Community-based Research Process Report

Income Security, Race and Health Project

Produced by: Access Alliance Multicultural Health And Community Services

May 2010







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1. Introduction

This report provides an overview of the community–based research (CBR) principles and processes in two phases of research conducted by the Income Security, Race and Health (ISRH) working group. It outlines the partnerships, collaboration frameworks and tools, CBR trainings and peer researcher involvement in the project. The report also discusses the challenges, successes and subsequent lessons learnt by the research team as the process has unfolded, particularly the advantages and disadvantages of conducting research using a community-based approach. This CBR process report is a supplement to the Executive Summary and Exposed Photobook produced for the Wellesley Institute. Copies of these reports can be downloaded from the Wellesley Institute's website: www.wellesleyinstitute.com. In Fall of 2010, the Income Security Working Group will release a series of research bulletins that will highlight key findings from phase 2 of this study.

The Income Security, Race and Health (ISRH) team is an interdisciplinary research group established in 2006 in Toronto under the leadership of Access Alliance with the goals of investigating the systemic causes of, and the relationship between, the growing racialized inequities in employment, income, and health. The team is comprised of academics, service providers, and peer researchers (low-income racialized community members who have been recruited and trained to serve as co-researchers). This study is focused on the Black Creek area. For the purposes of this project, we identify Black Creek as a composite of four neighborhoods (Humber Summit, Humbermede, Black Creek and Glenfield-Jane Heights) located in the northwest inner suburb area of Toronto. Black Creek was selected for this project not just because it is a low-income neighborhood with a high proportion of racialized people, but also because of the rich history of strength-based, grassroots activism in this community.

The team has successfully conducted two phases of research. Phase 1 utilized photovoice method to investigate the social impacts of poverty and racism. In Phase 2, the team conducted 8 focus groups with different racialized communities (and a survey with focus group participants) and 3 focus groups with service providers to investigate the systemic barriers and discriminations that racialized families face in the labor market and the impact these have on the income security and health of their families. An overview of the project's activities is provided in Table 1.1 below. Phase 1 and Phase 2 were funded by The Wellesley Institute, Metcalf Foundation, Toronto Arts Council and Ontario Arts Council. Initially, the ISRH working group had hoped to have all three phases of data collection completed by the end of 2009. However, in light of the substantive time and resources required to facilitate meaningful collaboration, the working group has decided to extend the project timeline and pursue additional resources for phase 3 of the study. Data from phase 1 and phase 2 has generated rich and compelling evidence about multiple systemic barriers that racialized groups experience in the labor market and the adverse impacts these have on their health.

Table 1.1: Overview of Project Activities

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2. Guiding Principles of CBR

The research approach of the ISRH team is guided by community-based research principles. Community-based research (CBR) within Access Alliance and within the ISRH Project departs from traditional research and is defined as:

'Research conducted by, for and with communities on issues that are relevant to the communities and with the goal of bringing positive social change in the community. It is a research approach that enables community members to participate not as "research subjects" but as research collaborators and agents of change. In CBR, research is not an end to itself but rather a way to give greater power and control to community members through meaningful participation in research processes. Therefore, CBR projects seek to bring about positive social change using action and advocacy that is based on solid research evidence.' (http://www.accessalliance.ca)

There is a growing recognition that 'traditional' research approaches tend to have limited understanding of the socio-economic complexities and the related health disparities faced by marginalized communities, and as such the contextual realities and agency within these communities to effect change is often missed. This is largely due to the fact that traditional research perceives communities of interest merely as 'research subjects' rather than involving them as co-creators of knowledge and agents of social change in identifying research issues, producing and analyzing knowledge, and using knowledge to mobilize social and policy change geared at overcoming systemic inequalities. In response to this, members of the ISRH working group have a shared commitment to the development of strong community voices and comprehensive, long-term approaches to issues of poverty. Specifically, the community-based framework through which this project has been and will continue to be implemented, nurtures existing leadership in Black Creek and leverages organic knowledge already present with in this low-income neighborhood.

One of the key goals of the ISRH team is to build research capacity of low-income racialized people from Black Creek and meaningfully involve them as co-researchers in the full life-cycle of the research project, beginning from the design phase. Working from with in a CBR framework also requires building the capacity of academics, project staff and service providers to meaningfully engage in a collaborative and participatory process. The ISRH team adopted CBR principles with the hope of **building sustainable capacities within communities** of interest for critical inquiry, collaborative knowledge production and transformation geared at promoting equity and social justice. Our CBR commitment and outcomes are reflected in the (1) strong inter-disciplinary collaborative partnerships that we forged between academics, community agencies, peer researchers, and students; (2) meaningful involvement of community members as 'peer researchers' through out the life cycle of the project, beginning from identifying research priorities for the project; (3) the CBR training and capacity building tools that we developed and then delivered to ISRH team (particularly to peer researchers); (4) the capacity building activities we did within the Black Creek community (5) and numerous tools that we developed and utilized to promote collaborative and empowering modes of designing research, collecting data, and analyzing data.

3. Community Consultations

The commitment to explore the relationship between income security, race and health and the formation of the ISRH working group evolved out of a series of consultations with community residents, service providers and past research partners. At the time of these consultations, members of the Access Alliance research team were committed to initiating a community-based research project that would somehow

engage members of racialized communities in building a richer understanding of health inequities. It was our hope that consultations would:

- a) Assist in establishing research priorities for Access Alliance and narrow the focus of this community-based research project
- b) Inform Access Alliance's CBR project planning process and implementation, particularly in the development of key principles for collaboration. This included the transfer and integration of lessons learnt from previous research partnerships
- c) Inform the development of Access Alliance's Peer Researcher Training Program

3a) Community Focus Groups in Black Creek

As a first step towards developing a community-based research project and model, Access Alliance engaged Black Creek residents in a critical discussion on social determinants of health (particularly employment) and related health inequities and in identifying priorities for research and action in the community. A community development worker (CDW) from the Black Creek area was hired to conduct outreach and provide support at meetings. She also played a key role in eliciting the support of local service providers (beginning with the Program Manager at Black Creek Community Health Centre) and in recruiting participants (potential peer researchers) for the project. As part of the planning process for these consultations, the Program Director from Black Creek Community Health Centre presented our project idea to a network of local community agency managers. A larger meeting with service providers working in Black Creek soon followed. The goals of these meetings were to inform agencies of our desire to do participatory research in the community, collect their advice for the upcoming focus groups and elicit support in recruiting the participants. In total, we held four focus groups with racialized community members in four different locations in the Black Creek area. The workshops were attended by a total of 61 participants. The workshop facilitation guide included a series of interactive, plain language exercises that asked participants to document the following:

- The contrast between the expectations they (or their parents) had prior to coming to Canada in relation to work and to health and the reality after arriving to Canada
- Their understanding of racialized health disparities in a Canadian context and how these concepts play out in their everyday lived experiences
- Resources they use to address the challenges they face and negative impacts on their health
- Research ideas and advocacy priorities; Participants used "dotmocracy" techniques to vote on priorities for action.

In all groups, experiences in the labour market were identified as problematic, including the lack of recognition of non-Canadian work experience and credentials; language barriers; underemployment; low wages; temporary work; long hours; and poor working conditions. Participants named racism (discrimination, exploitation) as key factors affecting their access to work and to health. These difficulties encountered in the labour market led to limited income, which in turn impacts other determinants of health, such as access to housing and healthy food. In all focus groups, mental health issues were identified as a key problem, with stress being widespread and depression and low self-esteem common.

After the focus groups data was analyzed and summarized, Access Alliance research staff facilitated a meeting on the findings with a group of academics, service providers and community members who had either participated in the focus group or were part of the planning process. At that meeting, participants expressed interest in doing outreach and mobilizing their communities around the issues identified. It was decided that the group would support the idea of conducting community based research to explore barriers that racialized community members experience in the labour market and the impacts of these barriers on health. Many of the participants agreed to part of a working group that would act as a community advisory committee for the project. It was understood that the working group would engage in a collaborative research design process that would generate focused research questions, a detailed research proposal and methodology.

3b) Consultations with Former Research Partners

In February 2007, the research team at Access Alliance organized two community consultations with individuals who had participated in Access Alliance research projects in the past. These consultations were the first step in developing a Peer Researcher Training Program and identifying strategies for the development of a truly collaborative CBR model. A total of 15 participants were asked to share their understandings of community-based research, reflect on their experiences with CBR and their experiences with Access Alliance as a research partner, identify barriers and challenges that community members face in participating in CBR, and identify the kinds of supports and processes needed to enhance the participation of community members in CBR. Participants identified the following strategies that have since informed Access Alliance's approach to research:

- Equitable Partnerships: Community partnerships need to connect different organizations
 working on a project. Partnerships should be sustainable and promote equitable participation
 between organizations and community members.
- 2) Organizational Support: It is crucial to involve local, grassroots (neighborhood-specific if relevant) organizations in the partnerships. Local, grassroots organizations can provide continuity and support to some of the social action interventions coming out of the research, especially after the project funding has ended and the external research partners have left.
- 3) Develop research questions: Community members need to be involved in developing the research questions and the focus of the research. Rather than community members giving input into a set of already-established questions, the external researchers and community members should work together on developing the direction of the research.
- 4) Co-ownership of data: Community members need to be involved in interpreting the data, need to establish ownership over the project, need to have their names included as authors of the final report, and should have the final approval of how project information is disseminated.
- 5) Use accessible language: The training materials for the research program have to be in plain language so that all participants can understand the process and project concepts. The research trainers should also use plain language when talking to the group.
- 6) Create action and change: Partner organizations need to take a firm stance on creating change rather than rehashing old ideas. All partners in the project should be committed to using evidence from the study to take social action.

- 7) Build on existing skills: Community members will come to the research training with skills, and the research trainers need to assess what skills participants already have and what existing skills will be useful in a CBR project.
- 8) Use creative approaches: Workshops, trainings and meetings should utilize creative techniques/approaches to learning. Curriculum development should consider the needs of visual learners. Some participants suggested storytelling as a research training tool.
- 9) Create positive space: The spaces for research trainings, workshops and meetings need to be comfortable for everyone, not only in physical layout, but in creating a group process where people feel comfortable with each other and with the space.

The Income Security working group has integrated these strategies into their trainings and processes. In fact, these strategies served as a framework through which the working group developed their principles of collaboration agreement. A copy of the projects 'Principals of Collaboration' agreement is included as appendix A.

3c) Income Security, Race and Health Project Launch and 'Meet & Greet' Event

In May 2007, the ISRH working group launched the research project with a 'Meet & Greet' event. The event was held at the Driftwood Community Centre and was organized by community members in the

working group with support from Access Alliance research staff. The objective of the event was to bring academics and community partners together along with funders to meet and greet residents involved and interested in the project. Community members developed and preformed skits that captured some of the lived-experiences of racialized families in the labour market. One community member presented drawings of her experience as a newcomer struggling to make ends meet. Finally, community members developed and presented a powerpoint presentation on the intersection between poverty and



Drawing by Zahoor (Peer Researcher) presented at Project Launch

health, particularly barriers to health related services and programs. At the end of the event, community members invited funders, academics and Access Alliance staff to add their comments and reactions to their presentations. The format and success of the project launch demonstrated community ownership over the project and a collective commitment to engaging in a truly collaborative process moving forward.

4. Partnership Building

In contrast to traditional research where a few or a single academic researcher may be involved, a key tenet of CBR is to conduct research in a collaborative framework that brings together academics, community agencies, and community members to work together as co-producers of knowledge. As detailed above, Access Alliance invested substantial resources in the initial months to establish the ISRH research working group made up of relevant partners invested in doing CBR to investigate and overcome racialized

income and health disparities in Black Creek. Partnership agreements, terms of reference (for advisory committees), and Principles of Collaboration were drafted and signed by all partners. These documents clearly outline the roles and responsibilities of all working group members and formalized the working group's commitment to a partnership-based collaborative framework. A full list of working group members and examples of the ways partners contribute to and/or benefit from the project are outlined in Appendix B.



Having strong, multi-collaborative partners has resulted in (1) the

production of richer evidence/knowledge (as each partner adds to the production and interpretation of data); (2) multiple and ongoing co-learning opportunities between partners; (3) increased collaboration between partners that extend beyond the ISRH CBR project. The process of forging community connections in Black Creek has and will continue at all stages of the project. To sustain positive relationships and a strong presence in the community, the Research Coordinator for the project is involved in a number of local initiatives in Black Creek, including the Black Creek Community Collaborative and a Research & Knowledge Exchange Working Group at the YorkU-TD Community Engagement Centre. Her role in these initiatives entails identifying and coordinating knowledge exchange/transfer opportunities that can leverage the project's findings and encourage capacity building in community-based research practice. While our relationships with existing partners will remain the same during phase three of the project, we will be expanding our partnerships to include several other relevant stakeholders including the Workers Action Centre, the Income Security Advocacy Centre, Local Immigration Partnership (Black Creek), the Jane and Finch Action Against Poverty, and the Health Equity Council.

5. Peer Research Training , Involvement and Feedback

5a) Phase One: Photovoice

Fourteen Black Creek residents were invited to join the 'Exposed' photovoice project as photo-researchers. Photo-researchers were asked to attend 9 weekly, 3-hour Photovoice sessions where they received training in photography and participated in facilitated discussions about their photos and their experiences in Black Creek. Each session was designed in a way that nourished their abilities in photography and encouraged a critical analysis of how members of their community perceive and respond

to the impacts of poverty and racism in their everyday lives. At the end of 9 weeks, we collected over 18 hours of facilitated group discussions on racism and poverty in Black Creek, and over 500 photos and narratives. As part of the curriculum design for each weekly session, we developed several tools/exercises (the concentration game using photographs, investigative photography methods, statement photography, social change photography and the photo-researcher's scavenger hunt) to support data-collection within this arts-based method. A detailed summary of the weekly curriculum is outlined in Appendix C. Feedback from participants note that they left the project with an increased awareness of the issues that affect their community and how these issues are part of larger systems of oppression. One participant in particular, noted how the combination of learning about the impacts of poverty and racism in tandem with learning about photography and the power of photography made her critically aware of the messages layered within commercial images in her everyday life:

"I would say that, my eyes have opened even more so to photo, to print, to words that I see. Like there are some things that obviously grasp you, you know and some things you pay no attention to, but I found that I have a heightened sense now of paying attention to every advertisement everything that I see now I feel like I have to rethink about, wonder, you know, is that really it? ... [The Photovoice Project] has opened my eyes and I also ask my kids as well, you know. Now we pay more attention or I've even brought to my kids attention we pay more attention to commercials... now we're discussing the commercials and what do they mean... So that was my enlightenment from this project and I've brought that unto my kids and now they reflect it back to me that they're aware now. " (Photo-Researcher, Exposed Photovoice Project)

Further, the picture and narrative below is one example of how participation in the Exposed photovoice project has inspired participants to consider photovoice as an effective and accessible way to advocate about issues they care about:



My Story

I am a Karen from Burma. I was born in Burma but I was brought up in a Karen refugee camp located on the Thai-Burma border. I don't remember my life in Burma since I was very young when we came to the camp. I spent by whole life in the camp before coming to Canada. One day a resettlement worker came and announced the opportunity for this workshop. So I joined the project. In the future, I want to be a photo journalist reporting the news about Karen people to the world. Millions of Karens are now suffering inside of Burma and not many people know about it. This project inspires me to become a photo journalist.

5b) Phase Two: Community and Service Provider Focus Groups

As mentioned earlier, a fundamental principle and objective of this project was to build CBR capacity within our community of interest (residents from Black Creek from low-income, racialized backgrounds) and meaningfully involve them as co-researchers ('peer researchers') through out the life stage of the project. The ISRH working group recruited a total of 7 racialized residents from Black Creek who participated as peer researchers in all research activities including research design, data collection and data analysis. This team of peer researchers will continue to be part of the research team and assist with writing, dissemination, and policy change activities. To ensure that participation was both meaningful and equitable for all members of the research team, a training program based on CBR principles and using popular education approaches to curriculum development was designed specifically for the project. This program drew on Access Alliance's Peer Researcher Training program which aims to reduce barriers and create equal grounds for diverse community members to participate in and contribute their knowledge and skills to the process. The program gave participants the opportunity to learn, teach and apply research methods in a way that is collaborative, participatory and was delivered in accessible language, using meaningful and practical case-studies. We developed numerous training curricula and resources as well as delivered over a dozen workshops that incorporated a wide spectrum of critical concepts related to the research issues and methods used in our research design. Appendix D provides details of all the trainings delivered to the ISRH working group (particularly the peer researchers) to date.

5c) Feedback from Peer Researchers in Phase 2

"I did not know the meaning of research, ethics board, how you frame research questions, etc. ... This project opened doors for me ... the training was excellent, and built up my confidence. I can now put focus group facilitation on my resume"

(Peer Researcher, ISRH Working Group)

Feedback from peer researchers indicate that they have benefited in multiple ways from the project including increased confidence, increased ability to articulate community voice, increased respect within community, enhanced community engagement skills, practical skills in research, increased capacity to understand and tackle systemic causes of the inequalities faced by

Peer Researchers Reflections about the Strengths, Limitations and Dilemmas in CBR (presented at CBR seminar on January 2010)

- I can reframe the questions, based on my experience, to help generate sharing and discussion
- I can ask questions during focus groups informed by my experience
- If you have assumptions based on your experience, you might be shutting people down, or leading the discussion in a certain way
- Separating my own experience from participants' experiences
- Room for my own story? (during data collection versus analysis)

themselves and their community. A few of our peer researchers are taking leadership roles in other community projects and teaching other community members about the critical inquiry and engagement skills that they gained from the ISRH project.

The learning process has been mutual as well. Academics and service providers in the ISHR project have made note of the rich knowledge they have gained from peer researchers. Their contributions from have gone beyond offering insights into community issues. Academics in particular felt that they have learned a number of effective strategies for community engagement and outreach from the peer researchers. Academics in the working group have also commented on how the community-based approach and working with community residents has redefined their notions of valid data. Within the community-based model, academics in the working group now view validity as a dialogue with community stakeholders on the relevance and practical benefits of the findings for the community.

The ongoing feedback that peer researchers provide about benefits as well as challenges has helped to continuously improve our CBR processes. For example, peer researchers noted the ethical and political dilemma they face in taking the dual role of being a researcher and a community member at the same time (an 'insider' and 'outsider' at the same time). The ISRH team has worked closely with peer researchers to address these dilemmas in constructive ways that minimize the risks peer researchers may face. While Access Alliance has developed an in-house peer researcher training program and is committed to building research capacity of community members, we have experienced a number of research training related challenges. The key challenge is related to the varied learning capacity of marginalized community members. During the 4 day peer researcher training program, we discovered that offering training to a group with varied approaches to learning can not just undermine the learning/training process but also heighten tension between community members. To address this challenge the research team has complemented full group workshops with co-learning opportunities in smaller groups or in pairs between academics/project staff and peer researchers. In other words, peer researchers have worked one-on-one with academics and/or project staff on different aspects of data collection and analysis in the hope that peer researchers can learn about research at their own pace and through a mentorship model. At the same time, one-on-one time with peer researchers provide academics/project staff with the opportunity to proactively integrate their lived experience into the analysis process.

6. Collaborative Frameworks

CBR requires effective collaborative frameworks that enable each member of the research team to participate and contribute to the process in a meaningful and equitable way. The ISRH developed several innovative frameworks and tools for designing and conducting research in a collaborative manner and collaboratively analyzing the evidence. Our Collaborative Research Design (CRD) framework and Collaborative Data Analysis (CDA) have been replicated in other projects as well.

a) Collaborative Research Design (CRD) framework

The project's research questions and methodology were generated through two half-day collaborative research design (CRD) sessions with members of the ISRH working group, including peer researchers. Access Alliance designed a unique and innovative CRD framework specifically for this project. The goal of these sessions was to refine and narrow the focus of the broad research question that came out of community consultations in the hope of designing a study that is grounded in community needs and concerns; one that has high policy relevance. Prior to the first research design session, peer researchers attended a training session to learn more about the process of developing research questions. At the end of the training session, peer researchers identified criteria from which they could base their own assessment of potential research questions.

The first design session was dedicated to conceptualizing issues related to income and health security, race and then brainstorming potential research questions. A total of 15 potential research questions were generated during the question generation activity. During the second session, working group members assessed the research questions according to community relevance, potential for policy and service change, 'doability' (according to time, cost, and human resources) and overall the impact on the Black Creek Community. Eventually, members of the working group agreed on 2 research questions that would quide study. The balance of the second session was then spent discussing potential research methodologies, related ethical issues and the research population. At the end of the session, a smaller working group was formed to develop a more thoughtful research proposal that would later be submitted to the larger group for their approval. The Evaluation report from the CRD sessions indicate that all the members learned a lot from the process, found the process to be genuinely collaborative, and were very satisfied with the

Evaluation Feedback about the Collaborative Research Design Process

- "I think that the session was well organized and run. I continue to learn a great deal about the process and content, and it is nice to be getting to know others on the committee better. I liked the decision making process. It feels like everyone has a voice." (service provider)
- "Liked small groups, chance to discuss; mixing community members with academics made community members feel more confident" (peer researcher)
- "Time was given for people to speak and everyone seemed to listen to one another so I thought it went well." (academic partner)
- "Through the process, ideas were able to be grouped together in ways that made sense. I was surprised at how many of the ideas fit together. It seemed to me that this process made sense - I can't think of a better way of doing it." (service provider)
- "Different points of view and different backgrounds led to a better question." (peer researcher)

research questions and methodologies that were developed together. Another indication of the success of the CRD sessions was that by the end of the process, all members took ownership of the research questions even if they had not come up with the questions themselves. The CRD Logic Model is included in the Appendix E.

ii) Popular Education based Data Collection Instruments

We spent two months developing an innovative focus group guide grounded in a popular education framework, one that provides multiple mediums (drawings, pre-drawn symbols, charts, and discussions) for participants to share their views and experiences and also invites them to offer preliminary analysis in terms of trends and patterns they notice within the responses generated by the focus groups. The interactive and accessible nature of the focus guide not only allowed participants to link their experiences to the key concepts of the study but also provided opportunities for participants to engage in critical reflections and analysis of trends and systemic processes related to racialized disparities in the labor market overall. The focus groups were led by peer researchers for the specific communities in their first language.

iii) Collaborative Data Analysis

One of the key outcomes of CBR is the dissemination of findings that recognize and document the organic knowledge that lies within communities. This suggests a data analysis process that facilitates co-learning

opportunities through which academics "with knowledge of literature and conceptual abilities are in dialogue with service providers and community members who have a first-hand connection to what people said in the focus groups and who are familiar with the lived experience of being marginalized." (Jackson, 2007, p167)

In consultation with all members of the ISRH working group, a data analysis team that included 4 peer researchers, 2 academics and 1 project staff met regularly to organize, review, code and interpret the data. Meetings were structured in a format that introduced each step in the data analysis process in understandable and engaging ways. The first step in the process was to bring the team together to review the data collected, revisit the project's research questions and identify potential audiences and dissemination ideas for the final report. As part of the training process, the entire team then reviewed and coded the same transcript collaboratively developed a together and thematic framework for that transcript. Each peer researcher was then partnered with either an academic or a member of the project staff. Partners were asked to code and develop a thematic framework for one transcript. The thematic frameworks from 5 separate transcripts were then combined to form one comprehensive coding framework for analysis. Based on this framework, transcripts were coded and the subsequent data organized using NVIVO software. Once all transcripts are thoroughly



coded, the research team will meet regularly for more in-depth analysis and writing. The collaborative analysis framework has resulted in a richer and deeper analysis of each piece of research evidence generated.

7. Additional Challenges and Benefits

The project has faced many challenges along the way. We have tried to address many of these challenges in thoughtful, innovative and respectful ways. However, some of the challenges associated with human resources and time frame are intrinsic to community-based research and need to be accommodated rather than overcome. Human resources and staffing have been the most pressing challenges for the project. Our effort to ensure collaborative and community-based process in this project has exacted enormous amounts of staff time and effort to each step of the process. For example, recruiting, engaging, mentoring and training of peer researchers has been taking an exceptionally large amount of staff time and effort. Similarly, designing and implementing the Collaborative Research Design (CRD) and Collaborative Data Analysis (CDA) sessions took a lot more staff time and effort than we had expected. The original project proposal (submitted in 2006) did not budget in adequate staff salary/support for the project. As such,

Access Alliance has committed substantial internal resources (particularly around research training, project coordination and administrative support) to move the project along.

The project has been moving much slower than we have expected. While we were aware that involving multiple collaborators using consensus decision making process would take time, some of the delays have been much longer than we expected. For example, some critical tensions between community members involved in the project has stalled/delayed the project progress at several occasions. Project staff has had to ensure that decision-making and conflict resolution happens through clear and transparent processes in order to sustain productive, healthy and equitable relationships between working group members.

The project made proactive efforts to recruit low-income, marginalized community members. While this highlights the equity approach in our project, it also raises additional challenges for staff (and to some extent for project partners). Working closely with community members requires project staff to make time within the working relationship to listen the numerous challenges/issues that marginalized community members face in their everyday life and support their efforts to address these challenges. Having to listen to and address these challenges and difficulties that community members involved in the project face does not only take staff time but also has strong emotional impacts on staff. The standard procedure for project staff is to refer community members to relevant resources and services (eg social workers); nonetheless it is recommended that future CBR projects build in budget/plan to involve a designated social worker for the project.

Although overall peer researchers felt that their experiences in the project have provided them with many valuable and transferable skills (community outreach, focus group facilitation, critical thinking), some peers felt that employment within community-based research projects is in itself precarious. In a recent discussion on meaningfully opportunities for employment mobility within CBR, some peer researchers suggested that project staff should explore ways through which they can develop peer researcher positions with more stability as well as opportunities for professional growth and mobility as the project moves into different phases. The ISRH working group will be considering this feedback as we begin to plan and pursue funding for phase three of the project.

While CBR requires significantly more time, resources, effort and funds, the multiple benefits far outweigh the additional costs. Although, examples of the benefits of conducting research using a community-based approach are highlighted through out this report, we would like to summarize the key strengths in the follow way:

- 1) CBR is not just empowering but also enhances the quality and rigor of the research findings. For example, collaborative data analysis ensures that one transcript is read and coded by more than one member of the research team.
- 2) Strong local partnerships and peer researcher involvement enables research team to reach and recruit marginalized people that cannot be reached by traditional recruitment methods;
- 3) Peer researchers' roles as facilitators of the community focus group allowed the team to capture voices and narratives that may not be captured by traditional methods



- 4) The analysis and input from peer researchers provides richer context and interpretation of data collected.
- 5) Valuable knowledge and findings are produced within and through CBR process itself. For example, important knowledge about community issues were generated during outreach and recruitment process
- With relevant training and support, marginalized community members can become professional researchers and conduct high quality research. However, engaging marginalized community members as co-researchers requires that project staff proactively reduce barriers to participation and provide additional support and mentoring to address the systemic marginalization they face on an everyday level.

8. Knowledge Exchange/Transfer Activities & Next Steps

The ISRH working group has engaged in a number of knowledge exchange/transfer activities. As in all the other processes, knowledge exchange is also grounded in a participatory, collaborative framework with peer researchers taking a lead in most. Recent knowledge exchange/transfer activities include:

- ✓ Presentation on Community-University partnerships at CERIS Seminar
- ✓ Preliminary findings presented at 2010 Metropolis Conference in Montreal
- ✓ Project featured at two Community-based Research Expos: 1) York University and 2) York Gate Mall
- ✓ Project featured at Access Alliance's Research for Change Seminar on Racialized Health Disparities
- ✓ Peer Researchers presented at Access Alliance's Research for Change Seminar on the strengths, challenges and dilemmas of CBR
- ✓ Preliminary findings presented to the Network of Spanish-Speaking Workers in Black Creek
- ✓ Project team led a workshop on Racialized Health Disparities at 2009 Annual Conference for the Association of Ontario Health Centres on the intersection between health and poverty.

The next phase of research involves conducting qualitative longitudinal interviews with 10 - 15 racialized families over a year (complemented by workshops on job search and financial planning strategies) to get a better understanding of the everyday strategies and pathways in and out of employment/income security. The working group hopes that evidence obtained throughout all phases of this project will be used to contribute to community-led discussion and collaborative action on strategies that address the root causes of racism and poverty. Although the project hopes to inform a diverse range of policy interventions, the Working Group's current priority is to influence the evaluation, implementation, and revision of Ontario's Poverty Reduction Plan. The ISRH working group believes that once analysis from all three phases are brought together,, this project will not only contribute to the evaluation of Ontario's current plan but will also inform recommendations on how the province can move forward in the following fives years. In general, the work of the ISRH team will bring the 'every day' experiences and voices of low-income racialized families into public debates on poverty and its relationship to health. It is our hope that this will be accomplished through our partnerships with grassroots campaigns already engaging with community and policy makers on issues of racism and poverty, specifically the Jane and Finch Against Poverty and the Colour of Poverty Campaign.

APPENDICES



APPENDIX A

Principles of Collaboration

Income Security, Race and Health Community-Based Research Project

This Principles of Collaboration is intended to guide the work of the community based research (CBR) project titled, "Income Security, Race and Health: investigating the economic and health implications of strategies that racialized groups in Black Creek develop to achieve income security". The Principles of Collaboration document supplements the Partnership Agreement. By signing the Partnership Agreement, all partners agree to the principles outlined below. At the same time, it is understood that this document is considered a 'living document', one that can be revisited and revised in ways that improve collaboration and quality of the project.

1. Purpose of the CBR Project

Project Goal: Using CBR methods, this project seeks to deepen our understanding of the *root causes and health impacts* of the growing poverty and income inequalities that racialized
 communities are facing in order to develop better services and policies to overcome these
 inequalities.

Project objectives:

- Build capacity of racialized groups in Black Creek in community based research;
- Together with Black Creek community members, design and conduct CBR to deepen understanding about the growing poverty and income inequalities that racialized communities are facing and how it affects their health;
- Drawing on study findings, mobilize dissemination and advocacy strategies directed at improving social/health services and policies in ways that help to overcome racialized income and health inequalities.

2. Guiding Principles for the CBR Project

- 1) All project partners are responsible for *promoting a collaborative research partnership* that draws upon the different skills/knowledge of each partner (academic, community agency, community resident) in ways that help to fulfill the project objectives.
- 2) All project partners are responsible for promoting an *anti-racist/anti-oppressive working environment* in ways that proactively address power inequalities and barriers in the research process and outcomes.
- 3) All project partners are responsible for creating *an open and transparent process* where a collective vision of research goals and objectives is shared, and where the roles and expectations of team members are clearly understood.
- 4) All project partners are responsible for ensuring *open and respectful communication* and to hear and understand each other's points of view.
- 5) All project partners are responsible for promoting opportunities for *reciprocal (two-way) learning and capacity building* in ways that draw on the various skills and areas of knowledge of different partners.
- 6) All project partners are responsible for ensuring that the project engages in meaningful research, dissemination, and advocacy that leads to *community benefit and positive social change*.

3. General Roles and Responsibilities of Team Members

While project members are encouraged to work collaboratively at all stages of the project, the project recognizes that different members bring different skills/knowledge and may have specific roles and responsibilities.

- Principal Investigators: The PIs will provide leadership in every aspect of the project with support from partners (Co-Investigators/Collaborators, Peer Researchers). The PIs' roles include overseeing the entire project, coordinating research activities, reporting to funders, and ensuring research findings are widely disseminated and put to community benefit.
- Co-Investigators/Collaborators Responsibilities: For this project, the term co-investigators and collaborators will be used interchangeably in recognition of the fact that community agency collaborators may also be actively involved in research design and implementation. Co-Investigators/Collaborators will sit on the Advisory Committee and will be involved in making decisions on all aspects of the project. Depending on interest and time availability, each Co-Investigator/Collaborator can be involved in the project in additional ways (data collection, analysis, report writing, dissemination, and advocacy). Each Co-investigator/Collaborator will specify their additional roles as well as their expectations in the Partnership Agreement.
- Project Coordinator: The Project Coordinator will be responsible for overseeing the day to day operations
 of the project including organizing meetings, coordinating the research design, coordinating data
 collection, analysis and writing as well as overseeing the dissemination and advocacy work related to the
 project. The Project Coordinator will also be responsible for training and supporting community members
 (peer researchers) involved in the project.
- Community Members/Peer Researchers: About 4 6 community members/peer researchers will be recruited to sit on the advisory committee to bring a strong community perspective in the project. Additional community members may also be recruited to work on different components of the project. Community members/peer researchers will receive training in research, decision making, dissemination and advocacy to enable them to participate more actively and meaningfully in the project.
- Student: The project will be open to students with interest in the topic to be involved in the project.
 Students involved in the project will also have to sign a Partnership Agreement that outlines their roles and expectations (for eg, how this project will relate to their thesis research if at all).
- Consultants: The project may hire consultants to work on specific components of the project.

4. Governance Structure

The Advisory Committee, under the leadership of the Principle Investigator, is responsible for overall decision making and direction of the project. In addition to the Principle Investigator and Project Coordinator, the Advisory Committee will include all the key academic partners, agency partners and community members involved in this project. The workings of the Advisory Committee will be guided by a **Terms of Reference** for the Advisory Committee.

The project may have multiple research and associated components (eg photovoice, surveys, training). The Advisory Committee may delegate a specific 'subcommittee' or coordinator to oversee the activities of each of the different components of the project.

5. Access to/Dissemination of Data

Based upon the project's guiding principles, the PIs and the Co-Investigators share ownership and have access to the research data. Usage of the data will be in accordance with the advancement of the project goals and will adhere to all requirements of the Research Ethics Board. Data will be used for:

- advancement of knowledge;
- o identification of future research questions;
- o making recommendations for policy and service provision; and
- o supporting knowledge transfer, advocacy in relation to social justice and the social determinants of health, organizational development and the promotion of A/PHA leadership and involvement.

The data should not be used for:

o individual interests that are not related to the goals of the research (unless approved in the guidelines outlined above).

In accordance with CBR principles, we are proposing a model of dissemination that encourages the active involvement of all research team members while taking into account their varying needs, responsibilities and capacities. Research findings will be disseminated in various ways possibly including community forums, conference presentations, agency workshops, newsletters, and journal articles. The PIs, the Co-Investigators, and the Project Coordinator are all encouraged to engage in dissemination of the research findings, and are to share information about potential dissemination activities.

The team will establish analysis and writing groups for different articles and reports, with participants contributing different parts of the manuscript. We will offer capacity-building opportunities for team members who wish to expand their skills. Authorship will correspond with contribution to the research being reported, with the entire research team receiving acknowledgment. For example, a paper might be attributed to "A.B. Author, L.M. Writer, J.K. Researcher, for the Trans Health Research Project," with an acknowledgement listing all members of the project. Order of authorship and mechanisms for feedback on manuscript drafts will be decided up front by writing group members. This understanding applies to conference presentations, community forums, and other dissemination activities.

Acknowledgements

In all publications, media strategies and other public activities related to the Project, all team members will be acknowledged as investigators or authors, as appropriate. The members of the investigators team understand that 'authors' are those who participate in writing/publishing activities. The names of investigators'/authors' respective organizations will appear with acknowledgement, as appropriate.

7. List of Members

Principal investigators

Yogendra Shakya, Access Alliance

Patricia Landolt, University of Toronto

Grace-Edward Galabuzzi, Ryerson University

Co-investigators/Collaborators

Diane Broad, Griffin Centre

Lisa Brown, Black Creek Community Health Centre

Michaela Hynie, York University

Michelle Ashem, Toronto Public Health

Michaela Hynie, York University

Naomi Ives, Delta Family and Resource Centre

Sarah Flicker, York University

Project Coordinator

Ruth Wilson, Access Alliance

Community Members/Peer Researchers

Amina (Safy) Abouzaid

Celena Knight

Carina Reider

Zahoorunnisa

Tha Dar Hse

Sherine Dahy

Darren Pham

Felix Cabrera

APPENDIX B

Full List of Community & Academic Partners

Academic Partners:

Ryerson University (Co-Principal Investigator)
Dr. Patricia Landolt, University of Toronto (Co-Principal Investigator)
Dr. Sarah Flicker, York University (Co-Investigator, Co-Principle

Dr. Grace-Edward Galabuzi,

Dr. Sarah Flicker, York University (Co-Investigator, Co-Principle Investigator for Photovoice) Dr. Michaela Hynie (Co-Investigator)

<u>Community/Government Agency</u> Partners:

Lisa Brown, Black Creek
Community Health Centre
Michelle Ashem, Toronto Public Health
Naomi Ives, Delta Family and Resource Centre
Dianne Broad, Griffin Centre
Working Women's Resource Centre
YorkU-TD Community Engagement Centre
Color of Poverty Campaign



Mohamed Abdelrahim Amina (Safy) Abouzaid Celina Knight Zahoor Zahoornisa Sherine Dahy Darren Pham Felix Cabrera

Carina Reider

And 14 photo-researchers for the Photo-voice project

Student Placements in the Project

Davina Balram, York University
Denise Chung Guerero, University of Toronto
Theon Harrichand, University of Toronto





APPENDIX B

Overview of Community and Academic Partnerships

Existing/Continuing Partnerships	Nature of Current Relation
Black Creek Community Health Centre (BCCHC)	 ✓ Lisa Brown (Community Health Worker) has been an active member of the ISRH working group since 2006 ✓ Also contributes to the project as a facilitator and advisor on neighbourhood health relate issues ✓ Offers support with outreach and knowledge exchange/ transfer activities ✓ BCCHC also offers administrative and logistical support (space, child care, office supplicement)
Griffin Centre	 ✓ Diane Broad (Manager of Community/Family Support Services) has been an active member of the ISRH working group since 2007 ✓ Advisor on (social determinants of) mental health related issues ✓ Offers support with outreach and knowledge exchange/transfer activities
Toronto Public Health	 ✓ Michelle Ashem (Community Health Worker) has been an active member of the ISRH working group since 2008 ✓ Advisor on public health/policy related issues ✓ Offers support with outreach and knowledge exchange/transfer activities
Delta Family Resource Centre	 ✓ Alex Way (Community Outreach Worker) has been an active member of the ISRH working group since 2006 ✓ Offers support with outreach and knowledge exchange/transfer activities ✓ Advisory on Community health related issues, particularly social determinants of community health
York University	 ✓ Dr. Michaela Hynie (Professor, Faculty of Health) and Dr. Sarah Flicker (Faculty of Environmental Studies). Both have been active members of the ISRH working group sing 2008 ✓ Offers project office space at York University ✓ Advisor on mental health related and community health related issues; advisor on CBR principles and process, and research methodology ✓ Offers support with knowledge exchange/transfer activities
YorkU-TD Community Engagement Centre	 ✓ ISRH working group (via project coordinator) currently chairs the Centre's Research & Knowledge Exchange Working Group ✓ Access Alliance supports the Centre in their work to build capacity of York Faculty/stude and community residents in community-based research ✓ The centre offers support with meeting space, outreach and knowledge exchange/transfactivities
University of Toronto (Cities Center)	 ✓ Dr. Patricia Landolt is an active member of the ISRH working group and principal investigator of this study. ✓ Offers mentorship to peer researcher and project staff ✓ Advisor on precarious employment related issues and research methodology/rigour ✓ Offers support or leads knowledge exchange/transfer activities ✓ Co-facilitates data analysis process and offers support in synthesizing the findings ✓ Offers project access to graduate student support, office space and meeting space ✓ Offers support with knowledge exchange/transfer activities.
Ryerson University	 ✓ Dr. Grace-Edward Galabuzi is an active member of the ISRH working group & principle investigator of this study ✓ Offers mentorship to peer researchers and project staff ✓ Advisor on public policy and race relations and research methodology/rigor ✓ Co-facilitates data analysis process and offers support in synthesizing the findings ✓ Offers support with knowledge exchange/transfer activities
Colour of Poverty Campaign	 ✓ Grassroots campaign address the racialization of poverty in Ontario; Access Alliance (via the ISRH project coordinator) is a member of the steering committee ✓ COPC offers support with outreach and knowledge exchange/transfer activities
Black Creek Community Collaborative (BCCC)	 ✓ Network of community-based organizations in Black Creek; the ISRH working group (via the project coordinator) is a member of the Community Engagement Sub-Committee ✓ BCCC offers support with outreach and knowledge exchange/transfer activities



APPENDIX C Overview of Exposed Photovoice Curriculum

Week		Themes & Objectives		Exercises
Week 1	*	Consent Forms & Ethics	*	Homework: people,
	*	Establishing Guidelines for communications		places or things that
	*	Safety Guidelines		matter to you
	*	Understanding the Power of photography		,
	*	Introduction to the digital cameras		
Week 2	*	Research Presentation on the racialization of poverty (Introduction to	*	Homework: places you
		our research questions)		like and dislike in Black
	*	Introduction to Community-based research		Creek
111	*	Technical review of photos in a large groups		0110141 B
Week 3	*	Introduction to Photovoice as an arts-based research method	*	SHOWeD exercise
	*	Small group reflections on photos taken in the previous week	*	Homework:
	*	Introduction to Photography (slide show)		Investigative
Week 4		Colour of Poverty Campaign		Photography
WCCK 4	*	Photo-researchers joined other Black Creek residents at a 3 hour		
	•	workshop on the racialization of poverty. Members of the workshop		
		formed small working groups and developed recommendations for		
		action		
Week 5	*	Team building	*	Concentration Game
	*	More photography tips based on last week's photos	*	SHOWeD Exercise
	*	Small group discussion based on 2 favourite photos from last week	*	Homework: Statement
	*	Draft and/or select statements about poverty and racism in Black		Photography
		Creek		
	*	Help photo-researchers visualized the kinds of photos they will take for		
10/	_	next week's homework exercise		0 11 11
Week 6	*	Facilitators select photos from last week to review with the entire group	*	One word ball game
	*	Participants critically reflect (orally or in writing) on their 2 favourite	*	SHOWed Exercise
	*	photos from last week Discuss in detail the elements of photography		
Week 7	*	Give participants support and guidance as they are taking pictures	*	Guided Tour
WCCK /	•	while walking inside and around the Yorkgate mall	*	Homework: Photovoice
	*	Participants learn how to take portraits by practicing on each other and	•	Scavenger Hunt
		on themselves		
Week 8	*	Review all of their favourite photos and narratives and help the group	*	Show and Tell
		reflect on patterns and themes	*	Homework: Activism
	*	Ask participants to pick out strong photos that should be considered for		Photography
		the final exhibit		
	*	Have participants assess photos both technically and thematically		
Week 9	*	Participants work in pairs to develop story boards based on the		
		patterns and themes they identified last week		
	*	Photo-researchers present their story board to the entire group		
	*	Large group discussion on what changes are needed to improve their community and support/build on community strengths		
	*	Group photo		
	*	Collect Scavenger Hunt photos & narratives		
	*	Evaluation Survey		
	•	Evaluation July Cy	l	



APPENDIX C Research for Change Training List for Income Security, Race and Health project

Topic	Time	Description
Introduction to CBR	Half Day	✓ What is research? (reflect on the concept & practice of research)
		✓ CBR principles
		✓ Continuum between tradition research and CBR
		✓ CBR practice (steps in the research process, collaboration)
		principles, collaboration agreement, roles & responsibilities)
		✓ Peer Researchers (rewards & challenges of this role)
How to develop research	Half Day	✓ Introduction to Concept Mapping
questions		✓ Introduction to Research Methodology
		✓ Review/Understand/Develop criteria for a good research
		questions (community relevance, policy change, social service
		change and do-ability)
		✓ Review Agenda/Purpose of Collaborative Research Design
		itional Peer Researchers Hired
Project Orientation	2 hours	✓ Welcome, Introductions, Team Building
		✓ Introduction to ISRH Working Group & Access Alliance
		✓ Introduction to project approach, goals, expected outcomes
Introduction to CBR	3 hours	✓ What is research? (reflect on the concept & practice of research)
		✓ CBR principles
		✓ Continuum between tradition research and CBR
		✓ CBR practice (steps in the research process, collaboration
		principles, collaboration agreement, roles & responsibilities)
		✓ Peer Researchers (rewards & challenges of this role)
Research Ethics	3 hours	✓ Basic foundations of ethics in research and CBR
		✓ Focus on informed consent, confidentiality, accountability,
		minimizing risk/harm (individual & community)
		✓ Ethical Scenarios (role play)
		✓ Consent Forms & practice obtaining consent from a participant
		✓ Information Security & Data Management
Anti-Oppression Principles	Half Day	✓ Explore issues of power, oppression and research using popular
& Practice		theatre tool
		✓ Access Alliance's Anti-Oppression Policy
		✓ Explore privilege and power as well as knowledge and power
		(social location)
		✓ Systemic Oppression
Thematic Framework of	Half Day	✓ Explore concepts of income security, racialization of poverty and
the Study		social determinants of health
		Review statistics/literature related to the distribution of wealth,
		poverty and the relationship between poverty and health
		✓ Discuss in detail the project's research questions and
		methodology

Topic	Time	Description
Recruitment	Full Day	✓ What is recruitment/outreach? (various strategies, partnerships,
		tools/resources to support recruitment, mechanism to track
		recruitment)
		✓ Ethics in Recruitment
		✓ Review/Understand the projects inclusion/exclusion criteria
		✓ Develop recruitment plan and screening process
		✓ Recruitment Role Play (typical questions and answers)
Focus Group Facilitation	One and a half	✓ Intro to Research Methodology
	Days	✓ What is a focus group
		✓ Anti-Oppressive Facilitation (Tips, Skills, Planning, Practice)
		✓ Review/Understand Each Section of the Focus Group Guide
		✓ Focus Group Facilitation Practice
Introduction to Data Analysis	Half Day	✓ Introduction to Qualitative Data Analysis
(Co-Learning Workshop)		✓ Review/Assess Inventory of Data Collected
		✓ Review/Understand Collaborative Data Analysis Logic Model
		✓ Tips on how to read transcripts
		✓ How to extract themes from transcripts/ How to develop thematic
		framework for a transcript
		✓ Memoing: How to document critical reflections from transcripts

reSearch for Change: Collaborative Research Design

1. Issue/Question Identification Phase

- 1.1. What are the key issues? (Concept Mapping)
- 1.2. What do we want to know? (Question Generation)
- 1.3. Why do we want to know this?



2. Streamlining and Development Phase I

- 2.1. What do we already know? (Literature Review)
 - 2.1.1. Does the available knowledge/research reflect reality? (if not keep the question)
- 2.2. Overlaps? (combine/delete)









3. Streamlining and Development Phase II

- 3.1. Relevance/Urgency to community
- 3.2. Policy Impact
- 3.3. Service impact
- 3.4. Do-ability (time, cost, human resources, etc)





4. Research Question Refining Phase

- 4.1. Clarity (simple, clear, accessible language)
- 4.2. Detail (clearly specifies issue, target community, place, time period)
- 4.3. Inquisitiveness (triggers curiosity and critical inquiry; avoid yes/no, either/or questions; 'What-Why-How' questions result in richer answers)
- 4.4. Quality/Sensitivity (questions are non-judgmental; do not contain unsubstantiated claims)







reSearch for Change: Participatory Research Design

5. Identifying Data Collection Methodology Phase

- 5.1. Who do we ask? (identification of data source/research participants)
- 5.2. How do we ask? (research method identification)
 - 5.2.1. Survey, interview, focus groups etc?
 - 5.2.2. Individually or in a group setting?
 - 5.2.3. Verbal, written, non language based medium (photography, art etc)
- 5.3. How can we reach our target participants? (Outreach and Recruitment Strategies including building additional partners)
- 5.4. What specific questions do we ask? (development of 'questionnaire' or 'interview/focus group guide')

6. Improving Data Quality Phase

- 6.1. How can we get more accurate, reliable & richer answers? (peer researcher mediated?; trust building? Taking extra confidentiality measures?)
- 6.2. How can barriers to research participation be removed? (language support; transportation; child care etc)
- 6.3. How can the questions be made more contextually and culturally sensitive?
- 6.4. How can the data collection process be made more consistent? (eg if many people are involved in data collection)

7. Addressing Ethical Issues

- 7.1. How can we ensure that research participants participate in genuinely informed ways?
- 7.2. How can we make sure that any data that can identify research participants remain confidential? (Note: by law, researchers are required to report any information about abuse or harm to self or others)
- 7.3. What negative impacts can the research have (particularly on vulnerable/marginalized groups) and how can we overcome/minimize them?