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Variations in Structure and Content of Online Social Networks for Patients With Diabetes

With the exponential growth of Facebook and other social networking sites, patients are increasingly seeking information and emotional support online, from other patients.^{1,2} Recent qualitative studies highlight the great potential that online social networks represent as a source of information and encouragement in chronic disease management.³⁻⁵ However, recent research has also identified potential pitfalls in these unregulated sites.^{3,6} More than 25% of posts on Facebook sites for diabetic individuals were promotional in nature, largely directing patients to learn about products not approved by the Food and Drug Administration, and substantial efforts to gather data from Web site participants were noted.³ These findings underscore the need to guarantee the authenticity of participants and to ensure that online social networks are safe locations for patients to share information.

We know little about how commonly used sites validate the authenticity of participants' claimed identities or how they provide oversight over the content posted by participants. In addition, little is known about the structure of communication, the sources of funding, and the presence or use of advertising on these sites. Accordingly, we conducted a survey of online social networking sites to explore characteristics of these communities and to better inform physicians and patients about the choices available to them.

Methods. Search Criteria and Methodology. We identified the most commonly used online social networking Web sites focused on diabetes, a common but complex chronic condition. On November 17, 2010, using Google search methodology, we used the Boolean terms *social network AND diabetes* without language or geographic search modifiers and selected the top 300 results for further classification.^{7,8} We excluded any link to a secondary source (news, academic, or blog article), yielding 23 Web sites. Using a modified 3-part definition of social network sites developed by Boyd and Ellison⁹ as inclusion criteria, we identified 15 social networking sites as our final sample.

Social Network Web Site Assessment. Each Web site was evaluated and data was abstracted by 2 reviewers (W.H.S. and K.S.). The frequency of use of each site was determined using statistics listed on the Web site or by communicating with site administrators. We evaluated membership requirements and authenticity checks for each site. We assessed health professional participation and oversight on each site by evaluating the source and nature of their role. We also assessed the presence, source, and content of advertising on each site by clicking on each tab on the site once and clicking through each advertise-

ment once. We identified the source of funding for each site, when reported.

Results. Membership ranged from 3074 to more than 300 000 patients; 3 sites had more than 150 000 members, 8 had more than 10 000 members, while 2 were confidential and 1 was unavailable (**Table**). Eighty percent of the sites linked directly to Facebook and 67% linked to Twitter. All but 2 of the sites had an explicit membership process, a requirement to post a comment. Yet the information required for membership was minimal and ranged from simply providing a user name and e-mail address to offering limited information about the presence and type of diabetes or relationship to a patient with diabetes. Only 1 site (<http://www.tudidiabetes.org>) required an extensive profile to be sent to the site administrator for approval.

The level and type of health professional participation varied substantially across the sites. Site administrators reviewed the content of posts in 67% of sites we evaluated, and in 47%, administrators responded directly to questions from the members. Physicians were available to answer questions in 33% of the sites but systematically scanned postings and offered feedback in only 7% of postings. More than half of the sites used diabetes educators to answer member questions, and in 13% they scanned member discussions. Oversight practices also varied across the sites. In some (13%), there was no apparent policing of the sites. In others (67%), site administrators regulated postings to assure the validity of information purveyed, while others (7%) deleted any postings that appeared to be promoting any particular product. In 33% of sites, participants self-policed discussions and reported any activity thought to represent misconduct.

All the sites featured a discussion or question forum to facilitate communication. In some (67%), the topics were entirely member driven. In others, a moderator or site employee posted topics that any member could respond to. Staff members helped to categorize conversations in most (53%) sites, either by requiring members to post their discussions into prespecified categories or by categorizing posts once they were placed on the sites. One site required initial posts in each discussion thread to be phrased as a question. Forty percent of sites featured online "chatting"—opportunities that permit smaller groups to communicate directly. In addition, 93% of the sites featured blogging (online journals from individuals).

Industry advertising was permitted on all but 3 of the sites (**Table**). Half of the sites featured advertising from pharmaceutical manufacturers, 67% from diabetes device manufacturers, 13% from insurers, 67% featured products related to diet and exercise for diabetics, and 13% included advertising for not-for-profit services or foundations. Overall, 13% of the sites we evaluated either included no advertising or only not-for-profit advertising. Sources of funding for the sites varied dramatically, ranging from foundation sponsorship, industry sponsorship, advertisements, Web host sponsors, and voluntary donations. Three sites had no industry sponsorship.

Table. Characteristics of Online Social Networking Sites

Networking Site	No. of Members	Health Professional Oversight		Funding Sources	Advertising
		Responds to Questions	Reviews All Content		
http://www.tudiabetes.org	18 864	None	Administrator	Volunteer donations, foundation	Not-for-profit/no advertising
http://www.diabetesmine.com	Confidential	Administrator, diabetes educator	Administrator	Pharmaceutical manufacturer, device manufacturer, exercise/diet	Pharmaceutical manufacturer, device manufacturer, exercise/diet
http://www.diabeticrockstar.com	4334	Administrator	Members	Volunteer donations	Not-for-profit/no advertising
http://www.juvenation.org	11 785	None	None	Volunteer donations, foundation, pharmaceutical manufacturer, device manufacturer	Pharmaceutical manufacturer, device manufacturer
http://www.diabetescommunity.dlife.com	159 156	Administrator, diabetes educator	Members	Pharmaceutical manufacturer, device manufacturer, exercise/diet	Pharmaceutical manufacturer, device manufacturer, exercise/diet
http://www.presentdiabetes.com	Confidential	Administrator, diabetes educator, physician	Administrator	Pharmaceutical manufacturer, device manufacturer, insurer	Pharmaceutical manufacturer, device manufacturer, insurer
http://www.diabetes.org	18 451	Diabetes educator	None	Volunteer donations, foundation	Exercise/diet
http://www.diabetesdaily.com	48 227	Administrator	Administrator, members	Pharmaceutical manufacturer, device manufacturer, not-for-profit, exercise/diet	pharmaceutical manufacturer, device manufacturer, exercise/diet
http://www.thediabetesoc.com	30 930 ^a	None	Administrator, members	Web host	Not-for-profit/no advertising
http://www.childrenwithdiabetes.com	8939	Administrator, diabetes educator, physician	Administrator	Foundation, device manufacturer, not-for-profit, exercise/diet	Device manufacturer, exercise/diet
http://www.exchanges.webmd.com/diabetes-exchange	3074	Administrator, diabetes educator, physician	Administrator	Web host, pharmaceutical manufacturer, exercise/diet	Pharmaceutical manufacturer, exercise/diet
http://asweetlife.org/	Confidential	Physician	Administrator	Pharmaceutical manufacturer, device manufacturer, exercise/diet	Pharmaceutical manufacturer, device manufacturer, exercise/diet
http://www.healthcentral.com/diabetes	>160 000	Diabetes educator, physician	Administrator, diabetes educator, physician	Device manufacturer, not-for-profit, insurer, exercise/diet	Device manufacturer, insurer, exercise/diet
http://www.diabeticconnect.com	>300 000	None	Members	Pharmaceutical manufacturer	Pharmaceutical manufacturer, device manufacturer, exercise/diet
http://www.diabetessisters.org	5000	Diabetes educator	Administrator, diabetes educator	Device manufacturer, not-for-profit, insurer, exercise/diet	Device manufacturer, exercise/diet

^aNumber of visitors per month were reported when membership numbers were not available.

Comment. Online social networks may play an increasing role in health promotion, as primary care physicians are asked to see increasing numbers of patients, limiting time for telephone consultations to answer questions related to chronic disease management, and as a Web-savvy population ages and develops more chronic diseases. Our evaluation of the commonly used online social networks focused on diabetes highlights their popularity and wide variability. Existing sites differ in

their approach toward communication structure, authenticity and quality oversight, expert participation, and advertising or sources of funding. These metrics may be important to patients when selecting a community and may be of interest to health care providers who ultimately may advise patients about their particular needs. We hope additional research will further explore patient and health care provider perceptions about these metrics to build an evidence base to encourage so-

cial network development that will best promote patient health.

William H. Shrank, MD, MSHS
Niteesh K. Choudhry, MD, PhD
Kellie Swanton, BA
Sachin Jain, MD, MBA
Jeremy A. Greene, MD, PhD
Bari Harlam, PhD
Kavita P. Patel, MD, MPH

Author Affiliations: Division of Pharmacoepidemiology and Pharmacoconomics, Department of Medicine, Brigham and Women's Hospital and Harvard Medical School, Boston, Massachusetts (Drs Shrank, Choudhry, and Greene); Center for American Political Studies (Dr Shrank and Ms Swanton) and Department of the History of Science (Dr Greene), Harvard University, Cambridge, Massachusetts; Center for Medicare and Medicaid Innovation, Center for Medicare and Medicaid Services, Department of Health and Human Services, Baltimore, Maryland (Dr Jain); CVS Caremark Corporation, Woonsocket, Rhode Island (Dr Harlam); and Engelberg Center for Improving Value in Health Care, The Brookings Institute, Washington, DC (Dr Patel).

Correspondence: Dr Shrank, Brigham and Women's Hospital, 1620 Tremont St, Ste 3030, Boston, MA 02120 (wshrank@partners.org).

Author Contributions: *Study concept and design:* Shrank, Choudhry, Swanton, Jain, Harlam, and Patel. *Acquisition of data:* Shrank, Swanton, and Patel. *Analysis and interpretation of data:* Shrank, Choudhry, Swanton, Greene, Harlam, and Patel. *Drafting of the manuscript:* Shrank, Swanton, and Patel. *Critical revision of the manuscript for important intellectual content:* Choudhry, Jain, Greene, Harlam, and Patel. *Statistical analysis:* Shrank, Choudhry, Harlam, and Patel. *Obtained funding:* Shrank and Harlam. *Administrative, technical, and material support:* Shrank, Swanton, and Jain. *Study supervision:* Shrank and Harlam.

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HEALTH CARE REFORM

Black/White Racial Disparities in Health: A Cross-Country Comparison of Canada and the United States

Research on health disparities in the United States has consistently reported poorer health outcomes among racial/ethnic minorities relative to whites, particularly among African Americans.^{1,2} In Canada, there are limited studies on racial/ethnic groups, presumably because of concerns about small samples, confidentiality, and an emphasis on socioeconomic inequalities.³ The body of literature regarding black Canadians, which compose 2.5% of the nation, is beginning to emerge.

The existing literature indicates that the burden of disease may be greater for black Canadians compared with their white counterparts, and that black Canadians face a number of barriers to achieving good health, including poverty, difficulty accessing health care, discrimination, and poor health behaviors.⁴⁻⁸

We obtained nationally representative estimates of health indicators among native-born black Canadians, and compared these estimates with those of native-born white Canadians. We replicated the analyses using a US sample of African Americans and white Americans to compare racial disparities in health in Canada vs the United States.

Methods. Individual-level data came from the Canadian Community Health Survey (CCHS) and the National Health Interview Survey (NHIS). For both data sets, we pooled data from 4 survey cycles (2003-2008) into a single sample to increase sample size. Analyses in both countries were limited to native-born adults to isolate the effect of race from that of nativity. Final sample sizes were 729 blacks and 280 672 whites (CCHS) and 14 211 blacks and 64 625 whites (NHIS).

Outcomes included smoking status, body mass index (BMI), general health status, and various chronic conditions (ie, asthma, hypertension, diabetes, heart disease, cancer). Self-reported race was categorized as black vs white (respondents reporting multiple races were excluded). Sociodemographic characteristics were considered as covariates, including age, sex, marital status, education, annual household income, employment status, and health insurance coverage status (in the United States).

We compared health outcomes across black and white respondents in each country. Logistic regressions assessed associations between race and health outcomes. Estimates were adjusted for various sociodemographic factors. Sampling weights were incorporated to account for complex sampling. Adjustments were made for multiple comparisons, with $P < .01$ considered statistically significant.

Results. In Canada, native-born whites had higher rates of current (25%) or former smoking (45%), while native-born blacks had higher rates of smoking abstinence (52%; $P < .001$). Whites had higher rates of hypertension (21% vs 9%), dia-