COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR)

Nora Gimpel, MD
Associate Professor
Vice Chair Community Health
Community Health Distinguished Teaching Professor
Department of Family and Community Medicine

Objectives

- Define and review definition of CBPR
- Discuss the key principles of CBPR
- Discuss opportunities for CBPR training and implementation

CBPR definition

*"A **collaborative approach** to research that **equitably involves all partners** in the research process and recognizes the unique strengths that each brings.*

*CBPR begins with a research topic of importance to the community and has the aim of combining **knowledge with action and achieving social change**…"*

W.K. Kellogg Community Scholars Program (2001)

CBPR definition

Community-Based:

- *works in response to the needs of a community*

Participatory:

- *the community is part of the process*

Research:

- *systematic investigation that develops or contributes to generalizable knowledge*

CBPR key principles

Interplay of research, education, and action

- Balance between knowledge generation and intervention

Partnership/Mutual Benefit

- Involvement of community in all steps of the research process

Cooperative: sharing of expertise, decision-making and ownership

- Co-learning

Community as unit of identity

Building on strengths and resources within community

CBPR key principles

- **Focus on local relevance of public health problems**

Honoring local knowledge

- **Choice of methods based on research question and feasibility within community**

Quantitative and qualitative methods

- **Dissemination of results to ALL partners**

Understandable, respectful, useful

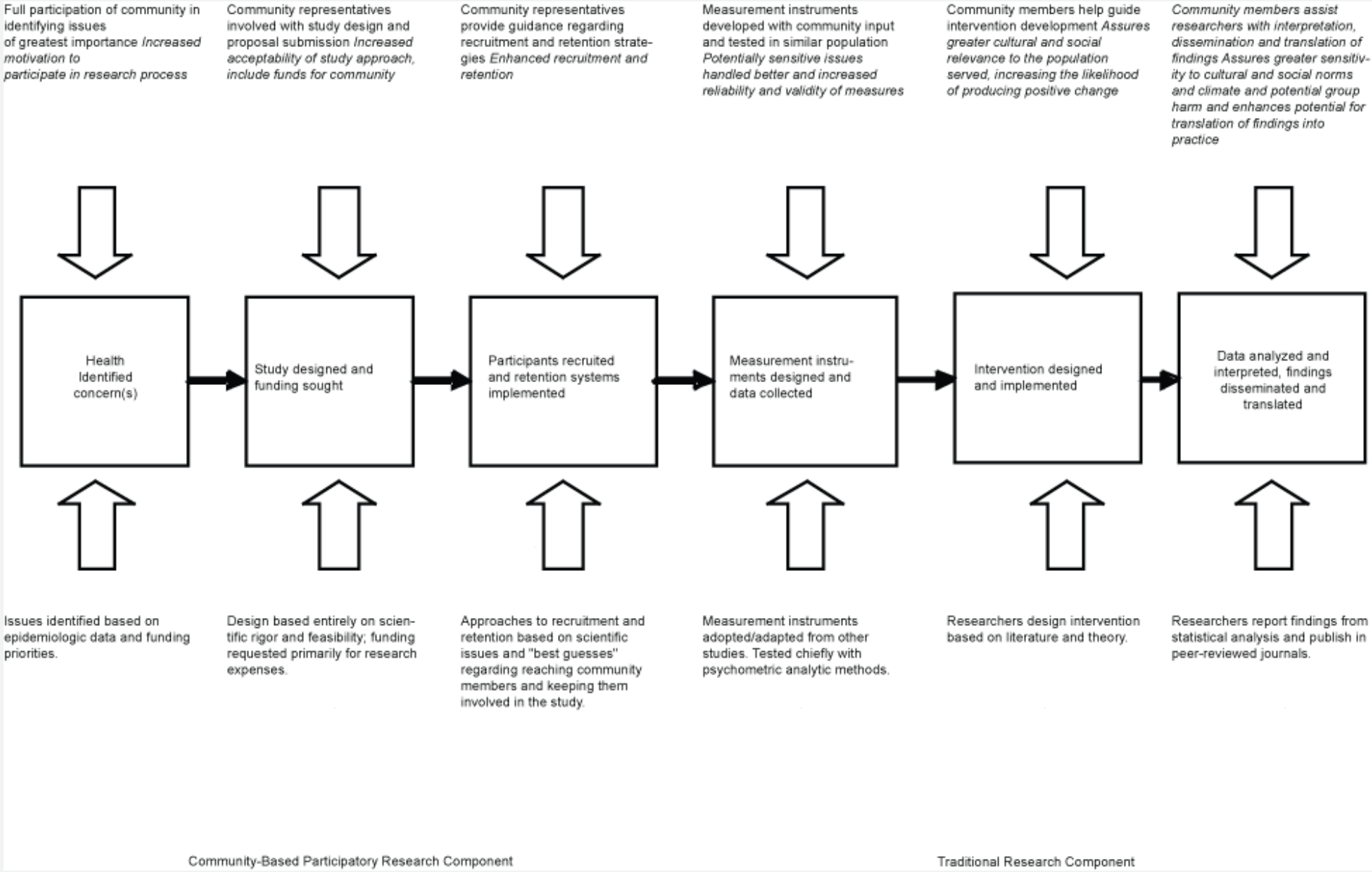
- **Time and long-term commitment**

Sustainability

CBPR: rationale

- There is a growing recognition that "traditional" research approaches have failed to solve complex health disparities.

- Increasing understanding of importance of local and cultural context


Full participation of community in identifying issues of greatest importance *Increased motivation to participate in research process*
Community representatives involved with study design and proposal submission *Increased acceptability of study approach, include funds for community*
Community representatives provide guidance regarding recruitment and retention strategies *Enhanced recruitment and retention*
Measurement instruments developed with community input and tested in similar population *Potentially sensitive issues handled better and increased reliability and validity of measures*
Community members help guide intervention development *Assures greater cultural and social relevance to the population served, increasing the likelihood of producing positive change*
Community members assist researchers with interpretation, dissemination and translation of findings Assures greater sensitivity to cultural and social norms and climate and potential group harm and enhances potential for translation of findings into practice
Health Identified concern(s)
Study designed and funding sought
Participants recruited and retention systems implemented
Measurement instruments designed and data collected
Intervention designed and implemented
Data analyzed and interpreted, findings disseminated and translated
Issues identified based on epidemiologic data and funding priorities.
Design based entirely on scientific rigor and feasibility; funding requested primarily for research expenses.
Approaches to recruitment and retention based on scientific issues and "best guesses" regarding reaching community members and keeping them involved in the study.
Measurement instruments adopted/adapted from other studies. Tested chiefly with psychometric analytic methods.
Researchers design intervention based on literature and theory.
Researchers report findings from statistical analysis and publish in peer-reviewed journals.
Community-Based Participatory Research Component
Traditional Research Component

Traditional research components vs CBPR research components

Traditional Research Approach	**Community-engaged Research**	
	Research with the community	***CBPR***
Researcher defines problem	Research IN the community, or WITH the community	Community identifies problem or works with researcher to identify problem
Research In or ON the community	Research WITH community as partner	Research WITH community as full partner
People as subjects	People as participants	People as participants and collaborators
Community organizations may assist	Community organizations may help recruit participants & serve on Advisory Board	Community organizations are equal partners with researchers
Researchers gain skills & knowledge	Researchers gain skills & knowledge, some awareness of helping community develop skills	Researchers and community work together to help build community capacity
Researchers control process, resources & data interpretation	Researchers control research, community representatives may help make minor decisions	Researcher & community share control equally
Researchers own data, control use and dissemination	Researchers own data & decide how will be used and disseminated together	Data is shared, researchers & community decide its use and dissemination

Why CBPR?

- Social equity and justice
  - Colorectal cancer screening disparities are greatest in those:
    - With no usual source of care
    - Uninsured
    - Recent immigrants
- Increasing interest in use of research to implement and disseminate best practices
- Increasing community and funder demands for community-driven research
- "Community-level" variables
  - Social determinants of health
    - Income, insurance, employment, education, healthcare access

Swan J, Breen N, Coates RJ, Rimer BK, Lee NC. Progress in cancer screening practices in the United States: results from the 2000 National Health Interview Survey. *Cancer.* Mar 15 2003;97(6):1528-1540.

Why CBPR?

- Community research participants are finding that they do not necessarily enjoy the benefits of their participation in research

- Relevance of research in which they don't participate?
  - Degrades trust in research
  - Degrades trust in researchers

- *Community-based interventions are conducted within populations to whom the benefits are directly targeted*

Benefits and Challenges of CBPR

Benefits

- New views
- Resources
- Results more easily translatable into practice
- Data for health improvement
- Visibility and voice for community
- Increased capacity for both researcher and community partners

Challenges

- Trust
- Time
- Awareness of potential positive and negative consequences of this approach
- Scientific rigor
- Clashing perspectives and responsibilities
- Access to and ownership of data
- Dissemination

Is CBPR right for you?

Is opportunism and self-interest driving the agenda?

Do you and your team have the necessary skills?

Are you as a researcher uncomfortable with changing your methods and/or approach to working with participants?

Are you a community member who simply wants an intervention or community service but who has no interest in research questions?

Do the ethical considerations related to burden and benefits to the community outweigh potential research benefits?

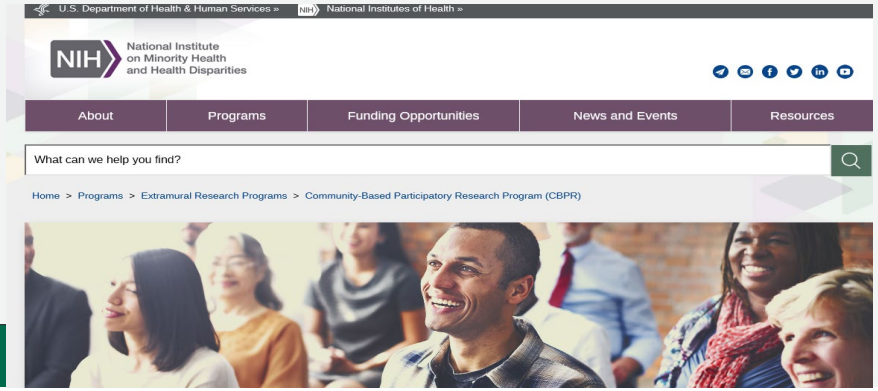
What if you don't "buy into" the values and principles of CBPR?

Objectives

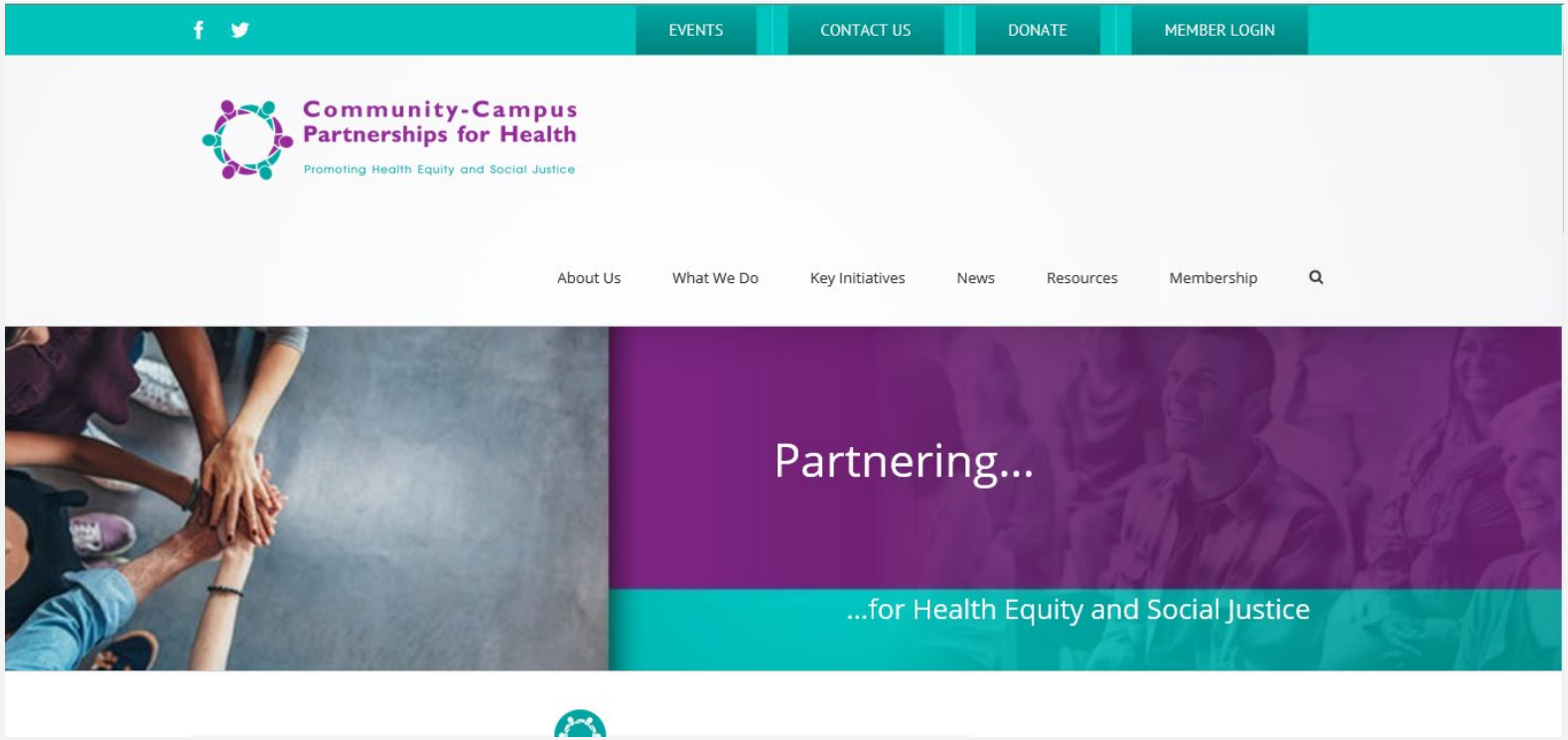
- Define and review definition of CBPR
- Discuss the key principles of CBPR
- Discuss opportunities for CBPR training and implementation in medical school

Models of CBPR training

- Multiple fields: education, organizational science, nursing, public health

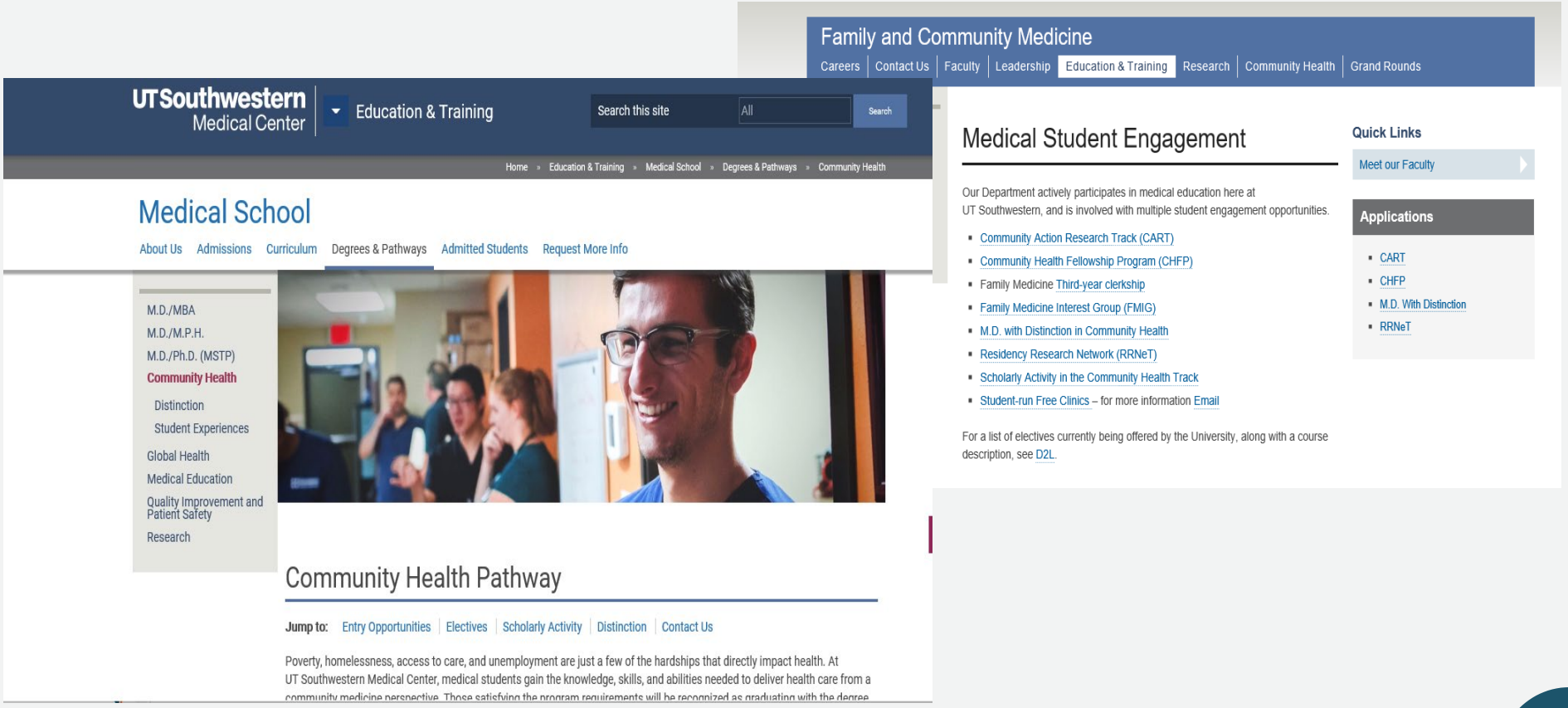


Models of CBPR training

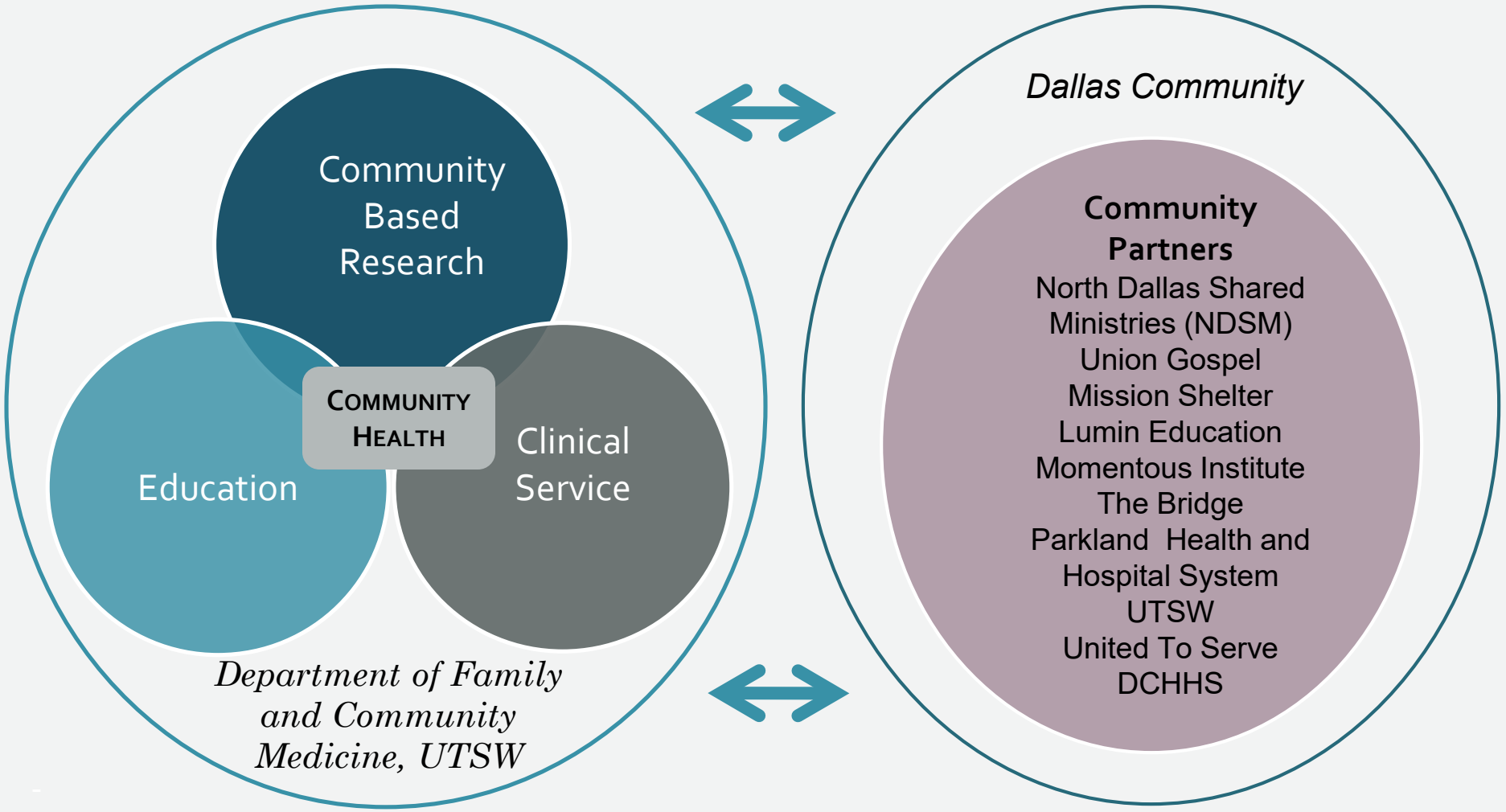


https://www.ccphealth.org/

Models of CBPR training, our experience



https://www.utsouthwestern.edu/education/medical-school/degrees-pathways/md-community-health/

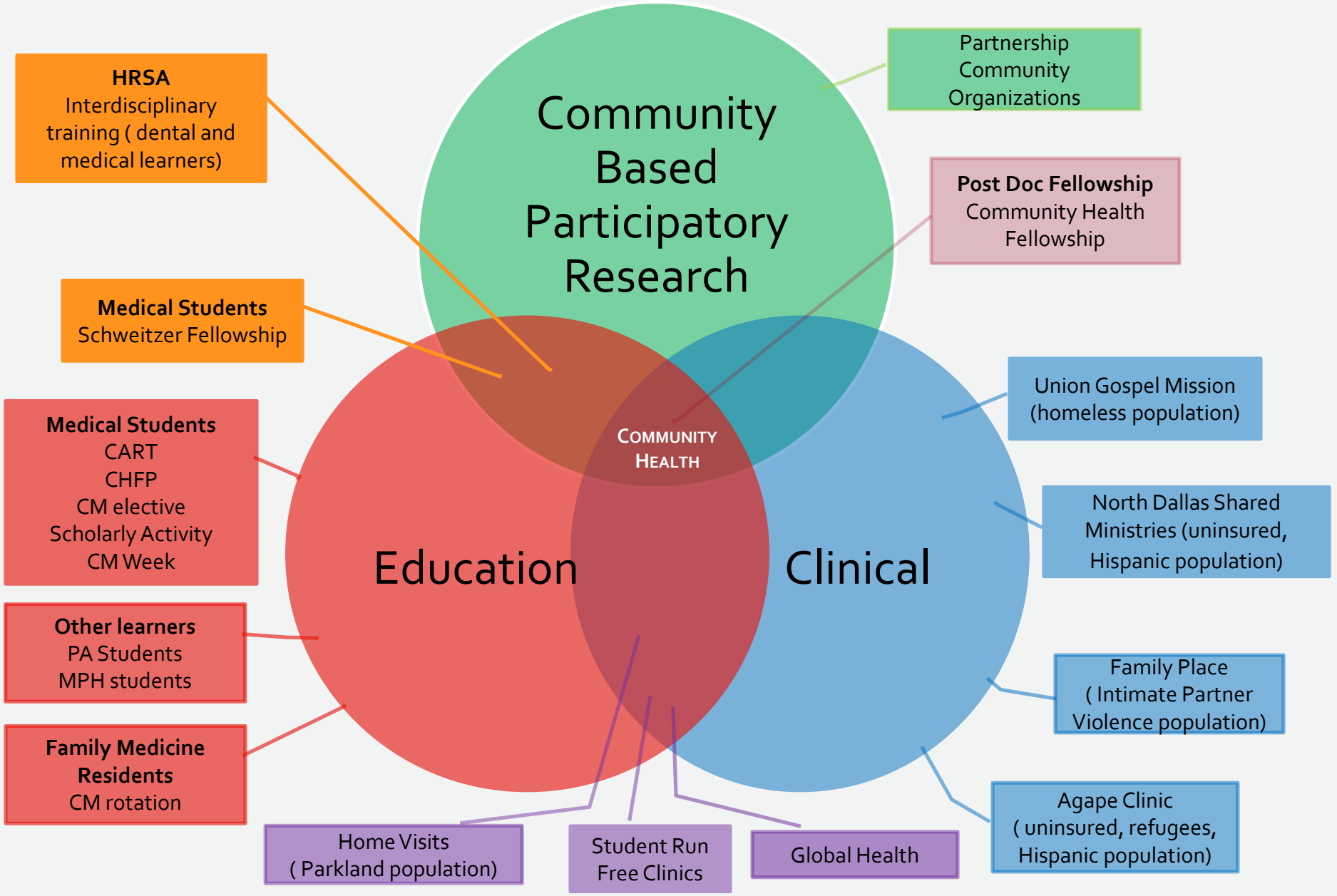


Community Action Research Track (CART)
Community Action Research Experience (CARE,FM residency)
Community Health Fellowship Program (CHFP)
Distinction in Community Health

Students' Projects
Community Medicine Fellowship (Postdoc)
Global Health Preclinical Elective
Community Medicine Rotation (FM Residency)
Student run free clinics

Community Health framework

UTSW Department of Family and Community Medicine



CBPR resources

- https://www.ccphealth.org/

  (resources)

- https://napcrg.org/resources/casfm/participatory-research-in-primary-care/

CBPR and clinical practice

J Cancer Educ. 2019 Mar 13. doi: 10.1007/s13187-019-01511-8. [Epub ahead of print]

Knowledge, Attitudes, and Practices Regarding Skin Cancer and Sun Exposure among Homeless Men at a Shelter in Dallas, TX.

Joseph A[1], Kindratt T[2], Pagels P[1], Gimpel N[3].

Author information

Abstract

This cross-sectional study evaluated the knowledge, attitudes, and practices regarding skin cancer and sun exposure among homeless men (n = 75). A 21-item survey was given to men residing at Calvert Place Men's Shelter in Dallas, TX. Results indicated that 49% knew that a change in a mole's appearance and a sore that does not heal were signs of skin cancer. Black homeless men were less likely to know that people with dark skin could get skin cancer and that sunscreen should be applied 15-30 min before sun exposure compared to white and other subgroups ($p < .05$). People were more likely to agree that sun protection is important (median = 5.0), but less likely to agree that they were at risk for skin cancer (median = 3.0). White men had higher levels of agreement that melanoma was dangerous compared to other racial/ethnic groups ($p = 0.0224$). Over half (52%) of individuals reported being in the sun often, yet only 21% reported the use of sunscreen. Most (71%) homeless men had never checked themselves for skin cancer and only 13% reported ever being screened by a health professional for skin cancer. Increased skin cancer education and increased screening efforts should be implemented to better protect the homeless population at Calvert Place from skin cancer.

KEYWORDS: Homeless; Skin neoplasms; Sun exposure; Underserved

J Community Health. 2019 Apr;44(2):332-338. doi: 10.1007/s10900-018-0591-0.

Awareness and Knowledge of Human Papilloma Virus and Cervical Cancer in Women with High Pap Uptake.

Alafifi R[1], Kindratt TB[2], Pagels P[3], Saleh N[4], Gimpel NE[5].

Author information

Abstract

This cross-sectional study explored knowledge, awareness, and health practices surrounding cervical cancer prevention and screening. Patients (n = 129) were recruited from three community clinics of underserved populations in Dallas, Texas. Women between ages 18-65 were surveyed using a self-administered questionnaire to evaluate their knowledge, awareness, and attitudes related to pap tests, human papilloma virus (HPV), HPV vaccines, and cervical cancer. Most women reported having a pap test in the past 3-5 years (86.6%). Over half knew that there was an increased risk of cervical cancer with an HPV infection, abnormal pap test, or both (52%). However, less than half of women knew the purpose of a pap test (40%), the purpose of the HPV vaccine (48%), or the transmission mode of HPV (25%). Over half of participants first heard about a pap test from a doctor (60%), about one quarter from their mother (24%), and less than a quarter from others (16%). More than half of women were aware of HPV (55%), while less than half were aware of the HPV vaccine (48%). Overall, we found that while most women had a high uptake of pap tests, they had low knowledge of the purpose of a pap test, the HPV vaccine, and transmission mode of HPV. They also had low awareness of HPV and the HPV vaccine. Given that almost all cases of cervical cancer are due to HPV infection, future studies should aim to further explore the gap between knowledge and awareness of HPV and pap uptake.

KEYWORDS: Cervical cancer screening; Community-based participatory research; HPV vaccine; Pap test; Underserved

CBPR and clinical practice

J Acad Nutr Diet. 2012 Nov;112(11):1852-8. doi: 10.1016/j.jand.2012.06.357. Epub 2012 Sep 18.

The cardiovascular health of urban African Americans: diet-related results from the Genes, Nutrition, Exercise, Wellness, and Spiritual Growth (GoodNEWS) trial.

Carson JA[1], Michalsky L, Latson B, Banks K, Tong L, Gimpel N, Lee JJ, Dehaven MJ.

Author information

Abstract

African Americans have a higher incidence of cardiovascular disease (CVD) than Americans in general and are thus prime targets for efforts to reduce CVD risk. Dietary intake data were obtained from African Americans participating in the Genes, Nutrition, Exercise, Wellness, and Spiritual Growth (GoodNEWS) Trial. The 286 women and 75 men who participated had a mean age of 49 years; 53% had hypertension, 65% had dyslipidemia, and 51% met criteria for metabolic syndrome. Their dietary intakes were compared with American Heart Association and National Heart, Lung, and Blood Institute nutrition parameters to identify areas for improvement to reduce CVD risk in this group of urban church members in Dallas, TX. Results from administration of the Dietary History Questionnaire indicated median daily intakes of 33.6% of energy from total fat, 10.3% of energy from saturated fat, 171 mg cholesterol, 16.3 g dietary fiber, and 2,453 mg sodium. A beneficial median intake of 2.9 cups fruits and vegetables per day was coupled with only 2.7 oz fish/week and an excessive intake of 13 tsp added sugar/day. These data indicate several changes needed to bring the diets of these individuals--and likely many other urban African Americans--in line with national recommendations, including reduction of saturated fat, sodium, and sugar intake, in addition to increased intake of fatty fish and whole grains. The frequent inclusion of vegetables should be encouraged in ways that promote achievement of recommended intakes of energy, fat, fiber, and sodium.

TRIAL REGISTRATION: ClinicalTrials.gov NCT00669630.

CBPR clinical practice and training

- Health Fairs
- Student-Run Free Clinics

Medical Follow-up through American Heart Association's "Check. Change. Control" program in an Underserved, High-Risk Population

Derek Udeh, BS, Nikita Agarwal, BA, Manasa Dutta, BA, and Nora Gimpel, MD

UTSouthwestern Medical Center

American Heart Association

Background

- United to Serve (UTS) is an annual health education and screening fair coordinated by UT Southwestern (UTSW) students with the aid of faculty and staff.
- The Health Awareness Program (HAP) evaluates the impact of UTS and establishes a follow-up system for participants to access medical homes in Dallas.
- HAP began a community partnership with the American Heart Association (AHA) in 2019, so participants could access the AHA's "Check. Change. Control" (CCC) resources.
- CCC is an evidence-based hypertension program that utilizes blood pressure self-monitoring to empower participants to take ownership of their cardiovascular health.
- CCC has been implemented in corporate settings, but its effect in underserved populations has yet to be seen.

Purpose

- To evaluate the ability of HAP in assisting UTS participants to establish a medical home.
- To evaluate the effect of AHA's CCC program in decreasing cardiovascular disease (CVD) risk in a community setting.

Methods

- **Participants:** HAP participants defined as UTS patrons ≥18 years who consented to receive follow-up calls regarding their primary care physician (PCP) visits and CVD risk factors.
- **Measures:** Blood glucose, BMI, blood pressure, and lipid panel measured for each participant on site to calculate atherosclerotic cardiovascular disease (ASCVD) risk.
- **Intervention:** Phone calls with medical home information provided to patrons. Participants received information about CCC events. Those who attend CCC sessions receive education on CVD risk reduction: diet, exercise, and self-monitoring blood pressure.
- **Follow-up:** Participants are contacted by phone at 1, 3, 6, and 9-month intervals within the year to determine whether they have visited a physician and to provide healthcare access information.

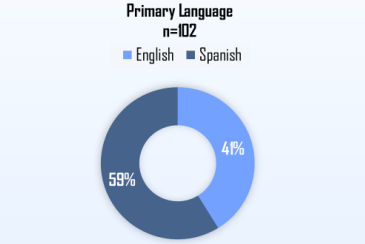
Cohort Demographics and Screening Data

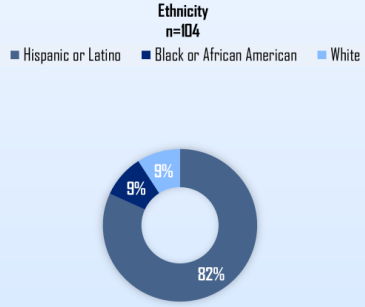
Cohort Screening Data

Measurement	Mean	Standard Deviation
Blood Glucose (n=98)	106.3	50.7
BMI (n=83)	29*	6.2
Systolic Blood Pressure (n=98)	129.2*	17.2
Diastolic Blood Pressure (n=98)	78.8	9.6
Total Cholesterol (n=96)	190.2*	38.9
HDL (n=96)	48.8	15.0
LDL (n=96)	117.5 *	33.7
Triglycerides (n=96)	154.9	80.5

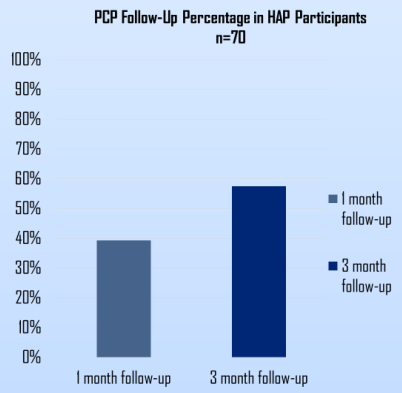
2019 cohort data

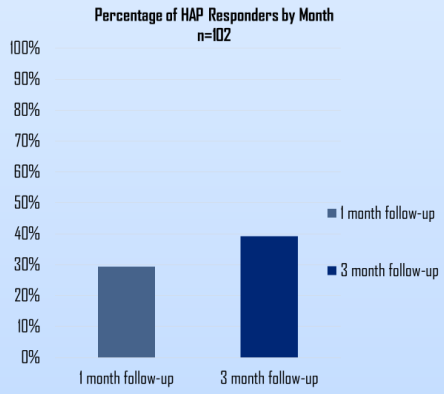
* Values outside of the normal range





Health Awareness Program (HAP) Follow-Up Data





Results

- The majority of UTS population is Hispanic.
- In 2019, 46% (n=100) of UTS health fair attendees (n=703) consented to participate in HAP.
- Of HAP participants, 79% were uninsured and 38% were enrolled in CCC.

Conclusions

- HAP has identified community members who lack a PCP follow-up and, through phone calls, has helped participants establish a medical home after a community health fair.
- The addition of CCC to HAP can be valuable in engaging participants in reducing CVD risks and promote self management .

Future Steps

- Determining whether to use HAP as a data gathering tool or an intervention.
- To improve effectiveness in contacting participants for better data collection.
- To evaluate continuity of participants in their medical home and identify clinic locations.
- To identify returning participants to UTS and evaluate their long-term PCP follow-up.
- To improve interventions that will ensure sustainability with the community every year.
- To assess change in participants' CVD risks by inquiring about medication regimen changes.

Acknowledgements

Special thanks to Suzette Smith, Cathy Day, and UTS volunteers!

Contact Information:
Derek.Udeh@UTSouthwestern.edu
Nikita.Agarwal@UTSouthwestern.edu
Manasa.Dutta@UTSouthwestern.edu
Nora.Gimpel@UTSouthwestern.edu

STUDENT-RUN FREE CLINICS: ENHANCING THE ABILITY TO EDUCATE MEDICAL STUDENTS AND COLLABORATE WITH OUR COMMUNITIES

Whitney Stuard, Kelly Kiser, Areon Thomas, Nikhitha Thrikutam, Amber Khan, Pooja Prabhakar, Tina Tran, Michaela Modén, Tu Bui, James Wagner M.D#, Patti Pagels, PA-C*, Nora Gimpel, M.D*
*The University of Texas Southwestern Medical Center, Dallas, Texas, USA

Background

- Student-run free clinics (SRFC) have become an increasingly recognized entity over the past few decades in providing healthcare to those with limited resources.[1]
- These clinics provide important medical services for an underserved part of the community.
- In addition, service learning at free clinics benefits students in a number of ways.
- Students develop clinical skills such as taking a history, performing a physical exam, and building a differential diagnosis.[2]
- At UT Southwestern Medical Center (UTSW), the increasing number of students volunteering at an expanding number of free clinics has created the need of enhancing communication, coordination and integration of the clinics' educational and service activities.

Objective

The goal of this project is to enhance the Free Clinics Committee's (FCC) ability to

- Educate students in clinical practices
- Support their innovative research
- Teach mentorship skills.

Education: To improve the real-world clinical education provided to students by the individual free clinics.
Collaboration: To provide channels to enhance communication between clinics and students.
Sustainability: To create the structure that could be sustained and further developed by future classes of medical students.

Methods

- The committee is representatives that are elected from UTSW SRFC managers.

Faculty leadership has led to the development of

- Shared protocols for recruiting and credentialing faculty members volunteering in the FCC clinics
- Grant writing and funding of special FCC projects
- Stimulating scholarly activity among SRFC participants.

Each representative chooses a sub-committee to chair. The sub-committees are:

- Research and Grants Patient and Community Outreach
- Education and Training
- FCC Summit planning
- Volunteer Coordination
- Physician Recruitment and Training

Results

During the period from 3/3/2016 – 12/10/2016 the FCC and SRFC accomplished the following:

1. 2400.75 volunteering hours with over 557 student volunteers[3]
2. Two student-led workshops on clinical skills necessary for adequate patient care in the SRFCs
3. A summit with all current managers of the SRFCs in which the FCC leadership was transferred to the newest Class and a discussion of the FCC project results. It also served as an educational meeting for the 2017 managers about the SRFC patient demographics and the social/religious/financial obstacles they face.
4. A central source of funding was established via the UTSW academy of Teachers (SWAT) grant and with the FCC Clinical Skills Workshops
5. Established a central website (SignUp.com) that organizes and tracks volunteering hours and posts opportunities for volunteering.

Image 1: Student Run Free Clinic managers and participating Free Clinics.

AGAPE CLINIC

The Monday Clinic
at North Dallas Shared Ministries

AMERICAN ASSOCIATION OF PHYSICIANS OF INDIAN ORIGIN
AAPI

Union Gospel Mission-Dallas

Image 2: SRFC's who have representatives within FCC

Conclusions

The FCC has and will continue to help integrate the variety of student-run free clinics at UTSW.

- The FCC has created easy access for medical students to Medical Service Learning and Scholarly Activities and Clinical Skill training.
- It created a common starting point for clinical educators interested in working with UTSW students on Service learning projects .
- It established a stable transferal of leadership process that allows for students of the Freshman Medical Class (PC1) to assume the managerial role.
- It has also produced a reliable source of clinical knowledge and guidance for the Student managers to assume their managerial roles.

Finally, this project represents an innovation in student-faculty partnership toward promoting the following in at all UTSW free clinics:

- Community service
- Optimal patient care
- Scholarly activity for students
- Health care administration that captures the potential of service learning
- Education for preclinical, clinical students, and other health professions individuals

References

1. Smith S, Thomas R3rd, Cruz M, Griggs R, Moscato B, Ferrara A. Presence and characteristics of student-run free clinics in medical schools. JAMA. 2014;312:2407–10.
2. Seifert LB, Schaack D, Jennewein L, Steffen B, Schulze J, Gerlach F, Sader R. Peer-assisted learning in a student-run free clinic project increases clinical competence. Med Teach. 2016 May;38(5):515-22.
3. VS activity report

Acknowledgments

Special thanks to the UTSWSRFC and the faculty advisers who have assisted us in making the FCC possible.

Journals Publishing CBPR

Public Health

- *American Journal of Health Behavior*
- *American Journal of Public Health*
- *Canadian Journal of Public Health*
- *Health Education and Behavior*
- *Health Promotion International*
- *Health Promotion Practice*
- *Journal of Public Health Management and Practice*
- *Public Health*
- *Public Health Nursing*

Community Health:

- *American Journal of Community Psychology*
- *Ethnicity & Disease*
- *Journal of Community Health*
- *Journal of Epidemiology and Community Health*
- *Journal of Urban Health*
- *Progress in Community Health Partnerships: Research, Education, and Action*
- *Education for Health: Journal of Primary Care and Community Health*
- *Perspectives on Medical Education*
- *Advances in Health Sciences Education*