

INLS 490-202
Health Information Sharing in Social Media
Tuesdays 2-4:45pm, Manning 304

Instructor:

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SILS Library

Office hours Tu1-2pm or by appointment

Course Description:

This course is intended to provide an overview of health information sharing using social media. It will cover a variety of types of social media, including social networking sites, blogs, online support groups, YouTube and Twitter. Students will be asked to consider the perspectives of various stakeholders in health-related social media exchanges, such as health information consumers (i.e. patients, caregivers, family and friends), health care providers, health information services, insurance companies, pharmaceutical companies and others. Lastly, the course will discuss benefits/drawbacks of health information exchange over social media and examine how application design can affect user experience of health information exchange.

Learning Objectives:

Upon completion of the course, students should be able to do the following:

- Describe different ways in which health information is shared across social media platforms.
- Explain how different persons, organizations or groups may have a stake in health information sharing and discuss how their respective actions/positions may influence others.
- Discuss critical issues involving health information sharing using social media and explain possible benefits and/or drawbacks to health information sharing.
- Be able to apply what you've learned to the design of social media applications that may be used to support health information exchange.

Course Expectations:

Students are expected to come to class and arrive on time. Please let me know if you are not going to be in class. Repeated absences or tardiness will affect your participation grade. In addition, students should read the assigned readings before the class session, think critically, and come ready to participate in discussion. You are welcome to use laptops for class-related activities. Students are expected to abide by the Honor Code. For more information about the Honor Code, please visit <http://honor.unc.edu>.

Assessment:

Your final grade will be based of the following:

Attendance and participation	15%
Health-related online community presentation	10%
Social media collection and analysis	30%
Health context analysis	25%
Term project	20%

Late assignments will be penalized by 5% for each day they are late. Please discuss with me in advance if you will have a problem submitting an assignment on the day it is due.

Attendance and participation (15%)

Students are expected to read the assigned readings for each class session prior to coming to class and be prepared to discuss them. In the context of this class, participation includes both contributions to in-class discussions as well as online participation. As students naturally have different communication styles, an individual's contribution will not be based solely on the number of times an individual participates, but also on the thoughtfulness of their comments.

During the course of this class, we will keep a discussion forum in which we discuss the week's readings. Students are expected to make at least one post per week in which they share their responses to the week's readings. On days where there is a social media collection assignment due (see assignment for details), students should post a brief summary of that assignment instead of commentary on the reading.

Comments should be posted by midnight the day before, to give students the opportunity to read and comment if they choose as well as to prepare to discuss in class.

Health related online community/social medium presentation (10%)

Each student is asked to introduce a health-related online community or social medium during the course of the semester. Examples of communities that you might choose include: dLife, Stupid Cancer (a.k.a. I'm Too Young For This! Foundation, i[2]y) and TakeThisLife.com. If you choose a large social networking site/platform like Facebook, MedHelp, or DailyStrength, please also select a specific group to focus on. For example, you might discuss the National Fibromyalgia Association's Facebook page, or the Type 2 Diabetes group on DailyStrength. You are encouraged to be creative in your choice of community.

Your presentation should include the following:

- Target population/users
- Reason/motivation for establishment of the community

- Basic features
- Strengths/weaknesses
- Suggestions for improvement

There will be 1-2 presentations per week, and each presentation should take approximately 10 minutes. Grades will be based on the extent to which the presentation addresses each of the points above.

Social media collection and analysis (30%)

During the term, we will collect tweets, forum posts and blogs by various stakeholders in a health information ecosystem, e.g. the patient, family, friends, caregivers, health care practitioners, hospitals, insurance companies, pharmaceutical companies, government agencies, etc. The purpose will be to explore the material collected and answer the following questions:

- Describe the authors of the content.
- What do they care about?
- What is the content about?
- How does the content reflect their views?
- Who is their intended target audience?
- Does the content achieve its purpose? If so, in what ways? If not, how might it have done a better job?
- What characteristics of the platform design or medium affected the affordances available for sharing health information?

You will work in pairs, and each pair will be assigned to one of the stakeholders identified above. For whichever stakeholder you are assigned, you will collect forum posts one week (1/22), tweets another (1/29), and blogs the third (2/5). You and your partner should collect one set of content each week, answer these questions on your own, and then meet to discuss your answers. Following discussion with your partner, write a 3-4 page analysis paper answering the questions enumerated above. Please also discuss the extent to which you two agreed.

For the second week of this exercise, include the tweets that you collect. Please submit the tweets as a comma-separated file; you can do this using Tweetseeker or some other method if you prefer. For the first and third week, including the URLs of the forum posts and blogs you examine will be sufficient. Submit both the analysis paper and your tweet/URL file via the Dropbox in Sakai. Please also post a brief description of your main thoughts to the forum for that week for all to discuss.

How much content should you collect? The exact number does not matter, but you want to collect enough so that you are able to write an insightful analysis. If you are collecting tweets, you would most likely want to collect 40-200; forum threads, 5-10; and blogs, 3-6.

Grades will be based on the extent to which the questions above have been addressed, not on the number of tweets or posts collected. Each paper is worth 10%. Each member of a pair will receive the same grade.

Health context analysis (25%)

Each of you will select a health management context to analyze. This “context” will focus on the health situation of a single individual that you know who interacts with social media in some way in the context of his/her health management and analyze different levels of this context using the Social Ecological Framework. During the course of the project, you will produce the following:

- Report of an interview of the focal individual and two others that affect the focal individual, due 2/26 (10%)
- Research on an organization/entity that affects this individual’s health, due 3/19 (5%)
- Context “map” and write-up, due 4/2 (10%)

These assignments will be evaluated based on completeness, clarity of the writing, and the extent to which the student has illustrated the context and interactions among the different entities in the context.

Design project (20%)

Students are expected to complete a design project that will enable them to delve more deeply into a specific aspect of health information sharing using social media. Students are encouraged to develop a project that will help them to accomplish their objectives in taking this course, or to explore topics of interest. Possible projects include a prototype for a social site that supports health communication and a preliminary design of an intervention or health communications campaign using social media. The deliverables for the term project follow:

- Project proposal (2-3 pages), due 3/5
- Presentation (12 min.), 4/23
- Final deliverable, due 5/7

The final deliverable should be a paper of 10-12 pages in length, double-spaced, in a standard 12-point font, not including diagrams, tables and references. The presentation will count for 5%, and final deliverable will count for 15%.

Grading Scale:

Graduate		Undergraduate	
95-100	H	95-100	A
90-94	P+	90-94	A-
85-89	P	87-89	B+
80-84	P-	84-86	B
70-79	L	80-83	B-
		77-79	C+

		74-76	C
		70-73	C-
69 and below	F	67-69	D+
		64-66	D
		60-63	D-
		59 and below	F

Syllabus Changes

This syllabus may be revised during the course of the semester. The current version of the syllabus will be available online in Sakai.

Course Schedule

With the exception of the Social Media Collection assignments, all assignments in the Due column are due at the start of class on the date specified.

Date	Topic	Due
1/15	Course introduction and overview	
1/22	Health information ecosystem: health care organizations, insurance and pharmaceutical companies	Social media collection I
1/29	Health information ecosystem: practitioners	Social media collection II
2/5	Health information ecosystem: family, friends and caregivers	Social media collection III
2/12	The patient, online communities and research ethics	
2/19	The nature of user-generated content	
2/26	Online social support	Health context interviews
3/5	Privacy and disclosure	Project proposal
3/12	Spring break (no class)	
3/19	Patient empowerment and impact on health decisions	
3/26	mHealth	Health organization analysis
4/2	Designing to support health information exchange	
4/9	Health promotion among youth and diverse communities	Health context map
4/16	Social media monitoring	
4/23	Final presentations	
5/7		Project paper

Readings and Additional Scheduling Notes

1. Course introduction and overview: definition of social media and types; brainstorm examples. (1/15)

Lewis, D. (2011). The multidimensional role of social media in healthcare. *Interactions*, 18(4), 17-21.

PricewaterhouseCoopers LLC (2012). Social media “likes” healthcare: From marketing to social business.

Introduce social media collection assignment.

2. Health information ecosystem: organizations and entities (1/22)

Sallis, J. F., Owen, N., & Fisher, E. B. (2008). Chapter 20: Ecological Models of Health Behavior. In K. Glanz, B. K. Rimer, & K. Viswanath. *Health Behavior and Health Education*. San Francisco, CA: John Wiley & Sons, Inc.

Angelle, D., & Rose, C. L. (2011). Conversations with the community: The Methodist Hospital System’s experience with social media. *Frontiers of Health Services Management*. 28(2), 15-21.

Silverman, L. (2012). Social media helps diabetes patients (and drugmakers) connect. *Shots: Health News from NPR*. Retrieved from:

<http://www.npr.org/blogs/health/2012/12/03/166241115/social-media-helps-diabetes-patients-and-drugmakers-connect>

Pogorelc, D. (2012). 4 innovative campaigns that have pushed pharma social media forward. *MedCity News*. Retrieved from <http://medcitynews.com/2012/06/4-innovative-campaigns-pushing-pharma-social-media-forward/>

{ social media collection discussion }

3. Health management ecosystem: health care professionals (1/29)

Modahl, M., Tompsett, L., & Moorhead, T. (2011). *Doctors, Patients & Social Media*. QuantiaMD.

Ryan, M. (2012). Guiding principles for physician use of social media. *Mayo Clinic Center for Social Media*. Retrieved from

<http://socialmedia.mayoclinic.org/2012/03/13/guiding-principles-for-physician-use-of-social-media/>

Federation of State Medical Boards (2012). Model Policy Guidelines for the Appropriate Use of Social Media and Social Networking in Medical Practice.

Retrieved from <http://www.fsmb.org/pdf/pub-social-media-guidelines.pdf>.

Optional:

Nelson, R., Joos, I., & Wolf, D. (2013). *Social Media for Nurses: Educating Practitioners and Patients in a Networked World*. Springer.

{ social media collection discussion }

4. Health management ecosystem: families, friends and caregivers (2/5)

Ginossar, T. (2008). Online participation: A content analysis of differences in utilization of two online cancer communities by men and women, patients and family members. *Health Communication*, 23(1), 1-12.

Grimes, A., Tan, D., & Morris, D. (2009). Toward technologies that support family reflections on health. *GROUP '09*.

Veinot, T. C. E., Kim, Y.-M., & Meadowbrooke, C. C. (2011). Health information behavior in families: supportive or irritating? *ASIST 2011*.

{ social media collection discussion }

Introduce online community presentation.

5. The patient, online communities and research ethics. (2/12)

Preece, J., Nonnecke, B., & Andrews, D. (2004). The top five reasons for lurking: improving community experiences for everyone. *Computers in Human Behavior, 20*, 201-223.

Wen, K.-Y., McTavish, F., Kreps, G., Wise, M., & Gustafson, D. (2011). From diagnosis to death: A case study of coping with breast cancer as seen through online discussion group messages. *Journal of Computer-Mediated Communication, 16*, 331-361.

Zimmer, M. (2010). "But the data is already public": on the ethics of research in Facebook. *Ethics Inf Technol, 12*, 313-325.

Introduce health context analysis.

6. The nature of user-generated content. Examining the types of content that are shared online and differences among different types of social media. Impact on chronic illness management. (2/19)

Adams, S. A. (2010). Revisiting the online health information reliability debate in the wake of "web 2.0": An inter-disciplinary literature and website review. *International Journal of Medical Informatics, 79*, 391-400.

Denecke, K., & Nejdil, W. (2009). How valuable is medical social media data? Content analysis of the medical web. *Information Sciences, 179*(12), 1870-1880.

Hartzler, A., & Pratt, W. (2011). Managing the personal side of health: how personal expertise differs from the expertise of clinicians. *J Med Internet Res. 13*(3): e62.

7. Online social support (2/26)

Malik, S., & Coulson, N. S. (2010). 'They all supported me but I felt like I suddenly didn't belong anymore': an exploration of perceived disadvantages to online support seeking. *J.Psychosom.Obstet.Gynaecol., 31*(3), 140-149.

Rier, D. A. (2007). Internet social support groups as moral agents: the ethical dynamics of HIV+ status disclosure. *Sociology of Health & Illness, 29*(7), 1043-1058.

Skim one and read the other:

Pfeil, U., & Zaphiris, P. (2009). Investigating social network patterns within an empathic online community for older people. *Computers in Human Behavior, 25*(5), 1139-1155.

Siriaraya, P., Tang, C., Ang, C. S., Pfeil, U., & Zaphiris, P. (2011). A comparison of empathic communication pattern for teenagers and older people in online support communities. *Behaviour & Information Technology, 30*(5), 617-628.

{ discuss health context interviews }

8. Privacy and disclosure (3/5)

Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2010). Online Social Networking by Patients with Diabetes: A Qualitative Evaluation of Communication with Facebook. *Journal of General Internal Medicine*, 26(3), 287–292.

Newman, M. W., Lauterbach, D., Munson, S. A., Resnick, P., & Morris, M. E. (2011). It's not that I don't have problems, I'm just not putting them on Facebook: Challenges and Opportunities in Using Online Social Networks for Health. In *Proceedings of the ACM 2011 Conference on Computer Supported Cooperative Work* (pp. 341–350).

Barak, A., & Gluck-Ofri, O. (2007). Degree and reciprocity of self-disclosure in online forums. *Cyberpsychology & Behavior: The Impact of the Internet, Multimedia and Virtual Reality on Behavior and Society*, 10(3), 407–417.

Hartzler, A., Skeels, M. M., Mukai, M., Powell, C., Klasnja, P., & Pratt, W. (2011). Sharing is caring, but not error free: Transparency of granular controls for sharing personal health information in social networks. *AMIA Annual Symposium Proceedings, 2011*, 559–568.

Guest lecture: Kaitlin Costello

Term project proposal due.

9. Spring break (no class)

10. Patient empowerment and impact on health decisions (3/19)

Fox, N. J., Ward, K. J., & O'Rourke, A. J. (2005). The 'expert patient': empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet. *Social Science & Medicine*, 60(6), 1299-1309.

Radin, P. (2006). 'To me, it's my life': medical communication, trust, and activism in cyberspace. *Social Science & Medicine*, 62, 591-601.

Swan, M. (2012). Crowdsourced health research studies: an important emerging complement to clinical trials in the public health research ecosystem. *JMIR*, 14(2):e46. Available at: <http://www.jmir.org/2012/2/e46/>

Frost, J.H., Massagli, M.P., Wicks, P., & Heywood, J. (2008). How the Social Web Supports patient experimentation with a new therapy: The demand for patient-controlled and patient-centered informatics. *AMIA Annu Symp Proc.*, 217-21.

Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2656086/>
{ discuss health context organization analysis }

11. mHealth (3/26)

Prasad, A., Sorber, J., Stablein, T., Anthony, D., & Kotz, D. (2012). Understanding sharing preferences and behavior for mHealth devices. *WPES '12*.

Shilton, Katie, Burke, J., Estrin, D., Govindan, R., & Kang, J. (2009). Designing the Personal Data Stream: Enabling Participatory Privacy in Mobile Personal Sensing. *Proceedings of the 37th Research Conference on Communication, Information and Internet Policy (TPRC)*. (Arlington, VA, 25-27 September 2009).

Guest speaker: Dr. Robert Furberg, RTI International

12. Designing to support health information exchange (4/2)

Alpay, L., Verhoef, J., Xie, B., Te'eni, D., & Zwetsloot-Schonk, J. H. M. (2009). Current challenge in consumer health informatics: bridging the gap between access to information and information understanding. *Biomed Inform Insights*, 2(1), 1-10.

Huh, J., Patel, R., & Pratt, W. (2012). Tackling dilemmas in supporting 'the whole person' in online patient communities. Paper presented at the *Proceedings of the 2012 ACM Annual Conference on Human Factors in Computing Systems*, Austin, Texas, USA.

Fernandez-Luque, L., Karlsen, R., & Bonander, J. (2011). Review of extracting information from the social web for health personalization. *JMIR*, 13(1), e15.

{ discuss health context maps }

13. Using social media to effect behavioral change to improve health outcomes: health promotion among youth and diverse communities. (4/9)

Gibbons, M. C., Fleisher, L., Slamon, R. E., Bass, S., Kandadai, V., & Beck, J. R. (2011). Exploring the potential of Web 2.0 to address health disparities. *Journal of Health Communication: International Perspectives*, 16(S1), 77-89.

Rice, E., Tulbert, E., Cederbaum, J., Adhikari, A. B., & Milburn, N. G. (2012). Mobilizing homeless youth for HIV prevention: a social network analysis of the acceptability of a face-to-face and online social networking intervention. *Health Education Research*, 27(2), 226-336.

Guest speaker: Kim Ashley, Manager, New Media Entertainment, BCBSNC

14. Social media monitoring, crowdsourced health research and participatory epidemiology. (4/16)

Neuman, Y., Cohen, Y., Assaf, D., & Kedma, G. (2012). Proactive screening for depression through metaphorical and automatic text analysis. *Artif Intell Med*. 56(1), 19-25.

Freifeld, C. C., Chunara, R., Mekar, S. R., Chan, E. H., Kass-Hout, T., Iacucci, A. A., & Brownstein, J. S. (2010) Participatory epidemiology: Use of mobile phones for community-based health reporting. *PLoS Med*, 7(12): e1000376.

Guest speaker: Dr. Stephanie Zerwas, Associate Research Director, UNC Center of Excellence for Eating Disorders

15. Final presentations (4/23)