



CENTER FOR CLINICAL AND TRANSLATIONAL SCIENCE

6th Annual Community Engagement and Research Symposium
March 3, 2017

Keynote 9:30 AM – 10:45 AM

Removing Barriers to Provider Communication with Multicultural Patients

Albert Sherman Center, 2nd floor, Lecture Hall/ Auditorium AS2-2102

Margarita Alegria, PhD

Chief of the Disparities Research Unit at Massachusetts General Hospital
Professor in the Department of Psychiatry at Harvard Medical School

Dr. Margarita Alegria has been instrumental in conducting research to eliminate disparities in mental health care. During this presentation, she will discuss major challenges of working across ethnic boundaries and propose alternative approaches to overcome them.

The therapeutic relationship has long been recognized as an essential factor in facilitating client engagement and retention in care. We know the challenges of establishing a relationship are amplified when cultural differences exist between client and provider, as an unfamiliarity and/or discomfort with a client’s beliefs, practices, understanding of etiology, acceptable approaches of treatment, and communication style create additional complexity. Recent studies have highlighted the unfortunate manifestations of such cultural disconnects, including:

- the presence of diagnostic bias with clients of color
- structural and interpersonal barriers that get in the way of establishing rapport

This presentation is designed to help improve shared decision making in the clinical encounter. Dr. Alegria will cover a variety of topics, including perspective taking; frequent attributional errors that providers make; and increasing receptivity to client participation and collaboration in decision making. Ways to improve the ability to listen, empathize and ask questions effectively will be discussed as will increased awareness of provider perceptions and misperceptions. These skills are not only important for patients and providers, but for everyone, particularly when interacting with those who are different in culture, background, and life circumstances.

Breakout Session 1 11:00 AM - 12:00 PM

Outer Cape Community Resource Navigator Program: Rural Community Engagement-Driven Service Delivery

5th floor Albert Sherman Center, Conference Room AS5-2072

Moderator: Andy Lowe, Director of Program Management Resources, Outer Cape Health Services

Presenters:

Marta “Dikke” Hansen, MSW, Director of Behavioral Health

Andrew Jorgensen, M., Associate Medical Director

Session Description

The Outer Cape Cod, Massachusetts region is famed for its beauty as a summer vacation destination. For many residents and migrant workers serving the tourism industry; however, the intersection of isolation, little affordable housing, and limited transportation options can exacerbate problems due to mental health, substance abuse, and co-occurring conditions. Police, emergency responders, and EDs encounter this at-risk population disproportionately. Outer Cape Health Services, the local FQHC, proposed a novel solution: a Community Resource Navigator (CRN) program. The CRN Navigator works with community partners to identify at-risk individuals, engage them right in the community, and guide them to appropriate services/treatment. A modified Self-Sufficiency Matrix based on evidence from other Navigator programs is

used as a tool to prioritize needs. The Navigator then helps clients attach themselves to options that make sense. The CRN program is a departure from classical case management approaches that features a light touch, with contact in the community rather than requiring clients to “come in” to the health center. A unique approach is that the Navigator uses a community-donated bicycle to pedal her way around the narrow Provincetown streets which can become virtually impassable during the busy summer tourism season. In addition, the Navigator sees clients in safe, accessible public spaces such as the public library. A critical success factor is community engagement that builds effective relationships with community partners such as police, EMTs, councils on aging, community mental health providers, etc. Since beginning the CRN program, data has been collected that provides some unexpected insights into how the Community Navigator approach can be both an outcome- and cost-effective alternative to traditional case management or social worker-oriented interventions. In addition, the CRN program is proposed as the basis for a research initiative under the auspices of the University of Massachusetts Medical School Center for Clinical and Translational Science.

The Ethics and Practice of Digital Storytelling as a Methodology for Community-Based Participatory Research in Public Health

2nd floor Medical School Building, S2-351 and 352

Moderator: Alice Fiddian-Green, PhD student, Department of Health Promotion and Practice, School of Public Health and Health Sciences, University of Massachusetts Amherst.

Presenters and Session Titles:

- “An Ethics Framework for Digital Storytelling as a Multi-Purposed Public Health Method”
 - Aline Gubrium, PhD
- Applying the Ethics Framework in Two Projects
 - Louis Graham, MPH, DrPH, and Sarah Lowe, MPW
 - “Stakeholder Engagement and Ethical Planning for Digital Storytelling: The MOCHA Moving Forward Project”
 - Mary Paterno, CNM, PhD
 - “Digital Storytelling as Health Promotion and Data: Ethical Considerations from a Peer-Mentor Based Project to Address Perinatal Substance Use Disorder in a Rural Community ”

Session Description

Public health often mislocates its lineage in the medical sciences. Being foremost about people and what happens when people live together, the field is equally rooted in the humanistic and social sciences. By providing a focus that is more open to the rich and variegated tapestry of health and wellbeing, participatory visual and digital approaches, such as digital storytelling, enhance understandings of health and well being. If carried out responsibly, digital storytelling has the potential to function both as a vehicle for community-based health promotion, and as a method for collecting culture-centered data that can assist researchers and practitioners in better serving local communities. Based on a Freirian model, which promotes active engagement as participants construct stories to promote change through a group process, the goal of our digital storytelling practice is to provide a creative forum for expressing the generative themes or collective issues of community members. Beyond being mere data points, digital stories enliven statistics, make research meaningful, and position research participants as experts in their own right by inviting them to define relevant issues, broaden the evidence base, and create an emotional product that attracts and influences policymakers and the public at large. Finally, digital stories can be re-purposed for use in health communication campaigns (on and offline) to effect broad reach.

Published literature on the ethics of community-based participatory research methods grounded in personal storytelling and participatory media approaches is in short supply, as are advanced training opportunities for public health researchers interested in these approaches (Gubrium & Harper, 2013; Gubrium, Hill, and Flicker, 2014; Gubrium, Hill & Fiddian-Green, 2016). Based on their previous research and practice experiences with digital storytelling, Gubrium and colleagues (2014) discuss the “situated practice of ethics” for participatory visual and digital methods in public health research and practice. Specifically, they write about six common challenges faced by researchers, advocates, and health promotion practitioners alike: the fuzzy boundaries that arise when negotiating between research, advocacy/action, and health promotion practice when using these methods; tensions related to recruitment of participants and consent to participate; the complex considerations specific to the release of the digital materials produced in workshops; power issues as they relate to the

shaping of both stories and digital media content; the potential for reproducing harm in visual/digital representation; and the promise of confidentiality/anonymity to research participants.

The proposed breakout session will provide a brief overview of the digital storytelling process (including discussion of recruitment, informed consent and release of materials, standard activities in the digital storytelling process, follow-up semi-structured interviews with participants, pre/post measures used to evaluate the impact of the process on participants, data analysis, and strategic communications based on produced digital stories). The session will enable participants to understand the myriad ethical issues that can present when carrying out community-based participatory research that employs digital storytelling as a methodology. By the end of the session, participants will be able to demonstrate critically enhanced awareness of ethical issues surrounding participatory visual and digital methodologies and identify effective ways to address these issues.

From the Community to the Classroom: Complementary Pathways to Service Learning and Community Engaged Research
1st floor Medical School Building, Hiatt Auditorium S1-608

Moderator: Tom Boone, PhD Associate Professor and Chair, Department of Psychology, UMass Dartmouth

Presenters

- Christina Cipriano, PhD, Assistant Professor, Department of Psychology
Emergent and Established Community-Based Service-Learning Opportunities
- Aminda O'Hare, PhD, Assistant Professor, Department of Psychology
- Josh Masse PhD, Assistant Professor, Department of Psychology
- Meredith Dove, PhD,, Assistant Professor, Department of Psychology

Session Titles and Descriptions

"Emergent and Established Community-Based Service-Learning Opportunities" - Christina Cipriano, Ph.D.

Funded by the William T. Grant Foundation and University of Massachusetts, The Recognizing Excellence in Learning and Teaching (RELATE Project) Project aims to promote quality special education learning environments by enabling effective instruction, evaluation, and professional development for special educators and the students they serve. Towards this end, the RELATE Project has been working closely with educational practitioners for the past five years to develop and refine an ecologically valid and sustainable technical manual and professional development approach. This presentation will discuss the key partnerships developed and developing since RELATE moved to the Southcoast, and provide explicit examples of established and emerging pathways for University student service-learning embedded within the RELATE Project. University student research projects, setting and measuring applied learning outcomes for university credit, balancing institutional and community partnership needs and presentation of outcomes will be highlighted.

"Engaging Members of the K-12 Community on Multiple Levels"- Aminda J. O'Hare, Ph.D.

K-12 communities can be cautious when partnering with higher education research projects as their students and teachers can often be treated as data points rather than humans with their own goals and values. Creating a sustainable partnership in K-12 communities requires the establishment of trust. On the researcher's part, this can often mean providing services and/or materials to these communities prior to enacting any data collection. Using this approach, we have provided free mindfulness training and education workshops for the Southcoast K-12 community and partnered with the New Bedford Wellness Initiative to promote healthy behaviors in our community and schools. In this way, we have interacted with parent-teacher associations, school boards, administrators, teachers, students, parents, and community members. This pathway has led to repeated student projects targeting the impact of mindfulness training on attention and anxiety with area schools. Different approaches to establishing trust in the community and future directions for this line of research will be discussed.

"Applying the Service-Learning Model to Mental Health Community Engagement on the Southcoast" -Joshua Masse, Ph.D.

This presentation will highlight the service-learning process as it relates to student involvement in various mental health contexts across the Southcoast. Specifically, it will discuss various engagement strategies employed with community

partners to develop and maintain sustainable relationships. The presentation will also present the bi-directional ways in which these partnerships have positively impacted UMass Dartmouth undergraduate students and the surrounding mental health community. Finally, specific curriculum-based methods utilized to process and reinforce service-learning experiences will be addressed.

“Project-Based Service Learning Opportunities to Improve Community-Based Pediatric Health Services”

-Meredith Dove, Ph.D.

Students often have a genuine interest in contributing to the local community surrounding UMass Dartmouth through engaged research and learning. This presentation will highlight initiatives to nurture existing university-community partnerships to develop community-based research projects that provide opportunities for student involvement. Project-based service learning opportunities developed through collaboration with community organizations and agencies after identifying organizational needs, often with a goal to strengthen or refine existing services, will be presented. The critical role of institutional support in the execution of community-based research and service learning projects will also be highlighted. A community-based research project funded by UMass Dartmouth to investigate the translation of childhood obesity prevention best practices into early childcare centers within communities at risk will illustrate the interplay between the areas of research, teaching, and learning.

Putting Health Equity Front and Center in Community Health Improvement by Empowering, Listening to, and Respecting Community Voices

Albert Sherman Center, 2nd floor, Lecture Hall/ Auditorium AS2-2102

Moderator: Kristin Bafaro, Executive Director, Coalition for a Healthy Greater Worcester

Presenters

Alexis Travis, PhD, CHES, Chief of Community Health, Worcester DPH

Judi Kirk, Director of Community Impact

Ashley Stockwell, Academic Health Department of Worcester Coordinator, Worcester DPH

Session Description

In 2012 the City of Worcester released the first Community Health Improvement Plan (CHIP), with the goal of making Worcester the Healthiest City in the Healthiest Region in the Commonwealth by 2020. Following tremendous success and leveraging lessons learned the Worcester Division of Public health, in collaboration with the Coalition for a Greater Healthy Worcester, UMass Memorial and Fallon Health released the 2016 CHIP, with the single goal of promoting health equity. During this session we will describe the comprehensive needs assessment process, research tools, long-term community engagement strategies and implementation practices that have created a community-driven movement across sectors to promote health equity.

Breakout Session 2

1:30 PM – 2:30 PM

Empowering Women in Underserved Communities: Using CBPR Approaches to Improve Health Literacy and Community Capacity

Faculty Conference Room, Medical School Lobby S1-342

Moderator: Elena Carbone, DrPH RD, LDN, Associate Professor, Department of Nutrition, UMass Amherst

Presenters:

Jennifer Manganello, MPH, PhD

Janine M. Jurkowski, MPH, PhD

Elena T. Carbone, DrPH, RD, LDN

Session Description

Promoting health literacy empowers individuals and communities to better navigate the health care system and health information environment, and allows for informed decision making for choices and actions that affect health.

Empowerment Theory and health literacy are inherent in Community-Based Participatory Research (CBPR) with low-income

and disadvantaged populations. In order for representatives to be engaged as equal participants in the research process, research and health capacity building need to occur. This breakout session will be presented in three parts. The first presentation will provide an overview and introduce how Empowerment Theory and health literacy can be used to build the capacity of community representatives and patient stakeholders. The other two presentations will highlight CBPR research projects currently underway or planned.

What is Health Literacy?

Presenter: Jennifer Manganello

Health literacy refers to a person's ability to obtain and understand health information and navigate the health system, as well as the health care environment itself. Definitions of health literacy will be discussed, along with how health literacy is relevant at each of the levels of the socio-ecological model (i.e., individual vs. community). We will provide a brief overview about health literacy research conducted in community and clinical settings. This presentation will also discuss how health literacy is related to empowerment.

Communities for Health Living (CHL): A CBPR Childhood Obesity Prevention Intervention Guided by Empowerment Theory

Presenter: Janine M. Jurkowski

CHL is an intervention research project that uses a parent-centered community-based participatory research (CBPR) in an RCT scale up of a childhood obesity prevention intervention guided by Empowerment Theory. CHL recognizes parents as family experts, engages them as co-researchers and embeds the resulting empowerment-focused intervention into Head Start, a national system of care reaching over one million low-income families. Building on a successful pilot assessment CHL researchers are collaborating with Boston/Somerville/Cambridge Head Start serving over 2000 children to expand the CBPR approach by engaging parents, community representatives and Head Start staff to adapt CHL to a new, more diverse setting. CHL is rigorously testing its efficacy to prevent obesity in children. To ensure the timely translation of this work this study is a practical behavioral trial that maintains a rigorous assessment of program efficacy. Primary innovations of this study are its explicit incorporation of Empowerment Theory into its participatory approach and intervention, which deviates from the traditional model of nutrition education to address broader family realities.

Mpower: Empowering Mothers for Health

Presenter: Elena T. Carbone

This project responds to the WUN Shanghai Declaration and the United Nations General Assembly call to promote health literacy in parents and empower women as a global strategy to reduce non-communicable diseases (NCDs). Because many NCDs originate in early development and from health disparities, the maternal health literacy of women in poverty is especially vital. Maternal health literacy refers to the *cognitive and social skills which determine the motivation and ability of mothers to gain access to, understand, and use information in ways that promote and maintain their health and that of their children*. Despite its importance, preliminary results of two scoping reviews indicate that few studies have examined maternal health literacy; fewer still have focused on skill development or empowerment of women in poverty. This project is designed to develop a long-term and sustainable research plan to fill these gaps and is part of a five-stage approach to develop a universal research strategy to promote health literacy in parents and empower women globally. Moreover, this project introduces an innovative community-based participatory method to the field of health literacy; and focuses on critical health literacy skills, empowerment, and health literacy for health protection and promotion -- all of which have been largely ignored.

Massachusetts Population Health Information Tool – a Tool for Community Health Needs Assessment and Planning

Albert Sherman Center, 2nd floor, Lecture Hall/ Auditorium AS2-2102

Moderators/Presenters: Glennon Beresin, Fran Medaglia, Massachusetts Department of Public Health, Bureau of Environmental Health/Bureau of Community Health and Prevention

Overview

Staff from the Massachusetts Department of Public (MDPH) will conduct a training and discussion on available MDPH data and in-development tools for accessing those data for community engagement, planning and assessment efforts. The

workshop will include the sharing of practical information on MDPH data and demonstrations of tools (for those with laptops, hands-on opportunities for data access may be possible).

Learning Objectives

- To learn about available MDPH data and data tools for community engaged research
- To understand possible MDPH roles in community engaged research
- To contribute to MDPH data access planning for meeting the needs of groups conducting community engaged research
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Background

In the spring of 2016, a partnership between two Massachusetts Department of Public Health (MDPH) bureaus, the Bureau of Environmental Health and the Bureau of Community Health and Prevention, and several MA hospital associations, embarked on a new project to make data more available for the purpose of helping to guide community partners in identifying community health needs and making decisions on resource allocation. The resulting Public Health Information Tool (PHIT) helps respond to two specific mandates requiring regular community needs assessments: (1) the Public Health Accreditation Board's requirement of certified local health departments and (2) Affordable Care Act's requirements of non-profit hospitals. The current vision of PHIT will incorporate expanded data and functionality so that it is applicable to local health, community health advocates, and academic institutions, among others. The project allows for the inclusion of many MDPH health indicators, including a focus on social determinants of health and identifying health disparities.

PHIT is currently in beta-test mode and is not yet available to the public. However, PHIT is built on the infrastructure for an existing BEH web tool, the Massachusetts Environmental Public Health Tracking (EPHT) portal, which is a web-based data system available to the public. EPHT is part of a national effort by the Centers for Disease Control and Prevention (CDC) to make environmental and health data readily available to the public in customizable maps, tables and charts at the county, community and census tract levels. Currently, the [EPHT website](#) includes the latest available health data for asthma, birth defects, cancer, carbon monoxide poisoning, childhood lead poisoning, heart attack, heat stress, pediatric diabetes and reproductive outcomes. In addition, Community Profiles for all 351 cities and towns are available that present a compilation of select indicators.

EPHT reflects over a decade of program development, which has been easily adapted into the PHIT system. Both EPHT and PHIT will continually evolve to add content, improve performance, and enhance system capabilities to best fit the needs of an expanding array of external stakeholders. To that end, this session not only provides an opportunity to introduce these tools to an interested audience, but also serves as a forum for gathering critical feedback from potential users.

Building Collaborative Health Research Drawing on New Lessons from Citizen Science

1st floor Medical School Building, Hiatt Auditorium S1-608

Moderator/Presenter: Linda Silka, University of Maine

Session Description

Community-based participatory research is growing. What is also growing is citizen science. There are useful lessons for the health field from this rapidly growing approach of citizen science. The National Institutes of Health and other health leaders such as Community Campus Partnerships for Health have begun encouraging cross-learning between those engaged in CBPR and those doing citizen science. There are many opportunities to spark innovation and problem solve by analyzing each others' practices and incorporating relevant aspects into community health research. The purpose of this workshop is to share with participants some of the latest practices in citizen science and consider ways of adapting some of these strategies to solve some of the problems we encounter in community-researcher health partnerships. In developing the session I will draw on my work in CBPR projects in Massachusetts and Maine, my service as an advisory board member for health citizen science projects in the western U.S., my webinar and keynotes in CBPR/CS for the National Citizen Association and NIH, and my development of graduate courses on stakeholder-researcher partnerships.

The UMCCTS Community Engagement & Research Section is part of the Clinical and Translational Science Award (CTSA) program, funded by the National Center for Advancing Translational Sciences (Grant # UL1TR001453-01) at the National Institutes of Health (NIH).

For more information on the UMass CCTS Community Engagement & Research Section, visit <http://www.umassmed.edu/CCTS/Community>.