



CHARN

Community
Health Applied
Research Network

Quarterly Newsletter

WINTER 2013

New CHARN
Conference
call-in information:

Toll Free: 888.858.2133

Toll: 646.746.3001

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CHARN Snapshot

The last quarter (October-December 2012) was another extremely productive one for CHARN. Not only did we meet previous goals, but we set new ones. Here are some of the highlights.

Steering Committee Meeting

In October, the Fenway node in Boston hosted a successful sixth steering committee meeting, providing informative talks and updates by CHARN steering committee members as well as a terrific overview of Fenway Health by CEO Dr. Steve Boswell. The 1.5-day meeting focused on proposal development, the data registry, and goals for our last year of funding. Regarding the data registry, we decided what version 2 (V2) should contain but still need clinicians to help define disease conditions of interest (e.g., hypertension, cardiovascular disease, and dyslipidemia) for V1. To help, contact your CHARN site liaison or Reesa Laws

(Reesa.Laws@kpchr.org) at the Data Coordinating Center. Also at the meeting, we formed a diabetes workgroup, led by OCHIN clinician investigator Dr. John Heintzman. In addition to developing papers on current diabetes research, this group will focus on generating proposals to procure funding for future research.

Proposal Submission

Planning continues for a proposal on health coach modeling and diabetes to the Patient-Centered Outcomes Research Institute for cycle III funding. Two nodes and three community health centers are contributing to this proposal and intend to participate if funding is awarded.

Community Health Center Reports

We also developed community health center reports based on V1 data from the registry and have made these available for sites to share with

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Nodal News

Alliance Nodal News

In November, Alliance's Research and Data Team hosted the third annual research meeting. More than 60 people attended, including representatives from all seven CHARN participating sites, eight non-CHARN sites, and academic partner Northwestern University. Dr. Stacy Lindau from the University of Chicago gave the keynote address on the power of community engagement. The meeting provided opportunities to discuss CHARN projects across the network, survey participants in real-time about "moments of compromise," and establish multidisciplinary workgroups to develop potential research questions, one of which has resulted in a seed grant application.

Alliance is seeking to support the development of our research infrastructure by establishing an indirect cost rate for the Alliance network, as well as for the individual community health centers. As part of this effort, we have recruited a consultant with experience working in community health centers and an understanding of electronic health record-related research costs.

The newest Alliance site to join CHARN, Glide Health Services, has made great progress in establishing a relationship with the institutional review board at the University of California, San Francisco, and has even obtained a Federalwide Assurance. This work has given Alliance additional

knowledge about academic review boards and has positioned Glide to participate in research at their site.

Alliance has made significant progress on its internal SQL-based data warehouse and has contributed data to its new integrating warehouse, Amalga, and the national CHARN registry.

Several of the Alliance community health centers are submitting research proposals to seed funding opportunities. The Alliance data and informatics teams are supporting these seed grants with data pulls, content changes in the electronic health records, and proposal writing.

AAPCHO Nodal News

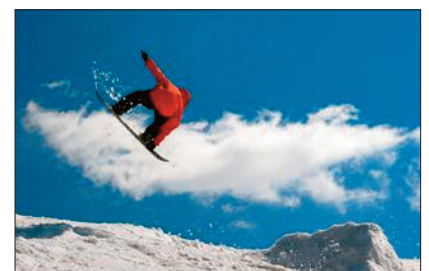
In August, AAPCHO and its partnering community health centers and UCLA successfully completed a two-day research training in Hawaii. The community health center staff and community members participated in this training to develop community criteria for reviewing community-based research projects. A total of four community health centers also worked on developing proposals for future research projects, with consultation provided by Drs. Ninez Ponce, Marjorie Kagawa-Singer, Art Chen, and Mary Ann McBurnie. The Data Coordinating Center, the Alliance of Chicago Community Health Services (another CHARN node), and three other AAPCHO community health centers also participated in the training.

Dissemination of results from this research training has already begun. AAPCHO included the community criteria for reviewing community-based research projects in its comments to the draft

methodology report of the Patient-Centered Outcomes Research Institute. AAPCHO plans to disseminate the community criteria more widely to funders, policy makers, and fellow academic and community researchers.

Also this fall, AAPCHO began the Enabling Services Validation Survey with three out of the four nodes. We are also continuing to develop research proposals with our partnering community health centers and UCLA, with the potential to expand to other CHARN members. One area of high interest for future research is social determinants of health.

Finally, AAPCHO is in the process of developing a community institutional review board (IRB) for AAPCHO members. AAPCHO recruited IRB members, conducted the first IRB member orientation in September, and developed the IRB policies and procedures.



OCHIN Nodal News

CHARN recently supported the purchase and installation of a dedicated research SQL server at OCHIN, which has greatly improved the speed and security of research data queries. Our research databases previously shared a server with other departments, which impaired performance.

CHARN funding was recently cited on an OCHIN publication coauthored by CHARN clinical and academic affiliates: DeVoe JE, Likumahuwa S, Eiff MP, Nelson C, Carroll JE, Hill CN, Gold R, Kullberg P. Commentary: Developing a New PBRN: Lessons Learned and Challenges Ahead. *J Am Board Fam Med.* 2012 Sep-Oct;25(5):560-564.

OCHIN collaborated with Mita Goel, MD, MPH, of Northwestern University to submit a proposal for Cycle II funding to the Patient-Centered Outcomes Research Institute. The proposal aims to expand Dr. Goel's work on eliminating health disparities by integrating the use of personal health records.

OCHIN is leading three CHARN initiatives. John Heintzman, MD, MPH, is heading a new diabetes working group involving three nodes. This group grew

out of an OCHIN-led research proposal, "Characterizing the Diabetes Population in the CHARN Network." Sonja Likumahuwa, MID, MPH, had an abstract on community-centered approaches to eliminating health disparities accepted at the NIH Summit on the Science of Eliminating Health Disparities. Coauthors were from all four research nodes and the data coordinating center. (The conference was postponed because of Hurricane Sandy but was be rescheduled.) Sonja Likumahuwa, MID, MPH, also led the national Communications and Community Engagement Committee, which she chairs, in the development of a feedback report for CHARN health centers. The report gives an overview of version 1 (V1) of the data registry.

In September, OCHIN met with the institutional review board (IRB) chair of Oregon Health and Science University, OCHIN's academic affiliate, to discuss IRB infrastructure at OCHIN and its member organizations, focusing on cross-institution research. Future discussions will determine whether this IRB will be formally designated as OCHIN's IRB.

In November, the OCHIN research department participated in the 2012 OCHIN Learning Forum, attended by more than 300 nationwide healthcare providers. CHARN was featured in a presentation entitled, "Research 101: Primary Care Research and OCHIN's Practice-Based Research Network."

In December, OCHIN presented a total of nine posters, panels, and oral presentations spanning six projects at the North American Primary Care Research Group Conference.

Finally, the OCHIN steering committee—made up of community clinicians, OCHIN executives, and affiliated researchers—met monthly this quarter to refine research proposals. The October meeting taught non-CHARN health centers about V1 of the data registry and brainstormed clinical research studies in which it could be used. The Research and Data committee—made up of clinicians from the four clinical affiliates, OCHIN staff, and partner data warehouse specialists—also met monthly to share information and get clinician input on CHARN research and data proposals.

Fenway Nodal News

The Fenway Health node conducts monthly conference calls to discuss current projects and future funding opportunities. At the nodal meeting prior to the October Steering Committee meeting, our investigators presented current work and discussed potential collaborations with our nodal partners.

Fenway has been submitting data to both the patient data registry and individual data research projects. Initial submissions included only HIV-infected patients but as of late November, the community health centers have

submitted data on all patients.

In December, Fenway began the Enabling Services Validation Survey. Dr. Kenneth Mayer at Fenway is leading the HIV Testing Survey Study, which is currently under final review, and Dr. Heidi Crane from University of Washington is leading the ePRO Working Group. Beaufort Jasper Hampton Comprehensive Health Services (BJHCHS) has completed 68 assessments and Chase-Brexton is expanding its bandwidth to be able to download increased volumes of patient

data. Fenway is setting up back-end capabilities to expand ePRO to our entire patient population (not just HIV-positive patients). Fenway continues to administer surveys to our HIV-positive population through C-NICS, completing 40-60 surveys per month.

Fenway has been working hard to standardize data collection methods, specifically regarding the sexual orientation and gender identity of patients (see the "Clinical Corner" page of this newsletter for more information);

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Nodal Spotlight:

The Fenway Institute Research Node

The mission of Fenway Health is to enhance the physical and mental health of our community, which includes people who are gay, lesbian, bisexual, or transgender, people who live and work in our neighborhoods, and beyond. Fenway Health began in 1971 as a one-day-a-week drop-in center in the basement of a residential building but grew rapidly to become the first community-based health care facility in New England to respond to the AIDS crisis. In 1981, Fenway collaborated with Harvard to identify the first cases of AIDS in Boston and provided outpatient care for people living with HIV/AIDS.

Today, Fenway Health provides medical and behavioral health services to more than 20,000 patients, 9% of whom are living with HIV/AIDS, at three practice sites in Boston. Fenway Health also offers dental, optometry, pharmacy, complimentary therapies, and substance abuse services.

Fenway Health has a staff of more than 300 people, including more than 90 people who work at The Fenway Institute, Fenway's center for research, education, and information dissemination. As one of the nation's first community-based HIV research programs, The Fenway Institute has a long history of participating in and leading collaborative multisite HIV and other community-based research. Fenway participates in more than 50 active health service/registry, population, behavioral, biomedical, clinical, epidemiological, and clinical research studies.

As part of CHARN, The Fenway Institute node aims to advance comparative effectiveness research in community health settings with a focus on improving health outcomes for people receiving HIV care in these settings. The Fenway Institute node comprises a strong team of investigators at Fenway, led by Dr. Kenneth Mayer, and at clinical affiliate

sites at Beaufort Jasper Hampton Comprehensive Health Services in Beaufort, South Carolina, and Chase-Brexton Health Services in Baltimore, Maryland. Our academic partner at the University of Washington Clinical Epidemiology and Health Services Research Core brings extensive experience in comparative effectiveness research implementation and analysis.



The CHARN Data Registry (Version 1)

Version 1 (V1) of the CHARN data registry is complete. All 18 community health centers (CHCs) have transferred electronic health record data to their respective nodes, and the nodes have loaded this data into a standardized CHARN database and sent it to the data coordinating center (DCC). In turn, the DCC has sent data queries to the nodes, most of which have been resolved. A team of clinician expert reviewers and the analytic staff at the DCC are currently classifying CHARN's seven diseases of interest by reviewing detailed data on diagnoses, medication orders, and lab results. The diseases of interest for V1 are diabetes, cardiovascular disease, hypertension, dyslipidemia, hepatitis B and C, and AIDS/AIDS-related diseases.

The V1 population comprises patients who had at least one primary care encounter at their CHC from 2008 to 2010. We determined if these patients had a CHARN disease of interest by reviewing their diagnoses, medications, and lab results. If they did, we captured

all their V1 data (encounters, diagnosis, medications, and lab results) for the registry. The goal of gathering this information was to identify and develop high-impact research areas and to inform the interpretation of results from CHARN studies.

We are expanding version 2 (V2) of the CHARN registry into a data warehouse structure to provide CHARN researchers with more inclusive data from each of the CHCs. We are adding years (2006 to 2012) and new data fields and tables to the original registry. The goal is to capture all data from all CHC patients who have had at least one primary care visit within the defined time period (2006-2012). We will gather electronic health record data on the following factors: patient demographics, encounters (face-to-face visits, phone calls, email, etc.), diagnoses, laboratory test results, medications ordered, vital signs (height, weight, temperature, pulse, blood pressure), procedures (all ordered and performed procedures), smoking status (tobacco status, type of

tobacco used, years of use, and packs per day), provider (provider type and specialty), problem list (diagnoses, dates, and status), referrals (all outside services for all referrals for multiple diagnoses and procedures), enabling services encounters (similar to encounter data but specifically defining enabling services encounters [case management, financial counseling, transportation, etc.]). The DCC and the data subcommittee have been busy developing the V2 data dictionary, the data submissions procedures, the data warehouse protocol, and a lay-language data dictionary that describes the data in something other than "data geek speak." The timeline for submission of V2 for steering committee approval is the beginning of January. Data use agreements can then be revised and resubmitted at the CHCs. The DCC will roll out the new database structure to the nodes and CHCs following steering committee and institutional review board approvals.

CHARN Snapshot, *continued from page 1*

their executive committees. The goal of these reports is to showcase what CHARN has achieved so far and to provide support as we proceed into V2 of our data warehouse.

Enabling Services Survey

The Enabling Services workgroup, in conjunction with the Data Coordinating Center, has launched an online

validation survey to enabling services providers across three CHARN nodes. To date, we have received 57% of responses (87 of 152). Results from this survey will inform how services are coded across nodes and community health centers within CHARN.

Mission Statement Update

Finally, the communications sub-

committee updated the "1-pager," a publicly available document on the CHARN website that outlines who we are and what we do.

You can find it here:

<http://www.kpchr.org/charn/public/index.aspx?pageid=1>.



Collecting Sexual Orientation in Clinical Settings, by Chris Grasso, MPH

Fenway Health is an independently licensed, federally- qualified Health Center in Boston, founded as a volunteer-run free clinic in 1971. The mission of the Fenway is to enhance the physical and mental health of its ethnically and racially diverse community, which includes lesbian, gay, bisexual, and transgender (LGBT) people throughout Massachusetts, and those who live and work in our neighborhoods.

In line with Fenway's mission, we evaluated the best way to ask sexual orientation on our patient registration form. Even though Fenway has a long history of caring for LGBT patients, there are still challenges and considerations in implementing a uniform system for collecting sexual orientation. Four main aspects to this process include agency commitment, question selection, staff training, and health information technology. Essential to this process is a commitment across all levels of the organization and without support; this undertaking will neither be successful nor sustainable. Highlighting particular health disparities among LGB populations, which are documented and often unaddressed in clinical settings, may be used to foster support. Selecting and obtaining consensus on a validated measure, which contains a well formulated question and response categories, is also a critical step early in the process.

Since the sexual orientation question will be included on the patient registration form and administered at 'check-in', a key department in the process is Patient Registration. Proper training and support are, therefore, critical to successful implementation and sustainability. Addressing concerns from Patient Registration staff, such as fearing that patients will feel that it is inappropriate to ask seemingly 'personal questions' at registration, are necessary to address. It was important to address these concerns

and provide staff with tools to sufficiently manage any potential discomfort or fears. At the time of registration, we found it helpful to provide our patients with a brief written explanation, written at an 8th grade level, on the importance of capturing all demographic data including sexual orientation. Equating sexual orientation to the collection of other demographic variables helped normalize the sexual orientation question for both staff and patients. Patients should also be assured that this information will be kept confidential similar to their other demographic and clinical data.

The advent of health information technologies (HIT) has introduced new avenues for data collection and sharing of information in clinical environments, particularly for sexual orientation. Electronic Health Records (EHR) and HIT enables clinicians' secure and timely access to information needed to treat the entire patient and not just a portion. EHR's can benefit both providers and patients by bringing a patients' complete demographic profile and health information together to support health care decisions and better coordinated care, particularly for LGB populations. Moreover, improvements in technology can facilitate data collection, remove barriers and improve information sharing for the LGB community in clinical settings. As EHR's become more sophisticated, HIT can be leveraged and customized to create opportunities for data collection fields not traditionally found in EHR's. In working with our EMR vendor, Centricity Practice Solutions (CPS), we were able to customize the registration section of our EMR by adding a discrete field to capture sexual orientation. Since the response categories are pre-defined we used a drop down field which had the added benefit of reducing data entry errors.

Once our staff was trained and CPS

programmed, we identified a subset of our staff to pilot the new registration form with our patients. Fenway Informatics and Patient Registration staff were in daily contact during the pilot phase. This initial pilot helped identify gaps or problems and allowed us to resolve issues on a smaller scale. Once the issues were resolved, the new registration form containing the sexual orientation question was disseminated to all locations and services. Monitoring data collection, using reports and staff communication, will provide ongoing evaluation and feedback.

Fenway Nodal News,
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the goal is to develop clinical projects to examine health disparities within these populations. The next step will be to gather information from each community health center in CHARN to examine the ways patients are asked about their sexual orientation and gender identity.

Monica Godfrey, MPH, recently joined BJHCHS as a Research Assistant. Ms. Godfrey earned BHS and MPH degrees from Armstrong Atlantic State University and is committed to public health research. As part of CHARN, she coordinates the collection of patient-reported outcome data in clinical care settings.



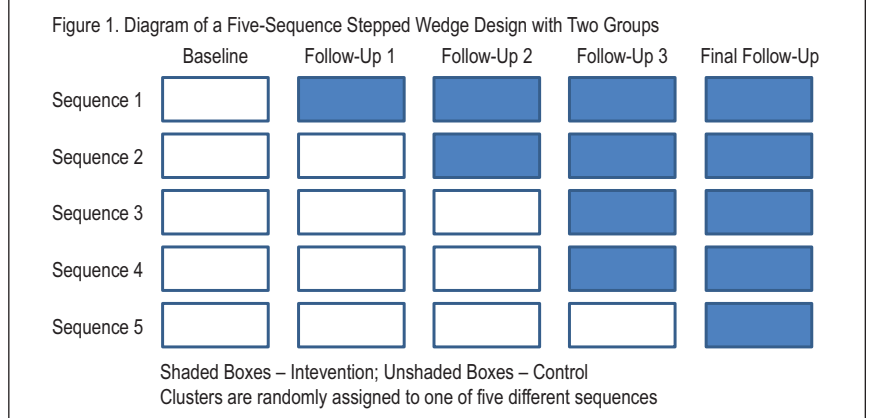
Methods Madness

Stepped Wedge Design, by Michael C. Leo, PhD

Many consider randomized controlled trials (RCTs) the gold standard of quantitative design for testing efficacy and effectiveness of interventions. The design characteristics of RCTs—such as the extent of blinding, number of groups, and randomization of participants at the individual or cluster (or community, or group) level—can vary.

RCTs that randomize at the cluster level are known as cluster randomized trials (CRTs) and are usually chosen for the following reasons: a particular intervention can be administered only on a community-wide scale; the potential for contamination across arms is high; or logistic, financial, or ethical constraints are present. CRTs frequently use a parallel design. For example, in a two-group study with 20 independent clusters, 10 clusters are randomly assigned to each group and are assessed before and after the intervention is implemented. In contrast, crossover designs are less commonly used in CRTs. In a crossover design, the order of the interventions is randomized for each cluster and a time period (“washout”) is often included between the two interventions so that the first intervention does not affect the second. This allows a crossover CRT to require fewer clusters than a parallel design but may take twice as long (or even longer) to complete because each cluster receives both the treatment and control interventions.

A variant of the crossover CRT, known as the stepped wedge design (SWD),^{1,2} eliminates the potential cross-contamination within groups and reduces the total amount of time necessary. With an SWD, different clusters cross over (switch treatments) at different time points. In addition, the clusters cross over in one direction only—from control to intervention. At the first timepoint, a baseline is established for all clusters (i.e., all clusters are in the control group).



At the following timepoints, a cluster(s) initiates the intervention of interest and the response to the intervention is measured; this continues until all clusters have transitioned into the intervention. Multiple clusters may start the intervention at a given timepoint. The unit of randomization in an SWD is the timepoint at which a given cluster begins the intervention, or the “sequence.” At the final follow-up timepoint, all clusters will have received the intervention. A visual depiction of the SWD with five sequences is given in Figure 1.

One disadvantage of the SWD is that although it requires less time than a true crossover design, it has a longer duration than a parallel design. The SWD also brings its own design challenges, such as the potential contamination between intervention participants and those waiting for the intervention and ensuring that those assessing outcomes are blind to group assignment. Blinding assessors is particularly important because in most cases participants or interventionists cannot be blinded, since both will be aware of the transition from control to intervention. Another concern is bias, which may be introduced from differential drop-out rates in sequences that spend a longer amount of time in the control condition. Finally, the SWD requires more complicated statistical analyses to properly evaluate the intervention.

Despite these shortcomings, SWDs should be considered over a parallel

design if one or more of the following circumstances is true:^{3,4}

- There is a strong prior belief or evidence that the intervention will do more good than harm (i.e., researcher cannot assume equipoise).
- It would be unethical to withhold the intervention from a proportion of the participants or to withdraw the intervention as would occur in a crossover design. The randomization of the sequence rather than the group is likely to be both ethically and politically acceptable and may improve recruitment.
- There are logistic, practical, or financial constraints that make the intervention feasible only if it is implemented in stages. The SWD allows for the roll out of the intervention for a smaller proportion of the clusters at a given timepoint.
- The intervention has been shown to be effective and researchers would like to evaluate population-level impact.

References

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2. The Gambia Hepatitis Intervention Study. *The Gambia Hepatitis Study Group. Cancer Research* 1987 Nov 1;47(21):5782-7.
3. Brown CA, Lilford RJ. The stepped wedge trial design: a systematic review. *BMC Medical Research Methodology* 2006;6:54.
4. Hussey MA, Hughes JP. Design and analysis of stepped wedge cluster randomized trials. *Contemporary Clinical Trials* 2007 Feb;28(2):182-91.

Data Management Tip

Training—Reesa Laws

Training research staff to use standardized procedures is a key aspect of any successful research project. When multiple researchers are involved in a project—whether they are collecting primary data from research subjects or conducting chart reviews of member charts—using standardized procedures is necessary to ensure the quality and validity of the data collected.

Training topics can range from the overall protocol, to how data is collected, to how specific measurements are used during the course of the study. A single project may require multiple trainings aimed at different populations. For

example, it may be important for all study staff—from the study coordinator to the principal investigator—to be involved in detailed protocol training, whereas training that focuses on how to collect data may be limited to staff who actually record or enter data.

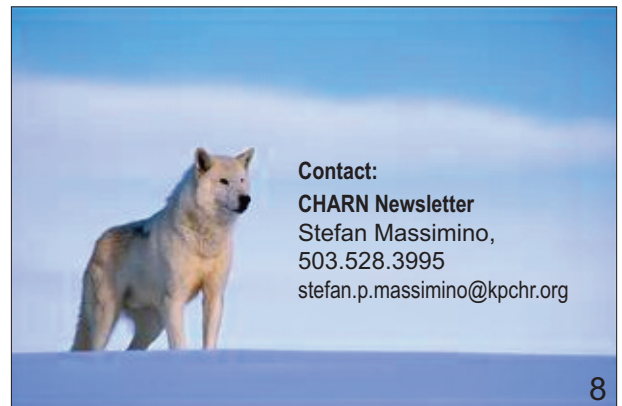
In addition to ensuring that all staff are adequately trained before the start of any study, some projects may also require periodic refresher training during the course of the study. Advances in technology can help reduce the cost of frequent trainings, making them more feasible. For example, a web-based refresher presentation can easily take the



place of a face-to-face training and significantly reduce the costs associated with frequent training.

2013 Conferences and Trainings

When	What	Where	Submission Deadline
March 13-15, 2013	CHARN Steering Committee	Washington, DC	N/A
TBD	Primary Care Research Methods & Statistics Conf.	San Antonio, TX	TBD
Mar. 19-20, 2013	6th Annual NIH Conference on the Science of Dissemination and Implementation	Bethesda, MD	January, 2013
July 31-Aug 2, 2013	CHARN Steering Committee	Portland, OR	N/A
June 20-21, 2013	PBRN Conference	Bethesda, MD	March, 2013
June 23-25, 2013	Academy Health Annual Research Meeting (ARM)	Baltimore, MD	January, 2013
August, 2013	CTSA Community Engagement	Bethesda, MD	July, 2013
Sept. 7-11, 2013	NACHC Community Health Institute (CHI) & Expo		May, 2013
September, 2013	AHRQ Annual Conference	Bethesda, MD	Spring, 2013
September, 2013	HDWA (Healthcare Data Warehousing Association) Annual Conference (Monitoring the Present- Improving the Future)	San Diego, CA	
November, 2013	APHA	Boston, MA	February 2013
November, 2013	NAPCRG Annual Meeting	Ottawa, Ontario, Can.	April 2013



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