A SOCIAL NETWORK PERSPECTIVE ON OWNERSHIP AND SELF-DETERMINATION IN PARTICIPATORY RESEARCH

by

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Abstract

Participatory research (PR) is the co-creation of new knowledge by researchers working in equitable partnerships with those affected by the issue under study or those who will benefit from or ultimately act on its results. A core driver of PR is the self-determination of stakeholders who intend to improve their lives, health or practice through active involvement in creating the evidence they need for action. In order to foster self-determination, PR utilises strategies intended to create community ownership over the research process, particularly when the research idea originates from outside the community. However, little is understood about the range of strategies employed or how community stakeholders perceive their utility in fostering ownership. This dissertation asks the question, what processes and strategies foster engagement within a participatory project, and how have these contributed to community ownership and self-determination over the research process? First, a systematic review was undertaken to synthesise best-practice participatory engagement strategies as employed by leading PR practitioners (manuscript 1). Then using social network techniques, we examined an active community-based participatory research project to ask, how do influence and decision-making evolve over the course of a participatory project as the project is developed and matures (manuscript 2)? A further set of network measures was applied in a longitudinal analysis to reveal changes in network structure, significance of change in actor roles, and demonstrate sustainability of change in ownership once the original non-community champion stepped aside (manuscript 3). Finally, through a qualitative case study using the participants from the same study, we explored what strategies were employed within the partnership to assure ownership and control by the community partners; and from the point of view of these participants, how responsible were these strategies for fostering the change in influence observed in the network analysis (manuscript 4)? Results show the dynamics of how community ownership emerged over the course of the PR project, and how stakeholders perceived engagement strategies to have fostered this change. Findings have implications for building community ownership and self-determination, while at the same time advancing methodological understanding of social network analysis for studying community partnerships.
Co-Authorship

The following co-authors are acknowledged for manuscripts 1 and 2, which were published in peer-reviewed journals prior to thesis submission.

Manuscript 1: David Parry, Pierre Pluye, Soultana Macridis, Carol P. Herbert, Ann C. Macaulay

(See note in Manuscript 1 for full citation)

For Manuscript 1, the doctoral candidate is first author, with the following contributions:

- Substantial contribution to conception and design of the research undertaken
- Participation in acquisition of data
- Substantial contribution to analysis and interpretation of data
- Substantial contribution to drafting of the manuscript, wrote final draft
- Substantial contribution to critical revision of the manuscript for important intellectual content

Manuscript 2: Soultana Macridis, Enrique Garcia Bengoechea, Ann C. Macaulay, Spencer Moore, Members of the KSDPP School Travel Planning Committee

(See note in Manuscript 1 for full citation)

For Manuscript 2, the doctoral candidate is first author, with the following contributions:

- Substantial contribution to conception and design of the research undertaken
- Sole contribution in acquisition of data
- Substantial contribution to analysis and interpretation of data
- Substantial contribution to drafting of the manuscript, wrote final draft
- Substantial contribution to critical revision of the manuscript for important intellectual content

For unpublished Manuscripts 3 and 4, the doctoral candidate is sole author, with the following contributions:

- Substantial contribution to conception and design of the research undertaken
- Sole contribution in acquisition of data
- Substantial contribution to analysis and interpretation of data
- Substantial contribution to drafting of the manuscript, wrote final draft
- Substantial contribution to critical revision of the manuscript for important intellectual content
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This dissertation is dedicated to the memory of my father, Seymour Salsberg, who was always more proud of me than I deserved. Dad, I promise to show the boys at the track.
I hereby certify that all of the work described within this thesis is the original work of the author. Any published (or unpublished) ideas and/or techniques from the work of others are fully acknowledged in accordance with the standard referencing practices.

Jonathan Salsberg

April, 2015
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<td>ANOVA</td>
<td>Analysis of variance</td>
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<td>ASRTS</td>
<td>Active and safe routs to school</td>
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<td>CAB</td>
<td>Community advisory board</td>
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<td>CBPR</td>
<td>Community-based participatory research</td>
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<td>CIHR</td>
<td>Canadian Institutes of Health Research</td>
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<td>IKT</td>
<td>Integrated knowledge translation</td>
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<td>inDC</td>
<td>In-degree centrality</td>
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<td>KSDPP</td>
<td>Kahnawake Schools Diabetes Prevention Project</td>
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<tr>
<td>KT</td>
<td>Knowledge translation</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institutes of Health</td>
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<td>PA</td>
<td>Physical activity</td>
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<tr>
<td>PCORI</td>
<td>Patient Centered Outcomes Research Institute</td>
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<td>PI</td>
<td>Principal investigator</td>
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<td>PR</td>
<td>Participatory research</td>
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<td>SNA</td>
<td>Social network analysis</td>
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<td>STP</td>
<td>School travel planning</td>
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Chapter 1

General Introduction

Participatory research (PR) is the co-creation of new knowledge by researchers working in equitable partnerships with those affected by the issue under study or those who will benefit from or ultimately act on its results. These could be, among others, communities, organisations, patients or practitioners. For health intervention research, proponents argue that PR strengthens academic-community relations; ensures relevancy of research questions; increases capacity of data collection, analysis and interpretation; minimises the negative or stigmatising effects of research, and enhances program recruitment, sustainability and extension (Cargo & Mercer, 2008; Israel et al., 2005; Israel, Schulz, Parker, & Becker, 1998; Macaulay et al., 1998; Macaulay et al., 1999; O'Fallon & Dearry, 2002). PR is believed to increase communities’ capacity to identify and solve their problems (Macaulay, et al., 1999) (Gaventa and Cornwall 2006) and decision-makers’ and service providers’ ability to mobilize resources, improve policies and enhance professional practices (Minkler & Wallerstein, 2008). Taking a PR approach has been shown to ensure culturally and logistically appropriate research, enhance recruitment capacity, generate professional capacity and competence in stakeholder groups, result in productive conflicts followed by useful negotiation, increase the quality of outputs and outcomes over time, increase the sustainability of project goals beyond funded time frames and during gaps in external funding, and create system changes and new unanticipated projects and activities (Jagosh et al., 2012). Participatory research furthermore integrates knowledge translation into the knowledge creation process by
assuring that the appropriate end-users of the results are implicated throughout all key phases of the research. Most importantly, end-users should be involved in the research phases of identifying the need and setting research questions, interpreting results, and disseminating and applying findings (Macaulay, et al., 1999; Minkler & Wallerstein, 2008; Parry, Salsberg, & Macaulay, 2009; Salsberg, Macaulay, & Parry, 2014).

The practice and processes of participatory research have been examined to provide practical recommendations (Cargo & Mercer, 2008; Green et al., 1995; Israel, et al., 1998; Trickett & Espino, 2004; Waterman, Tillen, Dickson, & de Koning, 2001), and to assess its value in relation to research goals, health status, and systems change (Boote, Telford, & Cooper, 2002; Gaventa & Barrett, 2010; Kreuter, Lezin, Young, & Koplan, 2001; Roussos & Fawcett, 2000; Viswanathan et al., 2004).

Cargo and Mercer (2008) identified community self-determination as one of the three principal goals or values that drive PR and lead researchers to take a partnered approach to knowledge creation. Self-determination, the ability of individuals or groups to determine their own future, is the driver behind community ownership and has been a central topic in health research – particularly public health research, since the 1980s as vulnerable or marginalised populations have attempted to take control over their own health and the evidence that informs the interventions, policies and programs that address it. This has been most evident among Indigenous and minority groups (Young, 1994; Young, Reading, Elias, & O’Neil, 2000), HIV/AIDS communities (Flicker et al., 2009; Travers et al., 2008), the poor (Labonte, 1986; Loignon et al., 2013; Robertson & Minkler, 1994) and other marginalised or underserved segments of society such as women in prison (Martin et al., 2009).
Little is understood about how participatory engagement strategies achieve community ownership and self-determination. Much has been written about the strategies for overall stakeholder engagement (Hermann et al., 2004; Kizer, 2001), particularly with communities (Macaulay et al., 1998; Minkler & Wallerstein, 2008). And the processes underlying knowledge translation, both in public policy and for health practice have been well described (Graham & Tetroe, 2007; Parry, et al., 2009; Salsberg, et al., 2014). Participatory processes that directly attempt to build ownership and self-determination are less well described and rarely if ever evaluated. Even where ownership has been evaluated (Cargo, Delormier, Levesque, McComber, & Macaulay, 2011; Cargo et al., 2003), it was as an outcome measure of overall ‘participation’ by community members, with no exploration of individual strategies within the participatory process that intentionally targeted ownership and self-determination.

The objective of this study, therefore, is to understand the process by which participatory engagement leads to community ownership, particularly in common instances where the idea for the research originates from a non-community, academic researcher. What participatory values, actions and engagement strategies foster community ownership and self-determination? Does ownership, as measured through leadership and decision-making within a participatory stakeholder committee, shift from the academic non-community members to community stakeholders as the project progresses? And if so, is this shift sustainable? Finally, what values and strategies do the stakeholders themselves see as having led to this sustained shift?

**Setting and Context:**
This study is part of the Kahnawake Schools Diabetes Prevention Project (KSDPP), a 21-year old community-owned participatory research partnership between the Kanien’kehá:ka (Mohawk) community of Kahnawake, Quebec and academic researchers from McGill University, Queen’s University and Université de Montréal. Kahnawake First Nation is located 12 km from downtown Montreal, Quebec, on the south shore of the St. Lawrence River. This community of approximately 8000 (2011 est. enrolled, on reserve) enjoys a high a level of socioeconomic development while valuing and maintaining the Kanien’kéha language and traditional institutions of culture and governance. The community has, since the late 1960s and early 1970s respectively, maintained control over both its health and education systems; and thus operates its own school board governing the curriculum of two elementary schools and one high school, full-service inpatient hospital, and a wide range of health and social services. Since 1994, KSDPP has developed and delivered community intervention programming to promote healthy behaviours with the goal of reducing incidence and prevalence of type 2 diabetes. KSDPP has continuously evaluated its efforts along a spectrum of process and outcome measures (Macaulay et al., 2007; Macaulay et al., 1997; Paradis et al., 2005); has evaluated its participatory partnership (Cargo, et al., 2011; Cargo, et al., 2003); has disseminated its prevention planning model to over 30 Indigenous communities across Canada (KSDPP, 2015); and has served as a platform for numerous studies on health promotion, primary prevention of diabetes, nutrition, physical activity, healthy school policy planning, and the participatory process (see http://pram.mcgill.ca/ksdpp_pubs.php for the full range of published KSDPP research). KSDPP is governed exclusively by its Community Advisory Board (CAB) comprised of community volunteers representing
many sectors of Kahnawake. CAB oversees and approves all intervention and research planning, including ethical review of protocols and dissemination plans. CAB serves as the primary site of engagement between community and researchers; it is where community voices inform the research agenda, and where community minds interpret its results. In 2010, KSDPP and its CAB received the CIHR Partnership Award, recognising excellence in researcher/knowledge-user engagement.

Outline of Dissertation Manuscripts:

This dissertation is comprised of four manuscripts addressing the various research objectives, namely, identifying participatory engagement strategies (manuscript 1), conducting a social network analysis to determine changes in community ownership (manuscripts 2 & 3), and understanding the perceived influence of identified values and engagement strategies in fostering community ownership and self-determination (manuscript 4).

Manuscript 1 (chapter 3): Successful Strategies to Engage Research Partners for Translating Evidence into Action in Community Health: A Critical Review. The first dissertation manuscript is a synthesis of best-practice engagement strategies as used by the leading participatory research practitioners. This review serves as the basis for then understanding how these strategies are applied within the community-based participatory research project described in this present study. As the principles of PR are used in a wide variety of research and contexts, this synthesis explored the following questions:
What are the key processes of PR and what are the practical ways to achieve equitable partnerships? What processes support the constant negotiation between all team members for research goals and objectives, partner roles and responsibilities, decision-making procedures, together with balancing knowledge generation with the need for action?

**Methods:** Data sources: A multi-disciplinary bibliographic database (ISI Web of Science) was searched using the phrase “participatory research” for all articles from 1995 (when the initial PR guidelines were published) until October 2009 (which was the year after the *Reliability Tested Guidelines* were published). These were then be imported into CiteSpace - a bibliometric network analysis tool which generated a map of author-citation frequency. A selection tool eliminated theoretical/foundational authors and retained only authors that have conducted practical PR studies. In order to limit the size of the study, we retained only the top four leading PR practitioners using their CiteSpace centrality scores. A librarian-mediated search was conducted for all published materials by these four authors in PubMed, Embase, ISI Web of Science, PsychInfo and CAB (Ovid database) for abstracts between January 1995 and October 2009, as well as chapters from books edited by these authors. Data extraction: A deductive qualitative content analysis was conducted to extract useful data from the sample of documents, generating themes derived from the partnership-related dimensions of the *Reliability-tested Guidelines for Assessing Participatory Research Projects* (Mercer, Green, Cargo, Potter, Daniel, Scott Olds, et al., 2008). These guidelines contain 25 questions, 21 of which target the PR partnership process, making them very suitable to serve as themes for data extraction and analysis. These questions informed the coding scheme to identify PR process strategies. Data analysis: Using a constant comparative technique, themes will be collapsed into
overarching categories. These categories are generated through initial and focused coding techniques by comparing and contrasting text segments and sorting codes into conceptually meaningful units (Lofland & Lofland, 1995). **Results and Implications:** The results of this review yield a synthesis of best-practice participatory engagement strategies as enacted by the leading participatory research practitioners. This serves as a basis for exploring the relationship between these strategies and observed changes in community ownership and decision-making to be undertaken in the latter phases of this thesis project.

**Manuscript 2** (chapter 4): *Engaging Community Stakeholders for School-Based Physical Activity Intervention.* This manuscript serves as a detailed introduction to the community-based intervention being examined within this thesis. Within community-based research, school-based health promotion intervention can have a significant impact on children’s lifestyles (Story, 2006; Veugelers, 2005). Yet, for it to be successful it needs to account for the community environment’s impact on the school’s ability to effectively change the opinions and behaviours of children (Bisset, 2009). Schools as organisations function within an environment of other community-based organisations concerned with the health and social needs of children. For community-based organisations to collaborate successfully, they need to establish and maintain working linkages between them (Provan, et al., 2003). These linkages foster the flow of knowledge and information needed to intervene successfully in areas of common interest (Valente, 2010; Provan, et al., 2003), such as children’s health promotion. The study of these linkages, the overall structures they create, and the impact these then have on the
behaviour of individuals, are the focus of social network analysis. However, it is not well understood how the structure of this network and the pattern of linkages within it evolve over the development of a community-based health promotion intervention. One way to investigate this is to ask how influence and decision-making evolve during the planning and development stages from the introduction of the idea to its full development when it is ready to be implemented.

*Setting and context:* This study is part of the Kahnawake Schools Diabetes Prevention Project (KSDPP), a 20-year old community-owned participatory research partnership between the Kanien’kehá:ka community of Kahnawake (Quebec), and academic researchers from McGill and Queen’s Universities and Université de Montréal. Within the KSDPP research environment, we will examine the evolution of the community/academic stakeholder committee governing the development of a school travel planning project for Kahnawake school children.

*Methods:* Social network analysis (SNA). *Sample:* This is a sociometric study creating a total network sample. Sociometric studies attempt to gather information from everyone within a bounded network. The study population is the community/academic stakeholder committee for the KSDPP School Travel Planning (STP) project. This closed-membership committee is a network of community stakeholders representing the various interests in the STP project, including school administrators and teachers, parents, public safety and public works officials, along with KSDPP intervention facilitators and academic researchers from McGill University. In all it consists of 13 individuals. This network was sampled at two intervals via network questionnaire, at project initiation and maturation when the committee complete development of the intervention. These
intervals were selected to represent natural sample points where changes in network characteristics might be expected. T1 represents events that took place in January 2013; T2 August 2014. **Measures:** Using UCINET SNA software, Freeman’s in-degree centrality (asymmetric model) was calculated for each committee member. Network centralisation was calculated at each time. Centralisation is related to individual centrality in that it is calculated on the difference between the maximum individual centrality score and all the others within the same network. **Network Questionnaire:** Using a roster technique (Valente 2010), participants were asked to answer the following network question (at T2): “From the provided list of names, please rank the committee members in order of who you turn to for information relating to the STP project.”

**Results and implications:** Results showed that there was significant shift in roles among the STP project committee members over the course of the project development phase. While the academic PI/champion remained central within the committee, community stakeholders were perceived by their peers to emerge and take on knowledge leadership roles. Understanding how influence and information flow shifts during the development of a community-based health promotion intervention project shows how individuals or specific organisations took the lead as the project evolved. Results demonstrate the emergence of new knowledge leaders, and the change in network centralisation within which these leaders function. Results allow planners to design network interventions intended to optimise inter-organisational working relationships to maximise chances for successful implementation.
Manuscript 3 (chapter 5): Examining the dynamics of actor roles and network structure over the lifecycle of a community-based participatory research project. In order to understand the power dynamics at play within PR partnerships, this manuscript takes a social network approach to examining the decision-making roles different stakeholders take throughout the evolution of a PR project. A partnership can be seen as a network of stakeholders, each representing an individual interest within the project. This network can often begin with decision-making power concentrated (centralised) within the hands of one or a few individuals who act as champions of the project. However, as the project evolves and participatory strategies are enacted, the centrality of the network may evolve either toward a more diffuse and democratic decentralised network, or to a new centralised network with decision-making power concentrated in the hands of very different stakeholders. What does the evolution of a stakeholder network look like from the time it is initiated by an academic, non-community champion (T1), to maturation, the end of program development when it is ready to be deployed (T2); to independence, the time when the original champion steps aside (T3); and finally maintenance, as the network has an opportunity to function independently of the original project champion (T4)? Does the network remain unchanged, or if it does change, 1) does it become more or less centralized? 2) do new central actors emerge? And 3) is there significance to the changing roles of actors within the network?

Using an existing community-based participatory research (CBPR) project as a case – the Kahnawake Schools Travel Planning (STP) Project, this study mapped the evolution of a researcher-stakeholder committee to determine its structure at the beginning when the project was first conceived; then when the committee finished
developing the program; then when the original champion stepped aside; and when the committee has functioned independently. The mapped network was analysed to observe changes in location and paths of influence and knowledge-seeking.

Methods: Social network analysis (SNA). This longitudinal study mapped a stakeholder network across four time periods to describe the change in individual in-degree centrality and network centralisation over time. Trend analysis explored network dynamics and determine significance of change. Sample: This is a sociometric study of the community/academic stakeholder committee for the STP project. The closed-membership committee is a whole network of community stakeholders representing the various interests in the STP project, including school administrators and teachers, parents, public safety and public works officials, along with KSDPP intervention facilitators and academic researchers from McGill University. The network consists of 13 actors, representing the 11 members of the STP-Committee plus two others identified as KSDPP individuals who played a significant role at the time the idea was initially being discussed. Each of the actors in this network was administered a questionnaire covering four occasions in the life of the project (project initiation, maturation, independence and maintenance). Project initiation (T1) was in January 2013, maturations (T2) was July 2014, independence (T3) was September 2014 and maintenance (T4) was November 2014. Network Questionnaire: The network questionnaire consisted of a fixed list (roster) of the 13 members of the STP committee. Participants were asked: “From the provided list of names, please rank the committee members in the order of who you would turn to for information relating to the STP project.” Measures: Network mapping and descriptive analysis: Using UCINET 6 SNA software, in-degree centrality and
network centralisation were calculated. Freeman’s in-degree centrality (asymmetric model) was calculated for each network member, including diagonal values. Network Centralisation was calculated for each sample time. Network centralisation is related to individual centrality in that it is calculated on the difference between the maximum individual centrality score and all the others within the same network. Description of Subgroups and Network Core-Periphery: Using UCINET 6 SNA software, core periphery fit index (Borgatti & Everett, 1999) was calculated. A core represents a dense pocket of interconnectivity (Valente, 2010). The fit index is an indication of how well the network conforms to a core-periphery structure, indicating the extent to which a core exists.

Dynamic network analysis: To assess longitudinal network dynamics, the evolution of centrality and network centralisation from T1 to T4 were measured. Friedman Rank Sum test was employed to examine whether there was change in in-degree centrality measures for individuals across time T1 to T4. The Friedman test is a non-parametric statistical test similar to the parametric repeated measures ANOVA, used to detect differences in treatments across multiple test attempts. Linear regression analysis for network centralisation over time was measured using the Cochran-Armitage linear trend test. Data were managed in MS Excel, network measures were calculated and graphs generated using UCINET 6.0 and analyzed using RStudio statistical software.

Results and implications: There was significant change (p<0.005) in the roles of committee member over the course of the development and deployment of the STP project in the community. While the PI/champion continued to play a central role from T1 to T2, by T2 community knowledge leaders were emerging to take leadership roles after the PI/champion left the project at T3 and these were sustained at T4. Although
network centralisation did not significantly change over the course of the study (increased at T2, but at T3 and T4 was similar to T1), the network displayed significant core-periphery structure indicating core of dense interactivity at all samples. Results of this study illustrate the trajectory of an evolving PR project, describing how community ownership and self-determination evolve as the influence of key actors changes over time. Findings have implications for designing PR processes that work to democratise the governance of research project.

**Manuscript 4** (chapter 6): *What participatory strategies foster community ownership and self-determination?* In community-based PR, community stakeholders collaborate with outside academic researchers who are often the originators of the intervention or research idea (Hogan et al., 2014; Macaulay, et al., 1999; Salsberg, et al., 2014). However, successful, sustainable change is founded on community stakeholders ultimately taking ownership over the research process (Green & Kreuter, 2005; Hogan, et al., 2014; Sanchez, Carrillo, & Wallerstein, 2011). This ownership is demonstrated when community research stakeholders possess meaningful and acknowledged control over the directions and resources supporting the research (Cargo, et al., 2011; Fetterman & Wandersman, 2005). The traditional research process tends to vest decision-making power with the (academic) principal investigator, who typically has conceived and designed the study and controls its funding. PR imposes a decision-making structure that spreads the control of resources among the stakeholders, creating opportunity for the non-academic partners to take control of the knowledge-creation process. Community self-determination is thus built through PR when communities take ownership of all aspects
of the research process (Cargo & Mercer, 2008; Goodman et al., 1998; Green, et al., 1995).

While PR utilises intentional strategies to help shift influence and decision-making from academic to community partners, and these strategies have been well documented (Salsberg, Parry, et al., 2015), little is understood about how these strategies lead to increased community engagement, ownership, and ultimately self-determination. Therefore we have examined a community-based participatory research project to describe how ownership and decision-making shift over the course of the project, from initiation, to project maturation, independence and maintenance. Particular focus was placed on how project stakeholders perceived specific enacted strategies to impact this shift and how they have described actions and events over the course of the project that facilitated community stakeholders’ ability to assume leadership roles.

In an earlier phase of this study, a longitudinal network analysis was undertaken to describe the dynamic structure of the stakeholder network from the time of project conception, through its growth and maturity, to its ultimate independence and maintenance, when it was functioning in the absence of the original academic initiator. From this analysis network maps emerged describing the shift in knowledge leadership as measured through network centralisation and individual centrality from T1 to T4. The current qualitative study introduced these same stakeholders to the network results and ask them 1) to interpret the changes of influence at each time; 2) to describe what actions, events or strategies helped democratize the decision making process leading to community ownership; and 3) to describe the extent to which they attribute the influence-shfits to these actions, events and enacted strategies.
**Setting and context:** This study is part of the Kahnawake Schools Diabetes Prevention Project (KSDPP), a 20-year old community-owned participatory research partnership between the Kanien’kehá:ka community of Kahnawake (Quebec), and academic researchers from McGill and Queen’s Universities and Université de Montréal. Within the KSDPP research environment, we will examine the evolution of the community/academic stakeholder committee governing the development of a school travel planning project for Kahnawake school children.

**Methodology:** This analysis is part of an overall mixed-methods study using a social network approach to describe and analyse network change over the course of the observation period. This current piece of that larger study employs a qualitative description methodology. Five community stakeholders and one academic stakeholder (the PI/champion) participated in individual 30-60 minute interviews between January and March 2015. The sample represents members of the KSDPP School Travel Planning Project who were identified as central actors in the earlier social network analysis phase. Data was collected using retrospective, semi-structured interviews. Prior to the interviews, the PI/champion was asked to complete a questionnaire based on best practice participatory engagement strategies derived from leading PR practitioners (Salsberg, 2015 [manuscript #1 in this dissertation]). This tool asked the PI/champion to identify which engagement strategies had been used during the course of the project, and to rate their significance to the project or frequency of use (see Table 4_2). During the subsequent stakeholder interviews, the interviewer first introduced the respondents to the results of the network analysis showing the evolution of the stakeholder committee and then led the respondent through the changes in stakeholder influence described therein.
The interviewer first asked the respondents if they agreed with or had any comments on the network findings. Then the respondents were asked about strategies, actions or events that may have led to the observed changes. Probes were used to ask about predetermined strategies that were identified by the PI/Champion.

Analysis: Qualitative description relies on thematic coding through constant comparative methods borrowed from grounded theory (Glaser 1969). In this way, texts were read, creating codes and code hierarchies that were continuously revised as they were applied to new text. Emergent codes were in turn grouped into overarching thematic categories, describing the phenomenon under study (Lofland & Lofland, 1995). Results of this qualitative study contextualise the results of the network analysis, by allowing the stakeholders themselves to explain the perceived meaning of the changes in influence documented at each stage. This is intended to provide insight into how influence shifts within community-academic PR partnerships.

Results and implications: The following emergent themes were perceived by committee stakeholders as fostering the sustained community ownership over the research process that was demonstrated in the social network analysis: the need for a strong champion; outside ideas can be stimulating; emergence of core people as the project develops; alignment of stakeholders’ professional roles with project goals; involving the right people; the personality of the champion; and trust-building. Active use of participatory engagement strategies were also perceived by stakeholders to facilitate engagement and actively transfer responsibilities. In particular, the following strategies were perceived as fostering community ownership: forming an advisory committee; developing a research agreement; use of group facilitation techniques; ensuring
frequent communication; researchers making active efforts to learn about the participants and their context; facilitating community involvement; building community capacity; and community interpretation, data ownership and dissemination. Results of this qualitative study contextualise the results of the network study, by allowing the stakeholders themselves to explain the perceived meaning of the changes in influence documented at each stage. Findings provide insight into how influence shifts within community-academic PR partnerships, and have implications for designing PR processes that work to democratise the governance of research project, ultimately leading to community ownership and self-determination.
Chapter 2

Literature Review

Participatory Research: History and Application

Participatory research (PR) is the systematic co-creation of new knowledge by researchers working in equitable partnerships with those affected by the issue under study or those who will benefit from or ultimately act on its results (Green, et al., 1995; Israel, et al., 1998; Macaulay, et al., 1999). These could be, among others, communities, organisations, patients or practitioners. For health intervention research, proponents argue that PR strengthens academic-community relations; ensures relevancy of research questions; increases capacity of data collection, analysis and interpretation; minimises the negative or stigmatising effects of research, and enhances program recruitment, sustainability and extension (Cargo & Mercer, 2008; Israel, Parker, et al., 2005; Israel, et al., 1998; Macaulay, et al., 1998; Macaulay, et al., 1999; O'Fallon & Dearry, 2002). PR is believed to increase communities’ capacity to identify and solve their problems (Gaventa & Cornwall, 2006; Macaulay, et al., 1999) and decision-makers’ and service providers’ ability to mobilize resources, improve policies and enhance professional practices (Minkler & Wallerstein, 2008). Taking a PR approach has been shown to ensure culturally and logistically appropriate research, enhance recruitment capacity, generate professional capacity and competence in stakeholder groups, result in productive conflicts followed by useful negotiation, increase the quality of outputs and outcomes over time, increase the sustainability of project goals beyond funded time frames and during gaps in external funding, and create system changes and new unanticipated projects and activities (Jagosh, et al., 2012). Participatory research furthermore integrates...
knowledge translation into the knowledge creation process by assuring that the appropriate end-users of the results are implicated throughout all key phases of the research. Most importantly, end-users should be involved in the research phases of identifying the need and setting research questions, interpreting results, and disseminating and applying findings (Macaulay, et al., 1999; Minkler & Wallerstein, 2008; Parry, et al., 2009; Salsberg, et al., 2014).

Participatory research finds its origins in both social action research and emancipatory philosophy; or as it has been suggested, from northern and southern traditions (Wallerstein & Duran, 2008). Kurt Lewin’s action research framework (Lewin & Lewin, 1948) proposed a cycle of continuous inquiry, action and evaluation, undertaken with or by – as opposed to for or on – society’s marginalised or disenfranchised. The aim of Lewin’s action research was to empower mainly urban-dwelling ethnic minorities to create social equity in overcoming racial and class disparities. The action research framework has been expanded and developed over the ensuing decades, most notably by Argyris and others (Argyris, Putnam, & Smith, 1985; Argyris & Schön, 1978) who applied it as a means of promoting improvement in organisational efficiency. Lewin’s and Argyris’s work, as we shall see below, later formed the basis for the modern knowledge-to-action cycle in health intervention research.

Emancipatory theory and practice, particularly in the southern developing world, questioned the value of both research and education by critically examining their products in relation to both political power and oppression. Paulo Freire’s *Pedagogy of the Oppressed* (Freire, 1970) posited individuals not as empty vessels but as potential
masters of their own future, able to determine their own needs to improve their lives. Both agendas for education and research should therefore serve their self-defined needs. Therefore, people, and indeed communities, should no longer be seen as objects of study, but full participants in inquiry (Freire, 1970; Wallerstein & Duran, 2008). Freire’s work has been particularly influential for action in developing area studies, where researchers and international organisations such as UNESCO and the World Bank have taken it to provide a framework for empowering marginalised and disenfranchised communities to generate the evidence they needed to force local or national policy change granting them hitherto denied rights and resources (Rahman, 1993). In this emancipatory and action-oriented work, social change and access to often life-sustaining resources was paramount, often devaluing the need or desire to apply rigorous research methods (Rahman, 1993). From an epistemological – and indeed Freirean perspective, if the standard of knowledge is that it motivates behaviour or action for change on an individual’s part (Bradbury & Reason, 2008; Semali & Kincheloe, 1999), then the products of people’s own self-research as well as the methods that produced them are valid if they foment the desired social change. This methodological consideration later became a point of contention when participatory methods were seen by some as ‘soft’ when applied to topics and areas where other scientific methods were the norm (Minkler & Baden, 2008). In one instance when public health had lauded CBPR as an approach it seemed unable to reconcile what it sees as epidemiological scientific rigor with community participation (Weed & McKeown, 2003).

For a long time, participatory research was seen explicitly as a qualitative methodology (Patton, 1990; Schwandt, 2007). It was that branch of qualitative enquiry
where people could come together, generally with outside support, to inquire into their
own social issues. This view is founded on the methodological realities of research that is
at the service of one more-or-less homogeneous group of people. If the knowledge
created through the PR process is to benefit a group of people, then how that knowledge
is defined and understood (epistemology) and the means of apprehending it (methods)
must match (McIntyre, 2008; Patton, 1990). For most groups or societies in which this
process was being applied, this did not mean a positivist paradigm founded on a dualistic
separation of the individual and objective reality; and therefore the means of approaching
knowledge resembled more the methods of data collection and analysis used in various
branches of qualitative analysis, appropriate for understanding action within its rich
context, and practicable by the people themselves (Fine, Tuck, & Zeller-Berkman, 2007).
It is also possible that this heritage of PAR using qualitative methods is a reflection of
which outside academics or activists were instigating it. We are still here discussing
partnered research, not peoples’ own self-inquiry without outside support. This is evident
from the fact that our record comes from published accounts by outsiders who were
involved in these local projects. And in the majority of cases these were social scientists
coming from political or economic development backgrounds (Rahman, 1993).

In the 1980s as participatory methods were beginning to be applied to health
promotion, two things began to change. First, many of the practitioners involved in public
health research had epidemiological training and were, from a health equity perspective,
interested in addressing the disproportionate burden of ill-health experienced by
marginalised or underserved communities. Focus began to shift from the developing
world as these new studies were primarily situated within industrialised nations, mainly
in North America (Epp, 1986; Labonte, 1986). And second, because the health promotion framework entailed addressing the social determinates of health, many projects began to include the more diverse stakeholders needed to address system and policy change (Robertson & Minkler, 1994). This meant that not only were the local populations participating, but also program planners, policy makers and service providers; anyone whose behaviour, opinion or practice also needed to change in order to create the social or health change intended by and for the target population. In this new multi-stakeholder, multi-perspective context, it became impossible to necessarily privilege one epistemology over another within a participatory research project. The knowledge or evidence needed to stimulate action needed to satisfy the various stakeholders, each with perhaps very different world views and knowledge needs (Kincheloe & Steinberg, 2008). At this point it became impossible to see participatory research as a methodology, or even as a set of methods, but rather an approach to equitable co-governance of the research process (Israel, et al., 1998; Macaulay, et al., 1999; Minkler & Baden, 2008). It became an approach where the multiple stakeholders could negotiate and align their action needs around a particular issue of common interest, and develop new knowledge products necessary from their own perspectives to address it. The fundamental principal of PR became the equitable co-ownership, and participatory ‘methods’ became no longer the methods of data collection and analysis, but rather the methods of partner engagement, locating power and ownership at every stage of the research process (Minkler & Baden, 2008). Therefore research on the participatory process became research on how best to create and maintain engagement among project stakeholders in a way that created meaningful and sustained ownership over the research and action process (Cargo et al.,
2008; Cargo, et al., 2011). Participatory research theoretical or conceptual models focussed on this building of ownership as the basis for sustained action and change (Sanchez, et al., 2011). Research on PR has now come to focus on understanding the effectiveness of strategies used to activate mechanisms of stakeholder engagement and ownership found within these conceptual models (Hicks et al., 2012; Oetzel et al., 2011; Oetzel et al., 2014).

1980’s and 1990’s: Participatory Research and Health Promotion:

As early as 1984, one development researcher recognised,

What is needed is a research process which incorporates both qualitative and quantitative methods adapted to field conditions. Such a process would include… a preliminary qualitative stage…, a quantitative stage…, a follow-up qualitative stage to investigate inconsistencies between initial qualitative and quantitative data which might indicate compounding or unidentified variables, representative in-depth case studies, [and] periodic follow-up research to account for social change (Nichter, 1984).

Nichter immediately follows this call with a question: "But who is there to conduct such research?" (Nichter, 1984). It is arguable that this call was taken up by the burgeoning field of health promotion, with its focus on the health-equity, the social determinates of health and, importantly, the primacy of the community in setting its own policy research and intervention agenda (Epp, 1986; Labonte, 1986; Robertson & Minkler, 1994).

By the mid-1980s and the Ottawa Charter for Health Promotion (WHO, 1986), Labonte (1986) described public health’s four tools for promoting health: 1) Health Promotion: mass-media awareness campaigns (more or less primary prevention); 2) Health education: individual-level awareness education; 3) Health advocacy: getting policy makers to enact healthy policy and laws; and 4) Community development: work
with communities and existing community organisations to ensure grassroots support for change. Robertson & Minkler (1994) saw ‘the new public health’ as a social movement whose key components are: 1) broader definition of health to include the social determinants of health; 2) emphasis on social and political intervention strategies over individual ones; 3) the centrality of individual and community empowerment; and 4) meaningful participation – i.e., implicate individuals and communities in the creation of the means of their own change. Robertson & Minkler use Arnstein’s ladder of participation to critique then-current notions of real participation (Arnstein, 1969).

The Ottawa Charter of Health Promotion (1986) called for action in five areas: 1) Build Healthy Public Policy; 2) Create Supportive Environments; 3) Strengthen Community Action to build communities’ capacity to set priorities and make decisions on issues that affect their health; 4) Develop Personal Skills to enable people to have the knowledge and skills to meet life’s challenges and to contribute to society; and 5) Reorient Health Services to create systems that focus on the needs of the whole person and invite a true partnership among the providers and users of health services.

Those involved in health promotion programming looked to participatory research as the basis of a process for populations to determine their own health priorities in an organic way that accounted for the various ecological spheres that encapsulated and constrained healthy behaviour. Green and Kreuter (2005) took participatory processes to be central to their PRECEDE-PROCEED Model of Health Promotion Planning and Evaluation (Green & Kreuter, 2005). This model has been the most robustly applied model of community intervention planning and evaluation since its initial introduction in the early 1990’s. Other health promotion practitioners and evaluators, understanding that
communities must have self-determination over the identification and redress of their own health issues, began to turn to the legacy of participatory action research as an appropriate model for community-university partnership for change (Israel, et al., 1998; Macaulay, et al., 1999; Minkler, 2000).

**From Health Promotion to Health Services Research and Integrated Knowledge Translation:**

Participatory research thus entered into the health research literature largely through its use as an approach to community-based health promotion. Leading health promotion researchers such as Meredith Minkler and Barbara Israel and Nina Wallerstein, were early to recognise the value of this approach to other areas of health research when they compiled their seminal text books (Israel, 2005; Minkler & Wallerstein, 2008). By the early 2000s, PR was once again experiencing a push as health services researchers and evaluators began to grapple with the limitations of evidence-based practice in both health care and in public health policy.

Despite significant investment by industrialised nations in developing new evidence to improve health, health services and systems, there has been recognition over the past two decades that despite significant gains, bridging these knowledge gaps does not necessarily lead to better health outcomes for the populations they are serving (Graham, Harrison, Brouwers, Davies, & Dunn, 2002; Graham & Tetroe, 2007; S. E. Straus, Tetroe, & Graham, 2009; S. E. Straus, Tetroe, & Graham, 2011). Knowledge created is not necessarily knowledge applied. In fact, it has been estimated that it takes on average 17 years for just 14 percent of all primary research to make it into practice.
(Green, 2008b; Weingarten, Garb, Blumenthal, Boren, 2000). Most students of this movement of knowledge into practice have viewed the process as a funnel, or pipeline, or filter, wherein vast amounts of knowledge derived from primary research is increasingly synthesized, refined, tailored and ultimately put into use. While this process is justifiable, and indeed important to assure only quality and efficacious findings are applied – especially in the biomedical clinical setting, it can also limit or unduly delay the application of beneficial findings from making it into practice to effect the health outcome of individuals. Furthermore, it is not always clear what the ‘beneficial’ findings are: beneficial to whom? Is beneficial to the patient the same as beneficial to the service provider, or to other health stakeholders? Is there a way we can better understand this process of moving knowledge into action, and accelerate the identification, uptake and use of beneficial knowledge? This question has led directly to the study and practice of bridging these implementation gaps: knowledge translation.

Knowledge translation (KT) begins from a different premise: the movement of knowledge into action is not a linear pipeline, but rather a cycle of interaction (Graham, 2006; Armstrong, 2006; Greenhalgh, 2004; Green, 2009) where the needs of ‘end users’ such as practitioners, interveners, policy-makers, communities and individuals drive primary research as much as the latter constrains practice. Knowledge translation has thus been defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system (CIHR 2012). This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of
engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user (CIHR 2012). This Canadian usage of KT is an attempt to define an overarching conceptual framework covering all stages of discovery from basic science, through clinical application, to health of populations. However its roots lie in clinical translational research and its applicability to the sphere of community and public health often has been applied or received coolly. In the US, for example, the National Institutes of Health (NIH) have clearly differentiated between Translational Research 1, bench to pre-clinical and clinical usage; and Translational Research 2, basic, clinical and intervention research to community and population health (NIH Roadmap, 2012). Until recently with the advent of the large NIH Clinical and Translational Science Awards, these two areas of KT have been seen as distinct, and the majority of resources were dedicated to the first.

KT, as the CIHR definition makes clear, is not a unidirectional flow. It is a complex, dynamic and multidirectional process based on the engagement and interaction of those generally distinguished as knowledge producers and knowledge users. As complex as this process can be at the level of bench to clinic, some see it as even more so when translating research results into effective outcomes at the community or population levels (Green & Glasgow, 2006). There are indeed added levels of complexity in public health; however, many of the issues are fundamentally the same at all levels, and founded on a contextual and epistemological mismatch between the assumptions and environments in which the knowledge is produced and the worlds in which clinical practitioners, policy-makers, patients and people at large operate and put this knowledge to use (Bradbury & Reason, 2008; Green & Glasgow, 2006).
Graham et al. (2006) outline a broad typology of definitions of KT which vary mainly on the directionality of flow, end-user audience and level of engagement between different stakeholders in the translation process. However, all but the most passive and linear of models (such as what Graham here described as dissemination, although later CIHR calls this diffusion) involve at least a degree of researcher-user engagement. For example, even knowledge transfer, which is seen as more unidirectional, involves much more than a one way, linear diffusion of knowledge of skills from a university to an industry; it depends on access to people, information and infrastructure (Graham et al., 2006).

Graham et al. (2006) were ultimately building toward a knowledge-to-action (KTA) model which will underlie the CIHR definition of KT. Their KTA model is based on a synthesis of 31 identified theoretical or logic models of knowledge implementation, mobilisation, exchange, transfer, utilisation and usage (Graham & Tetroe, 2007). Although their model acknowledges that at each phase knowledge producers can tailor their activities to the needs of potential users, the KTA model as originally presented seemed to describe the activities of knowledge creation and knowledge translation as structurally distinct. It displayed the KT process as beginning with the creation, refinement and tailoring of new knowledge, followed by a cyclical process of environmental and need assessment, knowledge adaptation, implementation, usage-monitoring, evaluation and sustaining (Graham & Tetroe, 2007), thus situating the model as cyclical (Ward, 2009). This seems in contradiction to the fundamental assumptions of engagement that pervade many of the underlying models or theories on which it is based. However, later refinement of the model (CIHR, 2012) highlight the dynamic relationship
between each stage of the translation cycle and the processes that take place within the ‘knowledge wedge’ at its centre. In other words, the impetus for knowledge creation can come from any stakeholder at any stage (e.g., from problem identification, knowledge implementation, usage-monitoring), and as well can begin its journey toward action at any stage of the cycle. This more dynamic model returns the focus to the engagement between those primarily involved in knowledge creation and those who must ultimately use it. But it still sees these groups as fundamentally separate.

The KTA model, as described, sees a multiplicity of stakeholders as implicated in the translation process, however it does not see them all, or the same ones, as having roles in all stages of the process (Armstrong, Waters, Roberts, Oliver, & Popay, 2006; Graham, et al., 2006; Ward, House, & Hamer, 2009). Indeed it acknowledges that some are better suited to act at one stage or another. However, Graham and indeed CIHR envision a different way of conceptualising KT, which moves it from a corollary of knowledge production to a fundamental part of it. Integrated KT (Bowen & Graham, 2013; Salsberg, et al., 2014) embraces the Canadian Health Services Research Foundation (CHSRF)’s definition of knowledge exchange

...collaborative problem-solving between researchers and decision makers that happens through linkages and exchange. Effective knowledge exchange involves interactions between decision makers and researchers and results in mutual learning through the process of planning, producing, disseminating and applying existing or new research in decision-making (Graham, et al., 2006).

It situates KT firmly as a dynamic, multidirectional process (Ward, et al., 2009). In integrated KT, researchers and appropriate knowledge users, i.e., those who must ultimately act on the results of the research, or for whom the outcome benefits are
intended, are meaningfully and equitably involved at all significant stages of the research, from identification of the need, through interpretation of results, to dissemination and application of the findings (Parry, et al., 2009; Salsberg, et al., 2014). And this participation of all stakeholders as co-producers of the actionable knowledge is what ultimately allows KT to address the epistemological and contextual divides necessary to make it most applicable to the community and population settings.

In his review of CIHR’s KT programs, McLean (2013) reports that, “researchers and [knowledge-users] describe building meaningful collaboration as key to research project success and impact, however, the term ‘meaningful’ is quite nuanced and contextually-bound” (McLean et al., 2013). In describing the dimensions of meaningful engagement, the report concludes that,

- Meaningful partnerships are characterized by: mutual learning, mutual respect, mutually agreed upon roles and responsibilities, mutual recognition of efforts, and mutual exchange of information;
- Mutual does not necessarily denote that partners give and receive equally, but that all parties play a role in negotiating roles and expectations;
- Researchers and knowledge users have different understandings of the roles and responsibilities required of each team member in order to make collaboration meaningful; and,
- Meaningful partnerships are negotiated based on many factors including, but not limited to: resources, external commitments, technical skills, and epistemology (McLean, et al., 2013).

Knowledge Translation and Evidence Based Practice: There is an historical link between the emergence of KT as a field of interest and the growth and predominance of evidence based practice, as manifest both as evidence based medicine (EBM) and evidence based public health (EBPH) (Kohatsu, Robinson, & Torner, 2004). In one sense these can be seen as the same endeavour: evidence-based practice is the translation of knowledge into practice. However, as we shall see, it is concerned with a specific
definition of what constitutes evidence. EBM first emerged in the early 1990’s (Sackett, 2000; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996), along the same epidemiological drive that led to the population health movement public health: a call for a greater clarity and rigor of scientific ‘evidence’ as the basis for health intervention and practice. Over the ensuing years it has become the predominant paradigm for training health professionals and for designing and delivering public health policy initiatives. The evidence-based practice process proceeds along the following steps (as summarised by Kohatsu, 2004): 1) state the scientific question of interest; 2) identify the relevant evidence; 3) determine what evidence is relevant to answering the scientific question of interest; 4) determine the best course of action considering the patient or population; and 5) Evaluate process and outcome. It is at the fourth stage, determining the best course of action, that the effectiveness of evidence-based practice as a guide to action tends to break down, as we will demonstrate below.

      Many criticisms of EBM have been put forward, summarised by Kohatsu (2004) as its de-emphasizing of patients’ [or community’s] values, perspectives and choices; failure to account for individual social and biological variation; de-emphasis of clinicians’ insights, and lack of a model for how these all could be combined to choose the optimal course of action. In short, EBM falls short based on its relative failure to address context and differing constructions of evidence (i.e., epistemology). One facet of the contextual problem is that ‘rigorous’ scientific evidence, based upon systematic synthesis of the prevailing research, is subject to the limitations of publication bias, where negative results do not get published or even submitted as frequently as positive results. Negative results are of interest because,
they often tell the practitioner about the intervention’s misfit with populations or conditions other than those in which the original research leading to guidelines was conducted (Green, Ottoson, García, & Robert, 2009).

And thus it fails practitioners because…

The literature on which the [evidence-based] guidelines are based constitutes an unrepresentative sample of the varied circumstances and populations in which the interventions might be usable or unusable (Green, et al., 2009).

Furthermore, there is a basic contradiction between the basis for EBM and the way it is interpreted and acted upon. Clinicians operate in a world that is epistemologically distinct from that in which the knowledge they must act on was produced. Evidence-based guidelines are (at their ‘highest level of rigor’) derived from a synthesis of controlled experimentation. Whereas clinicians rely heavily on experiential evidence accumulated over the course of their practice. Novice clinicians such as medical residents, are much more likely to adhere closely to evidence-based clinical practice guidelines (CPGs) than senior clinicians, who will rely more heavily on the context before them in deciding on a course of action (Greenhalgh, 2012). This is doubly confounded by the fact that multiple, often conflicting CPGs usually exist covering a given issue. For this reason, clinicians have a tendency to disregard CPGs and fall back on experience when faced with complex decisions (Greenhalgh, 2012).

Green (2008), Greenhalgh (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004) and others have proposed that the solution to these problems is not in the dilution of the rigors of scientific evidence, but in a re-contextualising of the impetus for the creation of action-oriented knowledge in the first place. As Green (2008) succinctly put it “if it is an evidence-based practice, where's the practice-based evidence?” Both Green
and Greenhalgh call for knowledge that is co-created with the full participation of those who must ultimately apply it (i.e., participatory research with end-users), and therefore is much more imbued with the contextual imperatives that will render the knowledge useful to the setting in which it need be applied. In other words, they are recommending integrated KT. Furthermore, it should focus on process (i.e., why the intervention is appropriate for the context, rather than is it effective); be ecological (i.e., explore the relationship between the intervention and the context in which it took place); and be theory-driven (i.e., based on a theoretical understanding of the mechanism for action or change) (Greenhalgh, et al., 2004).

**Implications for KT in Public Health:** Although all KT is concerned with the movement of research-derived knowledge into action, the differences in the types of knowledge being translated and the audiences or end-user communities to which it is being translated, mean that different barriers come into play in both the clinical and public health settings. In the preceding sections we have discussed the overall issues at stake in translating knowledge to action. In public health policy and programming, the knowledge or ‘evidence’ being translated tends to focus on the effectiveness of complex interventions intended for complex populations (Kohatsu, et al., 2004). Furthermore, the translation is taking place within a broader set of stakeholders, often with political, bureaucratic or social agendas that compete with the strict health-related goals. Beside government policy-makers, the stakeholders implicated in the success of public health policy intervention include community organisations and leaders, the healthcare delivery system, employers and businesses, the media and academia (Kohatsu, et al., 2004). At any given point in the translation process, any or all of these stakeholders’ interests may
conflict, leading to a breakdown of implementation. And it should not be forgotten that none of these groups are monolithic, and experience dissent from within. The formulation of EBPH policy and programing by policy-makers and practitioners comes up against several barriers. These include an absence of personal contact between researchers, policy-makers and practitioners; lack of timeliness of research; mutual mistrust [between stakeholders]; power and budget struggles [within or between agencies]; poor quality of research [from an evidence-based perspective]; political instability; and a debate over what constitutes evidence (Armstrong, et al., 2006). Policy planning and budgetary cycles also mean that it is often impossible to act on new significant evidence once policy-makers have already begun implementing a program; thus either delaying action on the new knowledge for years, or relegating it to perpetual obscurity (Parry, et al., 2009).

Public health interventions in themselves are complex, and the evidence for their efficacy or effectiveness is notoriously hard to come by (Pawson, 2006). The link between cause and effect established through experimentation for ‘pill and disease’ is practically impossible to establish for complex interventions designed to serve a large heterogeneous population whose health is constrained by myriad upstream social and environmental determinates. However, as stated above (Green, 2008; Greenhalgh, 2004) taking an integrated approach to KT helps address all of these issues by assuring that those whose health is being benefitted are implicated in: identifying the need; designing the means of filling it; applying the results; then helping to decide whether it was successful, and sustaining the effort (Parry, et al., 2009; Salsberg, et al., 2014). This participatory process helps assure that the knowledge produced actually meets a real world need. And second, and most importantly for public health, the participatory nature
of integrated KT directly addresses the social determinants of health by building community capacity in terms of human, social and environmental capital; addressing both community and organisational readiness; and fostering a sense of community ownership and empowerment that leads to the sustainability of both programs and health outcomes (Jagosh, et al., 2012; Labonte, 1986).

**Future Directions**: KT research, or implementation science, the field looking to advance the scholarship and practice of moving knowledge into action for change, is still growing. With each new study, we learn a bit more about what works, for whom and in what contexts. This in itself is an indication that perhaps an overarching framework for KT is not needed, or indeed is impossible to locate. If context is everything, then perhaps one need look toward the specific rather than the general. In any event, after more than a decade and a half of EBM and EBPH policy, the tides seem to be shifting once more towards less linear models and more contextually situated approaches to practice change. While public health intervention research is still firmly rooted in evidence-based models, the broad shift in clinical care to a reemphasis on the primary care setting, patient-oriented or managed care and the ‘medical home’, has resituated evidence-based practice as evidence-\textit{informed} practice. This much more nuanced approach explicitly places equal if not greater weight on the experiential evidence of clinicians, and the individual needs of patients, their lived lives and their families. In public health, this may be reflected in Kohatsu’s (2004) definition of EBPH as “the process of integrating science-based interventions with community preferences to improve the health of populations.”

In general, a continued emphasis on \textit{integrated KT} as the preferred means of co-creating action-oriented knowledge in both the clinical and population spheres, will
assure that contextual and epistemological factors are always at the core of knowledge translation; and thus improving relevance, uptake and sustainability of knowledge use. CIHR has been a global leader in promoting and funding Integrated KT initiatives, allowing non-academic co-investigators and even non-academic nominated PIs to lead grants, and even funding professional release time for knowledge-user co-applicants to become actively involved in the knowledge creation process. Alarmingly, CIHR seems poised to drastically cut back their support of both KT and KT research, and are doing so under political pressure despite the favourable results of the KT branch’s impact evaluation (McLean et al., 2012; McLean, et al., 2013).

**Key Limitations and knowledge gaps:**

The practice and processes of participatory research have been examined to provide practical recommendations (Cargo & Mercer, 2008; Green, et al., 1995; Israel, et al., 1998; Trickett & Espino, 2004; Waterman, et al., 2001), and to assess its value in relation to research goals, health status, and systems change (Boote, et al., 2002; Gaventa & Barrett, 2010; Kreuter, et al., 2001; Roussos & Fawcett, 2000; Viswanathan, et al., 2004). The gaps and limitations in our understanding of the process and outcomes of participatory research fall mainly into two categories. First there is the impact of taking a participatory approach on research outcomes. In other words, does, and if so then how does taking a participatory approach lead to better research outcomes than taking a conventional, research-lead approach? And, relatedly, what do we mean by better (Glasgow, Vogt, & Boles, 1999; Jagosh et al., 2011; Macaulay et al., 2011)? Secondly, what is the evidence supporting the various aspects or stages to a participatory research
conceptual model? Several conceptual models have been suggested for participatory research, most recent and noticeable those proposed by Cargo & Mercer (2008) and by Wallerstein, et al. (Cacari-Stone, Wallerstein, Garcia, & Minkler, 2014; Oetzel, et al., 2014; Sanchez, et al., 2011).

Viswanathan, et al (2004), in their review of community-based participatory research (CBPR) for the US Agency for Healthcare Research and Quality (AHRQ), concluded that difficulties in assessing the outcomes of participatory research were based on a number of barriers. These were:

1. Lack of completed studies (and restricted to CBPR)
2. Lack of consensus on the definition of PR in the conceptual literature
3. Diversity of studies presents difficulty developing an analytic framework
4. Difficulty assessing research quality due to the diversity of studies
5. Difficulty linking research quality to the quality of participatory elements
6. Difficulty attributing research outcomes to participation (Viswanathan, et al., 2004)

Cargo & Mercer (2008) note that lack of consistency in the use and measurement of core process indicators and the lack of comparative case studies have limited progress in understanding how variation in implementing PR approaches relates to research outcomes. They also note the absence of a conceptual framework for understanding and evaluating participatory research; an issue that both they and Wallerstein's team resolved by proposing two different conceptual models. Cargo & Mercer finally make four key recommendations for future research:

1. A future systematic review of PR effectiveness may be worthwhile.
2. Identify how variation in the core elements of capacity building, empowerment, ownership, and sustainability impacts health outcomes.
3. To strengthen the accountability of PR projects to achieve research outcomes, greater conceptual clarity is needed (a) among capacity building, empowerment, and ownership and (b) between capacity development and sustainability.

4. Determine whether there are patterns in best processes for PR according to driver. (Cargo & Mercer, 2008)

Recommendation #1 has been taken up and to a partly fulfilled by Macaulay, Jagosh, et al (Jagosh, et al., 2012). Recommendations #2-4 are interrelated and rely on designing studies aimed at understanding and evaluating the processes and effects of aspects of the PR conceptual models. As of 2015, Wallerstein and her team are currently proposing a program of research delving into the stages of their conceptual model. In the knowledge translation world, Graham and colleagues are similarly proposing a program of study through the Canadian Institutes of Health Research’s Foundation Scheme to investigate the processes and impacts of stakeholder involvement in improving both research and health system outcomes. The results of both these programs will significantly further our understanding of participatory processes.

Ownership and Self-Determination from a Participatory Research Perspective:

Of the various dimensions of the participatory research conceptual model, the fundamental place of ownership in creating and sustaining outcomes deserves particular attention. Cargo and Mercer (2008) identified knowledge translation, social justice and self-determination as the three principal goals or values that drive PR and lead researchers to take a partnered approach to knowledge creation. The particular PR processes that foster each of these three drivers have been explored. The recent literature
on knowledge translation shows a pointed turn toward integrating knowledge-users within the research process to make new evidence more responsive to end-user needs and to speed uptake (Bowen & Graham, 2013; Graham & Tetroe, 2007; Greenhalgh, 2012; Greenhalgh, Macfarlane, Barton-Sweeney, & Woodard, 2012; Parry, et al., 2009; Salsberg, et al., 2014). Social justice is about addressing the most vulnerable or marginalised segments of any population (Brown & Tandon, 1983; Freire, 1970). Participatory processes have been seen as fundamental means of creating equity for these individual and communities by emancipating them within the societal and political structures to which they had been excluded. This has been particularly true in the area of health equity, where participatory processes implicit in health promotion have attempted to shift policy towards serving vulnerable segments of society (Epp, 1986; Frohlich & Potvin, 1999; Labonte, 1986; Robertson & Minkler, 1994). Self-determination, the ability of individuals or groups to determine their own future, has been a central topic in health research – particularly public health research, since the 1980s as vulnerable or marginalised populations have attempted to take control over their own health and the evidence that informs the interventions, policies and programs that address it. This has been most evident among Indigenous and minority groups (Smylie et al., 2004; Young, 1994; Young, et al., 2000), HIV/AIDS communities (Flicker, et al., 2009; Travers, et al., 2008), the poor (Labonte, 1986; Loignon, et al., 2013; Robertson & Minkler, 1994); and other underserved segments of society such as prisoners (Martin et al., 2007; Martin, et al., 2009) and mental health service-users (Park et al., 2014; Pelletier et al., 2011). In recent years self-determination has also emerged as an issue in clinical implementation research (Jabbour et al., 2013). Healthcare providers such as doctors and nurses have
increasingly found evidence-based practice guidelines ill-suited to the real-life practice
decision-making situations in which they must be applied (Lugtenberg, Burgers, Besters, Han, & Westert, 2011; Lugtenberg, Zegers-van Schaick, Westert, & Burgers, 2009). This
has been particularly true in community medicine and primary care settings where
patients present with multiple health problems and complex socioeconomic realities
(Peters-Klimm et al., 2012). Evidence-based guidance is derived mainly from controlled
efficacy studies very removed from the realities of the practice settings in which it is
meant to be applied. Healthcare practitioners are realising that in order to have an
effective evidence-based practice, they need appropriate practice-based evidence (Green,
2008b). This means that the practitioners need to be implicated in the same key phases of
research described in other areas of PR: in identifying the need and setting the research
questions; in interpreting results; and in disseminating and applying the findings (Parry,
et al., 2009; Salsberg, et al., 2014). By doing so, practitioners are taking ownership of the
knowledge creation process that leads to the evidence-based guidance that best meets
their real practice needs – i.e., self-determination.

Although each of Cargo & Mercer’s three values is recognised as driving PR,
least is understood about the strategies undertaken to achieve ownership and self-
determination. Much has been written about the strategies for overall stakeholder
engagement (Hermann, et al., 2004; Kizer, 2001), particularly with communities
(Macaulay, et al., 1998; Minkler & Wallerstein, 2008). And the strategies and processes
for knowledge translation, both in public policy and for health practice have been well
described (Graham & Tetroe, 2007; Parry, et al., 2009). Participatory strategies that
directly attempt to build ownership and self-determination are less well described and
rarely if ever evaluated. Even where ownership has been evaluated (Cargo, et al., 2011; Cargo, et al., 2003), it was as an outcome measure of overall ‘participation’ by community members, with no exploration at all of individual strategies within the participatory process that intentionally targeted self-determination. There is therefore need to better understand/evaluate how PR can promote community ownership and self-determination.

**Social Network Analysis:**

A social network can be defined as connections among people, organisations or other social actors (Valente, 2010; Wasserman & Faust, 1997). Although the individual attributes of these actors can determine their social network, network analysis focuses rather on their relationships and how these affect their behaviour. These relationships – or network links or ties – are the connections *among, within and between* the actors and the goal of network analysis is to understand how a network can influence and constrain the behaviour of its members (Valente, 2010).

Freeman (Freeman, 2004, 2011) described the modern study of social network analysis as an approach that involves four defining properties: (1) It involves the intuition that links among social actors are important; (2) is based on the collection and analysis of data that record social relations that link actors; (3) draws heavily on graphic imagery to reveal and display the patterning of those links; and (4) it develops mathematical and computational models to describe and explain those patterns. Valente (2010) slightly restates these qualities to highlight that it: 1) considers the whole network structure; 2) makes arguments about how network structure influences individual action; 3) uses
graphical displays; and 4) uses mathematical formalism. Modern social network analysis is often cited as beginning with the work of Jacob Moreno (Freeman, 1996, 2004, 2011; Moreno, 1934; Valente, 2010). This was the first point where all four modern elements came together; although Freeman (1996) points out that several researchers, particularly American psychologists, were anticipating and applying Moreno’s sociometric techniques as early as the 1920s. Aspects of interest to modern social network inquiry, particularly interest in graphic representation and how relationships constrained individual behaviour, were applied much earlier by anthropologists and others involved in kinship studies. However it was not until Moreno’s work in the 1930s that mathematic analysis and modeling were applied to describe these relationships and make inferences about individual behaviour.

Social network studies tend to take either a whole network design, looking at the sum of component actors as members of a bounded social collective; or an egocentric design, examining networks from the perspective of the actors within them (Marsden, 2005). Studying networks of individuals has led to greater understanding of how, among others, diseases, ideas and opinions spread; how people access social support, and who or what influences their health behaviour (Turcot et al., 2009). Seminal theories, such as Rogers’ diffusion of innovations (Rogers, 2003) and Granovetter’s strength of weak ties (Granovetter, 1973) played a significant roles in bridging the gap between micro-level observations and macro-level sociological theory. Strength of weak ties theory demonstrating how important information and resources flow into a network via peripheral connections (the weak ties), is significant for understanding mechanisms of inter-organisational and network cohesion (Valente & Fujimoto, 2010), and an important
part of the network understanding of social capital – how individuals access resources via their social networks (Borgatti, Mehra, Brass, & Labianca, 2009). Rogers’ diffusion of innovations has been the seminal theory in understanding how information, opinions and resources spread within social networks (Valente & Fosados, 2006; Valente & Rogers, 1995).

Network analysis has examined how health service organisations collaborate to share information, plan and deliver services (Doak, Visscher, Renders, & Seidell, 2006; Potvin & Lamarre, 2009; Story, Kaphingst, & French, 2006; Turcot, et al., 2009). Within community-based participatory health research, it has been used to evaluate how community health workers share and use evidence (Campbell et al., 2014; Valente, Fujimoto, Palmer, & Tanjasiri, 2010), to examine interpersonal support networks (Fuller, Hermeston, Passey, Fallon, & Muyambi, 2012; Langhout, Collins, & Ellison, 2013; Leonard, Horsfall, & Noonan, 2014), and to examine issues of access and equity (Luque et al., 2011; Pauly, MacDonald, Hancock, Martin, & Perkin, 2013; Ramanadhan et al., 2012). Within community-based health promotion, social network analysis has been used to examine peer influence on intervention effects (Shin et al., 2014). Fuller, et al. (2012) showed that social network analysis could serve as an effective and culturally-acceptable approach within Aboriginal communities. Within that study, community members considered that the network analysis had accurately described the links between workers related to the exchange of clinical and cultural information, team care relationships, involvement in service management and planning and involvement in policy development (Fuller, et al., 2012).
Studying inter-organisational networks has led to greater understanding of how information spreads, collaboration takes place and resources are accessed across organisations (Luke & Harris, 2007a). Understanding the shape and dynamics of these networks has enabled the design of interventions to change information pathways, alter opinions or values, and ultimately affect behaviour change for improved health, health services and health systems (Luke & Harris, 2007a; Valente, 2010). Valente (2005, p. 36) outlines five specific areas where network analysis has been applied: social support and its influence on mortality and morbidity; HIV/STD and family planning research; community health; understanding and improving healthcare provider performance; and inter-organisational collaboration.

Examining how those organisations engaged in community-based health promotion share information provides an understanding of how interventions are planned and implemented, participants are reached and recruited, and public health goals are achieved. (Luke & Harris, 2007a; Provan, Nakama, Veazie, Teufel-Shone, & Huddleston, 2003; Reilly et al., 2011). Effective inter-organisational collaboration is essential to allow communities to address issues of public health or health promotion. It allows communities to effectively coordinate services, plan and implement interventions, cover the full range of community members’ needs, reduce redundancy, and increase access to external resources.

Several social network measures exist that look at how relationships influence behaviour of network actors, or the overall nature of the network and its impact on its members. As this implies, some of these are individual, actor-level measures and some are whole network-level measures. Individual-level measures include indicators of an
actor’s centrality in the network, its position, as well as the extent to which an actor’s connections are also connected to each other – or personal network density (Valente, 2010). Network level measures have included, among others, overall network density – or the number of links between actors as a proportion of the total possible number of links (Valente, 2010, p. 129); network cohesion as measured through its average path length – or number of steps it takes, on average, for actors to reach each other (Valente, 2010, p. 134); and indicators of how centralised it is – or to what extent a network’s ties are focussed on one actor or set of actors (Valente, 2010, p. 138).

**Individual-level measures.** Identifying the position of individuals or organisations and their relationships to others in their network allows for an analysis of their roles in influencing outcomes and controlling resources (Valente 2010, p. 125). A position is defined as a set of nodes that occupy a structurally equivalent place in the network; i.e., that have the same links to the same others (Valente, 2010, p. 114). However, there is disagreement among authors whether the same links must be to the exact same others (Mizruchi & Marquis, 2006) or more generally to the same type of others (Valente, 2010, p. 114). Studying structurally equivalent positions within a network can be significant because people or organisations that occupy the same position in a network are likely to be similar in defined ways and are to monitor each other’s behaviour (Valente, 2010, p. 124). For example, organisations that occupy a structurally equivalent position within their network are likely to serve the same clients or provide the same types of services, and are therefore interested in what each other are doing, even if they are not in direct competition. It has thus been argued that social influence may in some cases flow through structural equivalence (i.e., position), rather than through direct
ties; and thus a positional approach to analysis may uncover hidden paths of influence (Burt, 1987). Furthermore, Galaskiewicz (1979) asserts that position is important in explaining the influence of actors in a network; however access to those positions is governed by access to resources at the local level, thus implying the need for an analysis of connective measures such as centrality (Galaskiewicz, 1979). Valente (1995) however, concluded that outcomes such as adoption times did not differ significantly between positions, thus de-emphasizing a positional over connectivity approach (Valente & Rogers, 1995).

Because of the significance of central members as leaders influencing opinion or controlling resources (Valente, 2006; Valente & Pumpuang, 2007), those studying social networks naturally want to identify these central actors. Centrality can be defined as the extent to which an actor inhabits a prestigious or critical position in the network (Valente, 2010, p. 16). This place is often seen to accord status, control over resources, and influence over the opinions and behaviours of others. Centrality has been seen as having the strongest direct effect on organisations’ influence within their networks, such as among community-based service organisations (Galaskiewicz, 1979); and has been the frequent target of network intervention studies that aim to optimise a network’s ability to share information of spread desirable behaviours or practices (Poole, 2008; Valente, 2010, p. 197; Gest, et al, 2011). However, it is not always self-evident what constitutes centrality. Various measures of centrality have thus emerged; three prominent measures are degree, betweenness and closeness. Degree centrality, specifically in-degree, is simply a measure of the number of nominations someone receives from others within the network (Valente, 2010, p. 82). For example, how many others name the individual as
someone they go to for advice. This is a measure of local centrality (Valente, 2010, p. 88) and can identify opinion leaders, as an assumption is made that influence flows in the opposite direction of the nomination (Gest, et al., 2011). Betweenness centrality is a measure of the extent to which an actor lies on the shortest path between other members of the network (Valente 2010, p. 87). This can be an indicator of an actor’s strategic ‘gate-keeper’ position within the network, often controlling the flow of knowledge or resources, and can be important for understanding and influencing the roles of knowledge brokers (Eccles & Foy, 2011; Salsberg & Macaulay, 2013). And closeness centrality is a measure of the average distance an actor is from all other actors within the network (Valente, 2010, p. 8.3). This measure is useful, as an actor who is closer to everyone else is, on average, in a more central position (Valente, 2010, p. 85), and thus more likely to have access to others’ resources or influence their behaviour. Furthermore, actors with high closeness centrality are in a position to communicate or share information with many others rapidly. Identifying the position of individuals or organisations and their relationships to others in their network allows for an analysis of their roles in influencing outcomes and controlling resources (Valente 2010, p. 88). Social networks, however, tend to be asymmetrical. The flow of resources, information or opinion do not usually go equally in both directions, so the distance from A to B may not be the same as the distance from B to A. Closeness centrality, therefore, has direction (Valente, 2010, p. 85). In-closeness measures the links directed to an actor, and out-closeness measures those emanating from an actor. Although this measure has intuitive appeal, the difficulty in its calculation has left it a less useful measure than degree or betweenness centrality (Valente, 2010).
**Network-level measures.** Examining a social network as a whole is useful for understanding its influence on its members’ behaviour as well as its ability to act together. There are several key network-level measures. Network density measures the number of connections in a network as a proportion of the total number possible (Valente, 2010, p. 129). Density has significance in terms of understanding how a network influences behaviour and action, particularly in the association between network density and network cohesion. A network’s cohesiveness can be seen as its ability to act together, for instance to address organisational or community issues. Network cohesion can be assessed through measuring its average path length (APL) – the average distance or steps between all actors in the network (Valente, 2010, p. 135). In general, the lower the APL, the more cohesive a network is because members have greater access to each other and their resources. There is a measurable relationship between a network’s density and its cohesion (ability to function together), but this relationship is not linear. As density increases, i.e., as more links between actors are added, APL decreases, thus creating greater cohesion. But only up to a point. Once density reaches a critical point (generally around 50% density), many of the links become redundant and adding further linkages between actors simply confuses the network, and thus reduces cohesion (Valente, 2010, p. 136).

This relationship between network density and cohesion has implications for creating network interventions that are intended to increase the effectiveness of a network to tackle issues. If one can measure network density and average path length with some degree of confidence, then interventions can be designed to increase or decrease the
number of linkages between actors (i.e., tweak the density) in order to maximise network cohesion and thus effectiveness.

Centralisation is the extent to which a network’s ties are focussed on one actor or set of actors (Valente 2010, p. 138). In a highly centralised network, one or a few actors hold positions of power and control, while decentralised networks have defused power and control structures (Valente 2010, p. 138). Network centralisation is related to individual centrality in that it is calculated on the difference between the maximum individual centrality score and all the others within the same network. One key implication of the centralisation of a network is on the spread of knowledge, ideas, opinions and behaviour. Centralised networks have the potential to increase or decrease the pace of diffusion depending on the commitment of its central actors. Central actors are gatekeepers, possessing disproportionate amount of influence over the network (Valente 2010, p. 140); therefore opinion leaders are much more critical to diffusion of knowledge, opinion or behaviour in centralised networks than in decentralised ones (Valente 2010, p. 140). Centralised networks also have the potential to concentrate resources in the hands of the central actors. This has the potential to limit access to resources by others who may need them within the network.

Like network density, the measure of centralisation has implications for designing potential network interventions. Describing a network’s centralisation, and accurately identifying its central actors, allows for interventions to be designed which will exploit the influence of these actors over the behaviour of others within the network. Because centralisation is based on individual centrality scores, and recalling that individual centrality can be measured different ways, the measure of individual centrality used may
point to different potential interventions. *Betweenness* centrality, we recall, identifies individuals occupying gatekeeper roles within the network (Valente 2010, p. 87). Calculating centralisation based on betweenness centrality scores may shed light on the equity of the overall network, or its ability to function democratically. (Betweenness-) centralised networks may unduly concentrate resources in one or few sets of hands, while (betweenness-) decentralised networks may afford equitable access to resources. An accurate reading of these measures may allow interventions to be designed that will identify resource bottlenecks thus allowing for changes to be implemented that will allow for more equitable access to resources (Valente, 2010, p. 135).

**Network dynamics.** Network dynamics is the study of how structure or attributes of a network change over time. Temporal aspects are considered explicitly in longitudinal social network analysis, most often by means of cross-sectional states of networks observed at discrete time points (Brandes, Freeman, & Wagner, 2012). Examining network dynamics addresses research questions such as, how actor characteristics effect structural change, how structural conditions effect actor behavior, or how processes such as the diffusion of information take place within a network (Brandes, et al., 2012). Comparative graphic representation of the sequential time periods can describe and represent the network changes over time, while operations such as trend analysis can determine significance of change, and modeling can generate statistical inferences based on network variables (Marsden, 2005). One central problem with applying statistical inference to the dynamic analysis of networks is that social networks are by their very nature composed of interrelated nodes and thus tend to violate assumptions of independence. However, the strength of network analysis lies in this very fact that social
actors are not independent, but are nested in structures of social context that may in
themselves be predictive of individual outcomes (Brandes, et al., 2012; D. Straus &
Freeman, 1989).

Conclusion

Participatory research has come to be seen as an approach that enhances the
quality of the research process and its outcomes, including the relevance and uptake of its
products (Jagosh, et al., 2012; Macaulay, et al., 1999). At the same time PR builds
community capacity and self-determination while addressing issues of equity and social
and environmental justice (Cargo & Mercer, 2008; Israel, et al., 1998). Gaps remain,
however, in our understanding of the strategies, processes and mechanisms that support
these benefits. For the present dissertation, the question of how identified participatory
engagement strategies support community ownership and self-determination is
significant. This includes creating evidence of their effectiveness in increasing
community ownership, as well as new knowledge about the why this happens. Bridging
these knowledge gaps will benefit all research aimed at empowering end-users such as
community members and organisations, patients, care givers, service providers and other
decision makers, with the knowledge they need to create action for sustained change.
This is applicable to the areas of community-based research, health promotion
intervention, health services implementation research, public health intervention research,
and any other area where a partnered approach would be of benefit.

Social network analysis has been used within community-based participatory
research to examine how community members and organisations share and use evidence,
and access resources and support. It has also been used to demonstrate how involvement in a CBPR process can enhance community-university linkages. Although social network methods have been demonstrated to be appropriate and culturally acceptable when used within community – and particularly Indigenous contexts, gaps still remain in our understanding of how these methods can fit into a participatory process where community members must contribute to the selection of methods and the interpretation of results. A stronger understanding of this could make social network analysis a more accepted and widely used part of the participatory toolkit.
Chapter 3

Successful Strategies to Engage Research Partners for Translating Evidence into Action in Community Health: A Critical Review¹

Introduction

The creation and timely translation of action-oriented knowledge can rest on meaningful engagement with end-users, even before the research begins (Bowen & Graham, 2013; Salsberg, et al., 2014). Participatory research (PR)² and community engagement continue to attract increased attention as an approach to research, requiring formation of teams of researchers in partnerships with those affected by the issue under study in the community (Cargo & Mercer, 2008; Green, et al., 1995; Israel, et al., 1998) and those who will utilize the results to effect change (Graham, et al., 2006; Green & Mercer, 2001). Overall, the literature suggests that the PR partnership approach increases the relevance of research questions (Cargo & Mercer, 2008; Israel, et al., 1998; Leung, Yen, & Minkler, 2004), with the potential for effective knowledge translation (Trickett et al., 2011; Wallerstein & Duran, 2010), leading to faster uptake of evidence into practice (L. W. Green, 2008b). For these reasons research granting agencies, including the National Institutes of Health (NIH), the Patient Centered Outcomes Research Institute (PCORI), and the Canadian Institutes of Health Research (CIHR), are increasingly

² Following Cargo and Mercer [3] and Green et al [4] we use PR as an umbrella term to include all partnered research including community-based participatory research (CBPR), action research, participatory action research, participatory evaluation, community engagement and patient engagement.
requiring that researchers partner with community members, patients, health professionals, health organisations and policy makers, resulting in many more researchers adopting a participatory approach.

In 1995, Green and colleagues developed guidelines intended to allow reviewers of funding agencies to assess stakeholders’ engagement in PR projects (Green, 2008a; Green, et al., 1995). In 2008, these guidelines were further refined and reliability tested to develop the *Reliability Tested Guidelines for Assessing Participatory Research Projects* (Mercer, Green, Cargo, Potter, Daniel, Olds, et al., 2008) as a tool to: (i) help funding agencies and peer reviewers to assess the participatory nature of proposals submitted for funding as participatory research; (ii) aid evaluators in assessing the extent to which projects meet participatory research criteria; and (iii) assist researchers and intended users of the research (that is, non-academic partners) in strengthening the participatory nature of their project proposals and applications for funding (Cargo & Mercer, 2008; Green, 2008a; Mercer, Green, Cargo, Potter, Daniel, Olds, et al., 2008). In 2009, the original guidelines by Green et al. were applied, for the first time, to a single project to assess to what extent their research was participatory as perceived by community, advocacy and scientific partners. The authors concluded that this had been a very useful undertaking and that ‘further research should focus on the adaptation of PR principles to assist in evaluating the process and outcomes of PR (Van Olphen et al., 2009).

As the principles of the PR approach are used in a wide variety of research and contexts, there is a need to explore the following questions: What are the key processes of PR and what are the practical ways to achieve equitable partnerships? What processes
support the constant negotiation between all team members for research goals and objectives, partner roles and responsibilities, decision-making procedures, together with balancing knowledge generation with the need for action? Therefore, the purpose of this study is to build on recommendations (Van Olphen, et al., 2009) and use the 2008 Reliability Tested Guidelines to undertake a critical literature review of PR projects to synthesize key practical strategies that foster a successful PR process, resulting in continuous discussions between partners that will in turn facilitate knowledge translation activities throughout the research (Kitson et al., 2013).

**Materials and Methods**

**Data Sources**

A critical review goes beyond the description of primary studies, and includes an empirical analysis for exploring new ideas. “The ‘critical’ component of this type of review is key to its value” (Grant & Booth, 2009).

To begin, a multi-disciplinary bibliographic database (ISI Web of Science) was searched using the phrase “participatory research” for all articles from 1995 (when the initial PR guidelines were published) until October 2009 (which was the year after the Reliability Tested Guidelines were published). Results of this search yielded 1866 publications. These were then imported into CiteSpace® - a bibliometric network analysis tool (http://cluster.cis.drexel.edu/~cchen/citespace/) – which generated a map of author-citation frequency. Results contained foundational PR scholars such as Paulo Freire, theoreticians including Peter Reason as well as those with practical PR experience. Our selection tool eliminated theoretical/foundational authors and retained
only authors that have conducted practical PR studies. For this review we needed to limit the size of the study and chose to retain only the top four leading PR practitioners using their CiteSpace® centrality scores: Barbara A. Israel, Meredith Minkler, Nina Wallerstein and Ann C. Macaulay.

Next, a librarian-mediated search was conducted for all published materials by these four authors in PubMed, Embase, ISI Web of Science, PsychInfo and CAB (Ovid database) for abstracts between January 1995 and October 2009. In addition we also reviewed chapters from books edited these authors (Israel, Eng, Schulz, & Parker, 2005; Minkler & Wallerstein, 2003; Minkler & Wallerstein, 2008). Duplicates were removed, for a total of 151 records (title, authors, source, abstract).
Figure 1.2: Inclusion flow chart

The literature
N = 1866

Step I. (n = 151)
Is Barbara A. Israel, Meredith Minkler, Nina Wallerstein, or Ann C. Macaulay one of the first three or the last author(s)?
Yes
\[ n = 11 \]
No

Step II. (n = 140)
Is the text on PR or does it describe a PR project?
Yes
\[ n = 68 \]
No

Step III. (n = 72)
Does the text describe the PR process?
Yes
\[ n = 9 \]
No

Step IV. (n = 63)
Does the text describe theory or application of PR?
Application
\[ n = 56 \]
Apply data abstraction form (table 1)
Both

Theory
\[ n = 7 \]

Step V.
Does the text contain any useful excerpts?
Yes
\[ n = 54 \]
Retained texts
No
\[ n = 2 \]
Study Selection

A staged selection process was then completed to limit the sample using eligibility criteria. First, records were excluded when one of the above-mentioned PR leaders was neither one of the first three authors nor the last author (N=11) to ensure that the leader had substantive input into the work. The second step excluded records that were not PR related (N=68). The third step excluded records that did not contain any description of the PR process (N=9) or records that contained only the theory of PR (N=7). In the final step, records were excluded when they did not contain useful excerpts (n=2), leaving 54 retained records (Figure 1).

Data extraction

We conducted a deductive qualitative thematic analysis to extract useful data from our sample of documents (Paillé, 1996). For each of the 54 retained documents, relevant excerpts were selected and compiled in a Word document, and organized by theme. These themes were derived from the partnership-related dimensions of the Reliability-tested Guidelines for Assessing Participatory Research Projects (Mercer, Green, Cargo, Potter, Daniel, Olds, et al., 2008). These guidelines contain 25 questions, 21 of which target the PR partnership process, making them very suitable to serve as themes for data extraction and analysis. These questions informed our coding scheme to identify PR process strategies. Using a coding grid based upon these questions (Table 1), partnership process-specific excerpts from the retained documents were extracted for analysis. Each retained document was reviewed in its entirety, and all excerpts in those documents that directly answered one of the questions were extracted and compiled in a
matrix of “data by theme” for further analysis. Data coding was non-exclusive, and each excerpt could be coded to one or more questions on the coding grid.
Table 1.1: Data abstraction questions and rationale based on Mercer and colleagues (2008) guidelines

<table>
<thead>
<tr>
<th>Number</th>
<th>Question</th>
<th>Mercer</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>How are the needs of the project’s participants considered?</td>
<td>1(b) Is the mix of participants included in the research process sufficient to consider the needs of the project’s intended users?</td>
<td>Participants’ needs. Although this question asks more about the composition of the participants, it can be construed to enquire about how the needs of the intended users are considered.</td>
</tr>
<tr>
<td>Q2</td>
<td>How are the barriers to participation in the research project by the intended users addressed, especially those who might otherwise be under-represented?</td>
<td>1(c) Is effort made to address barriers to participation in the research process by intended users who might otherwise be under-represented?</td>
<td>Barriers to participation.</td>
</tr>
<tr>
<td>Q3</td>
<td>How has trust between the researchers and intended users been established?</td>
<td>1(d) Has provision been made to build trust between researchers and intended users participating in the research process?</td>
<td>Trust.</td>
</tr>
<tr>
<td>Q4</td>
<td>How have researchers and intended users decided to jointly manage the project?</td>
<td>1(e) Do the researchers and intended users participating in the research process have an explicit agreement (verbal or written) regarding management of the project?</td>
<td>Project management. Although the question is about an explicit agreement, the main theme is project management. This is a key question for PR process. NB: this question was modified half way into data collection. Decision to modify was mitigated by the fact that already capturing whether written agreement or not.</td>
</tr>
<tr>
<td>Q5</td>
<td>How was (were) the research question(s) collaboratively developed between researchers and intended users?</td>
<td>2(a) Was (were) the research question(s) developed through a collaborative process between researchers and intended users?</td>
<td>Collaborative development of research question.</td>
</tr>
<tr>
<td>Q6</td>
<td>How does the research plan to build the capacity of the intended users to address broader determinants of health?</td>
<td>2(e) Does the proposed research project plan to build the capacity of intended users to address individual and/or broader determinants of health?</td>
<td>Capacity building. NB: Green uses empowerment, which was originally used.</td>
</tr>
</tbody>
</table>
| Q7   | How does the research process apply the knowledge of intended users in the phases of 1) conceptualizing/designing, 2) planning, 3) implementation, 4) data collection, and 5) evaluation? | 2(b) Has the proposed research project applied the knowledge and experience of intended users in conceptualizing and/or designing the research?  
3(a) Does the proposed research project apply the knowledge and experience of intended users in the implementation of the research?  
3(e) Does the proposed research project provide intended users with opportunity to participate in planning and/or executing the data collection (whether or not the intended users choose to take that opportunity)? | Involvement in all research phases. Merely combined Mercer’s questions for simplicity. |
| Q8   | How does the research project provide for mutual learning between intended users and researchers? | 2(c) Does the proposed research project provide for the mutual learning among intended users and researchers? | Mutual learning. |
| Q9   | How does the research process allow for the intended users to learn about research methods? | 3(b) Does the proposed research project provide intended users participating in the research process with opportunity to learn about research (whether or not the intended users choose to take that opportunity)? | Intended users learning about research methods. Reference to “opportunity” removed because irrelevant here as not being applied as an evaluation tool |
| Q10  | How does the research process allow for the researchers to learn about the user perspective on the issue(s) being studied? | 3(c) Does the proposed research project provide researchers with opportunity to learn about user perspectives on the issue(s) being studied? | Researcher learning about user perspective. |
| Q11  | How does the research process allow for mutual decision-making in changing research methods or focus? | 3(d) Do the researchers and intended users participating in the research process have an explicit agreement (verbal or written) regarding mutual decision-making? | Mutual decision-making. Reference to explicit agreement removed as not important aspect of question, and already capturing whether written agreement exists or not. |
| Q12 | How are the intended users involved in analysis and interpretation? | 3(f) Does the proposed research project provide intended users with opportunity to participate in planning and/or executing the analysis (whether or not the intended users choose to take that opportunity)?  
3(g) Are plans to involve intended users in interpreting the research findings sufficient to reflect the knowledge of the particular context and circumstances in the interpretation? | Merged questions for simplicity. NB: modified to reflect Mercer’s working half way through data collection. |
| Q13 | How does the research process reflect a commitment by researchers and intended users to social, individual or cultural actions consequent to the learning acquired through research? | 4(a) Does the proposed research project reflect sufficient commitment by researchers and intended users participating in the research process to action (e.g. social, individual, and/or cultural) following the (learning acquired through) research? | Action based upon research results. Wording simplified (removed brackets). |
| Q14 | How is the process set out for acknowledging and resolving differences between researchers and intended users over interpretation of research results? | 4(b) Do the researchers and intended users engaged in the research process have an explicit agreement (verbal or written) for acknowledging and resolving in a fair and open way any differences in the interpretation of research results? | Conflict resolution. Reference to explicit agreement removed as irrelevant, and already recording whether written agreement or not. |
| Q15 | How is the process set out regarding the issue of data ownership and sharing? | 4(c) Do the researchers and intended users engaged in the research process have an explicit agreement (verbal or written) regarding ownership and sharing of the research data? | Data ownership and sharing. Reference to explicit agreement removed as irrelevant, and already recording whether written agreement or not. |
| Q16 | How do the researchers and intended users jointly disseminate research results? | 4(e) Do the researchers and intended users engaged in the research process have an explicit agreement (verbal or written) regarding the dissemination (and/or translation or transfer) of research findings? | Dissemination. Questions combined and simplified. |
| Q17 | How is feedback of research results to intended users handled? | 4(d) Do the researchers and intended users engaged in the research process have an explicit agreement (verbal or written) regarding feedback of research results to intended users? | Feedback of research results. |

**Excluded Questions**

<table>
<thead>
<tr>
<th>Number</th>
<th>Question</th>
<th>Rationale for exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mercer 1(a)</td>
<td>Are the intended users (may include users, beneficiaries, and/or stakeholders) of the research described in a way sufficient to assess their representation in the project?</td>
<td>Question pertains to the research proposal itself and not the project.</td>
</tr>
<tr>
<td>Mercer 1(b)</td>
<td>Is the mix of participants included in the research process sufficient to consider the needs of the project’s intended users?</td>
<td>Question examines the composition of the community partners and not the co-management structures of the researcher-partner interface.</td>
</tr>
<tr>
<td>Mercer 2(d)</td>
<td>Does the proposed research project consider multiple levels of determinants of health (e.g., individual, familial, organisational, political, and/or economic)?</td>
<td>Question examines the nature and content of the research itself, and not the co-management structures that exist between the researchers and intended users.</td>
</tr>
<tr>
<td>Mercer 4(g)</td>
<td>Is there sufficient provision for assistance to intended users to indicate a high probability of research results being applied?</td>
<td>Question concerns the outcomes and uptake of the research and not the process itself.</td>
</tr>
</tbody>
</table>
Data analysis

Data abstraction and coding was undertaken by one author (DP) using non-specialized software (MS Word), which is appropriate for a deductive qualitative data analysis using a limited number of themes (codes). Each excerpt extracted from the retained documents was assigned to one or more themes, which was verified by a second author (JS or PP). Disagreements were discussed for possible resolution, and any that could not be resolved were adjudicated by a third party (JS for PP and vice versa). Using a constant comparative technique, themes were collapsed into overarching categories. These categories were generated through initial and focused coding techniques by comparing and contrasting text segments and sorting codes into conceptually meaningful units (Lofland & Lofland, 1995). For example, sub-themes such as “advisory committee”, “steering committee”, and “planning committee” were all grouped under the main theme “committee”.

Results

Table 2 presents the references of the 54 documents that were retained for analysis and are organized by the four main authors. From these documents, 186 excerpts were assigned or coded to one or more than one theme. Of those, there was agreement between the reviewers for 180 (97%) of excerpts. For the six remaining excerpts where there was disagreement, consensus was reached on five, and final judgment was sought from a third reviewer (JS) for one excerpt.

The five most frequently mentioned strategies for fostering a researcher-community partnership are listed (unranked) and described in Table 3. These are:
forming an advisory board, developing a research agreement, using group facilitation techniques, hiring from the community, and having frequent meetings.

The remaining less frequently mentioned strategies are summarized in Table 4, which we felt could not be collapsed into categories without losing individual substance. However we consider these examples as also being extremely important for researchers to put into practice, including: the need for researchers to make active efforts to reach out and learn about their partners and their communities; facilitate engagement by being flexible and working around schedules of the partners; understanding community priorities and culture; establishing clear lines of communication; speaking frankly and agreeing to disagree; building community capacity; supporting partners interpretation of data; publishing results in community; including non-academic partners as co-presenters and co-authors; working with community partners to build resources based on results; using the results to influence policy; and regular evaluation of the partnerships.

Table 1_2: Summary of retained records for review organized by author

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Barbara A. Israel</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1995</td>
<td>Redesigning work systems to reduce stress: A participatory action research approach to creating change</td>
</tr>
<tr>
<td></td>
<td>1997</td>
<td>&quot;It's a 24-hour thing ... a living-for-each-other concept&quot;: identity, networks, and community in an urban village health worker project</td>
</tr>
<tr>
<td></td>
<td>1998</td>
<td>Review of community-based research: assessing partnership approaches to improve public health</td>
</tr>
<tr>
<td></td>
<td>1996</td>
<td>Role of control and support in occupational stress: an integrated model</td>
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<tr>
<td></td>
<td>1998</td>
<td>Detroit's East Side Village Health Worker Partnership: community-based lay health advisor intervention in an urban area</td>
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<tr>
<td></td>
<td>1998</td>
<td>Conducting a participatory community-based survey for a community health intervention on Detroit's east side</td>
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<tr>
<td></td>
<td>1999</td>
<td>Establishing LA VIDA: a community-based partnership to prevent intimate violence against Latina women</td>
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<tr>
<td></td>
<td>2001</td>
<td>The Detroit Community-Academic Urban Research Center: development, implementation, and evaluation</td>
</tr>
<tr>
<td></td>
<td>2001</td>
<td>Can communities and academia work together on public health research? Evaluation results from a community-based participatory research partnership in Detroit.</td>
</tr>
<tr>
<td>Year</td>
<td>Title</td>
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<tr>
<td>2001</td>
<td>The East Side Village Health Worker Partnership: integrating research with action to reduce health disparities</td>
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<tr>
<td>2002</td>
<td>The relationship between social support, stress, and health among women on Detroit’s East Side.</td>
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<tr>
<td>2002</td>
<td>Addressing social determinants of health through community-based participatory research: the East Side Village Health Worker Partnership</td>
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<tr>
<td>2003</td>
<td>Commentary: Model of community health governance: Applicability to community-based participatory research partnerships</td>
<td></td>
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<tr>
<td>2003</td>
<td>Community action against asthma: examining the partnership process of a community-based participatory research project</td>
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<tr>
<td>2003</td>
<td>Engaging Women in Community Based Participatory Research for Health</td>
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<tr>
<td>2003</td>
<td>Evaluation of a partnership approach to translating research on breast cancer and the environment</td>
<td></td>
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<tr>
<td>2004</td>
<td>Identification of gaps in the diagnosis and treatment of childhood asthma using a community-based participatory research approach</td>
<td></td>
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<tr>
<td>2004</td>
<td>Application of health promotion theories and models for environmental health</td>
<td></td>
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<tr>
<td>2004</td>
<td>Assessing and Strengthening Characteristics of Effective Groups in Community-Based Participatory Research Partnerships</td>
<td></td>
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<tr>
<td>2005</td>
<td>Strategies and Techniques in Effective Group Process in CBPR Partnerships</td>
<td></td>
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<tr>
<td>2005</td>
<td>Community involvement in the conduct of a health education intervention and research project: Community Action Against Asthma</td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>Documentation and evaluation of CBPR partnerships</td>
<td></td>
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<tr>
<td>2005</td>
<td>Community-based participatory research: lessons learned from the Centers for Children’s Environmental Health and Disease Prevention Research</td>
<td></td>
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<tr>
<td>2005</td>
<td>Developing and implementing guidelines for dissemination: The experience of the Community Action Against Asthma project</td>
<td></td>
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<tr>
<td>2006</td>
<td>Challenges and facilitating factors in sustaining community-based participatory research partnerships: lessons learned from the Detroit, New York City and Seattle Urban Research Centers</td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>Engaging urban residents in assessing neighborhood environments and their implications for health</td>
<td></td>
</tr>
<tr>
<td>2008</td>
<td>Evaluation of Community Action Against Asthma: A Community Health Worker Intervention to Improve Children's Asthma-Related Health by Reducing Household Environmental Triggers for Asthma</td>
<td></td>
</tr>
</tbody>
</table>

**Meredith Minkler**

<table>
<thead>
<tr>
<th>Year</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>Combining research, advocacy, and education: the methods of the Grandparent Caregiver Study</td>
</tr>
<tr>
<td>1996</td>
<td>Health of grandmothers raising children of the crack cocaine epidemic</td>
</tr>
<tr>
<td>1999</td>
<td>Grandparents as parents: A survival guide for raising a second family</td>
</tr>
<tr>
<td>2000</td>
<td>Using Participatory Action Research to build Healthy Communities</td>
</tr>
<tr>
<td>2001</td>
<td>Contributions of community involvement to organisational-level empowerment: the federal Healthy Start experience</td>
</tr>
<tr>
<td>2002</td>
<td>Ethical dilemmas in participatory action research: a case study from the disability community</td>
</tr>
<tr>
<td>2003</td>
<td>Ethical challenges in community-based participatory research</td>
</tr>
<tr>
<td>2003</td>
<td>Ethical challenges in community based participatory research: a case study from the San Francisco Bay Area disability community</td>
</tr>
<tr>
<td>2003</td>
<td>Attitudes of people with disabilities toward physician-assisted suicide legislation: broadening the dialogue</td>
</tr>
<tr>
<td>2003</td>
<td>Community-driven asset identification and issue selection</td>
</tr>
<tr>
<td>2003</td>
<td>Influencing policy through community-based participatory research</td>
</tr>
<tr>
<td>2004</td>
<td>Ethical challenges for the “outside” researcher in community-based participatory research</td>
</tr>
<tr>
<td>2005</td>
<td>Community-based research partnerships: challenges and opportunities</td>
</tr>
<tr>
<td>2006</td>
<td>Promoting Environmental Justice Through Community-Based Participatory Research: The Role of Community and Partnership Capacity</td>
</tr>
<tr>
<td>2006</td>
<td>Sowing the seeds for sustainable change: a community-based participatory research partnership for health promotion in Indiana, USA and its aftermath</td>
</tr>
<tr>
<td>2006</td>
<td>Promoting environmental health policy through community based participatory research: a case study from Harlem, New York</td>
</tr>
<tr>
<td><strong>Nina Wallerstein</strong></td>
<td>1999</td>
</tr>
<tr>
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<tr>
<td>2000</td>
<td>Community-based prevention: Programs that work</td>
</tr>
<tr>
<td>2003</td>
<td>The dance of race and privilege in community-based participatory research</td>
</tr>
<tr>
<td>2004</td>
<td>Intermediate outcomes of a tribal community public health infrastructure assessment</td>
</tr>
<tr>
<td>2004</td>
<td>Bridging community intervention and mental health services research</td>
</tr>
<tr>
<td>2005</td>
<td>Developing and Maintaining Partnerships with Communities</td>
</tr>
<tr>
<td>2006</td>
<td>Woman to Woman: Coming Together for Positive Change--using empowerment and popular education to prevent HIV in women</td>
</tr>
<tr>
<td>2006</td>
<td>Commentary: challenges for the field in overcoming disparities through a CBPR approach</td>
</tr>
<tr>
<td>2006</td>
<td>Using community-based participatory research to address health disparities</td>
</tr>
<tr>
<td><strong>Ann C. Macaulay</strong></td>
<td>1998</td>
</tr>
<tr>
<td>1999</td>
<td>Participatory research maximises community and lay involvement</td>
</tr>
</tbody>
</table>
Table 1.3: Summary and description of the most frequently mentioned strategies for developing a research-community partnership

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description</th>
</tr>
</thead>
</table>
| 1. Development of an Advisory Committee            | • A composition of researchers, the intended users of the research and/or representatives of community organisations  
• Advisory committees allow for inclusion of all viewpoints throughout the research process and joint development of dissemination strategies and action plans  
• Subcommittees are often used to divide up tasks (e.g., reviewing new proposed research topics, articles for publication, partnership evaluation) |
| 2. Development of Research Agreements              | • Before the research begins, clearly spell out researchers and partner roles and responsibilities, outline how decisions will be made (e.g., by consensus or by voting), and set out what to do if conflict arises.  
• Research agreements may also include plans for data ownership and control, interpretation of data, and procedures for resolving disagreement over research results  
• Developing agreements is seen as a trust-building exercise |
| 3. Use of Group Facilitation Techniques            | • Can be both a formal and an informal process to ensure meaningful involvement and participation of partners  
• Formal facilitation includes focus groups, workshops, and nominal group techniques  
• Informal techniques include circulating agendas ahead of time, small group work, and one-on-one informal discussions. |
| 4. Hiring Staff from the Community of Study        | • Hiring local persons as project staff recognizes community members’ abilities to establish good relationships with individual participants for recruitment and ongoing data collection  
• Projects hire well-respected community members as a “community champions”, field coordinators, intervention staff, interviewers, group co-facilitators, as well as for data collection and analysis. |
| 5. Frequent Communication                          | • Communication between partners through regular group meetings to keep all partners updated on progress, changes in procedures and as a way of discussing concerns and challenges  
• Other methods include telephone calls to partners who missed meetings to bring them up-to-date, and prompt circulation of meeting minutes and newsletters |
Table 1_4: Summary and description of less frequently mentioned strategies for developing a research-community partnership

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Examples</th>
</tr>
</thead>
</table>
| i. Researchers need to make active efforts to learn about the participants and their context | - Attending community-organized educational sessions or going on a community tour  
- Arranging retreats with community members  
- Organizing structured workshops with community members, as well as having informal conversations with them  
- Conducting formal interviews with community organisations  
- Actively involve intended users through hiring study staff from the community and utilizing a community organizer/champion  
- Form advisory board for the project with representation from organisations implicated in the research |
| ii. Facilitate intended user involvement | - Be flexible with partners’ work schedules and negotiate with their employers for study-related tasks  
- Utilize community contacts for recruitment of marginal community members or make use of ‘snowball’ referral  
- Reach out to places frequented by community members (e.g. schools)  
- Adopt group facilitation techniques  
- Approach partners individually for input away from larger groups  
- Understand community priorities and culture  
- Speak frankly and agree to disagree  
- Include representation in the project both from those affected directly by the research and the community as a whole  
- Evaluate the partnership frequently to elicit partners’ feelings |
| iii. Establish lines of communication | - Take time at the beginning to get to know one another and keep frequent contact with intended users  
- Spend time in the community (e.g. attend significant community events)  
- Jointly develop a written research agreement clearly spelling out roles and responsibilities of all partners  
- Follow through on the agreement and any other promises  
- Hire community members as project staff |
| iv. Form community-led board | - Include wide representation from key community organisations where implemented  
- Jointly develop operating norms including decision-making, conflict resolution and meeting facilitation  
- Adopt consensus decision-making  
- Hold monthly meetings, rotate meeting locations if possible, and circulate draft agendas and meeting minutes  
- Include intended users in the management structure by hiring a respected community leader for their project’s primary role |
<table>
<thead>
<tr>
<th>v.</th>
<th>Group facilitation techniques; an iterative process when deciding upon research goals and grounded research question(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Engage the project’s advisory committee in a series of discussions with the community to incorporate local knowledge</td>
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<tr>
<td></td>
<td>• Establish working relationships early</td>
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<tr>
<td></td>
<td>• Consider having the community apply as principal applicant for grants</td>
</tr>
<tr>
<td>vi.</td>
<td>Build community capacity</td>
</tr>
<tr>
<td></td>
<td>• Utilize and develop community resources and support networks when conducting research</td>
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<td></td>
<td>• Train community members as co-facilitators of research activities</td>
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<td></td>
<td>• Involve the community in needs assessment and planning processes</td>
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<tr>
<td>vii.</td>
<td>Outline community involvement in research agreements</td>
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<tr>
<td></td>
<td>• The community can be involved in all phases of research</td>
</tr>
<tr>
<td></td>
<td>• Ensure active involvement of community members in all study tasks (e.g. reviewing all study documents to ensure they are in an understandable language)</td>
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<td></td>
<td>• Solicit suggestions from community partners through focus groups or meetings (e.g. on data collection approaches)</td>
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<tr>
<td></td>
<td>• Hire and train lay community members or utilize an advisory board as field coordinators, interviewers, data collectors, intervention staff and analysts (e.g. identification of variables, selection of measures, questionnaire development)</td>
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<tr>
<td>viii.</td>
<td>Community training in research</td>
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<tr>
<td></td>
<td>• Provide training to community about health issues</td>
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<tr>
<td></td>
<td>• Use training sessions to get community perspective on these issues</td>
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<tr>
<td></td>
<td>• Have community members critique pre-existing research instruments as a way of learning about developing questionnaires and for researchers to learn about the community’s perspective</td>
</tr>
<tr>
<td></td>
<td>• Teach community public health and research skills</td>
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<td></td>
<td>• Conduct community workshops on research methods</td>
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<td></td>
<td>• Use focus groups to engage community members in discussions about research in their community</td>
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<tr>
<td>ix.</td>
<td>Engage in early community interactions while developing the project</td>
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<td></td>
<td>• Conduct in-depth interviews with community members and other key informants</td>
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<td></td>
<td>• Go on ‘wind-shield’ tours driving around the community</td>
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<td></td>
<td>• Involve community in developing context-specific models</td>
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<tr>
<td></td>
<td>• Make use of qualitative data</td>
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<td></td>
<td>• Use theoretical, convenience and open sampling</td>
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</table>
| x. Set up sub-committees of the advisory committee | • Set up a sub-committee of the advisory committee to review all partnership evaluation results and make recommendations to the overall advisory committee  
• Committee can facilitate data analysis and interpret results  
• Present and discuss results with community partners to facilitate interpretation  
• Researchers and community members can analyze data independently and present their interpretations  
• Engage in open, interactive analysis with community partners  
• Adopt a research agreement at the beginning outlining community involvement in results interpretation |
|---|---|
| xi. Action planning | • Establish action groups of community partners to develop intervention strategies and plan policy initiatives  
• Work with community members in deciding upon policy initiatives and action plans  
• Instrumental use of research results to lobby government  
• Work with community partners to develop community resources based upon study results  
• Hold meetings with community partners to discuss other non-study related, important issues |
| xii. Interpretation, data ownership and dissemination | • Community partners can communicate their own interpretation of study data along with researcher study publications  
• Adopt a no veto rule, meaning that neither researchers nor community partners can block a publication with results  
• Spell out this process in a written researcher agreement before it arises  
• Researchers can be guardians of the data during the project, but transfer data control to community after the project ends  
• Community obligation is to allow researchers the right to ongoing data analysis  
• Develop dissemination strategy outlining community involvement  
• Include non-academic partners as co-authors/co-presenters on manuscripts/abstracts  
• Disseminate results through local organisations, newspapers, media, and community-based practitioners  
• Jointly publish a community newsletter with results included  
• Make use of local cultural mechanisms, such as street theatre  
• Circulate a summary report to community members and/or have feedback/discussion sessions  
• Organize debriefing sessions with a luncheon or gala celebration  
• Discuss publication drafts with the community before submission |
Discussion

This is a first step in a larger research agenda to identify variation in PR practices across contexts and partnership stages that could in the future be drawn on to answer the question of efficacy of PR practices. As this review was exploratory and not systematic, we decided to include a purposeful sample of included studies. Citespace helped us to elicit a criterion for a purposeful sampling. The rationale was that most cited papers for our review played a role similar to ‘key informants’ in primary research. Given that this study had limited resources, we focused on the top four authors (most popular "key information resources").

From the four authors identified, committees such as steering committees and advisory committees – are the most frequently mentioned strategy as a way to engage key stakeholders around the table from the beginning – including patients, practitioners, service managers, communities and the public, and policy makers. The second most frequently mentioned strategy is drafting research agreements, which some recommend should be done early in the partnership in order to avoid misunderstandings and because the process of developing written agreements or partnership principles is in itself a partnership building process (Macaulay, et al., 1998; The Examining Community-Institutional Partnerships for Prevention Research Group, 2006). However, the authors of this article are also aware of teams who have not wanted a written agreement, either for cultural reasons where a verbal agreement is deemed very final, or because it could be construed to imply lack of trust between the researchers and the partners. Our review results show that group facilitation is often suggested as a way to offer equal opportunity for partners to participate in discussions and to afford more reserved partners the chance
to voice their opinion. Facilitation includes informal group discussions and formal techniques with many techniques borrowed from management. Hiring staff from the community increases credibility of the research, adds cultural relevance, builds capacity, promotes empowerment, provides work, brings in finances, and integrates knowledge translation throughout the process. Finally, frequent meetings are essential to maintain open communication as research evolves and to manage different expectations.

Table 4 shows many other additional practical strategies and supports the importance of meeting the needs of various partnerships in a wide range of contexts. It also emphasises the need for researchers to learn more about community issues, and fully engage community members throughout the research process including interpretation of data and dissemination of results both internally within the community where the research was undertaken and externally.

To our knowledge, this is the first time the Reliability Tested Guidelines have been used to undertake a critical literature review to document PR partnership processes. The strengths of this review include: (i) using a bibliometric methodology to identify leading PR practitioners (ii) a comprehensive identification of PR studies conducted by these authors, (iii) a transparent selection of relevant documents describing PR partnership processes, and (iv) a reproducible deductive qualitative data thematic analysis using the Reliability Tested Guidelines as basis for a coding scheme to analyze relevant excerpts from retained documents. This critical review has also identified that the four authors reviewed utilise these processes and also re-established the Reliability Tested Guidelines as a reliable criteria by which to measure partnerships.
It is noteworthy that four or fewer excerpts were identified for the following *Reliability-Tested Guidelines* dimensions: mutual learning (Q8), conflict resolution over interpretation of results (Q14), and data ownership and sharing (Q15). This is surprising considering that mutual learning is a fundamental PR principle and the latter two are key issues to be resolved for any PR project. More literature on these topics would be very useful; for example Jagosh and colleagues found that successful conflict resolution led to further strengthening of the teams (Jagosh, et al., 2012).

This review also highlights gaps that the *Reliability-Tested Guidelines* do not address. These include (i) the issues of power dynamics, and recommendations for ways of decentralizing power and decision-making either through subcommittees or a high level of local control, (ii) ways to address issues of equity of resources, i.e., equitable sharing of resources across community organisations and researchers, or providing grants or other funding to participating community-based organisations, and (iii) the common problem of adding or replacing new members throughout the project - which causes shifting group dynamics. We also recognize that other more human aspects of partnerships have not been addressed, including the time needed to consolidate partnerships, issues of power differences, personality clashes, and institutional cultures.

There is much diversity in the strategies discussed by the four PR leaders. This is particularly encouraging for three reasons. First, it suggests that PR is highly adaptable to many contexts and settings and the iterative nature of this research approach. As PR is rapidly expanding beyond its earlier application in health promotion with marginalized communities, this adaptability will become increasingly important for partnerships with new types of communities including communities of practice, organisations such as
practice-based research networks (Westfall et al., 2009), and also for partnering with patients and policy makers. Second, research teams can find many strategies in the results to draw upon when starting out. A given strategy does not always work for a given context and the whole team can discuss potential alternative strategies. Third, the diversity of results reinforces the notion that the PR process is an active, iterative endeavour, requiring energy and flexibility from all partners. The findings are supported by other authors including a critical review by Cargo and Mercer (2008), and incorporated by Wallerstein and Duran (Wallerstein & Duran, 2010) in a conceptual logic model of community-based participatory research. For those embarking on PR there are recommendations and training curricula from individual teams (Allen, Culhane-Pera, Pergament, & Call, 2011; Jones & Wells, 2007; Westfall et al., 2013) and organisations (Centers for Disease Control and Prevention, 2012; Israel & et al., 2009; Parry, et al., 2009; The Examining Community-Institutional Partnerships for Prevention Research Group, 2006) on how to build PR teams and maintain equitable partnerships throughout the research process, including dissemination of the results. There are also an increasing number of publications on the experiences of both academic (Kennedy, Vogel, Goldberg-Freeman, Kass, & Farfel, 2009) and community (Mason et al., 2013; Norman et al., 2013) team members from their participatory research experiences, and documented common characteristics of successful community- institutional partnerships (Examining Community-Institutional Partnerships for Prevention Research Group, 2006).

While this review provided an innovative synthesis of key PR strategies for researchers using a PR approach, a limitation is that it is based on only four authors’ publications. Because the review included book chapters not limited to the word count
restrictions of journal articles we may have captured more details than from journal articles alone. There are no standard recommendations for reporting on PR; from this review we recommend that journal editors require the key stages from the Reliability Tested Guidelines to be included, which would facilitate future synthesis. Our results consist of strategies that could be tested and explored in greater detail through a larger systematic literature review, which may include more detailed descriptions of applied strategies for planning and sustaining PR partnerships. Such a systematic review might be able to rank these strategies in terms of their effectiveness in different contexts, which would first require further basic research into the efficacy of particular participatory strategies and their effectiveness in generating and translating new knowledge into action.

As PR is becoming more widespread, this new evidence is slowly emerging within the fields of participatory research as well as in implementation and translational science.

Conclusion

This review is the first to adapt the Reliability Tested Guidelines for Assessing Participatory Research Projects to identify leading processes that support PR partnerships. Five key practical strategies to foster a successful PR process are identified, that in turn integrate knowledge translation throughout the research process. Some of these results have already been incorporated into the Canadian Institutes for Health Research (CIHR)’s Guide to Researcher and Knowledge-User Collaboration in Health Research (Parry, et al., 2009). One colleague remarked, “I will print these 5 strategies in big color letters and pin them in front of my desk. No one can remember 25 questions, while anybody can handle 5 ideas per day.” The guidelines, originally intended to allow funders to assess partnership engagement in grant applications, proved effective at
identifying and evaluating the same engagement strategies as reported by completed research projects. Adapting these guidelines for our use identified gaps where the tool was unable to assess the fundamental PR elements of power dynamics, equity of resources, and member turnover. Our resulting template serves as a new tool for research teams to apply to measure their own partnerships.

Acknowledgements

This work was partially supported through a grant from the Lawson Foundation, ON, Canada, (Grant # GRT-2006-037).
Chapter 4

Engaging Community Stakeholders for School-Based Physical Activity Intervention³

Introduction:

For children to live healthy lifestyles, they need to have the opportunity to eat healthily and engage in adequate and appropriate physical activity (PA) (Doak, et al., 2006). Family, community, and school have been identified as key environments where children form their opinions and habits regarding healthy living (Story, et al., 2006). Therefore, children’s health promotion efforts have focused on intervening in one or all of these areas (Doak, et al., 2006), and an ecological approach to health promotion suggests that sustainable interventions incorporate all three (Green & Kreuter, 2005; Richard, Potvin, Kishchuk, Prlic, & Green, 1996). Successful PA promotion must therefore take into account these ecological levels and their impact on the child’s life when designing and implementing interventions (Green & Kreuter, 2005).

At the organisational level, school-based health promotion intervention can have a significant impact on children’s lifestyles (Story, et al., 2006; Veugelers & Fitzgerald, 2005). Yet, for school-based PA to be successful, it also needs to account for the impact of the community environment on the intervention’s ability to change the opinions and behaviours of children (Bisset, Daniel, & Potvin, 2009). Schools as organisations

function within an environment of other community-based organisations concerned with the health and social needs of children. Therefore, to improve children’s health successfully, these organisations should be engaged and collaborate to avoid duplicated or conflicting policies and services, and to leverage each organisation’s expertise and resources in creating health promotion interventions (Luke & Harris, 2007a).

In community-based intervention research, such as school-based PA planning, community stakeholders may collaborate with outside academic researchers who are often the originators of the intervention or research idea (Hogan, et al., 2014; Macaulay, et al., 1999). However, successful, sustainable intervention outcomes are founded on community stakeholders being engaged and ultimately taking ownership over the development and deployment of the interventions (Cacari-Stone, et al., 2014; Green & Kreuter, 2005; Hogan, et al., 2014). Meaningful engagement with other organisations can lead to greater community input into school-based PA intervention planning (Valente, Coronges, Stevens, & Cousineau, 2008; Valente, et al., 2010) and therefore greater community ownership and self-determination over the intervention process.

For community-based organisations to be meaningfully engaged, collaborate successfully and thus build ownership and self-determination, they need to establish and maintain working linkages between them (Provan, et al., 2003). These linkages foster the flow of knowledge and information needed to intervene successfully in areas of common interest (Provan, et al., 2003; Valente, 2010), such as children’s PA promotion. Examining collaboration and knowledge-sharing among organisations engaged in community-based PA promotion provides an understanding of how interventions are planned and implemented, participants are reached and recruited, and public health goals
are achieved. (Kegler, Rigler, & Ravani, 2010; Luke & Harris, 2007b; Provan, et al., 2003). The study of these linkages, the overall structures that they create, and the impact that they may have on the behaviour of individual actors, are the focus of social network analysis.

To understand how engagement, community ownership and self-determination evolve, this study adopts a social network approach to examine the knowledge-leadership and decision-making roles stakeholders take throughout the development of a school-based PA intervention project. Control over knowledge flow is associated with opinion leadership and thus can serve as a useful measure of influence within a network (Eccles & Foy, 2011; Valente, 2010).

What does the evolution of a stakeholder network look like when it is initiated by a non-community champion, then grows into a functioning network once a coalition of community organisations are engaged and collaborating to develop the program?

Using an existing school-based PA intervention project (the KSDPP School Travel Planning Project), this study mapped the evolution of a researcher-stakeholder collaboration to determine its structure from project conception by the non-community champion (T1), to intervention deployment within the community (T2). Social network analysis was used to map the network and analyse changes in its structure, including the paths of influence and knowledge sharing.

Social Network Analysis:

A social network can be defined as connections among people, organisations or other social actors (Valente, 2010). Although the individual attributes of these actors can
determine their social network, network analysis focuses rather on their relationships and how these affect their behaviour. These relationships – or network links or ties – are the connections among, within and between the actors and the goal of network analysis is to understand how a network can influence and constrain the behaviour of its members (Valente, 2010). Social network studies tend to take either a whole network design, looking at the sum of component actors as members of a bounded social collective; or an egocentric design, examining networks from the perspective of the actors within them (Marsden, 2005). Studying networks of individuals has led to greater understanding of how, among others, diseases, ideas and opinions spread; how people access social support, and who or what influences their health behaviour (Turcot, et al., 2009).

Network analysis has examined how health service organisations collaborate to share information, plan and deliver services (Doak, et al., 2006; Potvin & Lamarre, 2009; Story, et al., 2006; Turcot, et al., 2009). Within community-based participatory health research, it has been used to evaluate how community health workers share and use evidence (Campbell, et al., 2014; Valente, et al., 2010), to examine interpersonal support networks (Fuller, et al., 2012; Langhout, et al., 2013; Leonard, et al., 2014), and to examine issues of access and equity (Luque, et al., 2011; Pauly, et al., 2013; Ramanadhan, et al., 2012). For children’s PA, social network analysis has been used to examine peer influence on intervention effects (Shin, et al., 2014). Fuller, et al. (2012) showed that social network analysis could serve as an effective and culturally-acceptable approach within Aboriginal communities. Within that study, community members considered that the network analysis had accurately described the links between workers related to the exchange of clinical and cultural information, team care relationships,
involvement in service management and planning and involvement in policy
development (Fuller, et al., 2012).

Within social network analysis, much attention has been paid to identifying and
understanding the roles of central actors. *Centrality* can be defined as the extent to which
an actor occupies a prestigious or critical position in the network (2010). This position is
associated with opinion leadership and is often seen to accord status, control over
resources, and influence over the opinions and behaviours of others. Centrality has been
seen as having the strongest direct effect on organisations’ influence within their
networks, such as among community-based service organisations (Galaskiewicz, 1979);
and has been the frequent target of network intervention studies that aim to optimise a
network’s ability to share information or spread desirable behaviours or practices (Gest,
Osgood, Feinberg, Bierman, & Moody, 2011; Poole, 2008; Valente, 2010). There are
various measures of centrality; of these measures *in-degree* measures the number of times
an actor is named by others in the network. For example, in-degree centrality can
measure how frequently a community-member is named by others as someone they turn
to for information or help. In both intervention planning and within the interventions
themselves, it is important for success that people with high in-degree centrality are
recruited early on as champions, as they are role models to whom others turn for
leadership, and therefore have potential to increase the adoption and sustainability of the
intervention (Rogers, 2003). In-degree centrality is furthermore the most robust of all the
centrality measures when working with missing or incomplete data (Costenbader &
Valente, 2003).
Besides examining central actors, social network analysis can also look at how centralised a network is overall. *Centralisation* is the extent to which network links are focused on one or few actors (Valente, 2010). One key implication of the centralisation of a network is on the spread of knowledge, ideas, opinions and behaviour. Centralised networks have the potential to increase or decrease the pace of uptake of an innovation or policy depending on the commitment of its central actors (Valente & Rogers, 1995). Central actors are gatekeepers, possessing disproportionate amount of influence over the network, therefore opinion leaders are much more critical to the success of community-based initiatives in centralised networks than in decentralised ones (Valente, 2010).

**Setting and Context:**

This study is part of the Kahnawake Schools Diabetes Prevention Project (KSDPP), a 21-year old community-owned participatory research partnership between the Kanien’kehá:ka (Mohawk) community of Kahnawake and academic researchers from McGill University, Queen’s University and Université de Montréal. Kahnawake First Nation is located 12 kms from downtown Montreal, Quebec, on the south shore of the St. Lawrence River. This community of approximately 8000 (2011 est. enrolled, on reserve) enjoys a high a level of socioeconomic development while valuing and maintaining the Kanien’kéha language and traditional institutions of culture and governance. The community has, since the late 1960s and early 1970s respectively, maintained local control over both its health and education systems; and thus operates its own school board, full-service inpatient hospital, and wide range of health and social services. Since 1994, KSDPP had developed and delivered community intervention programming to
increase healthy behaviours and reduce incidence and prevalence of type 2 diabetes. KSDPP has continuously evaluated its efforts along a spectrum of process and outcome measures (Macaulay, et al., 1997; Paradis, et al., 2005); has evaluated its participatory partnership (Cargo, et al., 2011; Cargo, et al., 2003); has disseminated its prevention planning model to over 30 Indigenous communities across Canada (KSDPP, 2014); and has served as a platform for numerous studies on health promotion, primary prevention of diabetes, nutrition, PA, healthy school policy planning, and the participatory process (see http://pram.mcgill.ca/ksdpp_pubs.php for the full range of published KSDPP research).

KSDPP is governed exclusively by its Community Advisory Board (CAB) comprised of community volunteers representing many sector of Kahnawake. CAB oversees and approves all intervention and research planning, including ethical review of protocols and approval of dissemination. CAB serves as the primary site of engagement between community and researchers; it is where community voices inform the research agenda, and where community minds interpret its results. In 2010, KSDPP and its CAB received the CIHR Partnership Award, recognising excellence in researcher/knowledge-user engagement.

In 2005, KSDPP began working with community members and organisations to develop and implement school-based wellness policies in support of children’s healthy active living. The first phase of work addressed the nutrition component of the wellness policy for two community elementary schools overseen by the Kahnawake Education Centre, the local school board. The combined population of these schools is approximately 410. The nutrition policy was implemented in the 2009-2010 school year. In response to a community-initiated call to complete a balanced wellness policy, in 2011
KSDPP researchers along with their university-based partners received a Canadian federal research grant to support the development and implementation of the PA policy component. This PA policy development began with a baseline evaluation that produced data about current PA levels of children, children’s preferences, perceived barriers and facilitators to PA, current school practices and programs, stakeholder opinions on potential policy content and more. These data, together with existing evidence and policy guidelines, were used by KSDPP along with the coalition of community stakeholders and university researchers, to develop a PA policy comprised of key target areas within schools where opportunities exist for PA promotion. Details of the PA Policy project can be found elsewhere (Hogan, et al., 2014).

The Intervention:

This current study focuses on the PA Policy’s identified target of school active transportation, the ability for children to be able to use physically active means of getting to and from school, such as walking or biking. (Hogan, et al., 2014). For this, the School Travel Planning (STP) project was developed using the Active & Safe Routes to School - Canada’s School Travel Planning process, as recommended by Active Healthy Kids Canada (Active Healthy Kids Canada, 2014). The STP process entails 5 collaborative phases: Setup; Data Collection & Problem Identification; Action Planning; Implementation; and Evaluation and Maintenance (Green Communities Canada, 2012). Phases 1-3 occurred between January 2013 and July 2014. For the setup phase, school and broader community members and organisations were invited to a community presentation in December 2012 to learn about the STP-Project. It was here that
community members signed-up for the project. These individuals were later contacted to form the STP-Committee and commenced meetings in January 2013. The STP-Committee comprised of 11 community, school and researcher stakeholders including: two principals, a classroom teacher, a physical education teacher, a bus transportation manager, a community protection officer, two KSDPP intervention staff, one KSDPP Community Advisory Board member, with one doctoral student in kinesiology and physical education (author SM), her PhD academic supervisor (author EBG) and PhD committee member (ACM) from the KSDPP research team. The doctoral student introduced the STP project as her dissertation project to KSDPP and the community and, after acceptance from both, then served as the project’s PI/champion and facilitator throughout its development.

The PI/champion began by recommending that the committee explore adapting the *Active & Safe Routes to School* (ASRTS) framework, which the STP committee agreed was culturally appropriate for the community. ASRTS provides samples of step-by-step procedures, timelines, and data collection activity samples to inform school AT program planning. From January 2013 – August 2014, PI/champion and committee members met monthly and successfully defined a terms of reference document and project timeline goals. Through a collaborative process, they also refined data collection activities to be culturally appropriate, as well as relevant for future program planning. Initially, five data collection activities were agreed upon, however, through reflection of early findings, a sixth activity was co-developed based on a knowledge gap. Activities included: i) school profile form; ii) student in-class travel survey; iii) parent survey; iv)
school walkability check-list; v) pedestrian-traffic observations; and vi) in-class mapping activities.

The data collection and analysis process occurred between September 2013 and May 2014, with some activities occurring at key seasonal dates; a decision made by the STP-Committee. Committee members were involved in one or more data activities as data collectors and/or organizers, which allowed for first-hand observations and experiences. While few were involved in analyses which was completed by the PI/champion, all had an opportunity to interpret the results, which allowed for enrichment of results and immediate dissemination of findings to the organisations to which the committee-members belonged. More specifically, through discussions of key findings, STP-Committee members were able to better define what needed to be done to support school AT programming in their schools and community. This aligned with STP-Process 3, action planning, which took place between March and August 2014. Through action planning meetings, members determined key goals and actions/initiatives for implementation in the 2014-15 school year. Examples of goals based on findings included: to increase the number of children using AT to and from school; improve traffic and pedestrian safety; increase law enforcement during peak school hours; and increase law enforcement presence.

Using the ASRTS STP-Action Planning template, members further identified key actions/initiatives under six key objective areas in support of their goals. Key objectives included: i) improve the safety of children on the active school journey; ii) raise awareness of the environmental and health benefits of AT; iii) encourage more students to walk to school; iv) encourage more students to walk from school to after-school
programs; v) facilitate safe bicycling to and from school; and vi) monitor the effectiveness of initiatives and revise School Travel Plan (Green Communities Canada, 2012). For example, to encourage more students to walk to school, committee members determined that a Walking School Bus program, an internationally used program (Buliung, Faulkner, Beesley, & Kennedy, 2011; Chillon, Evenson, Vaughn, & Ward, 2011), would be appropriate. Such programs are tailored towards students living within a school’s walkable distance policy. However, the STP-Committee wanted to be inclusive, and tailored their program to be a Walking School Bus drop-off program, where all students, whether bussed or not, could meet at specific location to walk to school under adult supervision. As part of raising awareness and to encourage student to use AT, various promotional and educational activities were developed, such flyers/brochures to students and parents, contests, and pedestrian, traffic, and cycling safety workshops. Committee members assigned themselves to one or more actions/initiatives based on their organisation, knowledge and expertise. Finally, the PI/champion provided support for various actions/initiatives up until and including their first Walking School Bus drop-off program during the first week of October 2014. At this time, as per initial agreement with the STP committee, the PI/champion had completed data collection for her thesis and left for other employment. This left committee members to carry the project forward into implementation and evaluation and maintenance phases.

Methods:

This study uses social network analysis (SNA). Sample: This is a sociometric study of the community/academic stakeholder committee for the STP project. This
closed-membership committee is a whole network of community stakeholders representing the various interests in the STP project, including school administrators and teachers, parents, public safety and public works officials, along with KSDPP intervention facilitators and academic researchers from McGill University. The network consists of 13 actors, representing the 11 members of the STP-Committee plus two others identified as KSDPP individuals who played a significant role at the time the idea was initially being discussed. Each of the actors in this network was administered a questionnaire covering two occasions in the life of the project (project initiation and completion). Project initiation (T1) was in January 2013, and completion of project planning (T2) was July 2014.

**Network Questionnaire:** The network questionnaire consisted of a fixed list of the 13 members of the STP committee with a box next to each name in which they could write their rank number. The retrospective item for baseline network relationships (T1) read: “Looking back to the beginning of the project, please rank the committee members in order of who you would turn to for information relating to the STP project *at that time.*” Participants were instructed to rank only those actors with whom they actually spoke to about the project at that time, and to leave the box blank if they had not spoken with the actor. At project completion (T2), participants were asked: “From the provided list of names, please rank the committee members in the order of who you would turn to for information relating to the STP project.” At both times, the respondents were invited to include themselves in their rankings.

**Measures:** Using UCINET 6 SNA software, *in-degree centrality* and *network centralisation* were calculated. In-degree centrality is a binary measure (nominated or not
nominated) that does not include rank-order of nomination in its calculation. In other words, if a respondent nominates the same alters (other members) at T1 and T2, but their ordering of alters changes over time to reflect a change in who they go to for information, these changes will not be reflected in the centrality scores. If all nominations are retained, then the resulting network maps for T1 and T2 will not demonstrate any marked change. However, because rank order can stand as a proxy for tie strength (Valente, 2010) we retained only the top 5 nominations from each respondent, representing their 5 strongest nominations; and thus producing network maps that are demonstrably different for each sample time. Freeman’s in-degree centrality (asymmetric model) was calculated for each network member, including diagonal values (because ego [oneself] valuing ego as information source is significant). Response ranks were reverse transposed, so that ranked 1st becomes the highest value for the calculation of tie strength. Network Centralisation was calculated for each sample time. Centralisation is the extent to which a network’s ties are focussed on one or a set of actors (Valente, 2010). In a highly centralised network, one or a few actors hold positions of power and control, while decentralised networks have defused power and control structures. Network centralisation is related to individual centrality in that it is calculated on the difference between the maximum individual centrality score and all the others within the same network (Valente, 2010).
Results:

Table 1 reports network centralisation scores at baseline and program maturation. Although centralisation increased at T2, comparing network densities (the number of actual ties as a proportion of the total possible number of ties) across times (paired t-test) showed no significant change from T1 to T2; so network density did not significantly increase or decrease the stakeholders’ ability to collaborate. Individual centrality scores for T1 and T2 are reported in Tables 2. Network maps describing the relationships between actors and the strength of their ties at T1 and T2 are shown in Figures 1 and 2.

Table 2_1: Changes in network centralisation (and standard deviation) from T1 to T2:

<table>
<thead>
<tr>
<th>Network Centralisation (in-degree)</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1</td>
</tr>
<tr>
<td>T2</td>
</tr>
</tbody>
</table>

Table 2_2: Freeman’s in degree centrality measures (*) for individual actors at T1 and T2:

<table>
<thead>
<tr>
<th>Committee Member</th>
<th>In Degree T1</th>
<th>Normalised</th>
<th>In Degree T2</th>
<th>Normalised</th>
</tr>
</thead>
<tbody>
<tr>
<td>M11</td>
<td>12.000</td>
<td>15.385</td>
<td>11.000</td>
<td>14.103</td>
</tr>
<tr>
<td>T13 (a)</td>
<td>9.000</td>
<td>11.538</td>
<td>0.000</td>
<td>0.000</td>
</tr>
<tr>
<td>J08</td>
<td>12.000</td>
<td>15.385</td>
<td>25.000</td>
<td>32.051</td>
</tr>
<tr>
<td>A05</td>
<td>15.000</td>
<td>19.231</td>
<td>20.000</td>
<td>25.641</td>
</tr>
<tr>
<td>A03 (a)</td>
<td>11.000</td>
<td>14.103</td>
<td>10.000</td>
<td>12.821</td>
</tr>
<tr>
<td>E07 (a)</td>
<td>26.000</td>
<td>33.333</td>
<td>18.000</td>
<td>23.077</td>
</tr>
<tr>
<td>PI (c)</td>
<td>36.000</td>
<td>46.154</td>
<td>61.000</td>
<td>78.205</td>
</tr>
<tr>
<td>D06</td>
<td>0.000</td>
<td>0.000</td>
<td>10.000</td>
<td>12.821</td>
</tr>
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</tbody>
</table>

Output generated by UCINET 6.532 Copyright (c) 1992-2014 Analytic Technologies
c = PI/project champion. a = academic stakeholders. All others are community stakeholders.
* Asymmetrical model including diagonals. Centralisation statistic is divided by the maximum value in the input dataset
Scores are normalised by to be comparable across networks of different sizes.

Figure 1: Network at T1 (project initiation) including link weights.
(Blue markers = members; lines = ties; arrow heads = direction of nomination; markers at top left = isolates [members not nominated])
Figure 2: Network at T2 (planning completion, start of implementation) including link weights (Blue markers = members; lines = ties; arrow heads = direction of nomination; marker at top left = isolate isolates [members not nominated])
At T1, the network was highly centralized around one individual, the PI/project champion, who was nominated and ranked first by every other alter (in-degree centrality [inDC] = 36.00). By T2, that same individual still dominated the information network (in-degree centrality increasing to 61.00 by virtue of larger size network at T2 with all members nominating this ego). However, the remainder of the network had nominated other knowledge leaders, with significant increases in centrality for several members, and one member (member J08) assumed a knowledge leadership role (with an in-degree centrality score of 25.00) second only to the PI/project champion. Standard deviation of the scores at T2 nearly doubled as a greater number of individuals became more central while network centralisation increased. At T1, the most central actors were academic stakeholders who were critical in the initial proposal of the project. However, by T2 academic stakeholders other than the PI/project champion have decreased significantly in their centrality scores as community stakeholders are increasingly seen as leading the project. It is notable that at T1 the school principals at the two participating elementary schools both received nominations even though they were not yet directly involved in the project. This is because they were seen as natural opinion leaders for school-based interventions. This is born out at T2 by the fact that one of the school principals became more central as the project developed (increasing from inDC=3.00 to inDC=21.00) while the other, who in the interim stepped down as principal to return to classroom teaching, maintained the same centrality score (inDC=4.00).

At T2 the network grew in size as new members and organisations were recruited following the initial team discussions that took place at T1. For the purpose of analysis these members are considered part of the network at T1, but generated no data because
they would not have nominated any actors as they had not yet begun to participate in the project. However, treating the network as a cohort across these two times, as well as for future samples, will allow for further analysis later in the project (to be discussed below).

Discussion:

As expected, the PI/project champion was the central figure in the knowledge network during these two stages of the project. Although the stakeholder committee was well developed and functional, it still required the regular leadership of the original project champion. However, over the course of the project, community members became increasingly engaged, as is measured by their increase in centrality. Once the committee had functioned for over a year to achieve its goals, the knowledge and competence concerning the project had spread among the stakeholders, with other central figures emerging. In particular, one KSDPP staff member who was responsible for organising the stakeholder meetings became more central. At the same time, several individuals who were central at the outset of the project (T1) played a reduced role at T2 and were perceived to have proportionately less influence over the project. This is particularly true for the university-based academic participants (other than the PI/champion), even one who was originally from the community and was involved early on in the project but then left the community for another academic appointment and was no longer involved in its regular operation.

During the course of the project, the PI/champion’s goal was to spread the work and the decision making among the stakeholders, to some success. However, the committee still relied on the direction of the project champion. Nevertheless, with the
emergence at T2 of other more central members, the network can be seen to be transitioning from a highly centralised one towards a network containing new knowledge leadership, a base on which to function once the original project leader steps down at T3, although its sustainability is only hypothesised at this point. By that time, it is expected that the continued trend may produce one or more new central champions, with other members occupying supporting knowledge roles within the network. The effectiveness of the new network structure for sharing and applying knowledge for successful intervention may depend on the overall network centralisation at that time, as knowledge-leaders are more influential in centralised networks (Valente, 2010).

**Implications for community ownership and self-determination:** Self-determination, the ability of individuals or groups to determine their own future, has been a central topic in health research – particularly public health research, since the 1980s as vulnerable or marginalised populations have attempted to take control over their own health and the evidence that informs the interventions, policies and programs that address it. This has been most evident among Indigenous and minority groups (Young, Kue, 1994; Young, et al., 2000), low socioeconomic status populations (Labonte, 1986; Robertson & Minkler, 1994) and other underserved segments of society. Cargo and Mercer (Cargo & Mercer, 2008) identified self-determination, alongside knowledge translation and social justice as the principal goals or values that drive participatory research and lead researchers to take a community-partnered approach to knowledge creation. Although the particular participatory processes that foster each of these three drivers have been explored, least is understood about the processes undertaken to achieve self-determination. Much has been written about the strategies for overall stakeholder
engagement (Hermann, et al., 2004; Kizer, 2001; Salsberg, Parry, et al., 2015), particularly with communities (Israel, et al., 1998; Macaulay, et al., 1998; Minkler & Wallerstein, 2008). And the strategies and processes for knowledge translation, both in public policy and for health practice have been well described (Graham & Tetroe, 2007; Parry, et al., 2009; Salsberg, et al., 2014). Participatory strategies that directly attempt to build ownership and self-determination are less well described and rarely if ever evaluated. Even where ownership has been evaluated (Cargo, et al., 2011; Cargo, et al., 2003), it was as an outcome measure of overall ‘participation’ by community members, with no exploration of individual measures within the participatory process that intentionally targeted self-determination.

Examining how influence and knowledge sharing shifts among organisations engaged in school-based PA intervention demonstrates how specific individuals or organisations take the lead as the project evolves. Results describe the emergence of new knowledge leaders, and the change in network centralisation within which the knowledge leaders function. Community ownership grew as the project developed and community members took on more central roles while university-based stakeholders were perceived to be of less influence. This emergent ownership can be seen as an assertion of community self-determination over the project. Furthermore, a direct line can be drawn from the recruitment of community members to the project, to their active engagement and finally the emergent community ownership over the project. This trajectory sheds light on how self-determination evolves as the influence of key actors changes over time. A hypothetical network reflecting full community ownership and self-determination would have community knowledge leaders in central positions, with non-community
stakeholders either absent or in positions of lower influence. The actual network is moving in that direction, but only future sampling will show if this trend is sustained.

These findings have implications for designing participatory processes that work to democratise the governance of community-university-partnered research project. PA intervention planning, though predicated on strong community ownership and inter-organisational collaboration, can nonetheless require academic attention particularly in its early stages, in order to foster this ownership.

Limitations:

There are many environmental influences on both the building of community ownership and the successful implementation of school-based PA interventions; social relationship is but one, albeit one that has received growing attention. By focussing on inter-stakeholder relations, we are not examining other aspects such as historical context, resource availability, encompassing physical and political environments, or other important factors. However, understanding the social dynamics can serve as a basis for later examination of how these other influences are accessed and applied within a multi-stakeholder community setting. Using the current data it is impossible to state the reason for the shift in network structure toward community ownership. To explain this shift, further samples will be needed at future key time points, as well as a qualitative exploration of stakeholders’ experiences. Finally, because this is a whole-network sample based on egocentric data, results may not be generalizable to network evolution in other settings. However, using this as a case study illuminates how a stakeholder network may evolve under similar contextual circumstances and under the influence of similar
participatory strategies. It may therefore be useful to others as a guide for designing participatory intervention processes within their own projects.

**Conclusion and further direction for research:**

This study set out to examine how a network of community and university stakeholders engaged in developing and deploying a school-based PA intervention changed over time. By looking at how the idea was initiated by an extra-community champion (whose goal was to support community capacity development), then community members and organisations were recruited, engaged and actively given the opportunity to take the lead, we hope we have increased our understanding of how community ownership and self-determination are grown. As stated, this has particular importance for community-based participatory intervention projects that are initiated by academics, but which must develop community ownership in order to be sustained (Cacari-Stone, et al., 2014).

As stated in the limitations, further study will attempt to explain the shifts in network influence described in the current data. Network data collected once the non-community PI removes herself from the project (T3), and again once the STP-Committee has run the intervention repeatedly in the PI’s absence (T4) will provide enough data to do a longitudinal network analysis using exponential random graph models to demonstrate the significance of change. Furthermore, qualitative interviews underway with members of the STP-Committee will explore the link between what occurred during the course of the STP project, including the use of participatory strategies to intentionally shift control to the community, and the observed shifts in network influence. This latter
phase will draw together the results of the current and proposed network analyses to
develop a clearer picture of how and why community self-determination emerges in
participatory health intervention research.

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Chapter 5

Examining the dynamics of actor roles and network structure over the lifecycle of a community-based participatory research project

Introduction:

Participatory research (PR) is the co-creation of new action-oriented knowledge by researchers working in equitable partnerships with those affected by the issue under study or those who will benefit from or ultimately act on its results (Green, et al., 1995; Macaulay, et al., 1999). A central supposition of PR is that sustained action or change is founded on end-users of research products taking ownership of the knowledge creation process (Cargo, et al., 2011; Minkler, 2000). These end-users could be, among others, communities, organisations, patients or health care practitioners. Ownership, in this sense, can be seen as the assertion of self-determination by end-user stakeholders who intend to improve their lives, health or practice through active involvement in creating the evidence they need for action, rather than being passive recipients or translators of evidence created by others (Cargo & Mercer, 2008; Freire, 1970). Influence in research decision-making, defined as the authoritative control of resources, can be seen to fall on a spectrum. At one end, the majority of influence is concentrated in the hands of one or a few academic researchers. In the middle is a state of diffused, shared power. At the other end is a concentration of influence in the hands of non-academic partners. The traditional research process tends to vest decision-making power amongst academic researchers, particularly with the principal investigator, who typically has conceived and designed the study and controls its funding. In order to foster self-determination, PR utilises strategies...
intended to shift ownership over the research process to the non-academic stakeholder partners (Salsberg, Parry, et al., 2015). If the principal investigator adopts a participatory approach and intentionally divests him/herself of this power by fostering a decision-making structure that spreads the control of resources among the stakeholders, opportunity arises for the non-academic partners to have control over the knowledge-creation process. This intentionally creates a situation where decision-making power can shift from the academic stakeholders toward the non-academic partners over the course of the participatory research project from the time of its initial proposal, to its maturation when program development is complete, to its independence when the original academic(s) depart, and finally to its sustained and maintained application by the end-users over time.

A partnership can be seen as a network of stakeholders, each representing an individual interest within the project. Therefore, to observe these power dynamics at play within a PR partnership, this study will take a social network approach to examining the knowledge leadership roles different stakeholders assume throughout the evolution of a researcher-initiated PR project. What does the evolution of a stakeholder network look like from the time it is initiated by an academic, non-community champion (T1); to maturation – the end of program development when it is ready to be deployed (T2); to independence – the time when the original champion steps aside (T3); and finally maintenance – when the network has had an opportunity to function independently of the original project champion (T4)? Does the network remain unchanged? If it does change: 1) Does it exhibit new structural qualities? 2) Do new central actors emerge? And 3) is there significance to the changing roles of actors within the network?
Using an existing community-based participatory research project as a case – the *Kahnawake Schools Travel Planning (STP) Project*, this study will map the evolution of a researcher-stakeholder committee to determine its structure and paths of knowledge leadership at various points in the project. Paths of knowledge flow are associated with opinion leadership (Valente 2010; Eccles & Foy, 2011) which serves as a useful measure of influence within a network (Valente 2010). The network will be mapped at its beginning when the project was first conceived; when the committee finished developing the program; when the original champion stepped aside; and finally when the committee has functioned independently. Network analysis will determine changes if any in the roles of specific actors in the network and their possible influence on other members.

**Social Network Analysis:**

A social network can be defined as connections among people, organisations or other social actors (Valente, 2010). Network analysis focuses on relationships between actors and how these affect their behaviour, even though the individual attributes of these actors can help shape their social network as well. These links and ties are the connections *among, within and between* the actors and the goal of network analysis is to understand how a network can influence and constrain the behaviour of its members (Valente, 2010). Social network studies take either a *whole network* design, looking at the sum of component actors as members of a bounded social collective; or an *egocentric* design, examining networks from the perspective of the actors within them (Marsden, 2005). Studying networks of individuals has led to greater understanding of how, among others, diseases, ideas and opinions spread; how people access social support, and who or
what influences their health behaviour (Turcot, et al., 2009). Network analysis has examined how health service organisations collaborate to share information, plan and deliver services (Doak, et al., 2006; Potvin & Lamarre, 2009; Story, et al., 2006; Turcot, et al., 2009). Within community-based participatory health research, it has been used to evaluate how community health workers share and use evidence (Campbell, et al., 2014; Valente, et al., 2010), to examine interpersonal support networks (Fuller, et al., 2012; Langhout, et al., 2013; Leonard, et al., 2014), and to examine issues of access and equity (Luque, et al., 2011; Pauly, et al., 2013; Ramanadhan, et al., 2012). For children’s physical activity, social network analysis has been used to examine peer influence on intervention effects (Shin, et al., 2014). Fuller, et al. (2012) showed that social network analysis could serve as an effective and culturally-acceptable approach within Aboriginal communities. Within that study, community members considered that the network analysis had accurately described the links between workers related to the exchange of clinical and cultural information, team care relationships, involvement in service management and planning and involvement in policy development (Fuller, et al., 2012).

Social network analysis has paid particular attention to identifying and understanding the roles of central actors. Individual centrality is defined as the extent to which an actor occupies a prestigious or critical position in the network (Valente, 2010). This position is associated with opinion leadership and is often seen to accord status, control over resources, and influence over the opinions and behaviours of others (Eccles & Foy, 2011). Centrality has been seen as having the strongest direct effect on organisations’ influence within their networks, such as among community-based service organisations (Galaskiewicz, 1979); and has been the frequent target of network
intervention studies that aim to optimise a network’s ability to share information or spread desirable behaviours or practices (Gest, et al., 2011; Poole, 2008; Valente, 2010). Measuring individual centrality can therefore serve as a lens into project ownership and community self-determination, as it locates decision-making influence within the network. There are various measures of centrality. In-degree centrality measures the number of times an actor is named by others in the network. For example, in-degree centrality can measure how frequently a community-member is named by others as someone they turn to for information or help (Salsberg, 2015 [Dissertation Chapter 4]). In both intervention planning and within the interventions themselves, it is important for success that people with high in-degree centrality are recruited early on as champions (Salsberg, 2015 [Dissertation Chapter 4]), as they are role models to whom others turn for leadership, and therefore have potential to increase the adoption and sustainability of the intervention (Rogers, 2003). In-degree centrality is furthermore the most robust of all the centrality measures when working with missing or incomplete data (Costenbader & Valente, 2003).

Besides examining the roles of various actors, social network analysis can also examine the overall structure of the network, including how centralised a network is and the existence of structural components such as pockets of dense interaction. Identifying and understanding the structure of a network is seen as important for understanding how and where information or influence flows. Centralisation is the extent to which network links are focused on one or few actors (Valente, 2010). One key implication of the centralisation of a network is on the spread of knowledge, ideas, opinions and behaviour (Salsberg, 2015 [Dissertation Chapter 4]). Centralised networks have the potential to
increase or decrease the pace of uptake of an innovation or policy depending on the commitment of its central actors (Valente & Rogers, 1995). Central actors are gatekeepers, possessing disproportionate amount of influence over the network, therefore opinion leaders are much more critical to the success of community-based initiatives in centralised networks than in decentralised ones (Valente, 2010). Sometimes, however, networks may have considerable structure yet low centralisation scores due to the similarity in individual centrality scores between highly interconnected actors (Valente, 2010). Therefore, measures such as core-periphery (Borgatti & Everett, 1999) can reveal network structure by identifying if there is a group of nodes (the core) who are densely connected to each other and a separate group of nodes loosely connected to this core and loosely or not at all connected to each other (Borgatti & Everett, 1999; Valente, 2010).

Network dynamics is the study of how structure or attributes of a network change over time (Salsberg, 2015 [Dissertation Chapter 4]). Temporal aspects are considered explicitly in longitudinal social network analysis, most often by means of cross-sectional states of networks observed at discrete time points (Brandes, et al., 2012). The study of network dynamics can answer such research questions as, how actor characteristics effect structural change, how structural conditions effect actor behavior, or how processes such as the diffusion of information take place within a network (Brandes, et al., 2012). Comparative graphic representation of the sequential time periods can describe and represent the network changes over time, while operations such as trend analysis can determine significance of change, and modeling can generate statistical inferences based on network variables (Marsden, 2005). Applying statistical inference to the dynamic analysis of whole networks can be problematic in that social networks are by their very
nature composed of interrelated nodes and thus tend to violate assumptions of independence (Snijders, 2005). The strength of network analysis, however, lies in the very fact that social actors are not independent, but are nested in structures of social context that may in themselves be predictive of individual outcomes (Brandes, et al., 2012; D. Straus & Freeman, 1989).

**Setting and Context:**

This study is part of the Kahnawake Schools Diabetes Prevention Project (KSDPP), a 21-year old community-owned participatory research partnership between the Kanien’kehá:ka (Mohawk) community of Kahnawake and academic researchers from McGill University, Queen’s University and Université de Montréal. Kahnawake First Nation is located 12 kms from downtown Montreal, Quebec, on the south shore of the St. Lawrence River. This community of approximately 8000 (2011 est. enrolled, on reserve) enjoys a high a level of socioeconomic development while valuing and maintaining the Kanien’kéha language and traditional institutions of culture and governance. The community has, since the late 1960s and early 1970s respectively, maintained local control over both its health and education systems; and thus operates its own school board, full-service inpatient hospital, and wide range of health and social services. Since 1994, KSDPP had developed and delivered community intervention programming to increase healthy behaviours and reduce incidence and prevalence of type 2 diabetes. KSDPP has continuously evaluated its efforts along a spectrum of process and outcome measures (Macaulay, et al., 1997; Paradis, et al., 2005); has evaluated its participatory partnership (Cargo, et al., 2011; Cargo, et al., 2003); has disseminated its prevention
planning model to over 30 Indigenous communities across Canada (KSDPP, 2014); and has served as a platform for numerous studies on health promotion, primary prevention of diabetes, nutrition, PA, healthy school policy planning, and the participatory process (see http://pram.mcgill.ca/ksdpp_pubs.php for the full range of published KSDPP research). KSDPP is governed exclusively by its Community Advisory Board (CAB) comprised of community volunteers representing many sector of Kahnawake. CAB oversees and approves all intervention and research planning, including ethical review of protocols and approval of dissemination. CAB serves as the primary site of engagement between community and researchers; it is where community voices inform the research agenda, and where community minds interpret its results. In 2010, KSDPP and its CAB received the CIHR Partnership Award, recognising excellence in researcher/knowledge-user engagement.

The specific KSDPP intervention serving as our case study is the Kahnawake School Travel Planning (STP) Project. The need to increase opportunities for active and safe routes to school had been identified in an earlier school-based physical activity policy process, described elsewhere (Hogan, et al., 2014). However, at the time no specific policy or intervention program had been proposed to meet this need. In 2011, a doctoral student and her academic supervisor approached KSDPP with the idea creating a ‘walking school bus’ intervention program [described in detail in dissertation manuscript 2 (Salsberg, Macridis, et al., 2015)]. This idea was welcomed by the community as an opportunity to fulfill the previously identified school physical activity policy need. STP project development commenced in January 2013 with the recruitment and formation of a project committee representing the various interested academic and community
stakeholders. Intervention planning was completed and the program was first deployed in the community in September 2014.

**Methods:**

This social network study uses a cross-sectional design to map a stakeholder network across four time periods in order to describe the change in individual in-degree centrality and network centralisation over time. Network dynamics and significance of actor role change was explored using linear trend analysis. **Sample:** This is a sociometric study of the community/academic stakeholder committee for the STP project. Sociometric studies attempt to gather information from everyone within a bounded network, can capture network influences, and are appropriate for instances where the total network membership can be enumerated such as in schools, organisations or small communities (Carrington, Scott, & Wasserman, 2005). This closed-membership committee is a whole network of community stakeholders representing the various interests in the STP project, including school administrators and teachers, parents, public safety and public works officials, along with KSDPP intervention facilitators and academic researchers from McGill University. In all, the community network includes 13 actors, representing the 11 members of the STP-Committee plus two individuals from KSDPP identified as having played a significant role at the time the idea was initially being discussed. **Data collection:** Network members were administered a questionnaire covering four periods in the life of the project. Project initiation (T1) was in January 2013, maturations (T2) was July 2014, independence (T3) was September 2014 and maintenance (T4) was November 2014.
Network Questionnaire: The network questionnaire consisted of a fixed list (roster) of the 13 members of the STP committee with a box next to each name in which they could write their rank number. The roster technique is appropriate as we are able to identify the total range of participants within the network beforehand, and can present such a roster to study participants as a means of eliciting their network responses (Valente, 2010). The retrospective item for baseline network relationships (T1) read: “Looking back to the beginning of the project, please rank the committee members in order of who you would turn to for information relating to the STP project at that time.” Participants were instructed to rank only those actors with whom they actually spoke to about the project at that time, and to leave the box blank if they had not spoken with the actor. For all other sample points (T2, T3 and T4), participants were asked: “From the provided list of names, please rank the committee members in the order of who you would turn to for information relating to the STP project.” At each time, the respondents were invited to include themselves in their rankings.

Measures: Network mapping and descriptive analysis: Using UCINET 6 SNA software, in-degree centrality and network centralisation were calculated. Freeman’s in-degree centrality (asymmetric model) was calculated for each network member, including diagonal values because ego (oneself) valuing ego as a knowledge source is significant. Response ranks were reverse transposed, so that highest ranking became the highest value for the calculation of tie strength. In-degree centrality is a binary indicator of whether an individual was nominated or not nominated, and does not include the rank-order in its calculation. However, because rank order can stand as a proxy for tie strength (Valente, 2010) we retained the top 5 nominations from each respondent, representing
their 5 strongest nominations; and thus produced network maps that are demonstrably
different for each sample time. Network centralisation was calculated for each of the four
sample times. Centralisation is the extent to which the ties within a network are focussed
on one or a few actors (Valente, 2010). In a highly centralised network, only one or few
actors hold positions of power and control, while decentralised networks are
characterized by defused power and control structures (Salsberg, 2015 [Dissertation
Chapter 4]). Network centralisation is related to individual centrality in that it is
calculated on the difference between the maximum individual centrality score and all the
others within the same network (Valente, 2010).

Description of Subgroups and Network Core-Periphery: The description and
analysis of groups within a network are important for understanding its structure and how
people work together, identify peers and share resources. In other words, groups provide
the context in which network members interact (Valente, 2010). The core-periphery
structure of a network is the extent to which there exists a group of nodes which are
densely connected to each other (the core) and a separate group of nodes only loosely
connected to this core or to each other (Borgatti & Everett, 1999). Core-periphery
networks may exhibit fairly low centralisation because members of the core have similar
centrality scores; yet these networks may still have considerable structure based on the
separation between this core group of nodes and others less connected nodes (Borgatti &
Everett, 1999; Valente, 2010). Using UCINET 6 SNA software, core periphery fit index
(Borgatti & Everett, 1999), was calculated. The fit index is an indication of how well the
network conforms to a core-periphery structure, indicating the extent to which a core
exists.
**Dynamic network analysis:** Network evolution can be examined by comparing a series of cross-sectional network maps generated from in-degree centrality scores at each sample time (T1 to T4). To assess longitudinal network dynamics, the evolution of centrality and network centralisation from T1 to T4 were measured. Because a sociometric (whole network) sample violates the statistical assumption of independence, a non-parametric test was employed to examine whether there was change in in-degree centrality measures for individuals across time T1 to T4. The Friedman rank sum test was used as a non-parametric statistical test similar to the parametric repeated measures ANOVA, to detect differences in treatments across multiple test attempts. It is a one-way repeated measures analysis of variance by ranks, and involves ranking each row (time sample) of individuals together, then considering the values of ranks by individuals within each row (Conover & Iman, 1981). If actor roles do not change over time, then the ranks of individual actors based on their in-degree centrality measure should remain similar across time, although the total number of connections within the network could change over time. This is similar to the situation that: n performances are each rated by k different judges; are the judges' ratings consistent with each other? Here performances become individuals, and judges become time period. Linear regression analysis for network centralisation over time was measured using the Cochran-Armitage linear trend test. This test is used in categorical data analysis to test for the presence of an association between variables across categories. Weights can be assigned to each variable to test for trends across categories (Agresti, 1996). In this case, it tested the trend in centrality scores over time. Data were managed in MS Excel, network measures were calculated and graphs generated using UCINET 6.0 and analyzed using RStudio statistical software.
Results:

Analysis assessed whether actor centrality, paths of information flow, as well as the overall structure of the network, including centralisation and core-periphery, have significantly changed over the course of the three samples. Because PR aims to activate ownership and self-determination mechanisms over the course of a program, it was hypothesized that the network structure would evolve from one centred around the PI/champion, either to a decentralized one, characterised by diffuse, democratised decision-making, or to a new network structure centralized on a different set of key actors from within the community.

Network centralisation is reported in Table 3_1. Cochran-Armitage linear trend test for network centralisation over time found that there was no significant linear trend of overall centralisation over time (p-value = 0.63), although a trend toward decentralisation can be observed from T2 – T4.

Table 3_1: Network centralisation at T1 to T4:

<table>
<thead>
<tr>
<th>Network Centralisation (in-degree)</th>
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<tbody>
<tr>
<td>T1 33.53% (SD 10.57)</td>
</tr>
<tr>
<td>T2 58.58% (SD 15.60)</td>
</tr>
<tr>
<td>T3 34.37% (SD 11.87)</td>
</tr>
<tr>
<td>T4 29.17% (SD 10.14)</td>
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This indicates that the network became more centralised from project initiation to maturation; then from maturation, through independence and maintenance, the network became steadily less centralised as influence was seen to be shared among a number of community stakeholders.

Table 3_2 reports individual centrality scores over time. Friedman Rank Sum test was employed to examine whether there was change in in-degree centrality measures for
actors across time T1 to T4. Results indicate that there was significant (Friedman chi-squared = 28.56, df = 12, p-value < 0.005) overall change in actors’ roles over time. Figures 3_1 to 3_4 provide a graphic representation of the changes in actor roles over the four sample periods. Figures 3_5 to 3_8 provide a visual matrix of the core-periphery analysis, highlighting the actors present in the core class at each sample time. The implications of the results reported in these tables and figures are described below.

At project initiation (T1), as anticipated, the academic PI/champion was the most central figure, with an in-degree centrality score (36.00) significantly above others in the network. As the project’s initiator, the PI/champion was by definition the knowledge leader and most significant actor in the development of the project at this point. At T1, other non-community, academic actors (E07; A03; T13) were playing a significant role in project development, as indicated by their centrality scores. Network centralisation was moderately low at project initiation (33.53%); however the fairly high core-periphery fit index (0.795) points to significant structure to the network, indicating that knowledge leaders in the core class (PI; A05; E07; J08; M11) formed a block of dense interaction with the ability to guide the direction of the entire network. At T1, this core class consisted of the PI/champion and her academic supervisor (E07), as well as three key members of KSDPP, the host organisation (A05, J08, M11), but not yet any members of other partnering community organisations.
Table 3.2: Freeman’s in degree centrality measures* for individual actors at T1 to T4 (Figures in red highlight evolution of central actors):

<table>
<thead>
<tr>
<th>Committee Member</th>
<th>In Degree T1</th>
<th>Norm</th>
<th>In Degree T2</th>
<th>Norm</th>
<th>In Degree T3</th>
<th>Norm</th>
<th>In Degree T4</th>
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<td>15.39</td>
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<td>26.00</td>
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<td>32.05</td>
<td>35.00</td>
<td>48.61</td>
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<td>8.00</td>
<td>11.11</td>
<td>13.00</td>
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</tr>
<tr>
<td>A03 (a)</td>
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<td>14.10</td>
<td>10.00</td>
<td>12.82</td>
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<td>11.11</td>
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<tr>
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c= PI/project champion.  a= academic stakeholders.  All others are community stakeholders.

* Asymmetrical model including diagonals. Centralisation statistic is divided by the maximum value in the input dataset.
Scores are normalised by to be comparable across networks of different sizes.

Once the project committee had worked for 18 months and was ready to deploy the intervention (project maturation – T2), knowledge leadership began to shift toward community stakeholders. At this point, the PI/champion was still involved in the project and playing a key leadership role as seen in her continued dominant centrality score (61.00). Note that the PI’s higher centrality score here is due to the fact that a larger network of actors was nominating her at T2 than at T1. However, other academic stakeholders (A03; E07; T13) were beginning to fade in influence while certain community stakeholders (A05; J08; K09; A04) were emerging to take on knowledge leadership roles, including stakeholders form key partnering community organisations. At T2, the network became more centralised (58.58%), indicating an environment in which
the emergent central community actors may have had increased influence over the course of project. The core-periphery fit index at T2 remains moderately high (0.626), with a core class (PI; A05; D07; J08; K09; M11) consisting of the PI/champion and community stakeholders, but no other academic (non-community) members. The T1 members of this class remained and were joined by two other community members seen as knowledge leaders by their peers at this point.

At T3 the project had reached the point of independence, with the PI/champion stepping aside and leaving deployment and management of the intervention program to the committee. At this point new knowledge leaders (A04; J08; K09; M11) emerged to assume central roles vacated by the departing PI/champion. Each of these most central figures is a community stakeholder; although the PI/champion’s academic supervisor (E07) remains active in the network with moderate influence (13.00). Overall network centralisation at T3 (34.38%) has returned to a level similar to that at T1; however core-periphery fit remains high (0.700), with a core class (A04; D07; J08; K09; M11) consisting of key community stakeholders.

Finally, at T4 and the point of project maintenance, the network appears to be stable with the same knowledge leaders (A04; J08; K09; M11) occupying central positions in a network with about the same degree of centralisation (29.17%) as at T3. At this point the committee has had the opportunity to run the intervention at least once in the absence of the PI/champion and is continuing to meet both individually and as a group to maintain and manage the program. T4 core-periphery fit remains high (0.708) with a core class (A04; A05; E07; J08; K09; M11) dominated by community stakeholders. However, it is notable that one academic stakeholder (E07) and one KSDPP
(community) stakeholder (A05) remain as part of this core block. The KSDPP stakeholder in question (A05), although seen as a community leader, had taken only a supporting role in the development of this project, but his appearance here along with the original PI/champion’s academic supervisor (E07) may indicate a sentiment of ongoing support from those most directly involved in running managing the intervention – particularly by members A04 and K09 who now are seen to champion the project at the two intervention sites.

Figure 3.1: Network at T1 (project initiation) including link weights.
(Blue markers = members; lines = ties; arrow heads = direction of nomination; markers at top left = isolates [members not nominated])
Figure 3.2: Network at T2 (project maturation) including link weights.

(Blue markers = members; lines = ties; arrow heads = direction of nomination; marker at top left = isolate [member not nominated])
Figure 3.3: Network at T3 (project independence) including link weights.
(Blue markers = members; lines = ties; arrow heads = direction of nomination; markers at top left = isolates [members not nominated])

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Figure 3.4: Network at T4 (project maintenance) including link weights.
(Blue markers = members; lines = ties; arrow heads = direction of nomination; markers at top left = isolates [members not nominated])

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Figure 3.5: T1 Core-Periphery Adjacency Matrix, indicating the core block in the upper left:

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</tbody>
</table>
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T1 core-periphery fit index = 0.795, indicating a fairly high core-periphery structure. Core-periphery class membership at T1 was:

1: PI (c); A05; E07 (a); J08; M11 (core)
2: K02; A03 (a); A04; D06; K09; L10; R13; T13 (a) (periphery)

(c)=PI/project champion; (a)=academic stakeholder; all others are community stakeholders

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Figure 3.6: T2 Core-Periphery Adjacency Matrix, indicating the core block in the upper left:

\[
\begin{array}{cccccc}
1 & 1 & 1 & 1 & 0 & 0 \\
1 & 1 & 1 & 0 & 1 & 0 \\
1 & 1 & 1 & 0 & 0 & 0 \\
1 & 1 & 1 & 0 & 0 & 0 \\
1 & 1 & 1 & 0 & 0 & 0 \\
1 & 1 & 1 & 0 & 0 & 0 \\
\end{array}
\]

T2 core-periphery fit index = 0.626, indicating a fairly high core-periphery structure. Core-periphery class membership at T2 was:

1: PI (c); A05; D06; J08; K09; M11 (core)
2: K02; A03 (a); A04; E07 (a); L10; R13; T13 (a) (periphery)

(c)=PI/project champion; (a)=academic stakeholder; all others are community stakeholders

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Figure 3.7: T3 Core-Periphery Adjacency Matrix, indicating the core block in the upper left:

```
   1  1  1
  4 8 9 1 6  1 7 2 3 0 5 2 3
A J K M D S E K A L A R T

---------------
  4 A04  |  1 1 1 |
  8 J08  |  1 1 1 |
  9 K09  |  1 1 1 |
 11 M11  |  1 1 1 |
  6 D06  |  1 1 1 |
---------------
  1 PI    |      1 |
  7 E07   |  1 1 1 |
  2 K02   |      1 |
  3 A03   |  1 1 1 |
 10 L10   |      1 |
  5 A05   |  1 1 1 |
 12 R12   |      1 |
 13 T13   |  1 1 1 |
---------------
```

T3 core-periphery fit index = 0.700, indicating a fairly high core-periphery structure. Core-periphery class membership at T3 was:

1: A04; D06; J08; K09; M11 (core)
2: PI (a); K02; A03 (a); A05; E07 (a); L10; R13; T13 (a) (periphery)

(c)=PI/project champion; (a)=academic stakeholder; all others are community stakeholders

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Figure 3.8: T4 Core-Periphery Adjacency Matrix, indicating the core block in the upper left:

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T4 core-periphery fit index = 0.708, continuing the trend of high core-periphery structure. Core-periphery class membership at T4 was:

1: A04; A05; E07 (a); J08; K09; M11 (core)
2: PI (c); K02; A03 (a); D06; L10; R12; T13 (a) (periphery)

(c)=PI/project champion; (a)=academic stakeholder; all others are community stakeholders

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Discussion:

Of the various dimensions of participatory conceptual models (Cacari-Stone, et al., 2014; Cargo & Mercer, 2008; Oetzel, et al., 2014; Sanchez, et al., 2011), the fundamental place of community ownership in creating and sustaining outcomes deserves particular attention. Cargo and Mercer (2008) identified community self-determination, the ability of a group to determine their own future, as a principal goal or value that drives PR and lead researchers to take a partnered approach to knowledge creation. Self-determination has been a central topic in community health research since the 1980s as vulnerable populations have attempted to take control over their own health and the evidence, interventions, policies and programs that address it. This has been very evident in research involving Indigenous and minority groups (Smylie, et al., 2004; Young, 1994; Young, et al., 2000) and other marginalised or underserved segments of society (Labonte, 1986; Loignon, et al., 2013; Robertson & Minkler, 1994) (Martin, et al., 2007; Martin, et al., 2009) (Park, et al., 2014; Pelletier, et al., 2011).

Social network analysis is here demonstrated to be an effective tool for describing the evolution of community ownership and self-determination within a participatory project. Results illustrate how these develop as the influence of key actors changes over time. Academic ownership over the project at its initiation (T1) was revealed through the central role of the PI/champion at that time. Core-periphery analysis proved useful for providing deeper insight into how academic ownership functioned at this stage. Along with the PI/champion was a core class of stakeholders who were seen to hold knowledge leadership over the direction of the project. However, even within this core class, the PI/champion and her academic supervisor had individual centrality scores significantly
above the three other stakeholders from the host/lead community organisation (KSDPP), indicating that despite interest and discussion within the community, academic stakeholders held initial ownership.

Social network analysis was then able to describe the trajectory of ownership over time. At project maturation (T2), the PI/champion remained the most central actor. Yet the centrality scores of all other academic stakeholders had diminished, while those of key community stakeholders from KSDPP as well as key community partner organisations had increased. Measuring overall network centralisation was able to provide insight into the context in which these emergent community actors functioned. The network became significantly more centralised from T1 to T2 (up to 58.58% from 33.53%). Because the role of central actors is more significant within highly centralised networks (Valente, 2010), this may indicate that these emergent community actors have an opportunity to hold stronger knowledge leadership roles in the project. Coupled with the diminished academic centrality scores, this indicates a growth in self-determination through community ownership over the project. By project independence (T3) and maintenance (T4), once the original PI/champion had departed and the project was being sustainably implemented, community leaders are shown to have emerged and maintained their positions over time. This was taking place at T3 and T4 within a network structure that exhibited only moderate centralisation, indicating a more collaborative structure where, once the PI/champion had departed, leadership roles were spread among a group of actors with no clear overall central knowledge leader. Although the PI/champion’s academic supervisor remained an active member of the network, his centrality score was
significantly below those of the four key community actors, pointing to a maintenance of community ownership and self-determination over the course of the project.

Research on the participatory process often focusses on the concepts, mechanisms and strategies to maintain engagement among community stakeholders in a way that creates sustained ownership over the research and action process (Cargo, et al., 2008; Cargo, et al., 2011; Jagosh, et al., 2012; Minkler & Baden, 2008; Oetzel, et al., 2011; J. G. Oetzel, et al., 2014; Salsberg, Macridis, et al., 2015; Salsberg, Parry, et al., 2015).

Findings from this study demonstrate the evolution of a participatory project from a state of academic ownership to one of sustained community ownership, and set the foundation for further research aimed at understanding PR processes that work to foster this change, particularly in cases where the research idea originates from outside the community.

Limitations and future research:

This study was able to describe the evolution of a community-based network, but was unable to explain why it evolved. Further qualitative research asking the network participants to describe events and strategies that led to the observed network change will help shed light on the strategies and mechanisms underlying the described change dynamics (see dissertation manuscript 4). One further limitation was that this study was only able to measure project sustainability (T4 network measures) at a relatively short interval after the departure of the academic PI/champion. This was due to limitations in time and resources. However, at the time of manuscript submission, the intervention was still actively being implemented under the leadership of the same community
stakeholders. Follow up evaluation at a future date will assess the long-term sustainability of both the intervention and its community ownership.
Chapter 6

What participatory strategies foster community ownership and self-determination?

Introduction:

Participatory research (PR) is the co-creation of new knowledge by researchers working in equitable partnerships with those affected by the issue under study or those who will benefit from or ultimately act on its results. These could be, among others, communities, organisations, patients or practitioners. For health intervention research, proponents argue that PR strengthens academic-community relations; ensures relevancy of research questions; increases capacity of data collection, analysis and interpretation; minimises the negative or stigmatising effects of research, and enhances program recruitment, sustainability and extension (Cargo & Mercer, 2008; Israel, Parker, et al., 2005; Israel, et al., 1998; Macaulay, et al., 1998; Macaulay, et al., 1999; O'Fallon & Dearry, 2002). PR is believed to increase communities’ capacity to identify and solve their problems (Gaventa & Cornwall, 2006; Macaulay, et al., 1999) and decision-makers’ and service providers’ ability to mobilize resources, improve policies and enhance professional practices (Minkler & Wallerstein, 2008). Taking a PR approach has been shown to ensure culturally and logistically appropriate research; enhance recruitment capacity; generate professional capacity and competence in stakeholder groups; result in productive conflicts followed by useful negotiation; increase the quality of outputs and outcomes over time; increase the sustainability of project goals beyond funded time frames and during gaps in external funding; and create system changes and new unanticipated projects and activities (Jagosh, et al., 2012). Participatory research furthermore integrates knowledge translation into the knowledge
creation process by assuring that the appropriate end-users of research findings are implicated throughout all key phases of the research. Most importantly, end-users should be involved in the research phases of identifying the need and setting research questions, interpreting results, and disseminating and applying findings (Macaulay, et al., 1999; Minkler & Wallerstein, 2008; Parry, et al., 2009; Salsberg, et al., 2014).

Cargo and Mercer (2008) identified the desire to influence knowledge translation, social justice and self-determination as the three principal goals or values that drive PR and lead researchers to take a partnered approach to knowledge creation. It is with these values in mind that participatory researchers apply participatory engagement strategies in order to foster community ownership. The particular PR processes that foster each of these three drivers have been explored (Epp, 1986; Frohlich & Potvin, 1999; Graham & Tetroe, 2007; Greenhalgh, 2012; Greenhalgh, et al., 2012; Labonte, 1986; Robertson & Minkler, 1994; Salsberg, et al., 2014). Self-determination, the ability of individuals or groups to determine their own future, has been a central topic in public health research since the 1980s as vulnerable or marginalised populations have attempted to take control over their own health and the evidence that informs the interventions, policies and programs that address it. This has been most evident among Indigenous peoples and minority populations (Young, 1994; Young, et al., 2000), as well as among HIV/AIDS communities (Flicker, et al., 2009; Travers, et al., 2008), the poor (Labonte, 1986; Loignon, et al., 2013; Robertson & Minkler, 1994) and other underserved segments of society. In recent years self-determination has also emerged as an issue in clinical implementation research as healthcare providers have begun to take a more active role in producing the practice-based evidence that guides their evidence-based practice (Green, 2008b).
Although each of these three values is recognised as driving PR, least is understood about the effectiveness of strategies undertaken to achieve self-determination. Even when community ownership of research has been evaluated over time (Cargo, et al., 2011; Cargo, et al., 2003), perceived ownership was measured as an outcome measure of an overall ‘black box’ process of participation by community members, with no exploration of individual strategies within the participatory process that intentionally targeted community ownership or self-determination.

In community-based PR, community stakeholders collaborate with outside academic researchers. Although research topics may originate from within the community, they often stem from the interests of the outside academic who may propose the intervention or research idea (Hogan, et al., 2014; Macaulay, et al., 1999; Reason, 2000; Salsberg, et al., 2014). The traditional research process tends to vest decision-making power with the (outside academic) principal investigator, who typically has conceived and designed the study and controls its funding. Successful, sustainable change is founded, however, on community stakeholders ultimately taking ownership over the research process (Green & Kreuter, 2005; Hogan, et al., 2014; Sanchez, et al., 2011). This ownership is demonstrated when community research stakeholders possess meaningful and acknowledged control over the directions and resources supporting the research (Cargo, et al., 2011; Fetterman & Wandersman, 2005). These characteristics are measurable in terms of influence and power dynamics, participatory decision-making, leadership and resource management, as dimensions of group dynamics and equitable partnerships (Oetzel, et al., 2014). PR imposes a decision-making structure that spreads the control of resources among the stakeholders, creating opportunity for the non-academic partners to take control of the knowledge-creation process. Community self-determination is thus built through PR when
communities take ownership of all aspects of the research process (Cargo & Mercer, 2008; Goodman, et al., 1998; Green, et al., 1995).

While PR utilises intentional strategies to help shift influence and decision-making from academic to community partners, and these strategies have been well documented (Salsberg, Parry, et al., 2015) [dissertation manuscript #1], little is understood about how these strategies lead to increased community engagement, ownership, and ultimately self-determination. Therefore we have examined a community-based participatory research project to describe how ownership and decision-making shift over the course of the project, from initiation, to project maturation, independence and maintenance. Particular focus was placed on how project stakeholders perceived specific participatory values and enacted strategies to impact this shift and how they have described actions and events over the course of the project that facilitated community stakeholders’ ability to assume leadership roles.

In an earlier phase of this study, a longitudinal social network analysis (described in dissertation manuscript #3) was undertaken which described the dynamic structure of the stakeholder network from the time of project conception, through its growth and maturity, to its ultimate independence and maintenance when it was functioning in the absence of the original academic initiator. A social network represents the links or ties between social actors such as project participants, community members or community-based organisations, and social network analysis focuses on these relationships and how they can influence or constrain behaviour (Valente, 2010). From this analysis, network maps emerged describing a significant shift in knowledge leadership from the non-community PI at T1 to community stakeholders at T4 (see dissertation manuscript #3 for full analysis of these and other network measures). This shift in knowledge leadership can represent the movement of ownership from the non-community PI to
community stakeholders, building community self-determination over the research process. Although the network results describe the shift in influence, they do not in and of themselves explain it. The current qualitative study introduced these same stakeholders to the network results after T4 and asked them 1) to interpret the changes of influence at each time; 2) to describe what actions, events or strategies helped democratize the decision making process leading to community ownership; and 3) to describe the extent to which they attribute the influence-shifts to these actions, events and enacted strategies.

Setting and Context

This study is part of the Kahnawake Schools Diabetes Prevention Project (KSDPP), a 21-year old community-owned participatory research partnership between the Kanien’kehá:ka (Mohawk) community of Kahnawake, Quebec and academic researchers from McGill University, Queen’s University and Université de Montréal. Kahnawake First Nation is located 12 km from downtown Montreal, Quebec, on the south shore of the St. Lawrence River. This community of approximately 8000 (2011 est. enrolled, on reserve) enjoys a high a level of socioeconomic development while valuing and maintaining the Kanien’kéha language and traditional institutions of culture and governance. The community has, since the late 1960s and early 1970s respectively, maintained control over both its health and education systems; and thus operates its own school board governing the curriculum of two elementary schools and one high school, full-service inpatient hospital, and a wide range of health and social services. Since 1994, KSDPP has developed and delivered community intervention programming to promote healthy behaviours with the goal of reducing incidence and prevalence of type 2 diabetes. KSDPP has continuously evaluated its efforts along a spectrum of process and outcome measures (Macaulay,
et al., 2007; Macaulay, et al., 1997; Paradis, et al., 2005); has evaluated its participatory partnership (Cargo, et al., 2011; Cargo, et al., 2003); has disseminated its prevention planning model to over 30 Indigenous communities across Canada (KSDPP, 2015); and has served as a platform for numerous studies on health promotion, primary prevention of diabetes, nutrition, physical activity, healthy school policy planning, and the participatory process (see http://pram.mcgill.ca/ksdpp_pubs.php for the full range of published KSDPP research). KSDPP is governed exclusively by its Community Advisory Board (CAB) comprised of community volunteers representing many sectors of Kahnawake. CAB oversees and approves all intervention and research planning, including ethical review of protocols and dissemination plans. CAB serves as the primary site of engagement between community and researchers; it is where community voices inform the research agenda, and where community minds interpret its results. In 2010, KSDPP and its CAB received the CIHR Partnership Award, recognising excellence in researcher/knowledge-user engagement.

In 2011, the KSDPP community-academic team received a Canadian federal research grant to develop and implement a school-based physical activity (PA) policy. Details of the PA Policy project can be found elsewhere (Hogan, et al., 2014). One key target area identified within the PA Policy was the need to support school active transportation, the ability for children to be able to use physically active means of getting to and from school, such as walking or biking. (Macridis & Garcia Bengoechea, 2015). In 2012, a doctoral student in the field of kinesiology and physical education approached KSDPP to introduce the idea of developing a program to encourage walking to school for students of the two community elementary schools. This idea was warmly received as it aligned with the identified PA policy area of promoting active
transportation to school; and KSDPP therefore initiated a school travel planning (STP) project (Macridis, 2015).

Kahnawake schools, as well as broader community members and organisations were invited to a community presentation to learn about the STP Project and sign up to participate. Interested individuals were later contacted to form the STP Committee which commenced meeting in January 2013. The STP Committee was composed of community and academic stakeholders including: two elementary school principals, a classroom teacher, a physical education teacher, a bus transportation manager, a community protection officer, two KSDPP intervention staff, one KSDPP Community Advisory Board member; with the doctoral student, her PhD academic supervisor and PhD committee member from the KSDPP research team. The doctoral student served as the project’s PI/champion and facilitator throughout its development.

Methodology

This analysis is part of an overall mixed-methods study using a social network approach to describe and analyse network change over the course of the observation period. This current piece of that larger study employs a qualitative description methodology. Five community stakeholders and one academic stakeholder (the PI/champion) participated in individual 30-60 minute interviews between January and March 2015. The sample represents members of the KSDPP School Travel Planning Project who were identified as central actors in the earlier social network analysis phase. Data was collected using retrospective, semi-structured interviews. Prior to the interviews, the PI/champion was asked to complete a questionnaire based on best practice participatory engagement strategies derived from leading PR practitioners (Salsberg, 2015 [manuscript #1 in this dissertation]). This tool asked the PI/champion to identify which
Engagement strategies had been used during the course of the project, and to rate their significance to the project or frequency of use. During the subsequent stakeholder interviews, the interviewer first introduced the respondents to the results of the network analysis and the maps representing the evolution of the stakeholder committee from T1 to T4 (see Figures 1 to 4) and then led the respondent through the changes in stakeholder influence described therein. The interviewer first asked the respondents if they agreed with or had any comments on the network findings. Then the respondents were asked about strategies, actions or events that may have led to the observed changes. Probes were used to ask about predetermined strategies that were identified by the PI/champion. The network maps served as useful interview tools, with respondents able to refer back to them during the course of the interview as they discussed actions and strategies.

**Analysis:** Qualitative description relies on thematic coding through constant comparative methods borrowed from grounded theory (Glaser 1969). In this way, texts are read, creating codes and code hierarchies that are continuously revised as they are applied to new text. In other words, as new interview texts are coded, code definitions are reconsidered and, if necessary, previous interview text is revisited to apply, reapply or remove codes based on the revised definition. Emergent codes are in turn grouped into overarching thematic categories, describing the phenomenon under study (Lofland and Lofland 1995). Thematic categories as well may be updated, with codes being added or removed from themes as they are revised. Results of this qualitative study contextualise the results of the network analysis, by allowing the stakeholders themselves to explain the perceived meaning of the changes in influence documented at each stage. This is intended to provide insight into how influence shifts within community-academic PR partnerships.
Results

Stakeholder Interpretation of the Social Network Results: All stakeholders interviewed, community members and the PI/champion, felt that the evolution of knowledge leadership described in the network results was an accurate reflection of what occurred over the course of the participatory research project. Stakeholders were able to look at the described network evolution and relate it to who they saw as actively contributing to the project at its various stages. According to community stakeholders,

Actually, I think it is what was going on. Most of the people with the higher [centrality scores] were the people who were usually at all the meetings and who… I could send a quick email off to. I would just send quick emails off to [J08], [PI], or [M11]. I would send to others and if I didn’t receive back an
answer or anything then… Because most of the times if there were any questions, any concerns or anything like that, those were the ones that I usually went to.

[K09 – Community Stakeholder]

And,

To begin with [at T1], the basis of the project was to begin with certain people that we could identify that would be able to give us resources, you know, we would be able to put this project, like, we’d be able to implement it in the community. We’d be able to get it going. Then moving to [later network results], obviously with their consultation with the meetings we had, we would be able to identify key stakeholders that would allow us to get more information on how this would work accordingly, so that obviously would increase the base for everybody to be involved. So it started with a few people and then we needed more help in certain areas and then we sought those people out and then it expanded to the people that were really involved with it [at T2-T4].

[M11 – Community Stakeholder]

The four graphic representations of the network at T1 – T4 served as useful tools for the remainder of each interview, with respondents frequently referring back to them while making points about people’s participation or leadership. For example,

[Referring to the network maps…] I think this is the way it went. Yeah, from the outside organisations and the [school] principals here at the tip end. Knowing that we would have to be involved, like you said. Then we relied more heavily on [the PI/champion] and it was almost a panic [respondent points to a network map] when she said she was leaving. I was, like: Oh, no! So who takes over? And it was us!

[A04 – Community Stakeholder]

**Stakeholders’ perceptions of the participatory process:** The STP Committee members reflected on their work process over the 18-month course of developing the STP project. From these reflections several key overarching themes emerged, summarised in Table 1. These themes represent values or aspects within the participatory process that respondents saw as underpinning
the described shifts in ownership over the course of the project. These emergent themes can be seen as an exploration of the processes underlying Cargo & Mercer’s (2008) PR dimension of self-determination and thus, can be seen as the context in which the participatory engagement strategies were enacted.

Table 4.1: Key themes describing participatory values or actions as elicited by community stakeholders

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
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<tbody>
<tr>
<td>Strong Champion</td>
<td>Strong initial and ongoing project management created space for committee to properly engage and take ownership</td>
</tr>
<tr>
<td>Outside ideas can be refreshing and stimulating</td>
<td>Novel perspectives from outside the immediate stakeholders can spark interest</td>
</tr>
<tr>
<td>Core people emerge</td>
<td>A smaller very active group emerges within the overall committee that disproportionately undertakes both decisions and action</td>
</tr>
<tr>
<td>Alignment of stakeholders’ professional roles with project goals</td>
<td>Engagement can depend on stakeholders holding a professional interest in the goals of the project</td>
</tr>
<tr>
<td>Involving the right people</td>
<td>Both in terms of professional/organisational role as well as personality</td>
</tr>
<tr>
<td>Personal Qualities of Champion</td>
<td>Personal qualities suitable to engage with community, such as personal and cultural humility</td>
</tr>
<tr>
<td>Trust-building</td>
<td>Engagement is built on trust between PI/Champion and community over time</td>
</tr>
<tr>
<td>Active use of engagement strategies:</td>
<td>Community stakeholders specifically discussed ways that the PI/Champion facilitated their active engagement in the project, including providing food, facilitating meetings, reminding them to take charge of actions, and intentionally taking a back seat in decision-making</td>
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</table>

**Strong Champion**: Several community stakeholders commented on the important role of strong project leadership and management, particularly early on in the project. None of the community stakeholders initially had the time to act as project champions, and were pleased to have someone fill that position. It was felt that strong project management at this point allowed community stakeholders the opportunity to be meaningfully engaged in the project. By assuring that administrative and coordinating tasks were taken care of, the PI/champion created the space
for the community stakeholders to easily step in and make program decisions and participate in actions in a way that did not impose unduly on their time.

When we showed up to do something, she was ready with all her paperwork. She was ready to tell us any results and things like that. We had information. So there was no questioning what was going on and why we were doing it. It made it easier.

[K09 – Community Stakeholder]

The community intervention facilitators encouraged the PI/champion to continue to play a leading role, even when she had been more inclined to step back:

Myself and [J08] had mentioned to her, we had our own meetings and they were such good discussions, where it’s: ‘you’re the champion, you have to act like it. You have to educate people and they then can take it over.’ I think that’s kind of where it went with it. That’s obviously where it did go.

[M11 – Community Stakeholder]

The PI/champion’s management was able to prompt independent interaction between the community stakeholders:

She had to be central to everything to get us going. Once that happened, I guess, looking at the results that she brought back, then I was able to call [D06] and say ‘What about this?’ you know. So she kind of made all the connections for us.

[A04 – Community Stakeholder]

And, her management enabled community stakeholders to take on and accomplish important project tasks:

If we received the minutes, she put on there if you said you were going to be doing this, she wrote on it and you kind of had to be accountable for what you said you were going to do.

[K09 – Community Stakeholder]

Outside ideas can be refreshing and stimulating: Community stakeholders, particularly those within the school system, valued the ideas and input of outsiders. They expressed the sentiment
that ideas from outside their organisation or even their community could be refreshing and stimulating, breaking them out of the inertia of their regular routines.

I think the idea, it sometimes help to take the idea from outside… because, um, like, it’s just something that you don’t see. You’re just so used to everything going on but somebody from the outside sees it.

[K09 – Community Stakeholder]

Having an outside stakeholder propose the idea was able to stimulate the initial action necessary to launch the project and create the seed for the early stakeholder network (see Figure 1).

Core people emerge: As the project development proceeded, it was clear that not all committee members played equal roles or took equal responsibility. By project maturity (T2), some community stakeholders played more central roles, taking responsibility for different tasks or actions. By project independence (T3) and maintenance (T4), leadership had settled on four community stakeholders ([K09], [J08], [A04] and [M11]). Other stakeholders saw them as responsible and reliable and began to turn to them more often than to others. From this, a core-periphery structure was evident at all periods of project development, where a core group at each project phase was seen to rely more heavily on each other, and less so on committee members on the periphery.

I would think, ‘it’s time for [an intervention event] in December,’ so I send an email out to all the people on my committee… And then those who answer show up and we do our little jobs and it just goes.

[K09 – Community Stakeholder]

Respondents viewed this as facilitating efficient decision-making:

Everything seemed to run well with the smaller group, the core group of people. It worked well with less of us. With less people involved. Decisions were made quicker.

[K09 – Community Stakeholder]
And this tighter group began to see themselves as taking ownership of the project:

It came down to a core group at the meetings and we did do our tasks, like, being involved in those tasks builds the ownership.

[A04 – Community Stakeholder]

Stakeholders who regularly missed meetings were referred to less and less, even if they held key positions in relation to the project:

And the people, I guess, on the fringe of who we would go to were not part of the meetings.

[A04 – Community Stakeholder]

Alignment of stakeholders’ professional roles with project goals: Community stakeholders expressed the importance of having a project that fit well with the needs of their individual organisations and their own job goals. The composition of the committee included not only those who could make a valuable contribution to the project, but those for whom the project made a valuable contribution to their individual needs and goals. The alignment of professional and project goals created space for engagement. This was accomplished by allowing stakeholders to take ownership in whole or in part of the project in ways that did not conflict with the needs or resources of their own jobs – such as time, and in fact allow them to accomplish their professional goals better than if they did not participate in the project. This can be seen most strongly in those who became central actors as the project evolved, while those for whom the project aligned less well gradually became less involved.

Because the people there, it was their mandate to do these things. They were the right people. We were generating data that was useful for more than just this project. We had something on paper that we could give to the powers-that-be [i.e., community political leaders] for when they decide on things.

[J08 – Community Stakeholder]
I think the reason we had such high buy-in was because these people wanted the data. Once we had the original buy-in from the stakeholders, it wasn’t an issue. It was going to happen.

[M11 – Community Stakeholder]

I felt that as the phys. ed. teacher I needed to be part of it.

[K09 – Community Stakeholder]

[Involve...] people who are in the right positions so that the goals of the project match the goals of their job… and they are very invested in the project if they are the kind of person who is serious about and invested in their work.

[D06 – Community Stakeholder]

Because people were asking questions… and figuring out all the details, it allowed them to take ownership of it. Absolutely. I think the school principals did, and if we didn’t have [D06] from public safety, and [R12] from bussing, and [A04], [K02] and [K09] from the schools taking care of the internal stuff… [Q: it would not have worked?] Yeah.

[J08 – Community Stakeholder]

Although people with aligned professional goals needed to be involved, one respondent expressed the opinion that conflicts in personality among the committee members might not matter:

Also, personality is not a big issue. Personality clashes aren't so bad, because they then bring out the best in others. If someone has a very different opinion, then you try very hard to be clear about your position, or else you compromise.

[D06 – Community Stakeholder]

**Personal qualities of project champion**: Community-based participatory research is predicated on relationship-building, particularly between community and outside stakeholders (Stoeker, 2008). Individual personalities must be able to work well together, and even further, must be able to enjoy their collaboration – particularly in projects spanning long periods of time. All
respondents talked at some length about the personality and commitment of the PI/champion. They felt that she, as an individual, was very well suited to work in their community, displaying interest, respect and friendship toward those with whom she was working. These qualities reflect the personal and cultural humility necessary to bridge the community-university divide (Minkler, 2004a; Tervalon & Murray-Garcia, 1998).

[The PI] worked very hard at working with us, or for us. She always said ‘we’, or ‘can I do this’ or how do you feel?’ or ‘how should I do this?’ and they would be very honest and say 'maybe you should let him do this because it’s his area'.

[J08 – Community Stakeholder]

Her manner was very, like, she was very diplomatic. She was easy to talk to.

[K09 – Community Stakeholder]

The PI/champion not only displayed qualities of cultural humility, but also the gentle persistence needed to sustain efforts at earlier phases before other stakeholders began consistently to take leadership roles:

And she didn’t just back off when things got tough. Like when people weren’t showing up and we were just two people she said: ‘Okay, well, we’ll just keep on going anyway.’

[A04 – Community Stakeholder]

This was perceived as fostering the gradual shift towards the closer inter-community-stakeholder collaboration observed at project maturation (T2):

"It was very gradual, um, switch from [the PI/Champion] being the key person to us starting to, um… interact and network with each other."

[A04 – Community Stakeholder]

**Trust-building:** Meaningful engagement is built on trust between academic and community stakeholders, built over time (Jagosh, et al., 2012). Building of trust comes from repeated
experience over the course of working together. However it rests on a foundation that may start before the actual project even begins. Community members found it easier to trust the non-community champion because they saw her giving and contributing before she asked for community support for her project. Furthermore, the PI/champion continued to contribute and ‘help out around the office’ at more than one organisation throughout the course of the project.

It helped that [the PI/champion] came in earlier as a student and did things and helped out in the community with things that weren’t related to her project. So people began to recognise her. It gave her a face, so if people saw her they would go ‘Ah, her! We know her. She was at the walk, she was ladling out soup over here, she helped at the elders’ lodge…’ People felt very comfortable about her. And she was a very nice person too!

[J08 – Community Stakeholder]

This period of trust-building both preceded and coincided with the project initiation phase (T1). However the PI/champion’s actions and interactions over the entire course of the project served to sustain and maintain the trust necessary to allow the participatory process to continue (Jagosh, et al., 2012; Salsberg, et al., 2014).

**Active use of engagement strategies to facilitate engagement and actively transfer responsibilities to the community:** Finally, community stakeholders specifically discussed ways that the PI/champion facilitated their active engagement in the project, including providing food, facilitating meetings, reminding them to take charge of actions, and intentionally taking a back seat in decision-making. Table 2 summarises participatory engagement strategies and how they were rated by the PI/Champion and applied by the committee. Noted within the table are the comments and quotes from respondents demonstrating the perceived utility of these strategies toward their ability to engage in and take ownership over the school transportation project.
Table 4.2: Participatory engagement strategies (Salsberg, Parry, et al., 2015) and how they were rated by the PI/champion and applied by the STP committee (*On a scale of 0-4, to what extent did you employ, planned or otherwise, any of the following strategies within the STP committee? 0 = not at all; 2 = somewhat or occasionally used strategy; 4 = crucial or frequently used strategy)

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description/Examples</th>
<th>Rating (0-4)*</th>
<th>Comments/Quotes</th>
<th>Social Network Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Form an Advisory Committee</td>
<td>A composition of researchers, the intended users of the research and/or representatives of community organisations • Advisory committees allow for inclusion of all viewpoints throughout the research process and joint development of dissemination strategies and action plans</td>
<td>4</td>
<td>• Committee became the main site of engagement and action planning for the project • Committee membership can change over time • Even when membership is constant, roles evolve</td>
<td>• Creates the focus for structured interaction among project stakeholders • Committee membership can change over time • Even when membership is constant, roles evolve</td>
</tr>
<tr>
<td>Develop a Research Agreement</td>
<td>Before the research begins, clearly spell out researchers and partner roles and responsibilities, outline how decisions will be made, and set out what to do if conflict arises. • Research agreements may also include plans for data ownership and control, interpretation of data, and procedures for resolving disagreement over research results • Developing agreements is seen as a trust-building exercise</td>
<td>3</td>
<td>• Committee terms of reference served as the working agreement between academic and community stakeholders • Committee also functioned under the overall auspices of the KSDPP Code of Research Ethics, governing community-university collaboration (see <a href="http://www.ksdpp.org/elder/code_ethics.php">http://www.ksdpp.org/elder/code_ethics.php</a>)</td>
<td>• Research agreement defines the terms of reference within which the committee functions • KSDPP Code set a foundation for valuing the leadership of community stakeholders</td>
</tr>
<tr>
<td>Use of Group Facilitation Techniques</td>
<td>Can be both a formal and an informal process to ensure meaningful involvement and participation of partners</td>
<td>4</td>
<td>• PI served as group facilitator. • PI circulated meeting documents ahead of time • Special workshops were convened around certain planning and development topics.</td>
<td>• Fostered collaboration • Increased community stakeholders’ interaction by helping to create and</td>
</tr>
</tbody>
</table>
| Hire Staff from the Community of Study | • Formal facilitation includes focus groups, workshops, and nominal group techniques  
• Informal techniques include circulating agendas ahead of time, small group work, and one-on-one informal discussions. | • Use of workshop questions as meeting facilitation points | • Sustain linkages between stakeholders from various community organisations, such as between the schools, and between schools and Community Protection. |
|---|---|---|---|
| | • Hiring local persons as project staff recognizes community members’ abilities to establish good relationships with individual participants for recruitment and ongoing data collection  
• Projects hire well-respected community members as a “community champions”, field coordinators, intervention staff, interviewers, group co-facilitators, as well as for data collection and analysis. | 0 | • Intended to but never had funds during planning and development phase  
• The community committee worked, but unpaid  
• They knew once they would take it over and they could hire people |
| Ensure Frequent Communication | • Communication between partners through regular group meetings to keep all partners updated on progress, changes in procedures and as a way of discussing concerns and challenges  
• Other methods include telephone calls to partners who missed meetings to bring them up-to-date, and prompt circulation of meeting minutes and newsletters | 4 | • Regular committee meetings, with detailed minutes of previous minutes circulated before each meeting  
• Frequent email communication between meetings  
• Regular face-to-face interaction with certain committee members, particularly KSDPP staff  
• Fostered collaboration  
• Increased opportunities for stakeholder linkages and interaction |
| Researchers need to make active efforts to learn about the | • Take time at the beginning to get to know one another and keep frequent contact with community | 4 | • PI/Champion “hung around” KSDPP  
• Volunteered to help out around the office and at KSDPP events  
• Fostered the foundation of trust for the community-PI/champion relationship |
| participants and their context | ● Spend time in the community (e.g. attend significant community events)  
● Attend community-organized educational sessions or go on a community tour  
● Arranging retreats with community members  
● Organizing structured workshops with community members, as well as having informal conversations with them  
● Conducting formal interviews with community organisations  
● Was given tour of community and introduced to important people from the project  
● Helped with school interventions  
● Also hung out with some individual community members at their offices.  
● Helped out at Community Protection when they were undertaking consultations on pedestrian crossings. |
| --- | --- |
| Facilitate community involvement | ● Be flexible with partners’ work schedules and negotiate with their employers for study-related tasks  
● Utilize community contacts for recruitment of marginal community members or make use of ‘snowball’ referral  
● Reach out to places frequented by community members (e.g. schools)  
● Adopt group facilitation techniques  
● Approach partners individually for input away from larger groups  
● Understand community priorities and culture  
● Speak frankly and agree to disagree  
● Include representation in the project both from those affected directly by the research and the community as a whole  
● Always provided meals for committee meetings “She provided food (laughs). You know, providing food was, like, an incentive. Especially at the dinner time. Because, you’re rushing and you know somebody’s going to actually feed you.” [K09]  
● Community stakeholders would pick the times for meetings and action events, such as data collections  
● PI/Champion made it as easy as possible for community stakeholders to participate, including:  
  ○ emailing committee members well in advance with notes, agendas and documentation  
  ○ planning next meeting at the end of current meeting  
  ○ Holding lunchtime meetings fit stakeholders’ schedules best  
“We considered alternating meetings between schools, but because of space issues, stayed at one school.” [PI]  
“Because of the convenience of being at the school; because it was at lunch hour; because it was brief; she would bring everything.” [J08]  
● Fostered collaboration  
● Increased community stakeholders’ interaction by helping to create and sustain linkages between stakeholders from various community organisations, such as between the schools, and between schools and Community Protection.  
● Created opportunities for community stakeholders to take on leadership roles  
● Therefore facilitated the shift from academic leadership at project initiation (T1) to community leadership (T2-T4) |
| Build community capacity / provide research training | • Evaluate the partnership frequently to elicit partners’ feelings | “Time issues with the administrators. You’re dealing with busy people. Not only that, we’re dealing with heads of departments where we only have a certain period of their attention span.” [M11] | • Made sure data collection times worked with their schedules and school events like harvest festival and winter carnival | • Opportunities for committee members to be directly involved in research activities “The committee coordinated and administered an action partnership survey to determine the suitability of the partners involved for the health promotion goals. They were they given the opportunity to participate in interpreting the results of the survey if they wanted. For items they rated lower, we discussed how we could improve them. For example, time: attendance at meetings. If you are not attending, maybe you aren’t contributing. But are there other ways they can contribute, via email, phone, make sure they feel engaged and contributing meaningfully, and that the others knew that too so that they didn’t feel bad that they were there while some others weren’t.” [PI] |
| • Utilize and develop community resources and support networks when conducting research | • Committee members learned new planning skills built around topics that emerged from the STP committee, but which were relevant to their regular jobs. | • Over the course of the STP project, inter-organisational cohesion grew as closer working relationships developed between stakeholders. | • Committee members and their organisations gained new knowledge about topics such as safety and sidewalks that they needed both for the STP project and for their own jobs. | • Learn the process of creating an Active Transportation Plan “We did more work than we had to, but they then understood the kinds of tools they needed to use to develop the project, but also could use to create |
| • Train community members as co-facilitators of research activities | 4 | • As community capacity developed necessary competencies, they were more able to take on project leadership roles independent of the PI/champion | • Lead to their ability to lead the project in her absence at project independence (T3) and sustain these roles at project maintenance (T4) | • Have community members critique pre-existing research |
| • Involve the community in needs assessment and planning processes | • Over the course of the STP project, inter-organisational cohesion grew as closer working relationships developed between stakeholders. | • Committee members and their organisations gained new knowledge about topics such as safety and sidewalks that they needed both for the STP project and for their own jobs. | • Learn the process of creating an Active Transportation Plan “We did more work than we had to, but they then understood the kinds of tools they needed to use to develop the project, but also could use to create |
| • Provide training to community about health issues | • Committee members learned new planning skills built around topics that emerged from the STP committee, but which were relevant to their regular jobs. | • Over the course of the STP project, inter-organisational cohesion grew as closer working relationships developed between stakeholders. | • Committee members and their organisations gained new knowledge about topics such as safety and sidewalks that they needed both for the STP project and for their own jobs. | • Have community members critique pre-existing research |
| • Use training sessions to get community perspective on these issues | • As community capacity developed necessary competencies, they were more able to take on project leadership roles independent of the PI/champion | • Lead to their ability to lead the project in her absence at project independence (T3) and sustain these roles at project maintenance (T4) | • Have community members critique pre-existing research |
| Form advisory committee sub-groups | • Set up a sub-committee of the advisory committee to review all partnership evaluation results and make recommendations to the overall advisory committee  
• Sub-group committee can facilitate data analysis and interpret results  
• Present and discuss results with community partners to facilitate interpretation  
• Researchers and community members can analyze data independently and present their interpretations  
• Engage in open, interactive analysis with community partners  
• Adopt a research agreement at the beginning outlining community involvement in results interpretation | 4 | • Formed sub-groups for workshop meetings in the action planning phase. Split up by school, with the principal from each school being the leader for their group. So they could plan for their own school.  
“Otherwise, always worked together so they weren’t reinventing the wheel, and they could share resources and ideas.” [PI]  
• Sub-group activity mostly took place during project development (period between T1 and T2)  
• School-specific sub-committees emerged between maturation (T3) and maintenance (T4), but did not appear to fragment the core group that still included the principals from each school |
| Interpretation, data ownership and dissemination | • Community partners can communicate their own interpretation of study data along with researcher study publications  
• Adopt a no veto rule, meaning that neither researchers nor community partners can block a publication with results | 4 | • Information and results were constantly fed back to the whole committee for discussion and interpretation  
“They were shocked and excited about the traffic stop data [many rolling stops] and really wanted to move on it.” [PI]  
• For certain activities, PI/Champion worked with specific members to score and interpret certain data before then discussing with entire committee  
“For the walkability assessment, [the public safety stakeholder] and I determined the routes together.  
• Participatory interpretation of results served two specific network roles:  
  ○ Served to further engage stakeholders interest and therefore participation  
  ○ Fostered role change as those engaged in interpretation emerged as knowledge leaders |
- Spell out this process in a written researcher agreement before it arises.
- Researchers can be guardians of the data during the project, but transfer data control to community after the project ends.
- Community obligation is to allow researchers the right to ongoing data analysis.
- Develop dissemination strategy outlining community involvement.
- Include non-academic partners as co-authors/co-presenters on manuscripts/abstracts.
- Disseminate results through local organisations, newspapers, media, and community-based practitioners.
- Jointly publish a community newsletter with results included.
- Make use of local cultural mechanisms, such as street theatre.
- Circulate a summary report to community members and/or have feedback/discussion sessions.
- Organize debriefing sessions with a luncheon or gala celebration.
- Discuss publication drafts with the community before submission.

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we walked the routes together, as we walked them we scored them and sometimes we had different thoughts about ratings, so we would discuss that and come to a consensus on how we should rate it.”

[P1]

“Once everything was entered into excel, we did a simple set of frequencies then, based on our experiences of walking certain areas, we developed a set of routes. Then we discussed these with the whole STP committee so that they could have time to look at it and interpret it, which made them decide they needed to know where the kids actually lived, so that led to the whole mapping exercise.”

[P1]
One significant strategy area was not captured in Table 2 since it did not emerge from the review of frequently-used engagement strategies (Salsberg, Parry, et al., 2015). The PI/champion took it upon herself to state and restate at regular intervals over course of the project that this was “your project, not mine,” and that the community stakeholders were the ones who ultimately would have to make it work. She did this intentionally to assure that the committee was not lulled into the comfortable state of relying on her to do work that they would ultimately need to do themselves once she had completed her PhD and was gone. Every respondent commented on this, feeling that this was significant in keeping them engaged, even at times when they felt the PI/champion should have continued to present strong leadership.

She kept kind of mentioning that she wouldn’t be there the whole, like forever. This isn’t her project. It’s our project.

[A04 – Community Stakeholder]

[The PI/champion] set up tasks for everyone to do. She didn’t let them let her do all the work.

[J08 – Community Stakeholder]

She really wanted to take that back seat, maybe a little too early in my opinion. But with programs like this uh you always need leadership.

[M11 – Community Stakeholder]

Kind of, like, telling us to do it instead of her. So she was giving us that bit of ownership.

[A04 – Community Stakeholder]

I knew we can’t just leave [the PI/champion] out there to do all this by herself. It wasn’t going to be her project.

[A04 – Community Stakeholder]
She didn’t want to interfere obviously, which was fine but you know she had to be the champion for I think maybe a little bit longer than she expected.

[M11 – Community Stakeholder]

KSDPP told her: you’re the champion, you have to act like it. You have to educate people and they then can take it over.

[M11 – Community Stakeholder]

This continuous prompting by the PI/champion can be seen as an intervention on the network, intended to shift knowledge leadership towards community stakeholders. This intervention was ongoing from the project’s initiation (T1) through its maturation (T2).

Discussion

Participatory research is an approach to co-creation of knowledge leading to action or change among a community of individuals. Despite PR often being described or defined as a methodology, particularly within more qualitative or constructivist research paradigms (Jordan, 2003; Schwandt, 2007), it is important to situate it as an approach to co-governance that encompasses whichever design or methodology is appropriate to answering the research question at hand (Green, et al., 1995). This understanding liberates PR practitioners from the confines of standardized application, allowing them to explore, adopt and adapt strategies that are contextually appropriate and most likely to lead to meaningful engagement and ownership among these community stakeholders. Context, in this sense, holds broader meaning than simply geography, history or culture. It refers to the mix of the particular stakeholders, their needs, goals and personalities, as well as other more intangible qualities of the partnership. Furthermore, the way
stakeholders link to interact and the structure of this interaction can help determine which engagement strategies are appropriate or will likely foster community ownership.

The KSDPP STP project, under the guidance of its non-community PI/champion, endeavoured to apply such strategies as they deemed appropriate for their setting, and for the particular mix of stakeholders who were involved. The thematic categories that emerged from this inquiry were: strong champion; outside ideas can be stimulating; emergence of core people; alignment of stakeholders’ professional roles with project goals; involving the right people; personal qualities of champion; and trust-building. These themes can be seen as an expression of the intangible partnership qualities that form a critical part of the context in which the identified participatory engagement strategies were enacted. These furthermore can be seen to form the baseline conditions on which the structural relations (i.e. social network) among the stakeholders are built and evolve.

Participatory research tends to attract academic researchers who are naturally predisposed to allowing the community to take the lead, possessing the professional and cultural humility required to intentionally divest themselves of power that traditionally falls to the principal investigator (Minkler, 2004b; Salsberg, et al., 2014). This project was no exception, with a PI/champion who presented herself and her idea with the very intention that the community would take it over and make it their own. To this end, the identified participatory engagement strategies were conscientiously selected and enacted to maximise this eventuality. Furthermore, they were enacted within the context of a long-standing overarching research platform (KSDPP) that values and supports community ownership over the research process and has the capacity and infrastructure
necessary to actively engage with outside academics without jeopardising community self-determination. This capacity includes having a dedicated community intervention staff and a detailed code of research ethics by which all partnering academic researchers are bound (Macaulay et al., 2006).

While the PI/champion and indeed the core committee members were determined to follow through with the development and deployment of their intervention program, they perceived that the enacted participatory engagement strategies did have a positive effect on facilitating their meaningful engagement and ultimately on allowing the core community stakeholders to ultimately take ownership of the project. This is particularly true with the emergence of key stakeholders in each of the two intervention sites (the elementary schools), specifically [K09] and [A04]. Furthermore, interaction over the course of the project led to a sustained increase in the level of collaboration between these two stakeholders and their respective schools, as was commented on by each of these two stakeholders, and by the PI/champion; and furthermore shows up in the structural analysis of the network, where they were both members of the core group of dense interactivity at T3 and T4. The principal from one of the schools [A04] felt more excited and engaged as the project developed, stating “Once I know something’s gonna happen, I get more involved” [A04 – Community Stakeholder]. While the key stakeholder at the other school [K09] went as far as to create an ad hoc in-school planning committee to run the intervention and network with [A04] at the other school.

**Implications for the science and practice of participatory research:** The review of participatory engagement strategies (Salsberg, Parry, et al., 2015) highlighted knowledge gaps in identifying certain relational aspects of participatory research. Among
these were the issue of power dynamics and ways of decentralizing decision-making, and ways to address the equitable sharing of resources between community and researchers. The review also recognized that more personal or human aspects of partnerships have not been adequately addressed, including the time needed to consolidate partnerships, personality clashes, and institutional cultures. Our current findings highlighted the significance of the PI/champion’s personality, particularly her affability, cultural humility and determination to have the community take the lead. These personal qualities were perceived to be at least as significant as the adoption of engagement strategies, and therefore can be seen to fill the gap in understanding how participatory research strategies foster community ownership.

Oetzel et al. (2014) explored the construct validity of properties of Wallerstein’s (Wallerstein & Duran, 2010) community-based participatory research conceptual model. In their exploration they identified influence and power dynamics, participatory decision-making, leadership and resource management, as dimensions of group dynamics that underpinned successful participatory research. Our social network analysis was well suited to the task of describing the partnership’s group dynamics, and our qualitative findings highlight the role of participatory engagement strategies in shifting leadership, influence and decision-making over the course of a participatory project. Both Oetzel and Jagosh et al. (Jagosh, et al., 2012) identify mutual trust-building as a key mechanism determining successful participatory partnerships. This trust, particularly community members’ trust in the values and intentions of the academic, non-community partners is critical in creating culturally and logistically appropriate research, enhancing the capacity of the community partners, and sustaining interventions and outcomes past the end of the
original project (Jagosh, et al., 2012). Our findings indicate that strategies that facilitated community involvement in planning and decision-making successfully led to the creation of an intervention program that was culturally appropriate and relevant to the needs of individual stakeholders and their organisations, and has been sustained to date since the departure of the original project PI/champion. The community’s perception of the PI/champion’s commitment to the project and determination to take a back seat to community leadership, fostered the trust that led to these outcomes.

**Implications for the science and practice of social network analysis:** Social network analysis has provided an impressive array of tools and models for understanding the social-relational dynamics of how people behave and how opinions, ideas and innovations spread. These methods have been able to model how network variables have led to various outcomes. However, just as randomised control trials are very good at uncovering causal links but incapable in-and-of-themselves of explaining why they happened or what they mean to those affected, social network analysis is less able to explain the motivations of individual actors that lead to network outcomes. A social network perspective focuses on relationships, raising concerns about the perception and interpretation of structure and agency in terms of influencing behaviour and how these are brought about (Araujo & Easton, 1996; Jack, 2005). The application of qualitative methodology to better understand the reasoning behind and implications from social network outcomes can bring explanatory power to network analysis from the perspective of those within the network, making it more suitable for action research where participants must have confidence in methods, results and meaning in order to take action for change.
**Limitations:**

This study’s focus on engagement strategies from leading participatory practitioners limited the emphasis to well established participatory processes. However, broadening the interview focus to allow respondents to discuss other actions and events led to a full discussion of participatory values that went beyond the documented strategies and were perceived by participants as equally important to successful outcomes. Limiting the interview sample to central stakeholders may have neglected opinions from stakeholders who did not become more central over the course of the project. However the focus of this study was to understand how enacted engagement strategies were perceived to have successfully fostered community ownership. Furthermore, less central stakeholders were not able to make themselves available for interview within the limited time constraints of this study. Further study should look at stakeholder roles and the strategies that maintain community engagement and ownership over a longer term than was afforded by this study. It should also investigate the perceptions of those stakeholders who did not become as engaged to understand the shortcomings of these identified strategies. Finally, using this as a case study illuminates how a stakeholder network may evolve under similar contextual circumstances and under the influence of similar participatory strategies. It may therefore be useful to others as a guide for designing participatory intervention processes within their own projects.

**Conclusion**

This qualitative component forms the concluding chapter to an overall social network examination of how participatory research builds community ownership over
research processes and results, ultimately leading to community self-determination over
the creation knowledge and its application to address community-identified issues. The
qualitative results serve to contextualise the results of the social network analysis,
providing explanation to the observed shift in influence within the network over the four
sampled time periods. The results from the overall social network study provide a robust
illustration of how and why ownership shifts toward community stakeholders over the
course of a project that had been initiated by a non-community, academic researcher. The
findings from this study, particularly the lessons learned from interviewing the academic
and community stakeholders, may be applied to the selection and application of
participatory engagement strategies in other settings where end-user engagement and
ownership is crucial to the sustainability of intervention efforts. This is particularly true
for community-based research, public health intervention research, as well as clinical
implementation research where successful outcomes require understanding the complex
interpersonal relationships that lead to sustained practice change.
Chapter 7

General Discussion

Integrated summary of the key findings

Participatory research is an approach to creating knowledge intended to generate action for change. This change may be systems change, improvement of services, policy, practice, or individual health behavior. In all cases, however, it is about the actions of people within that change; and participatory research is founded on the concept that those individuals need to be the drivers of their own change. Through this dissertation research we have attempted to understand the process of how people come to take ownership over the issue at hand, and the research which creates the knowledge and products they require for action and change.

To better understand this ownership-building process, this dissertation undertook the following objectives: 1) to document best-practice participatory engagement strategies as applied by leading participatory researchers; 2) to observe an active participatory intervention project through its lifecycle to describe changes in project ownership; and 3) to describe stakeholders’ perceptions of how participatory engagement strategies and other actions over the course of the project led to the described changes in ownership.

By following the evolution of the KSDPP School Travel Planning project, we have demonstrated that ownership, as measured by centrality in knowledge leadership among its members, did in fact change, significantly shifting influence from the academic PI/champion to emergent community leaders. This change in influence was sustained
after the PI/champion left the project. Furthermore, we were able to show that this shift in influence was perceived by the committee to have been fostered by the enactment of participatory engagement strategies; by engaging stakeholders who found a natural fit between what the project was generating and the needs of their own jobs; as well as by the values, actions strong initial leadership of the PI/champion. We conclude that in cases such as this where the community-university partnership project is initiated by the outside academic researcher, the combination of strong initial leadership by an academic champion with the appropriate personality for partnered research, coupled with the conscientious enactment of strategies intended to engage and empower the community members, will lead to sustained shift to community ownership.

Limitations and future research

Participatory research strives to create knowledge and action for long-term sustained change. One key limitation of this study was that it was only able to sample the stakeholder network for a limited period of time after the departure of the academic PI/champion. Therefore, although community ownership was sustained for the early deployment period without the PI/champion, with the present data we cannot determine that it will be sustained in the long run. The PR conceptual framework would predict that with the actions taken to-date, it will be sustained; and indications at the time of thesis submission (6 months following the T4 data) are that the STP project has in fact been sustained, with regular walking school bus days at both participating schools, growing student participation numbers and, significantly for this thesis, the community stakeholders identified as leaders at T4 maintaining their roles as project champions.
Future research will include further measurement at later dates to track long-term change and maintenance in community ownership, diffusion of the STP intervention to other schools in the community, and overall impact of the STP intervention on children’s levels of physical activity.

This research took place within an environment of atypically high baseline community engagement. KSDPP, as a successful, longstanding community-based participatory research project has achieved a high degree of community ownership over health promotion research and intervention. This may be perceived to have biased any attempt to measure how PR strategies impact the evolution of community ownership. However, the high level of pre-existing engagement and ownership is primarily to be found within KSDPP and its representative Community Advisory Board; and although other community organisations have been engaged in the past, the degree of ownership they take over individual projects has varied and some individual efforts have even failed. Therefore we do not feel that the context has effected the results of this present study looking at multi-stakeholders engagement and ownership. Success in engaging with community organisations, such as the schools or other public departments has depended on several factors – many of which have been explored in the strategies and events discussed in manuscript 4.

As mentioned in the network chapters, there are many environmental influences on both the building of community ownership and the successful implementation of community-based interventions; social relationship is but one, albeit one that has received growing attention. By focusing on inter-stakeholder relations, we are not examining other aspects such as historical context, resource availability, encompassing physical and
political environments, or other important factors. However, understanding the social dynamics of partnered research can serve as a basis for later examination of how these other influences are accessed and applied within a multi-stakeholder community setting.

Although the qualitative phase of the study attempted to explore the stakeholders’ perceptions of how and why ownership shifted over the course of the project, due to limitations in time and resources, as well as the limited availability of certain project stakeholders, we were not able to collect data from all members who were involved in the project. For this reason, the methodological decision was made to limit the interview sample to those stakeholders identified as most central during the network analysis phase of the study. On the one hand, these stakeholders were best situated to describe what worked and why. However, interviewing the remaining stakeholders who were deemed less central by their peers could have provided invaluable insight into why these stakeholders did not step into stronger leadership roles. For some, this is because they were academic, non-community stakeholders, which the PR process was actively moving ownership away from. However the remaining three community stakeholders who were not interviewed could have provided useful insight, had they been available for interview. Future research could more fully explore community ownership by examining these and other cases where community stakeholders did not become more fully engaged or step into key leadership positions.

Finally, the critical review of participatory engagement strategies undertaken at the beginning of this research was, for methodological reasons, limited to records published between 1995 and 2009. These dates represent the release of the original ‘Green’ guidelines for assessing PR projects and, latterly, the first application of the
revised and reliability tested ‘Mercer’ guidelines. This decision was made in order to impose a limiting factor on the number of possible documents for retention, in a way that would be consistent with the content of the tool being used to abstract data from the records. Because of this, it is possible that later strategies not covered in the retained records could have been missed. However, a re-running of the original CiteSpace bibliometric analysis in 2012 (when the review phase of the study was being completed) resulted in the same four authors possessing the highest centrality scores, as per the original search protocol. Then a brief scoping of these four authors revealed no new strategies that were not identified in our review. As stated in the review manuscript, our results consist of strategies that could be tested and explored in greater detail through a larger systematic review, which may include more detailed descriptions of applied strategies for planning and sustaining PR partnerships. Such a systematic review might be able to rank these strategies in terms of their effectiveness in different contexts, which would first require further basic research into the efficacy of particular participatory strategies and their effectiveness in generating and translating new knowledge into action.

**Strengths and contributions of the thesis work to the field of study**

This study has implications for creating community-university teams and designing participatory processes that are intended to create action and change for individuals and their contexts. If participatory research and integrated knowledge translation are founded on fostering end-user ownership over the research, then strengthening our understanding of how this takes place allows for more appropriate participatory processes to be designed and implemented. This applies to community-
based research, public health intervention research, as well as to clinical implementation research and all other areas where strong end-user engagement is crucial to creating meaningful and sustainable change.

We have also demonstrated that social network analysis is a useful and community-appropriate means of longitudinally measuring change in team member roles over the course of a participatory research project. Social network analysis may thus serve as a useful method for ongoing partnership evaluation during the course of a participatory project. Furthermore, the qualitative component, which is the final piece missing from most social network analyses, allows the members themselves to interpret the meaning of the network results. Not only does this help contextualize the findings for the study at hand, but provides a methodological contribution to network analysis by documenting the value of member-interpretation. This is of paramount importance in participatory research, where the community members themselves must understand and accept the meaning of the results for them to take action.

The systematic review undertaken at the beginning of this research represents the first use of the Reliability Tested Guidelines for Assessing Participatory Research Projects, developed by Mercer, Green, et al., to identify participatory strategies that support engagement and ownership. In this respect, it also represents the first use of these Guidelines as an extraction/abstraction template for published data. Therefore, it has contributed to the methodology of systematic review, particularly for mixed-studies reviews by documenting and discussing its usage as an extraction/abstraction tool.
Suitability of Research for a Doctoral Dissertation

The research undertaken for this dissertation was founded on the development of skills and competencies in a number of areas. These included participatory research, systematic review, social network analysis, and qualitative analysis. Furthermore, competencies were developed early on in my doctoral studies in the areas of health promotion and knowledge translation (representing two further areas of my comprehensive examinations). Although these did not feature as directly as originally planned in the research undertaken for this dissertation, they played an important role in framing how I approached my topic by situating this work within the frame of health equity and self-determination over knowledge production and application. In total, I feel that the sum of these scholarly areas form a sufficient range of academic competencies to warrant a PhD.

In remaining true to the philosophy of participatory research, many aspects of this dissertation were undertaken in collaboration with others who were as interested in the results as I was. A balance needed to be struck between the need of the student to demonstrate independent scholarship, and the participatory imperative to allow for equitable contributions from other stakeholders involved in the research. In one sense, this is no different from any thesis work where the student receives significant guidance from his/her supervisor and committee members over the course of developing and undertaking their research project. In this PR however, the ‘guidance’ comes from a wider range of non-researchers who have a stake in the study. For the purpose of this exercise, however, it was understood by all stakeholders that the candidate needed to demonstrate intellectual leadership over the content of this study. Therefore, although the
KSDPP Community Advisory Board made comments and suggestions as to the study protocol, they did not significantly alter it or contribute to its execution.

In the end, the manuscripts produced represent a significant contribution to our understanding of the participatory research process, while making methodological contributions to the tools of both social network analysis and systematic review. Although the work was collaborative with important contributions made by both community and academic colleagues, as a doctoral student I maintained sufficient independent control over the entire process to claim intellectual ownership of its products.
References:

Active Healthy Kids Canada. (2014). *Is Canada in the running? How does Canada stack up against 14 other countries on physical activity for children and youth?* Toronto: Active Healthy Kids Canada.


Kanien'kehaka (Mohawk) children 6 to 11 years old: 8-year results from the Kahnawake Schools Diabetes Prevention Project. *Pediatrics, 115*(2), 333-339.


APPENDIX I

Ethical Approval

Queens General Research Ethics Board (GREB) approval and amendment letters
January 28, 2013

Mr. Jon Salsberg, Ph.D. Candidate
School of Kinesiology and Health Studies
Queen’s University
28 Division Street
Kingston, ON K7L 3N6

GREB Ref #: GPHE-138-13; Romeo # 6007664
Title: "GPHE-138-13 Mapping Social Networks for Translating Knowledge from Community-Based Participatory Research into Policy and Practice Change: The Impact of the Kahnawake Schools Diabetes Prevention Project"

Dear Mr. Salsberg:

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled "GPHE-138-13 Mapping Social Networks for Translating Knowledge from Community-Based Participatory Research into Policy and Practice Change: The Impact of the Kahnawake Schools Diabetes Prevention Project" for ethical compliance with the Tri-Council Guidelines (TCPS) and Queen's ethics policies. In accordance with the Tri-Council Guidelines (article D.1.6) and Senate Terms of Reference (article G), your project has been cleared for one year. At the end of each year, the GREB will ask if your project has been completed and if not, what changes have occurred or will occur in the next year.

You are reminded of your obligation to advise the GREB, with a copy to your unit REB, of any adverse event(s) that occur during this one year period (access this form at https://eservices.queensu.ca/romeo_researcher/ and click Events - GREB Adverse Event Report). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example you must report changes to the level of risk, applicant characteristics, and implementation of new procedures. To make an amendment, access the application at https://eservices.queensu.ca/romeo_researcher/ and click Events - GREB Amendment to Approved Study Form. These changes will automatically be sent to the Ethics Coordinator, Gail Irving, at the Office of Research Services or irvingg@queensu.ca for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Yours sincerely,

John Freeman, Ph.D.
Professor and Acting Chair
General Research Ethics Board

cc: Dr. Spencer Moore and Dr. Ann Macaulay (McGill University), Faculty Supervisors
    Dr. Spencer Moore, Chair, Unit REB
    Josie Birchall, Dept. Admin.
December 10, 2013

Mr. Jon Salsberg
Ph.D. Candidate
School of Kinesiology & Health Studies
Queen's University
28 Division Street
Kingston, ON, K7L 3N6

Dear Mr. Salsberg:

RE: Amendment for your study entitled: GPHE-138-13 Mapping Social Networks for Translating Knowledge from Community-Based Participatory Research into Policy and Practice Change: The Impact of the Kahnawake Schools Diabetes Prevention Project; ROMEO# 6007664

Thank you for submitting your annual renewal form and amendment requesting to change the recruitment process as follows:

1) To begin recruiting with the Kahnawake community advisory board;
2) To continue to recruit mainly from the Kahnawake School Active Planning Committee; and
3) To recruit through other appropriate community organizations as necessary.

By this letter you have ethics clearance for these changes.

Good luck with your research.

Sincerely,

Joan Stevenson, Ph.D.
Chair
General Research Ethics Board

c.: Dr. Spencer Moore and Dr. Ann Macaulay, Supervisors
April 11, 2014

Mr. Jon Salsberg
Ph.D. Candidate
School of Kinesiology and Health Studies
Queen’s University
28 Division Street
Kingston, ON, K7L 3N6

Dear Mr. Salsberg:

RE: Amendment for your study entitled: GPHE-138-13 A Social Network Perspective on Ownership and Self-Determination in Participatory Research; ROMEO# 6007664

Thank you for submitting your amendment requesting the following changes:

1) To change the title from “Mapping Social Networks for Translating Knowledge from Community-Based Participatory Research into Policy and Practice Change: The Impact of the Kahnawake Schools Diabetes Prevention Project” to “A Social Network Perspective on Ownership and Self-Determination in Participatory Research”;

2) To change the research questions, design and methodology as follows:
   (a) Revised Consent Form (v. 11 April 2014);
   (b) Revised Letter of Information (v. 11 April 2014);
   (c) Revised Protocol (v. 09 April 2014);
   (d) Revised Questionnaire (v. 09 April 2014);
   (e) Revised Interview Guide (v. 09 April 2014).

3) New Kahnawake community ethics approval certificate to be sent to GREB upon receipt.

By this letter you have ethics clearance for these changes.

Good luck with your research.

Sincerely,

Joan Stevenson, Ph.D.
Chair
General Research Ethics Board

c.: Dr. Spencer Moore and Dr. Ann Macaulay, Faculty Supervisors
December 23, 2014

Mr. Jon Salsberg
Ph.D. Candidate
School of Kinesiology and Health Studies
Queen's University
28 Division Street
Kingston, ON, K7L 3N6

GREB Romeo #: 6007664
Title: "GPHE-138-13 A Social Network Perspective on Ownership and Self-Determination in Participatory Research"

Dear Mr. Salsberg:

The General Research Ethics Board (GREB) has reviewed and approved your request for renewal of ethics clearance for the above-named study. This renewal is valid for one year from January 28, 2015. Prior to the next renewal date you will be sent a reminder memo and the link to ROMEO to renew for another year.

You are reminded of your obligation to advise the GREB of any adverse event(s) that occur during this one year period. An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours. Report to GREB through either ROMEO Event Report or Adverse Event Report Form at http://www.queensu.ca/orr/researchethics/GeneralREB/forms.html.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example you must report changes in study procedures or implementation of new aspects into the study procedures. Your request for protocol changes will be forwarded to the appropriate GREB reviewers and/or the GREB Chair. Please report changes to GREB through either ROMEO Event Reports or the Ethics Change Form at http://www.queensu.ca/orr/researchethics/GeneralREB/forms.html.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Yours sincerely,

Joan Stevenson, Ph.D.
Chair
General Research Ethics Board

c.: Dr. Spence Moore and Dr. Ann Macaulay, Supervisors
    Dr. Brendan Gurd, Chair, Unit REB
March 20, 2015

Mr. Jon Salsberg
Ph.D. Candidate
School of Kinesiology and Health Studies
Queen's University
28 Division Street
Kingston, ON, K7L 3N6

Dear Mr. Salsberg:

RE: Amendment for your study entitled: **GPHE-138-13 A Social Network Perspective on Ownership and Self-Determination in Participatory Research; ROMEO# 6007664**

Thank you for submitting your amendment requesting the following changes:

1) To add one survey instrument (questionnaire) to the qualitative aspect of the study;
2) Questionnaire (v. 2015/03/20);
3) Article (v. 2015/03/20).

By this letter you have ethics clearance for these changes.

Good luck with your research.

Sincerely,

Joan Stevenson, Ph.D.
Chair
General Research Ethics Board

c.: Dr. Spencer Moore and Dr. Ann Macaulay, Supervisors
Kahnawake Schools Diabetes Prevention Project (KSDPP) Community Advisory Board (CAB) approval of protocol
KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT
Center for Research and Training
P.O. Box 989, Kahnawake Mohawk Territory
Quebec, Canada J0L 1B0

"Daily Physical Activity, Healthy Eating Habits & A Positive Attitude Can Prevent Diabetes"

Review and Approval Process for Ethically Responsible Research
Certificate of Approval

The Community Advisory Board of the Kahnawà:ke Schools Diabetes Prevention Project has granted approval:

For the Research Proposal Project entitled:

A Social Network Perspective on Ownership and Self-Determination in Participatory Research

Proposed by:

Name of Researcher: Jonathan Salsberg
Academic Supervisor: Spencer Moore, Ph.D.
Department: School of Kinesiology and Health Studies
Institution: Queen's University
Month and Date of CAB Approval: May 20, 2014

Confirmed by the CAB Executive Committee:

Signature: [Signature]
Name: EVA JOHNSON
Date: July 17, 2014
APPENDIX II

Consent Forms
Dear KSDPP Member:

You are invited to participate in a study aimed at understanding how strategies and practices undertaken within the Kahnawake Schools Diabetes Prevention Project (KSDPP) support community ownership and self-determination over research.

Summary of Study and Procedures:

A community’s ability to create its own knowledge, practices and interventions is founded on its ownership and control over the research process. The aim of this study is to explore the processes and strategies employed within community-based participatory research that help increase community ownership and self-determination. Using social network analysis techniques, we will examine your active participatory project and ask how influence and decision-making within your stakeholder committee evolved over the course of the project. Then, we will explore strategies that were employed within the partnership to assure community ownership and control; and from your point of view, ask how responsible these strategies were for fostering community ownership.

You are invited to participate in this study.

1) We would like you to answer a brief questionnaire asking you who you turn to for information and guidance concerning your School Travel Planning project. You will be asked to complete this 5-10 minute questionnaire at 4 intervals over the course of this study.

2) We would also like you to participate in a semi-structured interview in order to discuss the evolution of your committee, and how certain strategies have helped foster community ownership over the course of your project. The interview will come toward the end of the study, and will take 30-60 minutes.

Use of research results

The main reason for collecting this information is to better understand the way that participatory strategies employed by KSDPP help assure that control over research remains in the hands of the community. By better understanding the way these strategies work, KSDPP will be better able to plan partnered research strategies with outside (university) researchers that helps create action for change that will benefit Kahnawake:rnon, the wider Indigenous community, and the rest of Canada.

In order to address the stated goal, information from questionnaires and interviews will be analysed using appropriate social network analysis methods (a mathematical means of describing the pattern of
ties between people and organisations within a social setting) and qualitative methods (a way of understanding the meaning or value placed on these ties by the individuals within the social setting). Findings from this study will be reported first to the KSDPP Research Team and Community Advisory Board; then will be shared other community stakeholders including other organisations and individuals through presentations, meetings and community publications. Findings will be shared with other communities through KSDPP dissemination and the KSDPP Training Program in Diabetes Prevention; direct dissemination to national organisations such as NAHO and AK-NEAHR; as well as with the scientific community through publications and conferences. This work will also form the basis of a doctoral thesis by principal investigator, Jon Salsberg (Queen’s University School of Kinesiology and Health Studies, and KSDPP Research Team Members).

In accordance with the KSDPP Code of Research Ethics, no results will be shared outside Kahnawake until they have been presented to the community. At the end of the study, a summary of the results will be published in the Eastern Door.

Confidentiality

All of the information collected for this study will be kept strictly confidential. The questionnaire and interview will ask you to identify individuals with whom you associate on KSDPP business. With the exception of the use described in the next paragraph, your personal identity and the proper names of those you name will be replaced by project ID numbers and will be kept anonymous. We would also like permission to record what is said during the interview and then transcribe what is said word-for-word for analysis. Once the data collection is complete, no participant names will remain associated with their responses and any names or identifying details mentioned during the interview will be replaced with a pseudonym or removed completely where appropriate to protect anonymity. Only project staff will have access to a data file connecting your name with its project ID or pseudonym. This file will be guarded with a password known only to the principal investigator. All study documents will be kept in a locked safe at the Kahnawake Schools Diabetes Prevention Project office in Kahnawake. They will be destroyed after seven years.

Others whom you may identify in the questionnaire or interview will be contacted and will be informed that you have identified them as a working contact. Although we will start each interview or questionnaire by asking participants to act respectfully, with discretion, and to treat the discussion as confidential, there is little we can do to prevent others from talking about what is said outside of the study.

Ongoing throughout the study, data will be discussed among the KSDPP Research Team and Community Advisory Board, however, these data will have been anonymised and will not contain the names of individual participants. Due to the size of the community and the nature of the participants, it may sometimes be possible for participants to be identified by their responses even though they are not named.

In rare cases, the Research Ethics Board of Queen’s University may have access to your file for quality control purposes. However, they will treat your information with the utmost confidentiality.

Risks and Benefits

There are no risks known to be associated with participating in this study.

There is no direct benefit to you for participating in the project. By participating, you will help increase knowledge about how KSDPP creates new research knowledge for action, policy and practice change to
benefit the health of Kahnawakero:non, other Aboriginal communities, and the rest of Canada. This knowledge will help KSDPP plan the way it creates and delivers interventions and disseminates new knowledge.

**Compensation**

We will not be offering any compensation for participating in this project.

**Participation in the Study**

Taking part in the study is entirely voluntary – that is, you can decide whether or not to participate. You are free to withdraw and leave the study at any time. You may also refuse to answer any of the questions in the questionnaire or asked by the researcher during the interview. If you decide not to participate, there will be no impact whatsoever on you, your position within KSDPP or other organisation, or any services you receive from these or other organisations.

**Additional Information**

Any questions about study participation may be directed to Jon Salsberg at 514-398-1357 or jon.salsberg@queensu.ca. Any ethical concerns about the study may be directed to the Chair of the General Research Ethics Board at Queen’s University at chair.GREB@queensu.ca or 613-533-6081. All communications will be dealt with in confidence.

In addition, if you have any comments or concerns, need any additional information, or feel that you have been treated unfairly during the study, you may contact Amelia McGregor of the KSDPP Community Advisory Board at 450-635-4374.

This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies.

**Final remarks**

You may indicate whether you do or do not consent to participate in the study by the signing the consent form on the next page. You will find two copies of the consent form attached. Please sign the second one too and keep it for your records.

KSDPP and the entire research team would like to thank you for taking the time to consider participation in our study. Please do not hesitate to contact us with questions.

On Behalf of the KSDPP Research Team, Niawen Kowa!

Jon Salsberg, MA, PhD candidate (Principal Investigator)
School of Kinesiology and Health Studies,
Queen’s University
Kingston, ON
KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT

A Social Network Perspective on Ownership and Self-Determination in Participatory Research

CONSENT FORM
(Questionnaire and Interview)

You are invited to participate in a study aimed at understanding how strategies and practices undertaken within the Kahnawake Schools Diabetes Prevention Project (KSDPP) support community ownership and self-determination over research. Please be sure to read the attached presentation letter and description of the study, as it constitutes a part of this consent form. **Taking part in this study is voluntary.**

Also remember the following key points:

- You can ask any questions you like about the project by contacting Jon Salsberg at 514-398-1357. Do not sign the form until these questions have been answered to your satisfaction.
- You may also contact Amelia McGregor, of the KSDPP Community Advisory Board at 450-635-4374 with any concerns about this study or your participation.
- Any ethical concerns about study participation may be directed to the Chair of the General Research Ethics Board at chair.GREB@queensu.ca or 613-533-6081.
- You may refuse to participate and you may withdraw or be withdrawn from the study at any time with no impact whatsoever on you, your position, or any services you receive.
- You understand that all information about you will be kept strictly confidential, and persons other than the investigators will discuss only summaries of the results obtained without any identifying information.
- This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies.
- By signing this form, you are not waiving any of your legal rights.

Indicate your consent to participate to the study by completing the box below. Also fill out this box on the identical form on the next page and keep this second copy for your own records.

<table>
<thead>
<tr>
<th>I have read and understood the accompanying information letter, and</th>
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<tr>
<td>CHECK ONE BOX:</td>
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<td>to participate in the project “A Social Network Perspective on Ownership and Self-Determination in Participatory Research”.</td>
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__________________________________________________________________________

Name of participant

Signature of participant

__________________________________________________________________________

Date

I agree to have what is said during the interview audio recorded and transcribed word-for-word. The recording will be kept confidential and the transcript will not use my name.

☐ Yes ☐ No
APPENDIX III

Research Instruments

Network Survey
A Social Network Perspective on Ownership and Self-Determination in Participatory Research

- RETROSPECTIVE -

Please answer the following question by placing a rank number (1-15) next to the names in the list:

1. Please answer the question **LOOKING BACK** to when the project was first being discussed.
2. Please only rank people you know or would talk to about the project (**leave others blank**).
3. Please include **YOURSELF** in the ranking.
4. If you write in any **OTHER** names, please enter them BEFORE you start ranking.

For the KSDPP School Travel Planning Project, who would you turn to for information about the project **back when it first was being discussed**?

<table>
<thead>
<tr>
<th>RANK</th>
<th>PROJECT PARTICIPANT (alphabetical by first name)</th>
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<td>[NAMES DELETED]</td>
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Nia\:wen Kowa!
A Social Network Perspective on Ownership and Self-Determination in Participatory Research

Please answer the following question by placing a rank number (1-15) next to the names in the list

1. Please only rank people you know or would talk to about the project (leave others blank)
2. Please include YOURSELF in the ranking
3. If you write in any OTHER names, please enter them BEFORE you start ranking

For the KSDPP School Travel Planning Project, who would you turn to for information about the project?

<table>
<thead>
<tr>
<th>RANK</th>
<th>PROJECT PARTICIPANT (alphabetical by first name)</th>
</tr>
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<td>[NAMES DELETED]</td>
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</table>

Nia:wen Kowa!
**- 3rd SURVEY -**

**KSDPP School Travel Planning Project**

(A Social Network Perspective on Ownership and Self-Determination in Participatory Research)

Please answer the following question by placing a rank number (1-15) next to the names in the list

1. Please ONLY rank people you would talk to about the project (leave others blank)
2. Please include YOURSELF in the ranking
3. If you write in any OTHER names, please enter them BEFORE you start ranking

**Question:**

**Now that (PI/champion) has left, who would you turn to for information about the KSDPP School Travel Planning Project?**

<table>
<thead>
<tr>
<th>RANK</th>
<th>PROJECT PARTICIPANT (alphabetical by first name)</th>
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<tbody>
<tr>
<td></td>
<td>[NAMES DELETED]</td>
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Nia:wen Kowa!
Please answer the following question by placing a rank number (1-15) next to the names in the list.

1. Please ONLY rank people you would talk to about the project (leave others blank).
2. Please include YOURSELF in the ranking.
3. If you write in any OTHER names, please enter them BEFORE you start ranking.

**Question:**

*Now that you have had a chance to implement a Walk to School Day since (PI/champion) has left, who do you turn to for information about the KSDPP School Travel Planning Project?*

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<thead>
<tr>
<th>RANK</th>
<th>PROJECT PARTICIPANT (alphabetical by first name)</th>
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<tbody>
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<td>[NAMES DELETED]</td>
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Nia:wen Kowa!
Qualitative Preparatory Questionnaire
On a scale of 0-4, to what extent did you employ (planned or otherwise) any of the following strategies within the STP committee?
[0 = not at all; 2 = somewhat or occasionally used strategy; 4 = crucial or frequently used strategy]

Table 1: Most frequently mentioned strategies for developing a research-community partnership

<table>
<thead>
<tr>
<th>0-4</th>
<th>Strategy</th>
<th>Description</th>
</tr>
</thead>
</table>
| 1   | Development of an Advisory Committee         | - A composition of researchers, the intended users of the research and/or representatives of community organizations  
- Advisory committees allow for inclusion of all viewpoints throughout the research process and joint development of dissemination strategies and action plans  
- Subcommittees are often used to divide up tasks (e.g., reviewing new proposed research topics, articles for publication, partnership evaluation) |
| 2   | Development of Research Agreements           | - Before the research begins, clearly spell out researchers and partner roles and responsibilities, outline how decisions will be made (e.g., by consensus or by voting), and set out what to do if conflict arises.  
- Research agreements may also include plans for data ownership and control, interpretation of data, and procedures for resolving disagreement over research results  
- Developing agreements is seen as a trust-building exercise |
| 3   | Use of Group Facilitation Techniques         | - Can be both a formal and an informal process to ensure meaningful involvement and participation of partners  
- Formal facilitation includes focus groups, workshops, and nominal group techniques  
- Informal techniques include circulating agendas ahead of time, small group work, and one-on-one informal discussions. |
| 4   | Hiring Staff from the Community of Study     | - Hiring local persons as project staff recognizes community members’ abilities to establish good relationships with individual participants for recruitment and ongoing data collection  
- Projects hire well-respected community members as a “community champions”, field coordinators, intervention staff, interviewers, group co-facilitators, as well as for data collection and analysis. |
| 5   | Frequent Communication                        | - Communication between partners through regular group meetings to keep all partners updated on progress, changes in procedures and as a way of discussing concerns and challenges  
- Other methods include telephone calls to partners who missed meetings to bring them up-to-date, and prompt circulation of meeting minutes and newsletters |
Table 2: Less frequently mentioned strategies for developing a research-community partnership

<table>
<thead>
<tr>
<th>0-4</th>
<th>Strategy</th>
<th>Examples</th>
</tr>
</thead>
</table>
| i.  | Researchers need to make active efforts to learn about the participants and their context | • Attending community-organized educational sessions or going on a community tour  
• Arranging retreats with community members  
• Organizing structured workshops with community members, as well as having informal conversations with them  
• Conducting formal interviews with community organizations  
• Actively involve intended users through hiring study staff from the community and utilizing a community organizer/champion  
• Form advisory board for the project with representation from organizations implicated in the research |
| ii. | Facilitate intended user involvement         | • Be flexible with partners’ work schedules and negotiate with their employers for study-related tasks  
• Utilize community contacts for recruitment of marginal community members or make use of ‘snowball’ referral  
• Reach out to places frequented by community members (e.g. schools)  
• Adopt group facilitation techniques  
• Approach partners individually for input away from larger groups  
• Understand community priorities and culture  
• Speak frankly and agree to disagree  
• Include representation in the project both from those affected directly by the research and the community as a whole  
• Evaluate the partnership frequently to elicit partners’ feelings |
| iii. | Establish lines of communication            | • Take time at the beginning to get to know one another and keep frequent contact with intended users  
• Spend time in the community (e.g. attend significant community events)  
• Jointly develop a written research agreement clearly spelling out roles and responsibilities of all partners  
• Follow through on the agreement and any other promises  
• Hire community members as project staff |
| iv.  | Form an advisory committee                    | • Include wide representation from key community organizations where implemented  
• Jointly develop operating norms including decision-making, conflict resolution and meeting facilitation  
• Adopt consensus decision-making  
• Hold monthly meetings, rotate meeting locations if possible, and circulate draft agendas and meeting minutes  
• Include intended users in the management structure by hiring a respected community leader for their project’s primary leadership role to facilitate community connections, share perspectives, and provide project oversight |
| v.   | Group facilitation techniques; an iterative process when deciding upon research goals and | • Engage the project’s advisory committee in a series of discussions with the community to incorporate local knowledge  
• Establish working relationships early  
• Consider having the community apply as principal applicant for grants |
<table>
<thead>
<tr>
<th>Grounded Research Question(s)</th>
<th>vi. Build Community Capacity</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>• Utilize and develop community resources and support networks when conducting research</td>
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<td>• Train community members as co-facilitators of research activities</td>
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<td></td>
<td>• Involve the community in needs assessment and planning processes</td>
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<tr>
<th>Grounded Research Question(s)</th>
<th>vii. Outline Community Involvement in Research Agreements</th>
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<tbody>
<tr>
<td></td>
<td>• The community can be involved in all phases of research</td>
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<td>• Ensure active involvement of community members in all study tasks (e.g. reviewing all study documents to ensure they are in an understandable language)</td>
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<td>• Solicit suggestions from community partners through focus groups or meetings (e.g. on data collection approaches)</td>
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<td>• Hire and train lay community members or utilize an advisory board as field coordinators, interviewers, data collectors, intervention staff and analysts (e.g. identification of variables, selection of measures, questionnaire development)</td>
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<th>Grounded Research Question(s)</th>
<th>viii. Community Training in Research</th>
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<tbody>
<tr>
<td></td>
<td>• Provide training to community about health issues</td>
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<td>• Use training sessions to get community perspective on these issues</td>
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<td>• Have community members critique pre-existing research instruments as a way of learning about developing questionnaires and for researchers to learn about the community’s perspective</td>
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<td>• Teach community public health and research skills</td>
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<td>• Conduct community workshops on research methods</td>
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<td>• Use focus groups to engage community members in discussions about research in their community</td>
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<tr>
<th>Grounded Research Question(s)</th>
<th>ix. Engage in Early Community Interactions while Developing the Project</th>
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<tbody>
<tr>
<td></td>
<td>• Conduct in-depth interviews with community members and other key informants</td>
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<td>• Go on ‘wind-shield’ tours driving around the community</td>
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<td>• Involve community in developing context-specific models</td>
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<td></td>
<td>• Make use of qualitative data</td>
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<td></td>
<td>• Use theoretical, convenience and open sampling</td>
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<th>Grounded Research Question(s)</th>
<th>x. Advisory Committee Sub-Groups</th>
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<tr>
<td></td>
<td>• Set up a sub-committee of the advisory committee to review all partnership evaluation results and make recommendations to the overall advisory committee</td>
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<td></td>
<td>• Sub-group committee can facilitate data analysis and interpret results</td>
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<td></td>
<td>• Present and discuss results with community partners to facilitate interpretation</td>
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<td></td>
<td>• Researchers and community members can analyze data independently and present their interpretations</td>
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<td>• Engage in open, interactive analysis with community partners</td>
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<td>• Adopt a research agreement at the beginning outlining community involvement in results interpretation</td>
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<tr>
<th>Grounded Research Question(s)</th>
<th>xi. Action Planning</th>
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<tr>
<td></td>
<td>• Establish action groups of community partners to develop intervention strategies and plan policy initiatives</td>
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<td></td>
<td>• Work with community members in deciding upon policy initiatives and action plans</td>
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| xii. Interpretation, data ownership and dissemination | • Instrumental use of research results to lobby government  
• Work with community partners to develop community resources based upon study results  
• Hold meetings with community partners to discuss other non-study related, important issues  
• Community partners can communicate their own interpretation of study data along with researcher study publications  
• Adopt a no veto rule, meaning that neither researchers nor community partners can block a publication with results  
• Spell out this process in a written researcher agreement before it arises  
• Researchers can be guardians of the data during the project, but transfer data control to community after the project ends  
• Community obligation is to allow researchers the right to ongoing data analysis  
• Develop dissemination strategy outlining community involvement  
• Include non-academic partners as co-authors/co-presenters on manuscripts/abstracts  
• Disseminate results through local organizations, newspapers, media, and community-based practitioners  
• Jointly publish a community newsletter with results included  
• Make use of local cultural mechanisms, such as street theatre  
• Circulate a summary report to community members and/or have feedback/discussion sessions  
• Organize debriefing sessions with a luncheon or gala celebration  
• Discuss publication drafts with the community before submission |
APPENDIX IV

Copyright Permission to Include Previously Published Works


Dear Dr. Salsberg,

Journal of Environmental and Public Health is a peer-reviewed, open access journal, which means that all published articles are made freely available online without a subscription, and authors retain the copyright of their work.

Best regards,

Amr

--

***************************
Amr Yoseph
Editorial Office
Hindawi Publishing Corporation
http://www.hindawi.com
***************************

CERTIFICO

Que el artículo “Engaging Community Stakeholders for School-Based Physical Activity Intervention (Implicando a actores de la comunidad para la intervención en materia de actividad física desde la escuela)” escrito por Jon Salsberg, Soultana Macridis, Enrique García Bengoechea, Ann C Macaulay, Spencer Moore, una vez que ha sido revisado por el sistema de pares a ciegas e informado favorablemente por el Comité Científico de la revista, ha sido aceptado por el Comité Editorial y se publicará en julio de 2015 en Retos 28.

Dicha revista se encuentra incluida en los siguientes centros de documentación:

- DICE (Difusión y Calidad Editorial de las Revistas Españolas de Humanidades y Ciencias Sociales y Jurídicas), IN-RECS (Índice de Impacto Revistas Españolas de Ciencias Sociales), Catálogo Latindex, Dialnet, Base de Datos ISOC - Ciencias Sociales y Humanidades (CINDOC – CSIC), Catálogo Colectivo Español de Publicaciones Periódicas ARIADNA, Rebiun, DOAJ, Sport’docs, Ebsco, RESH, e-revistas, Sicapes (WebQualis), Periódicos Capes, LivRe, IRESIE, Sherpa/Romeo, MIAR, COPAC, SUDOC, Directory of Research Journal Indexing (DRJI), Google Académico, Recolecta, Ulrich’s, Fuente Académica Premier Collection, Redalyc, HINARI journals, Sport Discus, Google scholar, Socol@r, Redalyc, Colciencias/Publindex, PSICODOC

Por la presente, expido el presente certificado para que surta los efectos oportunos, en San Javier a 23 de marzo de 2015.

Fdo. Francisco Ruiz Juan
Director de la revista
Retos. Nuevas tendencias en Educación Física, Deporte y Recreación
Hola, adjunto el certificado solicitado. Espero que sea correcto, cualquier cuestión al respecto me la haces saber.
Un saludo
Paco

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-----Mensaje original-----
De: Enrique Garcia Bengoechea [mailto:Enrique.Garcia@uws.edu.au]
Enviado el: miércoles, 15 de abril de 2015 5:05
Para: pacoruizjuan@gmail.com
CC: Jon.salsberg@mcgill.ca
Asunto: FW: retos copyright permission letter
Importancia: Alta

Hola Paco,

Jon Salsberg necesita que le envíes urgentemente un permiso de copyright por parte de Retos para poder incluir su manuscrito en su tesis doctoral.
Enviaselo directamente a Jon, por favor.

Gracias,
Enrique

-----Mensaje original-----
De: Jonathan Salsberg, Mr. [jon.salsberg@mcgill.ca]
Sent: Wednesday, April 15, 2015 11:47 AM
To: Enrique Garcia Bengoechea; Enrique Garcia, Dr.
Subject: retos copyright permission letter

Hi Enrique,

I'm putting together my thesis submission package and realize I require a copyright permission letter from Retos in order to include that manuscript with my thesis.
I don't see a link on their website to get this letter. Could you please contact the editor and find out if he can send me the required letter of permission?

Hope all is well with you!

Thanks!!!

-j

Jon Salsberg
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