Scripps Translational Science Institute

Scripps Whittier Diabetes Institute

Toolbox for Conducting Community-Engaged Research

Acknowledgments

This manual was created, like all good community work, through a collaborative process that included the community engagement team at Southern California and Translational Science Institute Office of Community Engagement, Scripps Transitional Science Institute Community Engagement Program, Scripps Whittier Diabetes Institute, Project Dulce as well as members from the communities we serve. Thank you for your support and feedback!

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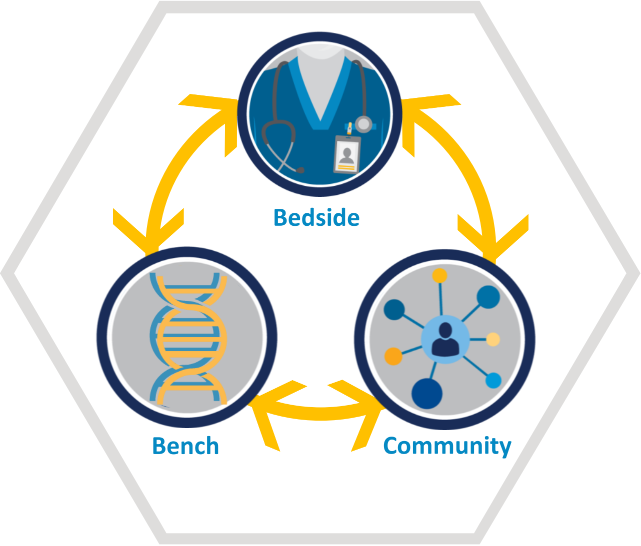
Overview of the Scripps Translational Science Institute

Founded in 2006, the Scripps Translational Science (STSI: www.stsiweb.org) is a multi-disciplinary **translational research** partnership between The Scripps Research Institute, Scripps Health, San Diego State University, and the San Diego Super computer Center at the University of California, San Diego. STSI is one of 62 research institutes that have been created through the Clinical Translational Science Award (CTSA) program. The CTSA is funded by the National Institutes of Health (NIH) to support research across all phases of the translational science spectrum, from basic discovery to clinical and community research. STSI is the only member of the CTSA consortium that is not affiliated with an academic university.

Under the leadership of Eric J. Topol, M.D., STSI has created major programs in both research and education/training that bridge science with medicine, and academia with industry. Research at STSI targets 3 main areas: **Digital Medicine, Genomics, Cardiometabolic Disease** including Diabetes (case examples from each of these areas will be presented), and emphasizes all dimensions of translation:

- Traditional bench to bedside,
- Bedside to bench and back to bedside, and
- Bedside to the community and the practice of medicine.



Community Engagement

Involving the community and collaborating with its members are integral components of the translational research process. Over the last two decades, health research and practice have increasingly employed Community-Engaged Research (CEnR), defined as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interests, or similar situations to address issues affecting the wellbeing of those people[1]." The primary goals of CEnR are to build trust, enlist new resources and allies, create better communication, and improve overall health outcomes as successful projects evolve into lasting collaborations[2].

The **STSI Community Engagement Program (STSI-CEP)** is led by the nationally recognized Scripps Whittier Diabetes Institute, which has provided the San Diego community with the most advanced diabetes care, education, and support for more than 30 years. In addition to leading its own CEnR projects in diabetes and cardiometabolic disease, the STSI-CEP aims to enhance the involvement of community in other areas of research.

CEnR Quiz Question #1: Community-Based Participatory Research (CBPR) is a synonym for Community-Engaged Research (CEnR).

A. True B. False

CEnR Consultation Services

To this end, the STSI-CEP provides consultation services to researchers, clinical providers and community organizations who are interested in incorporating CEnR principles in a new or ongoing project. The goal of STSI-CEP consultation services is to ensure researchers effectively engage with community organizations and key stakeholders to identify **research questions** and produce results that are relevant to the community. Consultation topics include: education on CEnR principles; identifying and developing community partnerships; **methods** for effective collaboration throughout the research process; CEnR methodology and results **dissemination**; and ethical issues in CEnR. To obtain consultation services, please contact us at: CommunityEngagement@scrippshealth.org

STSI Community Engagement Program Team	
Athena Philis-Tsimikas, MD Director, Community Engagement Corporate Vice President, Scripps Whittier Diabetes Institute, Scripps Health 858-678-7046 Tsimikas.athena@scrippshealth.org	**Monica Ruiz, MA** Supervisor of Community Programs and Research Scripps Whittier Diabetes Institute 858-678-7049 Ruiz.monica@scrippshealth.org
Linda C. Gallo, PhD Institute for Behavioral and Community Health San Diego State University lgallo@mail.sdsu.edu	**Addie Fortmann, PhD** Senior Research Scientist Scripps Whittier Diabetes Institute 858-678-7097 Fortmann.adelaide@scrippshealth.org
Magdalena Hernandez Community Health Promoter Scripps Whittier Diabetes Institute Hernandez.magdalena@scrippshealth.org	**Alma Ayala** Community Health Promoter Scripps Whittier Diabetes Institute Ayala.alma@scrippshealth.org

Challenge: Researchers and community members have different goals. Partnership building doesn't lead to tenure or promotions, but publications do.

Possible Solution: Utilize multiple strategies to disseminate research findings and illustrate the impact of research and meet the needs of both the researcher and the community. Traditional academic dissemination (e.g. papers, presentations, posters) and community-focused dissemination (e.g. community forums, newspaper articles, radio announcements) can also be used to build capacity in individuals to answer community questions.

Challenge: Not every person works well with evidence-based (aka "one-size-fits all") models or programs.

Possible Solution: Understanding the population you are working with and adapt models or programs to meet the needs and/or reflects the characteristics of that population.

Toolbox for Conducting CEnR

STSI supports CEnR that aims to bring researchers and community partners together to share their knowledge, skills and resources with a common goal of improving community health. This guide provides researchers and community partners with CEnR tools for every phase of a project (e.g. relationship building, proposal development, project execution and dissemination). Throughout this guide, various terms are used that you may or may not be familiar with. **These terms appear in blue**, and are defined in the glossary at the end of this guide. We encourage you to test your knowledge with the CEnR quiz questions that are placed throughout the text; the answer key is located at the end of this guide. Remember, the STSI-CEP is also available to provide consultations and technical assistance on the processes outlined throughout this guide.[3]

What is CEnR?

Before we describe CEnR in detail, it is important to define "community" and to explain what we mean by "research". *Community* is commonly defined as a group of individuals and/or organizations who are linked by specific geographical or political boundaries and share common interests, values, networks and/or demographic characteristics. In this guide, the terms *community* and *community partner* are used interchangeably to refer to any of the various layers of community (see Figure 1).

Community Layers
(1) Patients/Participants
(2) Support Persons/Immediate Social Network
(3) Non-licensed Personnel
(4) Clinicians & Non-clinician Licensed Practitioners
(5) Health System Administration
(6) Researchers, Fellows, Trainees *(e.g., across STSI, SWDI, SDSU…)*
(7) Inter-CTSA
(8) Community Leaders/Policy Makers

Figure 1. Who participates in Community Engaged Research.

CEnR Quiz Question #2:
Which of the following are included in the definition of ***community?***
(Select all that apply).
A.Hospitals
B.Community clinics
C.Patients
D.Patients' support persons
E.Schools

Research can be broadly defined as the search for knowledge, or as any systematic investigation, to establish new facts, solve new or existing problems, prove new ideas, or develop new theories. Research can take diverse forms, serve many purposes and be conducted in various laboratory, clinical, and/or community settings.

In traditional, "community-placed" research, the researcher initiates the research question and develops the study design with little-to-no community input. In contrast, in CEnR, the community plays a primary role in defining relevant research questions, conducting the research, and disseminating the results. Although it is commonly a researcher who initiates a partnership with the community, community members may also choose to approach researchers about a research question they are interested in pursuing. The degree to which the community becomes involved in CEnR can vary greatly across partnerships; however, common characteristics of CEnR are listed below.[4]

Characteristics of CEnR

- Community members and researchers contribute equally and in all or most phases of research.
- Trust, collaboration and shared decision making are integral parts of the process.
- Findings and knowledge benefit all partners.
- Researchers and community members recognize each other's expertise in a bidirectional, co-learning process.
- Researchers embrace the skills, strengths, resources and assets of local individuals and organizations.[5]
- The community is recognized as a unit of identity.
- Emphasis is on multiple determinants of health.
- Partners commit to long-term research relationships.
- Core elements include local capacity building, systems development, and empowerment and sustainability.

CEnR Quiz Question #3: In CEnR, what aspects of the research process can community members become involved with? *(Select all that apply).*

A. Research question generation
B. Grant writing
C. Data collection
D. Analysis and interpretation of findings
E. Dissemination

CEnR Quiz Question #4:
Conducting CEnR takes longer than traditional, non-CEnR.

A. True B. False

Challenge: Too many competing demands on community partners’ time takes time away from other responsibilities.

Possible Solution: Engage in dialogue early on (program-wise, budget-wise); researchers need to understand the unique challenges of the particular community partners and find creative ways to conduct research and minimize time disruption, time commitment, and expenses. Community partners need to communicate to researchers how to be respectful of their work and their challenges.

Challenge: Community organizations don’t always have the infrastructure or capacity to conduct research (e.g. data analysis, technology, etc.)

Possible Solution: Assess the capacity the community organization has to conduct research. Understand the power differential. Work with organizations that are “research ready” and offer training and/or technical assistance to clinics /organizations that may need capacity building and are willing to learn how to do research.

CEnR in Action #1: Diabetes/Genomics

Liliana Uribe-Bruce, MD
Athena Philis-Tsimikas, MD
Maria Isabel Garcia, RN, MSN
Scripps Translational Science Institute
Scripps Whittier Diabetes Institute

Linda C. Gallo, PhD
Institute for Behavioral & Community Health,
San Diego State University

Scripps San Diego Diabetes Genebank Program

*What is **genomics**?*

Genomics researchers can look at an individual's genetics to understand how traits (e.g., eye color) or disease are passed on within families. Although Latinos are at disproportionate risk for developing type 2 diabetes, there has been low participation by this group in diabetes genomics research. Thus, there is a need to carefully identify barriers to research participation, increase awareness, and facilitate access to clinical and genomics research among Latinos and other underrepresented groups.[6,7]

To address this gap, Dr. Liliana Uribe-Bruce, an endocrinologist by training, initiated the San Diego Diabetes Genebank program during her post-doctoral STSI Masters training in Clinical Investigation with an emphasis on Community-Based Research and Genomics. The Scripps San Diego Diabetes Genebank – Mexican Ancestry Cohort, attended Federally Qualified Health Centers in Southern California to collect and store blood and/or saliva samples and health information from Latinos of Mexican ancestry who were diagnosed with, or at risk for type 2 diabetes. Similar to other genebanks, the goal was to use the stored samples in future studies to find new ways to detect, treat, and maybe even prevent or cure type 2 diabetes.

How did the program meet the needs of the community?

Initially, it didn't! The bio bank (blood storage bank) was purchased, the **Institutional Review Board** (research ethics review committee; all research studies must pass this review before the consenting process begins) approved the study, and consenting was underway. But just then, the research team began to notice that: (1) some participants did not genuinely understand the concept of genomics, while (2) others seemed uncomfortable participating in a formal research study. The new challenge researchers faced was ensuring that the community understood exactly they were consenting to (i.e., full disclosure with comprehension are requirements of the informed consent process), and that they were comfortable participating in the study.

In response to this dilemma, the research team worked with the community to develop a culturally-tailored module to educate its members on the basics of genomics. The interactive education module was designing using a PowerPoint presentation program, which was 30 minutes long and was facilitated by a **peer educator** (i.e., lay people from the community who support health promotion by engaging and educating their peers). A "Survey about Heredity and Diabetes" was also created to make sure participants received the education they needed (the survey was completed before and after the education module), and to understand the communities opinions about heredity and health. Both the education module and the survey were created with input from patients, community health workers, members of academic institutions, and others.

The result, what we learned!

Survey results confirmed what researchers suspected – despite holding positive and altruistic attitudes towards participating in this type of research, members of the Latino community lacked important information about genetics.

Seeking community feedback is key!

Researchers assumed that the community was aware of, and comfortable with the genomics research. However, this was not the case. Therefore the research team had to take steps back to engage and educate the community before they were recruited to participate in the study. The community plays a big role in defining relevant questions that not only make sense, but also meet the needs of the community. Trust, collaboration and shared decisions making are an integral part of the process. It all starts with open communication!

A Comparison of Research Approaches

	Community-Placed Research (Traditional)	Community-Engaged Research	Community-Based Participatory Research
Research Objective	Based on researchers' interest and funding priorities	Community input identifying local relevant issues	Full participation of community in identifying issues of greatest importance
Study Design	Design based entirely on scientific rigor and feasibility	Researchers work with community to ensure study design is culturally acceptable	Community intimately involved with study design
Recruitment & Retention	Based on scientific issues and "best guesses" regarding how to best reach community members	Researchers consult with community representatives on recruitment & retention strategies	Community representatives provide guidance on recruitment and retention strategies and aid in recruitment
Instrument Design	Instruments adopted/ adapted from other studies. Tested chiefly with psychometric analytic methods.	Instruments adopted from other studies and tested/ adapted to fit local populations	Instruments developed with community input and tested in similar populations
Data Collection	Conducted by academic researchers or individuals with no connection to the community	Community members involved with some aspects of data collection	Conducted of the community, to the by members extent possible based on available skill sets. Focus on capacity building.
Analysis & Interpretation	Academic researchers own the data, conduct analysis and interpret findings	Academic researchers share results of analysis with community members for comments and interpretation	Data is shared; community members and academic researchers work together to interpret results
Dissemination	Results published in peer-reviewed academic journals	Results disseminated in community venues as well as peer-reviewed journals	Community members assist academic researchers to identify appropriate venues to disseminate results (public meetings, radio, etc.) in a timely manner and community members involved in dissemination. Results also published in peer-reviewed journals.

Challenge: Community members don’t understand how research teams function.

Possible Solution: Provide “Research 101” training for community research partners.

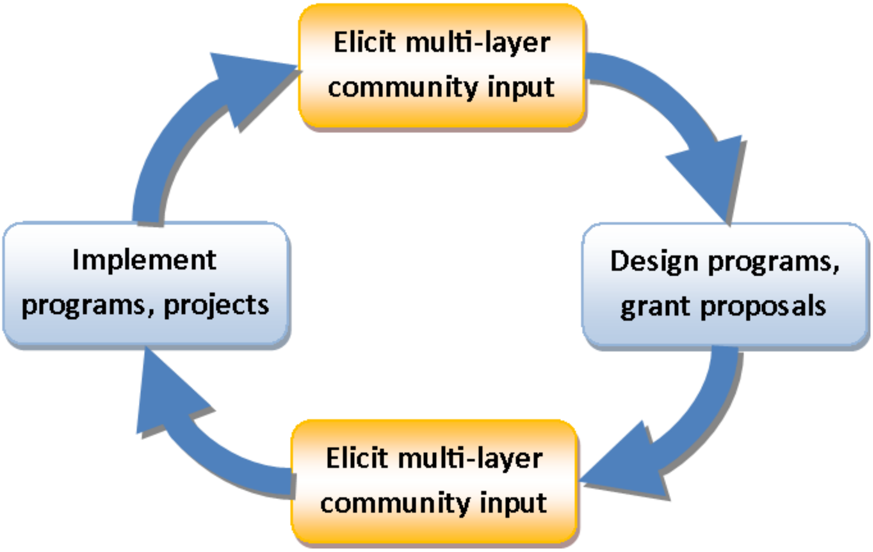
Challenge: Community burn-out exists when there have been previous bad experiences with researchers in “community-placed” studies.

Possible Solution: Build trust with communities early on (before research is initiated). Invest in the communities and leverage relationships.

Challenge: Researchers may not have a real understanding of the needs of the population or even understand what population an organization serves

Possible Solution: Get into the community early and “warm up the community” by participating in community events and activities. Also, have research staff representative of the communities you are working with.

Figure 2

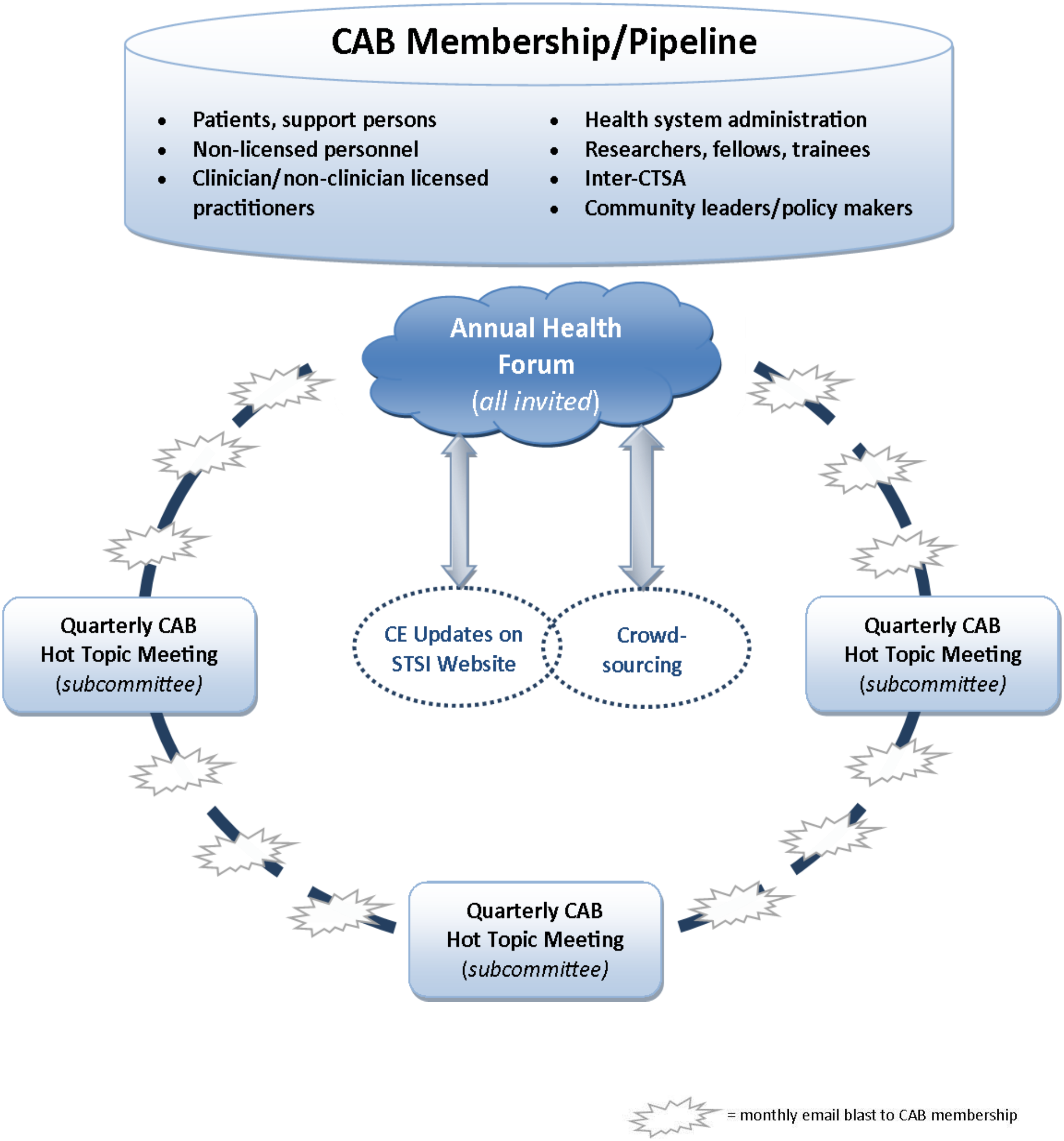


Figures 2 and 3: **Engagement Process.** The community engagement process is never ending. It is best practice to elicit feedback from the community throughout all phases of the research design process as illustrated in Figure 2. How does the STSI-CEP elicit community input? All community members are invited to a yearly annual forum. Feedback from the forum is synthesized and disseminated at through various venues, our community advisory group meetings (held 4 times per year), via the STSI website and through crowdsourcing.

CEnR Quiz Question #5: What roles can community research partners play in your CEnR study? *(Select all that apply).*

A. Community Advisory Board (CAB) members
B. Participants
C. Co-Investigators on a grant proposal
D. Research staff
E. Co-authors on peer-reviewed manuscripts

Figure 3


CAB Membership/Pipeline
Patients, support persons
Non-licensed personnel
Clinician/non-clinician licensed practitioners
Health system administration
Researchers, fellows, trainees
Inter-CTSA
Community leaders/policy makers
Annual Health Forum
(all invited)
CE Updates on STSI Website
Crowd-sourcing
Quarterly CAB Hot Topic Meeting (subcommittee)
Quarterly CAB Hot Topic Meeting (subcommittee)
Quarterly CAB Hot Topic Meeting (subcommittee)
= monthly email blast to CAB membership

Why Do CEnR?

- To facilitate the translation of research into meaningful health improvements for all communities.
- To facilitate the discovery of innovative solutions to difficult and current community health problems.
- To ensure that research questions, data and programs are based on community needs and meet standards of scientific integrity.
- To increase the relevance of research questions, data and programs devised are implemented in concert with those directly affected by the disease.
- To collaborate on a project that can improve sustainability, dissemination, replication and policy impact; community engaged research often has benefits that outlast research.
- To strengthen the research and program development capacity of all involved.[5]

CEnR Quiz Question #6: Researchers who are interested in approaching potential community partners should do so….

A. When they are ready to develop a research question
B. Immediately after developing a research question
C. At least 6 months prior to developing a research question
D. Only after they secure grant funding, so as to not waste the community's time

Benefits for Researchers - Gain entry into communities and to learn about community health needs, assets, and policy implications. By ensuring acceptability and relevance, researchers many find it easier to achieve recruitment goals and study aims.

Benefits for Community Partners - To gain access to research resources (e.g. library holdings, technological support, training opportunities) and knowledge about current evidence- based practices, and methods of program evaluation to create more opportunities for funding and collaboration.

CEnR is not for everyone!

Before starting a project, it’s important that you seriously consider the following questions:

- Do I possess the patience needed to work with a diverse team, to learn things I may not know anything about and teach others my skills and experience?
- Do I have a burning, genuine curiosity about how people live and what other people’s job entails?
- Do I possess or am I willing to learn the interpersonal skills necessary to build long-term lasting partnerships?
- Am I willing and able to mentor and inspire others?
- Do I have the ability to share control, to lead and be led?
- Do I want to make community concerns the focus of my research, project and/or program?
- As a researcher, am I able to supplement my scientific skills with humility?
- As a community partner, I am committed to learning the research process, sharing information on issues that are important to me, and participating on a research team.
- Do I have a commitment to self-evaluate, ensure an equal power distribution exists and develop a mutually respectful partnership with communities?

Challenge: Research participant stigma around a certain disease and/or about participating in research

Possible Solution: Provide community education around scientific literacy issues. Spend time in communities to assess what concerns exist about research participation and address those concerns in a community forum or by other methods.

Challenge: How do you work with community organizations without burdening and/or disrupting their system ?

Possible Solution: Learn about program culture (e.g. what’s appropriate to do in community organizations and what is not) and outside influences that may be impacting the organizations.

CEnR in Action #2: Digital Medicine

Athena Philis-Tsimikas, MD
Maria Isabel Garcia, RN, MSN
Monica Ruiz, MA
Addie Fortmann, PhD
Scripps Translational Science Institute
Scripps Whittier Diabetes Institute

Dulce Digital: A Mobile-Based Self-Management Intervention for Latinos with Type 2 Diabetes

Project Dulce a nationally recognized diabetes self-management and education program was developed by Scripps Whittier Diabetes Institute, the Council of Community Clinics and the county of San Diego. The program uses a nurse-led multidisciplinary team to provide clinical care, and peer educators to deliver diabetes education in federally-qualified health centers (FQHCs) serving disadvantaged (low-income, predominantly Latino) populations in San Diego, CA. Although Project Dulce has improved clinical outcomes and reduced hospital and acute care costs, barriers to access persist (e.g., lack of transportation and childcare, schedule conflicts). Mobile technology has the potential to reduce the barriers and expand the reach of diabetes care and education.

This study investigated a diabetes self-management intervention delivered via mHealth (mobile SMS messaging) in Latinos. A total of 126 Latinos with poorly controlled type 2 diabetes were recruited from FQHCs, and randomized to diabetes care-as-usual or *Dulce Digital.* Dulce Digital participants received 3 types of text messages: educational/ motivational, medication reminders, and blood glucose monitoring prompts; 2-3 messages/day were sent at the beginning of the study, with frequency tapering over 6 months. Study staff monitored blood glucose responses, assessed possible reasons for hyper/hypoglycemia, and encouraged follow up with a provider as needed.

The value community leaders and patient voices bring to the table!

Dulce Digital is an ideal example of a CEnR study. The research team engaged patients and peer educators early on to understand what type of technology-based programs they would be interested in. **Focus groups** (meetings of 8-10 participants to gather information) were held with members of the community to learn about their perceptions and use of cell phones and text messaging, and to get feedback on the program concept. Through group meetings and **key informant interviews**, these and other community members (e.g., community clinic partners) also provided input on the research objective, study design, outreach and recruitment strategies, consenting and **data collection** processes, and the content of the text messages. Once the study started, the same peer educators were involved in the recruitment, consenting and data collection processes. As part of the study protocol, focus groups and surveys were conducted with completed participants to learn about their perspectives on the Dulce Digital, including barriers to participation, and positives/negatives of the texting intervention.

Commitment to a bidirectional partnership = success!

Dulce Digital has not only achieved promising preliminary clinical results (better glucose control), it has also proven to be acceptable in the community. Due to the community engagement work that was implemented at the beginning of the study, Dulce Digital was relevant and met community needs; participants provided overwhelmingly positive feedback about the program during post-study focus groups.

Suggested CEnR Project Timeline

At least 6 months prior to starting your project:

- **Relationship building period**: Each partner enters into a potential research collaboration with their own perspectives, needs and agendas; some of which may overlap but will also be different from those of the other partners.[8]

- **Understanding the community/clinic you want to work with**: Researchers should plan to spend considerable time getting to know the community before they approach individuals, community clinics or organizations about partnering.[8] To connect with the community, researchers should consider searching for local community events and groups online; visiting local schools, churches and community/recreational centers; attending community and cultural events; reading local newspapers and magazines that are specific to particular communities or cultural groups; and/or contacting local non-profits and volunteering at their events.

- **Identifying potential partners**: Once a researcher really gets to understand the community, its members, organizations, needs and values, the next step is the identification of a potential partner. During this process, a researcher needs to consider the following:
    - Why do I want to work with a particular community or clinical organization? What are the benefits to us? What are the benefits to the community or organization? What is the mutual benefit?
    - A researcher will also have to identify if the community or clinical organization has the capacity to do research. Does the organization have the staffing infrastructure, technology capabilities, etc.? A researcher should initially approach research ready organizations and could also work with less ready organizations to help build their future capacity.
    - It is always easier to start a research relationship for a specific project if there have been previous positive connections with the community/clinic (or a researcher), through, for example, university services or centers, previous research collaborations, or referrals from trustworthy sources or through reputation.[8]

Strategies for Researchers

How do I approach the community about a project idea?

- Identify potential partners and partnerships through appropriate networks, associations and leaders. Researchers should approach the community with an open mind and recognize that the community members are experts in their community and have unique perspectives about the community's needs and assets. One of the best strategies to develop relationships with community members is to just show up; visibility is key to relationship building. You can attend community events, meetings, celebrations, etc. This will show community members that you are willing to meet on their "turf," rather than expecting residents to come to the university.

Strategies for Community Members

How do I approach researchers about a project?

- Finding the right researchers is more than just identifying an expert on the community need you have identified. You need to be able to identify a researcher who can work with you and your community and the questions you want to address. Research institute or university websites can be a good first step as they often provide search options by research interest or expertise. The next step would be to schedule a meeting with a researcher to learn more about his/her interests in and experience working with the community. When approaching a faculty/researcher you need to recognize YOU are an expert in the community and you have a lot of skills/assets that researchers need.

Challenge: There is a lack of financial incentives for community partners.

Possible Solution: Understand the financial burden of community partners. Involve community partners early on in the planning stage (budget-wise, program-wise); all partners need to be fully informed and transparency is needed. Develop a protocol to compensate your community partners fairly for their time and effort. The investigator can also provide his/her expertise and time outside of the collaborative project as a consultant on another one of the organization's projects.

CEnR in Action #3: Diabetes

Athena Philis-Tsimikas, MD
Addie Fortmann, PhD
Magdalena Hernandez, Peer Educator
Monica Ruiz, MA
Scripps Whittier Diabetes Institute

Linda C. Gallo, PhD
Institute for Behavioral & Community Health,
San Diego State University

Dulce Mothers: A Diabetes Prevention Program for Latina Women with a History of Gestational Diabetes (GDM)

Why Latinas with a history of gestational diabetes?

Latinos are the largest and fastest growing minority group in the U.S., with Mexican-Americans forming the largest Latino subgroup. Women with a history of gestational diabetes mellitus (GDM, or diabetes during pregnancy) have a 7x greater risk for developing type 2 diabetes later in life – in fact, 50-60% of Latina women develop type 2 diabetes within 5 years of delivery. Thus, low-cost, acceptable, and feasible prevention approaches targeting Latinas with a history of GDM are critical for preventing or delaying the onset of type 2 diabetes in this group.[9-11]

The Diabetes Prevention Program's (DPP) intensive lifestyle intervention was shown to reduce type 2 diabetes risk by 58% over 3 years by targeting diet and exercise.[12] Building on this program, the Scripps Whittier Diabetes Institute worked with community clinic organizations, women with a history of GDM, and peer educators, to develop a culturally appropriate translation of the DPP ("Dulce Mothers") to help reduce the disparate, high rates of progression to type 2 diabetes in Latino populations.

What we learned!

Community partners recommended several modifications to tailor the DPP curriculum to Latina mothers, including a focus on breastfeeding, family health, physical activities that are popular in this culture, culturally-driven beliefs about diabetes, and barriers related to low socioeconomic status. To further meet the needs of this community, the Dulce Mothers curriculum was delivered in Spanish, by a peer educator in a group-setting at a conveniently-located community clinic (where childcare was provided).

84 Latina women with a history of GDM piloted the revised curriculum. There were significant pre/post improvements observed physical activity, diet, cultural beliefs, cholesterol, and blood pressure.[13] In post-study focus groups, participants indicated strong positive acceptance of the program; they felt that the content was new, useful and culturally relevant. They also appreciated the convenient location and benefited from the social support provided by the peer educator and other group members – in fact, they requested that monthly support groups follow the formal educational offering. Based on participant feedback, support groups and a greater emphasis on weight loss (a strong predictor of type 2 diabetes onset) are being integrated into a revised version of the Dulce Mothers program with a focus on maintaining the acceptability in this community.

Proposal Development Period

As previously mentioned, the degree of community involvement in any CEnR collaboration can vary widely. Ideally the community or clinical partner is directly or indirectly involved with formulating the research question. This will benefit the research proposal because the community or clinical partner has an in-depth understanding of the characteristics and health needs of the community.

Community or clinic partners can play a very important role in all aspects of developing the research design including the review and selection of tools and assessments, recruitment and retention strategies, methods, and dissemination strategies being proposed. Community participation can help ensure that accomplishing them are sensible; that the means of accomplishing them are sensible; that the program considers the knowledge, attitudes, language, beliefs and practices of the target group and that results are shared, sustained and used for the good of the community.

Identifying Funding Resources

There are a variety of different sources that fund research including governmental agencies, local foundations and universities. Funding requirements differ between agencies and may even differ between various grant programs within an agency. There are also specific agencies that primarily fund CEnR. An example would be the California Breast Cancer Research Program www.cbcrp.org that funds CEnR projects focusing on breast cancer, the environment and disparities. CEnR funding has traditionally been awarded to organizations such as universities and academic medical institutions. As CEnR becomes more and more integrated into the design of research programs; funding institutions are catching on. As a result, we are beginning to see a shift in the diversity of institutions who fund CEnR.

Additional Funding Resources:

www.grants.gov
www.nih.gov
www.pcori.org
www.cbcrp.org
www.cchp.info
www.calendow.org

Another important resource is the listserv disseminated by the University of Washington. This listserv disseminates daily CEnR opportunities and was created in partnership with the Community-Campus Partnerships for Health www.ccph.info and the Wellesley Institute www.wellesleyinstitute.com

Research information that is already available for the topic at hand

In this process, the research partner can take the lead as he/she has access to the university library and electronic databases and journals to conduct literature reviews. Free public databases to access scientific literature to develop proposals are also available for non-university affiliated partners.

The following list provides some of the free, public on-line resources that exist for conducting literature searches.

- Free full text archive of biomedical and life science journal literature at National Institutes of Health National Library of Medicine. www.ncbi.nih.gov/pmc/
- Google search engine that provides abstracts and full text journal articles www.scholar.google.com
- National Institutes of Health/National Library of Medicine database that provides consumer health information on a variety of topics. www.nlm.nih.gov/medlineplus/
- Free resource that provides California residents access to data maps for the purpose of program planning, grant writing and/or service deliver. www.healthycity.org
- Free database that provides access to best current evidence on wide range of clinical topics www.bestbets.org

CEnR Quiz Question #7: Where should one apply for funding for CEnR studies? (Select all that apply)

A. National Institutes of Health (NIH)
B. Patient-Centered Outcomes Research Institute (PCORI)
C. Robert Wood Johnson Foundation

Challenge: Research focuses on outcomes and doesn't account for or measure the "value-added." This is needed for sustainability.

Possible Solution: Add a qualitative component to the research design including process evaluation measures, case studies, focus groups, key informant interviews, etc. These measures capture the "story behind the research."

Formalizing Your Research Partnership

Organize a meeting where everyone is able to speak openly, clarify expectations and concerns, and where questions are addressed from all parties.

- At this time, a draft **memorandum of understanding (MOU)** or a collaboration policy can be developed so that roles, responsibilities, expectations can be clearly defined for all parties, identify challenges that might occur and proposed solutions to meet those challenges.
- This can also be a time to identify the assets and skills in the group and see whether other partners are necessary to conduct the work.
- Discuss the budget. Define the specific resources each partner can contribute to the project through time, in-kind contribution, or with the use of grant funds (e.g. office space, project staff, training, etc.). Investigators s should ensure that their community partners are compensated for their time and contributions and that budgets are developed transparently.
- Also talk about the proposal responsibilities and requirements. Assignments should be made so that each partner contributes to the proposal development. Timelines and a review process should also be discussed.

Develop a plan for mediation in case things go awry; it may be included in your MOU.

- Conflicts or differences in opinion are inevitable in collaborations. Developing specific strategies for effective resolution of conflict is essential to demonstrate a commitment to research goals and continue the partnership. Effective conflict resolution may actually strengthen the research partnership.

CEnR Quiz Question #8: In CEnR, the researcher-community partnership should be initiated by:

A. Researchers
B. Community
C. Either group

Identify roles and responsibilities (e.g., are there multiple principal investigators or co-investigators?)

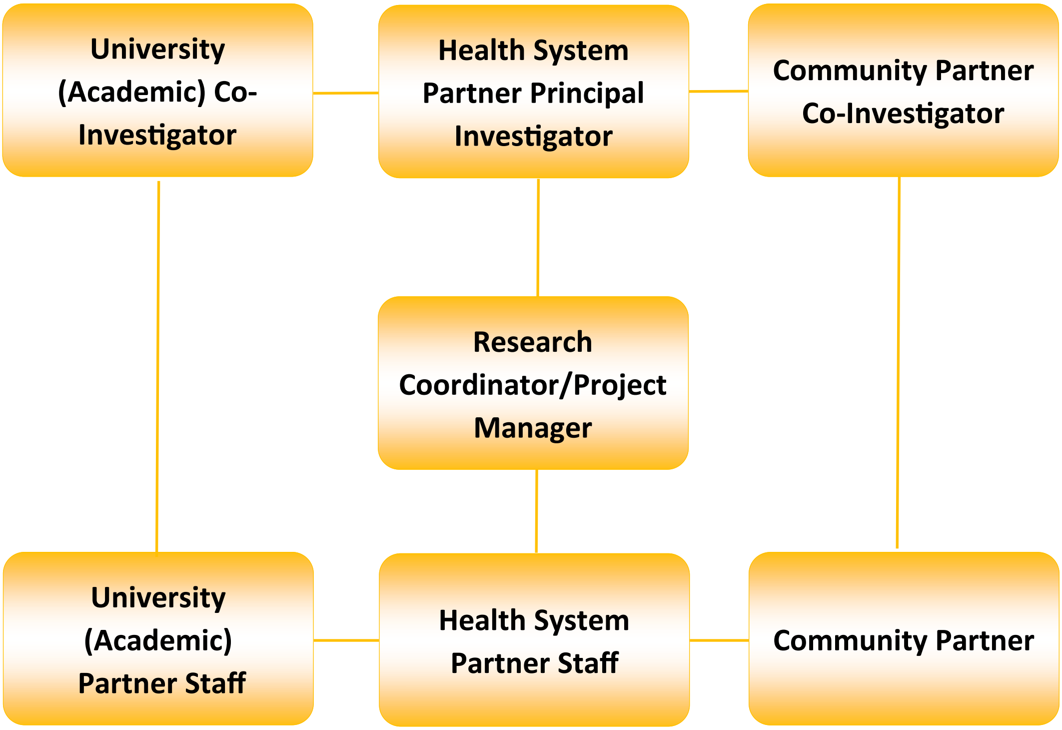
- Develop a leadership team and an organizational chart; if necessary it would be helpful to also create a job description for each project member to specifically outline roles and responsibilities. This will ensure that expectations are clear and eliminate duplication of effort.
- Develop a contingency plan for staff turnover/leadership changes "unexpected obstacles can surface, such as staff turnover or changes in leadership. Partnership means spending the time to develop trust and, most important, to develop the structures that support trust, so that a move in unexpected directions or setbacks can be seen as part of a long-term process that will continue."[8] This contingency plan may be included in the MOU.
- Make sure all parties understand the timeline to obtain funding. Investigators are often used to waiting for a year or more for funding. This needs to be explained to the community partners. Make sure to manage expectations; don't try to accomplish everything in one proposal. Rome wasn't built in a day.

CEnR Quiz Question #9: Compensating community research partners is not consistent with the guidelines of CEnR.

A. True B. False

Sample Organizational Chart:

STSI-CEP Academic - Health System - Community Research Partnership



Challenge: Approaching community organizations after research ideas are already developed leaves no room for modification or true collaboration.

Possible Solution: Approach the community at the inception of an idea. You need to engage community organizations as true partners.

CEnR Quiz Question #10: Which of the following are potential benefits of CEnR? (Select all that apply)

A. Community Advisory Board (CAB) members can also serve as participants to help meet recruitment goals.

B. Partnering with the community increases the relevance of research questions.

C. Community input can enhance retention by increasing the acceptability of the research protocol.

D. Community partners can improve access to potential research participants.

E. Researchers and community partners build upon each other’s strengths in a co-learning process.

Challenge: Community organizations may be reluctant to invest time and manpower in research projects that don’t reflect their needs and priorities.

Possible Solution: Identify the organizations needs and priorities early on in the research development process. Work collaboratively with the organizations staff to design research project that will answer the researcher’s research questions and will also address the organizations needs and priorities.

CEnR in Action #4: Genomics

Deborah Boeldt, PhD
Cinnamon Bloss, PhD
Scripps Translational Science Institute

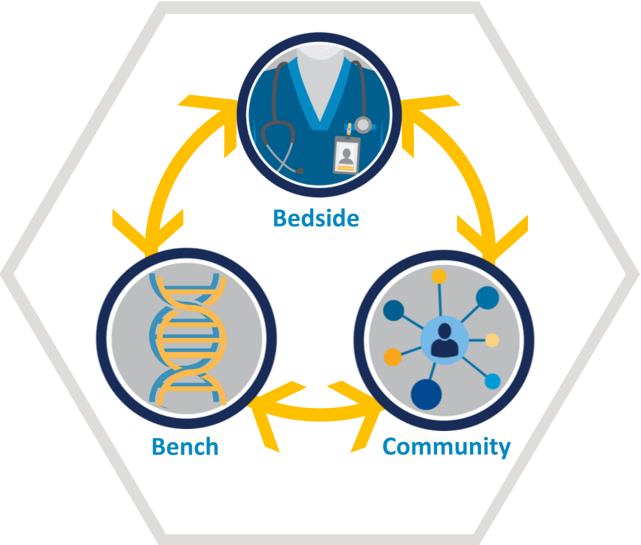
Enhancing Genomic Research Through Patient and Physician Engagement

The Idiopathic Diseases of Man Study (IDIOM) is an ongoing project at the Scripps Translational Science Institute that uses whole genome sequencing (WGS) to explore an individual's entire genetic code to identify causes of rare or undiagnosed diseases. To enroll in IDIOM, individuals must have a severe undiagnosed disease that appears to be genetic and symptoms that may be treatable. The patient must also have a physician champion who is willing to work with the research team and return the genetic results to his/her patient.

An important aim of the IDIOM Study is to understand the patient's experience during WGS process – an aspect that has rarely been formally examined in previous WGS studies. For example, the impact of receiving confusing genetic results (or findings that may have more than one interpretation) from a healthcare provider is still largely unknown. Thus important questions exist around the best way to return results to individuals, and to manage related (or secondary) findings. The IDIOM study implemented CEnR methods to explore these important issues with individuals who completed WGS. Brief surveys, and in-depth telephone or live interviews were used to learn about individuals' experiences and attitudes towards WGS both before and after the study. Similar information was obtained from the physician champions.

What we learned!

Analysis is currently underway, but researchers anticipate that the IDIOM participant and providers' perspectives will help identify important themes and increase understanding of a patient's experience during the sequencing process—all of which can shape clinical practice and future policy. For example, this information will help improve how physicians return genetic results to patients. The patient's reaction to the results from their physician champion helps improve future WGS research studies. Furthermore, understanding emotional responses to WGS results is essential to anticipating and preventing the potential for adverse psychological outcomes in future research.



Dissemination

After Data Collection and Analysis Ends: There should be real time and effort devoted to this phase; this is often a step that investigators omit and can create distrust in the community.

- **Community Dissemination:** Make sure that information is disseminated back to all levels of the community/clinic organization. Inquire about their preferred method (e.g., community forums, reports, web-based, etc.). Consider creative ways of disseminating the information such as media, local newspapers, community events, games, etc. Consider language as well; make sure your data are translated into the preferred language of the community.
- **Project Sustainability:** It is important to discuss project sustainability throughout the project period. Efforts should be made to develop a plan to identify supplemental funding sources to further the project after the initial funding period ends. This funding may come from the partner organization, a local foundation or from additional grant funding. Effective dissemination strategies (discussed above) leads to increased publicity and visibility, which in turn, may also lead to additional funding from unexpected sources.
- **Wrap-up Meeting:** A wrap-up meeting of the project should be considered to address final concerns, future projects and on-going communication. In a traditional research project, normally the end of a project is also the end of the collaboration and relationship with those involved; however, in CEnR an on-going relationship with collaborators is expected and encouraged. Many times the end of the first research project is only the beginning of the collaboration team, who will often explore other ways to work together.
- **Giving back to the community/community partner:** Potential shorten-term benefits for communities might include training provided by outside researchers, grant writing assistance or technical assistance, which may or may not be directly related to the research.[8]

Congratulations—You were funded!

Now the real work begins…… An initial project meeting with all parties should be held prior to submitting any Institutional Review Board (IRB) documentation or other paperwork. Everyone should review the proposal and identify any questions about each step of the research process including:

- Data collection
- Dissemination
- Analysis
- Sampling
- Tool development

The team should establish regular meetings as needed and make sure that all parties agree to the schedule. Regular meetings will establish consistent check-ins on project progress, address concerns and plan next steps. Communicating clearly and frequently during this phase is important. Hiring of staff for the project should be made jointly. Even though project staff will be employees of the organization or the community/clinical partner, efforts should be made to gather feedback about potential hires from the partnering organization.

Career Issues for Researchers

It is important to understand the different roles, responsibilities, timelines and work pressures often faced by faculty and researchers. A researcher (especially junior researchers) is motivated by grant deadlines, student research assistant availability during semesters and by pressures to produce manuscripts and papers for tenure and promotions, whereas community partners are typically focused on completing research quickly so that results can be disseminated to satisfy programmatic or clinical goals.

Community-based, collaborative research can be both intellectually gratifying and inspiring, as participants uncover connections between good science and tangible improvements in people's lives. Community -based collaborators need to recognize these studies often require more time to formulate and conduct. Investigators advance in their careers (e.g. rank, tenure and compensation) based on the appraisals by senior colleagues and by leading experts in their fields, nationally and internationally. These appraisals look at research quality and at productivity. STSI-CEP encourages investigators to have candid conversations with their department chair, promotion or tenure committees and professional mentors about ways that their achievement in CEnR can earn recognition that they deserve. One resource that faculty should consider is the Community Campus Partnership for Health (CCPH) which offers a number of resources for investigators including a link to a publication that provides a peer reviewed process for non-traditional media (e.g. curricula, handbooks, videos) that can be used to bolster CEnR profiles www.ccph.info.

Glossary of Terms

Analysis: Is a process of inspecting, cleaning, transforming and modeling research data with the goal of highlighting useful information, suggestion conclusions, and supporting decision making.

Cardiometabolic Disease: Combines both heart disease and metabolic disorders such as diabetes.

Clinical Research: Is type of research that determines the safety and effectiveness of new medications, medical devices, behavioral and therapeutic treatments intended for human use for prevention, treatment or relieving symptoms of a disease that can be applied in laboratory or real world settings.

Community Advisory Board: A panel that is made up of representatives of diverse layers of community. Its purpose is to provide a public forum for community members to present and discuss their needs and concerns related to the decision making process.

Crowdsourcing: The process of obtaining needed services, ideas, or content by soliciting contributions from a large group of people, and especially from an online community, rather than from traditional employees or suppliers.

Data Collection: The process of gathering and measuring information on variables of interest.

Digital Medicine: The use of digital technologies, social networking, mobile connectivity and bandwidth, increasing computing power and the data universe converging with wireless sensors, genomics, imaging, and health information systems to enhance healthcare delivery.

Dissemination: The sharing of knowledge by an appropriate means (e.g. publications, conferences, workshops, web-based activities, etc.).

Findings: Refer to the results of a research project.

Focus Groups: A form of qualitative research in which a group of people are asked about their perceptions, opinions, beliefs, and attitudes towards a product, program, or concept.

Genomics: The branch of molecular genetics concerned with the study of genomes, specifically the identification and sequencing of their constituent genes and the application of this knowledge in medicine, pharmacy, agriculture, etc.

Grant Proposal: Is a formal request submitted to a funding organization to apply for funding.

IRB (Institutional Review Board): An administrative board that is responsible for reviewing research studies to determine scientific integrity, participant safety, and study feasibility.

Key Informant Interviews: A semi-standardized, verbal assessment that is commonly conducted with individuals who have specialized knowledge about the topic you wish to understand.

Methods: In a research study, methods refer to study procedures and tools used (e.g. questionnaires, focus groups, surveys, interviews) the type of participants recruited, how participants are identified and enrolled and how research data are analyzed.

Memorandum of understanding (MOU): A document created for the purposes of outlining roles, responsibilities and expectations of two or more collaborating organizations.

Multiple Determinants of Health: Multiple personal, social, economic and environmental factors that influence health status.

Peer Educator(s): Also known as community health worker, community health advisor, outreach worker, community health representative, promotora/promotores de salud (health promoter/promotoers), patient navigator, peer counselor, lay health advisor, health educator and peer leader are frontline public health workers who are trusted members of and/pro have an unusually close understanding of the community served.

Principal Investigator: The Principal Investigator (PI)/Program Director (P/D) is defined as the individual(s) judged by the applicant organization to have the appropriate level of authority and responsibility to direct the project program supported by the research grant. The applicant organization may designate multiple individuals as PI/PDs who share authority and responsibility for leading and directing the project, intellectually and logistically.

Program Evaluation: A type of research that seeks to determine the effectiveness and efficiency of programs. Program evaluation typically involves quantitative (e.g. standardized questionnaires) and qualitative components (e.g. focus groups, interviews, etc.). Evaluations can also include process measures (e.g. tracking attendance, development of a program) and outcome measures that look at how the program or project has impacted individuals such as changes in behavior or knowledge.

Research Question: The primary question (or hypotheses) that you want your research project to answer.

Sampling: A representative selection of a subset of individuals from within a population to estimate the characteristics of the entire population.

Tool Development: The process of research questionnaires and procedures needed to carry out a research study.

Translational Research: An approach that seeks to move the application of science form laboratory experiments through clinical trials to actual point-of-care patient applications in the community (e.g. “from ben to beside to community”).

CEnR Quiz Answer Key

1. B
2. A-E
3. A-E
4. A
5. A, C-E
6. C
7. A-C
8. C
9. B
10. B-E

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Scripps Translational Science Institute

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CommunityEngagement@scrippshealth.org