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# Appreciating the Persona Paradox: Lessons from Participatory Design Sessions with HIV+ Gay Men

Jae-Yung KWON<sup>a,1</sup>, J. Craig PHILLIPS<sup>b</sup> and Leanne M. CURRIE<sup>a</sup>
<sup>a</sup> School of Nursing, University of British Columbia, Vancouver, BC Canada
<sup>b</sup> School of Nursing, University of Ottawa, ON, Canada

**Abstract.** Eliciting user requirements from HIV-positive gay men who smoke can be challenging. This is because of the complex relationship between social stigma and gender identities (e.g., gay, masculine, HIV+, and smoking status). Inspired to engage HIV-positive gay men in the development of a web-assisted tobacco intervention, we used personas as a main communication tool in our participatory design sessions. Personas are characters created by users that embody part of their own behaviours, thoughts, and motivations. In an apparent paradox, this article is a description of how the use of personas to ensure less realistic self-representation provided an impetus for more self-disclosure. Findings and feedbacks from this study reveal that personas are an effective design tool to engage users in sensitive topics. Implications for future work are also discussed.

Keywords. Personas, design tools, participatory design, HIV positive gay men

#### Introduction

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Smoking rates among HIV-positive gay men are considerably higher compared to the general population (40-70% vs 20%, respectively). This is a concern because smoking among people living with HIV are associated with increased risk of cardiovascular, lung and renal diseases, and HIV disease progression. Although advances in antiretroviral therapy improved health and life expectancy among HIV-positive gay men, deleterious health effects of smoking undermine the benefits gained from HIV treatment. For example, smoking is associated with lower CD4+ counts and higher viral loads. However, effective smoking cessation programs for this group have neither been fully developed nor have they had significant effects<sup>1,2</sup>; as a result, to understand the needs requirement of HIV-positive gay men and develop a web-assisted tobacco intervention (WATI), we conducted participatory design sessions using personas.

According to Blomquist and Arvola<sup>4</sup>, participatory design is a type of interface design that relies on mutual learning and co-operation between the designers and the users. One of the techniques to engage users in the design process is the persona, which typifies a group of users in pictorial and text formats.<sup>5</sup> Introduced by Cooper, personas are hypothetical representation of users that go beyond demographics, as personas

<sup>&</sup>lt;sup>1</sup> Jae-Yung Kwon, University of British Columbia, 708-5828 Thunderbird Blvd Vancouver BC, Canada V6T 0B8; Email: president@jykngroup.com

include information on how users think, feel and behave.<sup>4</sup> Personas are not only powerful design and communication tool, <sup>4,6</sup> but they also prevent designers, developers and various stakeholders from eliciting an "elastic user" to be manipulated on whim.<sup>7</sup> After the specificity of the personas are fully developed, the design team can then engage with the personas to develop a tailored interface. Although there is no set number of personas to be used in any given design problem, Cooper advises using between 3 to 12 personas.<sup>7</sup>

Despite potential benefits of personas, such as preventing designers from grounding themselves to conceptualizing mental model of users, its use has received little attention in health care informatics research.<sup>5,7</sup> There are several reasons for this, including the lack of know-how to concerns about validity.<sup>8</sup> Nevertheless, studies in certain population groups (e.g. older adults and patients with chronic illness) have shown that use of personas increased engagement and insight compared to traditional focus groups.<sup>5,9</sup>

In the context of HIV-positive gay men, engaging this population can be difficult due to multiple layers of stigmatization and prejudice in addition to other psychosocial factors. Furthermore, HIV-positive gay men may be hesitant to disclose personal information because of negative experiences. According to Hisham , using personas that the majority of participants can relate to without directly referring to themselves is important because many HIV-positive gay men feel significant stigma burden.

The benefits of using personas (e.g. increased self-disclosure and participation) provided a basis to use personas as a main communication tool in our participatory design sessions. Thus, the purpose of this paper is to determine whether the benefits of personas can facilitate discussions of a highly stigmatized group of HIV-positive gay men who smoke. Moreover, possible explanations of the personas effectiveness in eliciting user requirements and needs are discussed, as well as the implications of its findings.

#### 1. Methods

This paper is part of a broader study on implementing a web-assisted tobacco intervention (WATI) for HIV-positive gay men, entitled CoMUniTI QuitS (Collaboration for the development of HIV+ gay Men's Uniquely Tailored Intervention to Quit Smoking). To design and develop WATI, we facilitated participatory design sessions, which included the use of personas in one of the activities called Empathy Map. The specifics of the Empathy Map will be discussed in the following section.

Each focus group activity was facilitated by one member of the research team; a second member recorded field notes, and a third member observed the interactions of the group. The participants used colored felt pens, post it notes, and posters to identify user interface design and functions of the tailored website. The moderator explained the purpose of each activity and gave guidance as needed. Participants were informed that any identifiable information would be coded with a unique number to maintain and protect their confidentiality. There was a total of two group sessions with each session lasting approximately six hours, followed by a debriefing session and time for final questions.

#### Empathy Map

Developed by Scott Matthews of XPLANE, empathy map is a tool to gain deeper insight into the users. 12 The objective of the game is to develop a persona in collaboration with a group. In the beginning of the activity, the moderator asked the participants to divide into groups of two to three to create a persona that reflected part of themselves in their daily lives. The groups were told to give demographic information (e.g., name, age, job title) of the persona and be as creative as possible, using colored felt pens and post it notes. In the middle of the poster board, participants were asked to draw this persona with facial features such as eyes, ears, a mouth and a nose. The posters were divided into four quadrants labeled, "Think and Feel," "See," "Say and Do," and "Hear" to portray the sensory experiences of the targeted persona. Some of the guiding questions were as follows: in "Think and Feel" category, we asked, "What are some thoughts and feelings that go through this person?" In the "See" category, we asked, "What's the first thing that the person sees in the morning and throughout the day?" In the "Say and Do" category, we asked, "What does this person usually say and what is his routine?" In the "Hear" category, we asked, "What does he usually hear at home or at work?" This activity took about 45 minutes to complete.

# **Participants**

Ethical approval for this study was obtained by the University of British Columbia, Behavioural Research Ethics Board. Informed consent was provided and signed by each member of the focus group, which included informed, voluntary, and confidential nature of participation. Demographic information was also collected. Recruitment was facilitated by a staff member involved in Positive Living Society of BC and Friends for Life Society of BC. Inclusion criteria were HIV positive gay men who are currently quitting or have recently quit (within one year of study participation), age > 19 years, and speak English. After the session, each participant received an honorarium of \$50. There were a total of 13 participants in the two group sessions with 5 participants in the first session and 8 participants in the second session. Each session lasted approximately six hours and participants received an honorarium of \$50.

## 2. Findings from the Persona: Homo Riley

The benefits of using personas in facilitating group activities in HIV-positive gay men are highlighted based on our observations and feedback. Some of the statements made by participants are quoted verbatim to emphasize the effects of using personas. Although four personas were created from this group activity, only one persona, Homo Riley, will be described in detail because he exemplified many characteristics to the participants, which was evident during the discussions.

Figure 1 shows Homo Riley, a 36-year-old HIV-positive gay man who identifies himself as a single-sex hound. He is a movie production assistant. In the middle of the poster, participants drew a person with glasses, a simple t-shirt and shorts and facial stubs. In table 1, Homo Riley's sensory experiences are highlighted into four sections labelled "Think & Feel," "See," "Say & Do," and "Hear."



Figure 1. Persona of Homo Riley.

Table 1. Homo Riley's Sensory Experiences

Think & Feel	Scattered mind	Self-doubt	Work & Stress	Not enough time	lonely
See	What he wants to see	Happier People?	Successful + Rich People	Looking	Sees his friends at work+the pub as well as rivals
Say & Do	Always gets into trouble	As others want him to do	Don't sweat the small stuff	Hugs friends, dis's rivals	Wake up, coffee- smoke, check e- mail
Hear	Derogatory comments	Talked down to	Discouraging words	Friends reinforce his self- confidence	Try & do this

## Personas sparked engagement

For many of the participants, the process of using personas seemed transformational. Group members identified powerfully with the personas; one participant, after looking at Homo Riley, stated, "This is so like Bill!" (Pseudonym for his gay partner). As the group activity continued, participants started to reflect on their smoking behaviours, "Quitting smoking is the last thing because of the doom and gloom and not knowing how long to live, but with ART (antiretroviral therapy) it's changing, there's hope and optimism and programs should know how to change this doom attitude to positivism." After the activities, there was enormous positive feedback. Participants were saying, "This is not like any other focus groups I've been involved with!" or "Thank you for not sitting in the room ticking boxes."

#### Personas brought focus

Rather than chatting amongst themselves, participants focused the discussion on specific topics. For example, when one participant commented that smoking education is everywhere and counterproductive, other participants contributed to that discussion. If there were conflicting opinions, the moderator kept the discussions running smoothly by focusing on the persona and what the persona was experiencing.

# Personas encouraged openness

Lack of trust, commonality and inhibition between HIV-positive gay men and researchers can cause communication gaps; however, for many participants, use of personas not only facilitated discussions but also allowed participants to divulge. For example, one participant began to reveal his innermost thoughts, "I didn't want anyone to see me fail, I was hiding inside, I know now that it's ok to fail." Another participant explained what he thought each morning, "I'm glad to wake up because I might not survive." Moreover, the group members were openly discussing sensitive topics such as sex, even in the presence of a female researcher.

#### 3. Discussion

There are several explanations for why personas increased engagement, focus, and openness. One explanation is reduced social cues theory proposed by Kiesler, Siegel and McGuire. With the safety of a persona, the lack of cues can reduce the impact of social norms and constraints, resulting in increased understanding and trust. Similarly, computer-mediated communication can also have a noticeable effect on interpersonal behaviour and participation. For example, Bailenson, Merget, and Schroeder demonstrated that both verbal and non-verbal self-disclosure were lowest in videoconference, compared to voice-only and abstract avatar communications. Other studies have found that computer-administered interviews and text-based communications offered higher levels of self-disclosure, compared to face-to-face communication, because of the reduced perceptions of leadership, status and power. These studies suggest that the de-individuation process or loss of identity can, paradoxically, increase self-disclosure.

Another explanation is the Jungian theory of the persona. Jungian theorists define personas as a consciously created personality with amalgamation of the collective psyche through socialization, acculturation, and experience. <sup>16</sup> Jung believed that personas act as a mediator between the individual consciousness and the wider social community. <sup>17</sup> One interesting aspect of the empathy map is how the participants drew Homo Riley because he has glasses, facial stubs, and generally appears unkempt. Why was Homo Riley not clean-shaven and wearing a suit instead? Or why was he a movie production assistant rather than a film director? According to Jungian theorists, suppressed memories and social experiences were imparted into these personas. Paradoxically, this process of revealing the persona or what many therapists call the "individuation" process can have a healing effect. <sup>18</sup> In other words, once participants were liberated from the deceptive cover of the personas, they were free to express themselves through their true inner voice and strength. This also explains why participants in our study thought that our sessions were a "great support group." From a

researchers' perspective, the use of personas helped clarify assumptions and gave us a better understanding of the desires, motivations, and behaviours of HIV-positive gay men who smoke. While use of personas highlight an important data collection tool for user requirements and needs, further research is needed to rigorously determine the extent of the effect in using personas and whether its use would change data collection strategies.

#### 4. Conclusion

Personas can be a powerful design tool and a method to enhance engagement and reality especially for stigmatized groups such as HIV-positive gay men. Similar to other studies, we have found that personas provided an effective way to (1) engage HIV-positive gay men who smoke in design, (2) obtain psychological perspectives and (3) offer more in-depth insights regarding their experiences; however, use of personas are not without problems (e.g., increase in time and inappropriate use if all team members are not trained).<sup>18</sup> Nevertheless, our findings demonstrate personas as a valuable methodological approach that can complement existing quantitative and qualitative methods in design.

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