

Response to National Center for Research Resources Questions
Submitted by Kristine Wong (kristine@u.washington.edu), on behalf of a group listed below
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1. What are the most significant trends, developments, and/or needs in biomedical research that are likely to materialize over the next five years, and what can NCRR do to be prepared to respond to them?

We believe the significant trends, developments, and needs described below should be addressed by NCRR in its strategic plan. Although we realize the focus of this request for public comment is on NCRR's strategic plan, we stress that these issues must also be addressed by NIH as a whole.

(a) *Fostering equal participation*: Research involving communities as equal partners (i.e., in determining the research question and methods, implementing the research, disseminating and translating results into practice and policy) not only increases the validity and rigor of the data collected, but also builds capacity in communities to work on the issues affecting them. An approach to research called community-based participatory research (CBPR) is one of the best examples of how communities have worked side by side with researchers as equal partners. CBPR is “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change...” (Kellogg Community Health Scholars Program, 2001 – see references in answer to Question 6). We urge you to embrace CBPR as a strategy both for engaging communities as partners in the research process, and for increasing the quality and impact of research. (To learn more about CBPR, please visit Community-Campus Partnerships for Health's in-depth CBPR resource webpage at <http://depts.washington.edu/ccph/commbas.html>, and the online CBPR curriculum available at www.cbprcurriculum.info).

(b) *Clarifying language*: The language NIH uses to define and describe research should be clear and consistent (so that NIH, researchers and the communities involved in research are “on the same page” as to what is meant by certain terms). It is just as important to define terms as “participation,” “community,” “community engagement,” and “community-based participatory research” as it is to define technical terms, since the interpretations of these terms often depend on the context and environment in which they are used. The Clinical and Translational Science Awards, for example, are expected to include community engagement, but it is not necessarily clear what that means. Making this language clear and accessible to all who support and engage in research will result in reaching a greater proportion of those in the communities most affected by the health conditions and issues being studied.

(c) *Translating data to practice and policy*: If research is to have a positive impact in society, there must be an opportunity for results to be presented not only to the research community as is typically done through peer-reviewed presentations and publications, but to the communities involved in the research, the public at large, and policymakers. These groups can all use data to sponsor effective programs, policies, and interventions that will meet the specific needs of affected communities on local, county, state, and national levels. The more that NIH emphasizes a balance in its research portfolio [i.e., a balance between (1) community-based translational research that looks at the social determinants of health and how solutions can be preventive *and* (2) basic science research that falls under the biomedical model], the greater the likelihood that research findings will be translated into practice and policy outcomes. A community-based participatory approach that engages community and policy stakeholders will help to ensure that the research has significant practice and policy impacts.

(d) *Building the pipeline*: NCCR needs to continue its capacity-building programs targeted towards the next generation of researchers – especially those from underrepresented communities – so that future research will be conducted by people who have firsthand knowledge and expertise in not only emerging issues affecting communities that should be of concern to NIH, but in exactly how those issues affect communities and how to collaborate with those communities in the conduct of the research. NCCR’s funding priorities in this area should be expanded to explicitly include CBPR (see answer to question #4 below). A robust pipeline of graduate students and post-doctoral trainees from underrepresented communities will help to ensure that investigators of the future will know how to conduct research in the most culturally sensitive and appropriate ways.

(e) *Ensuring appropriate NCCR staffing*: If the above goals are to be reached, NCCR must hire staff whom possess a comprehensive understanding of the importance of authentic community participation and involvement in research (i.e., the benefits of a CBPR approach to research), and how this ultimately affects the rigor and usefulness of the data collected. This is inherently linked to issue (d) above.

(f) *Addressing additional issues of concern*: We have identified a number of additional critical issues that need to be addressed through NIH-funded research, including: racial and ethnic health disparities, the health effects of discrimination, discrimination in health care, ethical considerations in genetics research and genetics testing, the health effects of immigration policy on diverse populations, and the impact of language access on health care delivery and health outcomes.

2. From the standpoint of achieving the broadest impact among investigators, what new or expanded research resources and/or animal models should be developed over the next five to eight years?

NCCR needs to recognize the “community model” – that is, a model that is centered on the importance of having the community be equal partners in research, as well as ensuring that research is conducted on priority issues identified by communities.

Currently, NIH (including NCR) makes substantial investments that support faculty members and academic institutions to conduct research, but almost no investment is made in the infrastructure needed in communities to conduct and be partners in research. Some of the ways to address this need include developing funding streams that build in training programs that equip community-based organizations (CBOs) with the knowledge and skills to conduct research and mentoring programs that enable CBOs with CBPR expertise to guide less experienced (and in some cases, more isolated) peers around the country (Seifer SD, Shore N and Holmes SL, 2003 – see references in answer to Question 6).

Community partners must also be able to participate as Principal Investigators (PIs), Co-PIs and researchers on NIH grants. Although there are precedents for this within the NIH system (e.g., CBPR and environmental justice grants funded by National Institute of Environmental Health Sciences; CBPR grants funded by the National Center on Minority Health and Health Disparities), the rules and regulations around eligibility for PIs/Co-PIs should be re-examined and adjusted accordingly. It is not enough to point to eligibility criteria on paper that indicate that community and faith-based organizations can apply for NIH grants. Investments must be made in building the capacity of these organizations to be successful, just as investments are made in faculty members and academic institutions. NIH research resources need to be dedicated to train community members to serve as PIs, Co-PIs and researchers. There are a number of ways to approach this, including (a) developing structured mentoring programs where established academic PIs who are skilled in CBPR could train people from CBOs; (b) offering training workshops for community partners on research methods, grantwriting and grant administration; and (c) providing grant funding to CBOs to develop their research capacity. There are a number of funding agencies that serve as models for awarding research grants to CBOs and building community research capacity, including the California Breast Cancer Research Program, the Northwest Health Foundation, the Paso del Norte Health Foundation (though the Center for Border Health Research), the Ontario HIV Treatment Network and the Canadian Institutes of Health Research.

NIH (including NCR) needs to dedicate more funds to training researchers in CBPR. A good example from the private sector is the WK Kellogg Foundation-funded Health Scholars Program Community Track, a post-doctoral fellowship program in CBPR. Other programs that could be emulated by NCR include the Community-Based Research certificate program offered by the Wellesley Institute in Toronto. Other resources that can be developed for investigators (whether they are academic or from the community) are in-person, telephone, online training and mentoring programs, and in-depth training during the technical assistance meetings of NIH grantees. NIH grantees from all funding streams that incorporate a CBPR approach should be convened for the purpose of building collective knowledge, sharing experiences and lessons learned, and providing feedback to NIH for how to best support CBPR. These meetings should involve principal investigators and community partners.

Another strategy for ongoing (though informal) training of investigators new to CBPR is to have stronger monitoring and technical assistance from knowledgeable NIH staff that

enforces community accountability. For example, NCR staff with CBPR expertise should be available to give feedback and technical consultations to grantees involved in any form of community-based research. Progress reports should ask specific questions about the extent to which community participation is being practiced; reports should be written from all partners' perspective (for example, even if the PI is from the institutional side, there should be a requirement to turn in a progress report from the community side, to monitor and enforce accountability to the community).

Lastly, it is important to note that just as having funding for requisite lab space and supplies is absolutely crucial to successful basic science research, having funding for partnership development (e.g., providing partners with the tools and resources needed to establish an equitable partnership structure, processes for decisionmaking, conflict resolution and communications) is absolutely crucial to successful CBPR. Finally, grant reviewers who review CBPR submissions to all NIH institutes should receive more explicit guidance on how to assess what constitutes authentic community partnership in the context of CBPR. In the same way reviewers have guidelines by which to determine scientific rigor, they need guidelines to help determine authentic community partnerships in CBPR proposals.

3. The recently-introduced CTSA (Clinical and Translational Science Award) Program seeks to transform the local, regional and national environment for clinical and translational science, thereby increasing the efficiency and speed of clinical and translational research. What considerations will be most crucial to the long-term success of this initiative?

A key consideration for the long-term success of the CTSA Program is the recognition that community engagement in research takes time. We respectfully point out that if the NCR is coming from the perspective that research should be "efficient and speedy," then research partnerships involving communities (as exemplified by the CBPR approach and as expected by the CTSA) will not be successful, nor will the data coming out of the research be rigorous. We agree with the sense of urgency around having research findings be quickly applied and disseminated, but the reality is that community-based participatory approaches to research are dependent on relationships and trust that can only be achieved over time. It is disingenuous, for example, to expect the CTSA to emphasize community engagement and then turn around and expect efficient, speedy research. There are a number of examples of rigorous CBPR that have led to significant improvements in public health outcomes and changes in practice and policy, including CDC-funded Prevention Research Centers and Urban Research Centers (e.g., Detroit Urban Research Center, Harlem Community and Academic Partnership) (Israel et al., 2006 – see references in answer to Question 6).

It is essential that community partners be provided with a structure and mechanism to have a voice within the CTSA program. We have observed the development of an elaborate structure of committees within the CTSA program that are comprised of NIH staff, academic representatives of CTSA programs. Community partners must be provided an opportunity to serve on these committees and to determine which additional

committees may be needed. They must also be included as equal participants to the PIs and academic representatives in CTSA meetings. We recommend taking a look at the National Community Committee of the CDC Prevention Research Centers. Briefly, each PRC has a community committee, and representatives of each of these committees come together as an NCC that advises the PRC program nationally and provides peer mentoring and support to community partners involved in the PRC program. Giving communities their own space to connect and serve as resources for each other, and to have a direct communications link to CTSA staff at NIH, is crucial to the long-term success of the CTSA program.

Finally, there needs to be an evaluation of the nature and extent of community engagement in the CTSA program at the national and local levels, and the impact of the CTSA in translating research into practice and policy. The substantial public investment in the CTSA program demands this level of accountability, not to mention the important role the findings will have in informing “the field” and future practice and policy.

4. Despite significant progress, research institutions serving predominantly minority and underserved populations face stiff challenges. What can NCRR do to most effectively support the long-term advancement of these institutions?

To most effectively support the long-term advancement of these institutions, there needs to be a commitment to the continued development of not only the institution itself, but the individuals that comprise those institutions and make them what they are. We applaud NCRR’s Science Education Partnership Awards (SEPA) program that is currently awarding money to K-12 programs in the effort to build capacity within rural populations, underserved groups, and communities of color to pursue health and research careers. However, we ask that you expand SEPA’s funding priorities to not just “enhanced training for science teachers; the development and distribution of hands-on science curricula; and websites for students, teachers, and the general public,” but also for partnerships that engage rural, underserved and communities of color in determining the need and focus of the projects. We also encourage the inclusion of service-learning and CBPR, whereby K-12 students are engaged in community-based science and public health projects that can not only benefit communities at large, but also instill in students the value of giving back to one’s own community and spark a passion to pursue higher learning. (The federally funded National Service-Learning Clearinghouse is a wonderful resource on service-learning, www.servicelearning.org).

We also applaud the good work that NCRR is doing with the National Center of Minority Health and Health Disparities around the Research Centers in Minority Institutions (RCMI) to reach a 50 percent or greater enrollment of students from minority communities underrepresented in the biomedical sciences, among minority-serving institutions that award doctoral degrees in health-related fields. We recommend that CBPR be an explicit focus within the RCMI – in other words, that CBPR be explicitly supported through the RCMI mechanism.

5. NCRH has worked with many federal and private sector institutions, agencies, and organizations and will continue to do so as we move forward. What organizations should NCRH seek out for future partnerships to most effectively support, expand, and advance its programs and services?

Though not exhaustive, the following is a list of key organizations and networks that NCRH should reach out to as partners: Included are those mentioned in our answers to the other questions above.

Association of Asian Pacific Community Health Organizations (www.aapcho.org/site/aapcho/)
Asian and Pacific Islander American Health Forum (www.apiahf.org)
Asian Pacific Environmental Network (www.apen4ej.org)
CDC Prevention Research Centers (<http://www.cdc.gov/prc/>) and its National Community Committee (<http://www.hpdp.unc.edu/ncc/>)
California Breast Cancer Research Program (www.cbcrp.org/)
Community-Based Public Health Caucus of the American Public Health Association (www.sph.umich.edu/cbphcaucus/)
Community-Based Research/CBPR Funders Interest Group
Community-Campus Partnerships for Health (www.ccph.info)
Community Coalition for Environmental Justice (www.ccej.org)
Community Partner Summit Mentoring and Policy Work Groups (<http://depts.washington.edu/ccph/cps.html>)
Detroit Urban Research Center (www.sph.umich.edu/urc/)
For A Better Bronx/South Bronx Environmental Justice Partnership
Guam Communications Network (www.guamcomnet.org)
Harlem Community and Academic Partnership (www.nyam.org/initiatives/cues-research.shtml)
Hazard Perry County Community Ministries (www.hpccm.org)
Indigenous Environmental Network (<http://www.ienearth.org/>)
Institute for Community Research (www.incommunityresearch.org)
Kellogg Health Scholars Program (www.kellogghealthscholars.org/)
National Community-Based Organization Network
National Community Committee of the CDC Prevention Research Centers (www.cdc.gov/prc/about-prc-program/committees.htm)
National Association of Community Health Centers (www.nachc.com)
NIH Council of Public Representatives (<http://copr.nih.gov/>)
NIH Scientific Interest Group on CBPR (http://grants.nih.gov/grants/training/esaig/cbpr_sig.htm)
Northwest Health Foundation (www.nwhf.org)
Orange County Asian Pacific Islander Community Alliance (www.ocapica.org)
Paso del Norte Health Foundation (www.pdnhf.org/)
Policy Link (www.policylink.org)
Portland State University (www.pdx.edu)
Southeast Community Research Center (www.cbpr.org)
Southwest Network for Environmental and Economic Justice (www.sneej.org)

Southwest Organizing Project (www.swop.net)
University of Michigan-Ann Arbor School of Public Health (www.umich.edu)
University of North Carolina – Chapel Hill School of Public Health (www.unc.edu)
Urban Indian Health Institute (www.uihi.org)
West End Revitalization Association (<http://www.wera-nc.org/>)
Yakima Valley Farmworkers Clinic (www.yvfwc.org)

We also recommend looking beyond the United States for potential partners, such as the Wellesley Institute (www.wellesleyinstitute.com), the Ontario HIV Treatment Network (www.ohtn.on.ca/), and the Canadian Institutes of Health Research (<http://www.cihr-irsc.gc.ca/e/193.html>)

6. Is there anything else you would like to add that would be helpful to NCRRC?

1) Please remember to be inclusive of communities, CBPR and the social determinants of health in the phrasing of your public comment questions, and not just orient them around bench and biomedical research.

2) Develop an aggressive and robust outreach program to ensure that CBOs have opportunities at a grassroots level to provide public input on NIH policy and strategic directions, beyond the Council of Public Representatives level. This should include regional technical assistance workshops on the NIH funding process specifically designed for CBOs that cover such topics as demystifying NIH and the research funding process, navigating the IRB process and obtaining a federally negotiated indirect cost rate.

The following people and organizations are submitting these comments (listed below). We have come together through the support of the Community Partner Summit Policy Work Group [see (<http://depts.washington.edu/ccph/cps.html>)]. We are eager to work with you in the further development and implementation of the NCRRC strategic plan and look forward to hearing how we can become more involved, individually and collectively. Thank you.

Ella Greene-Moton, Community-Academic Liaison, University of Michigan-Ann Arbor, Flint, MI

Susan Gust, Grassroots Activism, Sciences and Scholarship (GRASSRoutes), Minneapolis, MN

Ann-Gel Palermo, Harlem Community and Academic Partnership, New York, NY

Alice Park, Urban Indian Health Institute, Seattle, WA

Sarena D. Seifer and Kristine Wong, on behalf of Community-Campus Partnerships for Health, Seattle, WA

Vickie Ybarra, Yakima Valley Farmworkers Clinic, Yakima, WA

Would you like a copy of the published plan? X Yes

If so, you must provide your e-mail address: kristine@u.washington.edu

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