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I am a sociologist whose career, both inside and outside academia, has been devoted to investigating patients' experiences with health and health care, and to involving them in the discourse, policy processes, and institutional arrangements, which impact that care. During the first 15 years of my career, I focused on applied strategies for impact in those domains by working in public health, community development, and patient/health advocacy while at the same time completing a doctorate in sociology. Although my focus for the past decade has shifted towards academic research, I maintain a strong dual commitment to knowledge generation and to the use of that emerging knowledge to create concrete impact for consumers, families, and communities.

My current multiple positions at the University of Wisconsin-Madison (Director of National Initiatives and Clinical Professor in the University's Center for Patient Partnerships; Senior Scientist in the School of Medicine and Public Health's Department of Family Medicine and Community Health) embody a bridge-building capacity. From this platform, I have pursued a range of research opportunities, applied projects, and team-based endeavors. For example, I am currently the qualitative research lead for the award-winning, internationally-vetted Database of Individual Patient Experience (DIPEX) initiative here in the U.S. and an elected member of the DIPEX International Board of Trustees guiding patient experience work in 12 countries. I serve as PI/co-PI/co-investigator developing some of the USA's first web-based patient experience modules -- on depression in young adults, cancer and precision medicine, and breast cancer -- using these methods. I am also the qualitative research lead on federal grants aimed at pioneering methods to reliably elicit patient narratives about their health care encounters as part of large-scale patient experience surveys, and to use these data to inform quality improvement and consumer choice. Past work has focused on patients' experiences with newborn screening, advocacy, low-value care, prenatal care, and other services, and on methods for using patient voices to enhance the performance of the health care system and inform the development of more effective health policy.

EXPERIENCE

Senior Scientist	2014 -- Present
Director of National Initiatives	2014 -- Present
Clinical Professor	2018 -- Present
Clinical Associate Professor	2014 -- 2018
Visiting Clinical Associate Professor	2011 -- 2014
Scholar in Residence	2011 -- 2014
Center for Patient Partnerships and Department of Family Medicine University of Wisconsin -- Madison	
Health Innovations Program Investigator	2018 -- Present
University of Wisconsin -- Madison Department of Family Medicine and Community Health	
Visiting Scholar	2016 -- 2017
Hastings Center for Bioethics	
Faculty, Health Advocacy Program	1998 - 2011
Sarah Lawrence College	

- Graduate-level courses including health advocacy transdisciplinary core courses; public health genetics/genomics; program on facilitating children's play.

Associate Dean of Graduate Studies **2003 – 2011**
Director, Child Development Institute **2007 – 2010**

Sarah Lawrence College

- Conducted research at intersection of health, science and society: newborn genetic screening (parent experience and policy-making); narratives of heritability (social construction of genetic meaning); changing nature of childhood (role of risk, play and nature in shaping children's lives); dynamics of advocacy (role of patient/parent voice in health care and health policy); assessment of community initiatives (community needs assessment and program evaluation)
- Secured funding, through grants and from donors, for research; academic program development (for both matriculated students and working professionals); public awareness and outreach initiatives (speakers bureau; documentary for public television; adventure playground pilot); capacity-building (faculty development; campus/community partnerships)
- Led program development, program review, and assessment initiatives for graduate programs in early childhood, health, education, and the arts; responsible for strategic planning, resource development, leadership role in local, regional and national academic and community consortia

Director of Policy Analysis and Planning **1997 - 2002**
Coordinator, Yonkers Early Childhood Initiative

Julia Dyckman Andrus Memorial

- Chaired the Yonkers Early Childhood Initiative, a multi-year grant-funded community-wide public and private collaborative (Andrus was the lead agency) devoted to improving young children's health and well-being through new service development, professional training, public awareness, community building, and a range of other activities.
- Acted as lead for projects ranging from Yonkers Family Day, to publication of Yonkers' Early Childhood Data Book, to development of collaborative funding proposals
- Directed Andrus child abuse prevention and family support programs for infant/toddlers; supervised professional and paraprofessional staff (1997 – 2001).
- Oversaw growth of Community Services Division, from 4 to 32 positions, and from 2 to 10 diverse funding sources (1997-2001).
- Represented the agency and the Early Childhood Initiative on local, county, and state task forces, integrated planning committees, advocacy groups, consortia, and coalitions; presented in public forums nationally.
- Provided consultative services on place-based family strengthening and early childhood to the Annie E. Casey Foundation.

Assistant to the Deputy Commissioner **1993 - 1997**
Program Administrator

Westchester County Department of Health

Program Specialist **1992 - 1993**

Westchester County Department of Health

Case Manager (HIV) **1991 - 1992**

Westchester County Medical Center

Case Manager **1990 - 1991**

Association for Retarded Citizens

GRANTS

Ongoing Research Support

UW Institute for Clinical and Translational Research Grob/Cottrell co-PIs 11/1/20- 3/31/22
Patients' Experiences with Opioid Use Disorder

The goal of this project is to use an internationally vetted qualitative methodology (DIPEX) to conduct a systematic qualitative research study about patients' experiences with opioid use disorder, and to analyze the data to develop both peer reviewed articles for the literature and a public-facing web-based resource (or "module") which features video and audio clips from the studies. The web-based module is intended for use by multiple audiences including clinicians, patients and their families/friends, medical students, researchers, and policy-makers.

Role: Co-PI

UW Institute for Clinical and Translational Research Smith (PI) 7/1/19 – 6/30/20
Patients' Experiences with Clinical Trials

The goal of this project is to use an internationally vetted qualitative methodology (DIPEX) to conduct a systematic qualitative research study about patients' experiences with clinical trials, and to analyze the data to develop both peer reviewed articles for the literature and a public-facing web-based resource (or "module") which features video and audio clips from the studies. The web-based module is intended for use by multiple audiences including clinicians, patients and their families/friends, medical students, researchers, and policy-makers.

Role: Site PI and Co-Investigator

Mack Institute Research Fellowship 2019 recipient Nembhard (PI) 9/1/2019 – 8/31/20
An Experiment to Enhance Narrative Feedback to Improve Quality of Health Care

This project consists of a field experiment to assess a two-stage intervention intended to enrich healthcare professionals' learning from patient experiences, as recounted in patients' own words. These surveys are designed to provide a quantifiable metric of performance, not convey details about what went wrong or right in patient experience. We will test the impact of the new form of feedback (first stage of project) as well as different report formats for staff and leaders (second stage). We will also examine the properties of feedback that prompt organizational learning and improvement efforts.

Role: Co-Investigator

AHRQ – Yale University Cleary (PI) 9/30/17 – 9/29/22
R21HS021858

Continuation of Consumer Assessment of Healthcare Providers and Systems – V (CAHPS V)

The goals of this project are to: 1) develop and test ways that organizations can use CAHPS data for quality improvement purposes, with an emphasis on using data from the CAHPS clinician and group instrument, 2) to more fully develop the capacity to integrate patient narratives into CAHPS surveys and to test ways of integrating narrative feedback into quality improvement initiatives, 3) to explore the different ways in which consumers from advantaged and disadvantaged circumstances engage with patient experience data to reduce disparities in their use of this information for informed choice.

Role: Co-Investigator; Site-specific PI

AHRQ – The RAND Corporation Hays/Elliott (PI) 10/1/17 – 9/29/22
2U18HS016980

Continuation of Consumer Assessment of Healthcare Providers and Systems – V (CAHPS V)

The goals of this project are to: 1) explore the ways in which CAHPS data is being used within the health care field and how it might be deployed more effectively for future uses, 2) to develop the capacity to process large numbers of patient narratives using natural language processing, 3) to expand narrative elicitation to additional health care settings, particularly inpatient care, and 4) to extend the scope of CAHPS surveys to assess patient

experiences with end-of-life care and develop new items to assess shared decision-making, care coordination, and patient safety issues.

Role: Co-Investigator; Site-specific PI

UW Institute for Clinical and Translational Research Grob (PI) 7/1/2018 – 6/30/20
Patients' Experiences with Breast Cancer

The goal of this project is to use an internationally vetted qualitative methodology (DIPEX) to conduct a systematic qualitative research study about patients' experiences with breast cancer, and to analyze the data to develop both peer reviewed articles for the literature and a public-facing web-based resource (or "module") which features video and audio clips from the studies. The web-based module is intended for use by multiple audiences including clinicians, patients and their families/friends, medical students, researchers, and policy-makers.

Role: PI

Completed Research Support

UW-Madison Davis (PI) 11/1/18 – 6/30/20
Health Experiences Experience-Based Co-Design Catalyst Film Project

The goal of this pilot project is to lay the groundwork for using patient experience research as the basis for interventions that will improve health of individuals and communities. Funding will be used to develop capacity for Experience-Based Co-Design (EBCD) in the following four stages: 1) conduct background research, develop a team and seek stakeholder input on the concept of EBCD for quality improvement and adaptation in the US, 2) work with multi stakeholder team to select materials from the "young adults' experiences with depression" study now published on the web at www.healthexperiencesusa.org, 3) create 3-4 "catalyst films" for use in quality improvement, and 4) refine the films and develop proposals for EBCD projects.

Role: Co-PI

The Cystic Fibrosis Foundation Tluczek/Grob, co-PIs 9/1/17
– 3/31/20

Cystic Fibrosis Patient and Family Experience of Care Survey (PFEC): Qualitative Grounded Dimensional Analysis of the Open-Ended Questions

The twofold purpose of this qualitative analysis of existing quality improvement data includes: (1) review of pilot data from the Partnerships for Sustaining Daily Care initiative to derive an inductively-informed conceptual framework for how ideal state Cystic Fibrosis (CF) care partnerships look and what facilitates them, and (2) analysis of PFEC data to gain an increased understanding about the perspectives of individuals (adult version of the PFEC survey) and families (pediatric version of the PFEC survey) regarding lessons learned and challenges shared in managing CF. Findings will help to inform clinical practice, institutional policies, and future quality improvement initiatives.

Role: Co-PI

UW Institute for Clinical and Translational Research Grob (PI) 9/1/17 – 12/31/19
Patients' Experiences with Genomic Medicine

The goal of this project is to use an internationally vetted qualitative methodology (DIPEX) to conduct a systematic qualitative research study about patients' experiences with hereditary cancer and/or hereditary cancer risk, and to analyze the data to develop both peer reviewed articles for the literature and a public-facing web-based resource (or "module") which features video and audio clips from the studies. The web-based module is intended for use by multiple audiences including clinicians, patients and their families/friends, medical students, researchers, and policy-makers.

Role: PI

- Patient Centered Outcomes Research Institute** **Joffe (PI)** **9/1/16 - 8/31/19**
Governance of Learning Activities in Learning Healthcare Systems
This project's goal is to define governance structures and processes for learning activities within Learning Health Systems, emphasizing the roles that patients, families and community representatives play. Funding will support research to describe current practices and identify optimal approaches.
Role: Co-investigator; PI on University of Wisconsin subcontract.
- 2U19HS016980-06** **Hays, Elliot (Co-PIs)** **9/1/12 – 9/30/17**
Continuation of Consumer Assessment of Healthcare Providers and Systems (CAHPS IV)
The goals of this project are to enhance reporting guidelines, update existing reporting resources, and extend the science of reporting. Initiatives will include sponsor interviews to inquire about composite labeling and other reporting challenges; development of composite labels; and research to advance the science of reporting and adapt reporting products to diverse audiences including those with poor reading and cognitive skills.
Role: Co-PI; PI on University of Wisconsin subcontract
- Canadian Institutes of Health Research** **Ware (PI)** **5/1/17 – 4/30/18**
Understanding experiences of using medical cannabis in different regulatory contexts: planning an international qualitative study
Through international collaborations, the research aims to (1) summarize the existing research on personal experiences of using medical marijuana; (2) review policies and programs related to medical marijuana use in participating countries; (3) to find existing patient stories within the international collaboration on health experiences about using medical marijuana for further review; and (4) to prepare a formal proposal to collect patient experiences in participating countries to compare and contrast patient experiences across different contexts.
Role: Collaborator
- UW Institute for Clinical and Translational Research** **Grob (PI)** **2/1/17 – 6/30/17**
Patients' Experiences with Genomic Medicine: An exploratory study
The goal of this grant is to lay the groundwork for a database of patient experience (DIPEX) module on experiences with genomic medicine in the USA. Outcomes will include a literature review; recruitment of advisory board members; plans for a conceptual approach to the project; and ethics approval.
Role: PI
- UW Institute for Clinical and Translational Research** **Pandhi/Grob (co-PIs)** **12/1/16 - 6/30/17**
Footprints in the Sand
The goal of this grant is to create dissemination models for the U.S. Database of Patient Experience (DIPEX) initiative by pioneering methods to increase uptake and impact of our first module (focused on experiences with depression), using patient experience ambassadors, earned media, social media, partnerships with medical schools and collaboration with non-profits.
Role: Co-PI
- P16-11**
Macy Foundation **Grob/Pandhi (Co-PIs)** **6/1/16 – 5/31/17**
The goal of this project is to generate curriculum using the U.S.A.'s new web-based Database of Patient Experience module; to integrate this curriculum into the third year primary care clerkship rotation, and to assess the impact of this curricular innovation on medical student learning. Grant funding supports development and implementation of the curriculum as well as assessment of its impact on student learning.
Role: PI
- ACTIVATE: Advocacy for Children** **Navsaria (PI)** **6/1/14 – 12/31/16**
Wisconsin Partnership Program

The goal of this project is to expand a nascent community/academic partnership to address key health issues for Wisconsin's children using participatory research techniques. We will define and launch specific projects addressing children's access to physical activity (in the form of play), health care, and environmental stressors.

Role: Lead on community-based participatory research aspects of project

UW Institute for Clinical and Translational Research Grob/Pandhi (Co-PIs) 10/1/14 – 9/30/16

Wisconsin Partnership Program Opportunity Grant

Department of Family Medicine Small Grant Program

Building an Accessible Database of Patient Experience for the US

The goal of this project is to launch a database of patient experience that uses an internationally vetted qualitative methodology (DIPEX). The first web-based "module" is a study of the experiences of young adults with depression. Grant funding supports development of the module, and capacity-building for the DIPEX patient experience methodology in the United States.

Role: Co-PI and primary interviewer

1R21HS021858-01

Schlesinger (PI)

9/1/12 -- 8/31/16

Eliciting Patient Experiences to Augment Public Reports on Health Care Quality

The goals of this project are to develop methods of systematically eliciting patient narrative accounts of their health care experiences and efforts to rectify the problems they have faced, then develop methods of incorporating these accounts in ways that constructively augment (rather than distract consumers attention from) standardized measures of clinical performance and patient experience. Experimental methods will be deployed to test the efficacy of these new techniques.

Role: Co-Investigator; PI on University of Wisconsin subcontract

Robert Wood Johnson Foundation: 71478

Schlesinger (PI)

11/15/13-11/14/15

Pre-commitment, Patient Choice of Physician, and Reducing the Use of

Low-Value Health Care

This project is designed to illuminate how a diverse, representative group of patients think about unnecessary medical procedures, how they respond when measures of excessive testing and treatment are incorporated to public reports on clinician quality, and how much having chosen a clinician who practices with a resource-conserving practice style will subsequently alter the choices that patients make about the kind of tests and treatments they want. The research uses mixed methods: (1) focus groups and interviews to examine patients' attitudes toward and comparative measures of overuse and (2) experiments that test for the impact of measures of excessive testing/treatment on choice of clinician and subsequent choices about patients' own health care.

Role: Co-PI, PI on UW subcontract.

Robert Wood Johnson Foundation: 76484

Grob (PI)

6/1/14-1/30/15

Consumer Support at a Crossroads: A Synthesis of Insights from State Program

Leaders and Others

This grant supports the organization, facilitation, and synthesizing of findings from a national roundtable on consumer support under the Affordable Care Act, co-sponsored by the Robert Wood Johnson Foundation and the Kaiser Family Foundation. Consumer support includes a range of functions and programs aimed at helping Americans enroll in and retain private insurance and Medicaid. Funding levels, operating models, and effectiveness across those functions differ substantially from state to state. This project is designed to increase understanding about the scope of this variation in terms of its impact on the experiences of individuals, its implications for the ability of policy-makers to track the implementation of reforms and take appropriate action, and the factors relevant to these differences. The grant will also support writing of an issue brief and paper for submission to a health policy journal.

Role: PI

Experiences with Serious Illness

Grob (PI)

2011 - 2014

Funded by the Center for Patient Partnerships, University of Wisconsin-Madison

The goal of this project is to elicit patient and caregiver narratives about experiences with serious illness with a focus on sources of support that mediated or did not mediate the illness experience. As P.I., I am responsible (with co-P.I. Dr. Schlesinger) for designing and conducting this qualitative research study; for hiring, training and supervising a team of interviewers; for coding and analyzing the data; and for publishing results.

Role: PI

Morgridge Center for Public Service **O’Connell (PI)** **2012 – 2013**
Taking Service Learning Online: Building Virtual Community

The goal of this project is to develop the Center for Patient Partnerships’ “eservice learning” curriculum within its Consumer Health Advocacy Certificate program and to create new externship opportunities for both on-campus and distance learning students.

Role: Key Personnel

State Variation in Consumer Assistance Programs **Grob (PI)** **2011 – 2013**
Funded by the Center for Patient Partnerships, University of Wisconsin-Madison

The goal of this project is to investigate, through qualitative interviews with administrators in every state, the impact that Health Reform has had on states’ existing Consumer Assistance Programs (CAPs). Responsible (with co-P.I.s Davis and Schlesinger) for designing and conducting this qualitative research study; for hiring, training and supervising a team of interviewers; for coding and analyzing the data; and for publishing results.

Robert Wood Johnson Foundation **Grob, Rothman (Co-PIs)** **6/1/06 – 5/31/11**
Investigator Award in Health Policy

Heel Sticks and Amnios: Disjunctures and Discrepancies in Prenatal and Newborn Genetic Screening

The goal of this project was to examine the sociological consequences and impact on patient and parental experience of newborn genetic screening and prenatal testing.

Ford Foundation Implementation Grant **Grob (PI)** **2005 – 2007**

For curriculum development in Public Health Genetics, and Applied Research Ethics.

Jane Engelberg Memorial Fund Annual Award **Lieber (PI)** **2005 – 2007**

For research related to lay understandings of heredity and development of teaching tools for genetics professionals.

Role: co-PI (with Marsha Hurst and Linwood Lewis)

Ford Foundation Planning Grant **Grob (PI)** **2003 – 2004**

For planning curricular innovations in graduate education in health care.

Grant Recipient, for various programmatic initiatives, from diverse sources including:

- University of Wisconsin-Madison (for professional development)
- Wallace Global Fund
- Marilyn Simpson Memorial Trust
- Community Playthings
- New York State Department of Health
- Department of Housing and Urban Development
- Community Development Block Grant, Yonkers
- Surdna Foundation
- Weyerhaeuser Family Foundation
- United Way/Yonkers Elder Friendly Initiative
- Project Liberty
- Annie E. Casey Foundation
- Westchester Community Foundation
- Helen Benedict Foundation.

CONSULTATION, POLICY ADVISING, AND COMMUNITY SERVICE

Member, Advisory Committee, Community Catalyst and the Health Care Transformation Task Force, a partnership of leading health care payers, providers, purchasers and patient organizations to align private and public sector efforts to clear the way for a sweeping transformation of the U.S. health care system, 2019 –

Chair, Health Experiences Research Network, a national network seeking to describe the widest possible range of patients’ experiences using rigorous qualitative research (www.healthexperiencesusa.org), 2017 –

Member, Organizing Committee, Symposium on Critical Qualitative Research Methods, an international training for experienced qualitative researchers, 2017 –

Member, Data Resources Advisory Committee, an organization aimed at rigorous analysis of existing data collected by the Patient Advocacy Foundation, 2016 –

Member, Patient & Family Engagement Network, an organization collaborating with measure developers at the Center for Outcomes Research and Evaluation under contract to the Center for Medicare & Medicaid Services, 2016 –

Member, National Advisory Council for the Cancer Support Community’s Cancer Experience Registry (Prostate Cancer), 2015 –

Member, Board of Directors, DIPEX International, the organization promoting rigorous patient experience research and widely-accessible web sites featuring this research internationally, 2014 –

Member, Research Committee, University of Wisconsin- Madison, School of Medicine and Public Health, Department of Family Medicine and Community Health, 2014 –

Member, Global Legal Studies Committee, University of Wisconsin-Madison Law School, 2014 –

Member, Institute for Clinical and Translational Research Patient-Centered Outcomes Research Advisory Group, University of Wisconsin-Madison, 2014.

Member, Ethics and Policy Advisory Board, Whole Genome Sequencing for Newborns, University of California U-19 NHGRI Grant, 2014 –

Member, Technical Expert Panel, Hospital Quality Star Ratings on *Hospital Compare*, convened by Yale-New Haven Health Services Corporation under contract from the Centers for Medicare and Medicaid Services, 2014 –

Member, Scientific Committee, International Conference on Narratives of Health and Illness, a conference bringing together scholars from around the world to advance the practice of collecting, synthesizing, and using patients’ narratives, 2015 – 2016.

Consultant, Universal Health Care Foundation of Connecticut, for developing co-designed advocacy leadership initiative, 2014 – 2015.

Consultant, Cystic Fibrosis Specialty Center Consortium, for Cystic Fibrosis Foundation-funded patient-centered quality improvement project, 2013 – 2015.

Member, Measures Application Partnership, Congressionally mandated in connection with the Affordable Care Act, Task Force on Patient- and Family-Centered Care, 2013 – 2014.

Member, Measures Application Partnership (Congressionally mandated in connection with the Affordable Care Act), and Task Force on Quality Rating System for Qualified Health Plans in the Health Insurance Marketplaces, 2013 – 2014.

Board Member, Helen Andrus Benedict Foundation, 2012 – 2013.

Advisor to the Food and Drug Administration, under auspices of the Hastings Center for Bioethics, regarding consumer participation and representation, 2012 – 2014.

Consumer representative, Measures Application Partnership (Congressionally mandated in connection with PPACA), Clinician Work Group, 2011 – 2016.

Advisory Board Member, Education Network to Advance Clinical Trials, 2011 – 2012.

National Advisory Board Member, Child Development Institute, Sarah Lawrence College 2011 – 2014.

Advisory Board Member, Westchester Children’s Association, 2010 – 2014.

Chair, Steering Committee of the Environmental Consortium of Hudson Valley Colleges and Universities, 2006 – 2010.

Board Member, Andrus on Hudson Retirement Community, 2004 – 2013.

Board Member, Child Care Council of Westchester, 2003 – 2007.
Advisory Board Member, Retired Senior and Volunteer Programs, 2003 – 2005.
Special Consultation Contract, Annie E. Casey Foundation, as part of “Making Connections” initiative, 2000 – 2002.
Advisory Board Member, Rockland Parent Child Center, 1999-2006.
Appointee, Nyack Parks Commission, 1998 – 2002.
Steering Committee Member, Planned Parenthood Inc., 1997 – 2000.
Advisor, Sarah Lawrence Health Advocacy Program, 1996 – 2002.
Board Member, Coalition for AIDS in Rockland, 1993 – 1998.
Appointee, Women’s Commission of Rockland, 1993 – 1997.
Board Member, Rockland Peace Dividend Campaign, 1992 – 1994.

SELECTED PUBLICATIONS

Books

Grob, R. (2011). *Testing Baby: The Transformation of Newborn Screening, Parenting, and Policymaking*. Rutgers University Press: New Brunswick, NJ.

Hoffman, B., Tomes N., **Grob R.**, Schlesinger, M. (2011). *Patients as Policy Actors*. Rutgers University Press: New Brunswick, NJ.

Grob, R., Harmon, M., LaGreca, K., and Mitchell, T. (2000). *Yonkers Early Childhood Data Book*. Yonkers Early Childhood Initiative: Yonkers, NY.

Articles

Ziebland, S., **Grob, R.**, Schlesinger, M., "Polyphonic Perspectives On Health and Care: Reflections From Two Decades Of The Dipex Project" *Journal of Health Services Research & Policy*, September 2020, <https://doi.org/10.1177/1355819620948909> .

Grob, R., Wise, M., Schlesinger, M., and Pandhi, N. “Stumbling Into Adulthood: Learning From Depression While Growing Up.” *Qualitative Health Research*, May 2020; OnlineFirst. DOI: 10.1177/1049732320914579.

Pandhi, N., Gaines, M., Deci, D., Schlesinger, M., Culp, C., Karp, Z., Legler, C., and **Grob, R.** “Broadening Medical Students’ Exposure to the Range of Illness Experiences: A Pilot Experimental Curriculum Trial.” *Academic Medicine*, Jan 2020; 95(1): 72-76. DOI: [10.1097/ACM.0000000000002893](https://doi.org/10.1097/ACM.0000000000002893)

Grob, R. “Qualitative Research on Newborn Screening: Robust but Marginalized.” *Hastings Center Report*, *Looking for the Psychosocial Impacts of Genomic Information*, special report, May 2019; 49 Suppl. 1:S72-S81. DOI: 10.1002/hast.1019.

Meyers, D., Darien, G., **Grob, R.**, Letter to the Editor, “Reply. Trust in Healthcare Why Physicians Should Trust in Patients” *JAMA*. 2019;322(8):782-783. DOI:10.1001/jama.2019.9200. August 27, 2019. DOI: 10.1001/jama.2019.9200.

Grob, R., Darien, G., Meyers, D., “Why Physicians Should Trust in Patients” *JAMA*. 2019;321(14):1347-1348. DOI:10.1001/jama.2019.1500. Published Online: March 22, 2019.

- Schlesinger, M., Rybowski, L., Shaller, D., Martino, S.C., Parler, A.M., **Grob, R.**, Finucane, M.L., and Cerully, J.L. “Americans’ Growing Exposure to Clinician Quality Information: Insights and Implications.” *Health Affairs*, March 2019; 38(3). DOI: 10.1377/hlthaff.2018.05006
- Grob, R.**, Schlesinger, M., Barre, L. R., Bardach, N., Lagu, T., Shaller, D., Parker, A. M., Martino, S.C., Finucane, M.L., Cerully, J.L., and Palamaru, A. “What Words Convey: The Potential for Patient Narratives to Promote High Quality, Patient-Centered Medical Care.” *The Millbank Quarterly*, March 2019; 97(1): 176-227. DOI: 10.1111/1468-0009.12374.
- Cerully, J.L., Parker, A.M., Rybowski, L., Schlesinger, M., Martino, S.C., Shaller, D., **Grob, R.**, and Finucane, M.L. “Improving Patients’ Choice of Clinician by Including Roll-Up Measures in Public Healthcare Quality Reports: An Online Experiment.” *Journal of General Internal Medicine*, Published Online, November 2018. Published issue, February 2019; 34(2): 243-249. DOI: 10.1007/S11606-018-4725-y.
- Schlesinger, M., **Grob, R.**, Shaller, D., and Martino, S.C., et al. “A Rigorous Approach to Large-Scale Elicitation and Analysis of Patient Narratives.” *Medical Care Research and Review*, 4 September 2018.
- Grob, R.**, Roberts, S., and Timmermans, S. (2018). “Families’ Experiences with Newborn Screening: A Critical Source of Evidence.” *Hastings Center Report*, Special Report: Sequencing Newborns: A Call for Nuanced Use of Genomic Technologies, Supplement: The Ethics of Sequencing Newborns: *Reflections and Recommendations*; 48(S2): S29-S31.
- J. Johnston et al. and **members of the NSIGHT Ethics and Policy Advisory Board**, “Sequencing Newborns: A Call for Nuanced Use of Genomic Technologies,” *The Ethics of Sequencing Newborns: Recommendations and Reflections*, special report, *Hastings Center Report* 48, no. 4 (2018): S2+ [20 pages], “Sequencing Newborns: A Call for Nuanced Use of Genomic Technologies,” *The Ethics of Sequencing Newborns: Recommendations and Reflections*, special report, *Hastings Center Report* 48, no. 4 (2018): S2+ [20 pages]. DOI: 10.1002/hast.874
- Finucane, M., Martino, S., Parker, A., Schlesinger, M., **Grob, R.**, Cerully, J., Rybowski, L., Shaller, D. “A Framework for Conceptualizing How Narratives from Health-Care Consumers Might Improve or Impede the Use of Information about Provider Quality.” *Patient Experience Journal*, 2018; 5(1): 15-26.
- Martino, S.C., **Grob, R.**, Davis, S., Parker, A.M., Finucane, M.L., Cerully, J.L., Rybowski, L., Shaller, D., and Schlesinger, M. “Choosing Doctors Wisely: Can Decision Navigators Enhance Patients’ Selection of Clinicians?” *Medical Care Research and Review*, Published Online: 25 October 2017; DOI: 10.1177/1077558717743822.
- Golinkoff, R., Hirsh-Paskek, K., **Grob, R.**, and Schlesinger, M. [Editors]. “Special Section: Bringing Developmental Science into the World.” *Child Development*, 2017; 88(5): Special Section 1403 – 1526.
- Grob, R.**, Schlesinger, M., Pace, A., Hirsh-Pasek, K., Golinkoff, R. “Playing with Ideas: Evaluating the Impact of the Ultimate Block Party, a Collective Experiential Intervention to Enrich Perceptions of Play.” *Child Development*, 2017; 88(5): 1419-1434.
- Golinkoff, R., Hirsh-Pasek, K., **Grob, R.**, and Schlesinger, M. “‘Oh, the Places You’ll Go’ If you Study Children in the World.” *Child Development*, 2017; 88(5): 1403-1408.
- Schlesinger, M. and **Grob, R.** “Treating, Fast and Slow: Americans’ Understanding of and Responses to Low-Value Care.” *Milbank Quarterly*, 2017; 95(1): 70-116.

Cerully, J., Martino, S., Rybowski, L., Finucane, M., **Grob, R.**, Parker, A., Schlesinger, M., Shaller, D., Martsof, G. Consumer Report Sponsor and National Multi-Stakeholder Alliance Perspectives on Reporting Health Care Quality “Using “Roll-Up” Measures in Healthcare Quality Reports.” *American Journal of Managed Care*, 2017; 23(6): e202-e207.

Martino, S., Shaller, D., Schlesinger, M., Parker, A., Rybowski, L., **Grob, R.**, Cerully, J., Finucane, M. “CAHPS and Comments: How Closed-Ended Survey Questions and Narrative Accounts Interact.” *Journal of Patient Experience*, 2017: 2374373516685940.

Grob, R., Schlesinger, M., Parker, A., Shaller, D., Wright, L., Martine, S., Finucane, M., Rybowski, L., Cerrully, J. Breaking narrative ground: Innovative methods for rigorously eliciting and assessing patient narratives. *Health Services Research*. 51 (S2): 1248-1272. Published Online: 29 APR 2016
DOI: 10.1111/1475-6773.12503

Grob, R. and Schlesinger, M. “Educating, Enrolling, and Engaging: The State of Marketplace Consumer Assistance.” *Health Affairs*, 2015; 34(12): 2052-2060.

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Grob, R. “Newborn screening: Guiding parents through the diagnostic maze.” *Contemporary Pediatrics*, 2011; 28(4): 38-47.

Hurst, M., Lieber, C., Lewis, L.J., **Grob, R.** “Family stories: narrative genetics and conceptions of heritability in pregnant women.” *Journal of Midwifery & Women’s Health*, 2011; 56(1): 26-32.

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Grob, R. “Not every playing field should be level.” *Encounter: Education for Meaning and Social Justice*, 2009; 25(4): 14-15.

Grob, R. “Is my sick child healthy? Is my healthy child sick?: Changing parental experiences of cystic fibrosis in the age of expanded newborn screening.” *Social Science and Medicine*, 2008; 67(7): 1056-1064.

Grob, R. “Parenting in the genomic age: The ‘cursed blessing’ of newborn screening.” *New Genetics and Society*, 2006; 25(2): 159-170.

Grob, R. “Celebrating and mobilizing: How we started a family day in Yonkers.” *America’s Family Support Magazine*, 2000; 19(1).

Book Chapters

Grob, R. and Schlesinger, M. (2018). “When Public and Private Narratives Diverge: Experiences with Newborn Screening in the USA.” *Illness Narratives in Practice: Potentials and Challenges of Using Narratives in Health-related Contexts*. Oxford University Press: New York.

Gaines, M., **Grob, R.**, Schlesinger, M., Davis, S (2013). Is There an Advocate in the House?: Professionalism from the Patient’s Perspective. In DeAngelis, D. (ed.) *Professionalism in Patient Care*, Oxford University Press: New York.

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Grob, R. and Schlesinger, M. (2011). Getting Engaged: Principles for Enhanced Patient Participation in American Health Care and Policy. In Hoffman, B., Tomes N., Grob R., Schlesinger, M. (eds.) *Patients as Policy Actors*. Rutgers University Press: New Brunswick, NJ.

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Grob, R. (2008). Genetic Theories. In Parrillo, V. (ed.) *The Encyclopedia of Social Problems*. Sage Publications: Thousand Oaks, CA.

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Policy Briefs, White Papers and Miscellaneous

Ish D., Parker A, Osoba O, Elliott M, Schlesinger M, Hays R, **Grob R**, Shaller D, and Martino S. “Using Natural Language Processing to Code Patient Experience Narratives: Capabilities and Challenges.” Santa Monica, CA: RAND Corporation, 2020. https://www.rand.org/pubs/research_reports/RRA628-1.html.

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Joffe S, Gleason K, **Grob R**, McGraw S, McLean P, Solomon M. “Strengthening healthcare through patient and family engagement in quality Improvement and research: A user’s guide for patient and family advisors and their learning healthcare systems.” The University of Pennsylvania Perelman School of Medicine, Philadelphia, PA; 2019. <https://medicalethicshealthpolicy.med.upenn.edu/learning-with-patients>

Davis S, **Grob R**, Culp C, Gaines JR, Pandhi N. “Engaging Research Participants in Disseminating Health Experiences Research.” The Center for Patient Partnerships, the University of Wisconsin – Madison Department of Family Medicine and Community Health, the UW Institute for Clinical and Translational

Research, and the UW Health Innovation Program. Madison, WI; 2018. Available at: <https://www.hipxchange.org/HealthExperiencesResearch>.

Cerully, J. L., Parker, A. M., Schlesinger, M., Martino, S. C., Shaller, D., Rybowski, L., **Grob, R.**, Finucane, M. L. (2017). The Select MD 2.0 Provider Choice Experiment: Methodological Overview (WR-1152-AHRQ). Santa Monica, CA: RAND Corporation. http://www.rand.org/pubs/working_papers/WR1152.html

Health Experiences Research Network USA Website. (2016). <http://www.healthexperiencesusa.org>
This website is the gateway for U.S. modules developed using the internationally-vetted DIPEX methodology. The young adults' experiences with depression, which I co-led, is the first module in the U.S. that uses this rigorous approach for examining diverse illness and health experiences.

Birschbach, C. and **Grob, R.** (2016). Pilot and Initial Implementation of the Resource Navigator Program at Wingra Family Medical Center: Process Evaluation, Recommendations, and Considerations.

Grob, R., Schlesinger, M., Pollitz, K., Grubstein, L. (2014). Taking Stock and Taking Steps: A Report from the Field after the First Year of Marketplace Consumer Assistance under the ACA. Kaiser Family and Robert Wood Johnson Foundations, commissioned report. Available at: <http://kff.org/> and <http://www.rwjf.org/en/research-publications>.

Grob R., Schlesinger, M., and Gephart, A. (2011). At Play in Central Park: An Evaluation of the Ultimate Block Party. Report Documenting Evaluation of the Ultimate Block Party Submitted to Event Organizers and the National Institutes of Health. February 2011.

Diamond, J. (Director). **Grob, R.** (Collaborator and writer). (2009). When Learning Comes Naturally. (Documentary). United States: The Child Development Institute and American Public Television.

Grob, R. (2009). When Learning Comes Naturally. Booklet published with documentary. Available at: <https://www.sarahlawrence.edu>.

Works in Progress

Grob, R., Joffe, S., McLean, P., Gleason, K., McGraw, S., Solomon, M., “Patients’ Roles in Governance of Learning: Results from a Qualitative Study of 16 Learning Healthcare Systems.” Manuscript in development for submission to *Health Affairs*.

Tluczek, A., **Grob, R.**, Yu, Z., Collins, L., Raymond, K., George, C., “Parent and Provider Perspectives about Partnerships in Cystic Fibrosis Care.” Manuscript in development for submission to *Journal of Communication in Health Care*.

Crowder, M., Pandhi, N., **Grob, R.**, Grevious, N., Davis, S. “Dissemination of Health Experiences Research Using Patient Experience Ambassadors.” Manuscript in development for submission to *Journal of Participatory Medicine*.

Grob, R., Mrig, E., Schlesinger, M., Wise, M., Warne, E., Smith, K., “The Blunt Edge of Precision Medicine: Hereditary Cancers and Persisting Uncertainty.” Manuscript in development for submission to *Social Science and Medicine*.

Grob, R., “The singular importance of plural voices for system change in health care.” Manuscript under development.

MEDIA COVERAGE (partial list)

Murphy, Brendan. "Patients as Teachers." *AMA*. May 9, 2019. <https://www.ama-assn.org/education/accelerating-change-medical-education/your-biggest-medical-school-lessons-may-come>

Carr, Teresa. "Many Anti-Vaxxers Don't Trust Big Pharma. There's a Reason for That." *Undark*. April 24, 2019. <https://undark.org/article/anti-vaxxers-vaccines-trust-big-pharma/>

Andrews, Michelle. "Your plumber offers a money-back guarantee. Should your doctor?" *The Washington Post*. December 6, 2017. https://www.washingtonpost.com/national/health-science/your-plumber-offers-a-money-back-guarantee-should-your-doctor/2017/12/06/665050da-da6e-11e7-a241-0848315642d0_story.html?utm_term=.3f1324a8d00e.

Lewis, Jacqui. "Growing up with Depression in the African-American Community." *Ebony Magazine*. October 24, 2017. Web. <http://www.ebony.com/wellness-empowerment/growing-depression-african-american-community#axzz4x0CrAVXM>.

Delozier, D. "UW Health website speaks to young adults with depression: Young adults with depression share their stories." WISC-TV News 3 *Channel 3000*. May 16, 2017. <http://www.channel3000.com/health/uw-health-website-speaks-to-young-adults-with-depression/501758085>.

On Faith Commentary, "Depression, Faith and Spirituality." Rachel Grob and Nancy Pandhi. March 9, 2017. <https://www.onfaith.co/commentary/depression-faith-and-spirituality>.

Milwaukee Journal Sentinel, "UW-Madison and collaborators launch website on patients' experiences." Guy Boulton. July 30, 2016. <http://archive.jsonline.com/business/uw-madison-and-collaborators-launch-website-on-patients-experiences-b99766363z1-388744461.html>

The Cap Times, "UW-Madison launches new online resource on depression." Lisa Speckhard. July 22, 2016. http://host.madison.com/ct/news/local/govt-and-politics/uw-madison-launches-new-online-resource-on-depression/article_3621be75-20a2-5539-8998-7e4085b06376.html

Wisconsin State Journal, "Patient insight website debuts with UW project about depression." David Wahlberg. July 19, 2016. http://host.madison.com/wsj/news/local/health-med-fit/patient-insight-website-debuts-with-uw-project-about-depression/article_ac25d7cf-0d34-5878-97a8-5ac552c0d418.html

Wisconsin Public Radio, "Central Time." December 3, 2013. Discussed far-reaching sociological consequences of newborn screening.

Associated Press, quoted in a story about Health Exchanges, September 30, 2013.

MENTORING

2020 Jane Evered

Post Doc in Qualitative Health Experiences Research, Department of Family Medicine and Community Health, UW-Madison

2019 Melissa Marver

Ph.D. Candidate in Population Health Sciences, UW-Madison

2017 Hayley Severson
Shapiro Fellow, UW Madison

2016 Casey Birschbach
Shapiro Fellow, UW Madison

SELECTED PRESENTATIONS

Health Policy, Quality Improvement, and Patient Experience

“Watching Science Evolve from the Front Row: Patients’ Diverse Experiences with Cancer Risk and Genomics.” Presenter at *2020 Wisconsin Genetics Exchange*; Madison, WI, September 25, 2020.

“Introduction to the DIPEX Methodology and the Health Experiences Research Network.” Co-Presenter with Nancy Pandhi and Erika Cottrell at *Community Engagement Broker’s Presentation*; Webinar, July 21, 2020.

“Maximum Variation Sampling and Saturation: A Conversation.” Co-Presenter with Maya Lavie-Ajayi at *DIPEX International Meeting*; Oxfordshire, UK, November 20, 2019.

“Reflections on Qualitative Methods.” Presenter at *DIPEX International Meeting*; Oxfordshire, UK, November 19, 2019.

“Trust: The Foundation of Partnership”

Co-Presenter with Stacy Van Gorp, Lisa Greene, Karen Homa, and Emily Warne at *North American Cystic Fibrosis Conference*; Nashville, TN, November 1, 2019.

“Visible and Invisible Work of Managing CF Across the Lifespan: What Care Teams Need to Know!”

[Poster Presentation] Co-Presenter with Audrey Tluczek, Stacy Van Gorp, Lisa Greene, Karen Homa, and Emily Warne at *North American Cystic Fibrosis Conference*; Nashville, TN, November 1, 2019.

“Visible and Invisible Work of Managing CF Across the Lifespan: What Care Teams Need to Know!”

Co-Presenter with Audrey Tluczek, Stacy Van Gorp, Lisa Greene, Karen Homa, and Emily Warne at *North American Cystic Fibrosis Conference*; Nashville, TN, November 1, 2019.

“Making a Good Match: Improving Care by Learning from Patient and Family Experiences.”

[Poster Presentation] Co-Presenter with Stacy Van Gorp, Lisa Greene, Karen Homa, Emily Warne, and Audrey Tluczek at *North American Cystic Fibrosis Conference*; Nashville, TN, November 1, 2019.

“Making a Good Match: Improving Quality of Care by Learning from Patient and Family Experiences.”

Primary Presenter with Audrey Tluczek, Lisa Greene, Stacy Van Gorp, Karen Homa, and Emily Warne at *North American Cystic Fibrosis Conference*; Nashville, TN, November 1, 2019.

“The Missions and Challenges of Learning Healthcare Systems: A Qualitative Study.”

Co-Presenter with S. Joffe, P. McLean, S. McGraw, M. Solomon, K. Gleason, and M. Terrasse at *American Society for Bioethics and Humanities Annual Conference*; Pittsburg, Pennsylvania, October 25, 2019.

“Understanding Diverse Health Experiences to Inform Education, Intervention Planning and Quality Improvement.”

Co-Presenter with Pandhi N, Cotrell E, Grevious N, Helfand M, Knight S, Schlesinger M, Smith K, Warren B. at *WONCA World Rural Health Conference*; Albuquerque, New Mexico, October 14, 2019.

“Leveraging health experiences research to amplify patient and caregiver voices in clinical and translational research.” [Poster Presentation] Co-Presenter with Dr. Erika Cottrell, PhD, MPP, K. Parker, V. Christiansen, T. Prescott, M. Krancari, L. Tarlow, P. Foley, **R. Grob**, N. Pandhi, D. Ellison, and C. Morris at *Clinical and Translational Science Award Program Meeting*; Washington, DC, September 27, 2019.

“Oregon Clinical & Translational Research Institute’s Optional Function: Leveraging health experiences research to amplify patient and caregiver voices in clinical and translational research.” Co-Presenter with Erika Cottrell, Kellee Parker, Vivian Christiansen, Tiffany Prescott, Molly Krancari, Lauren Saxton, Perry Foley, Nancy Pandhi, and David Ellison at *Oregon Clinical and Translational Research Institute Annual Meeting*. September 27, 2019.

“What Patients are Saying About Cancer, Genetics, and Genomics.” Presenter at *The National Patient Advocate Foundation Policy Forum*; May 15, 2019.

“AMA Innovations in Medical Education Webinar – Learning from the source: Patients as teachers.” Co-presenter with Meg Gaines at *American Medical Association Webinar*, March 25, 2019.

“Learning from Narratives.” Presenter at *Seminário Internacional Narrativas em Saúde (International Seminar on Health Narratives)*; Federal University of Rio de Janeiro, Brazil; March 22, 2019.

“Lost in Translation? Bringing Patient Experience to the Worlds of Practice, Policy and Public Awareness.” Co-Presenter with Mark Schlesinger at the *New Directions in Qualitative Health Research symposium*; University Medical Center Groningen, Netherlands, November 5, 2018.

“Provider and Parent Perspectives About Partnership.” Co-Presenter with Audrey Tluczek, Lisa Greene, and Cynthia George at the *North American Cystic Fibrosis Conference*; Denver, Colorado; October 18-20, 2018.

“Health Experiences 360: Multiple Uses of a Web-based Resource to Bring Patients’ Voices on Depression to Health Care.” Presenter at *Wisconsin Collaborative for Healthcare Quality (WCHQ)*; Madison, WI; October 16, 2018.

“New Methods for Eliciting Patient Narratives.” Presenter at *What Patients Say: Improving Quality, Safety and the Patient Experience Using Patient Comments*; Chicago, IL; October 11, 2018.

“Implementing the New CAHPS Protocol for Obtaining Patient Comments About Their Care.” Co-Presenter with Dale Shaller and Tara Servati at the *Agency for Healthcare Research and Quality (AHRQ)*; Webcast; October 3, 2018.

“Health Experiences 360: Multiple Uses of a Web-based Resource to Bring Patients’ Voices on Depression to Health Care.” Presenter at *Access, Quality, and Outcomes Research Network*; Madison, WI; September 18, 2018.

“Patient and Family Involvement in Governance of Learning Healthcare Systems.” Co-Presenter with Steven Joffe and Paul McLane at *The International Conference on Patient- and Family-Centered Care*; Baltimore, MD; June 11, 2018.

“Implementing the New CAHPS Protocol for Obtaining Patient Comments About Their Care.” Co-Presenter with Dale Shaller, Richard Evans, Tara Servati at *The Beryl Institute Patient Experience Conference*; Chicago, IL; April 17, 2018.

“Using Patients’ Experiences to Inform Advocacy.” Presenter at *The National Patient Advocate Foundation Advocacy Training Webinar*; April 5, 2018.

“Qualitative Research: Robust but Marginalized.” Invited Speaker at *The Hastings Center, Looking for the Psychosocial Impacts of Genomic Information*; New York, NY; February 27, 2018.

“A pilot curriculum developed from health experiences research: impact on third-year medical students.” Co-presenter with Dr. Nancy Pandhi, MD, PhD at *The North American Primary Care Research Group 45th Annual Meeting*; Montreal, Quebec; November 17-21, 2017.

“Using Patients’ Experiences to Improve Care.” Invited Speaker at *North American Cystic Fibrosis Conference*; Indianapolis, IN; November 2, 2017.

“Panel Discussion: Adapting DIPEX to the U.S. and VA” Co-presenter with Dr. Kate Smith, PhD, Dr. Erika Cottrell, PhD, MPP, and Dr. Mark Helfand, MD, MPH at *Society for Medical Decision Making and VA Health Services Research and Development Service’s Health Experiences Research Course*; Pittsburgh, PA; October 22, 2017.

“What Matters to Patients and Families.” Panelist at *National Patient Advocate Foundation’s Spring 2017 Policy Consortium: A Roadmap to Consumer Clarity in Healthcare Decision Making*; Washington, D.C.; May 17, 2017.

“Young Adults’ Diverse Depression Narratives: A New Resource for Improving Campus Mental Health.” Co-presenter with Dr. Nancy Pandhi, MD, PhD and Njeri Grevious at *The JED Foundation Webinars for Campus Program Leaders*; May 16, 2017.

“Moving from Voice to Voices: Capturing diverse patient perspectives on WGS.” Presenter at, *Sequencing Newborns: Ethics & Policy Meeting #3*; San Francisco, CA; February 27, 2017.

“Giving patients’ experiences their due: an innovative methodology for the USA.” Presenter at *The Hastings Center, Lunchtime Series*; Garrison, NY; February 7, 2017.

“Asking the Right Questions: A New Approach to Eliciting Experiences with Pediatric Care.” Presenter at *University of California – San Francisco Pediatric Grand Rounds*; San Francisco, CA; January 5, 2017.

“From One Voice to Many: Innovations in Eliciting, Synthesizing and Using Diverse Patients’ Experiences.” Presenter at *University of Wisconsin – Madison’s Department of Family Medicine and Community Health Fellowship Seminar*; Madison, WI; December 13, 2016.

“Learning from Patients’ Experiences for Better Culture, Health, and Care.” Invited presenter at National Academy of Medicine’s *Leadership Consortium for a Value & Science-Driven Health System: Care, Culture, and Decision-Making Innovation Collaborative*; Washington, DC; December 7, 2016.

“The Singular Importance of Plural Voices: A Roadmap.” Presenter at *The Hastings Center, Lunchtime Series*; Garrison, NY; December 5, 2016.

“From Patient Voice to Patient Voice to Patients’ Voices: Incorporating Patient Experiences to Enhance Medical Education.” Presenter at *DIPEX International Steering Committee Group*; November 13, 2016.

“Launching a website of US Patient Experiences with a Module about Young Adults with Depression.” [Poster Presentation]. Co-presenter with Dr. Nancy Pandhi, MD, PhD; Dr. Meg Wise, PhD; Dr. Mark Schlesinger, PhD; Myra Holloway; Natalie Wietfeldt; and Lane Hanson at *National American Primary Care Research Group Conference*; Colorado Springs, CO; November 13, 2016.

“The Singular Importance of Plural Voices.” Invited Plenary Lecture at *International Conference on Narratives of Health and Illness*; Tenerife; November 12, 2016.

“Patient Narratives and the Unvoiced Other: The Centrality of Pets in the Lives of People with Chronic Illness.” Co-presenter with Dr. Mark Schlesinger, PhD at *International Conference on Narratives of Health and Illness*; Tenerife; November 12, 2016.

“The CAHPS Narrative Elicitation Protocol: Research Results to Date.” Panelist at *Advancing the Science and Implementation of Patient Narrative Elicitation and Reporting*; Rockville, MD; September 08, 2016.

“Leveraging Health Experiences Research to Enhance Veteran Engagement in Research.” Co-presenter with Dr. Erika Cottrell, PhD at the *Veterans Affairs Health Services Research & Development Cyberseminar*; broadcast on July 13, 2016.

“Learning from patient experience: Where we have been, and where we can go.” Panelist with Dr. Mark Schlesinger, PhD at *Patient-Centered Primary Care Collaborative Webinar*; broadcast on July 26, 2016.

“Funding – Research Collaborations” Co-presented with Dr. Nancy Pandhi, MD, PhD at *I-PrACTISE Conference*; Madison, WI; April 24-26, 2016.

“Consumer Reports Webinar: Thinking Wisely About Choosing Wisely.” Panelist - Consumer Reports is producing reports, brochures, and videos with healthcare experts to help consumers talk with their doctors about avoiding unnecessary healthcare procedures; Webinar broadcast on April 12, 2016.

“Ongoing data analysis for DIPEX Projects.” Presented session at *International Training for Database of Patient Experience (DIPEX) methodology*; McGill University and St. Mary’s Hospital; Montreal, Canada; October 5-8, 2015.

“When Public and Private Narratives Diverge: Experiences with Newborn Screening in the USA.” Co-presented with Dr. Mark Schlesinger at the *DIPEX International Conference “Illness Narratives in Practice”*; University of Freiburg, Germany; June 26-27, 2015.

“Improving electronically mediated interactions: the importance of understanding the patient experience.” Co-presented with Dr. Nancy Pandhi, MD, PhD at the *I-PrACTISE Colloquium*; Madison, WI; March 18, 2015.

“Elevating the Patient Voice for Patients, Clinicians, and Policy.” Co-presented with Dr. Nancy Pandhi, MD at the *University of Wisconsin Department of Family Medicine “Whole Me, Whole We” Conference*; Madison, WI; October 23, 2015.

“Collecting and Reporting Patient Narratives to Capture Patients' Experiences.” Presented session at *2015 AHRQ Research Conference: Producing Evidence and Engaging Partners to Improve Health Care*; Arlington, VA; October 4-6, 2015.

“Patient Perceptions of Low-Value Care: Results from a National Survey and Implications for Future

Practice.” Co-presented with Dr. Mark Schlesinger at *Leadership Council, CT Choosing Wisely Collaborative*; North Haven, CT; March 14, 2015.

“Using Qualitative Research to Understand and Inform Public Representation of Patient Experiences” Presented to the *Department of Family Medicine, University of Wisconsin-Madison School of Medicine and Public Health*; Madison, WI; 2015.

“A Database of Patient Experience: Moving Beyond Anecdote.” Co-presented with Nancy Pandhi at the *2015 World Congress of Psycho-Oncology and Psychosocial Academy Workshops*; Washington, DC; 2015. <https://wcpo15.sched.org/event/51af9019ba4be34a321e09e5130a5d39#.VkYnP9-rTVo>

“Partnering with Patients in Health Care.” Co-presented with Sarah Davis, Meg Gaines, Nancy Pandhi, Margaret Schwarze and Elizabeth Cox at *Mini Med School, University of Wisconsin-Madison School of Medicine and Public Health*; Madison, WI; 2015.

“Health Policy and Patient Experience in the U.S.: A Big Picture Overview.” Invited lecture, co-presented with Dr. Mark Schlesinger, *sponsored by the Oxford Health Experiences Institute at Green Templeton College*; Oxford University; 2015. <http://mim.gtc.ox.ac.uk/speaker-events.html>

“Eliciting and Reporting Patient Experience Narratives: New Directions for Public Reports on Physician Performance in the U.S.” Seminar, co-presented with Dr. Mark Schlesinger, *sponsored by the Health Experiences Research Group for the Nuffield Department of Primary Care Health Sciences*; Oxford University; 2015.

“Empowering Consumers: Strengthening Our Voice to Transform Health Care.” Moderator of public forum *sponsored by the Connecticut Health Advancement and Research Trust*; North Haven, CT; 2014.

“Consumers Tell Us: Best Ways to Engage Them on Health Costs and Delivery System Reform.” *National forum sponsored by Consumer Reports*; Washington DC; 2014.

“Public Reporting of Patients’ Comments with Quality Measures: How Can We Make It Work?” *National Webinar sponsored by the Consumer Assessment of Health Plans and Providers (CAHPS) user network*; 2014.

“Patient Comments and Quality Assessment: Connecting the Narrative Thread.” *Baystate Medical Center*; Springfield, MA; 2013.

“The Affordable Care Act’s Plan for Robust State Consumer Assistance for Insurance Issues Remains a Work in Progress.” *New Era of Patient Engagement, Health Affairs Briefing*; Washington DC; 2013.

Health Advocacy

“Some (slightly better than) random thoughts about engaging patients: Lessons about what to do from the Center for Patient Partnerships.” Co-Presenter, with Meg Gaines at The Institute of Health Policy, Management & Evaluation – University of Toronto’s *Engaging Patients, Caregivers and the Community: Co-Designing what the Future Holds for IHPME*; Toronto, Ontario; June 7, 2018.

“Patients’ Voices in On-line Curriculum: The Virtues of the Virtual, the Relevance of the Real.” Presenter at *2nd International Conference: Where’s the Patient’s Voice in Health Professional Education – 10 Years On?*; Vancouver, Canada; November 13, 2015.

“Patient Advocacy: an Emerging and Evolving Professional Field.” *13th Annual Patient Assistance and Access Program*; Baltimore, MD; 2012.

“Educating for Advocacy: Teaching Skills, Framing Aspirations, Sparking Engagement.” Lecture, co-presented with Dr. Mark Schlesinger to medical school faculty; Dalhousie University; Nova Scotia; 2010.

Newborn Screening

“Qualitative Research on Expanded Prenatal and Newborn Screening: Robust but Marginalized.” Presenter at *Newborn Screening in the US-Israel Workshop*: University of California, Los Angeles; April 25-26, 2019.

“Rapid Expansion of Newborn Screening: Drivers and Dilemmas.” Presenter at *American Society for Bioethics and Humanities: Where Do We Stand? Critical Distance in Bioethics and Medical Humanities*; Washington DC; October 7, 2016.

“Parents’ Experiences with Screenable Conditions: Complexity, Uncertainty and Variation.” Co-Presented with Kirsten Isgro “Session 1: What are the reasonable and unreasonable hopes concerning the benefits of sequencing? What are the implications of these hopes for policy and practice?” at *Sequencing Newborns: Ethics & Policy Meeting #2*; Garrison, NY; June 27, 2016.

“Parental Involvement in the Expansion of State Screening Programs.” *Sequencing Health Newborns: Ethics and Policy Meeting, Hastings Center, UCSF*; San Francisco, CA; 2015.

“Improving Parental Experience with Cystic Fibrosis Newborn Screening in New York State.” *2015 North American Cystic Fibrosis Conference*; Phoenix, AZ; 2015.

“Testing Baby: Parents’ Perspectives on Expanded Newborn Screening.” *Annual Bioethics Lecture*, Dalhousie University; Nova Scotia; 2010.

“Qualitative Perspectives on Quality and Quantity in Newborn Screening,” and (with Mark Schlesinger) **“Astigmatism in the Public Eye: An Analysis of The Media Coverage of the Ethical and Social Issues Regarding Newborn Genetic Screening.”** *National conference on Ethical, Legal and Social Implications in Genomics*; Cleveland, OH; 2008.

“Expanded Newborn Screening: Parents’ Perspectives on Genetic Diagnosis.” *American Public Health Laboratories Annual Meeting*; Minneapolis, MN; 2007.

“Is My Sick Child Healthy, or Is My Healthy Child Sick?: Changing Parental Experiences of Cystic Fibrosis in the Age of Expanded Newborn Screening.” *Society for the Study of Social Problems Annual Meeting*; New York, NY; 2007.

EDUCATION

City University of New York Graduate Center

Ph.D in Sociology; focus on sociology of health and sociology of children and families

Sarah Lawrence College Graduate Studies Program

M.A. in Health Advocacy; concentration on children’s health and health policy

Wesleyan University

B.A. in Science in Society Program (interdisciplinary major)
Graduated with Honors; Phi Beta Kappa