ANNOTATED BIBLIOGRAPHY: PARTICIPATORY ACTION RESEARCH (PAR) AND COMMUNITY ENGAGED RESEARCH (CER) WITH YOUTH

MARCH 2019

Courtney Primeau*, Carla Giddings**, and Kendra Cheeseman*

*Project Research Assistant, Research Shop
**Project Manager, Research Shop

INTRODUCTION

During initial meetings, Ron MacKinnon (Executive Director, Community Resource Centre of North and Centre Wellington) and Chrissy Scott (Project Coordinator for Rural Youth Awareness Campaign, Community Resource Centre of North and Centre Wellington) outlined the importance of prioritizing the voices of youth in North and Centre Wellington in the development of youth services, resources, and spaces. As a team, we anticipate that youth will be more likely to access services and resources that they have had a stake in creating. Therefore, our goal in this project is to elicit North and Centre Wellington youth's perspectives on desired services and resources through effective arts-informed methods. This annotated bibliography is the first step in the project. In it, we give brief summaries of a small sample of the most relevant academic research on creative methods for engaging young people in research.

METHODS

Courtney Primeau (Research Project Assistant at the Research Shop), with support from Carla Giddings (Project Manager at the Research Shop) completed an annotated bibliography on arts-based or arts-informed participatory action research (PAR) and community engaged scholarship (CES) with youth. This is a brief overview of current research involving PAR and CES with youth, and includes a reference list with summaries of each research article. The annotated bibliography sets the stage for designing focus groups with youth through the Community Resource Centre North and Centre Wellington (CRC). This first step will inform future research by ensuring that we are paying attention to best practices and innovative approaches. Kendra Cheeseman (Research Project Assistant at the Research Shop) and Jessica Lukawiecki (Research Shop Assistant Editor) edited the document.

We scanned the literature by searching seven of the most frequently used databases and search engines (CINAHL, ERIC, Google Scholar, ProQuest, PsychINFO, PubMed, and MEDLINE) through the University of Guelph library. We used the following keywords to find as many relevant articles as possible, with the specific inclusion and exclusion criteria outlined for the project:

COMMUNITY ENGAGED
SCHOLARSHIP INSTITUTE

cesinstitute.ca

- Youth

- Participatory Research; Participatory Action Research; Community Based Participatory Research; Community Engaged Research; Community Engaged Scholarship

- Arts-based Research

- Focus Groups

Inclusion Criteria

- Peer-reviewed articles published between 2008-2018

- Articles published in English

- Articles focused on research with youth (aged 12-21 years)

- Research involving participatory or arts-based methods

- Research involving groups of youth (as opposed to research with individuals)

- Focus on Canadian contexts and small-town communities, completed in schools or community settings

Exclusion Criteria

- Research conducted before 2008

- Research involving individuals over 21 years of age

- Research involving individuals less than 12 years of age

- Research using individual methods, such as individual interviews

Based on the inclusion and exclusion criteria, Courtney and Carla selected the seven most relevant articles (listed below). We also included an article suggested by Karen Nelson (Research Shop Coordinator) and Melissa Tanti (Community Engaged Learning Coordinator, CESI). Courtney completed all annotations. We then sought input from the CRC partners (Ron and Chrissy) regarding content, formatting, and accessibility.

UNIVERSITY of GUELPH

COMMUNITY ENGAGED
SCHOLARSHIP INSTITUTE

GLOSSARY

Arts-based methods: Qualitative research methods that use art in some or all steps of the research. The researchers and participants use artistic methods to understand concepts or ideas, or to personally explore a particular concern, issue, or topic. Art forms (including visual, narrative, and performance methods) are necessary for the research process itself, and important for identifying the research question, generating and analyzing data, and presenting the results of the research (Coemans et al., 2015; Salkind, 2010). All articles in the annotated bibliography use arts-based methods in their research.

Community mapping: A data collection and communication tool that is created by developing maps of different neighborhoods to identify gaps, assets, capacities, and abilities of these neighborhoods. This tool tells a story about what is happening in the community, and can help identify areas that may require interventions (National Community Mapping Institute, n.d.). See **Robson et al. (2016)** in annotated bibliography.

Community engaged scholarship (CES): A mutually beneficial partnership between the researcher and the community. This results in the creation and communication of knowledge from teaching, discovery, engagement, integration, or application (Jordan, 2007). All articles in the annotated bibliography are forms of CES.

Digital storytelling: A multimedia art form combining storytelling with digital media to reveal a personal story, and to improve our understanding of human experiences. This typically involves a two to five minute audio-visual clip that brings together photos with voiceover narration, and has been used most commonly in research involving marginalized populations (de Jager et al., 2017). See **Derr et al. (2013)** in annotated bibliography.

Focus group: A qualitative research method that brings together a group of individuals to interact and share their opinions and beliefs to generate data. Participants are encouraged to ask questions, share their experiences, and comment on each other's experiences and points of view. A focus group is typically guided by a facilitator and has a specific discussion topic (Community Tool Box, 2018 ; Kitzinger, 1995). See **Bagnoli and Clark (2010)** and **MacDonald et al. (2011)** in annotated bibliography.

Mixed-method approaches: Research that collects and analyzes data, integrates study findings, and makes conclusions using both qualitative and quantitative research approaches or methods in a single study. Using both qualitative and quantitative data approaches may provide a more complete understanding of the research question and study findings (Salkind, 2010).

Participatory research methods: Study approaches in which the planning and conducting of the research process takes place in collaboration with the individuals groups or communities under study. Typically, researcher-participants also direct the research outputs and how the research will be shared (i.e., knowledge mobilization). The researcher-participants become equal partners in the research process by contributing their knowledge and experiences (Bergold & Thomas; Participate, n.d.). See **MacDonald et al. (2011), Moules and O'Brien (2012)**, and **Robson et al. (2016)** in annotated bibliography.

Photovoice: A participatory photography method that lets participants identify, represent, and enhance their community using a specific photographic technique. Study participants are encouraged to capture visual representations of their everyday lives to help identify challenges and opportunities the community faces (Wang & Burris, 1997). See **Derr et al. (2013)** in annotated bibliography.

Qualitative research: A term that includes a wide variety of research methods that provide in-depth data based on participants' experiences. These methods attempt to reflect the social world around us. A key characteristic of qualitative research is the use of non-numeric data, such as data derived from focus groups, key informant interviews, or visual material (e.g., photographs, movies, or advertisements) (Given, 2008; Salkind, 2010). All articles in the annotated bibliography use qualitative research methods.

Quantitative research: Studies that generate numerical data that can be used to describe changes in measurable characteristics of a study population of interest (Salkind, 2010).

Reflective writing: Products such as autobiographies, journals, or logs. A study participant personally reflects on an experience, situation, thought, or feeling. This type of writing is intended to lead to learning for the participant and to result in some kind of action or change in behaviour (Bashan & Holsblat, 2017; Jasper, 2005). See **MacDonald et al. (2011)** in annotated bibliography.

Video diaries: Digital diaries used to collect data on study participants' lives over an extended period of time. Participants are provided with a video camera and typically participate in a daily video session to share their feelings, reflections, and experiences with the researcher (Buchwald et al., 2009; de Jager et al., 2017). See **Bagnoli and Clark (2010)** in annotated bibliography.

ANNOTATED BIBLIOGRAPHY

1. **Bagnoli, A., & Clark, A. (2010). Focus groups with young people: a participatory approach to research planning. Journal of Youth Studies, 13(1), 101-119.**

The authors conducted focus groups with youth (13 year olds) in the United Kingdom as part of the Young Lives and Times project spanning over 10 years. The project examines the lives, relationships, and identities of youth and how these change over time. The focus groups were held in urban and rural schools. Youth involved in the study preferred to be interviewed in groups with peers, rather than alone. Participants also preferred more engaging research methods that reflect their own interests, as opposed to "sitting and talking" to adults. Additionally, the researchers noted a few challenges with participatory approaches to research with this age group. First, there was often a conflict between the goals of the research and the motivations of study participants. For example, some of the youth disagreed with the inclusion of questions on sensitive issues. Secondly, youth requested creative methods in the research, such as video diaries and self-portraits. However, these innovative approaches can pose difficulties with data analysis and dissemination. Generally, the participants had a desire for control over the research methods. Overall, the researchers concluded that engaging with youth in the research context encouraged more creative thinking about the methods.

Methods: Focus groups with 13 year olds in urban and rural locations in the United Kingdom.

COMMUNITY ENGAGED
SCHOLARSHIP INSTITUTE

cesinstitute.ca

- Qualititave research method where a facilitator guided group interviews.

- Incorporated arts-based methods of video diaries (i.e., videotaped personal reflections by participants) and self-portraits (i.e., drawing, painting, or collage made by participants to express how they understand themselves).

Strengths:

- Researchers can collect in-depth information in a short period of time.

- Youth may feel more comfortable, engaged, and in charge of the process when working with peers.

- Focus groups can be adapted to include creative activities and approaches.

Challenges:

- Participants may not want to answer certain questions.

- Creative approaches (e.g., video diaries and self-portraits) may be more difficult to analyse and share the results.

- The study took place in the United Kingdom and the results may not be representative of the experiences of youth in Centre and North Wellington, Ontario.

2. **Derr, V., Chawla, L., Mintzer, M., Cushing, D. F., & Van Vliet, W. (2013). A city for all citizens: Integrating children and youth from marginalized populations into city planning. Buildings, 3(3), 482-505.**

The United Nations has stated that it is important to include youth in decision-making and participation in local government (such as urban design) regardless of their age, ethnicity, and family income. All youth have a right to participate in decisions that impact the future of their city, and it is especially important to include marginalized youth such as those from low-income situations, immigrant families, and ethnic minorities. The Growing Up Boulder program (GUB) in Boulder, Colorado uses a participatory approach to integrate the perspectives of youth into urban planning and design. The authors of this article describe key lessons for achieving participation of youth in city planning and government decisions, as well as different approaches to engage youth participants.

COMMUNITY ENGAGED
SCHOLARSHIP INSTITUTE

cesinstitute.ca

Methods: Arts-informed approaches with youth in Boulder, Colorado. Research questions are outlined for youth participants, and artistic approaches act as an expressive device for participants in the research process.

- **Action groups:** GUB formed a Youth Steering Committee which includes middle and high-school students who show leadership skills. Principals at the school made recommendations for leaders. The committee organized an event that brought youth together to express their interests and concerns for civic development, and note three priority areas : 1) youth-friendly businesses, 2) public art, and 3) nightlife. The nightlife category used art, including drawing and creating banners, to identify aspects of the city that the youth like and dislike.

- **Digital storytelling:** Participants created digital media (i.e., mini documentaries) taking photos, recording a story, and choosing or making music to discuss issues from a personal perspective. This allows participants to tell their own stories. Youth participants took cameras around the community to identify community issues they felt were important and to create a short video. All videos were shown to the Boulder City Council at a screening session.

- **Photovoice sessions:** GUB staff engaged socially disadvantaged youth and families to participate in photovoice sessions, during which youth photographed city spaces that they like. Photos were shown at a public meeting. Photovoice was also used by youth to document their neighborhoods and issues they face within them. These photos were shown in a month-long exhibit at a local recreation centre.

Strengths:

- Engaging with research is important for youth, but is more important for youth who experience a lack of power to make decisions in their lives.

- Methods to engage youth must be on their own terms. Youth must find participation exciting and relevant to them.

Challenges:

cesinstitute.ca

- The translation of arts-based methods, such as photography and digital media, into results can be challenging for the researcher and may require extra time in comparison to findings from interviews or surveys.

- Reducing barriers does not automatically ensure youth engagement. For this reason, it is very important to go where the youth are (i.e., in a classroom or within the larger community) to establish a safe setting and encourage consistent participation. This can help shift to a more youth-centered discussion and minimize feelings of social exclusion.

3. **Fraser, K. D., & al Sayah, F. (2011). Arts-based methods in health research: A systematic review of the literature. Arts & Health, 3(2), 110-145.**

Arts-based methods or qualitative research that uses art in some or all stages of research, is an increasingly popular approach that can also serve important therapeutic purposes for participants. The authors conducted a systematic review of peer-reviewed literature in seven databases to summarize and describe the arts-based methods in health research. The authors included 30 studies in the review.

Methods:

- Across the 30 studies they identified quantitative, qualitative, and mixed-methods research approaches.

- Authors included a broad range of demographics in this review.

- Knowledge production and knowledge translation were the primary reasons for using arts-based methods.

- Search terms included three disctinct arts-based approaches: visual, performance, and literary arts.

Strengths:

- Two of the 30 articles included in this review (Hanna & Jacobs 1993, Hanna & Jacobs 1995) have a study population falling within our age inclusion criteria.

- Highlights the breadth of artistic methods (both alone, and in combination with other methods) that can be used in health research.

Challenges:

- Articles are not specific to youth in this review and vary in terms of their study population.

- Unit of analysis is not consistent across all of the studies in the review (i.e., some research is at the individual level, whereas others focus on groups).

4. **Hanna, K. M., Jacobs, P. M., & Guthrie, D. (1995). Exploring the concept of health among adolescents with diabetes using photography. Journal of Pediatric Nursing, 10(5), 321-327.**

The lens through which an individual views health can impact their participation in behaviours that could either positively or negatively impact their health. This research explores the concept of health among adolescents with diabetes using photography to capture the study participants' opinions, perceptions, and thoughts on health.

Methods: Nine participants ages 12-19 attending a diabetes clinic in December 1993.

- Participants used photography, an arts-based or qualitative method that utilizes art as an essential part of the research.

- Participants were given a Polaroid camera and took up to 10 photos that are examples of health, and then described how the photos demonstrate health.

Strengths:

- Photography approach could be useful for exploring perceptions related to other topics or issues among this demographic group.

Challenges:

cesinstitute.ca

- Time is needed for participants to communicate their thoughts through photography. The authors have experience adopting this method in another study and recommend using this approach when there are not strict timelines.

- Took place in a metropolitan city in the Midwestern United States, so its relevance to small-town Canadian communities may be lower.

5. **MacDonald, J. A. M., Gagnon, A. J., Mitchell, C., Di Meglio, G., Rennick, J. E., & Cox, J. (2011). Include them and they will tell you: Learnings from a participatory process with youth. Qualitative Health Research, 21(8), 1127-1135.**

MacDonald et al. describe how participatory or collaborative research designs that employ an arts-based process with youth can enhance the overall research process in a school setting. Arts-based research is described as qualitative research where art is central to the research process. The research team conducted a school-based study in Prince Edward Island to incorporate students' contributions to curriculum development around the prevention of sexually transmitted infections.

Methods: Students ages 15-17 attending a school in Prince Edward Island discussed sexually transmitted infections in focus groups.

- Focus groups brought together students ages 15-17 to interact and discuss their opinions on sexually transmitted infections in a directed, condensed period of time. Participants were encouraged to share their perspectives and to comment on each other's point of view.

- Participants consisted of 15 girls and 13 boys in eight initial focus groups. Four follow-up focus groups helped to evaluate curriculum resources.

- Use of arts-based methods or qualitative methods that have an art element were central to the process, including: role play, reflective writing, and drama or theatre.

Strengths:

COMMUNITY ENGAGED
SCHOLARSHIP INSTITUTE

- Having focus group facilitators who are similar in age and are the same gender as the participants in each focus group increases credibility and encourages peer acceptance and support on this topic.

- Research process improves with youth participation, and provides support for the benefits of using arts-based participatory methods.

Challenges:

- The topic of sexually transmitted infections is a sensitive topic, and facilitators may require specific training or strategies when facilitating these discussions.

- Focus groups took place at schools in Prince Edward Island, and may have limited relevance for schools in Wellington County, Ontario.

6. **Moules, T., & O'Brien, N. (2012). Participation in perspective: reflections from research projects. Nurse Researcher, 19(2).**

This article reflects on two participatory research projects that involve young people, and the authors use lessons from this research to discuss the benefits and limitations of current models of children's participation in research. Two research projects in the article have study populations of young people ages 8-16 years old. The first study aims to explore the role of young people in monitoring and evaluating the quality of hospital care. Youth are of secondary school age in this study.The second study is an evaluation of the use of children's services, with a study population between 8 and 15 years of age.

Methods: A comparison of youth services in hospital and children's services from two participatory research projects with youth ranging from 8-16 years old.

COMMUNITY ENGAGED
SCHOLARSHIP INSTITUTE

cesinstitute.ca

- For the first study, youth co-developed a survey for nurses on pediatric wards where the children had been patients. Due to ethical issues the surveys could not be completed and were published in a pediatric journal instead.

- In the second study, youth co-created and participated in arts-based research methods, including: T-shirt painting, youth-led reporting, collages, and a "diary room".

- Youth worked collaboratively with researchers and participated in all stages of the research process through a participatory research approach.

Strengths:

- Members who cannot be directly involved in the decision-making process (i.e., those who could not attend regular meetings) are still able to contribute from a more peripheral role and make valuable contributions to the research.

- For the needs-assessment, this finding shows that limited involvement in the development of research questions and participating in only one focus group means that the participants can still make important contributions to research.

Challenges:

- Roles of decision-making, initiation, and direction are a complex balance between the adult and youth researchers.

- Studies took place in hospital settings in the United Kingdom and the results may not be representative of the experiences of youth in Centre and North Wellington, Ontario.

7. **Robson, J., Ashbourne, L. M., & De Leon, K. (2016). The spectrum of visibility: youth experiences of marginalization and homelessness. International Journal of Child, Youth and Family Studies, 7(1), 104-124.**

This study is a small part of a youth participatory action project where youth ages 16-20 years old lacking stable or consistent housing worked with researchers to direct the research process through arts-based methods. This qualitative approach has art as an essential component in the research process, and allows research participants to contribute in a way that is self-expressive. This approach may reduce feelings of social

COMMUNITY ENGAGED
SCHOLARSHIP INSTITUTE

exclusion as a result of their living situations. The location is in a mid-sized urban centre in South-Central Ontario. The study group consisted of six participants aged 16-20 years old that attended weekly three hour sessions for a period of 10 weeks. Participants were recruited using posters at locations providing services to youth, such as youth shelters, alternative education programs, and drop-in centres.

Methods: Participatory research with youth in precarious housing aged 16-20 years old in South-Central Ontario.

- Group discussion and brainstorming led to arts-based activities that were specific to the interests of the study participants, including: painting, collages, drawing, self-portraits, mask-making, comic strips, and community mapping.

- Discussions were interactive and collaborative to encourage leadership.

Strengths:

- Collaboratively produced results with the participants ensure that youth experiences are being captured and reflected accurately.

- Use of community maps of different neighborhoods identified gaps, assets, capacities, and abilities of these neighborhoods. Community maps were a data collection and communication tool that helped tell a story about a neighbourhood and can be a resource for planners to distribute resources more equitably.

- Potential usefulness with North and Centre Wellington youth as an effective way for participants to highlight services and resources that may be lacking in their community.

- Investigates how youth envision their community, and provides great examples of ways to collaborate with youth and learn about their experiences and desires.

Challenges:

- Study participants need ongoing support. Authors note that checking in with participants after the group discussions was not successful.

ADDITIONAL REFERENCES

Bashan, B., & Holsblat, R. (2017). Reflective journals as a research tool: The case of student teachers' development of teamwork. *Cogent Education*, *4*(1), 1374234.

Bergold, J., & Thomas, S. (2012). Participatory research methods: A methodological approach in motion. *Historical Social Research/Historische Sozialforschung*, *37*(4), 191-222.

Buchwald, D., Schantz-Laursen, B., & Delmar, C. (2009). Video diary data collection in research with children: An alternative method. *International Journal of Qualitative Methods*, *8*(1), 12-20.

Coemans, S., Wang, Q., Leysen, J., & Hannes, K. (2015). The use of arts-based methods in community-based research with vulnerable populations: Protocol for a scoping review. *International Journal of Educational Research*, *71*, 33-39.

Community Tool Box. (2018). Section 6: Conducting Focus Groups. Retrieved from https://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/conduct-focus-groups/main

De Jager, A., Fogarty, A., Tewson, A., Lenette, C., & Boydell, K. M. (2017). Digital Storytelling in Research: A Systematic Review. *The Qualitative Report*, *22*(10), 2548-2582.

Given, L. M. (2008). *The SAGE encyclopedia of qualitative research methods, 1.* Thousand Oaks, CA: SAGE Publications, Inc.

Jasper, M. A. (2005). Using reflective writing within research. *Journal of Research in Nursing*, *10*(3), 247-260.

Jordan, C. (2007) Community-Engaged Scholarship Review, Promotion & Tenure Package. Peer Review Workgroup, Community-Engaged Scholarship for Health Collaborative, Community-Campus Partnerships for Health. Retrieved from http://depts.washington.edu/ccph/pdf_files/CES_RPT_Package.pdf.

Kitzinger, J. (1995).
Qualitative research: introducing focus groups. *Bmj*, *311*(7000), 299-302.

National Community Mapping Institute. (n.d.) What is Community Mapping? Retrieved
from http://communitymappingforhealthequity.org/what-is-community-mapping/

Participate. (n.d.) Participatory Research Methods. Retrieved from
http://participatesdgs.org/methods/

Salkind, N. J. (2010). Encyclopedia of research design Thousand Oaks, CA: SAGE
Publications, Inc. doi: 10.4135/9781412961288

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for
participatory needs assessment. *Health Education & Behavior*, *24*(3), 369-387.