Community Engagement for Translational Disaster Research: Fostering Public, Private & Responder Group Partnerships

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ABSTRACT

Vulnerable communities are disproportionately impacted by major disasters. Information scientists working to improve disaster planning and mitigation efforts in these communities often involve first responder (practitioner) groups in collaborative design; however, less emphasis has been placed on developing long-term, sustainable crisis informatics partnerships at the population level. Community-based participatory research approaches are gaining attention in the US as an important element in translational science efforts designed to move innovations "from the bench to the curbside." Community Engagement in Research (CEnR) is a community research approach adopted US National Institutes of Health (NIH) to improve public health intervention. CEnR has implications for improving the generalizability of ISCRAM research, may provide a roadmap for Public/Private/Community disaster research partnerships, and suggests modifications to training for information scientists working in this arena. The CEnR approach also recognizes conflicts that can occur in community/government partnerships, emphasizing the importance of predicting and preventing these situations.

Keywords

Community Engagement in Research (CEnR), community disaster informatics, translational research, professional development, FEMA Whole Community Initiative, Public Health

INTRODUCTION

Vulnerable communities often bear the brunt of natural and human-made disasters, in part because these populations are frequently located nearest or exposed to a variety of hazards within their environmental setting (e.g. floodplains, industrial waste facilities, etc.; Comfort, Wisner, Cutter, Pulwarty, Hewitt, Oliver-Smith, Viener, Fordham, Peadcock, Krimgold, 1999). Recent advances in computing, handheld devices, and wireless connectivity have allowed ISCRAM and other research groups to develop a variety of information technology solutions designed to be deployed during crisis events, which are intended not just for professional first responders, but the impacted communities themselves (Reuter, Marx, and Pipek, 2011; RoBnagel and Zibuschka, 2011). Yet several decades of experience on engaging communities in research-based interventions – particularly for those most at risk – suggests that omitting systematic, process-based community guidance of

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these technical solutions is a prospect that is, *at best*, doomed to expensive and often predictable failure. At worst, some of the solutions developed have the potential to *do more harm than good.* Not because the information scientists working in this domain intended to do harm, but because they may not have fully addressed or even have been aware of cultural nuances that impact the acceptance, utilization, and interpretation of these systems (Franco, Zumel, and Beutler, 2007).

Understanding the Needs of Vulnerable Communities in Disaster Events

For example, Hurricane Katrina provided evidence that many Americans lack the means to shelter themselves and their families during a disaster, particularly vulnerable communities (Eisenman, Cordasco, Asch, Golden, Click, 2007). Historically, due to economic status and resource availability vulnerable communities are more impacted and less likely to evacuate in a disaster (Fothergill, Maestas, and Darlington, 1999; Perry and Lindell, 1991; Perry and Mushkatel, 1986; Riad, Norris, and Ruback, 1999). On August 29, 2005 Hurricane Katrina came ashore on the gulf coast of the United States, east of New Orleans, with devastating effects (Dolfman, Wasser, and Bergman, 2007). Although not the most powerful hurricane to hit the US, Katrina was the most deadly and costly in the last 50 years (Congleton, 2006). More than 1.5 million people were directly affected with over 800,000 forced to evacuate their homes (HomelandSecurity, 2008). Of those directly affected, more than 300,000 were African American from one of the hardest hit parishes, Orleans Parish, where one third (89,000) of inhabitants were estimated to live in poverty prior to Katrina (Gabe, Falk, and McCarty, 2005). Many had no effective transportation to escape the path of the storm, nor protection or insurance for their property and thus did not evacuate – with disastrous results (Atkins and Moy, 2005). Adding to transportation and property barriers, a disbelief of the storms severity, confusing and often contradictory messages from different levels of government (Gheytanchi, Joseph, Gierlach, Kimpara, Housley, Franco, Beutler, 2007), coupled with concerns about money and job loss further impeded evacuation for vulnerable communities (Eisenman et al., 2007).

Following the storm, blacks were seven times more likely to lose their job than the average white worker (Elliott and Pais, 2006). The scarcity of information and essential resources, including shelter and transportation, had profoundly debilitating effects for those Katrina victims incapacitated by poverty. For example, because the event happened near the end of the month, many people who were instructed to evacuate simply did not have enough money to purchase fuel (Gheytanchi et al., 2007). After the evacuation, shelters were ill-equipped to handle the needs of those forced to leave the area. From a healthcare perspective, emergency workers were prepared to treat infectious disease outbreaks, but most of the individuals presented with needs for care of chronic conditions like diabetes and hypertension (Broz, Levin, Mucha, Pelzel, Wong, Persky, Hershow, 2009) and often required prescription medications, some of which needed to be refrigerated, creating significant logistical problems (Currier, King, Wofford, Daniel, Deshazo, 2006).

The above scenario transpired even though government officials had advance warning and intelligence regarding the pending landfall of the hurricane from NOAA (National Oceanic and Atmospheric Administration) and time to prepare and plan for anticipated emergency consequences related to economic, social and health impact within Gulf coastline communities (Gheytanchi et al., 2007). This draws into question our ability to respond to similar, but unannounced wide-spread catastrophe would impact a large urban area or region. Social, economic and health disparities are clearly magnified during every disaster response and recovery effort; we argue that sufficient community engagement and pre-planning can ameliorate these impacts.

The Community Engagement Gap

Preventing the types of catastrophic emergency response failures witnessed during Hurricane Katrina requires government agencies, researchers, and policy makers to engage with communities that are at risk during every phase of the disaster cycle. Further, it is incumbent on research groups that seek to develop disaster interventions to work collaboratively with the communities where these systems will be deployed. There are some exemplary cases of these types of collaborative design efforts with *emergency response professionals* or traditional community response agencies, including the American Red Cross (e.g., Landgren, 2010; Troy, Carson, Vanderbeek, Hutton, 2008). With the exception of disaster technology researchers working in humanitarian relief settings, far fewer long-term collaborations have occurred *at the community level* – involving local non-profits, community organizations, and individuals from local neighborhoods in the areas most vulnerable to major crisis events.

Further, many early career Information Scientists in this field lack the necessary skills, theoretical framework, and practical experience necessary to form and maintain productive community/academic partnerships. A small scale systematic review of ISCRAM papers found that many describe in detail the technical aspects of a

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community intervention (e.g., SMS text warning systems, social media solutions, etc), but fail to adequately consider input from the community in the development or dissemination of these systems(Franco, Zumel, and Beutler, 2007). This profoundly limits the generalizability of these systems outside of laboratory environments or results in very constrained real world uses. Researchers often do not fully understand the context of the input or know how to incorporate community input into the research question and assure community feedback and flexibility in implementation or research activities.

Recently, some initial efforts to connect disaster studies, information science and community engagement have been undertaken (e.g., Armour and Tameling, 2011). Our goal is to broaden and deepen this conversation into a discussion of how previously established community-based participatory research approaches used in other arenas (e.g., public health) can inform and enhance disaster planning and intervention efforts. *Community Engagement in Research* (Ahmed and Palermo, 2010) offers a clear framework for researchers working to create disaster management solutions for communities through a collaborative approach. CEnR is a flexible approach to community-based participatory research methods that is also sensitive to the needs of political, governmental, and institutional partners (for example, it has been adopted by the US National Institutes of Health). This framework provides guidance for researchers on best practices for involving the community in all stages of research, development and dissemination processes. Further, while the ISCRAM community may benefit from grounding some of its current activities in the prior theoretical and practical knowledge developed by community engaged researchers over the past several decades, the innovations and deep involvement with vulnerable communities typified by ISCRAM (e.g., humanitarian informatics) may also serve to further inform and develop the CEnR framework, in effect advancing both fields in significant ways.

COMMUNITY ENGAGEMENT IN RESEARCH – A BRIEF HISTORY

CEnR is a process of inclusive participation that supports mutual respect of values, strategies, and action for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community of focus (Fawcett, Paine-Andrews, Francisco, Schultz, Richter, Lewis, Williams, Harris, Berkley, Fisher, 1995; Jones and Wells, 2007; Minkler, Blackwell, Thompson, Tamir, 2003). CEnR draws on the tradition of community-based participatory research, while recognizing some of the limits of the CBPR approach in partnerships that involve large governmental organizations or other policy making bodies.

Community engagement is a core element of any research effort involving communities. It requires academic partners to become a part of the community and community members to become a part of the research team, creating a unique working and learning environment before, during, and after the research (Ahmed and Palermo, 2010). Unfortunately, the research indicates community partners rarely feel included as equal partners in the research process and often do not feel respected by their higher education partners (Sandy & Holland, 2006). Community engagement is a process that requires power sharing, maintenance of equity, and flexibility in pursuing goals, methods, and time frames to fit the priorities, needs, and capacities within the cultural context of communities. CEnR is often operationalized in the form of partnerships, collaborations, and coalitions that do the following: help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices (Ahmed, Beck, Maurana, Newton, 2004; Ahmed and Palermo, 2010).

The Institute of Medicine review (Gebbie, Rosenstock, Hernandez, 2003) suggested that this type of approach increases community understanding of the issues under study and enhances researcher understanding of community priorities, the importance of addressing community priorities, and the need for culturally sensitive communications and research approaches. In 2004, the Agency for Healthcare Research and Quality (AHRQ) published a review which demonstrated that community involvement improved the quality of interventions. The authors of several of articles included in the review stated that community engagement improves participation rates and decreases loss of participation in follow-up activities, increases external validity (generalizability), and improves the capacity of individuals and community (Viswanathan, Ammerman, Eng, Garlehner, Lohr, Griffith, Rhodes, Samuel-Hodge, Maty, Lux, Webb, Sutton, Swinson, Jackman, Whitener, 2004). Benefits documented by Leung et al., 2004 include better data quality and quantity, development of new research questions, and translation of research results into policies or actions that are relevant to the community.

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OVERCOMING THE TOWER OF BABEL – TOWARD COMMUNITY TRANSLATION IN DISASTER RESEARCH

Breaking down research silos is a lauded objective, but it is often easier said than done. Most academic incentives revolve around disciplinary or multi-disciplinary research and creating research partnerships within and between academic departments and institutions are often challenging enough. Performing transdiciplinary research – which integrates multiple academic disciplines, while also working with non-academic, government and private sector partners – results in an even more complex picture.[1] Understanding the nature of each of these groups within this context and the barriers to generating collaborative relationships across these groups is of central importance to forwarding basic research and appropriate community-based disaster interventions. Further, articulating and actualizing these relationships can help us to better understand and put into practice the *translational* nature of ISCRAM research, which seeks to move basic science developments in information systems laboratory settings toward much broader societal applications (Franco, Zumel, Blau, Ayhens-Johnson, Beutler, 2008). Through the Clinical and Translational Science Award, NIH has prioritized translational research in the United States. The translational framework is designed to move basic science discoveries into clinical research and apply these outcomes into meaningful real-world practice at the community level (Danka-Mullan, Rhee, Stoff, Pohlaus, Sy, Stinson, Ruffin, 2010).

Crisis Information Science Researchers (Translational Level: Basic or "Bench" Science)

Using the terminology and philosophical stance of translational science as it is being advanced by the National Institutes of Health (NIH) and other major research funding agencies in the US, Information Science is the *basic* or *bench* science activity within the ISCRAM community – the equivalent in medicine of a genetic sequencing laboratory, for example. Typically researchers in this context are focused on very narrow, well characterized problems. Productive research is driven by a shared set of theoretical assumptions, research methods, and analytical tools. There are significant barriers for basic information scientists to work with communities, which include academic incentive structures, personal characteristics (e.g., a lack of personal interest in working with communities and preference for working in laboratory setting), different values and assumptions, and "language" barriers (e.g., the way an IS research characterizes a problem may not match the language used by first responders or impacted communities to describe *the very same problem)*.

First Responder Groups, Government & Industry (Translational Level: Clinical or "Bedside" Science)

Again using the lens of translational science, first responder groups and government response agencies are those who are most deeply involved with the "treatment" or response phase of disaster. These groups typically hold a great deal of expertise and "on the ground" understanding of the types of problems faced during the acute crisis and immediate consequences of a disaster. They possess specific technical skills, physical resources and assets that can be deployed, and some have more frequent and direct interaction with affected communities. These groups are often required to be technologically savvy, and as such, many research partnerships between these organizations, researchers and industry have developed. However, responder groups and government agencies are often not focused on the longer-term recovery phases of disasters, and until recently have not contextualized preparedness more broadly in terms of overall community resilience. Further, industry involvement in disaster management can be seen as very similar to industry's role in device and drug development in translational medicine, often moving insights and techniques that have been developed in the laboratory and scaling them into commercially available tools for professional first responders.

Communities (Translational Level: "Curbside" Science)

Translation of academic research and evidence based interventions to community settings is increasingly recognized as central to improving the health of populations. Every community is unique and individual communities themselves hold deep expertise on the specific ways they are impacted by crisis events. Communities have priorities for what types of interventions should be developed or which would be most useful. These may not match, or may even be at odds with the priorities of the research and responder group objectives. Communities are less likely to characterize disaster response problems in technical terms, are often not as familiar with the types of technology solutions proposed and developed by groups such as ISCRAM, and

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[1] For a more extensive discussion of the differences between multidisciplinary and transdisciplinary research, see for example, Scholz & Marks, 2001.

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may be suspicious or fail to understand interventions deployed by researchers, first responder groups, or government agencies (Gheytanchi et al., 2007).

Developing Robust Government/Community Partnerships

In order to provide deeper context for this discussion, we consider Government/Community partnerships in particular, as this interface represented significant failure point in the Hurricane Katrina response. In the wake of Katrina, 9/11 and other major disaster events over the last decade, US Presidential Policy Directive 8 (Whitehouse, 2011) was issued and refers to a National Preparedness Goal, Framework and System. PPD-8 specifically calls for a more comprehensive and community-oriented approach by all federal agencies toward emergency preparedness and response, as well as a focus on improving community resiliency. Similarly, the Federal Emergency Management Agency (FEMA) adopted a "Whole of Community" approach to emergency management that promotes the engagement of diverse community stakeholders in achieving enhanced preparedness and community resiliency (FEMA, 2011). Both of these federally launched activities represent the beginning of a shift from a government-centric stance toward emergency management to that of a community engagement and empowerment model.

Furthermore, local public health agencies (LPHAs) have also seen changes in Centers for Disease Control and Prevention (CDC) funding objectives and performance metrics in FY2011-12. Fifteen core public health emergency preparedness capabilities have been established to serve as performance measures for state and local public health preparedness programs and activities that receive federal funding (CDC, 2011). Included in the capabilities are measures of community preparedness and community recovery that are linked to federal resiliency goals, as previously referenced. It is quickly becoming apparent that part of LPHA preparedness practice includes revisiting models of citizen engagement and participation in all aspects of emergency planning within their communities. This includes leveraging existing relationships, networks and social capital to achieve necessary surge capacity, resource allocation, and coordination in response and recovery activities conducted during or following the aftermath of severe or prolonged disaster.

State and local government agencies are now increasingly encouraged through federal grant initiatives and guidance to develop and participate in public-private coalitions and partnerships around community-wide emergency preparedness. These partnerships often are built on planning for community economic and social continuity during and following a catastrophic event to ensure the rapid recovery and strengthened resiliency of impacted vulnerable communities. These types of relationships have resulted in improved joint emergency preparedness field exercises, refined community emergency response plans and information sharing at state and local intelligence fusion centers and Emergency Operations Centers. Citizen groups and non-profit organizations have similarly become involved in local government emergency preparedness efforts that have led to more robust planning around special needs populations (e.g., the disabled, institutionalized, and elderly), integrating faith-based organizations in social service capacity-building, volunteer efforts, registries, and in planning for population mental and behavioral health needs.

Overcoming Translational Problems – Applications of CEnR

Yet, to accomplish the goal of FEMA's "Whole of Community" initiative, recognizing barriers to community engagement and using models to more effectively manage the community engagement process are necessary. Most case studies presented in inter-disciplinary literature elaborate on the successful processes of CEnR projects. Less is written about the challenges of conducting CBPR overall or CEnR in particular. CEnR is a learned process where the researcher has to actively look for learning lessons at different steps. Without deliberate reflection, a CEnR researcher cannot successfully nurture her or his intellectual capacity to effectively engage with communities.

Ahmed et al. (2011) proposed a framework of 5 P's for effectively addressing challenges of conducting CEnR: Participate, Prepare, Predict, Preempt, and Prevent. Authentic *participation* and development of community trust is essential in successful CEnR. This includes the participation of the researcher in the community's activities as well as allowing community members to be a genuine part of decision-making throughout the research process (Wallerstein, 2008). Authentic participation is not only the key ingredient of the CEnR process, but a truly participatory process enables partners to "prepare, predict, preempt and prevent" common CEnR challenges. To truly *prepare* for CEnR, the researcher should work to understand his or her research, the potential partners and the community in which the research will be conducted. Effective preparation requires exploration into the community's priorities and an understanding of the assets of a community. *Prediction* is the process of deliberately informed thinking which includes considering all the partners' differing perspectives.

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Preemption is the process of strategically planning for differences; to preempt, the partners might engage in a strategic planning process or discuss, in the initial phases of the relationship, how to resolve conflict when it arises. Prevention, in CEnR, includes strategies that will help to reduce or eliminate conflict and barriers.

PROFESSIONALIZATION OF TRANSLATIONAL RESEARCHERS IN DISASTER TECHNOLOGY

To achieve the goal of translating disaster technology innovations into community-level interventions, there is a need for education and training of academics in community engaged research methods, as most researchers have limited understanding of, and experiences with, effective community engaged processes (Ahmed et al., 2004; Ahmed and Palermo, 2010; Israel, Schulz, Parker, Becker, 1998). To maximize the benefits of community engagement in research, those conducting this type of research need appropriate knowledge and skills. For example, researchers need to understand the community engagement approach they are using, including its methodology, theoretical frameworks, and evaluation techniques (Faridi, Grunbaum, Gray, Franks, Simoes, 2007). Researchers also need strong communication and facilitation skills, the ability to develop equitable and "safe" connections with communities, sensitive to cultural competencies and an authentic commitment to working with community partners such as local public health agencies, social service agency providers and non-profit groups as well as grass-roots volunteer organizations (AHRQ, 2003; Israel et al., 1998). These types of relationships will better prepare national and local agencies to address the needs of vulnerable populations before and after a disaster.

Because of the NIH focus on translational research and the need to create a cadre of "community competent" researchers in fields related to public health, deeper evaluations of the barriers and facilitating factors for these learners are being considered at multiple levels. Despite new educational offerings and faculty interest to engage communities, faculty roles and rewards in the academic setting present formidable challenges (Calleson, Seifer, and Maurana, 2002). Developing relationships with communities by faculty is not only an iterative process, but one that takes long periods of time (Calleson, Jordan, and Seifer, 2005). There is a need for academic institutions to adopt policies that support and recognize the value of community-engaged research (Kennedy, Vogel, Goldberg-Freeman, Kass, Farfel, 2009). While these efforts are still being formulated in the healthcare/public health arenas, they draw on several decades of community engaged models for population based health interventions and thus may provide an important framework for ISCRAM researchers working to improve community-based disaster information systems.

CONCLUSION

It is widely accepted that government responses to large and especially unpredictable catastrophic events, especially in the first 72 hours, will be hampered by scarcity of resources, surge demand for immediate emergency medical services and stabilization of community infrastructure essential to sustained response and recovery. A stronger and more pre-emptive approach to public engagement in all aspects of emergency management will not only minimize the severity of health impacts on vulnerable communities, but also the economic, social and political consequences of an event and subsequently improve community resiliency. Community-based information systems are an important part of creating community resilience, but comparatively little work has been done at the nexus between Community Engagement in Research (CEnR) and disaster information systems. The CEnR framework has important implications in terms of collaborative, human-centered design of these technology systems. It could improve the translation of information systems from laboratory development to a wide user base that includes first responders, government agencies, community organizations, and the impacted populations as a whole. It may also support the training and professional development of technologists working in this profoundly transdiciplinary space.

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