

## FORMATIVE RESEARCH INSIGHTS FROM THE TRANS WOMEN CONNECTED PROJECT: KEY FINDINGS AND ONE COUNTER-INTUITIVE LESSON



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## Formative Research Insights from the Trans Women Connected Project: Key Findings and One Counter-Intuitive

In 2017-2018, we conducted formative research with transgender women to develop an HIV prevention and sexual health promotion app called Trans Women Connected. Our purpose was to a) understand the sexual health and HIV prevention needs of transgender women in the context of their overall health and well-being; and (b) to use these insights to guide the content development and framing strategies for a successful mobile app.

Formative research, done thoughtfully, can help ensure the likelihood that an app-based intervention is acceptable to potential users, addressing their needs and priorities and, ultimately, leading to a greater ability to support long-term behavior change. Yet as we experienced, formative research can also present counter-intuitive findings and insights.

We highlight our formative research methodologies (four focus groups and 57 in-depth interviews, each method offering unique strengths to further our understanding of community needs), a description of our study participants (57 regionally and racially diverse transgender women from 10 states, ages 18-59) recruitment partners (community-based organizations in San Francisco, Miami, Atlanta, and Portland, an expert panel who are multi-disciplinary experts in transgender health and work intimately with transgender communities through diverse organizational structures, including CBOs and health care systems, and community advisory board comprised of ten transgender women, a majority women of color.)

Using both qualitative and quantitative data from the study we will convey the four key themes we identified using both grounded theory and ethnographic methods for analysis. They were:

- Structural factors, especially employment, are viewed as central to discussions of health and health needs
- Transition-related medical care and mental health care are highly prioritized by transgender women
- Sexual health is viewed as broader than just a focus on HIV and STDs
- Connecting with other transgender women is valued, but can be challenging

These Phase I findings helped shape the development of our mobile app delivered intervention completed in Phase II of the project.

Finally, we explore an initially counter-intuitive finding identified during our subsequent Phase II randomized controlled trial studying the efficacy of the TWC app with 541 transgender women (n=259 treatment arm, n=282 control).

During our Phase I formative research, participants had expressed a keen interest in an app that would provide both mentoring support and a networking strategy for connecting with other transgender women. Both highly desired features were discussed, designed, and ultimately integrated into the app as features called "Mentor Matching" and "Trans Women Connected-Let's Talk" respectively. Yet we were initially surprised to learn that, based on usage data collected, both features were rarely utilized. Of the 259 women in the treatment arm, 134 (51%) signed up to participate on the TWC Forum, and only 21 women in the study (8.1%) participated by posting at least one post. Similarly, only 66 women (26%) in the study availed themselves of the mentoring feature (either seeking mentorship or offering it).

This unexpected outcome became more understandable as we considered it in the larger context of our earlier discussions with study participants. We believe that the structural inequities transgender women described facing made it difficult for them to engage in the very activities they specifically asked for and desired. These activities were not ultimately priorities compared to their more pressing daily needs.

This counter-intuitive finding was also related in interesting fashion to our Phase II outcome data. While we learned that the most requested and theoretically most impactful social support features were only minimally used (i.e., the mentoring feature and forum board feature), the overall perceived social support the women felt using the app was significantly higher when compared with the control group (p=.021). In fact, data showed this sense of perceived social support grew slowly but continually over the Phase II study follow-up timepoints, 1 month, 3 months, and 6 months. The treatment group (M = 3.46, M = 1.14) reported significantly higher social support at the 6-month follow-up than the control group (M = 3.14, M = 1.09). The social support score was calculated as a mean across all items on the social support scale.

As we considered possible explanations, we noted that this is a socially vulnerable population that has considerable reasons to feel guarded about their participation in both research studies and social networking forums. It seems reasonable to assume that as the study progressed over time, participants felt greater assurance that the TWC resource was genuinely a supportive application created for their legitimate use and benefit.

We believe these findings from both the Phase I formative research and the Phase II randomized controlled trial can guide the development of other HIV prevention interventions for transgender women by identifying framing strategies and content for interventions.