

# Integrating community-based participatory research and informatics approaches to improve the engagement and health of underserved populations

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## ABSTRACT

**Objective** We compare 5 health informatics research projects that applied community-based participatory research (CBPR) approaches with the goal of extending existing CBPR principles to address issues specific to health informatics research.

**Materials and methods** We conducted a cross-case analysis of 5 diverse case studies with 1 common element: integration of CBPR approaches into health informatics research. After reviewing publications and other case-related materials, all coauthors engaged in collaborative discussions focused on CBPR. Researchers mapped each case to an existing CBPR framework, examined each case individually for success factors and barriers, and identified common patterns across cases.

**Results** Benefits of applying CBPR approaches to health informatics research across the cases included the following: developing more relevant research with wider impact, greater engagement with diverse populations, improved internal validity, more rapid translation of research into action, and the development of people. Challenges of applying CBPR to health informatics research included requirements to develop strong, sustainable academic-community partnerships and mismatches related to cultural and temporal factors. Several technology-related challenges, including needs to define ownership of technology outputs and to build technical capacity with community partners, also emerged from our analysis. Finally, we created several principles that extended an existing CBPR framework to specifically address health informatics research requirements.

**Conclusions** Our cross-case analysis yielded valuable insights regarding CBPR implementation in health informatics research and identified valuable lessons useful for future CBPR-based research. The benefits of applying CBPR approaches can be significant, particularly in engaging populations that are typically underserved by health care and in designing patient-facing technology.

**Keywords:** community-based participatory research, research design, patient empowerment, mHealth, patient-centered care

## BACKGROUND AND SIGNIFICANCE

Health information technology, including mobile health technology, holds significant potential for engaging individuals in managing their health by providing tools to track, manage, and interpret personal health metrics.<sup>1–6</sup> These tools can empower patients to ask questions, communicate concerns, identify and assess alternatives, reflect on progress, and alter their health behavior. Despite the plethora of available technologies, the number of engaged and empowered patients using these technologies is still relatively modest.<sup>7–10</sup> Patient-facing technologies are adopted less frequently and used in a less-integrated fashion than intended by designers and implementers.<sup>8,11–13</sup> The reach of consumer health informatics technologies among underserved groups, including racial/ethnic minorities and low-income individuals, is especially problematic.<sup>14–19</sup>

Community-based participatory research (CBPR) is an approach that may improve both patient engagement in health care and representation of underserved groups in informatics research and practice.<sup>20</sup> CBPR, which originated in the public health field, is a collaborative, action-oriented research approach that involves

development of long-term, equitable research partnerships between academic researchers, community-based organizations (CBOs), and community members.<sup>21,22</sup> Community members are actively engaged at all stages of a research project, from problem definition to translation of results into action, with an effort to pursue equity in project authority, credit/authorship, and resources.<sup>23–25</sup> The most commonly applied framework for implementing CBPR was defined by Israel and colleagues (box 1).<sup>26</sup>

CBPR shares several concepts in common with other sociotechnical approaches to technology design and implementation, such as user-centered design (UCD)<sup>27,28</sup> and participatory design (PD).<sup>29</sup> All 3 approaches (CBPR, UCD, PD) share a common goal of incorporating the perspectives and needs of intended end users into technology design and can apply similar methodologies. Key differences between CBPR, UCD, and PD relate to their theoretical foundations and to the degree of CBO and community member engagement across project stages (figure 1). In UCD projects, researchers typically lead the entire effort from study design to dissemination.<sup>28</sup> In PD projects, researchers typically control study design and results dissemination,

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## Box 1: Key principles of community-based participatory research (adapted from Israel and colleagues<sup>26</sup>)

**Principle 1:** Viewing community as a unit of identity. The community has 1 or more unifying aspects such as a geographic area (ie, neighborhood), chronic disease identity, or professional role.

**Principle 2:** Understanding the existing strengths and resources within the community. The community brings resources to the table, and these resources should be valued for their unique contribution to the research process. Examples of resources could include long-term experience in working in a specific neighborhood, facilities in the community, and ongoing outreach networks and initiatives.

**Principle 3:** Building collaborative partnerships in all research phases. The community is not just included during data collection, but rather is included from problem definition through results dissemination. Examples could include the following: community members can help to define research questions that are important to them, can be included as members of the research team, and can contribute to research design and data analysis if they want to.

**Principle 4:** Integrating research results for mutual benefit. The research team builds new knowledge and incorporates the knowledge into action through iterative cycles. For example, a needs assessment study can provide direction for initial community interventions, but as needs are addressed through research, new or different needs could emerge.

**Principle 5:** Viewing research and partnership building as a cyclical and iterative process. Collaboration between researchers and the community is not a “one off” activity. Activities related to building and maintaining academic-community partnerships and refinement of research goals occur iteratively. For example, if new community needs emerge or existing needs change, the direction or emphasis of the research may evolve.

**Principle 6:** Empowering both academic and community partners through co-learning opportunities, with awareness of social inequalities. While researchers learn about community needs and community members’ expertise, community members are given the opportunity to learn about research processes and methodologies. Examples could include providing training to community members about data collection and data analysis or partnering with community members when presenting research results.

**Principle 7:** Incorporating positive and ecological perspectives into research. Research designs should incorporate perspectives focused on well-being and determinants of health. Examples could include leveraging community resources in the conduct of research and examining contextual behaviors that influence health-related behaviors.

**Principle 8:** Disseminating knowledge to all partners. Data and results should be provided to community partners, and community partners should provide input on results dissemination. Research results should not be distributed solely via peer-reviewed academic journals. Examples could include having community members/partners as coauthors on academic manuscripts and identifying alternate dissemination venues such as community meetings.

although end users collaborate in study implementation.<sup>29</sup> In contrast, CBPR is an all-encompassing research paradigm that defines purposeful engagement among researchers, intended end users, and other stakeholders throughout all stages of a research project.<sup>21</sup> This broader degree of engagement through CBPR fundamentally alters how technologies are designed, implemented, and translated into wider practice.

The CBPR approach has seen some diffusion into health informatics research, particularly in research seeking to engage with diverse communities.<sup>23,30</sup> Informatics researchers have applied CBPR in 4 major research areas to date: (1) exploring technology practices in a specific community<sup>24,31–33</sup>; (2) developing context-sensitive technology interventions<sup>30,34–39</sup>; (3) using technology to understand community problems<sup>40,41</sup>; and (4) studying the CBPR approach itself as applied to informatics.<sup>42–45</sup> There has been limited guidance, however, on appropriate approaches to apply CBPR principles specifically to informatics and on understanding lessons learned from past CBPR projects.<sup>35,40,46</sup> To address this gap, we present a comparative case study of 5 health informatics research projects that applied CBPR approaches, with the goal of extending existing CBPR frameworks to address issues specific to health informatics research.

## METHODS

Our research draws on experiences applying CBPR to 5 case studies (box 2). The case studies are geographically diverse, have a wide variety of academic and community partners, and involve different researchers. Contextual factors and research methods varied across

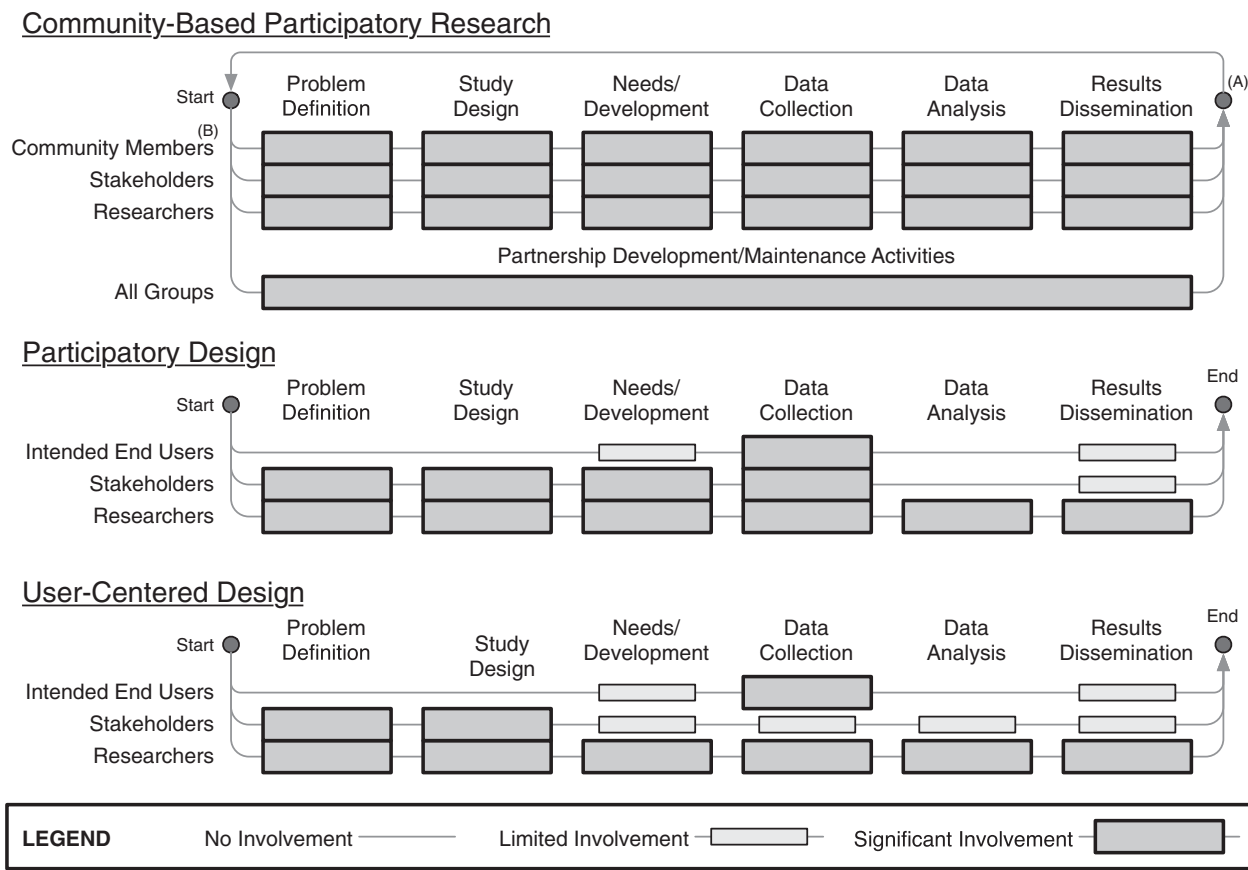
the studies, but all of the studies shared a common starting point: integration of CBPR approaches into a health informatics research project.

Over a series of meetings and electronic communications from October 2014 through February 2015, we collaboratively analyzed the implementation of CBPR principles and processes across the 5 cases.<sup>47–49</sup> Our cross-case analysis<sup>47</sup> sought to elicit common experiences across the projects and to develop extended principles for effective application of CBPR in this domain. Four of the authors (KMU, KAS, SB, TCV) presented a preliminary discussion of these common CBPR experiences in a panel at the Workshop on Interactive Systems in Healthcare Symposium in November 2014. After the symposium, we expanded the analysis group with 3 additional researchers (CLS, TRC, CS), including a community member who was an active collaborator on 1 of the case studies (TRC). The group of authors included researchers with significant expertise in the collection and analysis of qualitative data.

Because the 5 cases varied significantly in study procedures and metrics and quantitative comparisons were not feasible, the group of authors approached the collection and analysis of data for this manuscript as we would approach a qualitative research study. In initial group meetings, the full group of coauthors collectively identified important data elements needed to understand how each study implemented CBPR. These data elements were grouped into 1 table focused on study design and implementation logistics (table 1) and a second table focused on viewing the study through the lens of Israel’s CBPR Principles<sup>26</sup> (table 2). These 2 tables served as data collection

Figure 1: Comparison of sociotechnical approaches to technology design.

(A) Iteration occurs during the course of research projects using all 3 approaches. However, CBPR is the only approach of the 3 that includes iterative work across multiple projects, including continued partnership building and maintenance activities. (B) The Community Members group in CBPR projects includes intended end users for technology products, but not all individuals in the Community Members group may be intended end users.



instruments for the cross-case comparison and provided a standardized basis for qualitative comparisons.

A researcher involved with a specific case (TRC for Project HOPE—HIV/STD Outreach, Prevention & Education; TCV for Positive Youth; CLS for HealthBridge; SB for WICER—Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research; KMU for Middle Tennessee Sickle Cell) filled in content for table 1 and for table 2 to describe how the research project implemented CBPR while mapping the case to Israel’s CBPR Principles. The same researcher also contributed information regarding success factors and challenges/barriers encountered by the individual case, with additional material contributed from TCV for Project HOPE and from KAS for HealthBridge. Materials that the data collection drew on included publications and abstracts related to individual cases,<sup>31,32,35,53–60,62–68</sup> nonacademic communication media employed by some of the projects (eg, websites, social media accounts),<sup>50–52,61</sup> and discussion focused on both published and unpublished study information with researchers who were principal investigators or key study personnel for each case. The approach to data collection assisted the group with gathering information about study mechanics beyond material typically included in publications of

study results, enabling the group to have a deeper understanding of both the *what* and the *how* of CBPR research in health informatics.

All coauthors then reviewed and discussed all contributed information and examined the data for patterns across cases. During group discussions held over voice/video conference and via email, the group of authors probed deeply on all content to understand the meaning behind the information and the perspective of the researcher who contributed the data. Meeting notes were recorded by 1 coauthor (KMU) and provided to the full group of authors. The robust group discussion process sought to ensure contributed data were an accurate representation of study information, and it allowed coauthors to suggest and challenge individual interpretations of contributed data. During the discussion process, all coauthors worked collaboratively to identify common themes and patterns across cases as well as differences among the cases. Using the experiences of each case individually and all cases collectively, all coauthors collaboratively worked to examine gaps between commonly applied CBPR principles and the specific issues raised in CBPR projects in health informatics. After discussion of the common patterns of cases, 1 author (TCV) drafted the implementation checklist, which was later reviewed and discussed by all of the manuscript authors. In the final step of the analysis process, 1 researcher (KMU) standardized

## Box 2: Summaries of the 5 case studies

**The HIV/STD Outreach, Prevention & Education (HOPE) Project (Flint and Saginaw, Michigan).** The HOPE intervention focused on psychosocial factors related to communication with sex partners and other healthy sex behaviors to prevent sexually transmitted infections. The project was a quasi-experimental intervention study in which over 500 African American young adults (aged 18–24 years) in both Genesee and Saginaw counties in Michigan received a face-to-face intervention, HOPE Parties. Participants in Genesee County also received a social media intervention (HOPE Online) integrated into the intervention. Researchers sought to compare whether participants who received the HOPE Party and HOPE Online experienced a greater intervention effect or sustained this effect longer.

**Positive Youth Project (Ontario, Canada).** The Positive Youth Project took place in 2 phases. Phase 1 involved a needs assessment through qualitative interviews with 34 HIV-positive youth and young adults aged 12–24 years. HIV-positive youth were trained as researchers and played an active role in data analysis. Results were disseminated through scholarly and community-based venues. Phase 2 involved the creation of a youth-friendly website on HIV/AIDS treatment, including 3 serious games and an evaluation with youth via qualitative interviews.

**Project Health Bridge (Denver, Colorado).** Health Bridge is an on-going project exploring technology use to promote healthy lifestyles in a racially diverse, low socioeconomic status community. Over a 5-year time frame, researchers built a relationship and engaged in collaborative research with the Bridge Project, a community program to support people living in public housing projects. The team conducted research to understand community needs, which informed the iterative development of a mobile application to promote healthy snacking. The team then evaluated the application with 20 community members in a comparative field trial. A series of community dinners were held to share results with participants and other community members.

**Washington Heights and Inwood Informatics Infrastructure for Comparative Effectiveness Research, New York, New York (WICER).** The overall goals of the WICER project were to understand and improve the health of the Washington Heights Inwood community and to establish an informatics infrastructure for comparative effectiveness research. CBPR principles were used to develop and implement a survey of almost 6000 primarily Latino community members. Subsequently, the team designed a set of infographics for the self-reported health behaviors and outcomes, as well as physical measurements. The infographics were refined through participatory design sessions (2 in English, 18 in Spanish) as a prerequisite for returning data to study participants of varying levels of health literacy. The tailored infographics along with comparators were produced using the Electronic Tailored Infographics for Community Engagement, Education, and Empowerment (EnTICE<sup>3</sup>) system for distribution via a variety of formats as a data-driven community engagement strategy.

**Middle Tennessee Sickle Cell Project (Nashville, Tennessee).** The Vanderbilt-Meharry-Matthew Walker Center of Excellence in Sickle Cell Disease project is an ongoing collaborative effort between academic medical centers, community health centers, and community organizations to implement a medical home model for children and adults with sickle cell disease. Initial project phases did not include health informatics components; a CBPR-oriented health informatics needs assessment was later added to the project when informatics resources became available. Planned activities specific to the health informatics project included participatory design workshops with stakeholder groups. Research related to this project is ongoing.

the language across cases for purposes of manuscript readability, a process that was then discussed, refined, and approved by all coauthors.

Study procedures for each of the 5 cases individually followed the appropriate ethical oversight process (eg, Institutional Review Board, community organization research approval) required by the location and context where the research took place. The methods followed by the cross-case comparison itself did not involve human subjects, and thus were exempt from Institutional Review Board (IRB) approval.

### Case Overviews

High-level summaries of each of the 5 case studies are provided in [box 2](#). Additional specific details regarding each case study, including research goals, theoretical frameworks, funding models, and other study details are shown in [table 1](#). Results from 4 of the 5 case studies were previously published. Details of study methods and outcomes are provided in articles referenced by specific cases in [table 1](#).

## RESULTS

Despite the diversity of the 5 case studies and underlying research designs, the cross-case comparison identified common lessons and factors. Common elements related to benefits of applying CBPR, challenges encountered in the course of a project, and additional CBPR principles specific to health informatics research.

### Mapping cases to CBPR principles

The degree that each case translated individual CBPR principles defined by Israel<sup>26</sup> into research practice varied ([table 2](#)). Each case clearly identified the community with which they were working, although the unit of group identity was often a multilayered construct comprising several elements (eg, geographic area, age group, race/ethnicity, chronic disease, shared behaviors). Each case built on existing strengths within the community and relied on existing community resources, including relationships, physical space, knowledge about living with a specific chronic disease, and technical skills. In some cases, community partners were involved from identification of research questions through results dissemination while in other cases community partner involvement was more limited. Research results were used both for academic purposes (eg, publications, grant submissions) and to benefit the community directly through technology-based interventions, delivery of research results back to the community in context-appropriate modes, and events/activities designed to benefit the community. Across all cases, the research and collaboration activities took an iterative approach composed of cycles, with output from initial phases providing guidance and input to later research phases.

The concepts of “co-learning” and “empowerment” held different meanings for each case. Learning opportunities for community members included the following: (1) learning about research processes (eg, training a community member to be a research assistant, hiring

Table 1: Overview of case studies

Case Study (location)	Research Goal	Theoretical Framework(s)	Funding Model	Academic Partner(s) (Role)	Community Partner(s) (Role)	Research Methods Used	Collaboration Building Approaches	Research Outputs
The HOPE Project (Flint and Saginaw, Michigan)	Test the effects of integrating technology into an evidence-based, face-to-face prevention program for STIs among young adults aged 18–24 years (HOPE parties)	Theory of Planned Behavior; Diffusion of Innovation Theory; Trust-Centered Design Theory	Grant funding (CDC, NLM)	University of Michigan School of Public Health (Co-Pi) and School of Information (Co-I) (study design, data management, data analysis, dissemination)	YOUR Center (Co-Pi) (study design, recruitment, implementation, dissemination) Genesee County Health Department (recruitment) Saginaw County Health Department (recruitment, intervention implementation)	Intervention study with quasi-experimental design; Focus groups	Meetings (monthly); community members involved in intervention design; community members as coauthors and co-presenters in dissemination activities	Website <sup>60</sup> , Social media accounts <sup>51,52</sup> , Manuscripts <sup>52,53</sup> , Posters <sup>54</sup> , Presentations <sup>55</sup>
Positive Youth Project (Ontario, Canada)	Understand HIV-positive youth's experiences with HIV treatment and existing support services; Inform design of youth-friendly, interactive HIV treatment information resources	Grounded Theory	Grant funding (Ontario HIV Treatment Network; Canadian Foundation for AIDS Research)	University of Toronto (Pi) and Hospital for Sick Children (funding procurement and management; study design; partner training; data collection; data analysis; dissemination leadership)	Positive Youth Outreach (research framing; study design input; recruitment; data analysis; results dissemination) Canadian AIDS Treatment Information Exchange (literature review; study design input; website development; data analysis; results dissemination)	Qualitative interviews; interview-based technology evaluation	Planning meetings before funding proposal; strategic partnership planning; research skills training for community members; collaborative data analysis	Website with serious games; Youth-designed results zine; Conference for HIV-positive youth; Manuscripts <sup>46–58</sup>
Project Health Bridge (Denver, Colorado)	Identify opportunities for using technology to improve the health of community members; collaborative design and development of technology to address healthy eating challenges	User-centered Design; Social-Cognitive Theory	Grant funding (NSF)	University of Colorado Boulder, Department of Computer Science (technology research; technology development)	The Bridge Project (research framing, study design guidance; recruitment; community meeting space)	Multimedia elicitation interviews; technology needs assessment; Participatory design workshops; User studies	Research team mentoring for community youth; introductory meetings with community members; study planning meetings with program staff	Manuscripts <sup>31,35,59,60</sup> , Technology application (Snack Buddy for Android) <sup>61</sup>
WICER (Washington Heights and Inwood, New York, NY)	Gather data to understand community needs and present them back to community members in a manner that is comprehensible and actionable	Information visualization; User-centered Design; Health Belief Model; Sense making	Grant funding (AHRQ)	Columbia University, School of Nursing and Department of Biomedical Informatics (funding procurement and management; study design; data collection; data analysis; infographic and technology development; dissemination leadership)	Multiple Community Partners of the Columbia Community Partnership for Health	Focus groups; Community survey; Participatory design workshops for infographics	Communication strategies; appropriate financial compensation	Manuscripts <sup>62–65</sup> , Infographic designs, <sup>64</sup> , Style guide <sup>65</sup> , Technology application for infographic development (EntICE) <sup>63,66</sup>
Middle Tennessee Sickle Cell Project, (Nashville, Tennessee)	Identification of gaps between needs and existing health information technology features; design of process and technology solutions to address gaps	Workflow Elements Framework; Information Ecology Framework; Participatory Design; Grounded Theory	Grant funding for informatics-specific activities (NLM)	Vanderbilt University Medical School (technology research, clinical care); Meharry Medical College (clinical care)	Matthew Walker, Comprehensive Health Center (medical home development, clinical space, community meeting space); Sickle Cell Foundation of Middle Tennessee (health/wellness guidance)	Ethnographic approach to technology needs assessment; participatory design workshops for technology design (planned)	Community activities (back-to-school celebration, zoo day); meetings	Posters <sup>67,68</sup>

Abbreviations: HOPE, HIV/STD Outreach, Prevention & Education; STI, sexually transmitted infection; CDC, Centers for Disease Control and Prevention; NLM, National Library of Medicine; HIV, human immunodeficiency virus; NSF, National Science Foundation; WICER, Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research; AHRQ, Agency for Healthcare Research and Quality; EntICE, Electronic Tailored Infographics for Community Engagement, Education, and Empowerment.

RESEARCH AND APPLICATIONS

Table 2: Mapping the 5 case studies to CBPR principles

Principle	The HOPE Project	Positive Youth Project	Project Health Bridge	WICER	Middle Tennessee Sickle Cell Project
Community as a unit of identity	Geographic (2 counties); Race/ethnicity (African-American); Age group (18–24 years); Shared barriers to healthy behavior	Chronic disease (HIV-positive); Age group (youth); Sexual orientation (lesbian/gay/bisexual); Behavior (injection drug user)	Geographic (neighborhood); housing environment (public housing); Affiliation (community development project participant); Shared barriers to healthy behavior	Geographic (neighborhood); Primarily Spanish-speaking immigrants from the Dominican Republic	Geographic (region); Chronic disease (sickle cell disease)
Strengths and resources within the community	Community partner had long-term involvement and leadership role with the community. Incorporated ability of community members to recruit partners and participants and to deliver intervention. Community members leveraged their own social networks. Staff members from a community partner contributed information technology skills to the project.	Incorporated knowledge and skills from HIV-positive youth into project, including alternate results dissemination strategies. Community partner provided space for meetings. Community partners and members leveraged social networks to organize HIV-positive youth conference. A community partner provided library services for literature searching, designed and wrote HIV treatment content for a youth-friendly website, and organized educational workshops.	Community partner assisted with identifying potential participants and provided meeting space in the community.	Bilingual community health workers used their social networks to recruit for large community survey and follow-on studies such as participatory design sessions. Some data collection took advantage of the Columbia Community Partnership for Health physical space.	Informatics project centered in an existing collaboration between academic-community partners. Community partner had lengthy history and physical space (clinical, meeting) in the community.
Collaborative partnerships in all research phases	Community members helped define all aspects of the project, from inception to implementation and evaluation. Academic partner assisted community partner with technology capacity building. Academic and community partners coauthored all manuscripts, abstracts, and posters resulting from project.	All partners developed project research questions. Proposals reviewed by all partners prior to submission. Collaborative data analysis. Positive youth served as coauthors on all manuscripts. Nonprofit partner led preparation of one manuscript. Youth participated in presenting at scholarly and community-based conferences.	Community partner and community members helped define project focus on healthy eating as opposed to a number of other health behaviors under consideration. Community involvement continued through prototype design, study design, recruitment, intervention design, and results dissemination.	Community representatives suggested items for survey design through focus groups (eg, stress was added as a measure). Survey participants participated in iterative participatory design sessions. Community-based organizations and health care system input to research process and dissemination.	Limited, as informatics components were added later in overall academic-community collaboration.
Integrate research results for mutual benefit	Over 500 community members participated in HOPE parties. Nonprofit partner applied findings to initiative focused on additional community health issue.	Results informed web-based intervention for youth.	Research led directly to development of technology that aimed to address challenges identified by the community around healthy eating.	Participatory research informed the design of informatics for returning survey data to the community in a manner suitable for varied levels of health literacy.	Developed forms integrated into the electronic health record for at-home, self-care activities and communication with schools.
Cyclical and iterative process	Participants in 1 phase of project were incorporated into advisory board for second phase. Knowledge from early social media contests informed development of later contests.	Assessment of partnership undertaken throughout project by doctoral student. Assessment results used as a basis for learning in next phase of project.	Returned to community members at each project stage for feedback and guidance on revision and future direction. Community partners reflected with researchers on recruitment practices and introduced researchers to other Bridge Project neighborhood communities to expand recruitment.	Community representatives suggested items for survey design through focus groups. Survey participants participated in iterative participatory design sessions.	Iterative cycles of data collection and analysis during needs assessment. Plans to build on prior stages in later research phases.
Co-learning and empowerment, with awareness of social inequalities	A Community Advisory Board helped with better understanding of benefits to participants. Explored what participants and team members learned about their own behaviors, beliefs, and their community through the research process.	Training of youth to serve as research assistants.	Community participants gained knowledge around their current behaviors and identified ways that they may be able to improve those behaviors.	Strategies included hiring bilingual community health workers from the neighborhood and providing research compensation considered of value to community (eg, \$25 vouchers for a local supermarket).	Providing research compensation considered of value to community for interview participation (eg, supermarket gift card). Included local high school student and undergraduate students in non-technical degree programs on informatics research team.
Incorporates positive and ecological perspectives	As participants described challenges with health issues, worked to consistently validate their concerns and to create nonjudgmental research spaces. Framed research instruments and research experiences in positive manner.	Research questions reflected the full range of youth experiences.	Based on participant input, targeted the family as the unit for the intervention. Sought to influence the home environment and to leverage family support. Validated participant concerns and created nonjudgmental research spaces.	Survey collected a broad array of social determinants of health as well as health behaviors and patient-reported outcomes (eg, PROMIS measures). The majority of data collection occurred in Spanish.	Viewed clinical activities as one component of overall health management. Sought to build nonjudgmental research spaces.
Disseminates knowledge to all partners	Participated in presentations highlighting research results for different audiences, including the community. Provided opportunities for community partners to participate in dissemination, including identifying venues that were of high priority to them.	Dissemination to HIV-positive youth through a zine and a positive youth conference. Dissemination to community service providers through skills-building workshops offered at national and regional conferences. Dissemination to scholarly audiences through conference presentations, posters, and published manuscripts.	Researchers presented highlights of research findings to the community. Presented data collected during field trial to community and used the data in collaborative analysis and sense-making process.	Return of survey data to individuals as informatics for cues to action for health behavior change, in aggregate to Community Health Board and other community-based organizations for program planning, and to health care system for community needs assessment.	Forms developed were for use by individuals/families in self-management activities. Research still in progress; further dissemination activities possible.

Abbreviations: CBPR, community-based participatory research; HOPE, HIV/STD Outreach, Prevention & Education; WICER, Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research; HIV, human immunodeficiency virus; PROMIS, Patient Reported Outcomes Measurement Information System.

community-based health workers); (2) learning about health issues (eg, education about the impact of behavioral components on health, learning about the community); and (3) learning about technology. Learning opportunities for researchers also took a number of different forms. For example, in the Sickle Cell Disease case, a researcher with limited prior CBPR experience (KMU) learned about meaningful approaches to engaging communities and patients through working with an established academic-community partnership. CBPR-based research also provided opportunities for researchers in the 5 cases to learn about community practices and priorities, develop empathy for the life experiences of community members, and understand how individuals from different backgrounds interact with and experience technology. Co-learning opportunities influenced the trajectories and perspectives of both community members and researchers in the 5 included cases.

Social inequalities between researchers and community members were addressed through strategies such as research participation compensation, culturally sensitive data collection, and exploring the behaviors and beliefs of researchers and stakeholders. Positive perspectives on health were incorporated by collecting data regarding a wide range of health behaviors, as opposed to focusing exclusively on illness. Strategies for incorporating ecological perspectives were implemented through approaches such as focusing on the families rather than the individuals, focusing on trust as a cultural factor incorporated into design, and collecting data on social determinants of health. Dissemination of knowledge to all partners required development of strategies and dissemination routes beyond standard peer-reviewed literature and academic conferences. In each case, research teams sought to translate research results to participants and to the broader community. Projects included components such as a Community Health Board and presentations to CBOs to assist with dissemination. Alternate community-appropriate dissemination venues were used in several cases, such as a youth-friendly arts-based photocopied publication (zine), infographics of research findings designed with community input, websites, and social media accounts.

#### Benefits of applying CBPR to health informatics research

A clear theme in the cross-case analysis was that CBPR assists research projects to accrue benefits that would not have emerged through researcher-driven paradigms (table 3). We identified 7 categories of benefits: more relevant research, wider impact, better fit between interventions and target beneficiaries, more effective recruitment and retention of diverse populations, improved internal validity, more rapid translation of research into action, and development of people. Examples of each of these categories are provided in table 3, with some of the examples discussed in more detail in the following text.

Use of CBPR approaches resulted in more relevant research as projects sought to incorporate research questions of interest to the community rather than investigating areas mainly of interest to researchers. In some cases, this led to an expansion of the research focus and in others, a complete change of focus. For example, in the Bridge Project, needs and priorities of community members shifted the project's focus from personal health records to technology to support healthy eating.

A community focus, in turn, contributed to the research described in our cases, having a wider impact because of greater community interest in the research topics beyond individuals actively participating in the studies. For example, knowledge gained through research project participation led participants in Health Bridge studies to promote healthier eating behaviors among their families, friends, and

coworkers. In addition, because the Health Bridge informatics project was able to provide funding for a portion of a dietitian's salary, the community organization was able to recruit and hire a qualified dietitian, extending the impact of the informatics project to a wider community scale. The relevance of research topics also contributed to a better fit between interventions and target beneficiaries, as study participants helped to define potential interventions that were more meaningful in their lives, which often diverged from researcher perspectives on topics.

Unsurprisingly, community member involvement in defining and designing the research assisted with more effective recruitment and retention of diverse populations through use of context-aware recruitment strategies and linkage with CBOs who had closer relationships with research participants. Approaches such as snowball sampling, where research participants helped identify others who might be interested in research participation, proved especially valuable as a recruitment strategy for some cases. Active community member engagement in research design also led to improved internal validity, related to instrumentation and data collection design and data analysis. In some cases, the CBPR approach led to more rapid translation of research into action, with study results being directly integrated into changes in community outreach efforts and into knowledge shared with health care providers rather than only into standard academic research channels.

Beyond all of the direct benefits of applying CBPR to specific research studies, several of the cases yielded benefits related to the development of people, both within academic settings and in the community. Community members who assumed leadership roles in community aspects of research projects learned new skills and grew as leaders within their own social networks. Other community members, including 2 paper authors (TCV, TRC), chose to pursue further educational opportunities after their work with a CBPR research project or obtained jobs with CBOs. Human capital development through CBPR is also particularly indicative of the bidirectional benefits of a CBPR approach.

#### Challenges of applying CBPR to health informatics research

We identified common challenges that emerged across the 5 cases (table 4). Applying CBPR in practice required strong academic-community partnerships, and developing these relationships required time, energy, trust, and resources on all sides. Building rapport and trust between researchers, community members, and CBOs demanded skills and knowledge that are not commonly taught or developed in academic research settings. In particular, past negative community experiences in interacting with researchers led to difficulty in building trust.

Mismatches between academic and community settings contributed significantly to the challenge of initial development and ongoing maintenance of academic-community relationships. These mismatches occurred on multiple axes: organizational structures, hierarchical relationships, work cycles and timing needs, communication modalities and styles, and culture. For example, the periodic nature of academic work conflicted with the more constant flow of CBO work, resulting in differing expectations regarding speed and timing of project activities. In the 5 cases, research teams pursued a variety of strategies to assist with overcoming relationship and communication-related barriers, such as developing guides about common terminology within each group, defining rules and requirements of engagement, and discussing how different participating organizations worked.

Table 3: Benefits of applying a CBPR approach to health informatics research

Benefit	Examples (Case)
More relevant research	<ul style="list-style-type: none"> <li>Research questions expanded to reflect youths' interests in accessibility issues for a range of services, not just services related to HIV treatment as initially planned (Positive Youth Project).</li> <li>Community partner and youth focus group participants helped identify the importance of addressing issues of trust and capacity when delivering technology-focused intervention (HOPE Project).</li> <li>Assessment of top health concerns revealed needs beyond the project's focus of cardiovascular disease; an interdisciplinary Sexual Health Working Group was formed and collaboration was established with a Cancer Center to address high level of cancer worries (WICER).</li> </ul>
Wider research impact	<ul style="list-style-type: none"> <li>Community members who were participating in the research used knowledge and motivation from study participation to promote healthy eating behavior among friends and family members (Health Bridge).</li> <li>Health care providers in emergency departments and hospitals used forms developed for patient health self-management (Pain Action Plans) to understand patient pain management activities (Middle Tennessee Sickle Cell Project).</li> <li>Several HOPE party hosts proactively disseminated pro-safer sex messages to their friends as part of social media contests and beyond (HOPE Project).</li> <li>A large proportion of the survey cohort (88%) agreed to be contacted regarding future research studies; data sets are available to researchers beyond the study team; infographics and the style guide and software for creating the infographics are available to others (WICER).</li> </ul>
Better fit between interventions and target beneficiaries	<ul style="list-style-type: none"> <li>Specific effort was devoted to developing instruments and measures that fit with the needs of participants, and that integrated well with the HOPE party settings (HOPE Project).</li> <li>Research participants rejected intervention concepts that the research team developed before prototyping with the community. For example, researchers included information about food costs in the app because food cost was a barrier in needs assessments. However, participants indicated this information distracted from the focus on health when they saw it in app form (Health Bridge).</li> <li>Infographic designs were refined through extensive input, resulting in rejection of simple designs that lacked sufficient context to facilitate sensemaking (WICER).</li> </ul>
More effective recruitment and retention of diverse populations	<ul style="list-style-type: none"> <li>The project successfully recruited more than 500 African Americans, a demographic that is underrepresented in health informatics research (HOPE Project).</li> <li>Community organization staff's awareness about what was going on in community members' lives assisted with recruitment. For example, when we asked the program staff about whether a participant from an early research study could participate in the next phase of our research, they identified that the individual had recently had a death in the family and would have a difficult time participating. They identified another community member with a similar background who could more easily participate (Health Bridge).</li> <li>We used snowball sampling, whereby participants could identify other community members who might be interested in being involved (Health Bridge).</li> <li>The project specifically targeted a chronic illness that predominantly affects African Americans (Middle Tennessee Sickle Cell Project).</li> <li>Bilingual community health workers, snowball sampling, and incentives meaningful to the community facilitated recruitment of almost 6000 Latinos of whom &gt; 80% were immigrants (WICER).</li> </ul>
Improved internal validity	<ul style="list-style-type: none"> <li>Youth research assistants' active, experience-engaged reading of interview transcripts assisted with refining unique themes about youth perceptions of HIV treatment (Positive Youth Project).</li> <li>Iterative refinement of infographic designs resulted in designs perceived to be acceptable and actionable (WICER).</li> </ul>
More rapid translation of research into action	<ul style="list-style-type: none"> <li>The initial phase of the project focused only on needs assessment, but rapidly shifted to incorporate development of technology products to address patient needs identified through the research. Development and use of these products led to additional research opportunities (Middle Tennessee Sickle Cell Project).</li> <li>Findings were shared with the local government, clinical institutions (for community needs assessment), and CBOs prior to publication to inform actions by these groups (WICER).</li> </ul>
Development of people	<ul style="list-style-type: none"> <li>Several community-based partners chose to pursue further schooling, and/or later obtained employment in CBOs (Positive Youth Project).</li> <li>HOPE party hosts grew as leaders within their social networks. Project included training of youth as peer health information mentors so as to supplement the impact of the HOPE parties. Two attended the 2010 APHA conference to present. Project staff and volunteers obtained jobs in part because of experience gained in the project (HOPE Project).</li> <li>The informatics team included a local high school student and several undergraduate students with nontechnical majors. Working with the project led to development, educational, and employment opportunities, including the high school student presenting an additional informatics project at the AMIA conference (Middle Tennessee Sickle Cell Project).</li> <li>For 2 years, the Health Bridge team primarily had 3 male graduate students conducting the research. Since the community largely consisted of single mothers and their children, the PI (a woman) met with community members to check in on how the research collaboration was going. The mothers commented that the male graduate student researchers were excellent, that it was the first time in their children's lives that a man showed up when he said he would and helped them with what he promised to do. Likewise, the PI noticed that the graduate student researchers would reprioritize their own work based on their mentoring relationship. Indeed, sometimes research meetings got cancelled because a child in the community needed assistance with homework or a science fair project (Health Bridge).</li> <li>Several community health workers transitioned to higher-level research positions with the academic partner (WICER).</li> </ul>

Abbreviations: CBPR, Community-based participatory research; HIV, human immunodeficiency virus; HOPE, HIV/STD Outreach, Prevention & Education; WICER, Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research; CBOs, community-based organizations; APHA, American Public Health Association; PI, principal investigator; AMIA, American Medical Informatics Association.



Table 4: Challenges of incorporating CBPR approaches in health informatics and related lessons learned

Challenge encountered	Lesson learned
Time and effort involved in building relationships, rapport, and trust between researchers, community members, and community organizations	<ul style="list-style-type: none"> <li>• Many components are involved in building an academic-community partnership, including developing a common vernacular and defining collaboration processes. Plan appropriate amounts of time for partnership-building activities.</li> <li>• Academic and community partners need to equitably participate in meetings and partnership building activities.</li> <li>• Expectations about roles and responsibilities in the partnership need to be clearly communicated and understood by everyone participating in the partnership.</li> </ul>
Mismatches between academic and community settings: organizational structures, hierarchical relationships, work cycles and timing needs, communication modalities and styles, and culture	<ul style="list-style-type: none"> <li>• Partnerships should consider developing documents to provide guidance about organization-specific terminology and rules of engagement. These written documents can help avoid misunderstandings and conflict.</li> <li>• Organizations have many formal and informal rules and norms. Openly and honestly discussing these rules and norms can help promote transparency and clarity in understanding different partner organizations.</li> </ul>
Differences between academic and community partner visions of how research should be implemented	<ul style="list-style-type: none"> <li>• Both academic and community partners need to respect that different groups may have different ideas about research and dissemination. Identifying and understanding the basis of different ideas is important to moving a project forward.</li> <li>• The study design, including recruitment strategies, needs to be articulated clearly and in writing.</li> <li>• When possible, partnerships should consider negotiating flexibility in research plans to allow responses to emergent needs or requests.</li> </ul>
Identification and recruitment of appropriate CBO and community member partners	<ul style="list-style-type: none"> <li>• Academic partners should place value on the local knowledge that community partners contribute to the effort. Community partners can use this local knowledge to help identify appropriate research participants.</li> <li>• Research plans should acknowledge that not all community partners or community members are interested in every facet of the research. Iterative opportunities for training and involvement should be provided throughout all phases of the research.</li> </ul>
Shared control of research by academic and community partners	<ul style="list-style-type: none"> <li>• Partnerships should develop written governance policies that cover roles and responsibilities.</li> <li>• Both academic and community partners must accept that control of research is shared between partners.</li> <li>• Partnership plans should identify clear times for renegotiation of roles and responsibilities within the collaboration process.</li> </ul>
Requirement to plan for long-term sustainability	<ul style="list-style-type: none"> <li>• Both partnership and technology sustainability needs to be considered throughout all stages of a project, from problem definition to results dissemination.</li> <li>• Approaches such as identifying and using technology platforms and community activities already in place can assist with long-term sustainability.</li> <li>• Discussions about project changes (ie, grants ending, research assistants moving to other opportunities) should occur on a routine basis with as much notice as possible for all partners.</li> <li>• Expectations for continued use of technology after a specific project ends should be discussed in advance.</li> </ul>
Impact of shifting contextual factors on longitudinal research	<ul style="list-style-type: none"> <li>• Academic partners need to understand that contextual changes may occur in the community, and these changes may impact research directions.</li> <li>• Community partners need to understand that contextual factors may occur in the academic organization (eg, change in HIT security policy), and these changes may impact research progress or direction.</li> </ul>
Identification of resources and capacity (including technology infrastructure) needed to enable nonprofit community organizations to participate as research partners	<ul style="list-style-type: none"> <li>• Funding for community partner involvement in research activities must be included in grant applications (ie, paying for a community member to assist with recruiting).</li> <li>• Grant applications should also budget for community partner technology infrastructure (ie, hardware/software, training/development on technology, wireless or cellular services).</li> <li>• When possible, academic partners should work with community partners to build technological skills.</li> </ul>
Variability in access to and experience with different types of technology	<ul style="list-style-type: none"> <li>• Technology probes can assist individuals unfamiliar with different technology types with understanding the functionality and potential of these technologies.</li> <li>• Providing devices and equipment for participants to use during the study may be necessary.</li> <li>• Coaches may be necessary to facilitate initial use of technology resources in community sites, including basics such as setting up an email account that are prerequisite to use of many technologies.</li> </ul>
Ownership and maintenance of technology-oriented products	<ul style="list-style-type: none"> <li>• Partners should negotiate plans for ownership of intellectual property as part of contracts or funding agreements.</li> <li>• Early in a partnership or project, partners need to discuss expectations of conditions under which project outputs can be shared outside of the project.</li> <li>• Plans for maintenance of project outputs such as websites or social media accounts should be considered and discussed to enable long-term sustainability of these products. These plans should include ensuring that the partner responsible for maintaining the products has sufficient resources to provide persistent access to technology-oriented projects beyond the life of the project.</li> </ul>

Abbreviations: CBPR, community-based participatory research; CBO, community-based organization; HIT, health information technology.

The fundamental differences in perspectives between researchers and community members occasionally led to differing visions of how research should be implemented. For example, in the HOPE project, the academic team wanted to focus on recruiting “high-risk” individuals from sexually transmitted infection clinics, but the CBO partner wanted to provide the intervention to any interested community members. Such experiences demonstrated the need to articulate the research design clearly and in writing to enable all partners to understand research plans. Concurrently, building flexibility into research plans proved important, allowing participating organizations to respond to emergent needs and urgent requests.

Identifying and recruiting appropriate CBO partners and community members with requisite technological skills and research

literacy can also prove challenging for health informatics projects. Assisting community partners with building capacity for research participation through funding and other development approaches was crucial to long-term collaboration success. For research teams, addressing student involvement in CBPR projects was also important. Researchers needed to balance providing educational opportunities with challenges related to student reliability and experience. In some cases, these challenges led to allocation of research funds to staff positions rather than student research assistants. In other cases, projects were able to identify mutually beneficial educational opportunities for students, such as Masters in Public Health students who collaborated on manuscripts with the HOPE project, and high school and undergraduate biomedical informatics interns who

assisted with data collection and tool development in the sickle cell project.

CBPR fundamentally challenged the researcher-led perspective on research activities, requiring that all parties accepted sharing the control of research among partners. Some of the case studies, including the HOPE Project, employed approaches such as setting clear boundaries and developing governance policies to address requirements of sharing control. Additionally, participation in CBPR projects required that both academic and community partners accepted loss of some control, which was not always easy or comfortable.

A major division encountered in the cases was the need to plan for long-term sustainability for both the partnership and the research outputs. Some trust-related issues encountered in the cases related to previous CBO encounters with researchers who collaborated on a project and then severed all contact after project funding was spent. To address sustainability concerns, research teams stayed engaged with CBOs over multiple project phases. For example, the Bridge Project has been ongoing for 5 years across multiple distinct project phases. To address technological sustainability, research teams in the cases pursued strategies such as using open-source technology and working with existing community programs and events. Shifting contextual factors also posed a significant challenge to long-term project sustainability in some cases. For example, the Bridge Project encountered dramatic changes in population demographic characteristics within the geographic region they were working with, affecting their longitudinal study design. Academic-community relationships developed over the course of several years can be impacted by changes outside the control of academic researchers.

Finally, the 5 case studies encountered a number of constraints and challenges specifically related to technology. For example, the informatics components of the sickle cell disease project were identified after the initial academic-community partnership was established. Because the informatics components were not fully integrated into the larger collaboration, the project faced challenges related to access and contradictory goals. In other cases, the CBO partners did not have existing technology infrastructure to support a health informatics project. Providing funding to support technological requirements of research participation proved important in several cases, indicating the need for research partners to work with community partners to build capacity. For example, the peer health information mentors project was initiated as a supplement to the HOPE intervention study to address technology capacity issues among the young adults who were the target of the intervention. In several of the cases, research teams specifically sought to engage with minority and low-income populations who had variable access to and experience with different technologies. Research teams pursued strategies such as providing technology probes to enable people to see, use, and develop a greater understanding of different technologies. In some cases, researchers also included funding in grant budgets to provide devices and equipment to participants for use during the study.

Ownership and maintenance of technology-oriented products were also an issue. Technology products and other materials developed through the 5 cases were typically built specifically as part of the research project, raising issues of ownership and maintenance of grant-funded yet proprietary outputs. Academic and community partners in the 5 cases contributed significant amounts of time and effort towards creating products and materials. Defining the conditions under which project outputs can be shared with others proved important for one of the cases, where a CBO requested appropriate compensation if materials based on their work were shared elsewhere. Maintenance of technology products was also an issue in the Positive

Youth Project. A nonprofit partner managed the youth-focused website and games for a period of time, but once HIV treatment science changed significantly and a complete content rewrite was required, the maintenance arrangement was no longer sustainable. In another example, electronic forms developed as part of the sickle cell disease project became out-of-date with preferences and practices of the clinical teams. Maintenance and ongoing support for the electronic forms was transitioned from the research team to a group responsible for ongoing clinical informatics operations. This type of ownership transition is not always feasible for products developed under proprietary software ownership models. Although none of the 5 case studies experimented with open access models of technology development, open access models could assist with long-term maintenance and sustainability if resources are available in the community to contribute to the effort.

### Extending CBPR principles for health informatics research

Across the 5 cases, we identified common CBPR implementation patterns specific to health informatics research. Based on these patterns, we developed a practice-based “Implementation Checklist for Community-Based Participatory Research Projects in Health Informatics” (supplementary appendix 1). Additionally, the importance of CBPR principles in a health informatics project indicated a need to re-order Israel and colleagues’ principles to emphasize specific aspects (box 3). For example, empowerment and sustainability are particularly important and challenging issues to address in CBPR-based informatics projects.

In addition, several novel principles specific to health informatics projects emerged from our analysis (box 3). First, CBOs may require technological capacity building, including both skills and equipment, to fully engage in informatics projects. There may be a need to train CBO employees on technology concepts and tools in addition to providing funding for hardware and software purchases. Moreover, training and technology provision may also be needed for intended informatics intervention users. Technical capacity building can have a significant, positive impact on CBO staff and volunteers. One notable result from both the Positive Youth and HOPE projects was the link between project involvement and career paths for CBO staff and volunteers. For example, 1 of the paper authors (TRC) obtained a directorship in the economic and workforce development department of a local community college after working with the HOPE Project. Based on the experiences of the 5 research projects reviewed in the cross-case comparison, technical capacity building in CBPR projects can change lives.

Second, the need to clearly define ownership and plan for the maintenance of technology-related project outputs is crucial for health informatics projects guided by CBPR approaches. For example, The HOPE Project collaborative makes sure that at least 1 academic and 1 community designee are approved through group consensus to be part of any new product, service, or data sharing activity. The WICER survey data are broadly available to stakeholders; the infographics, style guide, and system for creating the infographics are open source. The degree of involvement of community groups and individuals in technology development raises important questions about who owns source code and products. Addressing ownership throughout all project phases is important for building relationships, developing trust, and ensuring equitable research experiences for all groups.

Third, community-based informatics projects often integrate CBPR with UCD or PD approaches. This is illustrated through the use of 20 iterative PD groups to develop infographics in the WICER project.<sup>64</sup> The Health Bridge project also used PD and UCD methods within a

### Box 3: Revised and extended CBPR principles for health informatics research

**Principle 1:** Understanding the existing strengths and resources within the community. The community, which has 1 or more unifying aspects, brings resources to the table. These resources are valued for their unique contribution to the research process.

**Principle 2:** Empowering both academic and community partners through co-learning opportunities, with awareness of social inequalities. Decisions are made in an equitable manner, and activities are planned and implemented collaboratively. Opportunities are made for partners to learn about community needs, strengths, and existing social inequalities.

***Principle 3:** Assisting community-based organizations and community members with building technological and research capacity. The project develops hardware and software infrastructures, sustainable technology models, and technological skills. Community members have the opportunity to learn about research processes and methodologies.*

**Principle 4:** Building collaborative partnerships in all research phases. The community is not just included during data collection, but rather is included from problem definition through results dissemination. Resources are accorded to partnership building efforts.

***Principle 5:** Defining ownership of technology-related project outputs and planning for technology maintenance. Ensuring that all partners contribute to and agree with plans for technology ownership through all phases of research is important to building trust in partnerships and enabling equitable access to project outputs. Because information and technology needs evolve over time, projects also need to ensure that plans are in place for maintenance of technology products.*

**Principle 6:** Viewing research and partnership building as a cyclical and iterative process. Collaboration between researchers and the community is not a “one off” activity. Activities related to building and maintaining academic-community partnerships and refinement of research goals occur iteratively.

***Principle 7:** Integrating user-centered design or participatory design into CBPR projects. User-centered design and participatory design are complementary approaches to CBPR and integrate well into the iterative, participatory framework developed in CBPR projects.*

**Principle 8:** Integrating research results for mutual benefit. The research team builds new knowledge and incorporates the knowledge into action through iterative cycles.

**Principle 9:** Incorporating positive and ecological perspectives into research and technology design/deployment. Research designs incorporate perspectives focused on well-being and determinants of health. Technologies should be deployed within, and leverage, trusted social networks.

**Principle 10:** Disseminating knowledge to all partners through multimodal approaches that build technical capacity and provide opportunities for additional informatics research. Presenting knowledge through informatics-enabled approaches can lead to better understanding of research results and wider dissemination of results in the community.

*Note:* Italic text represents new principles based on the health informatics context; and Underlined text marks principles, or their explanations, that have been revised based on the case studies presented in this paper.

broader CBPR framework. Specifically, the project engaged UCD in iterative development of a community-focused, sociotechnical intervention, including user studies, prototyping workshops, and usability evaluations. UCD provided a structured approach for the design and development process that supplemented the CBPR framework. Other PD methods may be complementary to CBPR and deployed in unison to develop community and user-centered health interventions.

Fourth, informatics approaches enable multimodal results dissemination, contributing to community technical capacity building and providing opportunities for additional informatics research. For example, the WICER team explicitly built the Electronic Tailored Infographics for Community Engagement, Education, and Empowerment system<sup>66</sup> to return tailored infographics to research participants and CBOs. In the Positive Youth Project, approaches such as youth leadership in creation of a zine to disseminate study results built research literacy among positive youth on the research team.

## DISCUSSION

We provided insights into how a CBPR approach in health informatics research benefits underserved communities and researchers by mapping 5 cases to an established CBPR framework. Our analyses showed that CBPR principles can be effectively applied in health informatics research, and that this approach resulted in concrete benefits such as research goals and products that addressed the expressed priorities of their target communities. Furthermore, we detailed unique, systematic challenges associated with informatics-oriented CBPR projects; these

will be important for health informatics researchers to consider as they contemplate using CBPR principles in their own research. Our analyses suggested that CBPR principles may need to evolve to account for the realities of CBPR implementation in health informatics; thus, we extend the CBPR framework<sup>9</sup> with 4 added principles and a revision of others. Additional principles included the following: the need for technological capacity building for CBOs, the requirement to clearly define ownership and plan for maintenance of technology-related project outputs, the potential for integrating CBPR with UCD or PD approaches, and the capacity to enable multimodal results dissemination through informatics approaches. Changes to Israel's CBPR principles included reordering the principles to emphasize empowerment and sustainability. Also, we offer practical implementation guidelines in the form of a checklist (supplementary appendix 1).

Researchers and community members must actively engage in building trust-centered relationships to successfully implement CBPR. The level and nature of these relationships is not typical of other research approaches, but is a critical CBPR component. Our cross-case analysis outlined the specific context necessary for building and sustaining these relationships and strategies to recognize and address communication barriers that may impact study design and project implementation. Our findings also reinforce the value of considering each contact with the community as an opportunity for engagement, especially during project planning. Including stakeholders in defining research aims, methodologies, and study designs establishes a commitment to engagement that can permeate subsequent project

decisions, which is important in sustaining engagement with underserved communities.

Technological capacity building was one of the novel CBPR principles emerging from our analyses. While the CBPR literature addresses research capacity development among community members, we further emphasize the importance of technological training and the enhancement of technology access and infrastructure among both CBOs and technology users. This emphasis aligns with the broader literature on capacity building, in which “capacity” is defined as the ability to address a problem based upon the availability of resources such as knowledge or skills, social relationships/networks, and infrastructure.<sup>69</sup> Moreover, we identified instances where working on CBPR projects expanded career opportunities available to community members. In a sense, CBPR itself becomes an intervention, because building technical capacity can affect social determinants of health for stakeholders and technology users. As such, CBPR projects in informatics can be conceptualized in part as career and technical education for marginalized communities. One implication is that the CBPR process is worthy of dedicated funding, and that suitable funding sources might reframe broader impacts to include workforce training and college outreach opportunities. Groups such as the Patient-Centered Outcomes Research Institute (PCORI) are beginning to acknowledge the importance of funding CBPR-related engagement strategies that include stakeholder development and academic-community partnership building through funding opportunities, including the Eugene Washington PCORI Engagement Awards and Pipeline to Proposal Awards. One opportunity that the work of this cross-case comparison has highlighted is the potential need to establish a community of practice or other research consortium focused on CBPR within health informatics. This type of consortium, with appropriate funding, could assist with identification and dissemination of CBPR best practices within the informatics field and promote use of consistent, validated metrics such as measures of engagement and effectiveness across CBPR projects.

Our cross-case analysis specifically pointed to the importance of ownership of research products. Research indicates that IRBs may not be experienced with considering implications of nontraditional approaches such as CBPR, particularly with respect to data ownership.<sup>70–72</sup> Empowerment through community engagement extends to joint ownership of data, or at minimum, to upfront negotiation on procedures for the collection and use of data.<sup>73</sup> Researchers must consider data ownership guidelines, and anticipate that their existing IRB approval process may not adequately address data ownership and use at the level necessary for CBPR work. Given the intricacies of intellectual property issues in the technology field, we recommend that CBPR research teams directly address this issue prior to beginning data collection or technology development.

Community-based participatory research approaches emphasize dissemination of knowledge to all research partners. However, a distinct characteristic of CBPR in health informatics is the technological capacity for multimodal dissemination to various stakeholders, including research partners and technology users, other CBOs, community members, and policy makers. Our research identified several modes for disseminating research findings such as tailored infographics and zines, building on previous research using technology to disseminate findings from CBPR studies in novel ways.<sup>24,30,44,74</sup>

### Limitations

The 5 cases were not selected based on their ability to represent all aspects of CBPR approaches in health informatics research. Rather, case selection was driven by the collaboration experience in

preparation and presentation of a panel on CBPR at the Workshop on Interactive Systems in Healthcare Symposium in November 2014. The 5 cases were diverse in contexts and methods and, based on our literature review, represent diversity in how CBPR is currently applied to health informatics research. Future evaluations can build upon this contribution to health informatics research by further describing how applying CBPR principles can help address persistent issues concerning technology adoption and use. In addition, data for the cross-case comparison were collected and analyzed by researchers who were involved in the 5 research studies, raising questions about objectivity. The rigorous discussion and analysis process described in the methods sought to address these potential concerns by allowing researchers from different projects in-depth access and insight into research studies designed and conducted by others. All of the authors engaged in extensive and robust discussion around all parts of data collection and data analysis for the cross-case comparison. The process provided researchers with alternate perspectives on research design and study implementation, similar to the process of co-learning that is a central principle of CBPR research. The aspect of personal involvement in the research studies also was in some ways an asset in data collection and analysis, providing greater depth of information regarding the inner workings of research studies, a type of knowledge that is often abstracted or limited in publications.

### CONCLUSION

Through a cross-case analysis of 5 case studies, we examined how CBPR principles can be applied to, and extended for, health informatics research. We described specific benefits, furthering our understanding of how using CBPR principles can result in improved outcomes and increased trust. We illustrated how health informatics research projects can more effectively translate research into practice, as shown by tangible impacts to community partners. We also detailed challenges associated with the CBPR approach and strategies for addressing them. We encourage researchers to consider using a CBPR approach, particularly for research involving patient-facing technology and for outreach to traditionally underserved populations.

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## COMPETING INTERESTS

None.

## SUPPLEMENTARY MATERIAL

Supplementary material is available online at <http://jamia.oxfordjournals.org/>.

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