# CPHHD Santa Monica Meeting Summary May 18, 2006 Working Group and Research Interest Group Reports

# **Community Assessment & Intervention (Chanita Hughes-Halbert)**

#### **Discussion Points:**

- Goal is to provide consultation for dissemination and outreach strategies (e.g., issue brief about myths and concerns about prostate cancer)
- Consultation can be provided to all centers (centers would just seek rep from this WG)
- This group also works on analysis of multilevel health disparities
- Provides information on dissemination and outreach to community partners (not only small groups, but also hospitals and dept. of public health) which strengthens mission

## Action Items:

- Examining issue of recruitment/retention of minorities in health disparities research
  - ➤ Evaluation form of recruitment strategies & methods in collaboration with Project Manager Workgroup
  - ➤ Looking at recruitment materials & referral sources
- Community involvement paper what types of organizations (volunteer, grassroots, health consortiums) contribute to health disparities cause/mission
- Considering various methods community advisory board (stakeholders), key informant interviews, focus groups
- Examining principles of collaboration and outcomes of intervention studies

#### **Evaluation (John Holmes)**

- Goal is to provide credible evidence that CPHHD program is working in a transdisciplinary (TD) way and adding value to health disparities research, and thus should be renewed
- Triangulation of evaluation, recommendations for improvement, plans for coming year
- Triangulation: Center evaluation report, objective outcomes (new coalitions, collaborations, identify evidence of media outreach beyond issue briefs; new environments, community partnerships), researcher web-based survey (see below)
- Center evaluation report
  - ➤ Has initiative effectively engaged community?
  - ➤ Has initiative developed new investigators?
  - ➤ Has it led to an integrative and unified model of health disparities?
  - ➤ How can we communicate our outcomes? (e.g., issue briefs, papers, etc.)
- Year 1 evaluations in midst of quantitative analyses and qualitative analyses will begin this summer.
- New timeline for this year to match NIH grant cycle for submitting evaluation materials (October 1)
- Researcher survey website for easiest deployment and get response rate up; looking at progress (perception about how your center is working for you and how it's being supportive and vice versa), and what has been happening at each center.

# Action Items:

- Think about issue-oriented approach (issues specific to each center and how they would apply across centers)
- Better utilize the web-based portal supports online discussion board, allows posting of evaluation reports, etc. (secure site for data)
- Determine whether evaluation questions answer what we want
- Administer researcher survey in summer (final report Nov 1, before BSA mtg.)
- Second wave of Center evaluations coming up in October
- Center process report (processes to engage in TD research).
- Will work with Renewal Workgroup on the matter of showing that CPHHD centers are working in transdisciplinary matter and thus should be renewed.
  - ➤ Would need to demonstrate TD work in and across centers
  - > Would need to demonstrate collaboration in and across centers
  - ➤ Would need to demonstrate emergence of new disciplines

# **Communication/Website (Peter Bakun)**

## **Discussion Points**

- Goal is to facilitate flow of information between various branches of knowledge through the integrative processes of a shared resource and to disseminate information in a global language via the websites. (Two-part mission)
- To share information in an integrated way TD research environment information flow should remain as simple as possible (trans-center information flow should be identical to intracenter info flow model of self similarity, provides structure w/out rigidity and allows for growth)
- Describes model centralized source of receiving information; can then take shared information and put it on the web. We use portal for receiving info; plone doesn't share data as well as it does manage documents or results of data/publications.
- Change the way we use portal at trans-center level the web portal could be used to provide access to multi dimensional database that can be stored at transcenter level (center level to transcenter level).
- Disseminating information on websites ubiquitous, translatable; websites are standardized to common endeavor (showing screenshots of homepages of sites e.g., Tufts, Penn, Wayne)
- We have 8 of these sites, would like transcenter site (like portal), but use the site to display info that is common to all centers...e.g., drill-down method general info at top, more specific data as you dig deeper down.
- Most websites have home page, projects page describing projects, faculty page, community news page, academic news (publications), affiliates; basic structure is the same across websites.

#### Action Item:

• Portal—he advises to look around portal—everyone should have login names and passwords; this is how we share information across centers (workgroups, calendars, upload/download info, share documents and ideas); would like to use it as front-end to database to house transcenters' data. In portal itself, links to websites, and then can link back to portal.

# **Project Managers (Benita Weathers)**

# **Discussion Points:**

- Managing complex research projects
- Project Managers (Workgroup) are 'new kids on the block', started last year at the meeting in Chicago, since PMs play an important and integral role to projects that occur across the centers
- We wanted the Workgroup to facilitate cross center work, and to achieve tangible end-product that can be used across centers w/ new PMs that come on board, and that can also be used w/ other research entities engaged in this type of research.
- Background: Centers that involve multiple partners & multilevel data are becoming more commonplace, so PMs play an integral role in these studies, so they need tips in friendly format toolkit important information at a glance, practical, easy to read various aspects of project management, how to handle challenges, how to facilitate research.
- Handbook/toolkit contents developed by PMs to engage in day to day work of implementing the research:
  - o Introduction purpose of handbook, describes the type of complex multilevel research that we're doing and how to use the toolkit.
  - o Roles of PMs managing budgets, hiring staff, other aspects
  - o Recruitment strategies -- we're collecting info already about recruitment strategies; diff levels of recruitment to think about (theory vs. reality, local/long distance, race/ethnicity, health issue), also take into account recruitment during diff seasons, monitoring progress, staffing that's required to recruit participants.
  - o Retention strategies not only retention of participants, but also clinic site staff, financial resources
  - O Data mgmt across centers; work w/ Measures workgroup; primary vs. secondary data collection, data process, mgmt, analysis and preparation.
  - Regulatory issues this section has links to NIH websites that offer info about the IRB guidelines, office of human research protections, HIPAA info; also, working within your own institution.
  - o Staffing issues responsible for hiring of staff, defining staffing needs, providing orientation to center, delegating responsibility
  - o Awareness that PMs manage multiple projects
- Discussion of community participation in projects; identifying stakeholders, advisors; disseminating findings to those stakeholders and others, and obtain community feedback so that we act on that feedback.
- We will also have appendices so that new PMs to the centers will have forms they can use, and see sample correspondences.
- Uses of toolkit for PI's to train new PMs, and for PMs to use for reference; perhaps we can have a bound toolkit vs. one on portal there are pros to portal, since revisions can be immediately, other PMs can add info on the portal (vs. waiting for another print version), facilitates info sharing and feedback.

# Action Item:

• Hope to have finished product in next few months; will work w/ Communications group to get it placed on the portal.

# **Research Interest Group – SES (Nancy Breen and Steve Meersman)**

- Been harmonizing the Centers' SES data with Steve; trying to bring Centers together to show collaboration and to show this is a basis for underpinnings for health disparities research in this country; so, where could we take some data that everybody's doing and pull it all together so that we can plan for some cross-cutting projects.
- Would like to discuss posters & brainstorming; would like to commend you in your
  contributions to health disparities research, really responding to the RFA, delighted with endroads you all are making; impressed with infrastructure that you're building (e.g., handbook,
  portal, publications); thank you for your responsiveness and Tim Rebbeck and Chris Masi,
  Electra and Dick and Sarah who've helped us get together the information we have today.
- Why bother with harmonization? We want to refund the centers and need to justify that the centers aren't just RFAs doing great work, but RFAs contributing something new and to move the field forward, ~ paradigm shift. Funding has been declining and so we need strong arguments more than ever. Shobha thought to standardize SES data across centers and projects; it would be helpful if everyone did participate. We anticipate some funding for add'l scope of the work.
- Today's goals are to brainstorm potential projects and publications; interested in longer term and in things that we can do almost immediately we'd like to say to the board that we have articles in press, or present some data to BSA, or have you present that data. So, preliminary foundation is to harmonize the SES data it really is the underpinning for health disparities.
- SES tries to characterize the hierarchies in country, and those hierarchies affect public health.
- How we define SES (or Socioeconomic "position" more dynamic, has time factor in it) what data are already being collected by centers? Background and contextual SES data? RAND data, geocoding (Steve). What can we do w/ these data?
- PIs are preparing paper to Centers, shows model, social conditions and policies/institutions (from literature, about 20 yrs), leading to pop health outcomes and behaviors...can look at mortality but look at intermediate measures in health disparities. Also, level 2, neighborhoods and social relationships variables. Finally (level 3) downstream factors, which include biologic/genetic pathways, individual risk factors/behaviors, metabolic pathways. More interaction between level 2 and 3.
- How do we define SES? Income/employment/education. Anyone who defines it would say those are included. Income can be ranked (more is 'better'), employment can be ranked (widely used in Europe), education is also rankable.
- We can add race, age, gender, not natural hierarchies; community characteristics, census tracking. RAND focusing on neighborhood SES and position.
- Would like to walk through the matrices common themes from PI paper (Warnecke provided) can see what's being looked at (levels correspond to matrices levels) all centers are examining impact of macro level, institutions, role of individual behaviors, and the micro level (biological and genetic mechanisms) lots of cross-cutting research going on; this is summary matrix, there are other more detailed ones.
- [Nancy describing matrices], what questions would we ask to get consistent information across centers; we should be spending time interpreting data, not necessarily collecting data
- Each center has been color coded, where mult projects, mult columns for that center; data from census surveys (nat'l health interview survey); everyone is collecting birthday and age, gender,

ethnicity, race; immigration not being collected by all centers (depends on research question), sites are getting education, employment, job type, income info, housing characteristics, some are collecting residential tenure; marital status, household members, home ownership, address info, healthcare access (not all ctrs), type of insurance, length of coverage (increasingly we're getting data on this).

- Would like to introduce you to these other matrices these are actual questions; if you look at income, can be differently worded, so we might want to ask them in same way (race is generally asked same way)
  - Someone brought up that it's challenging to have it the same wording; e.g., would you put >200,000 income for Appalachia that might not be necessary]; these details can be worked on
- Matrices can serve as starting point for centers' research questions
- Use questions that are widely used so to be comparable; let's come up with a process so we agree on which questions would work for diff centers.

#### **RAND Data**

# **Discussion Points:**

- Multilevel projects, so looking at neighborhood SES is very important (address info)
- When talking about community/contextual/neighborhood data, important to harmonize data
- There are a number of purposes for geocoded data (mapping functions representing study areas, complex maps for layering of data).
- Slide of a project we're currently working on gone through a process of harmonizing a number of diff data sources in order to understand multilevel approach to disparities (Cali Health Interview Survey, within LA county eg, mammography use). Trying to approach looking at these measures in unique ways and do unique analyses.
- Physician's survey practice composition, types of patients they see, where revenue comes from, etc., got this info for county level, but not meaningful for analysis; looked at diff level of aggragation.
- Census data, National health and nutrition examination survey, etc, are used by RAND.
- SES related constructs there are 1000s that are being created and we pulled a few from census (neighborhood disadvantage, racial composition, stability, crowding, residential density, etc.)
- Also, there's collection on land use mix data variables, walkability data, sprawl, air pollution and air quality data.

#### **CaBIG**

- Nancy indicated that Peter Schad could assist if people have questions
- NCI initiative Cancer biomedical informatics grid (CaBIG) Dr. VonEschenbach funded CaBIG and supports it might be something that's going to stick.
- Getting data elements into CaBIG could be helpful for re-funding; framework for consolidating data, can protect and restrict data and software as it enters this system.
- Could accelerate research, enables creative uses of data, facilitates and improves meta-analyses.

# Themes (Nancy Breen)

- Common themes will help us in research questions; I think Steve has just handed out a list of research questions (slide) and then I'll mention other efforts of data harmonization and then open it up for discussion:
- Do neighborhoods facilitate or impede development (or whatever outcome) of individuals? (growth over life cycle) If no-one is doing this, we can mark it out in our minds; yet there is literature to support that it has an effect on health outcomes.
  - Someone commented we need to be broad, out of the box about outcomes
  - Let's say all 8 centers find this, but what if it's not found across all 8 observation points? Inconsistent findings could look at methods or how data were collected.
  - Maybe questions as they're stated are narrow we can still look at patterns, though.
  - ➤ We should find out exactly what people are doing
- Low income & education is everyone doing something related to Stress and Coping? Yes
  - ➤ Article about SES from NIH/Natcher '99 ranking associated w/ inequities is when it starts to affect your health consistent finding?
  - ➤ More work still to be done in this area (neighborhoods)
- Low wages & precarious employment related to chronic stress?
  - ➤ Is info being collected by survey? Self-report and biological marker measures can be studied across centers.
  - ➤ Nicole Lurie mentioned NHANES data meta-analysis can be possibly done to look at data across centers and making sense of it time, effort and investment needed but worth it.
  - Paige & Steve will take lead on Stress and Coping and try to move that forward.
  - ➤ Poverty/low household income how to ask/measure consistently for next round of funding
  - ➤ Employment patterns and gender differences labor force participation stress how money comes in and how it gets distributed among the household members.
- Do residents of lower SES have less ability to participate in community life than higher SES?
  - ➤ How to define community life?
  - ➤ Collective efficacy, social capital? There are measures of this.
  - > Define social isolation as a construct
  - > 5 centers measuring this vis-à-vis health outcomes
- Is SES both a cause and an outcome of poor health? Both. Need to decide though what is the cause and what is the effect. You would want panel data associated w/it 3 of the centers are surveying people 12 months out, maybe another. This is probably not good for us to pursue in the short run...this would be if centers were funded for 25 years.
  - ➤ Sidenote -Intergenerational data? Data about parents possibility to ask (needs tweaking).
- Do various psychosocial resources modify stress coping/outcomes? Centers are looking at this; could be something promising here.

- What types of resources are needed to change the existing economic and social environment to eliminate health disparities? (What resources have been used?)
  - ➤ Recent finding in literature Low SES individuals in low SES neighborhoods have lower health outcomes than those in higher SES neighborhoods what are the individual characteristics that influence this relationship? Dynamic relationship/activity (Wayne, UPenn, everybody)
- To what extent do perceptions of neighborhood stress consistent with measures of neighborhood stress and are they associated w/ health outcomes? Are people measuring neighborhood stress objectively and subjectively? e.g., feel safe, how they perceive it?
  - ➤ Might not be consistently asked Nancy noted that Dick had measured perceived neighborhood stress and Electra said she had perceived neighborhood stress (not objective). Perceived stress does moderate the relationship. In Chicago, there's local dataset about neighborhood stress (someone mentioned LA would have crime rate info).
  - > Geocoding of crime data = objective. Different methods are being used to look at this.

#### Action Items:

- Steve and Paige will work to harmonize stress and coping variables
- UPenn will work on stage of cancer diagnosis.
- Looking at intergenerational data (noted above)
- Possible meta-analysis of NHANES data (noted by Nicole Lurie above)
- Nancy to work with R. Warnecke about gentrification studies; expanding his research
  - ➤ Gentrification study study on neighborhood characteristics low property values to high property values yielded higher odds ratio of later stage breast cancer diagnosis...so, census and registry data can do this. Took median property value in '90 and '00 and those who went from below median to above median were considered gentrified.
  - > So, Nancy mentioned expanding Dick's research; looking at other gentrification studies? Maybe Penn, DC (registry data in DC)
  - ➤ Other thought is neighborhood sprawl might be affecting stage of diagnosis b/c it's another way that neighborhoods are disrupted.