Climbing the “Ladder of Participation”: Engaging Experiential Youth in a Participatory Research Project

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ABSTRACT

Objectives: Street-involved youth are at high risk for acquiring HIV and hepatitis C infection due to potential engagement in high-risk behaviours, including injection drug use. The Youth Injection Prevention (YIP) Project sought to identify factors that prevented street-involved youth from moving into injection drug use in Vancouver, BC. Our project used a participatory research orientation to study these factors. This paper describes the level of participation observed among the street-involved youth taking part in our project.

Methods: The YIP project employed street-involved youth as co-researchers. To assess the level of participation among the co-researchers, we applied Roger Hart’s “Ladder of Youth Participation”. Each advancing rung in the ladder represents a higher level of participation. We compared the youth’s involvement in the project to the rungs in Roger Hart’s tool.

Results: Throughout the duration of the project, the youth’s participation increased. Initially the youth had low levels of participation as they were hired based on their life experiences and initially consulted and informed. Over the course of the project, team- and skill-building activities took place. This helped the project environment evolve into a safe space where youth felt comfortable to engage at the highest levels of participation.

Conclusion: The YIP Project was successful in being a highly participatory research project. In a safe and open environment, the youth felt comfortable to question and take on initiatives that went beyond the academic researcher’s initial expectations. This project highlights the success of engaging street-involved youth in participatory research.

Key words: IDU; youth; participatory research

La traduction du résumé se trouve à la fin de l’article.

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In Canada, approximately 150,000 youth aged 15-25 years are estimated to be street involved.¹ “Street involved” is defined by the United Nations as “Any boy or girl... for whom the street in the widest sense of the word... has become his or her habitual abode and/or source of livelihood, and who is inadequately protected, supervised, or directed by responsible adults”. These youth are at risk for many negative health outcomes, including HIV, hepatitis C and sexually transmitted infections, addictions and overdoses, due in part to corresponding high-risk behaviours involving sexual practices and substance misuse.²⁻⁴

In Vancouver, British Columbia, approximately 16% of young persons who inject drugs are infected with HIV, and 57% with hepatitis C.⁵ Injection drug use is reported by 41% of youth in a cohort of Vancouver street youth who use an illicit drug in addition to marijuana, and 36% of street youth surveyed in another Vancouver-based study.^{6,7} The Youth Injection Prevention (YIP) Project aimed to obtain the perspectives of street-involved youth in Vancouver regarding youth injection and prevention behaviours. The results will contribute to an understanding of factors, supports and services that can prevent youth from injecting drugs and promote youth resiliency. In order to best obtain the youth perspectives on these topics, experiential youth were hired to facilitate the focus group discussions. “Experiential”, in this case, meant experience with street entrenchment and/or illicit drug use. The inclusion of experiential youth as co-researchers placed the YIP project within the range of research described as participatory research (PR).

Participatory research and youth involvement

PR, in its various forms, is an increasingly popular method of research in public health.⁸⁻¹⁵ The aim of PR is to engage individuals who have personal experience of the research topic as co-researchers and implementers. Some of these PR projects have involved marginalized youth in areas of relevance and importance to them.^{9-13,15}

“Youth PR” studies have been criticized as involving youth as “tokens” or as research *subjects*, resulting in low levels of youth self-advocacy and empowerment.¹⁶ In previous studies, youth co-researchers and peer helpers were engaged based simply on age similarity rather than their life experience or ability to relate.^{12,17-20} Full involvement of marginalized youth in participatory research requires that they be involved in all aspects of the research process from inception to dissemination.¹⁶ Unfortunately, few research

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projects involve truly *experiential* youth, while even fewer involve these youth at a level of engagement where they are empowered by their participation.^{12,20}

Roger Hart's "Ladder of Youth Participation" is a modelling tool that describes 8 possible levels of youth participation in the context of research projects (see Figure 1). The creation of the ladder in 1992 was part of a global drive for participation, with the purpose of being a directive tool for this relatively unknown field.^{21,22} It has been used previously to evaluate youth participation in research, including youth participation in harm reduction interventions involving illicit drug use.^{20,23} The rungs at the bottom of the ladder, which consist of manipulation, decoration, and tokenization of youth in research projects, are considered "non-participatory". Through figurative "climbing" of the ladder, participation occurs with increased engagement and active involvement.

The Youth Injection Prevention Project

The main objectives of the YIP project were to explore the factors that street-involved youth identify as preventing themselves and their peers from injecting, and factors that promoted resiliency. These themes were explored through focus groups with street-involved youth. Involvement of youth with personal experience and insights as co-researchers was expected to increase relevance and validity in the process and interpretation of the findings, as well as potentially providing research capacity and personal growth. Youth co-researcher participation in the project was intended to involve focus group moderation, note-taking and validating the research findings. This paper describes how youth co-researcher participation in the YIP project evolved from the initial intent – shown as climbing a metaphorical "participatory ladder" – and the successes, challenges and lessons learned during this process. Ethical approval for the YIP study was obtained from the University of British Columbia/Providence Health Care Research Ethics Boards.

Climbing the ladder of participation

Community organizations providing service to street-involved youth and interested in collaborating on the YIP project were identified during the funding proposal development. These organizations distributed the youth co-researcher job description and encouraged appropriate youth to apply. Ten youth, most of whom were experiential, were hired to conduct the focus groups. Although the intent of the project was for youth to co-facilitate the focus groups, we did not know if this would be feasible and what role the youth would be able to take. At the beginning of the project, the youth according to Hart's ladder would be classified as non-participatory, i.e., rungs 2 (decoration) and 3 (tokenization).

The youth and academic researchers developed a bilateral agreement of respect and expectations. During the initial training, four youth who needed to focus on other priorities left the research team; six youth remained with the team until focus group completion. Of these six youth aged 19 to 24 years, three were female, one identified as having Aboriginal ancestry and two had previously injected drugs.

The youth co-researchers provided input into the interview and focus group guides for face validity (rungs 5 and 6, consultation and shared decisions). The project coordinators designed and led the qualitative research methods training which consisted of three

Figure 1. Roger Hart's Ladder of Young People's Participation

general aspects: 1) how to lead focus groups and take field notes, 2) sensitivity training and 3) community partner site visits to familiarize the youth co-researchers with the sites where the focus groups were held. The sensitivity training helped the youth develop an awareness and understanding of themselves, of group dynamics, and of their behaviour and role within both the team and the focus groups. Mock focus-group training sessions were held in which the youth and project coordinators performed role playing.

In addition to the formal training sessions, optional team-building activities occurred, including movie nights, bowling, and participation in community events. These activities improved team cohesion and allowed the coordinators to better understand the youth co-researchers' needs and growth within the project. The youth were encouraged to reflect and discuss their learning and achievements throughout the project. During the training and development of the YIP project, the youth co-researchers were involved at participatory levels on the metaphorical ladder rungs 4 and 5.

The training enabled the youth co-researchers to co-facilitate the focus groups, with one youth moderating discussions and a second taking field notes. The YIP team conducted 10 focus groups with 45 street-involved youth and these were audio-recorded. The project coordinator or assistant coordinator attended the focus groups to provide support. Throughout the data collection, the YIP youth co-researchers were involved at rungs 4 and 5 of Hart's ladder. The youths' pre-determined roles in data collection as focus group moderators and note-takers were consistent throughout the project, although their skills and confidence increased.

The initial plan was for the project coordinators to code the focus groups transcripts. However, the youth requested training in the basics of qualitative analysis methodology. The youth were provided with quotes from the transcripts; they grouped similar concepts on poster boards and identified and named themes. Themes identified by the youth were compared with those identified by the study coordinators and these were discussed to develop consensus. By initiating their own participation in creating the coding framework, the youth were situated on rungs 6 and 7. Not all focus group transcripts were coded by the youth and continued involvement at this level was based on their motivations, skills and interests.

Table 1. Location of Youth Co-researchers on the Participatory Ladder Throughout the YIP

Ladder Level	Description	Reasoning	YIP
1. Manipulation	Youth are told to support a cause or project and pretend it was inspired by them, when it was actually created by established researchers.	Attract attention, increase likelihood of obtaining funding, or portray community relevance.	Preparing the proposal and decision to include experiential youth.
2. Decoration	Youth are asked to show support for a cause, but researchers do not pretend it was inspired solely by the youth.	Attract attention, increase likelihood of obtaining funding, or portray community relevance.	Hiring of the youth.
3. Tokenism	Youth led to believe they have a “voice”, but their opinions bear little weight in research planning or implementation.	Attract attention, increase likelihood of obtaining funding, or portray community relevance.	Hiring of the youth.
4. Youth are assigned and informed	Youth are well informed of their role, which is inflexible, but false impressions are not given to youth or to the public.	Youth are given the experience of being involved in research. Potential added validity or relevance to research methodology.	Youth trained to facilitate and take notes at focus groups; visits to community sites; instruction (re: qualitative research).
5. Youth are consulted and informed	Youth asked to critique and give advice on projects created by established researchers. Youth are well informed of their role and the effect of their inputs on the research projects.	Increase in validity or relevance of the project to youth communities. Give youth the experience of being involved in research projects.	Developing questioning guide; youth feedback (re: how focus groups went and suggest changes for next focus group).
6. Adult initiated and shared decision making with youth	Youth invited to share in decision making and running of the project that adult researchers have created. Youth and adult inputs are taken into account. Example: participatory action research.	High validity and relevance of the project to youth communities. Give youth the experience of being involved in research projects.	Performing qualitative analysis; developing presentations; practising presentations; presenting at the community forum.
7. Youth leading projects and initiating action	Youth initiate and run a research project on their own, with some advice and support from adults and other researchers. Most decisions are made by youth, and the adult roles are subject to youth requests.	Project is relevant to youth communities. Youth are able to express their voices to their full ability. Youth gain the experience of creating and running a research project.	Youth request qualitative research training; youth select quotes for presentations; youth request to attend conference in order to present; youth lead fundraising activities.
8. Youth and adults sharing in decision making	Youth and adult researchers are involved in an equal partnership, but the project itself is inspired by youth. Decision making is split equally between both parties.	Adults grow to understand the youth perspectives. Youth are empowered and are also able to learn from established researcher expertise.	Youth lead fundraising activities; youth develop funding proposal for dissemination video.

Oral presentations of the preliminary findings were accepted at two Canadian conferences. The youth requested to co-present at these conferences; as youth attendance was not included in the initial proposal, no funding was allocated. The youth co-researchers therefore took the initiative to organize two fundraising activities: a presentation and silent auction of donations solicited from the community and a “drag show” performed by one of the youth co-researchers. To reduce the registration costs, the youth volunteered at the conferences and one youth received a scholarship.

The project coordinators accompanied four youth co-researchers to the Canadian Conference on AIDS/HIV Research and two other youth presented at the Canadian Public Health Association conference. Each youth, with input from the coordinators, chose the quotes to correspond with the themes they presented. Presentation practice sessions were held prior to the conferences. Preliminary findings and experiences at the conference were shared with the community partners at a “community forum”. Youth’s overall involvement in this stage is described as being on the metaphorical ladder rungs 7 and 8.

Further dissemination

Once the youth’s official involvement in the project was complete, youth continued to be engaged in activities to disseminate results. These activities included: 1) a presentation in a masters of public health qualitative research course at a local university, 2) the creation of a “how to involve experiential youth in research” video – the story board and editing of the video, including interviews with the YIP team, were co-led by a youth co-researcher, and 3) a successful application for a grant to disseminate the study findings through a video.²⁴

This paper is informed by a review of the researchers’ field notes and the minutes from the team meetings and debriefing sessions, semi-structured interviews with the youth at the completion of the project, and insights shared during the making of the “how to involve experiential youth” video.

DISCUSSION

The progression of youth participation seen throughout the YIP project can be metaphorically linked to the climbing of a participatory ladder, similar to that created by Roger Hart.²¹ In our study, we found that the youth co-researchers moved between various levels of participation in a way that was not predicted in the initial design of the project. The ease with which youth were able to exert their autonomy in project involvement, and the ability of the project coordinators to gauge appropriate project involvement of the youth at each stage, were made possible through the flexibility of the project as well as through mutual understanding between the youth and project coordinators, which was strengthened through training and team-building sessions.

Overall, we saw the youth climb up the ladder towards increased participation (see Table 1). However, not all youth climbed at the same speed or participated at the same level at each stage of the project. This flexibility in movement between levels of participation allowed youth to determine their own level of involvement based on their ability. This contrasts with predetermining uniform expectations of all youth regardless of their strengths or concerns.

The knowledge and expertise of marginalized youth and other non-academic populations have often been disregarded in other settings.^{21,25} Such views are changing and lay community members with real-life expertise are increasingly valued as effective inter-

ventionists and co-researchers in their own communities.^{11,26,27} Engaging youth with first-hand experience of the research issue has a variety of benefits; it can address issues of trust and respect of the focus group participants and ensure relevance of the research.^{9,14,28,29}

Due to many challenges associated with involving non-academic experiential youth in research, some researchers believe that PR is not the most effective method of gathering valid results from marginalized populations.¹⁵ These challenges include time limitations and steep learning curves.¹¹ To accommodate increasing participation (including training regarding qualitative research and presentation skills and fundraising to enable conference attendance) and differential learning during the YIP project, extra sessions were created and deadlines extended, which had budget implications; this has been noted as a common issue in youth PR.^{10,11} Despite this accommodation and as noted in other studies, it was not feasible to fully involve the youth in all aspects of the YIP project, as many methodological techniques were too advanced to teach in our short time frame and not all youth were interested in or capable of long work hours.^{11,15,23} Furthermore, some communities and research agencies may not have confidence in experiential youth involvement and expertise,¹¹ however, this was not evident in the YIP project.

Involvement of youth co-researchers creates a more relevant research project as they bring their realities and their interpretation of the findings is based on experience. It also benefits the youth co-researchers themselves. As found in other PR studies where youth have opportunities to impact their surrounding communities, the YIP youth co-researchers were empowered and developed “pro-health” identities.^{11,12,14,17,20,30} The positive outcomes for “at-risk” youth co-researchers in the project were potentially greater than for youth chosen simply for age similarity.²⁰ Other studies have also found that engagement in public health research and initiatives contributed to youth making positive health and developmental choices, such as re-enrolment in school, reducing/stopping drug use, and addressing behavioural issues.^{9,11,30} The YIP co-researchers also gained public speaking experience, research skills, and opportunities to network with public health agencies and organizations, leading to further employment opportunities, appreciation of services available and the gaining of confidence to advocate for themselves and others with service providers; these are common benefits of youth PR.¹¹⁻¹³

CONCLUSIONS/RECOMMENDATIONS

Hart’s ladder is a useful tool to assess the level of participation of youth in a research project. However, youth do not remain static or climb in one direction; instead they may move up and down the ladder. Team members bring varying skills and interests and so climb at different paces; they may also attain different rungs for different activities and components. Youth should be encouraged to climb to the highest level they are able and comfortable to reach. The individual’s and team’s achievement and growth should be acknowledged but individuals within the team should not be compared.

The team-building exercises that occurred throughout the YIP project were invaluable and led to increased understanding and respect between the youth co-researchers and the project coordinators. As the youth gained confidence in their research ability and developed interpersonal communication skills, they became

empowered to advocate for their own needs. To ensure that youth “truly” participate and determine their own level on the ladder of participation, we recommend that future studies involving experiential youth include frequent team-building exercises and evaluations of youth growth within the project.

We suggest that the benefits and challenges of involving youth in participatory research be assessed before embarking on such projects to ensure that both the youth and the research achieve maximum success.

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RÉSUMÉ

Objectifs : Les jeunes de la rue courent un risque élevé d'attraper des infections à VIH et à l'hépatite C du fait qu'ils peuvent s'adonner à des comportements à haut risque, dont l'utilisation de drogues par injection. Le projet YIP (Youth Injection Prevention) cherche à cerner les facteurs qui empêchent les jeunes de la rue de se tourner vers les drogues par injection à Vancouver, en Colombie-Britannique. Nous utilisons une approche de recherche participative pour étudier ces facteurs. Nous décrivons ici le niveau de participation observé chez les jeunes de la rue ayant pris part au projet.

Méthode : Le projet YIP a employé des jeunes de la rue comme co-chercheurs. Pour évaluer le niveau de participation chez les co-chercheurs, nous avons appliqué « l'échelle de participation des jeunes » de Roger Hart. Chaque barreau de l'échelle représente un niveau de participation plus élevé. Nous avons comparé l'implication des jeunes dans le projet aux barreaux de l'échelle de Hart.

Résultats : Au fil du projet, la participation des jeunes a augmenté. Au départ, leurs niveaux de participation étaient faibles, car ils étaient embauchés en raison de leur vécu et simplement consultés et informés. Au cours du projet, des activités de développement de l'esprit d'équipe et de renforcement des compétences ont eu lieu. Elles ont contribué à faire de l'environnement du projet un espace sûr où les jeunes se sont sentis libres de s'engager aux plus hauts niveaux de participation.

Conclusion : Le projet YIP a atteint un niveau de participation très élevé pour un projet de recherche. Dans un environnement sûr et ouvert, les jeunes se sont sentis libres de poser des questions et d'accepter des initiatives dépassant de loin les attentes initiales de la chercheuse universitaire. Ce projet montre l'efficacité de recruter des jeunes de la rue pour faire de la recherche participative.

Mots clés : UDI; jeunes; recherche participative