

CAROLYN PETERSEN

PRESENT POSITIONS

Senior Editor, Mayo Clinic Global Business Solutions. Rochester, MN. June 2014 to the present

Patient Advocate, 2002 to the present

EDUCATION

Master of Biomedical Informatics, Oregon Health & Science University

Master of Science, Exercise and Movement Science (emphasis in Sports Medicine and Exercise Physiology), University of Oregon

Bachelor of Science, Animal Science, with minor in Technical Journalism, Oregon State University

CERTIFICATIONS

American Medical Writers Association Core Curriculum and Advanced Curriculum Certificates

American College of Sports Medicine Exercise Physiologist with Certificates of Enhanced Qualification for Exercise and the Older Adult, Nutrition and Performance, and Advanced Personal Training

YMCA of the USA certifications in Exercise Leadership, Strength Training, Flexibility Training, Walk Reebok Fitness Walking, and Walk Reebok Distance/Interval Walking

PREVIOUS PROFESSIONAL EXPERIENCE

Freelance Journalist/Editor, January 1982 to December 2010

News writer, United Press International, Portland, OR. June to September, 1987

Sports Editor, *Wallowa County Chieftain*, Enterprise, OR. October 1987 to April 1988

Agriculture Editor, *Ontario Argus-Observer*, Ontario, OR. April 1988 to June 1989

Associate Editor, *GPS World*, Advanstar Communications, Eugene, OR. June 1990 to July 1992

Staff Writer, *Managed Healthcare*, Advanstar Communications, Eugene, OR. July 1992 to August 1995

Contributing Editor, <http://www.sportsci.org/>. February 1997 to June 1999

Graduate Assistant for Publications, International Institute for Sport & Human Performance, University of Oregon, Eugene, OR. September 1995 to June 1998

Instructor, University of Oregon, Oregon State University, Portland Community College, and Linn-Benton Community College. Part-time, January 1990 through January 1999

Senior Editor, *Pharmaceutical Executive*, Advanstar Communications, Eugene, OR. June 2000 to July 2000 (previously Senior Associate Editor, February 1999 to June 2000)

Managing Editor, Special Projects, *MayoClinic.com*, Rochester, MN. August 2000 to March 2002

Web Communications Consultant, Mayo Clinic, Rochester, MN. April 2002 to December 2007

Teaching Assistant, Department of Medical Informatics and Clinical Epidemiology, Oregon Health & Science University, June 2007 to December 2015.

Managing Editor, Mayo Clinic, Rochester, MN, January 2008 to June 2014

PROFESSIONAL & COMMUNITY MEMBERSHIPS, SOCIETIES, AND SERVICE

Professional Memberships & Services

American College of Sports Medicine, Member, 1998 to the present

American Health Lawyers Association, Member, 2011 to the present

American Medical Informatics Association, member, 2003 to the present

Ethics Committee member, Fall 2004 to the present

Consumer and Pervasive Health Informatics Working Group Public Policy Liaison, Fall 2010 to through 2012

Public Policy Committee member, January 2012 to the present

Ethical, Legal, and Social Issues Working Group Chair, 2013-2014

Food and Drug Administration Anesthesiology and Respiratory Therapy Devices Panel, Consumer Representative, August 2002 through November 2005; September 2007 through November 2010; September 2017 through November 2020

Internet Healthcare Coalition, Board of Directors, June 2002 to November 2003

Mayo Clinic in Minnesota, Ethics Subcommittee of the Clinical Practice Committee, January 2007 through December 2008

National Cancer Informatics Program (formerly National Cancer Institute Cancer Bioinformatics Grid) Patient Advocate, August 2009 through Fall 2012

North Central Cancer Treatment Group, Patient Advocate, October 2002 to July 2003

Patient Centered Outcomes Research Institute Patient Stakeholder Reviewer, August 2012 to the present

Patient Centered Outcomes Research Institute Stakeholder Mentor, September 2014 to the present

Scientific Program Committee member, American Medical Informatics Association 2015 Annual Symposium, November 2014 to November 2015

Program Committee member, TILTING Perspectives 2015, Tilburg Institute for Law, Technology, and Society, Tilburg University, The Netherlands, January 2015 to April 2015

Advisory Committee member, Concordium 2015: Data and Knowledge Transforming Health, January 2015 to September 2015

Patient-Centered Outcomes Research Institute Improving Healthcare Systems advisory panel member, May 2015 to May 2018

Advisory Committee member, Concordium 2016: Data and Knowledge Transforming Health, January 2016 to September 2016

Office of the National Coordinator Health Information Technology Policy Committee member, May 2016 to April 2017

Office of the National Coordinator Health Information Technology Advisory Committee co-chair, August 2017 to December 2018

Associate Editor, *Applied Clinical Informatics* editorial board, August 2017 to the present

Community Memberships & Services

Center Against Rape and Domestic Violence (Corvallis OR), Board of Directors, 1985 to 1986

Committed Partners for Youth (Eugene OR), Board of Directors, June 1996 to March 2000

Mid-Valley Rotary Club (Eugene OR), Webmaster, January to June 2000

Rochester (MN) Area Disabled Athletics and Recreation, Board of Directors, September 2001 to November 2003

United Way of Olmsted County Community Basics Solutions Team, Co-Chair, August 2004 to December 2010

United Way of Olmsted County Vision Council, Co-Chair, February 2005 to August 2010

Parkway Neighborhood Association (Rochester MN), Vice President, March 2009 to October 2011

United Way of Olmsted County Board of Directors, October 2009 to August 2010

Legal Assistance of Olmsted County (Rochester, MN), Board of Directors, February 2014 to October 2016

PRESENTATIONS AND PUBLICATIONS

Petersen C, Berner ES, Embi PJ, Hollis KF, Goodman KW, Koppel R, Lehmann CU, Lehmann H, Maulden SA, McGregor KA, Solomonides A, Subbian V, Terrazas E, Winkelstein P. AMIA's code of professional and ethical conduct. *J Am Med Inform Assoc* 2018 (in press).

Lehmann CU, Petersen C, Bhatia H, Berner ES, Goodman KG. Advance directives and code status information exchange: a consensus proposal for a minimum set of attributes. *Camb Q Healthc Ethics* (in press).

DeMuro PR, Novak LL, Petersen C. Festschrift for Dr. Samantha Adams: Adamsian discourse: the patient, and everything else. *Appl Clin Inform* 2018;9(3):500-2.

“Embracing interdisciplinarity: a commemoration of the work of Dr. Samantha Adams,” member of panel at the American Medical Informatics Association Annual Symposium, San Francisco, CA, November 2018 (accepted).

“Citizen science & patient voice in research: an informatics perspective,” member of workshop presented at the American Medical Informatics Association Annual Symposium, San Francisco, California, USA (accepted).

“Participatory health and the future of co-created eHealth,” member of panel at Medical Informatics Europe, Gothenburg, Sweden, April 25, 2018.

“Advancing personalized medicine through patient engagement, telemedicine, data analytics, and payer modeling,” member of panel at Medical Informatics Europe, Gothenburg, Sweden, April 24, 2018.

Petersen C. Patient informaticians: turning patient voice into patient action. *J Am Med Inform Assoc Open* May 23. doi: 10.1093/jamiaopen/ooy014.

Petersen C. Keynote address: Through patients' eyes: regulation, technology, privacy, and the future. *Yearb Med Inform* Apr 22. doi: 10.1055/s-0038-1641193. [Epub ahead of print].

Kuziemyk C, Gogia SB, Househ M, Petersen C, Basu A. Balancing data access and privacy concerns from a telehealth and patient-centred connected health perspective. *Yearb Med Inform* Apr 22. doi: 10.1055/s-0038-1641195. [Epub ahead of print].

Househ M, Grainger R, Petersen C, Bamidis P, Merolli M. Balancing between privacy and patient needs for health information in the age of participatory health and social media. *Yearb Med Inform* Apr 22. doi: 10.1055/s-0038-1641197. [Epub ahead of print].

Petersen C. Content strategy: writing for health consumers on the Web. In *Consumer Informatics and Mobile Health: Solutions for Health and Health Care*. New York, NY: Springer Publishing Company. 2018 (in press).

Siegel SH, DeMuro PR, Petersen C, Norwood H. Health information technology. In *E-Health, Privacy, and Security Law*, 4th ed. Arlington, VA: BNA Books. August 2017.

“Social media for participatory biomedical knowledge management,” member of panel at MedInfo 2017, Hangzhou, China, August 23, 2017.

Petersen C. Visualization for all: the importance of creating data representations patients can use. Workshop on Visual Analytics in Healthcare, Chicago, IL, November 2016. Accessed April 16, 2018 at http://www.visualanalyticshealthcare.org/VAHC2016/docs/VAHC2016_Proceedings.pdf.

“Social media research in the health domain,” co-instructor of tutorial at the American Medical Informatics Association Annual Symposium, Chicago, IL, November 2016.

Siegel SH, DeMuro PR, Petersen C. Health information technology. In E-Health, Privacy, and Security Law, 3rd ed. Arlington, VA: BNA Books. August 2016.

Adams SA, Petersen C. Precision medicine: opportunities, possibilities, and challenges for patients and providers. *J Am Med Inform Assoc* 2016 Jul;23(4):787-90.

Petersen C. Patient-generated health data: a pathway to enhanced long-term cancer survivorship. *J Am Med Inform Assoc* 2016 May;23(3):456-61.

Lavallee DC, Chenok KE, Love RM, Petersen C, Holve E, Segal CD, Franklin PD. Incorporating patient-reported outcomes into health care to engage patients and enhance care. *Health Aff (Milwood)* 2016 Apr;35(4):575-82.

Petersen C. The future of patient engagement in the governance of shared data. *eGEMs (Wash DC)* 2016 Mar 30;4(2):1214. doi: 10.13063/2327-9214.1214.eCollection 2016.

Petersen C, Adams SA, DeMuro PR. mHealth: don't forget all the stakeholders in the business case. *Med 2.0* 2015;4(2):e4 doi: 10.2196/med20.4349.

“Precision medicine and the PMI Cohort Program: a new paradigm for engaging patients in research,” member of panel at the American Medical Informatics Association Annual Symposium, San Francisco, CA, November 2015.

“E-health's global reach in the quest for increased quality of care: new developments, key considerations, and consumer health informatics,” member of panel at MedInfo 2015, Sao Paulo, Brazil, August 2015.

Petersen C, DeMuro PR. Legal and regulatory considerations associated with use of patient-generated health data from social media and mobile health (mHealth) devices. *Appl Clin Inform* 2015;6:16-26.

“Patient health records (PHRs), patient access to their records/medical information: issues and challenges,” member of panel at the American Medical Informatics Association Annual Meeting, Washington, DC, November 2014.

“mHealth: don't forget all the stakeholders in the business case,” member of panel at Med 2.0, Malaga, Spain, October 2014.

Kuziemyky CE, Monkman H, Petersen C, Weber J, Borycki EM, Adams S, Collins S. Big data in healthcare – defining the digital persona through user contexts from the micro to the macro. *Yearb Med Inform* 2014:82-9.

“The current state of mHealth (mobile health): legal and regulatory issues,” panelist of Webinar presented by the American Bar Association Health Law Section Distance Learning Committee and eHealth, Privacy & Security Interest Group, May 15, 2014.

“Issues relevant to and regulation affecting social media use in healthcare, including privacy and security,” panelist of Webinar presented by the eHealth, Privacy & Security Interest Group of the American Bar Association Health Law Section, January 31, 2014.

“Genomic sequencing and genetic testing: current technological, regulatory, clinical, and social issues and future directions,” member of panel at the American Medical Informatics Association Annual Meeting, Washington DC, November 2013.

“Social media for more patient-centered, cost-effective healthcare delivery,” member of panel at MedInfo 2013, Copenhagen, Denmark, August 2013.

Petersen C, DeMuro P, Goodman KG, Kaplan B. Sorrell v. IMS Health: issues and opportunities for informaticians. *J Am Med Inform Assoc* 2013(1);20:35-37.

“Privacy, mHealth and social media: consumer data smackdown, patient empowerment opportunities,” member of panel at the American Medical Informatics Association Annual Meeting, Chicago IL, November 2012.

Goodman KG, Adams S, Berner ES, et al. AMIA’s code of professional and ethical conduct. *J Am Med Inform Assoc* 2013(1);20:144-151.

“AMIA’s code of ethics: professionalism, patient-centeredness, and best practices,” member of panel at the American Medical Informatics Association Annual Meeting, Washington DC, October 2011.

“Sorrell Vs. IMS Health,” member of panel at the American Medical Informatics Association Annual Meeting, Washington DC, October 2011.

Eills AB, Harlow DC, Petersen C, Schwartz RH, Trostorff D (DeMuro P, Trostorff D eds.). (2011) Quality and other reporting requirements. Member Briefing, American Health Lawyers Association Accountable Care Organization Task Force, Washington DC.

“Will the National Health Information Network impact the security and privacy of health data in Minnesota?” member of panel at the 2010 Minnesota Government IT Symposium, St. Paul MN, December 2010.

“Data security in the wired world: risks, strategies, and opportunities,” workshop at the American Medical Informatics Association Annual Meeting, Washington DC, November 2010.

“Content for the Web,” presented at the annual meeting of the Public Affairs Network of the National Cancer Institute, Tampa FL, May 2010.

“Research implications of the Genetic Information Nondiscrimination Act (GINA) on secondary data research uses,” presented at the 137th American Public Health Association Annual Meeting, Philadelphia PA, November 2009.

“Secondary uses of data: ethical and social considerations in data sharing, quality improvement, and patient internet interaction,” member of panel presented at the American Medical Informatics Association Annual Meeting, Washington DC, November 2008.

Hurdle JF, Adams S, Brokel J, Chang B, Embi PJ, Petersen C, Tarrazas E, Winkelstein P. (2007) A code of professional ethical conduct for the American Medical Informatics Association: an AMIA board of directors approved white paper. *J Am Med Inform Assoc* 14, 391-3.

“Information on the Internet: what users expect, what they find, and how they feel about it,” member of panel presented at the American Medical Informatics Association Annual Meeting, Washington DC, October 2005.

Kaihoi B, Petersen C, Bolander M. “Providing 'just-in-time' medical genomics information for patient care,” poster presented at the American Medical Informatics Association Annual Meeting, Washington DC, October 2005.

Petersen C. “Development of an internal Web-based genomics education program for a clinical practice,” poster presented at the American Medical Writers Association Annual Meeting, St. Louis, MO, October 2004.

Petersen, C. (2003) How to trust information on the Internet. *Gynaecology Forum*, 8(4), 25-7.

“Online informed consent: not just a check box,” member of workshop presented at the American Medical Informatics Association Annual Meeting, Washington DC, November 2003.

“Basic Web design for editors,” a workshop presented at the American Medical Writers Association Annual Conference, September 2003, Miami, FL.

“The basics of exercise physiology,” a workshop presented at the American Medical Writers Association (AMWA) Annual Conference, October 2004 (St. Louis, MO), September 2003 (Miami, FL), and October 2002 (San Diego, CA).

Petersen C. “Representation of exercise guidelines on direct-to-consumer promotional Web sites for cardiovascular medications,” poster presented at the American College of Sports Medicine 50th Annual Meeting, San Francisco, May 2003.

“Do industry-sponsored web sites adhere to health information standards for the internet? An analysis of 7 web sites marketing prescription medications for osteoporosis.” Presented at Qualit-e-Health: Mednet 2002 7th World Conference on the Internet in Medicine, Amsterdam, The Netherlands, December 2002.

“International perspectives on patient empowerment through the internet,” member of panel presented at Qualit-e-Health: Mednet 2002 7th World Conference on the Internet in Medicine, Amsterdam, The Netherlands, December 2002.

Risk A, Petersen C. (2002) Health information on the internet: quality issues and international initiatives. *JAMA*. 287(20), 2713-15.

“Making the transition from traditional publishing to the Internet,” workshop presented at the American Medical Writers Association (AMWA) 2002 Annual Conference, October 2002, San Diego, CA, and at the AMWA 2001 Annual Conference, October 2001, Norfolk, VA.

Petersen C. “From clinic to practice: Bringing cutting edge health care expertise to cyberspace,” poster presented at the American College of Sports Medicine 48th Annual Meeting, Baltimore, June 2001.

“Helping clients take the fast lane on the information superhighway.” Presented at the American College of Sports Medicine Northwest Chapter Annual Meeting, Salem OR, March 2001.

“The practice of physical activity among persons infected with the Human Immunodeficiency Virus.” Presented at the American College of Sports Medicine 46th Annual Meeting, Seattle, June 1999.

“Prevalence and characteristics of exercise programs of exercise programs for HIV+ persons in North America.” Presented at the American College of Sports Medicine Northwest Chapter Annual Meeting, Seattle, February 1999.

“A descriptive study of North American exercise programs for persons infected with the Human Immunodeficiency Virus.” Presented to the Department of Exercise & Movement Science in partial fulfillment of the degree of Master of Science, University of Oregon, May 1998.

“Breaking tradition: How the Human Immunodeficiency Virus is changing research design.” Presented at Interface '97, the 22nd Annual Humanities and Technology Conference, Southern Polytechnic State University, October 1997.

Petersen, C. (1996). Managed care and clinical trials, part 1: reimbursement for patient costs. *Applied Clinical Trials*, 5(6), 72-76.

Petersen, C. (1996). Managed care and clinical trials, part 2: a new paradigm in health care. *Applied Clinical Trials*, 5(7), 42-45.

Petersen, C. (1996). Managed care and clinical trials, part 3: new strategies for academic medical centers. *Applied Clinical Trials*, 5(8), 32-34, 40.