December 2, 2013

Christopher P. Austin, M.D
Director, National Center for Advancing Translational Sciences (NCATS)
National Institutes of Health (NIH)
Bethesda, MD 20892-4874

Dear Dr. Austin:

We are writing as members of the CCPH-CTSA Member Interest Group (MIG) as a follow-up to our letter of September 28, 2012, in which we expressed our concerns about, and recommendations for, the future of community engagement (CE) in NCATS and the Clinical and Translational Science Award (CTSA) program. As you may know, we shared these with the Institute of Medicine (IOM) Committee to Review the CTSA Program at NCATS. We were pleased to see that the IOM Committee’s June 25, 2013 report cites our recommendations and identifies CE across the entire research spectrum as integral to advancing clinical and translational research. We were also impressed by your pledge that same day to immediately implement the report’s recommendations.

We understand that the NCATS Advisory Council has established a work group to advise you on the NCATS response to the IOM report. In advance of the first meeting of the work group scheduled for December 6, 2013, we have developed a set of practical actions that NCATS can take to implement each of the seven IOM recommendations, with a particular focus on those pertaining to CE. We have shaded in grey the practical actions we view as high priority. For the most part, these are relatively low cost, easy to implement and provide opportunities to leverage existing resources.

Thank you for the opportunity to provide our input. We look forward to working with you to ensure that the CTSAs fully realize their potential to improve the health of communities. If we can be helpful in any way to implementing the IOM committee recommendations, please contact us through MIG Chair Gail Newton at gail_newton@urmc.rochester.edu or CCPH Executive Director Sarena D. Seifer at sarena.seifer@gmail.com

1 Founded in 1997, Community-Campus Partnerships for Health (CCPH) is a national membership organization that promotes health equity and social justice through partnerships between communities and academic institutions. A CCPH-CTSA member interest group was established in 2010 to provide a space for CCPH members involved in CTSAs (from community and academic settings) to meet regularly. The group is comprised of 109 people from 32 CTSAs and 2 CTSA applicants. In 2011 and 2012, with support from the National Institutes of Health, CCPH and the Center for Community Health Education Research and Service in Boston sponsored a National Community Partner Forum on Community-Engaged Research that together drew nearly 200 community leaders, 30% of whom are involved in CTSAs. Input from both groups has been incorporated into this letter.
<table>
<thead>
<tr>
<th>IOM Recommendation</th>
<th>Practical Actions That Can Be Taken By NCATS</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1: Strengthen NCATS Leadership of the CTSA Program</td>
<td>• Undertake a strategic planning process in which diverse stakeholders within and outside of the CTSA program are not only consulted but also actively engaged over time through multiple mechanisms that are not limited to Requests for Information (RFI). Along a continuum of CE, RFI are regarded as consultative and fairly passive. Further, the usually quick turnaround time for comments limits the participation of the full range of stakeholders, in particular community partners. The Canadian Institutes of Health Research’s Citizen Engagement Framework and specifically the “spectrum of citizen engagement activities” appendix may serve as a model: <a href="http://www.cihr-irsc.gc.ca/e/41270.html">http://www.cihr-irsc.gc.ca/e/41270.html</a></td>
</tr>
<tr>
<td>Ensure that the CTSA program as a whole covers the full spectrum of clinical and translational research. CE should be part of all phases of research in every CTSA institution</td>
<td>• Define “clinical and translational research” to explicitly include CE. • Make a strong and unequivocal statement of support for CE as essential to the full spectrum of clinical and translational research from T1 to T4. Display this statement in a prominent position on the NCATS and CTSA websites, in all CTSA presentations and in all CTSA funding announcements.</td>
</tr>
<tr>
<td>Form strategic partnerships with NIH institutes and centers and with other research networks and industry</td>
<td>• Urge the NIH Director to reinvigorate the NIH Council of Public Representatives and restore it to its full membership (the Council agenda, meeting schedule and membership have been significantly restricted in recent years). • Urge the NIH Director to reactivate the “CE in Research Initiative Workgroup” and invite the participation of all federal agencies that fund research (recommended by COPR in 2010 and initially formed but then disbanded when Dr. Raynard Kington left his position in the NIH Office of the Director). • Provide leadership for reactivating the NIH Scientific Interest Group on Community-Based Participatory Research (here is a link to an announcement about it when first established in 2007: [<a href="http://nnlm.gov/bhic/2007/06/05/">http://nnlm.gov/bhic/2007/06/05/</a> NIH-establishes-cbpr-scientific-interest-group/](<a href="http://nnlm.gov/bhic/2007/06/05/">http://nnlm.gov/bhic/2007/06/05/</a> NIH-establishes-cbpr-scientific-interest-group/)). • Provide leadership for initiating NIH-wide funding announcements for community-engaged research.</td>
</tr>
<tr>
<td>Establish an innovations fund through a set-aside mechanism that would be used for collaborative pilot studies and other initiatives</td>
<td>• Include funding for CTSAs to test and rigorously evaluate models of CE in every phase of research across the continuum of clinical and translational research. • Include funding for CE collaborations among CTSAs, other research institutions and community partners located in the same city/region.</td>
</tr>
<tr>
<td>#2: Reconfigure and Streamline the CTSA Consortium</td>
<td>• Ensure community partners are integrated and supported in any reconfigured or streamlined CTSA Consortium structure. This includes providing more opportunities for community partners to serve in leadership roles and contribute to the direction of the CTSA Consortium. • Ensure any reconfigured or streamlined CTSA Consortium includes an ongoing and supported mechanism for those involved in CTSA CE to regularly meet to share best practices, address shared challenges, plan collaborations, etc.</td>
</tr>
<tr>
<td>IOM Recommendation</td>
<td>Practical Actions That Can Be Taken By NCATS</td>
</tr>
<tr>
<td>---------------------</td>
<td>--------------------------------------------</td>
</tr>
</tbody>
</table>
| **#3: Build on Strengths of Individual CTSAs Across Spectrum of Clinical and Translational Research** | Involve patients, family members, health care providers and other community partners in all phases of the work of the CTSA  

- Require CTSAs to have external advisory boards that must include community stakeholders, including community-based organizations.  
- Require CTSAs to demonstrate meaningful roles for community stakeholders, including community-based organizations, with specific supports for their participation in CTSA proposal preparation and governance, including compensation for their time, expertise and travel. |
| **#4: Formalize and Standardize Evaluation Processes for Individual CTSAs and the CTSA Program** |  

- Ensure that CE is included in the evaluation of all of the components of CTSAs at local and national levels, rather than only in the evaluation of components specifically identified as being related to CE.  
- Conduct a participatory evaluation of CTSAs in which CTSA leadership, faculty, students, community partners, funders and other key stakeholders collaboratively develop the indicators, metrics and methods to be used. There are a number of existing assessment frameworks and tools that could be built upon – for example, those developed by the CTSA Outcomes of CE Workgroup ([http://www.ncbi.nlm.nih.gov/pubmed/23752038](http://www.ncbi.nlm.nih.gov/pubmed/23752038)), CDC Prevention Research Centers ([http://www.cdc.gov/prc/program-material/report_winter2010.htm](http://www.cdc.gov/prc/program-material/report_winter2010.htm)), NIEHS Partnerships for Environmental Public Health Program ([http://www.niehs.nih.gov/research/supported/programs/peph/metrics/index.cfm](http://www.niehs.nih.gov/research/supported/programs/peph/metrics/index.cfm)) and NIH/IHS funded Research for Improved Health: A National Study of Community-Academic Partnerships ([http://narch.ncaiprc.org/index.cfm](http://narch.ncaiprc.org/index.cfm)). |
| **#5: Advance Innovation in Education and Training Programs** | Emphasize innovative education and training models and methods, which include a focus on team science, leadership, community engagement and entrepreneurship  

- Collaborate with other Centers and Institutes at NIH to include support for CE and community-engaged research into their K awards.  
- Develop a Career Development Award (K-series) for CE and community-engaged research rather than relying on the disease- and technology-oriented Centers and Institutes for Career Development Awards.  
- Fund education and training programs in CE and community-engaged research for academic researchers and community partners.  
- Fund education and training programs for community partners and academic researchers that support using data for evidence-based practice and policy. |
<table>
<thead>
<tr>
<th>IOM Recommendation</th>
<th>Practical Actions That Can Be Taken By NCATS</th>
</tr>
</thead>
</table>
- Revise the current definition of “clinical and translational research” to explicitly include CE.  
- Make a strong and unequivocal statement of support for CE as essential to the full spectrum of clinical and translational research from T1 to T4. Display this statement in a prominent position on the NCATS and CTSA websites, in all CTSA presentations and in all CTSA funding announcements. |
| Ensure active and substantive community stakeholder participation in priority setting and decision making across all phases of clinical and translational research and in leadership and governance of the CTSA program | **National participation, leadership and governance: NCATS**  
- Appoint at least two community partners to serve on the NCATS Advisory Council.  
- Ensure at least two community partners serve on any NCATS Advisory Council workgroups.  
- Compensate all community partners serving in NCATS leadership roles (e.g., Council and Council workgroup members) for their time, expertise and travel.  
**National participation, leadership and governance: CTSA**  
- Immediately begin to compensate the community partner who has been volunteering for over one year as co-chair of the CTSA CE Key Function Committee for his time, expertise and travel.  
- Designate funds to support community engagement in consortium-wide activities, including funds to compensate all community partners serving in national CTSA leadership roles (e.g., Committee and Subcommittee co-chairs) for their time, expertise and travel.  
- Extend the CTSA CE Key Function Committee leadership structure (i.e., with a CTSA community partner serving as a co-chair) to all other CTSA National Committees and Subcommittees. The National Community Committee of the CDC Prevention Research Centers program could serve as a working model of meaningful community stakeholder participation in the leadership structure of a federal research grant program ([http://www.cdc.gov/prc/community-voice/index.htm](http://www.cdc.gov/prc/community-voice/index.htm)).  
- Ensure that CTSA community partners serve as planning committee members, speakers and participants for NIH-funded CTSA meetings and conferences.  
- Require each CTSA to budget for community partner attendance at NIH-funded CTSA meetings and conferences.  
- Provide opportunities for CTSA community partners to meet independently as a group at NIH-funded CTSA meetings and conferences.  
- Host an NCATS webinar to brief CTSA community partners on national opportunities for their participation, leadership and governance.  
**Peer review of funding applications**  
- Require all NCATS and CTSA funding announcements be assessed by reviewers with relevant CE related experience who are properly prepared and compensated for their roles – including at least one community-based peer reviewer for each
<table>
<thead>
<tr>
<th>Define and clearly communicate goals and expectations for CE at individual CTSA level and across the program and ensure the broad dissemination of best practices in CE</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Develop goals and expectations for CE at the individual CTSA level and across the program through a participatory process involving community stakeholders and the broader public. Leverage the CTSA investments that have already been made in developing CE logic models and evaluation frameworks (e.g., <a href="http://www.ncbi.nlm.nih.gov/pubmed/23752038">http://www.ncbi.nlm.nih.gov/pubmed/23752038</a>).</td>
</tr>
<tr>
<td>- Leverage the CTSA investments that have already been made in online clearinghouses and toolkits to support community-engaged research (e.g., <a href="http://communityresearchpartners.net">http://communityresearchpartners.net</a>, <a href="http://researchtoolkit.org">http://researchtoolkit.org</a>, <a href="http://ctsacorus.org">http://ctsacorus.org</a>), as well as those developed outside of the CTSA program (e.g., <a href="http://cbprcurriculum.info">http://cbprcurriculum.info</a>, <a href="http://CES4Health.info">http://CES4Health.info</a>), by providing funds to better coordinate and publicize them.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Explore opportunities and incentives to engage a more diverse community</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Develop long term funding mechanisms for community-engaged research that are similar to NIMHD’s Community-Based Participatory Research initiative which provides up to 10 years of support through 3 sequential competitive funding announcements for planning, implementation and dissemination (described at <a href="http://www.nimhd.nih.gov/our_programs/communityParticipationResearch.asp">http://www.nimhd.nih.gov/our_programs/communityParticipationResearch.asp</a>).</td>
</tr>
<tr>
<td>- Develop funding mechanisms for community research capacity building and research infrastructure that prioritize community organizations as lead applicants.</td>
</tr>
<tr>
<td>- Provide community organizations with training and technical assistance in NIH grant writing, submission, peer review and federal indirect rate negotiations (either directly or through intermediate organizations).</td>
</tr>
<tr>
<td>- Develop funding mechanisms to support CTSA involvement in increasing the public’s appreciation for and understanding of science and research.</td>
</tr>
<tr>
<td>IOM Recommendation #7: Strengthen Clinical &amp; Translational Research Relevant to Child Health</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Identify and designate CTSAs with expertise in child health research as leaders in advancing clinical and translational research relevant to child health and as coordinators for CTSA program-wide efforts and other collaborative efforts in this research.</td>
</tr>
<tr>
<td>Identify and designate CTSAs with expertise in CE and community-engaged child health research.</td>
</tr>
<tr>
<td>Promote and increase CE specific to child health by raising awareness of the opportunities for children and families to participate in research efforts with clear information conveyed on risks and potential benefits.</td>
</tr>
<tr>
<td>Ensure families, youth, caregivers and youth service providers are engaged in identifying and developing the mechanisms and messages related to participation in child health research.</td>
</tr>
<tr>
<td>Promote and increase CE specific to child health involving parents, patients, and family members more fully at all stages of the research process, including identifying priorities and setting research agendas.</td>
</tr>
<tr>
<td>Go beyond the IOM recommendation to also include children, youth and youth service providers as key stakeholders in child health research.</td>
</tr>
<tr>
<td>Develop goals and expectations for CE in child health research through a participatory process involving key stakeholders and the broader public. Leverage the CTSA investments that have already been made in developing CE logic models and evaluation frameworks (e.g., <a href="http://www.ncbi.nlm.nih.gov/pubmed/23752038">http://www.ncbi.nlm.nih.gov/pubmed/23752038</a>).</td>
</tr>
</tbody>
</table>
Signed by,

Cynthia (Cee) Barnes-Boyd, Senior Director, Office of Community Engagement and Neighborhood Health Partnerships, Office of the VP for Health Affairs-Community Based Practice and Research and Associate Clinical Professor, School of Public Health and College of Nursing, University of Illinois at Chicago, Chicago, IL

Bruce Beauverd, Ph.D. Student, Walden University

Jen Brown, Director, Alliance for Research in Chicagoland Communities, Northwestern University Clinical and Translational Sciences Institute. Chicago, IL

Suzanne B. Cashman, Professor and Director of Community Health, Department of Family Medicine and Community Health and Co-Director, Community Engagement Section, University of Massachusetts Medical School Center for Clinical and Translational Science, Worcester, MA

Karen Calhoun, Senior Health Officer, City Connect Detroit and Clinical Research Associate, Michigan Institute for Clinical & Health Research. Detroit, MI

Melany Cueva, Alaska Native Tribal Health Consortium, Anchorage, AK

E Hill De Loney, Director, Flint Odyssey House, Inc., Health Awareness Center, Flint, MI

Milton "Mickey" Eder, Director of Research and Evaluation, Access Community Health Network, Chicago, IL

Stephanie Farquhar, Associate Professor, Portland State University School of Community Health, Portland, OR

Elmer Freeman, Executive Director, Center for Community Health Education Research and Service, Boston, MA

Regina Greer-Smith, S.T.A.R. Initiative, An Engagement Project of Healthcare Research Associates LLC, Chicago, IL

Susan Ann Gust, Community Activist, Past Board Chair, Community Campus Partnerships for Health and member of the Executive Committee, MN Center for Cancer Collaboration, University of Minnesota, Minneapolis, MN

Ernest Hopkins III, Executive Director, The Phoenix Group Foundation, Inc., Atlanta, GA

Chien-Chi Huang, Executive Director, Asian Women for Health, Nashville, TN

William A. Kearney, Owner/President Bill Kearney and Company LLC and Vice Chair, National Community Based Organization Network, Warrenton, NC

Arthur Lee, Community Partners' Network at Friendship Missionary Baptist Church, Nashville, TN

Chikezie Maduka, Chair, CDC Prevention Research Center National Community Committee and Co-Chair, Seat Pleasant Community Campus Partnership for Health, Seat Pleasant, MD

Marlynn May, Professor Emeritus and Associate Head, Department of Public Health Studies, Texas A&M Health Science Center, School of Rural Public Health, Houston, TX

Gail L. Newton, Director, Community Health Partnerships, Center for Community Health, University of Rochester Medical Center and Chair, CCPH-CTSA Member Interest Group, Rochester, NY
Jennifer Opp, Community Liaison, Community Health Innovation and Research Program, Harvard Catalyst, Boston, MA

Alex Pirie, Coordinator, Immigrant Service Providers Group/Health, Somerville, MA

Jean J. Schensul, Senior Scientist and Founding Director, Institute for Community Research, Hartford, CT

Sarena D. Seifer, Executive Director, Community-Campus Partnerships for Health, Seattle, WA

Hal Strelnick, Assistant Dean for Community Engagement, Professor of Clinical Family & Social Medicine and Chief, Division of Community Health, Department of Family and Social Medicine, Albert Einstein College of Medicine, Bronx, NY

Darius Tandon, Associate Professor, Northwestern Feinberg School of Medicine and Associate Director, Center for Community Health, Institute for Public Health and Medicine, Chicago, IL

Laurene Tumiel-Berhalter, Associate Professor, University at Buffalo and Buffalo Clinical and Translational Research Center, Buffalo, NY

Consuelo H. Wilkins, Executive Director, Meharry-Vanderbilt Alliance, Nashville, TN

Cc’d to:

Frances Collins, Director, National Institutes of Health

Elaine Collier, Acting Director, Division of Clinical Innovation, NCATS

NCATS Advisory Council

NCATS Advisory Council Work Group on the IOM CTSA Report

NIH Council of Public Representatives

Sergio Aguilar-Gaxiola, Nancy Bennett and Al Richmond, Co-Chairs, CTSA Consortium CE Key Function Committee

Anantha Shekhar and Harry Greenberg, Co-Chairs, CTSA Consortium Steering Committee

Cathy Liverman and Andrea Schultz, Study Directors, Review of the CTSA Program at NCATS, IOM

Alan Leshner, Chair and Sharon Terry, Vice Chair, IOM Committee that Reviewed the CTSA Program