 20.7% of OHC posts (207 out of 1000).

How OHC members inquire about decision-making
Since knowledge of choices is necessary for making informed decisions[29], we are interested in how members obtain knowledge of choices. This was done through extracting choice inquiries. Following that, we further categorized the inquiries based on whether the member seeks to identify unknown choices, evaluate known choices, or both. For example, one member asked: "*Hello, I am T2. I recently tasted a sugar free beer. I know it is better for me not to*

drink alcohol. But sometime I do. Am I better with a sugar free beer?" Since this member knows of the sugar free beer choice and he is getting input on whether it is a better alcoholic drink choice, we coded this post as "evaluate choice". We found that a little over half (54.6%, 113 out of 207) of choice inquiries identify choices only, one third (33.8%, 70 out of 207) evaluate choices only, and the remaining 11.6% (24 out of 207) both identify and evaluate choices.

Who do OHC members make decisions for
While the majority of the choice inquiries are members making decisions for themselves (84.5%, 175 out of 207), the rest of the posts (15.5%, 32 out of 207) seek input for others. We looked the subjects that members make decisions for, when it's not about themselves (the "others" category). We found "significant other" tops the list. "Significant other" includes husband, wife, boyfriend or girlfriend. Following "significant other", is member's child, parent, and other family. There is a small percentage that is for a friend and the remaining 16% is unknown.

What do OHC members make decision on
Our content analysis informed topics OHC members needed to gather information for and make decisions on. These include a range of topics specific to diabetes care, from oral medication, to insulin pumps and dietary supplements. The complete list and the breakdown from the analysis is shown in Figure 4.

Medication and treatment was the most popular topic of decision making, accounting for one in five choice inquiries. Medication and treatment refers to substance(s) used to treat diabetes, its related complications or other conditions experienced by members, such as oral medication, and insulin. Members were concerned about medication efficacy, side effects, costs, and when is the best time to take the medications (example 1). Questions members ask could be in the form of detailed narration including personal medical history, responses to medication (example 2).

Example 1: "What medication(s) can/should be prescribed for a Type 2 Diabetic, elevated LDL-C, with Renal disease? What's safe?"

Example 2: "Good evening. I am a diabetic who also suffers with a herniated disk. I have been revisited by a lot of pain in recent weeks as the nerve has become inflamed. My physician has injected predisolone as well as prescribed further tablets of the same drug and Cataflam, all of which has sent my blood glucose sky high (383+). What drugs are there for such a situation (diabetic/inflamed nerve/pain) that would be suitable/safe for a diabetic? Thank you."

Blood sugar management follows medication and treatment as the second most popular topic in choice inquiries. Members expressed needs in learning ways to keep blood sugar under control: "*Does someone have some good ways to lower my blood sugar?*" Similar to medication and treatment, member questions could include very detailed, personalized information, and in this example, a running log of events and blood sugar numbers: "*...My blood sugar is out of control! ...On the 20th, at 12:15 AM my reading was 84. At 1 PM I took my evening meds and ate a Pop Tart, went to bed about 3 AM. At 9:30 AM my BS was 66... At 12:45 AM on the 21st it was 88...At 6:30 AM by BS was 70. ...any suggestions on how to get back under control besides keeping track of the BS and eating?*"

Following blood sugar management, food is the third most popular topic. Newly diagnosed patients were eager to learn diabetic friendly food choices, as illustrated in this example: "*As a newbie I am wondering about breakfast...Love my coffee and cream...What is the better creamer? fat free or sugar free? liquid creamer or powder creamer?*" Veteran patients expressed long-term struggles with coping with food cravings: "*I was diagnosed with type 2 diabetes in 1999, and I have always loved cakes... I have tried to resist cakes...but it's impossible for me to say no... I would like to know what you would suggest as a way to overcome that craving before it kills me?*"

Why do OHC members make decisions
Patients with diabetes reconstruct life with illness through the process of learning, making choices, and identifying changes needed[30]. This process was reflected through their choice inquiries in this OHC, triggered by various problems, events, or changes along their illness trajectories. These triggers were important to identify they contextualize the motivations behind decision making. We found blood sugar problems, desire for information, and forming goals to be among the top triggers for decision making.

Blood sugar problems
Blood sugar control is a key aspect of diabetes self-care and it was reflected in our findings as the top trigger for decision making. Members expressed frustrations on lack of control on blood sugar: "*I'm having a very hard time keeping my bg in check...*" or they were puzzled by unexpected rise in blood sugar: "*My blood sugar just spiked to 260 and I don't know what to do...*". Though diabetes is characterized by elevated blood sugar, members also faced

the problem of low blood sugar and blood sugar swings: "*First my sugar was high now I'm having lows 66 70 and 80s when it gets low how do you know how much juice or sweets you should eat to get it up a little…*"

Desire for information
When patients do not receive adequate or useful information through conventional channels, they fill their information gap on OHCs[31]. One member came to the community to confirm the applicability of prior knowledge on new choices: "*A few years ago I attended a diabetes class where the instructor said strawberries and watermelon were ok for diabetics to eat because of their water content. Now I need to confirm this…What about other melons? Honeydew and Cantaloupe?*" Another member desired personalized information on whether it is ok to get tattoos now that she is diagnosed with type 2 diabetes.

Forming specific goals
Members make decisions when they form a specific goal. Weight management is a popular goal among members. For instance, a member is "trying to lose weight by dieting" but she has trouble walking. As a result, she inquired about exercise choice as a starting point so she "can work up to a point…to begin a walking regime". While much of diabetes-related weight management focuses on losing weight, our findings revealed weight gain as another goal weight management. One member asked "how to gain weight even though you are diabetic and underweight" and inquired about the supplements for people with diabetes to gain weight. Another member acknowledged that she might be "an anomaly" but she needed help on keeping the weight on. Besides weight management, members that are at risk for diabetes or prediabetic come OHCs to decide on preventative measures so that they do not progress to diabetes.

Discussion
The daily requirement of decision making is an important aspect of the challenges in chronic illness self-care, with patients having to select from options in a wide range of issues, however it is less well understood[21]. As a result, Thorned et. al called for "a more complex, grounded, and nuanced body of knowledge that will illuminate individual experience in chronic illness self-care decision making." In response to this, our findings filled a gap in understanding decision making and its contexts. We should utilize existing and on-going peer patients' contributions on OHCs to build a patient-driven personalized and evidence-based information support for patient decision making.

Patient-driven Personalized support
Our findings demonstrated two distinct aspects of diabetes self-management: the common challenges experienced by many, and the highly contextualized personal concerns. Recent research looked into developing a problem-solving knowledge base for diabetes self-management[32]. Building on that idea, we can construct a patient generated information repository with both questions and existing responses to questions. As diabetes self-care is a highly personalized process, OHC should capitalize on the range of contexts members discuss in their personal problems. These contexts should be tagged and organized to reflect the rich and nuanced challenges patients face. From there, a personalized approach to decision making could be developed through matching mechanisms. Sepucha et al. pointed out the quality of the decision-making process can be improved by helping patients feel informed about the options, as well as the risks, benefits, and consequences of the choices[16]. Guided by this measurement construct for patient decision aids, we can present aggregated information on the choices people have discussed, as well as their pros and cons. Since the mechanism of comparison is central in human decision-making[33], we can externalize this process by presenting options from previously generated content in an easy-to-compare format.

Evidence based information enhancement
As a characteristic of OHCs, patients gain support through the narratives of peer patients. Patient narratives presents strength and weakness for aiding informative decision making[34–36]. First person narratives are powerful in their persuasiveness and are known to powerfully influence one's health belief[34]. However, they can be harmful at the same time in creating bias and discouraging individuals to systematically evaluate information[35]. In addition to this, the quality of online health information varies widely, with much of the information lacking accuracy and completeness[37]. Failure to address to the quality of information obtained by patients can lead to serious consequences[38,39]. Prior research demonstrated a need for professional input in the context of peer support[40], in that a system that offers response from professionals to address peer patient questions was deemed helpful[41,42]. To this end, we propose inclusion of clinical evidence to enhance information quality.

Conclusion
In this paper, we discussed the findings from a diabetes online community's posts to help us understand patient information needs surrounding everyday decision-making. The knowledge generated through this study shed light

on patients' experience and challenges in diabetes self-care, and in particular when they inquire about choices to make decisions upon. Our study contributes to understanding decision making that takes place in OHCs and inform how clinicians, system developers, healthcare institutions, and researchers should approach supporting patients' everyday decision-making process.

References

1.   Beeney LJ, Bakry AA, Dunn SM. Patient psychological and information needs when the diagnosis is diabetes. Patient Educ Couns [Internet]. 1996 Oct [cited 2016 Jun 25];29(1):109–16. Available from: http://linkinghub.elsevier.com/retrieve/pii/0738399196009391

2.   Association of the british pharmaceutical industry. The Diabetes Information Jigsaw Seek knowledge for informed choice and better health. 2006.

3.   Longo DR, Schubert SL, Williams CD, Clore JN, Wright BA, Lemaster J, et al. Health information seeking and Use in Diabetes Self-Management. Ann Fam Med. 2010;8(4):334–40.

4.   Duggan C, Bates I. Medicine information needs of patients: the relationships between information needs, diagnosis and disease. Qual Saf Health Care [Internet]. 2008;17(2):85–9. Available from: http://www.ncbi.nlm.nih.gov/pubmed/18385399

5.   Beeney LJ, Bakry AA, Dunn SM. Patient psychological and information needs when the diagnosis is diabetes. Patient Educ Couns [Internet]. 1996 Oct [cited 2016 Jul 20];29(1):109–16. Available from: http://linkinghub.elsevier.com/retrieve/pii/0738399196009391

6.   Peel E, Parry O, Douglas M, Lawton J, Jedlicka-Köhler I, Götz M, et al. Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions and views about information provision. Patient Educ Couns [Internet]. 2004 Jun [cited 2016 Aug 2];53(3):269–75. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15186863

7.   Lamberts EJF, Bouvy ML, van Hulten RP. The role of the community pharmacist in fulfilling information needs of patients starting oral antidiabetics. Res Soc Adm Pharm. 2010;6(4):354–64.

8.   Vilhauer RP. Perceived benefits of online support groups for women with metastatic breast cancer. Women Health [Internet]. 2009;49(5):381–404. Available from: http://www.ncbi.nlm.nih.gov/pubmed/19851944

9.   Qiu B, Zhao K, Mitra P, Wu D, Caragea C, Yen J, et al. Get Online Support, Feel Better -- Sentiment Analysis and Dynamics in an Online Cancer Survivor Community. 2011 IEEE Third Int'l Conf Privacy, Secur Risk Trust 2011 IEEE Third Int'l Conf Soc Comput. 2011;274–81.

10.   Hilliard ME, Sparling KM, Hitchcock J, Oser TK, Hood KK. The Emerging Diabetes Online Community. Curr Diabetes Rev. 2015;11:261–72.

11.   Centers for Diesease Control and Prevention. 2017 National Diabetes Statistics Report. Estimates of Diabetes and Its Burden in the United States. 2017.

12.   Rothman AA, Wagner EH. Chronic illness management: what is the role of primary care?. Ann Intern Med [Internet]. 2003 Feb 4 [cited 2016 Sep 20];138(3):256–61. Available from: http://www.ncbi.nlm.nih.gov/pubmed/12558376

13.   Celler BG, Lovell NH, Basilakis J. Using information technology to improve the management of chronic disease. Med J Aust. 2003;179(5):242–6.

14.   Corbin JM, Strauss a. A nursing model for chronic illness management based upon the Trajectory Framework. Sch Inq Nurs Pract. 1991;5(3):155–74.

15.   Karni E. Savages' Subjective Expected Utility Model. In: Durlauf SN, Blume LE, editors. The New Palgrave Dictionary of Economics. Second Edi. Palgrave Macmillan, 2008.; 2008. p. 1–12.

16.   Sepucha KR, Borkhoff CM, Lally J, Levin CA, Matlock DD, Ng CJ, et al. Establishing the effectiveness of patient decision aids: key constructs and measurement instruments. BMC Med Inform Decis Mak [Internet]. 2013;13 Suppl 2:S12. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=4044563&tool=pmcentrez&rendertype=abstract

17.   Kahneman D, Tversky A. Prospect Theory: An Analysis of Decision under Risk. Econom J Econom Soc. 1979;47(3):263–91.

18.   Kahneman D. A perspective on judgment and choice: mapping bounded rationality. Am Psychol. 2003;58(9):697–720.

19.   Mann L, Harmoni R, Power C, Beswick G, Ormond C. Effectiveness of the GOFER course in decision making for high school students. J Behav Decis Mak [Internet]. 1988;1(3):159–68. Available from: http://search.ebscohost.com/login.aspx?direct=true&db=bth&AN=16566640&site=ehost-live

20.   Guo KL. DECIDE: a decision-making model for more effective decision making by health care managers. Health Care Manag (Frederick) [Internet]. 2008 Apr [cited 2016 Sep 15];27(2):118–27. Available from:

http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00126450-200804000-00005

21. Thorne S, Paterson B, Russell C. The Structure of Everyday Self-Care Decision Making in Chronic Illness. Qual Health Res [Internet]. 2003;13(10):1337–52. Available from: http://qhr.sagepub.com/cgi/doi/10.1177/1049732303258039

22. Gionfriddo MR, Leppin AL, Brito JP, LeBlanc A, Boehmer KR, Morris MA, et al. A systematic review of shared decision making interventions in chronic conditions: a review protocol. Syst Rev [Internet]. 2014;3(1):38. Available from: http://www.systematicreviewsjournal.com/content/3/1/38

23. Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: The case of diabetes. Heal Expect. 2006;9:25–36.

24. Scott GC, Lenert L a. What Is The Next Step in Patient Decision Support. AMIA Annu Symp Proc. 2000;784–8.

25. Mamykina L, Heitkemper EM, Smaldone AM, Kukafka R, Cole-Lewis H, Davidson PG, et al. Structured scaffolding for reflection and problem solving in diabetes self-management: Qualitative study of mobile diabetes detective. J Am Med Informatics Assoc. 2016;23(1):129–36.

26. Huh J, Yetisgen-Yildiz M, Pratt W. Text classification for assisting moderators in online health communities. J Biomed Inform. 2013;46(6):998–1005.

27. Park A, Hartzler AL, Huh J, Mcdonald DW, Pratt W, Park A. Automatically Detecting Failures in Natural Language Processing Tools for Online Community Text Corresponding Author : 2015;17.

28. Kwon BC, Kim SH, Lee S, Choo J, Huh J, Yi JS. VisOHC: Designing Visual Analytics for Online Health Communities. IEEE Trans Vis Comput Graph. 2016;22(1):71–80.

29. Boland L, Kryworuchko J, Saarimaki A, Lawson ML. Parental decision making involvement and decisional conflict : a descriptive study. 2017;1–8.

30. Emery C. Women living with chronic illness experienced transition that involved stages of distress and a quest for ordinariness. Evid Based Nurs [Internet]. 2003;6(2):63–63. Available from: http://ebn.bmj.com/cgi/doi/10.1136/ebn.6.2.63

31. Huh J, Kwon BC, Kim S-H, Lee S, Choo J, Kim J, et al. Personas in online health communities. J Biomed Inform. 2016;63:212–25.

32. Cole-Lewis HJ, Smaldone AM, Davidson PR, Kukafka R, Tobin JN, Cassells A, et al. Participatory approach to the development of a knowledge base for problem-solving in diabetes self-management. Int J Med Inform [Internet]. 2015;85(1):96–103. Available from: http://www.sciencedirect.com/science/article/pii/S1386505615300277

33. Mussweiler T, Posten AC. Relatively certain! Comparative thinking reduces uncertainty. Cognition. 2012;122(2):236–40.

34. Cody R, Lee C. Behaviors, beliefs, and intentions in skin cancer prevention. J Behav Med. 1990;13(4):373–89.

35. Beyerstein BL. Alternative medicine and common errors of reasoning. Acad Med. 2001;76(3):230–7.

36. Wright K. Social support within an on-line cancer community: an assessment of emotional support, perceptions of advantages and disadvantages, and motives for using the community from a communication perspective. J Appl Commun Res. 2002;30(3):195–209.

37. Eysenbach G, Powell J, Kuss O, Sa E-R. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. JAMA [Internet]. 2002;287(20):2691–700. Available from: http://www.ncbi.nlm.nih.gov/pubmed/12020305

38. Bekker HL, Winterbottom AE, Butow P, Dillard AJ, Feldman-Stewart D, Fowler FJ, et al. Do personal stories make patient decision aids more effective? A critical review of theory and evidence. BMC Med Inform Decis Mak [Internet]. 2013;13 Suppl 2:S9. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=4044102&tool=pmcentrez&rendertype=abstract

39. Mühlhauser I, Berger M. Evidence-based patient information in diabetes. Diabet Med. 2000;17(12):823–9.

40. Griffiths C, Foster G, Ramsay J, Eldridge S, Taylor S. How effective are expert patient (lay led) education programmes for chronic disease? BMJ Br Med J. 2007;334(7606):1254–6.

41. Paul G, Smith SM, Whitford D, O'Kelly F, O'Dowd T. Development of a complex intervention to test the effectiveness of peer support in type 2 diabetes. BMC Health Serv Res [Internet]. 2007;7:136. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2080630&tool=pmcentrez&rendertype=abstract

42. Sillence E, Briggs P, Harris P, Fishwick L. Going online for health advice: Changes in usage and trust practices over the last five years. Interact Comput. 2007;19(3):397–406.