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Participatory Technology Development to Enhance Community Resilience

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Objective: To assess the feasibility of a novel, partnered technology development process to co-create mobile health applications (apps) addressing community health priorities, using psychoeducation of cognitive behavioral therapy (CBT) principles for enhancing resilience as an example.

Design: Stakeholder engagement, workgroups, pilot feasibility study using mixed methods during October 2013 through January 2016 over three phases: 1) defining the vision of the project and increasing technical capacity, 2) co-development and pilot testing of the app, and 3) planning for sustainability.

Setting: An academic-community partnership in South Los Angeles, California.

Participants: Eight stakeholders; 30 pilot participants from the community.

Main Outcome Measures: Qualitative analysis of audio-recordings of the app development process and stakeholder interviews, surveys of stakeholders' perception of the development process, app use data, and feedback from pilot participants.

Results: The participatory technology development process resulted in creation and pilot-testing of a resiliency-focused text messaging app. Of the 1,107 messages sent, 23 out of 30 (77%) app users responded to explore interactive content. Stakeholders reported increased perceived competency in creating mobile apps and that the process fostered a culture of co-leadership. There was also sustained engagement in mobile app development by stakeholders beyond the initial project period.

Introduction

Despite improvements in the health of the US population in recent decades,[1] significant racial/ethnic disparities in mental health care quality and outcomes persist, including for depressed persons,[2,3] and impact the resiliency of communities to respond to individual and community-level stressors.[4,5] Health information technologies such as mobile applications (apps) hold promise for improving access to care and health outcomes.[6] Yet, there are significant challenges

Conclusions: This is the first study, to our knowledge, to demonstrate the feasibility of participatory technology development, an approach involving direct participation in the development, tailoring and maintenance of a mobile app by a broad set of stakeholders with high representation from racial/ethnic minorities from an under-resourced community. Participatory technology development is a promising approach for creating sustainable, relevant and engaging health technologies across different technological, clinical and community settings. *Ethn Dis.* 2018:28(Suppl 2):493-502; doi:10.18865/ed.28.S2.493.

such as improving the relevance to specific communities or individuals and building trust in how technologies and data are used.[7,8] In addition, existing racial/ethnic disparities are compounded by the inherent barriers around health information technology development including the technical complexity and cost of development, resulting in a high barrier of entry for creating, and challenges in sustaining, technologies implemented in practice and in the community.[9,10]

Participatory approaches such as community partnered participatory

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research (CPPR) have been recommended to address health disparities in under-resourced communities and there has been growing interest in the application of partnered approaches in technology development.[10] CPPR involves engagement of broad stakeholders (including community leaders, providers, patients, researchers,

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In our study, we adapted and implemented partnered methods from CPPR, combined with an accessible technology development platform, to explore the feasibility of a partnered process to health technology development.

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health systems) with an emphasis on equal power sharing, creating a culture of trust and respect, two-way knowledge exchange, and community and academic co-leadership in all aspects of research.[11] A key goal in CPPR, and in addressing health disparities, is the focus on equity of power sharing. This is especially challenging to achieve with technology development, where the locus of control rests with those members able to directly create and maintain an intervention. Typically, for-profit companies as well as academic or health system stakeholders have greater technical and

financial capabilities to do so.[12] In addition, a recent review of five case implementations of partnered approaches to health technology development highlighted several issues including the resources and capacities needed by community organizations to participate in technology development, limited opportunity for tailoring technologies to individual or community needs, and challenges in sustaining these technology interventions.[10]

Like the emphasis on direct engagement in CPPR, direct engagement by individuals has also been increasingly recognized as a key determinant of behavior change and better health outcomes and satisfaction. Patient engagement is a function of organizational and societal factors[13] as well as dependent on the motivation of the individual to engage in them.[14] Individuals with greater autonomy and perceived competence regarding their health care are more likely to adhere to health recommendations[15-17] and exhibit greater satisfaction.[17] To conceptualize the effect of individual-level engagement, we draw on Self-Determination Theory that frames the extent an individual is motivated to initiate certain behaviors as related to the psychological needs of autonomy (having the power to make decisions), competence (capable of ascertaining goals and aims), and relatedness (a positive connection with the intervention).[18] Satisfaction of those needs increases individuals' ability to regulate and maintain their behavior, including those behaviors related to management of their mental and physical health, and may also extend to involvement in health technology development.[19]

End users and/or stakeholders have been involved in creating health technologies in at least some phases of development (eg, participatory design,[20] user-centered design[21] and community-level participatory approaches[10]). Yet, we have found no reports of an integrated process of development that pairs the co-leadership and equal power sharing approach of CPPR with involvement of partners who have no technical expertise in creating, tailoring, and maintaining health technology interventions. This direct involvement in the creation of technologies may help support increased adaptability and sustainability of technologies, as well as uptake of evidence-based health interventions.

In our study, we adapted and implemented partnered methods from CPPR, combined with an accessible technology development platform, to explore the feasibility of a partnered process to health technology development. Together, we co-created an interactive, text messaging mobile app based on content adapted from an evidence-based manual to support community resiliency. We subsequently conducted a feasibility pilot of the co-created mobile app.

METHODS

Our study builds upon a long-standing partnership between researchers at University of California Los Angeles (UCLA) and Healthy African American Families II (HAAF), a community-based agency in South Los Angeles. This partnership stemmed from the Community Partners in Care (CPIC) study, a co-

alition approach to improve health of minority communities.[22] CPIC also resulted in creation of a psycho-education manual for CBT-informed approaches to resiliency (B-RICH).[23] As there was a need identified by this partnership for increased access to and dissemination of evidenced-based interventions within the community, the partners decided to adapt the B-RICH manual into an interactive, text messaging mobile app. Study activities were conducted from October 2013 through January 2016 over three phases: 1) defining the vision of the project and increasing technical capacity; 2) co-development and pilot testing of the app; and 3) planning for sustainability.

South Los Angeles has a population of 1.5 million (63.3 % Hispanic, 32.4 % African American) with high morbidity and mortality from health conditions.[24] The project team comprised eight primary stakeholders (three academic, five community partners; two male, six female) including four African American, three Caucasian, and one Hispanic/Latino partner. Stakeholders varied in education level: three stakeholders had some college, one had a 4-yr degree, and three had post-graduate education. All procedures were approved by the UCLA Institutional Review Board.

Participatory Technology Development

The initial goal of the partnership was to create an interactive mobile app to address stakeholder health priorities using a participatory technology development approach. This approach combines best practices from CPPR (including equity of power

sharing and direct involvement of stakeholders in all phases) with a technology platform (Chorus) previously created by our group.[25] Chorus enables individuals without technical expertise (eg computer programming) to be directly engaged in app development. It provides a simple, visual, web interface to create interactive mobile apps including interactive web-based, text messaging and voice apps without requiring programming skills. This enabled the group to directly create and iteratively modify their app in real-time during workgroup sessions throughout the project period. The partners named the mobile app "B-RESILIENT", to reinforce the positive, wellness framing of the intervention.

Pilot Test

We assessed the feasibility and acceptability of the B-RESILIENT interactive text messaging app using mixed methods. Thirty community participants were recruited from a convenience sample from the HAAF site in South Los Angeles to participate in the pilot. Participants were adults aged ≥18 years, who had previously interacted with HAAF such as attending community workshops and seminars. Consistent with CPPR approaches of involving end-users as stakeholders, four members of the stakeholder group that were members of the end-user community also participated in the pilot study. Twenty-two (73%) participants were female. Participants included 17 (57%) African Americans, 9 (30%) Hispanics/Latinos, 1 (3%) Asian and 3 individuals (9%) where race information was not avail-

able. Individuals used the app for 28 days and received daily text messages with the option for responding to the text messages for interactive content.

Analysis

Participatory Technology Development Process

We conducted qualitative analysis of the audio recordings from the partnered workgroup sessions and interviews of members from the project team. We hypothesized prior to analysis that key constructs from Self-Determination Theory (autonomy, competency, relatedness) would be present in workgroup interactions.[18] Two stakeholders collaboratively identified conversation topics in four representative recordings. The workgroup came to a consensus on the meaning of each conversation, and how it related to the Self-Determination Theory constructs. Four stakeholders then used the notes from the workgroup to develop a codebook of themes, using the Self-Determination Theory constructs as global codes, and through consensus identified granular codes. Two stakeholders then independently used the codebook to analyze the workgroup recordings, followed by discussion of the coding to ensure reliable application of the codes.

Use Metrics and Experiences

Use metrics of the app were generated through review of activity logs, including messages sent by the app and responses received from users. At the end of the pilot, we invited participants to an optional workgroup to discuss experiences using the app. Nineteen (63%) of
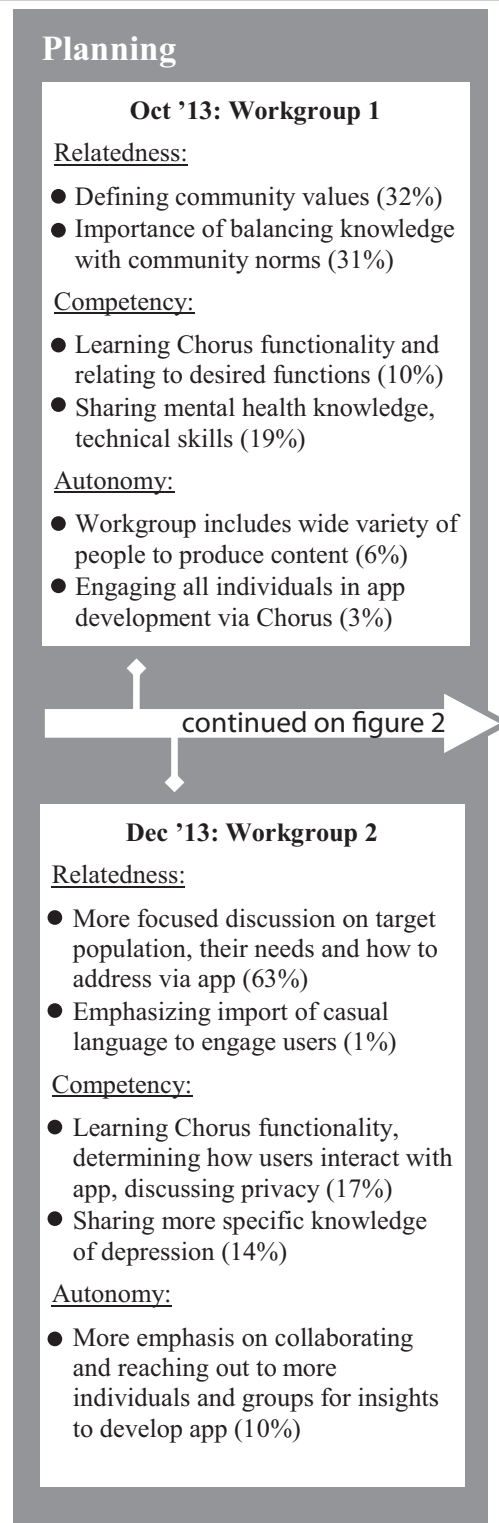
Planning

Oct '13: Workgroup 1

Relatedness:

- Defining community values (32%)
- Importance of balancing knowledge with community norms (31%)

Competency:

- Learning Chorus functionality and relating to desired functions (10%)
- Sharing mental health knowledge, technical skills (19%)

Autonomy:

- Workgroup includes wide variety of people to produce content (6%)
- Engaging all individuals in app development via Chorus (3%)

Dec '13: Workgroup 2

Relatedness:

- More focused discussion on target population, their needs and how to address via app (63%)
- Emphasizing import of casual language to engage users (1%)

Competency:

- Learning Chorus functionality, determining how users interact with app, discussing privacy (17%)
- Sharing more specific knowledge of depression (14%)

Autonomy:

- More emphasis on collaborating and reaching out to more individuals and groups for insights to develop app (10%)

Figure 1. Timeline of participatory technology development
Stakeholder events over the engagement period displayed in relation to Self-Determination Theory constructs. For identified topics within each construct, the percent of time it was discussed is shown. Constructs are listed in order of most discussed. Three phases of engagement are highlighted including: initial planning and setting the goals of the partnership; app development and pilot testing; and planning for sustainability.
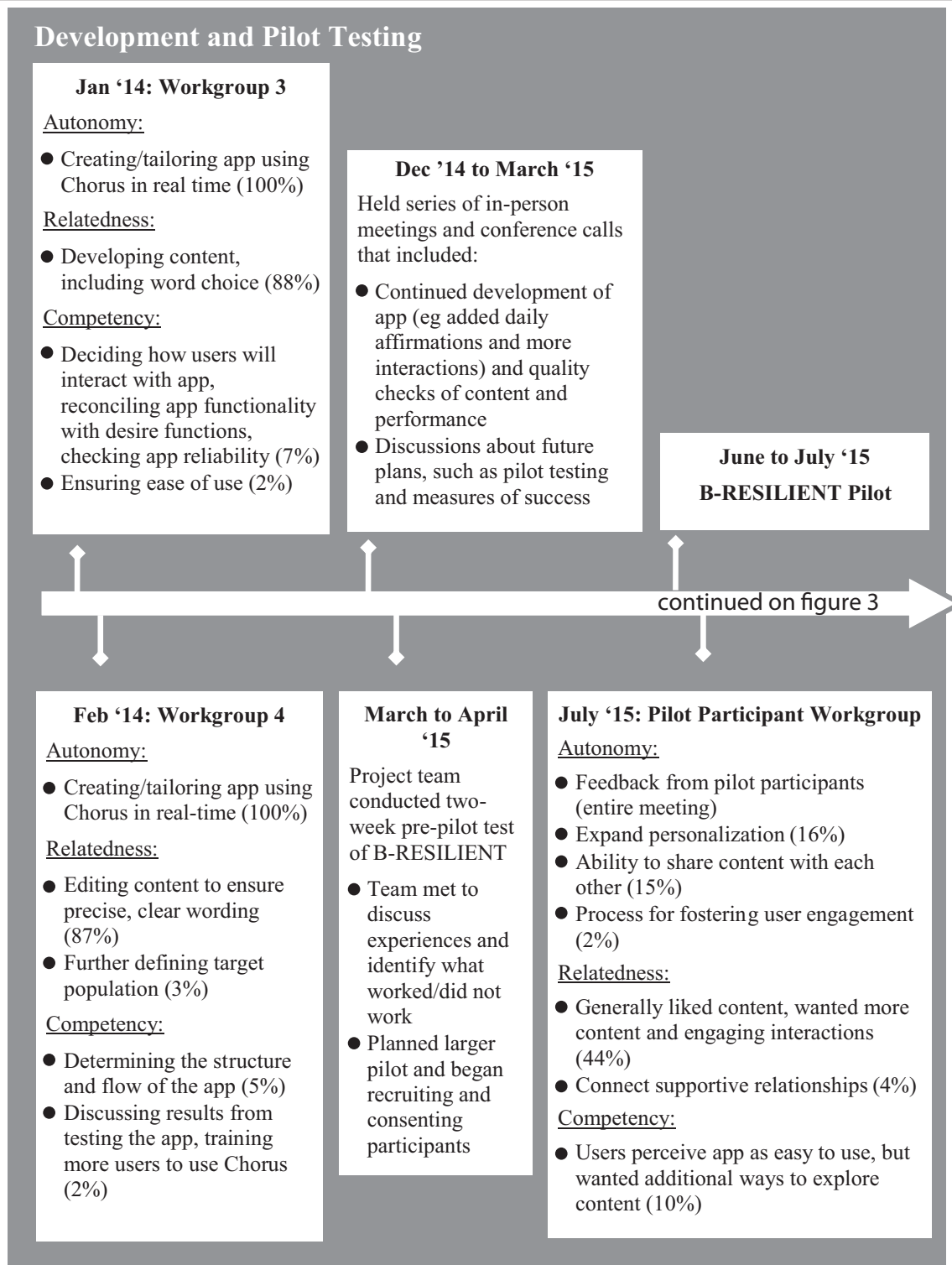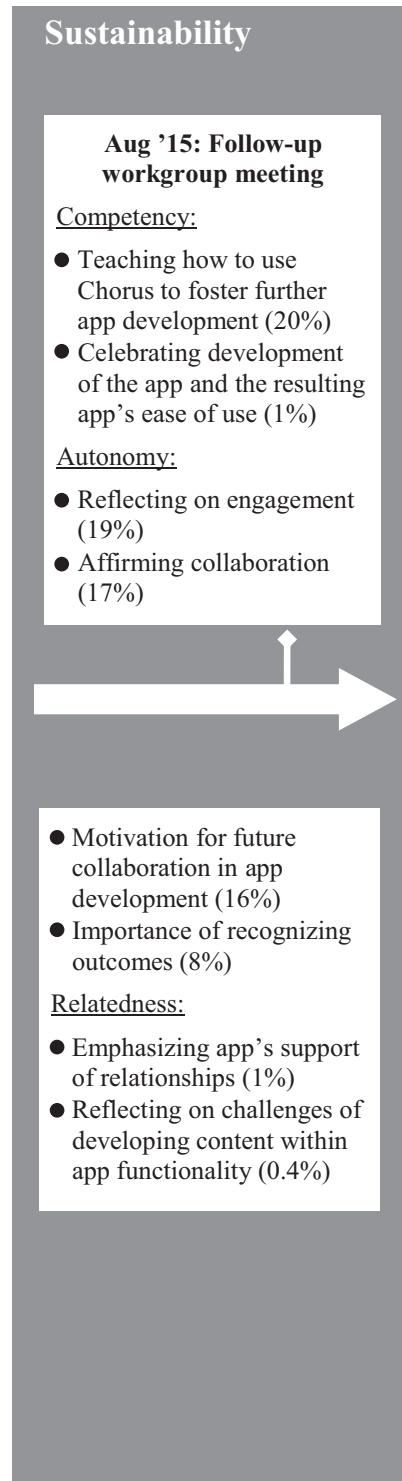
Development and Pilot Testing

Jan '14: Workgroup 3

Autonomy:

- Creating/tailoring app using Chorus in real time (100%)

Relatedness:

- Developing content, including word choice (88%)

Competency:

- Deciding how users will interact with app, reconciling app functionality with desire functions, checking app reliability (7%)
- Ensuring ease of use (2%)

Dec '14 to March '15

Held series of in-person meetings and conference calls that included:

- Continued development of app (eg added daily affirmations and more interactions) and quality checks of content and performance
- Discussions about future plans, such as pilot testing and measures of success

June to July '15
B-RESILIENT Pilot

Feb '14: Workgroup 4

Autonomy:

- Creating/tailoring app using Chorus in real-time (100%)

Relatedness:

- Editing content to ensure precise, clear wording (87%)
- Further defining target population (3%)

Competency:

- Determining the structure and flow of the app (5%)
- Discussing results from testing the app, training more users to use Chorus (2%)

March to April '15

Project team conducted two-week pre-pilot test of B-RESILIENT

- Team met to discuss experiences and identify what worked/did not work
- Planned larger pilot and began recruiting and consenting participants

July '15: Pilot Participant Workgroup

Autonomy:

- Feedback from pilot participants (entire meeting)
- Expand personalization (16%)
- Ability to share content with each other (15%)
- Process for fostering user engagement (2%)

Relatedness:

- Generally liked content, wanted more content and engaging interactions (44%)
- Connect supportive relationships (4%)

Competency:

- Users perceive app as easy to use, but wanted additional ways to explore content (10%)

Figure 2. Timeline of participatory technology development

Stakeholder events over the engagement period displayed in relation to Self-Determination Theory constructs. For identified topics within each construct, the percent of time it was discussed is shown. Constructs are listed in order of most discussed. Three phases of engagement are highlighted including: initial planning and setting the goals of the partnership; app development and pilot testing; and planning for sustainability.

Sustainability

Aug '15: Follow-up workgroup meeting

Competency:

● Teaching how to use Chorus to foster further app development (20%)
● Celebrating development of the app and the resulting app's ease of use (1%)

Autonomy:

● Reflecting on engagement (19%)
● Affirming collaboration (17%)

● Motivation for future collaboration in app development (16%)
● Importance of recognizing outcomes (8%)

Relatedness:

● Emphasizing app's support of relationships (1%)
● Reflecting on challenges of developing content within app functionality (0.4%)

Figure 3. Timeline of participatory technology development
Stakeholder events over the engagement period displayed in relation to Self-Determination Theory constructs. For identified topics within each construct, the percent of time it was discussed is shown. Constructs are listed in order of most discussed. Three phases of engagement are highlighted including: initial planning and setting the goals of the partnership; app development and pilot testing; and planning for sustainability.

the 30 participants from the pilot attended the workgroup. Key points from this workgroup were extracted from review of audio recordings.

RESULTS

Participatory Technology Development

We implemented CPPR techniques to engage a stakeholder group representing community and academic partners over a two-year period. The degree to which the stakeholder discussions reflected constructs from Self-Determination Theory (autonomy, relatedness, and competency) are outlined in Figures 1-3. During the initial stage of the workgroup process, discussions largely focused on the constructs of autonomy and relatedness. During this period, stakeholders were introduced to the Chorus website and discussed the types of interactive applications that could be created using the platform. This enabled real-time planning of the direction for the intervention, characterized by one stakeholder stating, "*Our plan is happening right here with you all.*" The degree of co-creation was reflected in conversations among stakeholders, for example one stakeholder stated, "*We're producing [the app] together,*" to which others replied, "*We're finally on a roll*" and "*This is the vision of doing it together.*"

Through this process, the workgroup determined that interactive text messaging would enable a greater number of community participants to use the app since a smartphone was not required and

because text messaging was considered generally easy to use. The group also identified community resilience as the primary framing and chose to adapt content from a resiliency manual created as part of a previous CPPR project (B-RICH).[23] During the development phase of the app, the workgroup adapted content in the B-RICH manual for the target population, simplified content for the shorter format of text messaging, and decided on how users would interact with the app.

B-RESILIENT App

The interactive texting app was organized around three topics from the B-RICH manual and prioritized by the group to include: social support; healthy activities; and cognitive restructuring. To improve accessibility and reduce stigma, these concepts were framed by the group as "BUDDY," "BREAK," and "BOOST" respectively. Due to the framing of the app around wellness, the workgroup decided that positive affirmations would be beneficial; these were also included, adapted from existing affirmations available to the community partners. Participants would receive daily affirmation text messages in the morning, followed by a text message asking what they needed that day. Users could optionally respond via text message to explore interactive content from any of the three main topics of the app ("What do you need today? TEXT back 1 for a BUDDY, 2 for a BREAK, or 3 for a BOOST"). For example, if texting "BREAK" the app would respond with messages to learn concepts of healthy activities.

Pilot Test

Of the 30 pilot participants, 28 (93%) completed the study, with only two individuals texting "STOP" to end the study early. A total of 1,107 text messages were sent by the app during the pilot. More than three-fourths of users (n=23; 77%) interacted with the app by texting back at least one response to explore interactive content, sending an average of 17.7 text messages per person over the 28-day period of use (SD 16.8; Max: 56; 406 total messages received from participants).

Based on user feedback from the workgroup at the end of the pilot period, participants regarded the app as easy to use. For example, one participant shared, "*I am not technically savvy. And [the app] was simplistic. It was constant. I didn't have to think about it, how to figure stuff out.*" Workgroup participants agreed that the content was helpful, particularly the "BOOST", "BREAK", and daily affirmation components and ability to explore topics by responding to the text messages. Participants also made requests for expanding content available in the app and suggested organizing content around actionable tasks they could implement in their daily routine. Some participants found the text messages to be "*too generic.*" One participant explained, "*It's just too redundant after I've already gone through the prompts [text messages].*" The participants discussed the importance of making the content delivery motivational, as a "*call to action*" or "*something enticing that would draw [them in to using the app]*" and a desire to further tailor the app such as setting their own

schedule of when to receive the messages and customizing the content by the mood of the user on that day.

Sustainability

After the B-RESILIENT pilot, the stakeholder group assessed the state of the partnership and planned for fu-

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We engaged stakeholders, with high representation from racial/ethnic minorities from an under-resourced community, as equal co-partners at all stages in the development process to co-create, evaluate, and plan for sustainability of a resiliency-focused mobile health app.

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ture directions. In the stakeholder exit-survey, all partners agreed with the statements: "This project builds on resources and strengths in the community" and "This project balances research and social action for the mutual benefit of all partners." Almost all agreed with the statement: "This project views community-engaged research as a long-term process and a long-term commitment" (n=7/8).

The partnership also resulted in commitment to ongoing efforts with all members agreeing or strongly agreeing with the statement "I am committed to continuing to adapt and expand the type of mobile health apps created in the B-RESILIENT Project."

Regarding competency to create an app, six stakeholders reported in the exit-survey that before participating in this project they strongly disagreed or disagreed that they thought they were competent to help create a mobile app. This contrasts with their views after participating where six stakeholders agreed or strongly agreed with that statement. Interest in being involved in technology development also changed among stakeholders. Before participating, two stakeholders strongly disagreed or disagreed and four neither agreed nor disagreed with the statement "I hoped to be involved in creating apps (such as automated texted messages or mobile app) in the future." After participating, seven stakeholders agreed or strongly agreed with that statement.

We also assessed the state of the partnership through stakeholder interviews at the end of the project period. Stakeholders described a desire to expand the project ("*My hope for the next phase is that we continue to move forward and do it on a larger scale*"), expressed improved competence in technology development ("*I have no background in technology, and [Chorus] made me feel like our partnership could do anything… it was a whole new level of feeling like we could step up to the plate and use even modern technology in a way that was respectful of the community*"), and stimulation of new intervention ideas for next steps

("*This project has given me the idea that there are other ways that you can create things, using the technology, to change things and to make quality of life better for people*"). The stakeholder group also subsequently received additional grant funding based on this pilot work to continue development, integrate changes based on pilot phase feedback, and conduct a pilot randomized control trial of the modified app.

DISCUSSION

This study describes the feasibility of a novel process of technology development that integrates community-partnered research principles with a technology platform (Chorus) aimed at reducing the technical and financial barriers of mobile app development. Through this process, we engaged stakeholders, with high representation from racial/ethnic minorities from an under-resourced community, as equal co-partners at all stages in the development process to co-create, evaluate, and plan for sustainability of a resiliency-focused mobile health app. To our knowledge, this is the first report describing this level of engagement of community stakeholders without technical expertise directly in the technology development and maintenance process. The pilot test of the co-created app demonstrated broad engagement by end-users with 93% completing the pilot and 77% responding to prompts to explore interactive content of the app. Feedback from end-users noted the ease of use and simplicity of the texting app and also that additional content was desired.

When considering opportunities to address the technical and financial barriers to health technology development, there are two broad approaches: 1) increase the technical skill and infrastructure capacity available within communities; or 2) reduce the level of technology resources required. Previous groups utilizing partnered methods for technology development have suggested strategies to support the first option (eg, encouraging education in computer programming skills by stakeholders), while primarily utilizing academic stakeholders and capacities for technology development.[9,10] This is reasonable considering the limited access to computer programmers and that supporting their efforts requires significant financial resources.[26] Our approach is complementary, but uniquely focuses on the second option by using a technology platform that reduces the level of technical skill required through the use of a visual interface to configure applications. Ultimately, this approach may also promote an increase in technical capacity of communities as we observed an increase in both interest and perceived competence in creating mobile health interventions from stakeholders. Facilitating this level of direct involvement may help shift the locus of control in technology development to the stakeholder group by enabling members to directly create and maintain technologies, rather than the control resting only with those having advanced technical capacities and financial resources. This partnered approach also encourages an evolving, iterative process for developing technologies rather than framing development as resulting in

a specific app as a final endpoint. This is consistent with diffusion of innovation theory in which adoption is considered a "process rather than an event, with different concerns being dominant at different stages."[27]

Limitations

This study has several limitations. First, it builds on a single, longstanding community partnership. It will be important to evaluate this process with different kinds of partnerships at different stages of engagement (early vs long-standing). The stakeholder survey was assessed at the end of the project period and relied on recall of perceptions prior to engaging in the project. Future studies may examine the longitudinal effect of participatory technology development approaches, for example if they result in sustained engagement in technology development and increases in community technical capacity over time. The pilot study used a convenience sample to assess the feasibility of the app. Randomized clinical trials using larger study populations and examining the effectiveness of co-created apps in modifying clinical outcomes may be informative. Our approach utilized a single technology platform (Chorus) but it may also be possible to implement this process with other platforms that enable direct development of technologies by individuals with limited technical expertise. The emergence of these additional platforms may be supported by focusing new technology development around reusable, accessible platforms as opposed to developing customized tools for individual projects.

Conclusions

To our knowledge, this is the first study to demonstrate the feasibility of participatory technology development, involving direct participation in the development, tailoring and maintenance of a mobile app by a broad set of stakeholders with high representation from racial/ethnic minorities from an under-resourced community. The approach resulted in not only the creation of a community-tailored text messaging mobile app to support resiliency but also represents a potential model for a sustainable process of technology development. Participatory technology development, while applied in this study to mobile app development, is a promising approach for health technology development across different technological, clinical and community settings.

Conflict of Interest

AA developed the Chorus platform used in this study and is founder of Insight Health Systems, Inc. (a technology company that licenses Chorus) and founder of Arevian Technologies, Inc. and the non-profit Open Science Initiative.

Author Contributions

Research concept and design: Arevian, O'Hora, F. Jones, A. Jones, Banner-Jackson, Pulido, Mango, L Jones, Wells; Acquisition of data: Arevian, O'Hora, F. Jones, A. Jones, Banner-Jackson, Pulido, Mango, L Jones, Wells; Data analysis and interpretation: Arevian, O'Hora, Wells; Manuscript draft: Arevian, O'Hora, Booker-Vaughns, Williams, Wells; Statistical expertise: Arevian, F.

Jones, Wells; Acquisition of funding: Arevian, Wells; Administrative: Arevian, O'Hora, A. Jones, Banner-Jackson, Williams, Pulido, Mango, Wells; Supervision: Arevian, F. Jones, Wells

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