Improving immunization and health literacy through a community-based approach enhanced by technology

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Abstract. This report illustrates the importance of capacity-building to advance immunization literacy through a community-based participatory research (CPBR) approach using technology to decrease child health immunization disparities. The research project utilizes culturally-tailored immunization and technology literacy modalities for dissemination in targeted low-income neighborhoods. The results suggest successful outcomes are dependent upon contributions and engagement of community members in all project processes, ensuring community buy-in and cultural relevance. The latter approach is time-intensive due in part to the need to build broad-based community partnerships, which can result in a promising approach to foster broader population impact.

Keywords: Health literacy, immunization, technology, community based participatory research, health disparities

1. Introduction

Advancements in the utilization of immunizations have been recognized as one of the top 10 achievements in public health \cite{1}. However, some populations have not benefitted equitably from this achievement. In fact, in the U.S. city of Milwaukee, WI, immunization coverage rates have been documented to be as low as 45\% for the 4 doses of diphtheria-tetanus-pertussis (DPT), 3 doses of Polio (IPV), 1 dose of measles-mumps-rubella (MMR), 3 doses of Hepatitis B (HBV), 3 doses of Haemophilus influenzae...
(Hib), 1 dose of Varicella (VZV), and 4 doses of Pneumococcal vaccine (PCV), commonly referred to as
the 4:3:1:3:3:1:4 antigens. These vaccines antigens will be referenced as the age-appropriate vaccinations
for children between the ages of 19–35 months for the remaining of this text [2].

The U.S. federal government’s Healthy People 2020 targeted goal for childhood immunizations in this
age cohort is 80% [3]. In Milwaukee, the percentage of children living in households below the U.S.
poverty threshold is 42.1%, and children in low-income (<200% Federal Poverty Level) households is
69% [4]. Milwaukee is a city of about 595,000 people located in the Midwestern region of the U.S.

The CHIMC (Community Health Improvement in Milwaukee’s Children) Project was established in
2005, guided by community-based participatory research (CBPR) principles [5], to address immunization
disparities in Milwaukee, while following a Knowledge-To-Action Framework [6, 7]. The CBPR approach
promotes a collaborative effort between community partners, community agency leaders and researchers,
with community members involved in topic selection, research/program design, intervention, evaluation
and dissemination of findings [5]. The community representatives’ voices and roles in the CBPR processes
and interventions sought to foster beneficial skill development and positive outcomes for intervention
neighborhoods and was sponsored by the U.S. National Institute on Minority Health and Health Dispari-
ties and the Pfizer Foundation during a 12-year period.

Phase I of CHIMC encompassed a Pilot (2005–08), which focused on community buy-in, awareness of
the scope of the health disparities, and agreement regarding the research approach. In addition, partners
agreed upon an infrastructure to cultivate co-learning and power-sharing to address health disparities
within two primarily Black zip codes in Milwaukee. Phase II (2008–13) incorporated the intervention
phase of research that sought to increase immunizations in four target zip codes by enhancing the impacted
populations’ awareness of the safety and efficacy of immunizations. During this time, a web-based toolkit
and interactive eLearning Café were developed along with customized immunization messages. CHIMC-
TCI!Team operationalized the research and immunization literacy of this Project through interfaces across
several web-based platforms. Phase III (2008–13) was a dissemination phase, where tools developed
during previous phases were expanded to 10 adjacent zip codes for use by parents, caregivers, and childcare
agency staff members. The CHIMC dissemination tools to enhance immunization literacy were adapted
into a culturally-relevant Spanish-version and disseminated within two predominately Hispanic zip codes
from 2013–2017. The following sections will discuss adaptations and dissemination of immunization
information using different modalities within two vulnerable populations in Milwaukee. Immunization
outcomes and lessons learned from these CBPR efforts to expand immunization literacy levels are
described in this report.

2. Methods/assessment

CBPR principles (see Table 1) guided the approach and development of health literacy materials within
the CHIMC Project by focusing on community perceptions and input to facilitate partners’ engagement
and co-ownership from multiple sectors in

Milwaukee, WI. CHIMC’s infrastructure consisted of the Community Forward Team (CFT), two
Workgroups, a Steering Committee, and the Executive Committee. CFT members were community
members recruited from multiple family resource centers collectively administered under the United
Neighborhood Centers of Milwaukee, a charitable organization. These agencies predominantly serve and
reside within the CHIMC 12 targeted zip codes.
Table 1
Community-based participatory research principles [5]

<table>
<thead>
<tr>
<th>Recognize community as a unit</th>
<th>Build on community strengths</th>
<th>Facilitate collaborative equitable partnership: power-sharing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foster co-learning and capacity building</td>
<td>Balance knowledge generation with actions</td>
<td>Focus on local relevant public health problems</td>
</tr>
<tr>
<td>Build a cyclic and iterative process</td>
<td>Disseminate findings to all partners</td>
<td>Involve long-term process and sustainability</td>
</tr>
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CFT members worked vigorously with academic and community partners within CHIMC’s structural and operational components. Active engagement was accomplished through monthly meetings with the Executive Committee and participation in two Workgroups: (1) Communication Strategies and Tactics, and (2) Dissemination and Evaluation. Workgroups consisted of community members and academic partners in shared roles as co-chairs, with a membership ratio of two community members to one academic partner. Workgroups developed policies and outreach procedures and assisted in the development of evaluation instruments to ensure cultural relevancy. The day-to-day execution of the project was guided by the Executive Committee consisting of members from the Steering Committee. The Steering Committee fostered reporting from the Workgroups for ratification and consensus building. For example, the CHIMC Team developed a tagline to communicate their involvement with the Project: “Take Control-IMMUNIZE!” (TCI!). Consistent with principles of CBPR, all project members mutually benefited from co-learning, collaboration, and equitable power sharing.

The CHIMC Team operationalized the immunization literacy of this project through interfaces across several web-based platforms. Through existing institutional affiliations, the Project facilitated the creation of interfaces between the community and Medical College of Wisconsin (MCW) licenses to REDCap (Research Electronic Data Capture) database and Citrix server; as well as Children’s Hospital of Wisconsin (CHW) learning management system (e.g., Moodle). Other information technologies utilized to execute this Project included the State of Wisconsin Immunization Registry (WIR) and consultation with Marquette University (MU) Diederich College of Communications [8,9] to build a social media Facebook page using Weebly. MU Diederich College of Communications also facilitated the development of a customized on-line Parent Toolkit (See description below). In addition, an e-Learning Café was developed as an interactive platform with community partners and CHW’s Community Service Division. TCI! e-Learning Café is a Learning Management System (LMS) technology which enables computer-based instruction in the delivery of CHIMC-TCI! educational materials and immunization-related health information. Linkages to CoCasa, a publicly available software immunization management system, for childcare agencies, were incorporated into the Toolkit for use by local childcare agencies to monitor children’s immunization status.

During the CHIMC-TCI! Dissemination phase, there were administrative and technical elements that the Project Team put into place to lay the groundwork for successful implementation. Satellite locations for the Project’s research were established at five Family Resource Centers of the United Neighborhood Centers of Milwaukee (UNCOM) and five WIC locations. These satellites allowed easy access to the technology platforms. Technology for satellite offices was installed, with special attention to processes that ensure data safety and management at these community sites with local IT experts as referenced above.
Technology infrastructure was established to:

- Manage on-site participant enrollment and data collection and safety;
- Provide staff and partners with remote access to online databases; and
- Maintain hardware and software system interfaces to coordinate and support daily operations.

Steps required to meet fundamental technology infrastructure included hardware and software procurement and licensure, such as:

- Acquiring desktop computers at satellite locations (set-up May 2014);
- Confirming Citrix access for appropriate CHIMC-TCI! staff; Citrix is a server used by MCW for access to secure documents at offsite locations;
- Updating outdated laptops with the appropriate software;
- Deploying two mobile Wi-Fi hotspots for CHIMC-TCI! Outreach/Community Health Specialists; and
- Monitoring data security, analysis and interpretation through current technology reports.

Social media and technology were tailored to the populations most impacted through involvement of community members throughout all stages of the Project. During Communications Strategies and Tactics (CST) Workgroup meetings, partners discussed progress of technology-assisted recruitment strategies, and reviewed the effectiveness of social media and web-based communication platforms. Community members and academic partners deliberated on venues to disseminate health-related and immunization information, such as locations to access government-sponsored Vaccines for Children (VFC). Parents'/caregivers' assessments included questions on accessibility to internet, phones and social media sources. This assessment supported input into the savviness of community members in the use of community technology. Again, the CHIMC-TCI! team consulted with experts in communication and technology use (e.g., Marquette University Diederich College of Communications, MCW Information Services) to obtain critical input into ensuring data safety and security to incorporate information into satellite locations partnering with the CHIMC-TCI! Project.

Key steps taken to address data safety and information systems security included:

- Streamlining access to protected health information upon enrollment such that the raw data was only available to the Project Team, however, community members had access to aggregate data with restrictions on how that data could be used.
- Ensuring that encryption software was installed on all portable devices (laptops).
- Utilizing REDCap for identifiable data as it is stored on MCW/CHW HIPAA compliant servers and is password protected. REDCap allows for administrators to assign different levels of access to different individuals to ensure the security of the data. All research trained, Institutional Review Board (IRB) approved CHIMC-TCI! staff members have access to the database, but only the Principal Investigator and research coordinators have access to update or delete files to ensure that data is not inadvertently changed. Additionally, data can only be exported by certain individuals to ensure that raw data remains encrypted on computers and/or servers so that identifiable data was secured.
- Collecting only de-identified data through the learning management system (Moodle) for the e-Learning Café platform.

CHIMC used the CBPR approach to advance immunization health literacy in a central area of Milwaukee through the creation of co-learning opportunities. CHIMC partners planned and implemented 11 training workshops with topics that included: healthcare navigation; public health issues; biostatistics;
technology education; community health assessment; and grant writing. The trainings provided bi-directional knowledge exchanges between community and academic partners. CHIMC partners improved their capacity building as a result of these trainings with community members, which advanced beyond immunization health areas to broader health disparity concerns, such as social determinants of health and advocating for system changes. The training curricula were inclusive of institutional review board (IRB) requirements and ultimately, provided essential steps in research skill development and knowledge exchange among the project’s partners. Training workshops were geared towards community building, community assessment, research methodology, statistical analysis, youth empowerment, and mentoring across cultural groups (predominantly Black and Hispanic) as well as fostering bi-directional training and learning opportunities between community and research members.

CFT members and other training attendees acknowledged the professional development and individual capacity-building that occurred as a result of these trainings. Academic partners benefited from community members sharing their community-relevant experiences and community historical knowledge. Trainings were evaluated using a self-report satisfaction scale rated up to 100%; members of the CHIMC team ratings ranged from 82% to 100% for the various topics listed above. Collectively, CHIMC’s Workgroups propelled the project forward and ensured continuous communication and equitable representation from community members, representatives of local community-based organizations, and academic partners. The Workgroups were instrumental to the project’s ability to successfully employ technology platforms that planned culturally-tailored dissemination strategies and tactics to meet the goal to eliminate Milwaukee’s immunization disparities.

CHIMC inclusion/exclusion criteria and baseline data collection were as follows: parents/caregivers had to live within the targeted zip codes and have at least one child less than four years old living in the household. Participants were able to enroll siblings older than four for tracking of their vaccine status. The primary exclusion criteria included households that: (a) did not have a child in household who was less than four years old or, (b) lived outside of the targeted geographic areas.

3. Immunization knowledge enhancement opportunities

The CHIMC Project applied several modalities to enhance immunization health literacy. These modalities were utilized at different phases throughout the Project and included: (1) a CHIMC website inclusive of a Toolkit and Interactive eLearning Café; (2) a social marketing campaign; and (3) implementing an intervention grounded in the theory of planned behavior. The three selected modalities are summarized below. Data from participation in the modalities are summarized as contributing to the therapeutic change in the enrollee’s immunization status at the end of this report.

3.1. CHIMC Website

(https://www.chimcmke.org): A culturally-tailored, website platform was created by the research team and CFT members.

The website was divided into five sections: (1) Homepage: included the description of CHIMC; (2) Parent Toolkit (description below); (3) The history of CHIMC: included information on the phases of CHIMC; (4) Faces of CHIMC: provided biographies of CHIMC project staff; and (5) CHIMC eLearning Café (description provided below). CFT members played an integral role in designing and refining the website so it was culturally and linguistically relevant (in English and Spanish). CFT members also
were integral to teach parents/caregivers how to navigate the website, thus increasing parents’/caregivers’ information technology literacy.

The Parent Toolkit was embedded within the web platform, which enabled parents/caregivers to have multiple opportunities to enhance their immunization awareness through diverse information sources. The Toolkit included six components: (1) Recommended immunization schedules in a parent/caregiver-friendly infographic; (2) How to look up your child’s immunization records on the Wisconsin Immunization Registry (WIR), which is the U.S. State of Wisconsin’s immunization internet database where healthcare professionals record and track immunizations. The guidance included step-by-step video directions on how to use the WIR. Having access to the WIR fulfilled the “Take Control Immunize!” tagline message; (3) Milwaukee clinical sites of low-income populations: included a map of clinics and information, and links to transportation assistance; (4) Health care appointment checklist: provided a list of required and optional items families should bring to their child(ren)’s routine health care appointments; (5) Links to reputable, evidence-based immunization websites, such as information from the U.S. Centers for Disease Controls and Prevention; and (6) Frequently asked questions on immunizations including benefits, risks, side effects, cost, etc.

Website analytics were conducted using RGoogle Analytics package for sessions entered, page views, interactions, and referrals sources. A Facebook page was developed and analyzed for page visits, audience reach, posts and engagement as likes, comments, and shares.

### 3.2. eLearning Café

An interactive web-based platform enabled parents/caregivers to educate themselves about immunizations, with data stored in REDCap (a database management system). This on-line, interactive eLearning Café was offered in English and Spanish versions and provided an immunization educational module with four sections: introduction; vaccines for children zero-four years old; catch-up vaccines; and vaccines for persons 10–18 years old. The eLearning Café consisted of a 15-item pre-knowledge assessment (true/false/don’t know format) to determine parents’/caregivers’ baseline immunization knowledge. Post-knowledge assessments were embedded within each module of the eLearning Café.

After parents/caregivers consented to participate in the study and prior to completing the eLearning Café, parents were invited to complete an assessment. This assessment consisted of a 38-item questionnaire separated into five domains: (1) immunization attitudes, values, and beliefs; (2) perceived discrimination; (3) general self-efficacy; (4) immunization-related self-efficacy; and (5) social support. During the first dissemination phase, which occurred with a predominately Black cohort, data for enrollees was assessed based on eLearning Café completion status (completed, incomplete or no eLearning) to compare if there were baseline differences for demographic, socioeconomic or knowledge-based factors. If significant differences were found between demographic groups, the results could have skewed eventual findings and influenced the data interpretation about enrollees’ immunization gaps.

### 3.3. Social marketing campaign

In order to increase community awareness and behavioral intent around childhood immunizations, a social marketing campaign was launched in the intervention phase of the CHIMC Project [10]. This social marketing campaign included walking billboards, radio announcements, and a Facebook page. Assessment of the effectiveness of the social marketing campaign occurred through determination of CHIMC message recognition rate through community intercept interviews.
3.4. Using the theory of planned behavior

Four focus groups were conducted with parents/caregivers to assess for barriers and facilitators to immunization completion in children ≤4 years old, as suggested by theory of planned health behavior \[11\]. Small groups of eight-twelve parents/caregivers received education to build specific skills and knowledge through observational learning. According to Montano 2008, the integrated behavior model (IBM), a person’s intention to perform a behavior is influenced by their attitude (experiential and instrumental) toward the behavior, perceived norms (injunctive and descriptive), and personal agency (self-efficacy and perceived control).

In order to obtain objective measurements of the impact of the CHIMC Project on child and youth immunization rates, documented immunization data was obtained at baseline and quarterly through Project completion from the Wisconsin Immunization Registry (WIR). Immunization status analysis for children/youth included up-to-date (UTD), Not UTD (NUTD), and Late UTD (LUTD) for age-appropriate antigen series. The CHIMC Team forwarded quarterly reminders to parents/caregivers for each child/youth enrolled with a NUTD status.

4. Outcomes of the Milwaukee CHIMC health literacy initiative

A total of 1,651 parents/caregivers were enrolled in the CHIMC Project during the dissemination phases \((n = 1,335\) Black cohort, \(n = 316\) Hispanic cohort; overall: 69% self-reported as Black; 17% self-reported as Hispanic; 14% self-reported as other race/ethnic groups which is inclusive of Caucasians, Hmong, Multiracial, etc.). More than half of the enrollees \((n = 863, 52\%)\) participated in the eLearning Café. Enrollees were predominantly female (>90%). The range of enrollees who lived in households with income less than or equal to 200% of the federal poverty threshold ranged from 76%-Hispanics to 85%-Blacks. Enrollees unemployed at enrollment ranged from 55% for Blacks to 65% for Hispanics. The self-reported educational attainment of enrollees at or below a high school degree/GED was 57% for Blacks and 78% for Hispanics. Mothers (>90%) were the primary decision-maker for children getting immunizations.

4.1. CHIMC interactive website and Parent Toolkit

Site-wide statistics suggested that more than 80% of users accessed the CHIMC-TCI! website using a personal computer such as a desktop or laptop, while less than 20% used a smartphone or tablet. The primary website referral occurred when enrollees directly typed in the URL address or accessed it via Google. Other major referral sources included Facebook, Bing, and project participants. The earliest spike in utilization occurred during fall months, consistent with school entry. The home page received the most Internet hits, followed by the look up your child’s immunizations record page within the Parent Toolkit. The Facebook page, including training newsblast, had the highest reach and likes, followed by the community recruitment page. Customizing social media messages seemed to generate more interaction with the CHIMC-TCI! health promotion messages.

Exposure to the CHIMC-TCI! Toolkit and e-Learning Café were significantly correlated with increased immunization rates (from 63% at baseline to 83% at follow-up one quarter after enrollment and exposure). Use of web-based platforms was recommended as a sustainable mode to increase parents’/caregivers’
access to immunization health information. e-Learning Café participants demonstrated a statistically significant increase in knowledge.

The Project Staff documented that our immunization materials impacted over 13,000 individuals via technology utilization. Technology that CHIMC-TCI! utilized provided ease-of-use for enrolling participants in real-time community-oriented research. This allowed the Project staff to quickly enroll participants, with heightened sensitivity to the needs of the target population. In addition, it allowed participants to utilize technology to expand their own knowledge about immunizations beyond the research period.

4.2. CHIMC Project overall impact on immunization rates

As a result of the CHIMC Project, parents/caregivers improved their immunization and technology literacy, leading to behavior change evidenced by statistically significant increases in immunization rates for targeted children ages zero-to-four years. In the first dissemination phase with the predominantly Black cohort, at enrollment, a larger percentage of parents reported their youngest child (0–4 years old) was UTD (82%, n = 1,096), as compared with WIR-verified UTD status (71%, n = 948). Following completion of the modalities to improve health immunization literacy described previously, there was a statistically significant increase in WIR-verified UTD immunization status for all child age groups from baseline to project completion (age-cohorts and n’s): 6–18 months pre: 68% (334) - post: 75% (452); 19–35 months pre: 63% (322) - post: 70% (536); and 36–59 months pre: 62% (414) - post: 86% (577).

During the second dissemination phase with a predominately Hispanic cohort, parents were offered the option to complete the eLearning Café in Spanish or English on the website. Baseline reported parental perceptions of their child’s 0–4 years UTD status was higher for the Spanish-version (97%) versus the English-version (86%), which were both higher than WIR-verified UTD status (75%). Unlike the predominantly Black cohort, increases in the predominantly Hispanic cohort WIR-verified child UTD status from baseline to project completion were not statistically significant. The difference in significance could be due to a smaller sample size for children ages 19 to 35 months within the Hispanic cohort (n = 82) compared to the Black cohort (n = 427). Additionally, there was a shorter follow-up time period for the Hispanic cohort compared with the Black cohort (14 months versus 8 months). UTD immunization status for Hispanic children in the age cohort of 19-35 months increased by 2% (pre: 75% (n = 52) - post: 77% (n = 82)) from baseline which was three quarters post enrollment. However, if compared to the 2014 immunization baseline for the Hispanic children in the same zip codes, immunization rates trended positive for UTD status increasing above the baselines of 63% and 70% for the 53215 and 53204 zip codes, for ages 6-18 months and 19-35 months, respectively.

4.3. Ancillary benefit in older siblings for HPV impact

In an ancillary analysis of Black adolescent (13 to 17-year-old) siblings (n = 118) of the original 19 to 35-month child cohort from the first dissemination phase, adolescent’s HPV-UTD immunization status increased from 30 (25%) at enrollment to 54 (46%) at study completion [p = 0.004] [12]. Moreover, a statistically significant larger proportion of adolescents became HPV-UTD in the study cohort (20%) compared to the City of Milwaukee [14%, p = 0.042] and the State of Wisconsin [14%, p = 0.046]. The increase in youth immunization rates is evidence of increased parental/caregiver immunization literacy, as the focus of the intervention was on the younger children, and not on youth. The materials parents/caregivers received in the various immunization health literacy modalities included information on
youth age-appropriate vaccines. A similar comparison has not been done for the Hispanic cohort because of smaller enrollment numbers.

4.4. Social marketing campaign

A social marketing campaign resulted in a successful dissemination of the tagline message “Take Control-IMMUNIZE! (TCI!)” to the broader community beyond enrollees. A secondary study evaluated community awareness of childhood immunizations and the intent to immunize children using the “Take Control-IMMUNIZE!” social marketing campaign. Parents/caregivers had an 85% recognition rate of the CHIMC message amongst a random cohort of persons participating in intercept interviews within the targeted zip codes. Almost half of those who saw the “Take Control-IMMUNIZE!” message reported the message motivated them to act, which included getting their children immunized. Overall, these findings suggest social marketing may be an avenue to increase immunization messaging across diverse communities in urban areas [10].

4.5. Using the theory of planned behavior

The theory of planned behavior allowed for exploration of parents'/caregivers’ attitudes and barriers to immunize their child(ren). Building on these ideas, parents'/caregivers’ perceptions were explored along with education on how to access immunization records. Modeling and rehearsing effective health care navigation strategies resulted in effective behavior change as evidenced by increased immunization rates. The major themes derived from parent/caregiver focus groups included: (1) parents believed both they and their community were responsible for their children’s immunizations and overall health; (2) there were positive views regarding the CHIMC logo and messaging; (3) the CHIMC logo was associated with positive individual and community health; and (4) enrollees suggested their community should have a multi-level approach to promoting immunization rates. Parents/caregivers suggested slogans such as, “Health Begins with You” and “Save the World, One Immunization at a Time.”

As a result of the technology procurement processes listed above, CHIMC-TCI! was able to boost its technology capacity and abilities to garner community buy-in throughout the recruitment, enrollment, data collection, data management, data analysis and interpretation. Community members also shared in the scholarly dissemination of the data at local, regional and national settings. The Project was also able to establish new-electronic and web-based dissemination materials and technology vehicles for broader reach of the effectiveness and safety of immunizations. In addition, the Project balanced the use of technology in data collection and dissemination with maintaining high standards of ethical conduct in research, safeguarding community trust throughout the research process.

5. Sustainability and dissemination

Part of the success of the CHIMC Project has been its sustainability, which was enhanced by establishing community-wide immunization collaborations, including the Immunize Milwaukee! Coalition, and the Milwaukee Succeeds Immunization Network. Immunize Milwaukee! is a non-profit, independent, community coalition that seeks to improve immunization rates in the Milwaukee metropolitan area [13]. The Milwaukee Succeeds Immunization Network seeks to improve and sustain vaccination rates for younger children (ages 19–35 months) within the City of Milwaukee [14]. The impact of both groups stems
from a diverse membership that reflects organizations which represent different demographic sectors within Milwaukee. Both groups seek to build consensus toward common goals and agendas and emphasize providing recognition and progress to accomplish therapeutic social goals.

In addition, the academic-community partnerships that started during this Project opened the door for subsequent research projects that addressed other health-related issues. Essentially, the capacity building and professional development of the CFT members empowered them to become engaged in additional health and community-engaged efforts beyond the CHIMC Project. A sample of 11 CFTs suggested each were engaged in multiple other community-health promotion service and leadership activities. The ensuring activities were organized broadly within three categories: (a) health disparity issues; (b) local social determinants of health; and (c) systems impact.

Subsequent dissemination about immunization (and related disparities issues) also has occurred on a local, national, and international level through media outlets, publications, abstracts, posters, and presentations at meetings [7,10,12,15,16].

The Project’s technology and web-based platforms promoted lasting impact within the community through providing stakeholders with sustained access to CHIMC-TCI! findings and information. More specifically, a 2017 follow-up of the surveyed subgroup agencies reported increased utilization of the Wisconsin Immunization Registry (WIR) compared to reported intention to use WIR during the initial survey (48% compared to 42% at 18-month follow-up).

Community buy-in and ownership of different technologies is also needed to create sustainable change. Long-term success for the CHIMC website will depend on keeping the partners engaged in maintaining currency of the CHIMC-TCI! website and possibly broadening topics covered to include other health disparity conditions impacting this population.

6. Lessons learned

The four core lessons learned through the CHIMC Project were: (1) The CBPR approach, with a focus on integrating community engagement and broad community-based partnerships, was foundational to the Project’s success; (2) bidirectional learning occurred for both the community and the researchers; (3) while technology facilitated the dissemination of health literacy messages, the integration of data across platforms is a barrier for sustained implementation by local organizations; and (4) improved health literacy empowered families/caregivers and advanced a broader population impact that eclipsed its original goal – to increase immunizations. These lessons and their broader implications are introduced below.

6.1. Lesson one

The community-based participatory research (CBPR) approach, with a focus on integrating community engagement and broad community-based partnerships, was foundational to the Project’s success. The guiding principles of CBPR fostered processes of shared ownership by community leaders within health, social services, IT systems, and public health systems for community health improvement and health promotion among significantly impacted populations.

The CHIMC Project facilitated partnership through all phases of the research, incorporating partners from multiple sectors: community residents, public health professionals, academic researchers, IT and communication specialists, community leaders/agency representatives, and medical practitioners. Having sustained the partnership for more than a decade, the Milwaukee Project illustrated the CBPR principle
to sustain long-term community commitments. Partnership stakeholders also were involved in multiple areas and dimensions of decision-making throughout the Project to include: website content development, recruitment material, data collection tools, eLearning Café, and other Project domains. This level of involvement demonstrates that CBPR fosters high-level engagement at multiple sectors of the community. In addition, high-level engagement, while time-intensive, was the key to the Milwaukee Project’s success. For students and health literacy researchers, the Milwaukee Project’s results suggest there are no substitutes for intense time commitments and transparency in order to build trust and rapport with community partners.

Community Forward Teams (CFTs) significantly contributed to success of this CHIMC Project and influenced community-relevant health literacy by involvement in the Milwaukee Project’s decisions about intervention design, implementation, evaluation, and dissemination. CFTs guided word choices to ensure relevance to the targeted populations. CFT involvement in outreach, recruitment, and implementation bolstered the Project’s success in meeting enrollment goals; CFTs even participated in the interpretation of the Project’s findings. In fact, during the first dissemination phase, CFTs facilitated surpassing the original target enrollment goal by 5-11%, enrolling a total of 1,651 parents/caregivers instead of the original goal of 1,500. Given their knowledge and relationship with the community, CFTs opened doors to the targeted communities, providing unique access points.

6.2. Lesson two

Capacity building is bidirectional and occurs for both the community and the researchers. The CBPR approach resulted in bidirectional learning that benefitted both the Project’s researchers and community members (CFTs). As a result of diverse projects, CFT members improved individual health literacy and IT knowledge. At the same time the investigators expanded their understanding of community health literacy knowledge, IT systems knowledge, and health disparities issues. This bidirectional learning environment was intentionally cultivated by the Project team. One of the key principles of CPBR is to facilitate co-learning, collaboration, equitable power sharing and capacity building among all partners, which was implemented throughout the Milwaukee Project.

For example, the training topics for capacity building were selected via input from academic partners and CFTs. Fifty-eight percent of the subsequent trainings were conducted by an academic expert; 33% of trainings were conducted by community experts; and two trainings were conducted by nationally recognized community/academic experts.

Overall, the approach enhanced collaboration and skill-building by building on the strengths and resources of an entire community. For researchers and partners interested in technology utilization to promote health literacy, the Project’s findings suggest that learning is bidirectional and investigators need to strive to advance the strengths of all involved community participants. While researchers bring individual and public health expertise, the Project’s findings suggest research findings and intervention programs are more effective and relevant to enrollees as a result of community engagement. Power-sharing and valuing each partner’s contribution to research agendas and interventions are critical elements of an intervention’s success.

6.3. Lesson three

Technology can facilitate dissemination of health literacy messages, however, integration of data across platforms remains a challenge for implementation by local organizations. Exposure to the CHIMC-TCI!
Project and its web-based Toolkit empowers parents/caregivers to access immunization information and resources, enhancing their abilities to keep child(ren) up-to-date on age-appropriate immunizations. The use of technology in CHIMC-TCI! provided opportunities to reach larger populations of parents/caregivers and children. One essential benefit of technology was it fostered this research Project to rapidly extend its reach due to real-time access to the web-based platform at satellite locations in the targeted community. The CHIMC Project established neighborhood locations to gain access to targeted populations using key community entry points that were familiar to families within the selected intervention zones. The web-based platform of the Toolkit and eLearning Café at neighborhood locations enabled the rapid extension of the reach of the CHIMC Project’s immunization literacy message. The CHIMC-TCI! Team explored the potential of mobile applications (apps); however, they discovered that the use of customer-designed apps was less efficient than having access to a web-based platform through the targeted communities.

However, technology introduced challenges to include the following: (1) concerns regarding data safety and security across the partnering agencies; (2) the need for technology updates; and (3) sustainability following Project’s funded period. The Project Team addressed concerns regarding data safety and systems security by creating firewalls at satellite locations to ensure that computers were secure to access the internet websites necessary to execute the CHIMC-TCI! Project. As many of the data platform did not communicate with each other, workflows had to be created for data tracking purposes. For example, the CHIMC team had to establish data sharing and monitoring processes with the Wisconsin Department of Health Services-Immunization Program and the City of Milwaukee Health Department to track immunization status of individual CHIMC-TCI! participants through the WIR.

Technology updates required significant investments of resources, including personnel. While the partnering systems such as MCW’s IT team and Marquette University Diederich College of Communications provided support for this during the Project implementation period, smaller partnering agencies did not have the IT support needed or the bandwidth to make these changes post-Project completion.

6.4. Lesson four

Improved health literacy empowers families/caregivers and can result in a broader population impact. CHIMC-TCI! adopted the web-based Toolkit to disseminate and expand to a larger targeted population of families with children/youth. The development of culturally-relevant materials was implemented in partnership with academic and community partners. Community residents, parents/caregivers, and Community Forward Team members (CFTs) continue to be vital partners. Culturally-tailored processes, inclusive of focus groups to assess social media preferences, web-based platforms, and social media networks such as Instagram, YouTube, Twitter, LinkedIn, Facebook, etc., allowed the group to capitalize on technology utilization in this dissemination phase of the Project.

The evolution of the Milwaukee Project’s success from its early dissemination phase to completion - within its Black cohort - suggests educational efforts coupled with technology utilization prompted improvements in community education and population health literacy. The result of community-based efforts to improve population literacy among enrollees also is evidenced by unanticipated findings, such as improved human papilloma virus immunization rates among adolescent siblings within the project’s Black cohort. While there was not a statistically significant increase in child up-to-date immunization rates resulting from the subsequent Hispanic dissemination phase, the results might be confounded by a shorter intervention time frame and a smaller, enrolled cohort. Regardless, the predominately Hispanic cohort experienced a 10% to 22% increase in up-to-date immunization status that initially had baseline rates of 63–70%.
Buy-in from all partners was the most productive component of this Project with the populations being most impacted leading the knowledge exchange process. Technology allowed for the Project to have broader reach and timely input at the local levels. Keeping this current and sustainable has been realized at the local levels and we have realized stronger ambassadors of health improvement with community health workers evolving from the community participants. This CBPR approach has resonated into other local health-related initiatives such as tobacco control programs, children’s mental health initiatives, and HPV vaccine initiatives.

Finally, the Milwaukee community-based Project demonstrated the effectiveness and value of engaging impacted neighborhoods in sustained community-developed interventions and dissemination – that included educational efforts which boosted individual and population health literacy and eventually, increased immunizations within vulnerable populations. While partnership with institutions were vital to the execution of this Project, advocating for adoption of this model throughout the public sector and stronger alignment with established partners would have been vital for continuation of these user-friendly and readily accessible tools.

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