

1 BACKGROUND

2 Youth engagement in substance use research is critical to the understanding of correlates that  
3 lead to detrimental health and social outcomes for adolescents. Challenges to engaging  
4 historically marginalized youth, including youth of color and immigrant youth, as participants for  
5 research include housing and transportation instability, low socioeconomic status, race/ethnicity,  
6 cultural norms, and safety and legal concerns (Bradley, Lanier, Miller, Brawner, Sutton, 2019).  
7 Latinx youth in high-risk settings may be difficult for researchers to engage in substance use  
8 research because they could face retributory harm if they identify their experiences to any entity  
9 perceived as an authority (e.g., researchers). Latinx youth on the U.S.-Mexico border experience  
10 perceived disordered neighborhood stress, drug trafficking, militarized border security,  
11 disproportionately punitive drug and immigration enforcement, and racial profiling (Valdez,  
12 2019; Salerno Valdez 2020). Thus, Latinx youth on the border may be unwilling to engage in  
13 substance use research that elicits information of personal substance use history, or sharing  
14 knowledge of personal or familial experience in the drug trade due to substantial fear for their  
15 personal safety or social repercussions. Empirical findings that posit viable strategies to engage  
16 marginalized youth in substance use research are lacking.

17 Participatory approaches show promise in increasing participation of historically  
18 underrepresented youth in research (Ozer, 2016). This article discusses the youth-led  
19 participatory approach used to (a) develop and pilot test a culturally, regionally, and  
20 linguistically tailored substance use instrument, and (b) engage 445 Latinx youth to participate  
21 in a cross-sectional study to assess epidemiological patterns of youth substance use on the  
22 U.S.-Mexico border.

23 METHODS

24 *Partnership Development*

25           A local youth health coalition and the principal investigator (PI) engaged in a youth  
26 participatory action research (YPAR) project to examine the environmental factors that influence  
27 substance use among youth in a community on the U.S.-Mexico border. YPAR is a form of  
28 participatory research whereby youth learn how to conduct research, and use their findings to  
29 engage in social action at the local community and policy levels (Ozer, 2016). The research team  
30 consisted of the PI, the youth coalition, and the youth coalition coordinator. Faculty from the  
31 University of Arizona and mentors of the PI, a doctoral candidate, had fostered a long-standing  
32 relationship with this specific border community and the youth coalition. Because the PI was a  
33 white academic outsider, it was important to work closely with the youth coalition coordinator,  
34 who was a bi-cultural, bi-lingual, and civically engaged member of the community. The youth  
35 coalition's primary focus was tobacco prevention policy in the border community, and a focus on  
36 substance use in general, therefore, fell within the scope of their purview. The coalition consisted  
37 of 25 Latinx youth ages 14-18 from the community, who provided parental consent and assent to  
38 participate in the study. The research team met several times to build rapport; develop bilateral  
39 goals of the project outcomes, processes for accountability; and establish data ownership  
40 agreements prior to the study (Mercer et al., 2011). This study received human subjects approval  
41 from the University of Arizona's Human Subjects Protection Program.

42 *Study Design*

43           In Stage I, the academic-community collaborative team used a Photovoice process to  
44 examine the perceived environmental factors that increase risk of, or protect against, substance  
45 use among adolescents living at the border. The youth were responsible for data collection,  
46 analysis and parts of the dissemination for the Photovoice phase of the research (Valdez, 2019).

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47           In Stage II, the academic-community research team developed and pilot-tested the  
48 Border Adolescent Substance Use Survey (BASUS). We used the overarching themes, relevant  
49 terms and definitions identified in the Photovoice process to identify existing validated  
50 instruments to measure select variables. For those novel variables not represented in the  
51 literature, the research team developed new questions for the BASUS. The PI crafted the  
52 questions and presented the questions to the youth coalition for approval. Finally, the PI pilot  
53 tested the BASUS with the youth coalition.

54           In stage III, we developed a recruitment strategy to recruit students from the local high  
55 school to participate in the cross-sectional study using the BASUS. One week prior to data  
56 collection, the lead author described the study to 10 math classes composed of freshmen,  
57 sophomores, juniors and seniors in order to get a representative sample of youth ages 14-18 in  
58 the community. Students provided parental consent and assent prior to participation. The  
59 research team delivered the BASUS during math class at the school computer lab. As an  
60 incentive to participate, BASUS participants received 10 *student dollars* (to be used in the high  
61 school's student store) for submission of the parental consent and participant assent forms, and 5  
62 *student dollars* for completion of the BASUS. A total of 597 students received invitations to  
63 participate, and 445 eligible consented participants completed the BASUS. We achieved 100%  
64 of our recruitment goal (n=400) and a 75% response rate overall out of 597 youth (Salerno  
65 Valdez, 2020).

### 66 KEY LESSONS LEARNED

#### 67 *Youth-Led Instrument Design*

68           The youth coalition provided critical insights on the design of the BASUS (stage II),  
69 particularly the phrasing of the questions. They expanded the definition for youth involvement in

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70 drug trafficking to include store, sell, or transport drugs. They also identified a theme that was  
71 not adequately queried by existing questions and proposed additional questions, including, “In  
72 my community, music that glorifies drug trafficking or the *narco* lifestyle, like *corridos*, hip-hop,  
73 reggae, and bachata, influences adolescents to get involved in moving, selling or storing drugs”.  
74 Youth contributed their regional, cultural and linguistic expertise to develop a community-  
75 tailored substance use instrument.

### 76 *Youth-Led Recruitment Strategy*

77         The youth coalition suggested that the BASUS data collection should be at the local high  
78 school (stage III). The PI met with the school board, the principal, and the school superintendent  
79 to determine their level of interest and engagement with the study. All parties agreed that the  
80 data collected would be owned by the community and used to better understand the youth in the  
81 community, develop tailored prevention strategies, and apply for grants to support prevention  
82 initiatives. The youth coalition advocated that the recruitment messaging should frame the data  
83 as being beneficial to the youth (i.e., data could be used to apply for grants, allocate local  
84 resources to a youth center). The youth coalition also provided unique insight regarding the  
85 general culture of the student body, who to partner with, and how to incentivize participation.  
86 We determined that more students would return parental consent forms and participate in the  
87 study with *student store* dollars as an incentive, paid for with grant funds. *Student store* dollars  
88 are used to purchase snacks and other school promotional items (e.g., t-shirts) from the *student*  
89 *store*. The decision to use *student store dollars* resulted in an 83% submission rate for  
90 consent/assent forms. This particular success illustrates the importance of partnering with the  
91 youth coalition to enhance recruitment.

### 92 *Assure Participant Confidentiality*

93           The youth coalition determined that students might not want to participate in the study  
94 due to legal and personal safety concerns. Illustrating the youth coalition’s concerns, during one  
95 class presentation a student declared “I’m not doing that. I ain’t no snitch”. Thus, we took a  
96 number of steps to emphasize participant confidentiality. We obtained a Certificate of  
97 Confidentiality from the National Institutes of Health. Further, we assured students that their  
98 responses would be de-identified, locked in a safe place, and would not be released to school  
99 officials or parents. As an additional security measure, the research team use the online *REDCap*  
100 (*Research Electronic Data Capture*) platform, which guarantees data safety and participant  
101 confidentiality. The team carefully conveyed this information to participants both verbally and  
102 written at two time points. We believe that by emphasizing participant confidentiality and safety,  
103 as suggested by the youth coalition, students felt sufficiently safe and comfortable to respond to  
104 the BASUS.

#### 105 CONCLUSIONS

106           Our lessons learned illuminates that using participatory methods (e.g., YPAR) can  
107 enhance instrument design and recruitment efforts to increase underrepresented youth  
108 engagement in in substance use research. Future substance research should prioritize more fully  
109 engaging youth in the research process, particularly when trying to reach historically  
110 marginalized populations.

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