

## Implementation, Policy and Community Engagement Review Article

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# Engaging community in the translational process: Environmental scan of adaptive capacity and preparedness of Clinical and Translational Science Award Program hubs

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### Abstract

This paper is part of the Environmental Scan of Adaptive Capacity and Preparedness of Clinical and Translational Science Award (CTSA) hubs, illuminating challenges, practices, and lessons learned related to CTSA hubs' efforts of engaging community partners to reduce the spread of the virus, address barriers to COVID-19 testing, identify treatments to improve health outcomes, and advance community participation in research. CTSA researchers, staff, and community partners collaborated to develop evidence-based, inclusive, accessible, and culturally appropriate strategies and resources helping community members stay healthy, informed, and connected during the pandemic. CTSA institutions have used various mechanisms to advance co-learning and co-sharing of knowledge, resources, tools, and experiences between academic professionals, patients, community partners, and other stakeholders. Forward-looking and adaptive decision-making structures are those that prioritize sustained relationships, mutual trust and commitment, ongoing communication, proactive identification of community concerns and needs, shared goals and decision making, as well as ample appreciation of community members and their contributions to translational research. There is a strong need for further community-engaged research and workforce training on how to build our collective and individual adaptive capacity to sustain and improve processes and outcomes of engagement with and by communities—in all aspects of translational science.

### Introduction

The Clinical and Translational Science Award (CTSA) program, a national network of around 60 medical research institutions (“hubs”) [1] funded by the National Center for Advancing Translational Sciences (NCATS), engages and brings together scientists, patients, communities, and their advocacy organizations to address local and system-wide scientific and operational problems in clinical and translational science (CTS) research. The Principles of Community Engagement define “Community Engagement” as “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people” [2,3]. The World Health Organization considers “community” as stakeholders and “community engagement” as “a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes” [4]. In the context of emerging diseases, public health threats, and environmental changes, both effective adaptation and building adaptive capacity rely on broad and profound community engagement, as a prerequisite for sustainable implementation of CTS and to ensure health equity. Indeed, promoting and advancing community engagement in research and science has long been a central role for CTSA hubs, i.e., medical research institutions and academic health centers with CTSA awards that maintain an integrated research and training environment for CTS, in collaboration with affiliated hospitals, clinics, and community health centers.

The COVID-19 pandemic has highlighted how inextricably linked responses and adjustments to emerging threats are with the local communities that they affect [5]. In the United States, specifically, minority groups and rural communities suffered from disproportionately high infection and death rates [6–9] in addition to greater vaccine hesitancy [10,11]. Discussing the coronavirus crisis and the importance of community engagement [12], Dr Karen Emmons, the faculty lead of the Community Engagement program at CTSA-funded Harvard Catalyst, observed that “Given the longstanding issues that we have in this country

around social determinants of health and inequities, we should expect that anything with such a profound impact on our country and our way of life would have a differential impact on various communities.” In response to local needs, the CTSA hubs have intensified their efforts to engage communities in the research processes, implementing a wide range of initiatives to accelerate the discovery and delivery of COVID-19 treatments and vaccines to patients and communities, and pivoting rapidly to address COVID-19 health disparities.

This paper is part of the Environmental Scan of Adaptive Capacity and Preparedness (AC&P) of CTSA Hubs [13], implemented by a special AC&P Working Group approved by the CTSA Steering Committee in 2021. The Working Group participants represented multiple CTSA hubs, translational research and operations areas, and scientific disciplines, with broader and diverse engagement of representatives of community organizations, NCATS, and the CTSA Steering Committee. The Environmental Scan incorporated several data sources and methods as part of searching for COVID-19, emergency preparedness, response, and adaptation titles and content — to illuminate successful practices, challenges, and lessons learned related to how CTSA hubs have used their expertise, resources, and collaborations to advance clinical and translational research, while their efforts were focused on actively engaging partners to reduce the spread of the virus, address barriers to COVID-19 testing, identify treatments to improve health outcomes and raise community awareness about the disease. Data sources included: scientific publications and white papers on CTSA’s (and other) AC&P-related activities; a diverse sample of CTSA hubs’ websites: public stories, news, highlights, measures; NCATS and other clinical and translational science organizations’ websites; select CTSA hub Research Performance Progress Reports (RPPRs) de-identified information; experiences and expert opinions of the E-scan collaborators, reviewers, and stakeholders [13].

To guide our analysis of those processes and their intersection with adaptive capacity and preparedness, we applied the following key characteristics of the Local Adaptive Capacity Framework [13,14]: asset base (key assets that allow hubs to respond to evolving circumstances); institutions and entitlements (an appropriate and evolving institutional environment that allows fair access to key assets and capitals); knowledge, information, and learning (the ability to collect, analyze, and disseminate knowledge and information to learn in support of adaptation activities); innovation (an enabling environment to foster innovation, experimentation, and the ability to explore pragmatic solutions and opportunities); and flexible forward-looking decision-making and governance (the ability to anticipate and respond to changes with regards to its decision-making, governance, and operational structures).

Community engagement projects, tools, and resources have been developed, implemented, disseminated, and adaptively used by CTSA hubs and their partners to educate and engage with researchers and communities, and to establish and strengthen community trust. Additional useful examples, lessons, tools, and ideas from other organizations and fields will be shared to help us learn from how to be productive, efficient, inclusive, and broadly engaged in building adaptive capacity and preparedness in order to deal with future emergencies. More details regarding the integration of special and underserved populations can be found in the Integrating Special and Underserved Populations in Translational Research: Environmental Scan paper [15]; however, the focus of this one is on describing how the community

engagement capacity of the CTSA hubs was leveraged to adapt and pivot during the pandemic and on the challenges to be addressed in the future to make the translational process more widely participatory.

### Asset Base

The worldwide response to the SARS-CoV-2 (COVID-19) outbreak required extraordinary engagement of the population in adopting practices to slow the spread of the disease until vaccines and drugs could be developed to protect the population from infection or reduce the severity and lethality of the disease. The effectiveness of the response depended, in part, on existing assets such as trust in public authorities, trust in science, and the use of communication strategies to inform the public of rapidly changing understanding of the disease, the threats to individuals and communities, and methods to prevent or treat the disease.

Like brand loyalty [16], *trust in public authorities* [17–19]—such as medical professionals, government officials, and academic researchers—is a critical asset for the dissemination and adoption of health behaviors and practices and of medical research advances [20]. This trust has been and continues to be tested during the COVID pandemic. The rapidly evolving understanding of the disease and best practices for preventing the spread or treating the infected proved challenging as the communication of the new information often made by public authorities appeared to be flip-flopping, introducing doubt in the ability to trust the information and advice offered.

Another critical asset in responding to the COVID pandemic has been the communications resources available. Organizations that had developed trust relationships with the communities they served, as well as messaging strategies to advance adoption of interventions such as mask wearing and social distancing, tended to be more successful in persuading the public to adopt these measures [20–23]. As Wilson pointed out, during a health emergency, clear, bidirectional communication between academics and all stakeholder communities is a precondition for creating trust, in itself a requirement for meaningful uptake of new treatments and vaccines [24].

The CTSA hubs are expected to develop trust relationships through community engagement [25], create communication strategies to disseminate accurate information on research advances, and advocate for the adoption of science-based interventions [26,27]. These community engagement efforts positioned hubs to serve as reliable sources of information during the often chaotic, early stages of scientific research into COVID-19. For example, the Indiana CTSA Hub partnered with the state public health authority to engage a panel of scientific experts to review articles regarding COVID-19 research and share the curated materials with the scientific community and the general population [28].

The University of Minnesota CTSA hub conducted a virtual celebration of Community Engaged research, “Power of Partnerships 2021,” to engage with the community and ascertain drivers of trust in research products, barriers to vaccine uptake, especially in historically underrepresented and underserved communities, and potential solutions to these hurdles. There were five meeting take-aways that can contribute to effective asset base building:

1. *People want information before they make a decision:* Communities want detailed information. As trained professionals, researchers should take the time to listen to their questions and concerns and offer science-based explanations.

2. *Messaging is important*: Create a unified, confident, fact-based message to both communities and media.
3. *Who delivers the message matters*: Trusted community members are more likely to get the message across.
4. *Access is crucial*: Economic, social, and historical disparities impede access. Taking account of them and creating opportunities to break those barriers is essential to reaching all communities.
5. *Once a relationship has been built with specific communities, follow up*: Researchers are often great to reach out to communities, but some researchers never come back, which creates mistrust. Following up with research findings is essential [29].

Relatedly, the Miami CTSA hub was a collaborator in the NIH-sponsored Community Engagement Alliance (CEAL) which focused on raising COVID-19 awareness, research, and education in the communities most affected by the pandemic (Black, African American, Latinx, farmworkers, sexual and gender minorities) through communication and information [30]. Early findings from their focus groups revealed that the communities themselves were eager to provide solutions in the way of strategies to address the major challenges they were facing in terms of vaccine uptake and trust in science. For instance, among the Black community, doctor's recommendations and support for the vaccine from high-profile individuals was recommended, while for the Latinx and farmworker communities, vaccine requirements were considered better incentives.

The outbreak of the novel COVID-19 virus and its rapid movement into a pandemic created significant challenges to the trust relations developed by CTSA hubs and the communication capabilities of local, state, national, and international research and public health authorities. The work to strengthen those relationships and develop and deploy enhanced communications methods contributed to slowing the spread of the virus as vaccine and pharmaceutical interventions were developed. The promotion of effective behaviors in the absence of those vaccines and drugs may well be needed for the next pandemic [4].

## Institutions and Entitlements

Collaborative institutional and inter-institutional environments are essential for managing fair and efficient access to important assets and opportunities during the time of crisis and beyond. Capitalizing on the strengths of their *collaborative inter-institutional environment*, Florida Community-Engaged Research Alliance Against COVID-19 in Disproportionately Affected Communities (FL-CEAL) members worked together with community partners to implement successful community-based outreach activities, addressing education, awareness, access, and inclusion of special and underserved communities in COVID-19 vaccine and therapeutic clinical trials [30]. Throughout the COVID-19 Research Community Forum series, co-organized by Harvard Catalyst, its presenters emphasized the importance of such collaborations, especially during emergency situations. According to Dr Lee [31], the Harvard Catalyst's Community Engagement program leader, "Working together with the other programs in Massachusetts and each of our community advisory boards, we were able to develop a community forum that centered around issues of health equity and provided an opportunity for dialog with experts." One of the participants emphasized the importance of sharing resources by saying that "We're all standing shoulder to shoulder trying to face this challenge, and we need to be able to provide tools and share knowledge and experiences." Also

highlighted was the value of institutions collaborating that have been reluctant to work together before the pandemic crisis.

A critical role played by the CTSA hubs involved the *engagement of diverse populations in the conduct of clinical trials* to test vaccines, drugs, and prevention measures [32]. CTSA hubs utilized their existing partnerships and recruitment capabilities, such as the All of Us Research Program (AoURP), to identify and engage potential diverse participants for clinical trials to make sure that study populations are representative of the population [33]. Community engagement experts believe that responding to community need and requests (even those that are "out of scope") is a powerful way of earning trust. Hubs also listened and helped coordinate response to community needs unrelated to research (e.g., helping community members find and provide PPE, food, and housing was not uncommon across hubs during the pandemic). Promoting racial equity and inclusion within the entire biomedical research enterprise, NIH developed the UNITE initiative, crosscutting all NIH Institutes and Centers. UNITE sets out the following specific aims (pursued by respective committees and initiatives):

U — Understanding stakeholder experiences through listening and learning

N — New research on health disparities, minority health, and health equity

I — Improving the NIH culture and structure for equity, inclusion, and excellence

T — Transparency, communication, and accountability with our internal and external stakeholders

E — Extramural research ecosystem: changing policy, culture, and structure to promote workforce diversity.

These aims and associated strategies and activities are in alignment with the directions and expectations for CTSA hubs when it comes to institutional environments, values, and capacity building [34].

Eder et al. [26] illuminated some of the strategies bolstering the *adaptive institutional environment for communicating science and addressing misinformation*. In multiple CTSA hubs, community members and partners shared their need for access to science-based information about COVID-19 and approaches and resources to stay healthy. To provide access to researchers and information resources on the available scientific evidence, hubs organized COVID-19 community virtual town halls, and community engagement professionals posted blogs, contributed to online newsletters, and appeared at virtual and in-person events. Important partners in this process were public health professionals and health providers, medical students, government officials, and others who shared credible information and explained the importance of incidence data by zip code and race, co-developed dashboards, and disseminated personal protective equipment. For instance, the Northwestern University CTSA hub created databases to help share resources and ideas for addressing community needs.

Clear understanding of and fair access to community benefits of clinical and translational research are within purview of an institutional environment that properly coordinates and distributes its key assets. As part of supporting communicating science, the NIH developed the Checklist for Communicating Science and Health Research to the Public [32]. This checklist provides a resource for CTSA hubs to create messages related to research advances in understanding and addressing COVID.

Strategies and resources developed by CEAL (the NIH Community Engagement Alliance that also includes CTSA hubs)

can work across different groups of stakeholders, including clinical researchers themselves. For instance, a CEAL fact sheet titled "Community Benefits of COVID-19 Research: An Overview for Community Members" is designed to provide concise and clear information to answer the seemingly simple, yet challenging questions of: "What is research? Why is research needed? What are the benefits of taking part in research? Why should I or my community take part in COVID-19 research? How do I know I'll be treated fairly?" It can assist CTSA and other researchers and community advocates in facilitating discussions in multiple settings to explain pandemic and other clinical research and encourage people to participate in it. It is also a good reminder to the researchers themselves to be properly prepared, adaptive, and proactive in their promoting and delivering those vital benefits of research.

CTSA Hubs, reportedly, also improved and expanded their collaborative relationships with local public health departments, oftentimes by organizing in coalitions [26]. CTSA were instrumental in developing registries to collect data (e.g., health, economic, behavioral, and exposure) for surveillance and contact tracing purposes, as well as to optimize recruitment for COVID-19 and other research. Such efforts also incorporated secondary partner networks to increase registry enrollment and strategies to engage participation across multiple languages, depending on the local community characteristics and needs. For example, the University of Rochester Center for Community Health and Prevention worked with the Monroe County Department of Health on collecting, analyzing, and disseminating data locally and nationally.

A community engagement (CE) expert and stakeholder some ways to overcome institutional barriers to the impactful implementation of community engagement. Examples include the mechanisms for PIs being supported in their CE efforts (e.g., based on shifts in incentive models for faculty advancement) such as: (1) carving out the time to build trusting relationships as part of research projects/timelines, (2) adapting/pivoting research projects based on community inputs such as needs assessments (CE expert/stakeholder, email communication, January 20, 2022).

### Knowledge, Information, and Learning

It is hard to overestimate the importance of learning and sharing knowledge, resources, tools, and experiences when working with our community partners and other stakeholders, and CTSA hubs have used a variety of mechanisms to achieve these goals. Eder et al. [26] argue that:

"Data collection and analyses are integral to research, and this activity was by necessity an anchor for engagement through the CE cores of the clinical and translational hubs. Data gaps regarding COVID-19 cases were noted early in the pandemic, particularly a lack of data concerning what turned out to be significant disparities in community disease burden."

At the beginning of the pandemic, four Massachusetts clinical and translational science centers, including Harvard Catalyst, hosted webinar series focused on COVID-19 research and health equity. These webinars highlighted the *dialogues between investigators and community members*. According to Dr Karen Emmons [11], the faculty lead for Harvard Catalyst's Community Engagement program, "Community engagement allows us and our community partners to understand the ways in which possible responses, policies, and programs would impact different groups. With strong community partnerships, we've been

able to quickly *get a sense of what's happening on the ground* during this pandemic."

The Florida Community-Engaged Research Alliance Against COVID-19 in Disproportionately Affected Communities (FL-CEAL) found that *collaboration, strong partnerships, and understanding the levels of awareness, attitudes and beliefs* towards COVID-19 were crucial in developing impactful outreach and education strategies that are tailored to address the needs of each community [27]. Representatives of the groups traditionally underrepresented in clinical studies can offer valuable, unique perspectives to help develop new approaches and a knowledge base for engaging a diverse participation in clinical and translational research.

Based on their analysis of CTSA hub reports of their responses to COVID-19, Eder et al. [26] emphasize the necessity of *listening to the community and responding to their concerns*. Indeed, many adaptation activities require and involve attentive, responsive, active listening. *Ongoing, bi-directional communication* supports awareness and understanding of perceptions and issues experienced by community members. Some of the vehicles of productive communication include: implementing Community Advisory Board and Council activities; engaging other hub centers and institutes; capitalizing on established connections with community partners; and taking part in coalitions of community organizations, multi-level health departments, and other agencies. A related theme in the CTSA responses was *collecting data to understand the impact* of COVID-19 on distinct communities and groups. A case in point was a collaboration of the community with the University of Minnesota School of Nursing on collecting information about COVID-19 knowledge and attitudes that was utilized by the local health department to inform their programming, e.g., addressing the huge uptick in opioid overdoses and deaths during the pandemic.

There exist multiple (also including CTSA-developed) sources, methods, and approaches for obtaining, generating, and sharing useful information to support adaptation activities and beyond. For example, the COVID-19 Recruitment and Retention Toolkit [35] provides rich, practical information on *integrating community feedback into the operations of recruitment and retention* planning for COVID-19 research. This knowledge is grounded in the experiences and recommendations of a diverse group of patient and community stakeholders who participated in Community Engagement Studios conducted for multi-site COVID clinical trials.

Some tried-and-tested examples of *methods of getting information for effective adaptation* include Community Engagement Studios, COVID-19 study teams, feedback at presentations on COVID-19 research to community organizations, interviews with partners, and conversations with extended families disproportionately affected by COVID-19 [35]. As a specific notable example, a Community Engagement Studio is a consultative method that engages diverse groups of patients and community stakeholders in the planning and implementation of research. Studios can solicit guidance on identifying and addressing barriers to participation, developing and refining recruitment messages and materials, conducting the study, and disseminating results. When considering comprehensive sources of information, we should *include diverse perspectives coming from multiple stakeholders*, such as: members of communities disproportionately impacted by the pandemic; healthcare and essential workers; individuals living in COVID hot-spot cities who were at a higher risk of being hospitalized for COVID due to age, race, ethnicity, or chronic health diagnosis.

Indiana COVID-19 Daily Digest is a fine example of the adaptive capacity to engage communities in collecting, analyzing, and disseminating timely knowledge and information [28]. WISE Indiana (Wellbeing Informed by Science and Evidence in Indiana, a partnership between the Indiana CTSA and the Indiana Family and Social Services Administration) enabled academic experts and IT professionals to *identify, evaluate, and provide easily accessible, relevant, emerging evidence-based information to diverse audiences*: community organizations, healthcare providers and systems, managed care entities, state personnel, and other stakeholders engaged in the pandemic response. Daily Digest's data reports, dashboards with metrics, expert reviews of emerging literature, state/national/international updates, expert responses to key questions from the community, and links to useful resources make this initiative an invaluable community information asset from the adaptive capacity and preparedness standpoint.

### Innovation

From the CTSA Program's inception, its "DNA" was coded to catalyze innovation, experimentation, and the ability to explore pragmatic solutions to create and take advantage of new opportunities within the realm of clinical and translational science. Dr Marsh, faculty director of MICHR Community Engagement (CE), observed that "the COVID-19 pandemic has magnified and amplified health disparities" and "fortified our commitment to our community partners." Tricia Piechowski (CE program director) shared that "CE staff and faculty, together with community partners, have had to *pivot services to respond in meaningful ways to community needs during the pandemic*" and "come together to support one another and create innovative approaches in this unprecedented time." To *make educational resources more inclusive or accessible*, MICHR collaborated with academic and community partners to tailor and disseminate their community-focused flyers to literacy level (2nd to 3rd grade reading), language spoken (English, Spanish, Arabic, Japanese, and Chinese), and age group (youth and older adults). At the time of the interview, the statewide campaign reached over 10,000 people in print and over 100,000 people digitally [36].

Indigenous and rural communities, historically experiencing disparities in rates of communicable diseases and access to healthcare, have felt the COVID-19 burden more strongly. Funded by the UMN CTSA's COVID-19 Rapid Response Seed Grant program in April 2020, university researchers and local Indigenous community partners collaborated to *develop evidence-based and culturally appropriate COVID-19 resources helping stay healthy and connected during the pandemic*. Conducted by the Memory Keepers Medical Discovery Team, the project "Helping Indigenous communities stay connected in light of COVID-19" pivoted to engage local communities and promote health equity.

The initial social distancing *guidelines did not properly address the community-based lifestyle* of Indigenous peoples. According to the project PI, Dr Jacklin [37]: "Some of the advice coming from medicine was isolationist, which stands in sharp contrast to Indigenous life; . . . our unique contribution was *focusing on how to preserve connection to culture and community in safe ways during the pandemic*." To identify community-specific needs, the research team consulted with Indigenous advisors and local experts, Tribal leadership, Indigenous community researchers,

and advisory groups. This work translated into culturally appropriate resources: fact sheets with tips for staying healthy, a medicine wheel chart of healthy activities, and a longer packet of information about staying connected during the pandemic. The resources were shared with local tribes and the public, distributed at a local health fair, promoted via social media, an elderly nutrition program, and the project website.

The Penn State CTSA's Community-Engaged Research Core team developed an innovative research curriculum that allowed bidirectional learning and greater engagement in translational efforts for a variety of community stakeholders, such as patient partners, organizational representatives, and Community Health Workers [38]. Their approach introduced: *motivational interviewing to overcome barriers to change* during COVID-19 (asking open-ended questions, providing affirmations, demonstrating reflective listening, and effectively summarizing community concerns); *myth-busting while respecting one's beliefs*: best practices to debunk misconceptions circulating in the community; and creative community engagement strategies to *overcome face-to-face barriers caused by the pandemic* (e.g., using telecommunication platforms, gamification, graphic medicine, social media).

Novel virtual/remote engagement approaches are now a valuable part of the community engagement toolkit. Marsh et al. [39] point out that many components of community engagement and community-engaged research can be done virtually by using remote engagement and non-face-to-face strategies and leveraging rapidly improving technology (e.g., video-conferencing and asynchronous communication) to ensure just-in-time communication between investigators, community partners, and study participants. The use of the Zoom platform for training (including interactive breakouts, chat, annotation, whiteboard, vignettes, and case studies) contributed to increased participation, bolstered discussion, and strengthened knowledge transfer [38]. Nonetheless, virtual engagement is not a permanent replacement for "live", face-to-face communication; personal interactions are fundamental to impactful community engagement and missed by community and academic collaborators.

The Recruitment Innovation Center (RIC), a division of the Trial Innovation Network (TIN), which includes CTSA membership, developed the COVID-19 Recruitment + Retention Toolkit, with novel *tools and strategies that work in the pandemic-transformed clinical trial space* and reflect the values of community engagement, participant-informed methods, and scalable design [35]. The Toolkit's pragmatic solutions and approaches to reducing barriers that impede participation, designing patient- and community-informed materials, messaging, and recruitment strategies should help CTSA and other CTR organizations optimize their participant recruitment and retention efforts for COVID-19 trials and beyond [35].

A notable example of the adaptive capacity to experiment and explore niche solutions in order to take advantage of new opportunities is the CTSA-supported Save Da Hoomans (SDH) campaign that was featured in the media and recognized at a national CTSA Program meeting as one of the best of CTSA communications initiatives. The SDH campaign was developed through a collaboration between The New Normal institutions, including multiple Chicago-area CTSA hubs, health systems, the Chicago Department of Public Health, and other regional and national partners. There is a lot of interesting, useful, fun information and engaging visuals on the SDH website, "where pets are

mobilizing to save their humans from COVID-19, cancer, and more by telling people to sign up for health research information and join studies.” [40]

### Flexible, Forward-Looking Decision-Making and Governance

Flexible, forward-looking decision-making is an important characteristic of adaptive capacity to anticipate, respond, and adapt to changes by incorporating relevant mechanisms, initiatives, and partnerships into future planning and decision-making. Jones et al. [14] astutely observed that:

“Any analysis of governance must look both at the ‘technical’ capacity of institutions and the power relations behind decision-making. The decisions that are made are usually less about the ‘technical’ features of decision-making forums and far more about whose voice is heard, and whose interests count. Various power imbalances exist in all societies – e.g. between rich and poor, between men and women and between old and young. How these imbalances are reflected in any specific society will influence the capacity of individuals to adapt to changing shocks and trends.”

Accordingly, the CTSA Consortium’s Community Engagement Key Function Committee [2] in the second edition of the “Principles of Community Engagement” made it clear that “to achieve successful collaboration with a community, all parties involved need to strive to understand the point of view of ‘insiders,’ whether they are members of a neighborhood, religious institution, health practice, community organization, or public health agency.” Eder et al. [26] suggest that “the translational science business model must support both community-engaged research projects and the engagement of community voices and perspectives in facilitating institutional transformation to become translational science centers.” For instance, for reaching underrepresented populations, Medical College of Wisconsin found extremely helpful their previous experiences and research on disaster preparedness and existing connections with community collaborators, government offices, and school districts. A CE expert/stakeholder suggested thinking beyond the traditional Community Advisory Boards (CAB) models and perhaps moving into the realm of policy changes as part of the CTSA’s scope of work. For that engagement to be deeper, there should be “specific budget allocation for training and capacity building, a more systematic approach to compensating the community for its participation, and renewed efforts in science education and dissemination” (CE expert, email communication, January 20, 2022). Similar points are reiterated in the recent National Academy of Medicine commentary on “Assessing Meaningful Community Engagement” [19].

Forward-looking governance structures having community members as equal partners can facilitate rapid responses to crises, particularly those affecting rural communities and racial and ethnic minorities. One example is from SUNY Buffalo CTSA hub, where along with key community partners, the Buffalo Translational Consortium (BTC) integrates the leading academic, health care, and research institutions in the Buffalo region, and all those institutions are represented in the governance of UB’s Clinical and Translational Science Institute (see Fig. 1) [41].

The Buffalo Center for Health Equity is an equal partner with the CTSI in the Buffalo Translational Consortium, and the hub PI is also the Director of the Community Health Research Institute at University of Buffalo. Both entities have an existing relationship

with the African American Health Equity Task Force. Such pre-existing governance structure poised the groups to be prepared to mobilize a robust community response to the COVID pandemic in an underserved urban community in Buffalo, New York. As reported by University of Buffalo CTSI [39], that response “partially mitigated the devastating impact that the pandemic was having on African American neighborhoods by reducing the proportion of fatalities among African Americans (from 34% in April 2020 to 16% in June 2020).”

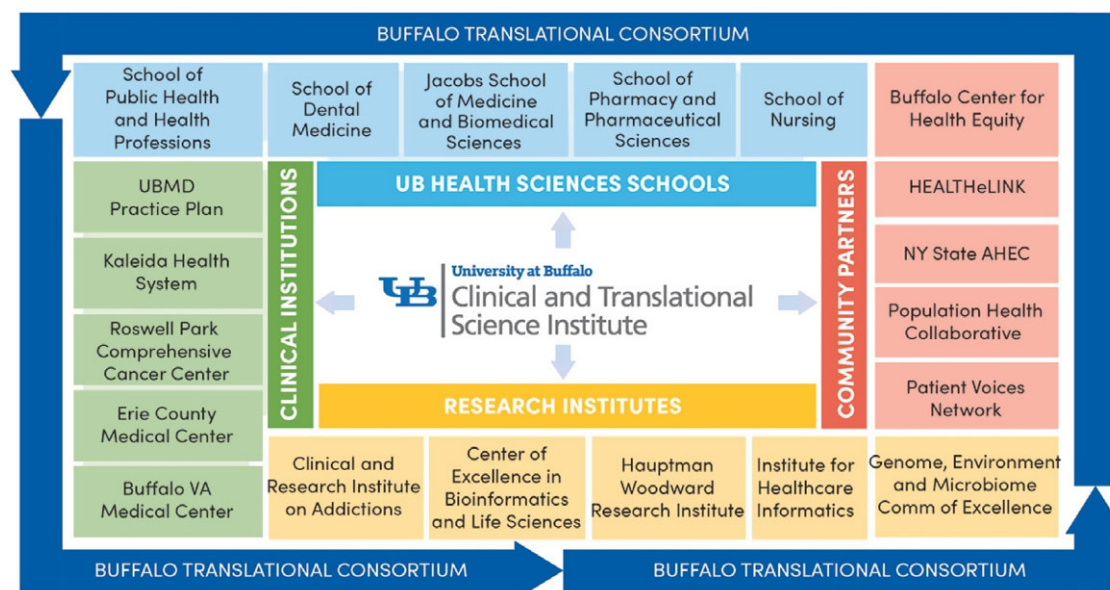
Unfortunately and disquietingly, the pandemic situation demonstrated, according to Grumbach et al. [42], that even though the NIH requires community engagement programs in all CTSA’s, the dominant culture of clinical research has not been significantly changed, where researchers failed to involve community stakeholders early in the research processes addressing prevention and treatment of the deadly virus. Indeed, one of the community representatives was straightforward with this paper’s authors in sharing that “Many times people feel tolerated, not valued. . . . Often, engagement with the community only comes when the research community needs their input. As a community member, I recognize the importance of bi-directional conversations, even when no study is planned.” (Community member, email communication, January 27, 2022).

In their manuscript, provocatively titled “It should not require a pandemic to make community engagement in research leadership essential, not optional,” Grumbach et al. [42], also representing the Association for Clinical and Translational Science Partners for the Advancement of Community Engaged Research (PACER) Special Interest Group, call on research institutions and funders to take transformative actions with regards to their decision-making structures, operations, and planning, such as:

1. Implement a strategic plan to increase racial and ethnic diversity among the institution’s research workforce.
2. Modify IRB policies to require a section with the study’s community engagement plan for all community health and human participant research protocols.
3. Require a course in community-engaged research for all clinical research training programs.
4. Support and utilize standing community advisory boards for institutional offices of research and CTSA-funded institutes.

Resilient, forward-looking decision making and leadership in times of crisis stay true to the essential ideas of meaningful and genuine stakeholder engagement. Marsh et al. [39] give particular emphasis to “continuous check-ins, maintaining rather than withdrawing from engaged relationships, identification and recognition of challenges, recalibration of expectations and timelines, and, most importantly, prioritizing the core needs of community partners.”

In a similar vein, during their “TNN: We’re Making History” presentation at the CTSA Program Meeting in December 2021 [40], “Chicago CTSA Hubs: The New Normal™ Campaign” representatives shared some quite familiar to organizational leaders, yet often underutilized, and always relevant “principles and practices that work.” They include: “Building a Vision & Shared Goal, Establishing Trust, Listening, Meetings!, Commit, and Care.” Indeed, the history of how well prepared, adaptive, and capable our institutions are will largely depend on the level of decision makers’ commitment to the above principles.



**Fig. 1.** Community engagement in governance at the UB CTSA (the coordinating center of the Buffalo Translational Consortium).

Source: <http://www.buffalo.edu/ctsi/about-us/buffalo-translational-consortium.html>.

## Implications and Conclusion

Pandemic-related challenges and needs have called for adjustments in and re-conceptualization of the approaches to clinical research, putting a greater emphasis on the need to actively involve patients, communities, and local stakeholders. The topics of “trust,” “collaborations,” “knowledge and data sharing,” “mutual learning,” “integration,” and “shared decision making” are some of the important components of authentic community engagement. The following are some takeaways from the environmental scan of adaptive capacity and community engagement.

**Asset Base:** The overall concept of community engagement as both a continuous process and potentially powerful outcome is an indispensable, long-standing principle and value for CTSA hubs and for the entire translational science. The success of our response and adaptation depends on such strengths as trust in public authorities, trust in science, and the use of communication strategies to inform—and be informed—by the public at large and individual communities. CTSA hubs are well positioned and expected to serve as trusted sources of information and other support during all stages of scientific research into pandemic and other health issues. CTSA’s efforts to strengthen community relationships and deploy enhanced communications methods to promote effective behaviors have contributed to slowing the spread of the virus and implementing biomedical research. The CTSA hubs are expected to deepen trust-based community engagement, optimize communication strategies to disseminate accurate health promotion and research information, and strengthen advocacy for health equity.

**Institutions/Entitlements:** During the time of emergency and beyond, collaborative institutional and inter-institutional environments are key to managing fair and efficient access to essential assets and opportunities. CTSA hubs’ community engagement efforts played a significant role in addressing the public health, medical, and research challenges prompted by COVID-19. CTSA Hubs expanded their collaborative relationships with local community organizations, public health departments, coalitions, and other stakeholders. Still, more assistance is needed to research

teams and community advocates to enable more impactful collaboration in clinical and translational research and its equitable integration of all populations. Challenges and limitations associated with reach and outreach on a community-wide scale should provide a capacity-building perspective for CTSA hubs as they advance in their mission.

**Knowledge, Information, and Learning:** CTSA hubs have used various mechanisms to advance co-learning and co-sharing of knowledge, resources, tools, and experiences between academic professionals, patients, community partners, and other stakeholders. Bidirectional flow of information and learning between investigators and community members allowed them to better understand and guide the ways in which possible responses, programs, and activities would impact communities and clinical research. CTSA hubs have developed and utilized sources, methods, and approaches for obtaining, generating, and sharing useful information to support adaptation activities and beyond, while integrating perspectives offered by diverse stakeholders. Undoubtedly, there is a room for more focused listening to community partners, understanding their levels of awareness, attitudes, and beliefs towards research and responding to their concerns and ideas.

**Innovation:** CTSA hubs are expected to play a role of a catalyst of innovation, experimentation, and the ability to explore pragmatic solutions to create and take advantage of new opportunities within the realm of clinical and translational science. The COVID-19 pandemic amplified public expectations, as well as the attention to the CTSA ability to effectively respond and pivot services to address community needs during the time of crisis. University researchers and community partners collaborated to develop evidence-based and culturally appropriate resources helping community members stay healthy, informed, and connected during the pandemic. Concerted efforts were invested in making such resources more inclusive and accessible. Hubs utilized novel and enhanced remote-engagement and non-face-to-face strategies and leveraged rapidly improving technology (e.g., video-conferencing and asynchronous communication) to ensure timely communication between investigators, community partners, and study

**Table 1.** Challenges for community engagement in the context of emergency and approaches to address them (derived from the AC&P E-Scan)

Challenges in the context of emergency	Approaches for community engagement in the context of emergency
Uncertainty. Lack of trust in public authorities and science.	Build on existing connections, trust relationships. (Asset Base)
Communities feel used once and then forgotten by scientists who do not come back.	Truly integrate communities as equal partners in the entire research process. Share the benefits of science and partnership with the community. (Institutions and Entitlements)
Lack of communication. Misinformation. Lack of knowledge/ understanding of science.	Communicate clearly, effectively, honestly, and in the community's terms. Listen to the community to learn from their wants and needs. (Knowledge, Information, and Learning)
Crisis-related disruptions or lack of access to traditional recruitment and participation mechanisms.	Identify and implement technology solutions to continue engagement in culturally appropriate, community-approved, and respectful ways. (Innovation)
Communities are included only as "target populations," "guests," or at a single point in time.	Maintain bi-directional communication. Explore new compensation models to improve engagement. (Flexible, forward-looking decision making)

participants. At the same time, overreliance on digital technology innovations also created new access barriers for certain special and underrepresented communities and exacerbated the digital divide and social-health disparities among communities [15].

*Flexible, Forward-looking Decision Making:* CTSA experiences demonstrated that governance structures having community members as equal partners can facilitate rapid responses to crises, particularly those affecting rural communities and racial and ethnic minorities. Some observers lamented that the core culture of clinical research has not significantly changed to properly integrate community stakeholders in all research processes and to ensure suitable responsiveness and adaptation when an emergency strikes. Forward-looking, effective, and adaptive decision-making structures are those that prioritize deepening trust and commitment, continuous communication, proactive identification of community concerns and needs, shared goals and expectations, ample appreciation of community members, appropriate compensation, and their contributions to research and its translation – at all times, not just in crises.

Some of the challenges, lessons learned, and approaches to community engagement—grounded in the pandemic experiences and captured by the Environmental Scan—are summarized in Table 1.

This review is expected to be useful to clinical and translational researchers and practitioners when designing principles, concepts, policies, and practices enabling effective preparedness, response, and adaptation to rapidly emerging community needs. There is a strong need for further *community-engaged* research, policy making, and workforce training on how to build our collective and individual adaptive capacity to sustain and improve processes and outcomes of engagement with and by communities—in all aspects of translational science. It is our hope that the emerging clinical

and translational research system is cultivated to be highly prepared, adaptive, and proactive in co-creating vital benefits of research—with the community, for the community.

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