Information quality, privacy policies, and data safety practices in online social networks for health: A longitudinal analysis

Kaitlin L. Costello
School of Communication and Information
Rutgers University
k.costello@rutgers.edu

ABSTRACT

This paper describes a longitudinal analysis of online social networks designed for patients diagnosed with chronic kidney disease. Observational analysis of 20 indicators in three domains – practices for auditing and moderating the quality of content provided by users, accessibility of privacy policies, and data sharing policies and member control over data sharing – was conducted on 10 sites in 2013 and again on 12 sites in 2015, with 7 of the same sites included in both samples. The sites were identified using Google. Indicators for each domain were scored dichotomously. These scores were compared among sites in order to analyze their general practices and policies. Total composite scores were also analyzed to determine whether individual sites had significantly different practices and policies in comparison with the group. Finally, scores for each domain were compared across years in order to assess whether practices and policies had changed over time.

Differences in site practices and policies between 2013 and 2015 were not significant, although there is much room for improvement in all domains. Quality was variable across all sites, with gaps in medical disclaimers, a lack of external review of privacy policies and data safety audits, and missing information about internal quality control in the form of moderators. Although most sites employ moderators, their credentials are not often reported. Privacy policies are inaccessible across the board, with none readable at below a twelfth-grade level. Data safety practices are also problematic, with most sites sharing user data with third parties.

The quality and safety of social networks for CKD is variable, and improvement is feasible. Suggested improvements include auditing privacy policies and data safety practices, making information about moderators easily available, and third-party audits of information posted by users to ensure the removal of misinformation.

Keywords
Data safety practices, health information, online social networks, privacy policies

INTRODUCTION

Patients are increasingly turning to the Internet to search for and share health information with one another, particularly in online social networks for health (Fox & Duggan, 2013). However, a recent meta-analysis indicates that there are many concerns about information quality, reliability, advertisements, and privacy on health-related social networks (Moorhead et al., 2013). Users with chronic health conditions are often willing to compromise their personal privacy when they use these sites, as disclosure of personal information is often intrinsically linked with information seeking activities in online support groups (Costello, 2015). Furthermore, users may not understand what risks are involved in using social networks for health: they frequently misjudge the accessibility of the information they've posted online, have a limited sense of how the information they post might be used by others, and are often unaware of what data might be shared with third parties (Williams, 2010). In fact, many of these sites use a business model that relies on sharing patient-provided data with third parties as a main source of revenue (Li, 2013). In order to address these concerns, more analysis into the practices and policies of online social networks for health is necessary.

This article examines three domains related to information quality, privacy, and data security on fifteen online social networks designed for patients diagnosed with chronic kidney disease (CKD). CKD was chosen as the illness of interest as it is a lifelong, chronic condition that affects over 636,000 people in the United States, with annual Medicare expenditures at $28.6 billion and rising (US Renal Data System, 2014). Many individuals with CKD turn to the Internet to search for health information (Seto et al., 2007), and this number will likely increase as the incidence of CKD continues to rise.

In this study, two research questions are addressed:

> RQ1. How are information quality, privacy, and data security addressed in the policies of social

networking sites designed for patients with chronic kidney disease?

RQ2. Have these policies changed over time?

This article uses a protocol for evaluating online social networks for health developed by Weitzman et al. (2011) for diabetes social networking sites. This protocol has four domains: safety practices for auditing content, supporting transparency, and moderation; the accessibility of privacy policies and the communication of risks to privacy; centralized sharing of member data and the control members have over that sharing; and alignment of editorial content with science and clinical practice recommendations. The methods used in the present study follow Weitzman et al.'s (2010) protocol; only minor changes were needed in order to adapt it for CKD social networks. Using a systematic search strategy, ten online social networks for CKD were found and examined in 2013. This search and analysis was repeated in 2015. Finally, the analysis from 2013 was compared with the analysis from 2015, demonstrating that the protocol is applicable for longitudinal analysis.

METHODS
This observational, longitudinal analysis of online social networks for CKD used a strategic approach for identifying, reviewing, and categorizing content using only publicly available information. No additional information or clarification was requested from site administrators. Therefore, reviews are based on information that any user could glean from information made publicly available by the sites.

Site identification and evaluation was carried out twice during two separate review periods. The first review period began February 24, 2013 and concluded on March 22, 2013. The second review period began March 26, 2015 and concluded on April 20, 2015. Search strategies were identical during both periods. In addition, all of the links gathered during the first period were re-checked at the start of the second review period. Sites that still fit the inclusion criteria were automatically included in the second review. Ten sites were selected for review during the first period, and twelve sites were selected during the second period. Three of the sites from 2013 were no longer active in 2015. Seven of the sites were analyzed both in 2013 and in 2015.

Site selection
Sites were identified through Google searches conducted at a public computer at a public library. The searcher did not log in to her Google account when these searches were conducted, as Google tracks searches and may determine relevance based on prior search activity (Google, 2015). Given that the researcher has conducted multiple studies focused on online information behavior in people diagnosed with chronic kidney disease, her search results would likely differ from the results of typical searchers. Public computers were therefore used in order to better simulate

the results that most users would see if they conducted a similar search.

To select sites, the disease term "kidney disease" was coupled with five network terms: "social network," "community," "virtual community," "forum," and "online support group" for a total of five search terms (e.g. "kidney disease social network"). All of the links that were returned on the first search engine results page for each search string were evaluated for inclusion. Results on subsequent pages were not examined, as users tend to only view results on the first results page (Huang, White, & Dumais, 2011).

To be included in this evaluation, sites had to be in the English language and be publicly viewable. They also had to contain at least one comment posted within 30 days in order to be considered active. Sites had to require membership in order to allow users to post content, and had to allow users to create a member profile on the site. In order to keep audience scope homogeneous, only patient-oriented sites were included; practitioner-based online networks were considered out-of-scope. Sites had to be publically available to view; social networks that require a password to view content were excluded from this review. Both pan-health sites, which contain multiple forums for a variety of health conditions, and sites specific just to CKD were included in this analysis; this differs from Weitzmen et al.'s study, which excluded pan-health sites. In the present study, the largest discussion group for CKD was analyzed from the pan-health sites included in the review. All sites were masked for the purposes of this report, as the aim of this analysis is to make general claims about social networks for CKD, not to identify or recommend specific sites to healthcare providers or patients.

Site review
To review the sites, an evaluation protocol developed by Weitzman, et al. (2011) was adapted for use with CKD. For all sites, three domains were evaluated: information quality monitoring and auditing practices, privacy policies, and sharing of member data. For sites that offered additional static web resources about CKD, the alignment of this information with clinical practice guidelines was also analyzed. A total of 20 indicators within each domain were chosen for review: nine quality indicators, eight privacy indicators, and three in the data security domain. Eight additional indicators of alignment with CKD science and clinical practice were chosen for review of static resources provided by sites.

Information quality monitoring
Information quality was assessed by reviewing internal information auditing and monitoring practices along nine dimensions. The presence of moderators, number of moderators, and their credentials were all characterized. Moderator effectiveness was assessed by searching for user-generated content about a "cure" for CKD by using the terms "cure," "herb," and "sauna." These terms were

selected based on prior research on CKD patients and misinformation posted on the health-related social networks they frequent online (Costello, 2015). Once a week for three consecutive weeks, the researcher searched for these terms in the discussion forums on each site and looked for the presence of and persistence of content that promoted a cure for CKD. Sites that did not have such content posted by users were deemed "free" of cure misinformation. Sites where such information was removed or directly refuted were also deemed free of cure misinformation.

Advertisements were also assessed on each site. Pharmaceutical ads influence patient decision-making and treatment choices (Donohue, Cevasco, & Rosenthal, 2007), and deceptive health advertisements in particular can cause great harm to vulnerable patient populations (Pirsch, Grau, & Polonsky, 2013). Therefore, indicators in this domain assessed the presence of pharmaceutical advertisements, deceptive advertisements, and whether advertisements were labeled clearly. As with misinformation posted by users about false cures, the presence of deceptive advertisements was assessed each week for three weeks. The final indicator in this domain determined whether the front page included a clear reminder to discuss information found on the site with a healthcare provider.

Privacy policies
This domain was included in order to determine whether sites effectively communicate privacy risks to users. The presence of an easily accessible privacy policy, defined as being available within two clicks of the homepage of the site, was the first indicator in this domain. For sites that had privacy policies, several aspects of those policies were addressed. Their readability was estimated using two quantitative estimates: the Gunning Fog readability index and the Flesch reading ease score. The Gunning Fog readability index determines how many years of education are needed to understand a text (Gunning, 1968), while the Flesch reading ease score uses a scale from 0 to 100 to determine the difficulty of text, with higher scores indicating easier-to-read material (Flesch, 1948). Policies that scored at or below an 8th grade level on the Gunning Fog index or with a Flesch reading score above 90 were deemed readable for the purposes of this assessment.

Privacy policies often contain technical terms that may not be familiar to users. To address this issue, the presence of the definition of the term "cookies," which are commonly used to track user activity, was checked in each policy. Three controls for user privacy were also evaluated: whether sites used encrypted media for data storage, whether data was transmitted using either secure sockets layer or transport layer security, and whether the site employed external audits of their security practices.

Data sharing
Three indicators for measuring data sharing practices were assessed. Two indicators focused on data sharing with third parties, including whether personally identifiable data was shared with third parties, and whether aggregated data was shared. The final indicator in this domain addressed whether users are given the option to restrict the information they have shared on their profiles to private or to friends-only.

Sites were also reviewed to determine whether demographic and/or geographic information was required to open a user account. Demographic information included birthdate, age, gender, and/or occupation; and geographic information included country, state, and/or zipcode. This was done in order to determine what additional information sites may keep about users that is not publically available on the site. This demographic information is of particular note as it greatly increases the risk of deductive disclosure for users, particularly if the site shares this data with third parties.

Alignment with clinical practice guidelines
For sites that also provided static web resources about CKD, the alignment of those resources with CKD science and clinical practice guidelines was also evaluated. The National Kidney Foundation's guide, *About Chronic Kidney Disease: A Guide for Patients and their Families* (2010), was selected as it provides a succinct overview of the clinical practice guidelines offered to practitioners. Alignment was assessed using eight indices: clear definitions of central terms related to CKD: the stages of the illness, and the meaning of the most common diagnostic test, the estimated glomerular filtration rate (eGFR). Six additional indices were used to measure whether sites offered information about CKD that was in alignment with recommendations made by the National Kidney Foundation:

- The importance of early treatment before dialysis.

- The importance of controlling diabetes and/or hypertension.

- A discussion of at least four of the nine most common symptoms of CKD: low energy/fatigue, trouble concentrating, poor appetite, trouble sleeping, muscle cramps, fluid retention/puffy eyes, dry or itchy skin, and changes in urination.

- At least one of the common tests for diagnosis described: blood tests, ultrasounds, and/or kidney biopsies.

- Three common treatment options explained: hemodialysis, peritoneal dialysis, and kidney transplants.

- Discussion of the emotional and/or social aspects of CKD: depression, isolation, and quality of life.

Analysis
Sites were masked and assigned letters (A – O) for ease in reporting. All of the indicators were scored dichotomously,

allowing for comparison among and across sites across time. Higher scores denote better practice. For example, the absence of false advertising or pharmaceutical ads was coded positively as '1'. The presence of false advertising or pharmaceutical ads was coded negatively as '0'.

Sites were collected and scores for each indicator were determined in 2013 and again in 2015. Findings for each domain and its corresponding indicators are reported in separate tables for each domain, with results from sites only present in the 2013 sample separated from results from sites present in both samples and sites only from the 2015 sample. Paired Student's t-tests were also performed between the 2013 and 2015 samples for each domain in order to determine if any differences over time were statistically significant.

RESULTS
Ten sites met the study criteria in 2013 and were analyzed (sites A – J). Of these twelve sites, five of them were pan-health sites (D, E, F, I, and J) and four of them offered static web resources about CKD (A, B, D, E, and G). In 2015, twelve sites met the study criteria and were analyzed (D – O). Seven of these sites overlapped with the sample from 2013 (D – J). Three sites from 2013 (A – C) were no longer active, and five new sites were added to the sample (K – O). Of the new sites added to the sample, two were pan-health sites (M and N) and two offered static resources (L and O).

Information quality monitoring
Table 1 presents information about information quality monitoring on all sites. In 2013, five of the ten sites

included a medical disclaimer for readers, reminding them to discuss medical information found online with healthcare providers. In 2015, eight of the 12 sites included medical disclaimers; one site (F) added this disclaimer sometime after the data were analyzed in 2013.

In 2013, six of the ten sites had moderators, including all of the sites with medical disclaimers as described above. Of these sites, two of them marked the number of moderators present, and one site (E) offered additional information about moderators. This site clearly stated the credentials of its moderators, all of whom were professionally accredited healthcare professionals. In 2015, ten sites employed moderators, although again most sites did not offer information about the moderators beyond their existence. Again, site E was the only site with professionally accredited moderators; it was also the only site that clearly stated background information about their moderators in an easily accessible location. On some sites, such as site I, moderators discussed their experiences with CKD or with moderating other online communities in their profiles or in comments on the discussion forums. However, this information was not accessible in a central location on these sites. Nothing about moderation on the sites in both samples changed between 2013 and 2015. However, it is notable that all of the sites added in 2015 had moderators, and that their presence was made clear to users.

In 2013, five of the ten sites were free of misinformation about cures posted on the discussion forums by users. In 2015, nine of the twelve sites were free of misinformation about cures. One site (D) changed practices and is now free of misinformation. In 2013, only one site did not allow advertisements; of the nine sites that allowed

	2013			2013 and 2015							2015				
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**	**M**	**N**	**O**
HCP disclaimer	1	0	0	1	1	0 1	1	0	0	1	0	0	1	1	1
Internal content checks															
Forum moderation present	1	0	0	1	1	0	1	0	1	1	1	1	1	1	1
Number moderators marked	0	0	0	0	1	0	0	0	1	0	0	0	0	1	0
Moderator credentials stated	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0
Professionally accredited moderators	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0
Free of cure misinformation	0	0	1	0 1	1	1	0	1	0	1	0	1	1	1	1
Advertising content															
No pharmaceutical ads	1	1	1	1	1	1	0 1	0	1	0	1	1	1	1	1
Advertisements clearly labeled	1	0	1	1	1	1	1	0	1	1	1	0	1	1	1
Free of deceptive cure advertising	1	0	1	1	1	1	0 1	0	1	1	1	1	1	1	1
Quality index (Sum of above)	**5**	**1**	**4**	**5 6**	**9**	**4 5**	**3 5**	**1**	**5**	**5**	**4**	**4**	**6**	**7**	**6**

Table 1. Information quality monitoring scores. Split cells indicate differing scores between 2013 and 2015.

advertisements, seven did not have pharmaceutical ads, and on all of the sites but two advertisements were clearly labeled. Finally, in 2013 seven of the sites were free of deceptive advertising about false cures for CKD. This changed slightly in 2015, when all of the sites but one were free of deceptive advertisements, including one site that no longer hosted advertisements for false cures (G). This site also no longer hosted pharmaceutical advertisements in 2015; in fact, ten of the twelve sites reviewed in 2015 did not have pharmaceutical ads.

Only one site received the highest total possible quality index score (E). The mean quality index in 2013 was 4.3 (with a 9 being the highest score on the scale), and the mean quality index in 2015 was 5.4. However, this difference is not statistically significant (p = .289).

Privacy policies
Privacy policy scores are listed in Table 2, and readability scores for privacy policies are listed in Table 3. Most sites have privacy policies that are accessible to users: in 2013, eight of the ten sites had policies, and in 2015, 11 of the 12 sites offered one. Additionally, privacy policies are largely accessible: in 2013, all sites with privacy policies had them available within two clicks of the homepage; in 2015, ten of the 11 sites with privacy policies were accessible. Technical term definitions are a bit more variable: in 2013, all but one site defined the term "cookies" in the privacy policy, whereas in 2015 only nine of the twelve sites provided a definition for the term.

For all sites with a privacy policy, readability is an issue. As seen in Table 3, no sites offer a privacy policy that is readable at or below an 8th grade level, according to the

Gunning Fog index. Currently, only one site is readable at a 12th grade level. On average, privacy policies on these sites require 15 years of education to read and understand. This has not changed much since 2013, when the lowest grade level was 13 (e.g. one year of college) and the average readability was 14.7 years of education according to the Gunning Fog index. Flesch reading ease scores are similarly problematic, with the highest score for 2013 at 48.9 ($\mu = 39.1$) and the highest score in 2015 at a 50.7 ($\mu = 38.8$), indicating that some college education is needed to read and understand these policies.

Controls for individual privacy are similarly problematic. No sites in 2013 performed external audits of their privacy policies, and only one site in 2015 did. The use of encrypted media for data storage is also not common: two sites did so in 2013, and five of twelve sites do so in 2015. The use of SSL or TLS technology for data transmission is also not common, with five of the ten sites in 2013 employing such technology and four of the twelve sites in 2015 doing so. Although some minor changes in practice are observed, privacy policies on these sites have not changed significantly between 2013 and 2015 (p = .356).

Data sharing
As indicated in Table 4, most sites do not require additional information beyond an email address in order for users to register and post comments. In 2013, two of the ten sites required additional demographic information and two required geographic information. In 2015, three of the twelve sites required users to enter demographic information and only one required users to submit geographic information.

Although user-submitted demographic information is

	2013			2013 and 2015							2015				
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**	**M**	**N**	**O**
Privacy policy available	0	1	1	1	1	1	1	1	0	1	1	1	1	1	1
Privacy policy accessibility															
Within two clicks of homepage	NA	1	1	1	1	1	1	1	NA	1	1	0	0	1	1
Technical terms defined	NA	1	1	0	1	1	1	1	NA	1	0	1	0	1	1
Readability at or below 8th grade level	NA	0	0	0	0	0	0	0	NA	0	0	0	0	0	0
Any of 3 security measures used	NA	1	0	1	0	1	1	0	NA	0	1	1	1	0	0
Controls for individual privacy															
Encrypted media for data storage	0	0	0	0	0	1	1	0	0	0	1	1	1	0	0
SSL or TLS for data transmission	1	1	0	1	0	1	1	0	0	0	0	0	1	0	0
External audits of privacy policy	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
Privacy index (Sum of above)	**1**	**5**	**3**	**4**	**3**	**6**	**7**	**3**	**0**	**3**	**4**	**4**	**4**	**3**	**3**

Table 2. Privacy policy scores

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
2013 scores															
Flesch reading ease	NA	27.8	42.4	37.9	48.9	36.8	40.5	42.1	NA	36.6					
Gunning Fog index	NA	15.3	12.9	14.4	13.9	14.9	15.5	13	NA	17.7					
2015 scores															
Flesch reading ease				36.9	50.2	36.8	40	42.2	NA	36.6	26	40.3	30.7	36.4	50.7
Gunning Fog index				15.9	14.2	14.9	16.3	13.7	NA	17.7	17.4	12.1	17.5	13.2	12.7

Table 3. Readability scores

typically not required, most sites do engage in data sharing practices. In 2013, eight of the ten sites shared aggregated or de-identified data with third parties; eight sites also did so in 2015. Practices for sharing personally identifiable data were a bit better, with four sites doing so in both 2013 and 2015. It is also notable that two sites changed their policies between 2013 and 2015, deciding to share either aggregate or personally identifiable data with third parties and changing their policies to reflect this decision. Finally, half of the sites in 2013 allowed members to restrict their profile information so that it was only available to other members or to people they listed as friends. In 2015, this number rose to seven of twelve sites allowing members to restrict access to their profiles. In 2013, no sites scored a three (the highest possible data sharing index total), but in 2015 three of the twelve sites did so. Despite this, changes in data sharing practices were not statistically significant (p = .781). For the majority of sites, information about data security and the protection of member data was available in the privacy policies – which, as noted above, were often available but unreadable by anyone without some college education. Furthermore, as explained in the section on privacy policies, there was not much evidence of technical strategies used to carry out the data security practices described in those policies.

Alignment with clinical practice guidelines

Finally, Table 5 includes scores for sites that offered static resources about CKD. These resources contain information about the illness, its progression, and various treatments; a review of static web resources specific to CKD is available in Lutz et al. (2014).

In 2013, five of the ten sites offered additional static resources about CKD (A, B, D, E, and G). In 2015, two of these sites were no longer active, but two new sites were identified that offered static resources (L and O) for a total of five sites with static resources in 2015. Overall, scores in this category were fairly high (2013 μ = 5.6; 2015 μ = 5.8)

	2013			2013 and 2015							2015				
	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
Information required for registration															
Demographic information	N	N	N	Y	N	N	Y	N	N	N	Y	N	N	N	N
Geographic information	N	Y	N	Y	N	N	N	N	N	N	N	N	N	N	N
Data shared by sites															
Does not share aggregate/personally de-identified data	0	0	0	0	1	1	1	0	0	0	0	0	1	0	1
Does not share personally identifiable data	0	1	1	1	0	0	1	1	0	1	0	1	1	1	1
User control over data															
Members can restrict profile to private	1	1	0	1	0	0	1	1	0	0	0	0	1	1	1
Data sharing index (Sum of above)	**1**	**2**	**1**	**2**	**1**	**1**	**3**	**2**	**0**	**1**	**0**	**1**	**3**	**2**	**3**

Table 4. Data sharing scores. Registration information not included in data sharing index.

	2013		2013 and 2015					2015	
	A	B	D	E		G		L	O
Definitions of central terms in line with care standards									
Stages of CKD	1	0	1	1		0		1	0
GFR or eGFR	1	0	1	0	1	1		1	0
Central information aligned with National Kidney Foundation recommendations									
Importance of early treatment	1	0	1	1		0		1	0
Common symptoms (4 of 9)	1	1	1	1		1		1	1
Common tests for diagnosis (1 of 3)	1	0	1	1		1		1	0
Treatment options explained (3 of 3)	1	1	1	0		1		0	1
Importance of controlling diabetes/hypertension	0	0	1	0		1		1	1
Emotional/social aspects of CKD	1	0	1	1		1	0	0	1
Alignment index (Sum of above)	**7**	**2**	**8**	**5**	**6**	**6**	**5**	**6**	**4**

**Table 5. Alignment with clinical practice guidelines.**

with only one site scoring below a 4 for both 2013 and 2014. All sites described at least four of the nine the common symptoms of CKD, although none of the sites mentioned muscle cramps as a symptom. All sites discussed low energy, poor appetite, fluid retention, and changes in urination as common symptoms of CKD; most mentioned at least one additional symptom as well. Most sites discussed the common tests for diagnosis, although most only covered blood tests and did not mention ultrasounds or kidney biopsies as diagnostic tests that may be performed. However, detailed information about the importance of the estimated glomerular filtration rate (eGFR), a common blood test that estimates the filtration rate of the kidneys and the test that is used to determine CKD stage, was not available on most of the sites. Moreover, most sites did not discuss the stages of CKD.

Only two of the sites in 2013 and three in 2015 stressed the importance of controlling diabetes and/or hypertension, which is surprising given that these two conditions are the most common causes of kidney disease in the United States (US Renal Data System, 2014). It is also surprising that the importance of early treatment for CKD was not more prominent in the static resources offered by these sites; only three sites mentioned this fact in both 2013 and 2015.

DISCUSSION

As seen in Figure 1, the composite scores for information
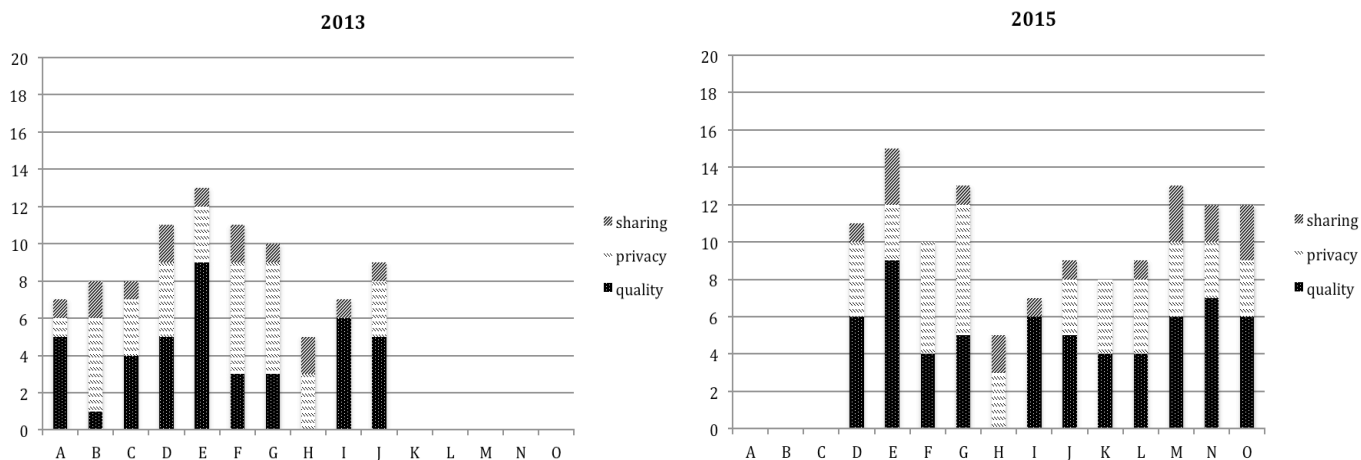
Figure 1: Composite indices for 2013 and 2015.

quality monitoring, privacy policies, and data sharing are varied, answering RQ1. No site scored more than a 13 out of a possible total of 20 in 2013, and none scored higher than a 14 in 2015. The mean of composite scores in 2013 was 8.9 and 10.3 in 2015; this is not a statistically significant difference (p = .321). This finding shows that there is much room for improvement.

In 2015, there are a cluster of sites that have better practices along all domains, scoring above a 12 on the composite score (E, G, and M) while in 2013 there was only one site that scored above a 12 (site E). Site E is moderated by credentialed health professionals; it is therefore unsurprising that this site also scores highly in all of the other domains as a result. This site also employed more stringent data sharing policies in 2015 than it did in 2013.

The score improvement for site G can be attributed to better policies surrounding advertisements – in 2015, there were no advertisements on the site – and to the employment of a third-party auditor that periodically reviews their privacy policies, a practice instituted after analysis was conducted in 2013. In fact, site G is the only site that undergoes an outside audit of their policies and procedures for privacy or data security. Such audits are one method by which health-related social networks can guard against threats to privacy (Li, 2015), so it is disappointing that more sites do not employ this safeguard.

Few sites in this sample use standard tools, such as SSL technology, to protect personal information, and the communication of privacy risks to users is weak across the board. Moreover, although users are not required to submit demographic information, some of this information is still collected passively by sites; e.g., IP addresses and cookies are used to track user activity. This data may be shared with third parties, although users may not be aware that this data is even collected (Li, 2013).

Finally, information about moderators is limited at best on nearly all of the sites. Nearly all of the sites provide at least some control over the quality of information posted by users because they employ moderators, although information about the number of moderators working on each site and their respective credentials is extremely limited. In fact, m sites are free of deceptive information about false cures. Given that healthcare providers often cite this as a concern when they discuss patients using online social networks for health (e.g. Pant et al., 2012), this finding illustrates that moderators and other users of social networking sites designed for patients with CKD are able to successfully correct misinformation if and when it is presented by other users. However, more research is necessary in this area, particularly among social networks for other illness populations.

Although nearly all of the sites in this assessment offer published privacy policies that are easy to find, their readability is limited. None of the sites assessed in this study were readable at below a 12th grade level. Given that

cognitive impairment (Murray et al., 2014) and health literacy (Devraj et al., 2015) are both issues for patients diagnosed with CKD, this must be addressed. Sites should strive to provide privacy policies that are more universally readable. Offering two versions of a privacy policy – one that is clear and readable at an eighth-grade level, and another that is more detailed and readable at a higher grade level (e.g. grade 12) – may be a workable compromise for sites that cannot sufficiently communicate privacy risks in straightforward, simple language.

Finally, this study shows that there are no significant differences over time in any of the domains analyzed, addressing RQ2. There is much room for improvement in the privacy policies, data security practices, and information quality monitoring in social networking sites for CKD.

CONCLUSION

There are several recommendations for better practice that arise from this analysis. This is a list of guidelines and actionable steps that can be taken by administrators and designers of online social networks in order to ensure that the information provided on these sites is useful, of high quality, and does not mislead or take advantage of individuals in difficult health situations like CKD.

- Allow for members to control the use of the data they provide to the site.

- Conduct periodic external reviews of content and of privacy policies.

- Conduct periodic reviews of content offered on the social networks to ensure that members or moderators refute or remove misinformation.

- Ensure that privacy policies are findable and readable by a majority of individuals.

- Publish information about moderators, including how many moderators are available, their credentials, and what hours they are online.

- Set defaults to protect members and their information (e.g. all profiles are automatically set to "Private" and not "Public").

- Stress the importance of treating diabetes and hypertension, as well as the importance of early treatment in general, in any static health resources offered.

This study also illustrates that the protocol developed by Weitzmen et al. (2011) is extensible and adaptable for use in other types of health-related social networks beyond diabetes, its original application. It is also possible to employ this protocol longitudinally, illustrating changes in practices and policies over time.

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