Conference Summary

The 2014 Annual National Community Engagement Conference, Engaging Patients, Families and Communities in all Phases of Translational Research to Improve Health was held August 21-22, 2014 at the Bethesda North Marriott Hotel and Conference Center in Bethesda, MD. The conference is sponsored through a cooperative agreement between the National Center for Advancing Translational Sciences (NCATS) – a component of the National Institutes of Health (NIH) and the U.S. Department of Health and Human Services (DHHS) – and Duke University Medical Center. A diverse audience of 184 individuals representing federal, state and local governments, academic medical centers, and various community agencies attended. See Appendix A for a breakdown of academic, government, and community conference registrants. The conference was convened to address the following aims:

1. Present models demonstrating community engagement in each phase of translational research to improve health.
2. Identify methods and metrics for assessing the success of community-engaged research in each phase of research.
3. Determine best practices for sustaining community-engaged research in all phases of research.

2014 Conference Sponsorship

Funding for this conference was made possible (in part) by grant U13TR000184 from the National Institutes of Health’s National Center for Advancing Translational Sciences. The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services, nor does mention by trade names, commercial practices, or organizations imply endorsement by the U.S. Federal Government.

Background

This year’s conference was an exciting exchange between a diverse audience and mix of speakers to introduce ideas focusing on partnerships and engagement in all phases of translational research. This conference provided ample opportunities for attendees to engage and learn from a wide range of professionals in the field of public health and community-based research. Presentations focused on advances in community-engaged methods and metrics, identifying gaps, and outlining future directions for the field of community-engaged research. Emphasis on scientific aspects, discussions and action steps were encouraged throughout the conference.

Breakout sessions for each day of the conference offered five separate workshops. The facilitators for each workshop encouraged the participants to address the following questions as they relate to engaging patients, families and communities in translational research to improve health: current practices, what is working, what are the barriers and facilitators, and what are recommendations for next steps? Facilitators for each small group presented their group’s recommendations during a panel session on both days of the conference.

Welcome and Plenary Discussions

In opening remarks to kick off the 2014 conference, Lloyd Michener, MD, chair of the Department of Community and Family Medicine at Duke University, acknowledged and thanked the planning committee for their assistance in the designing of the 2014 conference. He also acknowledged the committee members who have been involved in the planning and design of the conferences since 2008. Dr Michener provided a brief overview of lessons learned, the challenges still ahead and next steps needed. He reported that over the past seven years, the conference has moved from the goal of accelerating the dissemination of information to discussing how to partner, with whom to partner, how to evaluate the progress being made, and the importance of having community partners involved in all phases of research beyond just the sharing of information. He laid out that the challenges still ahead include: (1) determining how to organize and support patient/community engagement across the
Plenary Discussions

**Chris Austin, MD**, director of National Center for Advancing Translational Sciences, presented the first of the plenaries on *Engagement of New Voices and Perspectives in all Phases of the Research Process*. Dr Austin began by focusing on the meaning of translation, translational science, and why engagement is so critical to translational science. Dr Austin’s emphasis on this connected well with the overarching conference theme as and mission to engage patients, families, and communities in all phases of translation research and with the importance of engaging the community. Dr Austin talk explained some of the challenges to community engagement and translational research, and he challenged the audience to look at translational science as a research problem and approach accordingly. This approach Institutes and Centers at NIH. He stated that translation is problematic due to a lack of consensus in the scientific community on what translation means and what it entails. Dr Austin provided an enlightening and exciting presentation. His “take-home” observations was that the opportunities and needs of large systemic problems require systems solutions. Other observations included: CTSA must work as a community; the scale of needs and opportunities require transformational solutions along with exponential improvement; CTSA can envision and substantiate new models; since NCATS is research oriented, it is an experimental venture freed from limitations of other service delivery organizations; NCATS is an experiment that is currently mid experiment, and transformation has just begun. The goal is to benefit patients and communities.

The keynote by **Judith Auerbach, PhD** School of Medicine, University of California, San Francisco complemented the 2014 conference theme with her talk on the topic “Nothing About Us Without Us:” Community Engagement in HIV Research. She chronicled the AIDS advocacy movement that successfully defined a collaborative research agenda through vertical and horizontal integration of community, academic government, and business entities. The entities aligned to employ an ecological approach with tightly linked, seamlessly integrated initiatives. Dr. Auerbach discussed how advocacy developed and was made operational to affect a relevant research agenda for AIDS with demonstrable population level outcomes. She emphasized that CBPR was and continues to be utilized to initiate efforts in moderate and low resource global environments and that CBPR is essential to sustaining urgency and social and capital interest if the disease is to be controlled globally and ultimately eradicated.

Following Dr. Auerbach’s presentation was Plenary II speaker **Robert Beall, MD** from The Cystic Fibrosis (CF) Foundation who presentation was titled *Engagement of New Voices and Perspectives in the Translational Research Process*. The Cystic Fibrosis Foundation has a long history of nearly 60 years of sustaining community-engaged research. Dr Beall began by explaining that the work of the Cystic Fibrosis Foundation started out as being able to diagnose, manage and provide supportive services to those with the illness. In 1960, standards of care were developed based on knowledge of the illness, and care centers were opened. The Foundation continues to work hard to ensure that all data is available to everyone -- patients, family members, and communities. Dr Beall highlighted that family engagement and participation was important early on, and the Foundation has strived to maintain this involvement. He shared the lessons learned, and noted that the success of the Foundation shows the great strides that have been made over the years.

Additional plenaries during the conference included **Grace Damio** with the Hispanic Health Council (HHC) in Hartford, Conn. Her talk focused on the importance of health disparities at multiple levels of research and the need to address those gaps. She emphasized that it would be impossible to address all of the social determinants with one program, but an individual could keep track of them in order to address those determinants with another program. There is expertise in community-based research that practitioners, researchers and students need to learn such as, peer mentoring, skill building, and advocacy that go hand in hand with addressing health disparities.
**Petra Kaufmann, MD** with the Division of Clinical Innovation, National Center for Advancing Translational Sciences, presented on *Engaging Community Perspectives in all Phases of Research: The CTSA Program*. Dr Kaufmann started out sharing the goals of community engagement in translational research which are: (1) to translate basic and clinical discoveries into better health for individual patients and communities, (2) accelerate and streamline the process, and (3) broaden the impact to include rare/neglected diseases, special populations, and access. She provided an overview of the IOM recommendations and shared the NCATS discussions. Strategic goals, as recommended by the Advisory Council Working Group, include workforce development, collaboration and engagement, integration, and methods and processes.

**Ann Bonham, PhD** with the Association of American Medical Colleges (AAMC) presented on *Partnering with Patients, Practices, and Communities in Clinical and Implementation and Dissemination Research*. Dr Bonham noted that “open science”, “patient data sharing”, and “reframing privacy-partners” will redefine what it means to partner with patients and communities. Global networks will be transformed from “global competition” to “global collaboration” and will in turn engage communities globally, increasing emphasis on engagement across the research spectrum, and assisting the work going on in communities by influencing policies. She recommended getting practice guidelines out to the community with the people engaged in the beginning, middle, and end, and that when reaching out to communities it is good to do a pilot social contract. It is also important to remember that improving the dignity, well-being, and health of others through research is a privilege, and an obligation of researchers.

### Summary of the Breakout Sessions

This year’s planning committee members participated as a facilitator and/or scribe for each of the small groups during the breakout sessions. On the first day of the conference, breakout sessions offered workshops focused on the following themes: *patients and families, people and community members, clinicians and practice networks, organizations and local, state and federal agencies*. The second day of the conference, breakout sessions offered workshops focused on: *governance, ethical issues and consent, study design and recruitment, informatics, and analysis and dissemination*.

Deliverables from each small group included 1) methods for processes that are effective in accelerating translational research, 2) The need for facilitators who have skills that can assist the translational research process, 3) lists of barriers that can inhibit translational research, and 4) recommendations for improving the development, demonstration, and dissemination of translational research, with emphasis on those associated with

The following were recommendations from the small groups that were discussed during the Panel I session on Thursday, August 21:

- **Patients/Families:**
  - create training programs for families and patients to help educate them on the importance of participating in research
  - work with patients and families on metrics of effective engagement
  - address how researchers are supported (or not) in their ability to be community engagement experts
  - provide training to academic leadership, research teams, and regulatory bodies about the value of patient engagement

- **People/Community Members:**
  - funding for outcomes that matter
  - developing and building an infrastructure for community health workers
  - beginning certificate training
  - shifting the paradigm, building trust to develop measures for community engagement efforts
  - trusting collaboration and partnerships
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- developing dissemination strategies as well as strategies for sustainability beyond grant funding
- focusing on outcomes that matter with the use of principles of community engagement in all phases of translation research.

- Clinicians/Practice Networks:
  - assessing relevance
  - soliciting input from clinicians
  - creating concise and ongoing communication with clinicians and patients
  - managing expectations
  - keeping projects manageable
  - conducting research that requires time and resources
  - supporting flexibility
  - making iterative, innovative projects that advance more traditional research processes.

- Organizations:
  - the community-engaged/CBPR groups should look to rare disease network successes and adapt their best practices
  - develop business models for maintenance, growth, and development with the recognition of social justice issues

- Local, State, and Federal Agencies:
  - standardization—metrics that matter across agencies
  - cost effectiveness—metrics that matter to specific agencies
  - community engagement portfolio diversity—not limited to NCATS
  - community organization around stronger federal/state/local commitment to community engagement research activities
  - identifying backbone organizations for elevating role of community engaged research (such as AAMC survey on ACA community health benefit to spark next steps).

The following were recommendations from each small group that were discussed during the Panel II session on Friday, August 22:

- Governance:
  - The group recommended asking existing networks to share best practices in governance.

- Ethical Issues and Consent:
  - standardize metrics
  - develop methods for assessing researching excellence
  - invite the community
  - develop standard training and methods of IRB engagement
  - determine best practices in knowing your community

- Study Design and Recruitment:
  - develop standard methods of obtaining input from clinicians and matching needs with resources
  - improve communication with clinicians and patients
  - manage expectations by keeping projects manageable and following through on promises
  - identify materials that support organization
  - develop the capacity with practices to examine research-based questions
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- **Informatics:**
  - more research to assess/understand how people actually use information
  - focus on the ability to produce on multiple platforms, while partnering with industry and communications specialists to maximize the innovation
  - consider the need for transformational informatics.

- **Analysis and Dissemination:**
  - open a dialogue about the issues of race and ethnicity
  - develop a set of expectations for analyses and dissemination
  - present research as an iterative and circular and not linear process
  - assess and disseminate promising practices
  - develop “writing retreat” as well as community studios and reviews
  - The following is a resource: [www.CES4health.org/policies/authorship](http://www.CES4health.org/policies/authorship).

*Conference presentation slides, agenda, and breakout summaries are available at: [https://www.dtmi.duke.edu/ce-workshop/conference-presentations](https://www.dtmi.duke.edu/ce-workshop/conference-presentations)*

**Poster Presentation**

There were 60 posters presented at the conference. The posters reflected an array of local innovative and successful programs aligned with the conference goals of presenting models that demonstrated community engagement in each phase of translational research. These phases include research to improve health, to identify methods and metrics for assessing the success of community-engaged research in all phases of research, and to determine best practices for sustaining community-engaged research in all phases of research.

*Example presentations showing the diversity of topics:*

- *A Multi-Institutional Collaboration to Pilot a Two-Phase Community Engagement Self-Assessment Process*, Karen Vitale, MSEd
- *A framework and strategy for stakeholder engagement: Promising early findings of a community/university collaboration to improve capacity to conduct patient-centered outcomes research*, Paula Darby Lipman, PhD
- *Community Based Participatory Research Training for Academic and Community Partners*, Haera Han, PhD
- *Working with PBRNs: New Opportunities for Engaging Patients and Communities in Research*, Kristine Schmit, MD
- *Exploring trust in research: A community-academic research partnership across 5 CTSA sites*, Linda Cottler, PhD
Overarching Conference Outcomes

1. Recommend to NCATs and the CTSAss a renewed focus on engagement of patients, caregivers, providers and communities in the translational research process. To promote engagement, trust, and participation, stakeholders need to be involved in all phases of research (T1-T4), not just brought in to aid in study recruitment.

2. Summarize and disseminate the results of the meeting and its small groups, so that the work done thus far in developing processes and metrics for engagement are broadly known.

3. Continue to assess, analyze and share effective practices in community engagement within and across institutions, and within and across communities.

Outcomes related to the aims:

- Present models demonstrating community engagement in each phase of translational research to improve health.
  - This was achieved by the….
- Identify methods and metrics for assessing the success of community-engaged research in each phase of research.
  - Systems thinking, etc.…
- Determine best practices for sustaining community-engaged research in all phases of research.

Conference Evaluations

An electronic post-conference evaluation was sent to attendees to assess whether they perceived the conference goals were met with respect to content and overall organization. Sixty-three of the 184 attendees completed the evaluation. Based on a five-point Likert scale from Strongly Disagree to Strongly Agree), a majority of responders – 75 % (47/63) -- either agreed or strongly agreed that the conference discussed state-of-the science of community engaged research and where the gaps are in this science. Only 35% participants (35 %) indicated that the conference identified %the weaknesses in engaging patients, families, and communities in all phases of translational research to improve health. All presentations’ content predominately received good, very good, or excellent ratings. A majority, 51 % (32/63), ranked Dr Bonham’s Plenary IV as excellent based on a five-point Likert scale (Poor/Fair/Good/Very Good/Excellent). Receiving a similar ranking was Dr Auerbach’s “Nothing About Us Without Us:”

These results suggest that the strengths of the conference related strongly to the first two aims (present models demonstrating community engagement in each phase of translational research to improve health; identify methods and metrics for assessing the success of community-engaged research in each phase of research); but that continued work will be needed to address the third aim (Determine best practices for sustaining community-engaged research in all phases of research). Ways to improve the conference will include….

Appendix A - Breakdown of academic, government, and community conference registrants
The table below reflects responses from those individuals who answered the online registration questions:

Please indicate your primary employment affiliation (> 50% time) below:

- Academic Institution
- Community Organization/Agency
- Government Organization
- Other____________________ (further breakdown not captured in data)

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<th>Percentage</th>
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