Building capacities to author change: community-based participatory design as a form of positive youth development and adolescent sexual and reproductive health care intervention design

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Abstract

The term "community-based participatory design" (CBPD) recently emerged as a distinctive space in the Participatory Design tradition (DiSalvo, Clement & Pipek, 2013; LeDantec, 2016). This move marks a shift from treating the process of design primarily as a product development method, to one that builds social and technical capacities – or infrastructures – of individuals and communities (Björgvinsson, Ehn, & Hillgren 2010; Karasti 2014; LeDantec 2016). This paper describes participant gains from a design workshop conducted as part of a research collaboration involving a university-based research center, and four NGOs, the participatory design workshop aimed to: (1) build the capacities of young people; (2) guide young people in the creation of novel and locally relevant gender and sexual and reproductive health (SRH) solutions; and, (3) bring voices of young people into research and programmatic questions around gender and SRH in the public health domain. The workshop was conducted with 31 young people aged 15-25, over 2.5 weeks, in Lucknow, Uttar Pradesh, India. The evaluation demonstrates that the workshop resulted in exposure to working in mixed-gender teams, developing problem-solving skills, and increasing SRH awareness and knowledge. The workshop produced six low-fidelity prototypes, five of which were subsequently refined and piloted by three Lucknow NGOs.

Keywords: community-based participatory design, adolescent sexual and reproductive health, user gains, evaluation, infrastructuring

Participatory design (PD) processes have been adapted and reinterpreted for a variety of design contexts and purposes, resulting in a broad range of philosophies in PD. Most recently, "community-based participatory design" (CBPD) has emerged as a small subfield of PD research and practice that aims to foreground social constructs and group relationships in settings that may include, but also reach beyond, the organizational structures foregrounded in typical workplace studies (DiSalvo, Clement & Pipek, 2013). This move also marks a shift from treating the design process primarily as a product development method, to one that builds social and technical capacities – or infrastructures – of individuals and communities (Björgvinsson, Ehn, & Hillgren 2010; Karasti 2014; LeDantec 2016).

The concept of "infrastructuring" has surfaced in PD literature to describe the creation of socio-material assemblies that support sustainability of design outcomes (Björgvisson, Ehn, & Hilgren, 2012). Star and Ruhleder (1995) were the first to describe how infrastructures emerge in relation

to organized practices. Björgvisson, et *al*., (2012), have described the socio-material assemblies that emerge from infrastructuring in design processes as "design Things," suggesting that 'Things' are not merely the byproducts of the design processes but the objects of design in and of themselves. This framing naturally calls for a better understanding of the evolution of relationships, networks and resource flows that drive Things forward.

Participation is central to Things. Understanding what participants gain from participation then represents another way for us to understand and evaluate the distributed and diffuse impacts from CBPD. However, not until very recently has the evaluation of "user gains" become of interest to the design domain (Bossen, Dindler, & Iversen, 2010, 2012, 2016). Balka (2010) notes, that despite the ideals the PD community holds close, rarely do we research what participants in design processes gain from their participation, or their views of PD processes and outcomes. According to Bossen et *al*. (2016), there have been few explicit, systematic process evaluations in PD. Muller (2002) has noted that the dearth of formal evaluation represents a weakness in the literature on participatory practices.

This study seeks to better understand what participants gain from their participation in a design workshop, in order to contribute to discussions in the PD literature about user gains relative to CBPD processes and Things. This study describes how a research collaboration involving a university-based research center, and four NGOs, used a participatory design workshop with the aim to: (1) build the capacities of young people; (2) guide young people in the creation of novel and locally relevant gender and sexual and reproductive health (SRH) solutions; and, (3) bring voices of young people into research and programmatic questions around gender and SRH in the public health domain.

Kissa Kahani Participatory Design Workshop

Background

The Center for Interdisciplinary Inquiry and Innovation in Sexual and Reproductive Health (Ci3) at the University of Chicago is executing Kissa Kahani, a study that uses participatory research methods, and qualitative and quantitative methods, to understand gender, and sexual and reproductive health (SRH), among young people living in Lucknow, Uttar Pradesh (UP), India. As India's most populous state with a large percentage of young people ages 15-24, UP has among the highest levels of gender inequality in India. The state ranks 34 out of 35 on the gender development index, which measures differences between men and women in health, education, and economic capital (UNDP). These disparities create intersecting, systemic challenges to the health and wellbeing of women and girls. Nearly 21% of girls in UP get married before the age of 18 (DLHS-3). Almost 18% of women age 15-49 have an unmet need for family planning, and only one-third use any modern method of contraception (NFHS-4). Kissa Kahani addressed these and other such indicators in gender and SRH by exploring the lived experiences of young people in UP.

Kissa Kahani has four phases. In phase one, four narrative-based participatory research methods were employed to help youth discuss gender and SRH. Phase one used four narrative participatory methods: (1) life course interviews that explored critical moments in the lives of young people such as their birth, education and marriage, n=123; (2) body mapping workshop

for visual representation and analysis of young people's experience with gender and SRH, n=40; (3) narrative-based game workshop to co-create stories related to gender and SRH, n=40; and, (4) story circles that formed safe spaces to conceptualize, share and receive feedback on personal stories around gender and SRH, n=74.

In phase two, grassroots organizations in India applied for funding to develop innovative, adolescent-led interventions to address the issues identified through phase one research activities. In phase three, young people participated in a 2.5-week participatory design workshop to create novel and locally relevant gender and SRH solutions. Phase four involved funding local organizations to refine and pilot adolescent-generated solutions.

The participatory design workshop, the focus of this study, had two goals: First, to use a community-based, human-centered, participatory design process as a form of Positive Youth Development (PYD), in which youth were engaged as equal partners. PYD seeks to build or fortify relationships with adults and social networks, to develop the skills necessary to engage in real-world roles and activities, as well as orient youth toward future goals (Catalano, Gavin, & Markham, 2010). As a form of PYD, the workshop aimed to: (a) be a vehicle for young people to think about adolescent health issues from their point of view and the point of view of others in Lucknow; (b) offer an opportunity to explore everyday problems in new ways; and (c) bring meaningful collaborations into being ('thinging'). The second workshop goal was to guide young people in the creation of novel and locally relevant approaches to mitigate gender disparities and improve adolescent sexual and reproductive health (ASRH).

Workshop structure

Thirty-one participants (22 girls, 9 boys), between the ages of 15-24, were recruited to the workshop by three local NGOs. Participants were organized into six mixed-gender teams, of 5-6 participants according to the NGO that recruited them, meaning that participants in each team were all recruited by the same NGO. Workshop materials, including a bespoke 70-page human-centered design (HCD) primer, and the workshop itself, were delivered in Hindi. Themes for workshop design challenges were developed from the four narrative-based participatory research methods, used in the parent study, Kissa Kahani, designed to help young people discuss gender and SRH in phase one.

Six design challenges were developed around themes that emerged from phase one data: (1) healthy bodies and healthy relationships: providing SRH education to young people; (2) public safety for girls and young women; (3) gender equality in high school completion rates; (4) supporting young men in their SRH needs; (5) rethinking gender roles; and (6) social media.

The Ci3 team trained five coaches, adults recruited through NGO partners, to co-lead the workshop. They received a two-day crash course in HCD, and worked along Ci3 Design Thinking Lab team members to teach five workshop teams the HCD process through activity-based modules. HCD modules included problem framing and reframing; qualitative methods for contextual research (e.g., identifying research questions and sampling strategy, conducting intercept and in-depth interviews, data collection methods); data analysis (e.g., clustering themes, identifying insights and design criteria); concept generation and evaluation; prototyping (e.g., storyboarding user journeys, role plays, low-fidelity "franken" prototyping); and

Figure 1. Excerpt from workshop primer module on qualitative methods for contextual research.

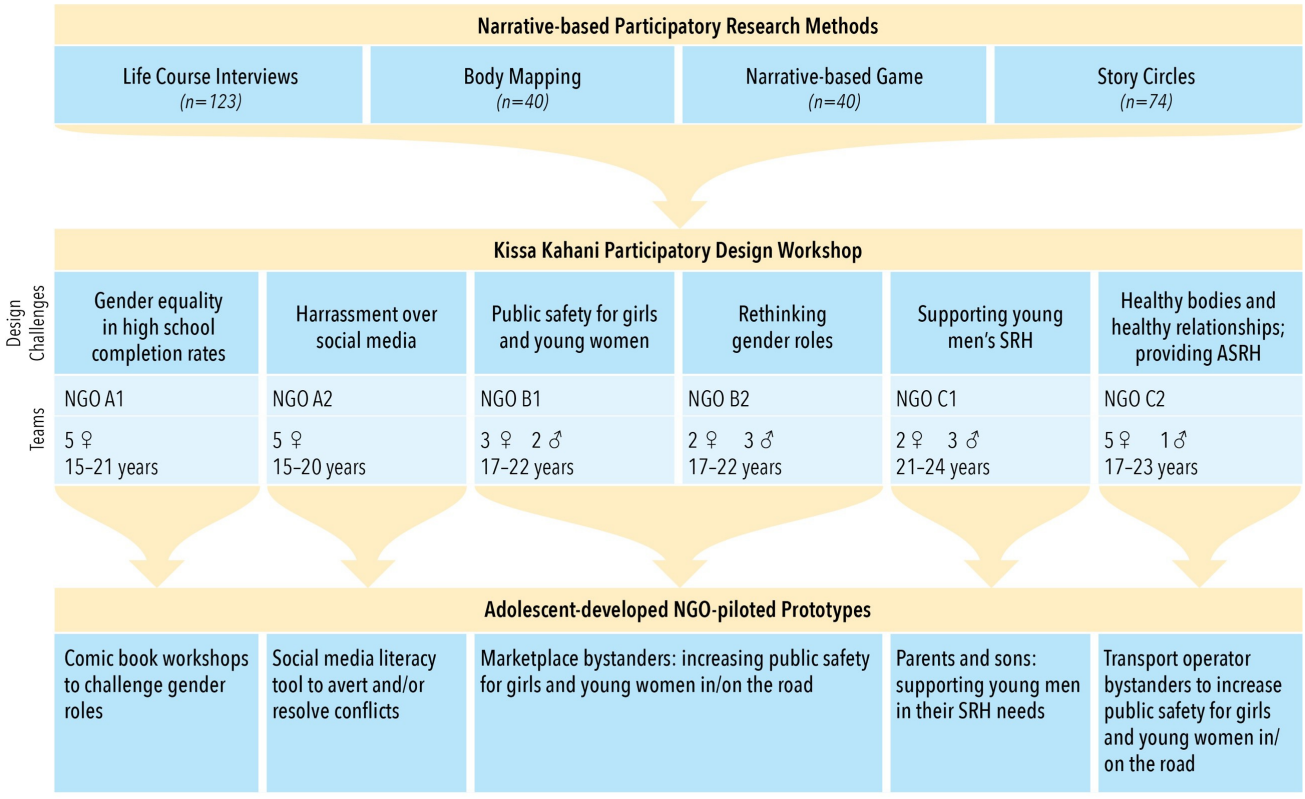

Figure 2. Overview of Kissa Kahani participatory design workshop.

communicating novel ideas to new audiences (i.e. pitching). Modules were immediately followed by in-context application of methods to explore the design challenges selected by each team. For instance, teams interviewed a variety of people including parents, peers, tut-tut drivers, pedestrians, shopkeepers, a local alderman, a Lucknow police director, a UP cricket coach and a gynecologist.

After the workshop, the five concepts prototyped by the participants were further refined and developed by the three partner organizations in Lucknow and Ci3. These concepts, with accompanying evaluation tools, were piloted in Lucknow in the six-months following the workshop and were recently completed.

Evaluation activities

Baseline and endline surveys were conducted before and after the workshop and took, on average, 30 minutes to complete. Due to time and financial constraints, survey questions could not be pre-tested prior to their use in the field. Surveys were conducted in Hindi by UChicago and Lucknow-based, partner-affiliated research staff, using an android-based tablet with REDCap software. The baseline survey was conducted with participants in-person and over the phone. Endline surveys were completed in-person. The survey aimed to measure participant attitudes and capabilities relative to the skills-based activities that constituted the foundation of the workshop by asking questions about their familiarity with human-centered design, about how likely participants felt like they could participate in new activities, like talking with strangers (i.e., interviewing), et cetera. The survey data was analyzed by members of the UChicago research team using the Wilcoxon signed rank tests and Mann Whitney tests in STATA.

Focus group discussions were completed in a closed room with each team. Discussion topics included questions about what participants liked about the workshop, what could have been improved, what they learned through the workshop, and current challenges they face as adolescents. Focus group audio recordings were translated and transcribed by a third party, de-identified, and coded for major themes by the UChicago research team.

Discussion

Analyses of the data suggest that the use of a participatory design workshop as a form of PYD resulted in user gains in three areas: building relationships and networks, skill building, and an increase in ASRH awareness and knowledge.

Building relationships and networks

Focus group data suggests that the workshop provided a unique opportunity to work in mixed-gender groups resulted in greater exposure and comfort in working with the opposite sex and in groups. For instance, one participant described:

> *I had individually worked at a lot of places, but this was my first opportunity to work in a group. So, I gained the experience of working in a group, so that was the best thing for me. There were girls with us in the group as well, so that was an entirely different experience. So that was really good for me (FGD 06).*

Skill building

Both focus group and survey data suggested that participants experienced an increase in their likelihood to generate new ideas in response to a social problem, and to speak to someone they had never met before to seek help for solving the problem. One participant noted:

> *To make an idea and to present that--it was difficult as well as challenging. We did make it and present it. It was quite fun. I am now confident that if I get a chance again, I can make an idea and execute such kind of job at ease (FGD 03).*

Focus group data also indicated that the workshop increased self-confidence for interviewing individuals as well as public speaking. For instance, one participant stated: *I liked it because we were able to take interviews and this way we developed confidence to work and interview others (FGD 01).*

According to survey data, both young men and women reported an increase in attitudes about and capacity for implementing design activities; however, young men reported a stronger change in this compared to girls.

Increase in SRH awareness and knowledge

The workshop raised awareness about issues in ASRH and gender, and generated further interest in learning about them. One young person stated:

> *Things like we were not aware about body parts and what happens between girls and boys during sex, but we came to know on that day, and we were stunned to see and hear that these sorts of things happen between girls and boys (FGD 05).*

These findings suggest that the workshop may have built participant capacity to act beyond the activity of solving for an acute problem, in this instance, creating locally relevant design solutions for gender and ASRH-related challenges.

Limitations

This evaluation was conceptualized as a formative research to identify suitable measures for assessing user gains in the context of CBPD. The authors recognize there are limitations to the study design. First, evaluation tools were not pre-tested with Indian adolescents to assess potential issues of clarity and acceptability of questions. Second, participants had been involved in community-based work with local NGOs prior to the workshop, therefore they may have had more opportunities to acquire and implement skills taught in the workshop when compared to other young people. Lastly, the overall project structure did not allow for a follow-up survey at a later time interval to assess (a) if the change in attitude toward capacities that were reported at endline were retained by participants for a longer duration, and (b) to learn about their subsequent experiences applying skills.

Conclusion

This study makes a contribution to the small, emerging body of CBPD research concerned with the evaluation of user gains. It illuminates specific affordances that Kissa Kahani design workshop processes had relative to facilitating new socio-material infrastructures for young

people engaged in the design of novel gender- and ASRH-related public health interventions. Exposure to teamwork and mixed-gender teams allowed for new forms of social infrastructuring for participants. Building skills that could be used in real-world roles and activities, and increasing SRH awareness and knowledge such that it could inform orientation toward future goals, represent kinds of technical knowledge infrastructuring.

In turn, these infrastructures also connect to the prototypes and pilots conceived in the workshop, and the subsequent evolution of the relationships, networks, and resource flows that may support the sustainability of their implementation in the community. Therefore, at its center, this study represents a case about how social configurations, give rise to, and then evolve in response to, new kinds of Things.

In the context of gender disparities in Uttar Pradesh, the user gains suggested by this small study challenge the usual ways how social and technical infrastructures might normally emerge in the design of public health interventions, allowing for the evolution of locally relevant approaches to mitigate gender disparities and improve ASRH. In this way, the study connects to the ongoing discourse about the role of PD as means to engage with power structures and marginalization.

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Author Biographies

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Amanda is the Director of the Ci3 Design Thinking Lab at the University of Chicago where she develops innovative community- and clinic-based interventions to advance the health and assets of young people around the globe. Amanda holds a MPH in community health sciences from the University of Illinois at Chicago School of Public Health and is currently pursuing a PhD at the IIT Institute of Design. Her doctoral research explores the development and evaluation of community-based participatory design processes that seek to build capacity. Previously, Amanda led national program replication for Cure Violence, an evidence-based public health approach to reduce shootings.

Suchi Bansal, MPH

Suchi is a research associate on Kissa Kahani. She has extensive experience with adolescent sexual and reproductive health issues in developing countries, specifically in South and Southeast Asia. Prior to joining Ci3, Suchi worked with multilateral and public health organizations including The World Bank and Pathfinder International, where she examined issues of teen pregnancy, menstruation management, and family planning. Suchi has a Master's degree in Public Health from Columbia University and Bachelor's degree in Economics and International Relations from Knox College.

Melissa Gilliam, MD, MPH

Dr. Gilliam is the Principal Investigator on Kissa Kahani. She is Professor of Obstetrics/Gynecology and Pediatrics, founder and director of Ci3, co-PI of the Game Changer Chicago (GCC) Design Lab and Vice Provost for Academic Leadership, Advancement, and Diversity at the University of Chicago. Dr. Gilliam's research focuses on understanding and addressing health disparities among youth. Early in her career, Dr. Gilliam recognized that research and intervention efforts needed to broaden from traditional clinical models to effectively address social and structural determinants of health. Thus, Dr. Gilliam founded Ci3 to leverage technological and academic resources against the ecology of factors that lead to health disparities among youth. Under her leadership, Ci3 undertakes innovative projects with youth, including summer digital storytelling workshops and game-based learning experiences**.**

Shirley Yan

Shirley is the current outgoing program manager for Kissa Kahani, which aims to understand how adolescents think about gender and sexual and reproductive health in Lucknow, Uttar Pradesh, India. As part of her role she manages all parts of project implementation to ensure stakeholders are involved and deliverables are met. Previously, she has worked on projects that center around how communities can be motivated to make healthy behavior changes, specifically through community-based and human-centered design perspectives. Examples of these projects include job creation in the Indian textile sector; assessing benefits of a food prescription program in Chicago; and developing a waiting room app around contraceptive knowledge. She is currently pursuing a Masters in Science in Public Health in Social and Behavioral Interventions at Johns Hopkins Bloomberg School of Public Health and holds a Bachelor's degree in Public Policy from the University of Chicago.