

A CASE STUDY OF  
KNOWLEDGE TRANSLATION  
&  
THE ENHANCED STREET YOUTH STUDY  
IN SASKATOON

A Thesis Submitted to the College of  
Graduate Studies and Research  
in Partial Fulfillment of the Requirements  
for the Degree of Master of Science  
in the Department of Community Health & Epidemiology  
University of Saskatchewan  
Saskatoon

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## ABSTRACT

In the past few decades knowledge translation has emerged as a common strategy intended to improve the effectiveness of health interventions and increase the utilization of research. Underlying the emergence of knowledge translation is a belief that new research findings will increase the efficiency of the present health care system, decrease the inequitable distribution of negative health outcomes, and improve the health of individuals. One growing population that faces increased risk of negative health outcomes in Canada, and Saskatoon, is street-involved youth.

The purpose of this qualitative case study is to understand how the organizational context of a national surveillance study targeting street-involved youth, the Enhanced Street Youth Study, influences knowledge translation activities in Saskatoon, Saskatchewan. This case study traces the history of knowledge translation related to the surveillances study, and describes and analyzes the knowledge translation activities that took place in early 2011. Informed by document analysis, interviews, and participant observation, this study captures the perspectives and opinions of representatives from the key organizational and individual stakeholders: the Public Health Agency of Canada, Public Health Services of the Saskatoon Health Region, local community agencies, and street-involved youth.

The experiences of the diverse stakeholders reveals the central influence of history, study processes and relationships on the success of engaging youth and local agencies in knowledge translation activities. In particular the Results illuminate how limited roles for agencies and youth within study process limit the extent of their engagement in the study and related knowledge translation activities. Importantly, the thesis study sheds light on the significance of participation and power in knowledge translation activities. Furthermore, the challenges and opportunities facing knowledge translation within a public health environment are discussed, and recommendations for future knowledge translation activities are provided. Although knowledge translation holds potential to address health inequities, intentional effort to address inequities must be made throughout the entire study process, including knowledge translation activities.

## ACKNOWLEDGEMENTS

Undertaking such a journey as this does not happen independently or in isolation. It is with much gratitude and recognition that I acknowledge the profound support I have received from numerous mentors, colleagues, friends and family.

Throughout my time studying in the Department of Community Health & Epidemiology, I have received an abundance of encouragement and guidance. I want to thank Katrina Plamondon, a member of my thesis committee, along with my committee chairs, Dr. Sylvia Abonyi and Dr. Bonnie Janzen for their support and guidance in developing this project and seeing it through. Dr. Lori Hanson, my thesis supervisor, has guided this project from the days of exploring research opportunities in her office, to the strategic and impeccable direction and support needed to write this document. Thank you for your patience and ongoing encouragement as you guided my thoughts and tangents into a coherent place.

This project would not exist were it not for the ongoing curiosity and availability of Public Health Services of the Saskatoon Health Region and the Public Health Agency of Canada. The openness of the individuals involved with the Enhanced Street Youth Study at all levels has allowed this thesis project to come to fruition. Judith Wright invited me into the world of the Enhanced Street Youth Study, answering questions and requests with endless enthusiasm and support.

The support and encouragement of friends and family cannot be overstated. Any industriousness and inquisitiveness that I bring to this project was given to me in abundance by my Mom and Dad – thank you for your continued support. The friends I made throughout this project have shared their own experiences and passion, and I would be lost without their inspiration, support and guidance. I am most grateful for the support, clarity and love given to me from Aileen. Thank you for your unwavering love and belief in my ability to take on anything – without you I would never have begun this journey, let alone navigated it.

Lastly, I am honoured to have received the financial support of both the College of Medicine and the Department of Community Health & Epidemiology, which have made this project possible.

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## **LIST OF ABBREVIATIONS**

CBO	Community-based organization
CIHR	Canadian Institutes of Health Research
E-SYS	Enhanced Street Youth Study
KTE	Knowledge transfer & exchange
KT	Knowledge Translation
PHAC	Public Health Agency of Canada
PHS	Public Health Services
RIC	Regional Intersectoral Committee
SDOH	Social determinants of health
SHR	Saskatoon Health Region
STBBI	Sexually transmitted blood-borne infection
STD	Sexually transmitted disease
STI	Sexually transmitted infection
WHO	World Health Organization

## CHAPTER 1 INTRODUCTION & CONTEXT

In the past few decades, knowledge translation (KT) has emerged as a common strategy intended to improve the effectiveness of health interventions and increase the utilization of research. Knowledge translation, as defined by Canadian Institutes of Health Research (CIHR), is the process of synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health and the health system (1). Underlying the emergence of KT is a belief that new research findings will increase the efficiency of the present health care system (2-4), and in turn improve the health of individuals (1,3). Some scholars even argue that effective KT can reduce the present inequitable distribution of negative health problems (5).

KT literature increasingly recognizes the essential role end-user participation plays in increasing the effectiveness of KT and the adoption of research findings (2,4,6-8). Since the Alma-Ata Declaration (9) and the Ottawa Charter (10) public participation has been a common theme in Canadian health research and programming. In fact, the fourth declaration of the Alma-Ata recognizes the “right and duty” of citizens to participate in health planning (9). Although Canadian public health literature recognizes the importance of citizen participation, encouraging citizen participation is not without its challenges, particularly when the population faces marginalization such as street-involved youth.

The number of street-involved youth<sup>1</sup> in Canada continues to rise, as do the health problems facing them. The Public Health Agency of Canada estimates that there are 150,000 street youth in Canada (11). Research indicates that everything from sexually transmitted infections (STIs) to mental illness to poor overall health is disproportionately high in the street-involved youth population relative to mainstream youth (11). Unsurprisingly, for street-involved youth there are many barriers to participation in health research, health planning, and KT due to the conditions in which they live (12). Additional structural barriers exist within the organizations that traditionally engage in health planning and research for this population (13). Although successful examples of engaging street-involved youth in health research do exist, they are infrequent. Participation within health research and planning takes various forms, and the intensity of participation shapes the positive effect the participation has on the participants (6).

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<sup>1</sup> Street-involved youth as defined in this thesis study refers to youth ages 15 to 24 years of age with some involvement with the street economy and/or living in some degree of homelessness (see Section 2.3.1 for further discussion of this definition).

This study explores KT efforts in the context of a national surveillance study targeting street-youth, describing and analyzing how KT evolved over several years of the study's implementation in Saskatoon, Saskatchewan.

### **1.1 Research Purpose & Questions**

KT is increasingly understood as a concept that permeates the entire research process, and is thus influenced by the organizations and stakeholders involved throughout that process. The purpose of this qualitative case study is to understand how the organizational context of the Enhanced Street Youth Study (E-SYS) influences the efforts of study partners to engage local agencies and street-involved youth in knowledge transfer & exchange (KTE) activities<sup>2</sup>. The E-SYS process in Saskatoon involves four main organizations and stakeholders including the Public Health Agency of Canada (PHAC), Public Health Services (PHS) of the Saskatoon Health Region, Saskatoon-based agencies that work with street-involved youth, and street-involved youth themselves. This study explores the KT efforts associated with Cycle<sup>3</sup> VI of the Enhanced Street Youth Survey (E-SYS), with a focus on the efforts of PHS to engage local agencies and street-involved youth in KTE activities.

The central research question of this thesis study aims to recognize the reality of the organizational context of E-SYS, and thus appreciate the process of conducting KT within that context. The primary research question is: *What do Public Health Services' efforts to engage local agencies and street-involved youth in knowledge transfer and exchange activities reveal about the influence of the E-SYS organizational context on youth and local agency engagement?*

In an effort to be precise in responding to this research question there are three more specific research questions that inform and frame the primary research question. These secondary research questions are:

- (1) What is the organizational context of E-SYS and the Phase VI KTE activities in Saskatoon?
- (2) What are the activities that PHS undertook to engage local agencies and street-involved youth in E-SYS Phase VI KTE?

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<sup>2</sup> The distinction between the use of the terms KTE and KT as it relates to this research project will be further explained in Section 2.5.1.

<sup>3</sup> Both the terms “phase” and “cycle” are used interchangeably within E-SYS documentation to refer to each process of data collection, analysis, etc. As such, the terms are also used interchangeably throughout this thesis.

(3) What do the Phase VI KTE activities reveal about the influence of the E-SYS organizational context on engaging street-involved youth and local agencies in knowledge translation efforts?

The three secondary questions provide guidance to the analysis process, and structure the presentation of the results in Chapter 4.

## **1.2 Study Context: The Enhanced Street Youth Study**

The full context of this study – including roles of organizations, emergence of KT as a priority, and other important details – is explored in depth in Chapter 4. The following section is intended to only provide a brief synopsis of the study context. The Enhanced Street-Youth Study (E-SYS), led by PHAC in collaboration with community sites across Canada, is a surveillance system designed to monitor the health of street-involved youth in Canada, particularly related to sexually transmitted and blood-borne infections (STBBIs) (15).

In 1998, E-SYS was initiated through Health Canada<sup>4</sup> with local community partners across Canada (14). The Saskatoon Health Region (SHR), through PHS has served as a local partner for E-SYS since 1999, and has been involved in five of the six phases of this study. As a local partner, PHS has been involved in recruitment, interviewing, and data analysis of the findings from the E-SYS in Saskatoon. As part of the recruitment strategy for E-SYS, PHS has partnered with Saskatoon-based agencies that have involvement with street-involved youth.

The purpose of E-SYS as a surveillance study has been primarily to assess and monitor the rates of STBBIs among street youth (15). However, E-SYS examines over 600 variables and attempts to capture types of risk-taking behaviour, as well as the social context surrounding this risk-taking (15).

### **1.2.1 E-SYS and Knowledge Transfer & Exchange**

Over the twelve-year duration of E-SYS there has been increasing recognition by PHAC and other stakeholders that KT needs to receive more attention. This is particularly significant if E-SYS results are to have an impact on the health risks facing street-involved youth. Although dissemination is the term that is most commonly used within public health surveillance literature in reference to the link between surveillance findings to action, PHAC and E-SYS have adopted the term knowledge transfer & exchange (KTE). KTE has emerged as a priority for E-SYS

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<sup>4</sup> Although E-SYS is presently coordinated by the PHAC, E-SYS was initially coordinated by Health Canada. In 2004 responsibility for E-SYS was moved to the Community Acquired Infections Division of PHAC when it was established (159).

relatively recently. In fact, Phase VI is the first time that KTE has been made an explicit priority by PHAC. Two stated KTE objectives of E-SYS Phase VI include, “to disseminate results that can be utilized for prevention and control efforts in this population” (p. 2) and, “to educate youth about STBBIs” (p. 2)(16).

The March 2009 E-SYS National Meeting set the stage for KT to be a priority in the present E-SYS cycle. The PHAC written *Cycle VI Protocol* explicitly outlines the importance of both national and site-specific dissemination activities. In fact, “as a condition of participating in cycle VI of E-SYS, sentinel sites will be supported to develop appropriate local KT&E strategies” (p.13)(16). For site-specific dissemination, a number of traditional KT approaches are described (e.g. conference presentations, journal publications), but it is also states that, “it is imperative that the data be returned to the youth” (p. 13)(16). The focus on youth as a target for E-SYS KTE is thus a new priority.

PHS’ approach to Cycle VI KTE in Saskatoon has focused on two different target audiences, youth and local agencies. The Phase VI KTE activities undertaken by PHS to engage local agencies and youth are the central focus of this study.

### **1.3 Organization of the Thesis**

I have organized this thesis into six chapters. Chapter 2 provides an overview of the academic literature related to public health surveillance, the history of public health within Canada, the health of street-involved youth, and knowledge translation. In Chapter 3, I outline the theoretical orientation and methodology that guided this thesis project. I provide an overview of the results, including the historical context of E-SYS and reflections from those involved in the E-SYS KTE activities in Chapter 4. In Chapter 5, I address the main research question through discussing the results and suggest future directions for KT related to E-SYS and possible research avenues. I conclude this document in Chapter 6 with a brief overview of the main themes and findings gleaned from my time with this thesis project.

## CHAPTER 2 LITERATURE REVIEW

### 2.1 Public Health Surveillance

As identified in the introduction, E-SYS is designed as a surveillance system. The origin of modern public health surveillance systems is often attributed to Langmuir's work in the 1950s (17). Public health surveillance is defined as, "the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know" (p. 3)(18). What differentiates surveillance systems from typical health studies is that surveillance systems are ongoing, whereas research projects are often designed with a specific endpoint. In the case of E-SYS, it began in 1999 and is presently in its sixth cycle.

Regarding public health surveillance systems, what is particularly significant for this thesis project is that they are traditionally attached to some form of public health action (17-19). As stated by Declich and Carter (19), "surveillance is more than the collection of reports of health events" (p. 385). Although the target of surveillance dissemination is often left very generally as "those who need to know," the dissemination of findings from a surveillance system is viewed as an essential component of any surveillance system; "action is what distinguishes surveillance from the task of simply monitoring events" (p. 3)(18). This explicit interest in public health action creates a natural fit with the field of knowledge translation.

While acknowledging the importance of surveillance systems to inform public health action, it is also important to acknowledge the limitations of surveillance systems. Thacker (17) suggests that, "to date, infectious disease surveillance has focused on measuring incidence; it has not focused on finding ways to reduce the burden of infectious disease on the general population or the disproportionate burden of infectious disease morbidity on special populations" (p. 387). This limitation is further echoed by Braveman (20), who also highlights the importance of surveillance systems; "public health surveillance is certainly not sufficient to reduce health disparities, but without monitoring how the size of disparities between more and less advantaged social groups changes over time in relation to policies, there is a lack of accountability for the differential effects of policies on vulnerable groups." (p.188).

Surveillance systems face a unique challenge in the balance they must strike between maintaining their relevance and allowing for accurate comparison from cycle to cycle. In order for the surveillance systems to benefit from their ongoing surveillance, the markers that are

measured in each cycle must not change significantly from cycle to cycle. However, maintaining these indicators also limits the ability of the surveillance system to be responsive to changes in the disease or behaviour being monitored. If these two issues are not appropriately balanced, the usefulness of surveillance systems to inform public health action and policy is compromised.

## **2.2 Public Health & Citizen Engagement**

In an effort to appropriately conceptualize this thesis study, it is useful to understand public health practices in Canada and Saskatchewan. In particular, how public health has understood health and viewed citizen engagement and public participation provides an understanding of the context in which knowledge translation and the E-SYS takes place.

### **2.2.1 Relevant Public Health Developments in Canada**

Beginning with the 1974 Lalonde report, *A New Perspective on the Health of Canadians*, the conceptualization of health within public health discourses began to change. Lalonde laid the groundwork for a structural understanding of health<sup>5</sup> within Canada, and an understanding of health that cut across sectors and jurisdictions (21). This structural approach to health was further developed and built upon with the 1978 *Declaration of Alma-Ata*, Epp's 1986 *Achieving Health for All* report, and the *Ottawa Charter for Health Promotion*. In fact, one of the driving points of Epp's report was inequity as a key determinant of health (21).

Today the social determinants of health (SDOH) and health promotion language can be found within Health Canada literature (21,22). One of the perplexing challenges of this conceptualization of health is that despite the seemingly widespread acceptance of a health promotion approach within health literature, there are relatively few interventions and actions within Canadian public health that address the SDOH (21,23-27). In fact, policies within Canada largely reflect a focus on lifestyle and behavioural interventions to address health (22,23,28-30). This is despite a number of concerns with behavioural approaches, including the question of the effectiveness of behavioural change approaches (29,31) and significant government documents urging a shift in approach (i.e. the Lalonde report). Reasons that have been put forward for the lack of a SDOH approach in Canada include: political and economic ideology (21,23,29,32-34), difficulty in developing interventions or strategies (21,33,35), and the inability of public health

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<sup>5</sup> A structural approach to health moved the definition of health beyond the biomedical understanding of health as the absence of disease, to recognizing that one's health is influenced by societal structures. Furthermore it recognized that certain populations are inequitably impacted by societal structures (21).



groups to keep up with new theoretical developments (29). There is a lack of targeted interventions to address the SDOH, and it is conspicuously absent from Roy Romanow's *Building on Values: The Future of Health Care in Canada* (29). However, the SDOH approach is not fading away, as seen in such noteworthy reports as the World Health Organization's Commission on Social Determinants of Health final report, *Closing the gap in a generation: Health equity through action on the social determinants of health* (36).

As a structural approach to health developed within Canada, so did the recognition that there was an important role for citizens to play in the development and implementation of health care. The fourth declaration of the 1978 Alma-Ata explicitly identifies the importance of citizen participation; "the people have the right and duty to participate individually and collectively in the planning and implementation of their health care" (p. 1)(9). Furthermore, the Alma-Ata's definition of primary health care recognizes the importance of full participation by communities in determining their health care (9).

The 1986 Ottawa Charter highlights the importance of citizen participation in health planning within a community development context. Health promotion is defined as "the process of enabling people to increase control over, and to improve, their health" (p. 1)(10). In this way, citizen participation and empowerment are central to the role of health services. It is also important to note that the Ottawa Charter views the responsibility for a health promotion approach within health services as the joint responsibility of individuals, community groups, health professionals, health services institutions and government.

In *Achieving Health for All*, Epp affirms the importance of health promotion and the broader definition of health outlined in the Ottawa Charter. Furthermore, as stated by Epp, "encouraging public participation means helping people to assert control over the factors which affect their health. We must equip and enable people to act in ways that preserve and improve their health"(p. 8)(37). Given these statements, it is important to consider that within Health Canada, public participation is seen as a duty and right and the responsibility of all sectors to ensure that citizens are able to participate within the systems that citizens operate within, including the health system (37).

### **2.2.2 Relevant Public Health Developments in Saskatchewan**

The history of healthcare in Saskatchewan is well known and became the model adopted for national healthcare in Canada in 1972 (38). With regards to the SDOH, Saskatchewan, along

with many other provinces in Canada “had no evidence of mandated programs that were explicitly health focused, that addressed broader determinants of health, or used multiple strategies” (p.247)(25) in 1997. However, in 2001 *Caring for Medicare: Sustaining a Quality System*, commonly known the Fyke Report, laid out a vision of balancing downstream (i.e. diagnosis and treatment) and upstream services (i.e. disease prevention, health promotion and protection). Citizen participation appeared central to Fyke’s vision with Primary Health Networks providing local knowledge to allow health services to be tailored to local needs, although no specific design for citizen participation was outlined. The Fyke Report envisioned the health sector taking a less active role in population health promotion strategies, however partnership and “cheerleading” with other partners regarding health promotion is suggested (39). In a collection of responses to the Fyke report, the Regina Health District outlined how “the pressure for immediate services takes priority [over health promotion and prevention]” (p. 24), and recommended that Saskatchewan Health designate a certain percentage of the funds provided to the Districts for health promotion and prevention (40). Saskatchewan Health did not designate a suggested or required quota for health promotion and prevention, and placed the responsibility of prioritizing funds on the health districts or regions. What Saskatchewan Health did provide was an overview of population health services that public health departments throughout the province could be involved in based on province-wide consultations (41). Furthermore, in 2003 Saskatchewan Health, in collaboration with the health regions and their partners, developed *Healthier Places to Live, Work and Play: A Population Health Promotion Strategy for Saskatchewan*. “The Strategy emphasizes “upstream” approaches to address root causes of ill health by focusing on changing the conditions and environments in which people live, work and play” (p.4)(41). The document also outlines priority issues (i.e. mental well-being, accessible nutritious food, decreased substance abuse, and active communities), as well as general strategies to change the conditions and environments in which we live (i.e. strengthen community action, create supportive environments, and build healthy public policy). One of the identified short-term goals of the health promotion strategy is to increase “community participation in population health promotion” (p.10)(41). Also of relevance to this study is the strategy’s emphasis on evidence-based decision-making. Within the strategy, evidence is defined as emerging “from research, evaluation of policies, programs and projects, or knowledge gained through practice and experience” (p.12)(41).

With regard to the SDOH and the Saskatoon Health Region specifically, there is clearly recognition of the importance of the SDOH to improving the overall health of citizens and reducing inequity as is evident in numerous reports produced by the SHR (see: SHR Health Status Report, 2008). While the majority of these reports end with recommendations to improve the health of citizens and address health inequities, the implementation of these recommendations is challenging to trace. One group that appears to be strategically placed to address some of the SDOH is the Saskatoon Regional Intersectoral Committee (RIC). The (RIC) “is co-chaired by the Health Region’s vice-president for primary care and the city’s director of parks and recreation. The committee includes representatives from various provincial and federal government departments, municipalities, regional health authorities, housing authorities, educational institutions, tribal councils, police, and Metis organizations” (p. 10)(11).

### **2.2.3 Health & Citizen Engagement**

As mentioned above, the right and duty for citizens to participate in health care planning can be traced to the *Alma Ata Declaration* (1978), and is further emphasized in the *Ottawa Charter for Health Promotion* (1986) and *Achieving Health for All* (1986). In fact both participation and empowerment are increasing seen as core values of the ‘new public health’<sup>6</sup> (22), and are increasingly linked within health literature.

Empowerment of citizens as a result of participatory practices is seen as one of many potential benefits to increased citizen participation within health program planning. As envisioned in the *Ottawa Charter for Health Promotion*, and described by Bracht, Kingsbury, and Rissel (42), “participation facilitates...empowerment by developing personal efficacy, develop a sense of group action, developing critical understanding of social power relationships, and developing a willingness to participate in collective action” (p.87). It is important to note that participatory processes alone are not sufficient for empowerment; Laverack and Wallerstein (43) state, “participatory approaches do not necessarily seek emancipation or empowerment” (p. 182). Therefore, if one wishes to evaluate the benefit of citizen participation, clear objectives of

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<sup>6</sup> The “new public health,” as defined by Robertson (160) is “a broad socio-environmental conceptualization of health, a recognition of the social determinants of health, and a call for broad-based changes in the social and economic environment in order to improve overall health” (p. 156). In short, it refers to the social determinant of health approach to health, encapsulating how health is conceptualized within the Ottawa Charter and *Achieving Health for All*.

engagement must be stated, whether they are solely participation, empowerment through participation, or otherwise (44-46).

Entwistle et al. (47) argue that increased citizen input can increase the relevancy of health research. Other research indicates that citizen input provides an important complementary perspective to professional knowledge or perspectives (44,47), can result in more cost-effective services (45) and in increased accountability of service providers to the public (44,45,48). Furthermore, increased citizen participation increases the likelihood of effective dissemination and application of knowledge or research (49) and will be discussed in further detail below.

It is also important to recognize that there are political motivations for more actively engaging with the citizens in health planning (45,50,51). In an environment of fiscal constraint and “a decade of neo-liberal inspired public sector reform” (p. 160)(51), involving citizens in health decision-making allows the government to share the responsibility of tough decisions related to health priorities.

Despite the many potential benefits of increased citizen participation within health program planning and research, scholars have found mixed results on whether or not citizen participation is increasing. Raphael & Bryant (22) suggest that citizen participation is on the rise, while a number of other scholars have found little evidence of increased citizen participation (44,52,53).

#### **2.2.4 Conceptualizing Participation**

Prior to discussing how best to conceptualize the actual participatory process, it is important to explore who initiates the participatory process (50,54). Similar in principle to what the KT literature reveals, the more participants have a sense of ownership of the problems and solutions being addressed, the more likely they are to be actively engaged (50,52). If an organization is willing to accept citizens' issues as valid and adopt these issues as their own, citizens are more inclined to be committed to the participatory process (50). Whereas, if an organization presents its own agenda, that may or may not be similar to citizens, and tries to encourage participation, the level of engagement is not as promising. If empowerment is one of the goals of engaging citizens in participation, it is even more important that the agenda arises from citizens, as opposed to the agenda and process being predetermined by professionals (54). All of these issues are grounded in the fact that participatory processes are ultimately about power (46,50).

Numerous frameworks have been developed in an effort to more fully articulate how participation occurs in practice. As one can imagine, each framework has its strengths, and is not without its weaknesses. Arnstein’s ladder is still the most commonly used model for discussing citizen participation (51), despite the fact that it was developed over 30 years ago. Other commonly utilized frameworks include those developed by Rifkin (55), Pretty (56), Charles & DeMaio (44), and Oliver (54).

For the purposes of this thesis study, Arnstein’s ladder of participation will be utilized to encapsulate the perspective of the local agencies and youth that were engaged in the KTE activities in Saskatoon. Arnstein’s ladder provides explicit acknowledgement of the role of power in participation, as well as framing participation from “the receiving end” (p. 270)(50). Arnstein’s ladder has 8 levels of citizen engagement, from manipulation to citizen control, based on the citizen power that is built (Figure 2.1).

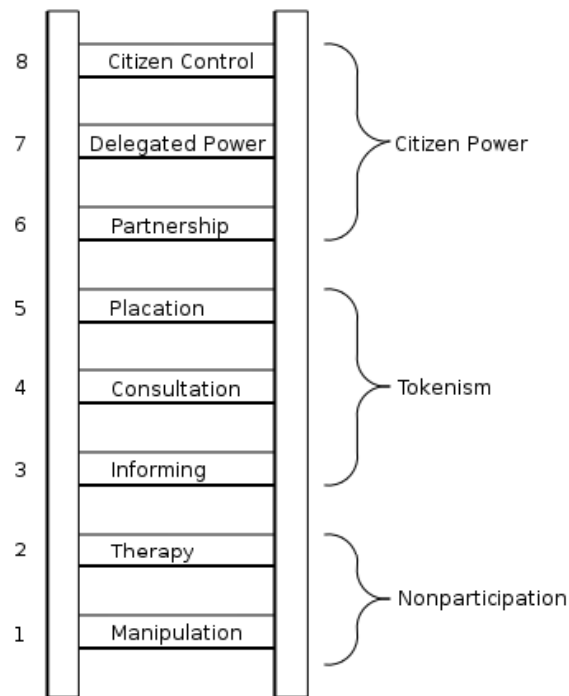


Figure 2.1: Arnstein’s ladder of participation (57).

As with any framework, Arnstein’s framework is not without its faults. Tritter and McCullum (51) argue that Arnstein’s ladder does not consider the involvement of citizens in defining the problem in which they are engaging, but solely citizen involvement in seeking

solutions. As is discussed in more detail below, citizen participation in problem definition can be key to effective engagement and empowerment. Furthermore, Tritter and McCullum (51) argue that Arnstein's ladder is oversimplified and doesn't consider the potentially harmful impacts that can result from a 'tyranny of majority.' Despite these limitations, Arnstein's framework will be utilized to discuss the participatory processes within this thesis study given its explicit consideration of power and the participants' perspective.

### **2.2.5 Organizational Influence on Citizen Engagement**

It is important to recognize that numerous factors influence citizens' ability to engage in participatory processes. Structural factors have a significant influence on participation, particularly the participation of disadvantaged groups such as street-involved youth (52). Boyce (52) identifies three dimensions of structural factors: (1) the organizational dimension, (2) the social-cultural dimension, and (3) the political-legal-economic dimension. Although all three dimensions can affect participation, the primary focus of this thesis study is the organizational dimension. This focus is due PHACs and PHS' ability to shape the organizational dimension in a relatively straightforward manner.

The organizational dimension, as defined by Boyce (52), "includes administrative networks, resources, mandates, and attitudes of planners that shape decision-making roles" (p. 1553). The organizational influence on participatory efforts is echoed by a number of scholars (50,55,58). For example, in Higgins (58) work on participatory health reform in British Columbia, she identifies that citizens must be comfortable with the physical venue where engagement efforts are taking place. Furthermore, the process must be respectful of citizens day-to-day life; "citizens must be able to see some reflection of themselves in the participatory endeavour in order to trust the process and participate" (p. 32)(58). In considering the organizational dimensions within E-SYS, one must consider the resources, mandates, and perspectives of planners at PHAC and PHS, and how these factors influence the involvement of local agencies and youth.

### **2.2.6 Challenges of Citizen Engagement**

As advantageous and beneficial as citizen engagement in health research and planning can be, there are a number of challenges to achieving effective citizen engagement. One of the commonly cited limitations of citizen involvement is attaining representative participation (50,51). Engagement in health planning, particularly in a formal government process, requires

citizens to have a high degree of agency or empowerment (45). The need for personal empowerment to engage often results in the most marginalized populations being underrepresented in participatory processes. As put forward by Cornwall (50), “being involved in a process is not equivalent to having a voice. Voice needs to be nurtured” (p. 278). This same issue is present when including health professionals or local agencies in health planning; the most vocal participants are not necessarily the most representative. Another common concern of citizen engagement is what benefit citizens obtain out of the process. A system reliant on citizen contribution can drain limited community resources, particularly from community-based agencies or active citizens (48). Due to these challenges, engaging citizens in participatory process is often a resource intense process, requiring substantial time and financial resources from all parties involved (45,51,53,59).

## **2.3 Street Involved Youth In Canada**

### **2.3.1 Definition of Street-Involved Youth**

Although there are a variety of definitions and terms used to describe the population targeted by the E-SYS, the term that I will be utilizing is “street-involved youth.” Other common terms used in the literature include “street youth” or “homeless youth.” The term homeless youth has a number of limitations. First, not all youth involved in street culture are homeless. Secondly, many youth that fit within the category of “street-involved” do not identify with the term “homeless” (60). It is also important to acknowledge the diversity among street-involved youth, including the varying extents of their involvement in the street economy (61), and varying degrees of homelessness (62). This diversity results in a diversity of needs and vulnerability (62).

Within the E-SYS documentation, the Public Health Agency of Canada (PHAC) utilizes the term “street youth” to refer to this population. Although the written definition of street youth as used by PHAC (15) appears to capture the diversity of involvement with street culture, the term street-involved youth will be utilized in this study to make the diversity of involvement explicit. Street-involved implies a connection with street culture or the street economy, and includes those who are in conditions of absolute homelessness, as well as those who are in temporary states of homelessness, or housed but involved in the street economy.

As for defining the age of “youth,” PHAC, and most Canadian research define youth as those between the ages of 15 to 24 years of age (15). Although some researchers argue for no

lower age cutoff, this study is focusing on E-SYS and PHACs working definition of youth is framed by the ages of 15 to 24 (16).

### **2.3.2 Demographic Characteristics of Street-Involved Youth In Canada**

PHAC estimates that there are 150,000 street youth, and the Canadian Mortgage and Housing Corporation estimates there are 8,000 to 11,000 youth homeless each night in Canada (as cited in (11)). Most researchers agree that this number is likely underestimated due to the challenges of identifying street-involved youth, such as the street-involved youth who do not sleep in homeless shelters (63). The national E-SYS data from 1999, 2001, and 2003, report that the majority of street-involved youth surveyed are male (with twice the number of male to female), born in Canada, and Aboriginal youth are over-represented among street youth (14). The mean age of street-involved youth that have participated in E-SYS is 19 (14).

The primary source of Saskatoon-specific demographic data is E-SYS. However, in the 2008 homelessness count in Saskatoon conducted by the Community University Institute for Social Research, 23% of the identified homeless were estimated to be under the age of 25 (64). Of the youth who participated in Phase VI of E-SYS in Saskatoon, the age ranged from 16 to 23 years of age, and 55.7% of participants identified as male (44.3% identified as female) (65). Ninety-five percent of respondents self-identified as Aboriginal<sup>7</sup>.

### **2.3.3 The Health of Street-Involved Youth**

The largest health study conducted in Canada specifically focusing on street-involved youth is E-SYS. Although E-SYS is a surveillance study initially designed to monitor the trends of STBBI's (14), in its present inception E-SYS also captures the social context of street-involved youth. To this end, there is significant information available about the health of street-involved youth related to STBBIs, and their social context. However, E-SYS does not capture a lot of information regarding the broader health status of street-involved youth.

E-SYS data indicates that the rates of STIs among street-involved youth have increased significantly in Canada and Saskatoon over the past decade (11). Of the youth that participated in E-SYS in Saskatoon in 2005, 40% reported a history of STIs (66). This increase in STIs follows a

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<sup>7</sup> It is essential that any statistics regarding Aboriginal populations be framed within a historical perspective. This perspective acknowledges the historical and ongoing marginalization many Aboriginal peoples experience, and results in increased negative health outcomes. As stated by Smye, et al. (129), “persistent inequities in health and social status are indicators of longstanding, historically mediated disadvantages and economic and political conditions that affect many Aboriginal peoples” (p. 18). This will be discussed in greater detail in subsequent sections.



similar pattern of increasing rates of STIs in other developed countries such as Australia, the United Kingdom, and the United States (67). Within Canada, the reported rates of chlamydia infections have risen 13.6%, gonorrhea by 124.2%, and infectious syphilis by 516.7%, between 1998 and 2007 (14). In Saskatchewan, the reported rates of gonorrhea are fourth highest among Canadian territories and provinces (14). Across Canada, including Saskatchewan, street-involved youth face an increased risk of infection when compared to the general youth population (68).

The rates of HIV in Saskatchewan present a particularly poignant indicator of the increased health risks facing vulnerable populations such as street-involved youth in Saskatchewan. The incidence of HIV cases has continued to rise in Saskatchewan since 2006 (69). In addition, just under 50% of the new cases of HIV in Saskatchewan were reported in the Saskatoon Health Region (69). At particular risk for HIV in Saskatchewan are Aboriginal women under 30 years of age (69). Whereas the results from E-SYS in 2005 indicate that Saskatoon mirrors the national trend in most cases of STIs, reported rates of HIV and Hepatitis C in Saskatoon are higher than the national average (66).

The increasing rates of STIs within Canada, and specifically within the street-involved youth population, bring with them a number of critical public health concerns. As the rates of STIs in Canada increase, so do the health complications that result from STIs. For example, if chlamydia is left untreated in females, it can lead to infertility (70). Untreated STIs may also increase the risk of cancer, chronic pain, early death (62), as well as becoming infected with other, potentially more serious STIs such as HIV (71). These health risks are further compounded within Canada's street-involved youth population, who face additional barriers in accessing health care and social services (11,72).

Although there are not many epidemiologic studies quantifying specific disease risk in street-involved youth (68), it appears the overall health of street-involved youth in Canada closely mirrors the increased rates of STBBIs. Street-involved youth face increased risks of numerous poor health outcomes relative to the general youth population (11,68,73), including heightened prevalence of mental illness (60,68), substance abuse, and suicide, among others (68,74).

#### **2.3.4 Current Trends in Street-Involved Youth Intervention**

Currently there is an ongoing debate among academics and practitioners as to the best health intervention strategy targeting street-involved youth. According to Adimora and

Schoenbach (75), one of the greatest risk factors for STIs is poverty: “the physical and social circumstances associated with impoverishment hamper individually oriented behaviour risk-reduction approaches, because personal agency in situations of oppression is limited” (p. 119). Across North America, the majority of health interventions, including sexual health interventions, targeting street-involved youth focus on individual or behavioural change (13,76,77). However, given the continual rise of STI rates, there is increasingly a movement to amend these approaches, or shift more fully to a structural focus for health interventions. A number of these scholars argue for an adjustment to the traditional individual-level approaches of education and access (12,73,76,78); others argue for a paradigm shift, focusing on the structural determinants of sexual health in addition to the individual-level determinants (61,77,79-82). Whichever the case, there is an acknowledgement that more integrated involvement of street-involved youth is beneficial to the effectiveness of the intervention or program (11,60,82). Although research indicates the need for a change in health interventions with street-involved youth, the practice of health interventions has not heeded this call.

## **2.4 Engaging Street-Involved Youth**

There is growing interest in both research and health program planning to more actively include street-involved youth. There are a number of reasons why researchers and program planners are interested in street-involved youth playing a more active role in the planning stages, and there are an equal number of challenges. The following section will explore some of the motivations and challenges of engaging street-involved youth, as well as strategies to make engagement efforts more successful.

### **2.4.1 Why Engage?**

As discussed earlier, there are many reasons to include the population of interest in service design or research initiatives. This is also true of street involved youth, where the need for increased inclusion is even more apparent. As with many socially marginalized populations, street-involved youth are often disproportionately left out of service planning or research related to them (58,83). The exclusion of street-involved youth in planning and research also brings to question the representativeness and effectiveness of research and planning activities. The issue of representation is particularly important when considering street-involved youth due to the diversity within the population (60,73), as well as the manner in which data regarding street-involved youth is traditionally collected. Walters (84) argues that most data regarding street-

involved youth is collected through outreach services, but “fewer than one half of street youth use shelter or outreach services” (p. 188). It is also important to note that the majority of sexual health related programs targeted for youth are designed for mainstream youth, and generally the programs do not consider the differing life circumstances faced by street-involved youth (84).

One of the essential benefits of engaging street-involved youth is to better understand their conceptualization of health and the role of the health care system, which may differ from that of health professionals and the mainstream health organizations. For example, street-involved youth in an Ontario study expressed the importance of “feeling healthy involved having access to resources such as a place to have a shower and a safe place to live” (p. 1240)(85). Ensign (86) found that street-involved youth viewed the role of health care as improving their “functional status,” allowing them transition out of homelessness into more stable lifestyles. These conceptualizations of health differ significantly from a health care system steeped in a biomedical approach where health is about diagnosing and treating a disease (28). It is also important for researchers and program planners to understand how street-involved youth understand acceptable risk related to their health (84,87), and this means understanding their definition of health.

Involving youth in planning services and research can also serve to increase their confidence, social status in the community, and capacity to problem solve. Supporting the development of these characteristics within street-involved youth serves to improve their ability to navigate the structural barriers<sup>8</sup> youth face, improving their overall health (88). Engaging youth in planning also leads to the likelihood that youth will be engaged in phases of programming beyond planning, and increase the effectiveness of the program (89). Street involved youth also bring with them their insight and experiential knowledge. Youth have the primary knowledge of what motivates them to aspire to something different than street-involved life, and what the key barriers to this change are (82,85,90). Engaging youth can improve the effectiveness of programs (76,91,92), including ensuring programming is accessible to other street-involved youth (87,88).

#### **2.4.2 Challenges of Engagement**

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<sup>8</sup> Structural barriers refer to barriers that are created as a result of how a society is structured and include such social structures as government policy and social relations within a society. For a more detailed discussion of this concept see the work of Shoveller & Johnson (13).

There are a number of reasons that engaging street-involved youth is challenging for researchers and program planners. These challenges are both in the situational context in which street-involved youth exist, as well as in the organizational context in which researchers and program planners exist.

The experiences of youth becoming involved in street culture often create barriers related to trusting adults and barriers to meeting their own basic needs. As presented by Wingert, Higgitt and Ristock (74), “the process of becoming homeless involve[s] becoming increasingly alienated from the systems designed to support young people” (p. 65). This alienation often begins with experiences of youth losing or never establishing trusting relationships with adults. This mistrust of adults can be rooted in the home environment, as well as initial and ongoing experiences with professional services. The process of becoming homeless generally involves interaction with services designed to avert homelessness, and the failure of these services further compounds the precarious relationship youth have with adults, and services provided by professionals (84). Furthermore, many street-involved youth report experiences of discrimination from health and social service providers (12,72).

Presenting further barriers to engagement is the daily reality of street-involved life. Many health interventions targeting street-involved youth assume that health is a priority for street-involved youth; but, as discussed above, how health is conceptualized often differs between youth and professionals. Although youth are concerned about their health, the priority may be on securing basic necessities such as food and shelter (84,86). Furthermore, coping strategies utilized by street-involved youth such as drug and alcohol use may create their own set of barriers when interacting with service providers (12,72,83).

The structure and realities faced by the organizations attempting to engage the youth also pose significant barriers to engaging street-involved youth. Many community-based organizations as well as government services, face challenges of high staff turnover often resulting from inconsistent sources of funding (72). As mentioned above, trusting adults is a significant barrier facing street-involved youth, and developing a trusting relationship with adult service providers can take a significant amount of time that is undermined by staff turnover (76). Many organizations also require a significant amount of information from youth who access their services. This requirement can create barriers due to a lack of trust, as well as the reality that street-involved youth may not have a fixed address or necessary information (e.g. health card)

required by organizations. Services may also create access barriers through their limited hours or service location (12). Furthermore, the reality of street-involved life increases the likelihood that street-involved youth are engaged in some illegal activity. Youth may be hesitant to engage with services or staff they fear will report such activities to police, or report their existence to services that may apprehend and force them off the street (12). Given the limited understanding of street-involved youth and limited resources for services, many services are generic either to youth or homeless individuals. Many street-involved youth are not comfortable accessing services designed or accessed by homeless adults (74) and even services specifically designed for homeless youth may not be viewed as accessible (60).

Additional organizational barriers include the philosophy or ideology of the organization, as well as the differing agendas of service organizations and street-involved youth. Many organizations face a limited ability to establish their own research or program priority given that most funding comes tied to a previously established agenda set by the funding agency. The funders' agenda can limit the opportunity for organizations to embrace an agenda established or shaped by street-involved youth (52). The ideological or philosophical approach taken by organizations can significantly influence how engagement is conceptualized and whether it occurs at all. Boyce (52) argues that many agencies that offer technical services (e.g. housing, counseling) often perceive marginalized populations as passive clients, rather than active partners. Rew (93) argues that the deficit model is the base for many programs, and limits the conceptualization of services to merely achieving survival, and not necessarily thriving. As is often the case with marginalized or "vulnerable" populations, the populations are assumed to have restricted autonomy, and therefore not in a position to determine if they can participate or consent to their own involvement in research or planning efforts (94). Although the increased vulnerability faced by street-involved youth must not be dismissed, it is also essential that the autonomy they do have is respected and supported (60,73). Furthermore, if an organization perceives homelessness or street youth as an individual, rather than societal problem, it can significantly influence the type of engagement that is sought and received (89). In fact it has been convincingly argued that the discourse around "risky groups, risky behaviour, and risky persons," which dominates the public health field in Canada, serves to further marginalize and "unfairly punish" the youth that are most in need of support (13).

### **2.4.3 Successful Engagement Strategies**

Despite the many challenges in engaging street-involved youth, there are examples of successful involvement and engagement that can be learned from. One of the most crucial elements is to allow the time and flexibility to build relationships with the youth (86,95). The first steps in building this relationship is to show respect in interactions, and to meet youth where they are at. Respecting the youth in interactions means not only a non-judgmental attitude, but also speaking to youth in language they understand and not taking a lecturing tone (86). Meeting the youth where they are at also means understanding that the priority issues for the youth may not be the same as that of an agency or researcher. Respecting and supporting youth to address their priority issues will potentially build trust and establish a stronger relationship (12). It is also important to take into consideration where the youth live and exist, meeting them where they are comfortable and have established a sense of safety (58).

Establishing a relationship with street-involved youth also requires a genuine approach that acknowledges the difference in power between the youth and the professional (83). Youth engagement occurs in a context of organizational priorities and policies that shape the goals of youth participation. Acknowledging this environment and its influence is essential in establishing a genuine relationship (88). Despite the real limitations that exist in any organizational effort to engage youth, successful engagement activities should focus on the skills and strengths the street-involved youth bring to the process (93). In fact, proving that “street youth” can succeed can be an important motivator for street-involved youth (96). This is key to building a long-term committed relationship with street-involved youth and allows youth to represent as survivors with influence and control in their own lives (74). Lastly, Barry, Ensign, & Lippek (97) argue for a process that is not only youth-friendly, but youth centric, ensuring the youth are involved from the starting point and the process is formed around them.

#### **2.4.4 New Media & Youth**

Digital and interactive media (i.e. Web sites, social-networking platforms, multimedia and mobile media) have been shown to be particularly attractive to young people and is a new area for health care professionals to engage with youth (88,98-100). Even those youth facing socioeconomic barriers, such as street-involved youth, appear to be increasingly accessing and utilizing web-based media (98,99). Not only are the processes of utilizing new media attractive to youth, but creative approaches to working with youth in creating health promotion messages have been found to be particularly effective at incorporating youth perspectives (87,96).

One of the core components of PHS' KTE activities is to engage youth in creating digital stories about their experiences with street culture. Digital stories are, "short, first person video-narrative[s] created by combining recorded voices, still and moving images, and music or other sounds" (101). For the purposes of E-SYS, street-involved youth were invited to tell a story from their own lives, and shape that story into a digital story that lasts for approximately 90 seconds<sup>9</sup>.

## **2.5 Knowledge Translation**

Knowledge Translation (KT) is a common phrase across a number of disciplines, and generally refers to the process of research findings being disseminated and implemented or applied in real world settings or practice. The need for a focus on the application or implementation of research findings within the health field arose out of a number of concerns. First, there is an underlying belief that new research findings will increase the efficiency of the present health care system (1,3,4), and in turn improve the health of individuals (1,3,102). Secondly, there was a realization that merely the dissemination of research findings, without a focused implementation strategy, did not ensure the research findings were applied (102). Some KT scholars have even argued that KT will decrease the inequitable distribution of negative health problems (5,103,104). It is primarily these first two motivations that have driven the growth of KT literature within the field of health over the last number of years and will be the focus of the discussion below.

### **2.5.1 The Maze of Terms**

One of the challenges in providing an overview of KT is the many different terms related to knowledge translation and their varying perspectives on the process of implementing research into practice. Knowledge translation is closely related to implementation science, research utilization, knowledge dissemination or diffusion, research use, knowledge transfer, and knowledge exchange (102). According to Graham (2), knowledge transfer is the most common term within the health care field. Within PHAC's documentation of E-SYS, "knowledge transfer and exchange" is the term most frequently used. However "knowledge translation" is the term commonly used by the Canadian Institutes of Health Research (CIHR) and has also been adopted by the World Health Organization (WHO) (102). Knowledge translation, as defined by CIHR, is "a dynamic and iterative process that includes the synthesis, dissemination, exchange and

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<sup>9</sup> The specific process used in the digital story workshop put on by PHS will be discussed in more detail in Section 4.3.3.

ethically sound application to improve health, provide more effective health services and products and strengthen the healthcares systems” (p. 4)(102). Despite the various terms, it is important to keep in mind that what they share in common is “a move beyond the simple dissemination of knowledge into actual use of knowledge” (p. 2)(3).

For the purposes of this research project both the terms knowledge translation (KT) and knowledge transfer and exchange (KTE) will be used. KT will be used to refer to the general discipline of knowledge translation due to its common use within Canadian health literature. As KTE is used within PHAC and E-SYS literature to refer to knowledge translation, the term KTE will be utilized to refer to the KT efforts and thinking specifically related to E-SYS. Although the details of how PHAC influences the Saskatoon KTE process will be explored in more detail throughout the study process, it is important to recognize that PHAC does not adopt a specific definition of KTE or KT within their literature.

### **2.5.2 Knowledge Translation Frameworks**

Over time a number of different frameworks related to KT have been developed (2,105,106). These frameworks vary in their focus on what components make KT most effective (e.g. role of end-user, process of problem identification, dynamic vs. linear process) and have evolved to be linked to different theories of behaviour change. It is significant to note that these frameworks have evolved over time and while general agreement may exist between scholars on certain aspects of KT, there is still a gap between KT principles and practice (4). For example, it is now widely acknowledged within KT literature that the end-user should be involved in every component of the KT process, including problem identification and knowledge creation (2,4,6-8,107-109). This idea has not always been widely accepted, and there are still many cases where it is not practiced, and “end-of-grant” KT takes place (6). The gap between KT principles and practice is widely acknowledged among KT scholars (1,2,4,102,110), and is the basis for the breadth of KT research that has taken place in recent years, and part of the focus of this study.

### **2.5.3 Challenges in Knowledge Translation Practice**

Although there are a number of challenges between KT literature and the practice of KT, Lee and Garvin (111) identify three assumptions of traditional KT within the health field that merit exploration: (1) emphasis on the individualistic ethic; (2) privileging expert over lay knowledge and perspectives; and (3) information transfer as a “monologue.”

#### **2.5.3.1 Individualistic Ethic**



The concern raised by Lee and Garvin is that traditional health communication approaches emphasize individual-level education when targeting the public. This approach “assumes that a *better informed individual* is the most useful and appropriate solution to improving health: if people are given more and better information, they will behave in healthier ways” (p. 450)(111). This focus on the individual ignores the social, political and economic context in which the individual exists (112). Furthermore, it ignores the varying levels of agency individuals experience in their daily lives, and risks blaming the individual for any health problem. Most significant to this study, this approach can potentially ignore the SDOH and health promotion approach emphasized in Canadian health literature, and as adopted by PHAC (113). As previously discussed, many researchers have noted a prevailing emphasis on the individual lifestyle within the field of public health (22,23,28-30) and individual focused KT can serve to further reinforce this emphasis. This is not to say that all KT efforts emphasize the individual without considering the SDOH and other factors that influence health, but merely that one must approach KT dialogue with some caution and sensitivity to how health messages are framed.

#### **2.5.3.2 Privileging Expert Knowledge & Experience**

One of the central challenges that arises when applying KT frameworks is determining what constitutes knowledge (109). Within the field of health, knowledge has traditionally been defined as biomedical knowledge (49,110) or knowledge derived from scientific research (1,4). These traditional definitions of knowledge give “information providers – the ‘experts’ – the power to define ‘truth’” (p. 460)(111). As KT principles have developed over time, scholars have started to address this definition of knowledge. From a practitioner perspective, both Kirkham (49) and Hedges (114) acknowledge the role experience plays in day-to-day decision-making, and therefore argue for experiential knowledge to be incorporated into any conceptualization of knowledge. Smylie et al. (110) raise another important consideration in KT’s traditional definition of knowledge, proposing that “one major reason for the ineffectiveness of public health programs in Indigenous communities is that externally imposed strategies fail to take into consideration local understandings of health and illness” (p. 436). Although Smylie et al.’s work focuses on Indigenous communities, the impact of varying epistemologies between researchers and the end-user communities can also be applied to other communities, including street-involved youth. This concern with epistemology also brings to

light the importance of local context with KT strategies, as well as an integrated, dynamic exchange process, where the end-user community is intimately involved with the researcher(s) and common epistemological ground is located (5,109,115).

### **2.5.3.3 Information Transfer as a “Monologue”**

Although the majority of current KT literature addresses this concern, Lee and Garvin (111) raise the issue that KT can be “a monologue and [assert] that the provider can exercise power over the receiver” (p. 451). As mentioned, most of the current KT literature argues that the more end-user involvement in the research process, which includes determining the issue under study, the better and more effective KT will be. In most of the health-related KT literature the end-user is seen as health professionals (110), policy-makers or decision makers (108). When the end-user is the general public or a marginalized population, the issue of power is critical. As inclusive the study design and process may be, the issue of KT further enforcing the power of a health care provider over the user is still a concern especially when working with marginalized populations such as street-involved youth (109). Kirkham et al. (49) argue that the end-user population needs to experience more than participation to make KT successful; “inclusion alone is not sufficient – the nature of our questions, the research methods we use, the theoretical lenses informing research carry considerable importance in the types of knowledge that result” (p. 31). This raises important questions about how the research questions and theoretical framework determine the type of knowledge that is sought, and therefore the type of “solution” that is sought. Kirkham et al. (49) raise this question when stating, “traditional notions of evidence, based in Western science, may not sufficiently address the types of deep-rooted factors underlying health disparities...nor fully account for the complexities of people’s every day lives that ultimately shape health and illness to a significant extent” (p. 27). Concerted efforts must be made to ensure any participatory processes within KT address differences in power if the goal is empowerment.

### **2.5.4 Future of Knowledge Translation**

As mentioned above, there is a noted gap in research between KT literature and practice. Certain scholars have already identified significant omissions in the present conceptualizations of KT frameworks. Kirkham et al. (49) note the lack of consideration of power within knowledge development, and therefore a limited ability for present KT frameworks to uncover issues of injustice and marginalization. Other scholars (103,104) argue that there is presently a move

towards a “fourth wave” in KT research where social justice and issues of ethics receive greater attention.

### **2.5.5 Framing KTE within E-SYS**

Given the placement of the KTE activities as outlined in the *Cycle VI Protocol of E-SYS*, the KTE activities are most accurately conceptualized as “knowledge dissemination.” In fact, within the *Cycle VI Protocol*, the KT activities are described as “national” and “site-specific dissemination” (p. 13). Knowledge dissemination within KT literature (2) is conceptualized as occurring after problem identification, knowledge inquiry, and knowledge creation.

Within E-SYS, problem definition and creation of knowledge occur prior to the proposed KTE activities. As described by Venuta & Graham (116), “dissemination of knowledge focuses on communicating research results by targeting and tailoring the findings and the message to a particular audience” (p. 221). Given the proposed KT activities for E-SYS Phase VI, knowledge dissemination as described above, is a much more specific and accurate concept to describe the activities.

Although dissemination of the E-SYS results to local agencies and youth appears to be at the heart of KTE as outlined by PHAC, it is also important to acknowledge the potential for exchange. PHS engaged local agencies early on to determine the agencies’ interests in E-SYS data. Furthermore, the digital story process provides the potential for the E-SYS data to be framed by the local experiences of street-involved youth. Both these processes provide the opportunity to adapt the E-SYS findings to the local context and for exchange of ideas and knowledge between the various E-SYS stakeholders.

One of the challenges with how the E-SYS literature (16,117) frames KTE is that the great majority of KT literature focuses on the entire process of KT, and not specifically knowledge dissemination. For example, when exploring ways to effectively disseminate knowledge, the majority of KT literature explores potential improvements to the entire research or study process (i.e. problem definition, study design, etc.). To this end, I have included components of the E-SYS process that PHAC and PHS do not explicitly describe as related to KTE in responding to the research question.

Another significant challenge when applying the KT literature to E-SYS KTE is that the majority of the literature focuses on KT with policy makers, decision makers, and/or health

professionals, rather than “at-risk” populations. Despite these challenges, the core principles behind improving knowledge integration and accessibility to the end-user can still be applied.

### 2.5.6 Knowledge Dissemination Framework

Numerous frameworks aim to conceptualize the key factors involved in effective knowledge dissemination and integration. One of the greatest challenges in establishing a universal or objective model in knowledge dissemination is that each end-user is unique, making the process heavily dependent on context (5,109,112,115). To frame the interview guides for this thesis study, I utilized a conceptual framework developed by Jacobsen et al. (112). Jacobsen et al.’s framework is composed of five domains: (1) the user group, (2) the issue, (3) the research, (4) the research-user relationship, and (5) dissemination strategies. Within each domain, Jacobsen lists a series of questions that should be considered in developing KT activities.

In addition to these five domains, I also considered a sixth domain: resources available. In Dagenais et al.’s (103) research looking at KT in a population health framework they identify four general conditions that foster KT. These conditions are: (1) individuals, (2) organization, (3) strategies, and (4) resources available. The first three conditions fit within Jacobsen et al.’s framework, however the resources available are not explicitly considered within Jacobsen et al.’s framework. Resources, as described by Dagenais et al. include time, materials, and human and financial resources.

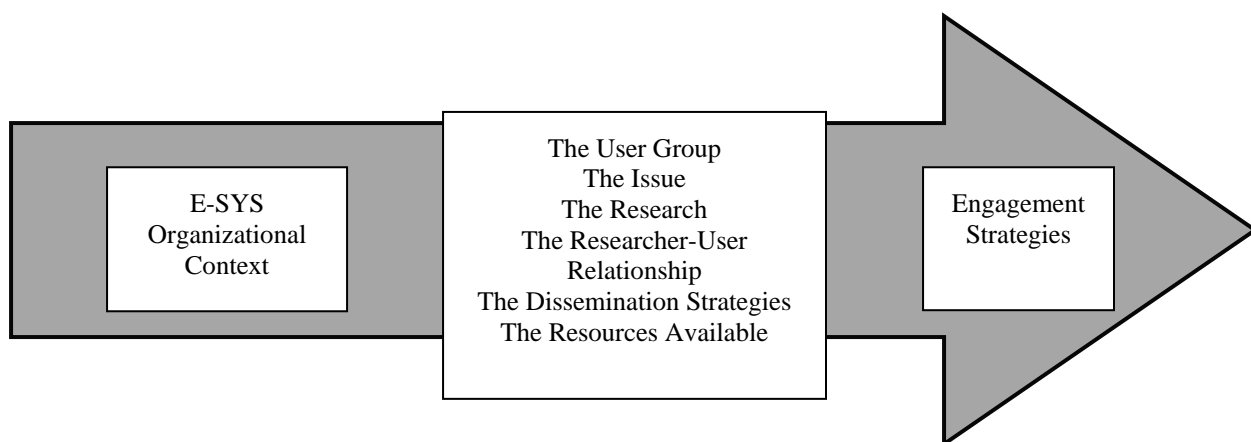


Figure 2.2: Six Domains of Influence on Engagement

As presented in Figure 2.2, the underlying conceptualization of the study is that the E-SYS organizational context influences the 6 domains described above, which in turn influence the engagement strategies, both in their success and the type of participation they envision for the youth. The domains were fundamental tools in the organization of the interview guide and were particularly helpful in the initial analysis.

### **2.5.7 Another Approach: Engaged Scholarship**

Although not formally adopted as a strategy by PHAC or PHS, engaged scholarship represents a body of work and approach to research closely related to KT in its concern with increasing the application of research findings (118-120). Similar to KT, engaged scholarship arose out of the gap that was occurring between principle and practice, or researchers and practitioners. In engaged scholarship, the gap is approached from the perspective of the scholar or academic. Although “typically framed as a knowledge transfer problem” (p. 802)(120), engaged scholarship views the gap as a knowledge production problem (119). To this end, engaged scholarship is defined as a “collaborative form of inquiry in which academics and practitioners leverage their different perspectives and competencies to coproduce knowledge about a complex problem or phenomenon that exists under conditions of uncertainty found in the world” (p. 803)(120). The focus within engaged scholarship on the issue of creating knowledge addresses some of the critiques of KT, and provides an important perspective on the knowledge-to-action gap.

Engaged scholarship academics acknowledge some of the tensions that arise out of conducting collaborative research (119-121), but conclude that the richness of research occurring within the practical world (120) as well as the ownership of the research by practitioners (119,121) improve knowledge integration and prove the value of an engaged scholarship approach.

Within this study, engaged scholarship serves as an alternate academic perspective to KT. In particular, engaged scholarship raises an essential perspective regarding the importance of knowledge production to increase end-user knowledge integration, a perspective that has not yet been fully integrated into KT literature and practice.

## **2.6 Conclusion**

Although dissemination of surveillance system findings to inform public health action is not a new concept, engaging in intensive KT is new to E-SYS, as is more in-depth engagement

with local agencies and street-involved youth. The concepts of citizen participation within health planning and research permeate throughout the history of public health. Although these concepts are well grounded in public health literature, there is no consensus on how integrated the practices of engagement and participation have become in public health practice. When public health agencies strive to engage populations in research and health planning, there are number of barriers facing the success of this engagement, particularly when that population faces marginalization such as street-involved youth. A clear and comprehensive methodology was needed in order to effectively navigate the complex issues and organizations involved within E-SYS and respond to the research questions, as will be presented in Chapter 3.

## CHAPTER 3 METHODOLOGY

This thesis study utilized a qualitative case study design, supported by semi-structured interviews, participant observation, and document analysis. The following section describes how the study emerged, the theoretical orientation, how the methods were applied and how analysis was carried out. Lastly, I review the considerations taken to ensure trustworthiness, and present my own KT efforts.

### **3.1 Background to the Study**

Importantly, this study was undertaken as an attempt to capture the realities of a public health organization undertaking KT in an everyday work environment of competing priorities and challenges. All the parties involved in E-SYS continually struggle with ways to share the E-SYS results in effective ways, agencies continue to support youth day-to-day, and street-involved youth continue to face the inequities that E-SYS strives to capture. This project was not conceived as an abstract concern, but as one grounded in this reality

This research project emerged out of a collaborative process between Public Health Services, the Department of Community Health & Epidemiology and myself as a student researcher. All three parties held a shared belief that research should strive to address existing health inequities. In order for research to possibly serve this function, it must be placed in context and informed by the experiences of those that would utilize the findings. All parties shared an interest in seeing research and practice connect, and applied this interest to how this study developed. Furthermore, this study fits with the emerging priority of KT within PHS and E-SYS. This study would not exist without the relationship that exists between the University of Saskatchewan and the Saskatoon Health Region, and their joint belief in the potential for research projects to provide some benefit to the institutions and the student researcher. Throughout this study, I have strived to respect this longstanding partnership, and hope that this project can contribute in some way to the ongoing fight to address the health inequities facing street-involved youth.

#### **3.1.1 Theoretical Perspectives**

Central to questions of knowledge, participation and equity, are issues of power. Power enforces certain forms of knowledge, certain forms of participation, and certain populations' participation over others. The structural implications of power also place certain populations at an increased health risk (22,29,32). Due to the central role of power within this thesis study,

critical theory's explicit focus on unequal relations of power and political grounding make it a uniquely pertinent theoretical perspective. As stated by Chinn (122), "a critical tale is one that reveals underlying social structures and power dynamics that influence and shape the world that has been studied or examined" (p. 281). Moreover, "from a critical perspective, research must be about empowering the marginalized and promoting action against inequities" (p. 208)(123). I also draw upon postcolonialism and postmodernism, two additional theoretical perspectives that highlight issues related to empowerment and giving voice to the marginalized. As described by Crush (124), "post-modern, post-colonial and feminist thought [have] converged upon the truth claims of modernism and shown how the production of Western knowledge is inseparable from the exercise of Western power" (p. 3). In addition to acknowledging the role of power, critical, postmodern and postcolonial theories are all explicitly political in their interest in empowerment and emancipatory processes (125).

### **3.1.1.1 Postmodernism**

Postmodernism represents a reaction to the privileged position of rational thought during and since the Enlightenment. To address the privileging of rational thought postmodernism invites traditionally excluded voices to be heard and understood, and their knowledge respected. Within research, "[a] postmodernist perspective seeks to include and use techniques, insights, methods, and approaches from a variety of traditions, reaching backwards, forwards, and sideways with little regard for academic boundaries or the myth of progress that condemns some texts as old fashioned while proclaiming others state of the art." (p. 417)(126).

Without the underlying structure of rational thought, postmodernists strive to present knowledge as embedded within a cultural, political and historical context. The result of this emphasis on context is that knowledge becomes localized (126,127). Local context is essential to this study, particularly as I will present differing forms of knowing from groups that are both traditionally empowered and those that are oppressed by historic and present systems of power.

Postmodernism also brings forward the issue of representation. As postmodernism questions the underlying ways that Western society has defined knowledge, it also brings forward questions of how knowledge is represented. To this end, postmodernism values diminishing the authorial voice, instead favouring multiple voices and "remaining faithful to the phenomena" (p. 210) (128). Accordingly, the goal of the postmodern researcher is to present the multiple voices engaged in the case under study. The underlying premise is that one form or type of knowledge



should not be valued above another, and therefore all truth claims or forms of knowledge must be presented on equal ground. This is particularly relevant with regard to the street-involved youth population whose voices are regularly ignored (94). Furthermore, the majority of street-involved youth in Saskatoon are Aboriginal, a population whose knowledge and voices have historically been and continue to be marginalized due to the colonial aftermath. Presenting the voices of street-involved youth on equal ground is ultimately an ethical responsibility.

### **3.1.1.2 Postcolonialism**

Postcolonial studies are particularly concerned with the relations and aftermath of colonialism that create a dominant discourse privileging certain voices over others (49). Similar to postmodernism, the intent of a postcolonial analysis is to challenge the dominant discourse and bring to light the material and discursive consequences of colonialism. Critiques of the dominant discourse are rooted in the understanding that knowledge and power are linked. Western systems have asserted, and continue to assert, their power over the subjects of colonization, and thus privilege Western knowledge over other forms of knowledge. As described by Crush (124), “there is a growing struggle within postcolonial thought to loosen Western knowledge and reassert the value of alternative experiences and ways of knowing” (p. 4). It is also important to note that postcolonial theory is not solely concerned with the historical acts of colonialism, but is concerned with the “ongoing neocolonialism characterized by oppressive tactics, economic and cultural hegemonies, and totalizing global expansions” (p. 29)(49). As such, postcolonialism informs my research approach as I challenge my own understandings of what constitutes knowledge, and aim to bring forward diverse voices and their knowledge.

In addition to reinforcing issues of power and knowledge, postcolonial theories provide their own unique perspectives to this research project. Browne et al. (129) suggest additional ways postcolonial theories can inform research including: (1) praxis-oriented inquiry and (2) “understanding how continuities from the past shape the present context of health and health care” (p. 19). Regarding praxis-oriented inquiry, this thesis project arose out of the realities of a public health field, and aims to provide insight into the practice of KT within a public health department. Although this thesis project is not overly focused on the history of health care, I do present a historical context of E-SYS, and how E-SYS sits within the larger public health discourse.

Lastly, Aboriginal youth are over-represented within the street-involved youth population in Saskatoon (65,130), and the history of and ongoing colonization, including the residential school system, heightens the importance of considering this study within a postcolonial perspective. As is evident in the following quote from Browne, Smye and Varcoe (129), colonial policies and actions continue to shape Canada to this day; “in the context of postcolonial (and some would say internal colonial or neocolonial) Canada, the regulation of the lives of Aboriginal peoples through social policies embedded in the Indian Act, the restrictions placed on Aboriginal self-government, land claims, and entitlements, and the restrictions placed on economic development in Aboriginal communities are vestiges of the colonial past. These in turn shape life opportunities, economic conditions, and the overall health status of individuals, families, and communities” (p. 19-20).

### 3.2 Case Study

Shaped by the theoretical perspectives of postmodernism and postcolonialism this study adopts a case study approach to explore KT efforts in Saskatoon. A case study approach defines what is being studied and this defined area of study represents one unit (125). In the study proposed, the case or unit, is the process of engaging street-involved youth and local agencies with the intent of disseminating the E-SYS Cycle VI results. As stated by Merriam (131), “there may be numerous events, participants, or phases of a process subsumed under the unit” (p. 46). As illustrated in Figures 3.1 and 3.2, this case study is composed of multiple stakeholders and multiple events, all of which compose PHS’ Cycle VI KTE activities.

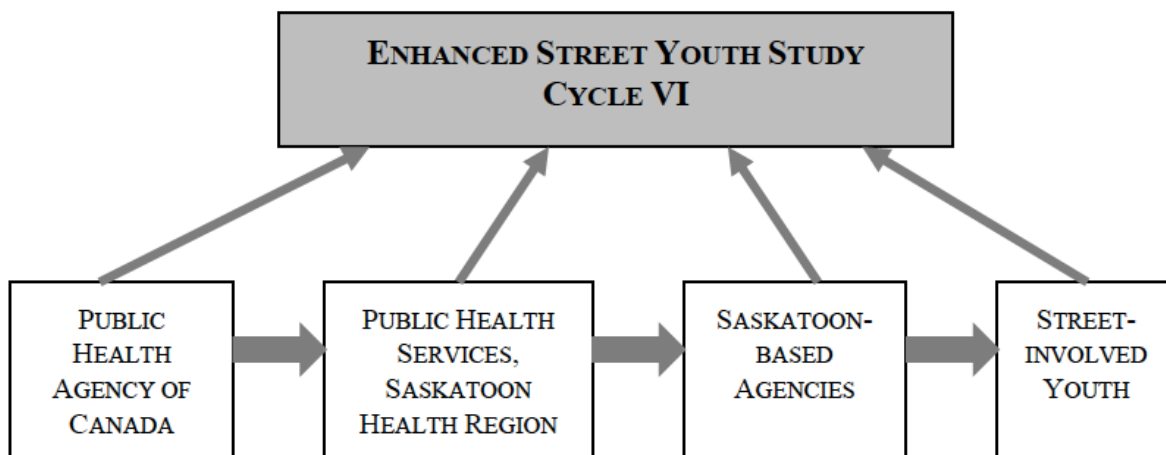


Figure 3.1: Diagram of E-SYS Stakeholders

Merriam's (131) four essential characteristics of qualitative case studies serve to highlight some of the underlying philosophical assumptions of case study research and guide this thesis project. First, Merriam views case studies as particularistic. Particularistic means case studies are grounded in a particular situation or phenomenon, defining case studies as bound to context. Stake (132) suggests that each case "is a complex entity operating within a number of contexts, including the physical, economical, ethical and aesthetic" (p. 239).

The second essential characteristic of qualitative case studies is that they are descriptive. Merriam states, "descriptive means that the end product of a case study is a rich, "thick" description of the phenomenon under study" (p. 13)(131). Hueristic is the third essential property of case study research, meaning it should "illuminate the reader's understanding of the phenomenon under study" (p. 13)(131). The goal of case study research is not objective generalizations, but providing the reader a detailed portrayal of the chosen case. Lastly, Merriam suggests that qualitative case study research is inductive. Any conclusions emerge from the contextual data, as opposed to the data being fit into a theory or pre-determined argument.

All four of these characteristics influence how this thesis study is designed and carried out, and how the results are presented and discussed. In an attempt to express the importance of context to this case study, the research questions explicitly explore the E-SYS context and its evolution over time. This study is based in the reality of the activities PHS undertook to engage local agencies and street-involved youth in knowledge translation efforts. These activities are in turn grounded in the broader context of E-SYS and the organizations that have shaped E-SYS. Thus, a "thick" description is provided of the E-SYS context and activities that PHS undertook. Presented alongside this description are the perspectives of those involved in designing and participating in the KTE activities.

In an effort to respect the four essential characteristics of case study, "one must physically go to the people, setting, site, institution...in order to observe behavior in its natural setting" (p. 19)(131). Prior to beginning my fieldwork for this research project, I was engaged with PHS in designing this thesis project, as well as supporting some of the early activities PHS engaged in to inform their KTE activities. This early engagement allowed me to enter fieldwork with a familiarity of the local agencies, PHS, and PHAC and the overall context of E-SYS in Saskatoon.

### **3.3 Data Collection**

The thesis project utilized key stakeholder interviews, participant observation, and document review as the primary forms of data collection. Data collection took place in Saskatoon between the months of January and May 2011. It is worth noting that data collection took place while the KTE activities were underway, and therefore the timing of data collection with these activities provided a natural limitation. Figure 3.2 provides an overview of the activities related to Phase VI of E-SYS, the KTE activities, and the actual process of collecting data, while the following sections describe how the methods were applied.

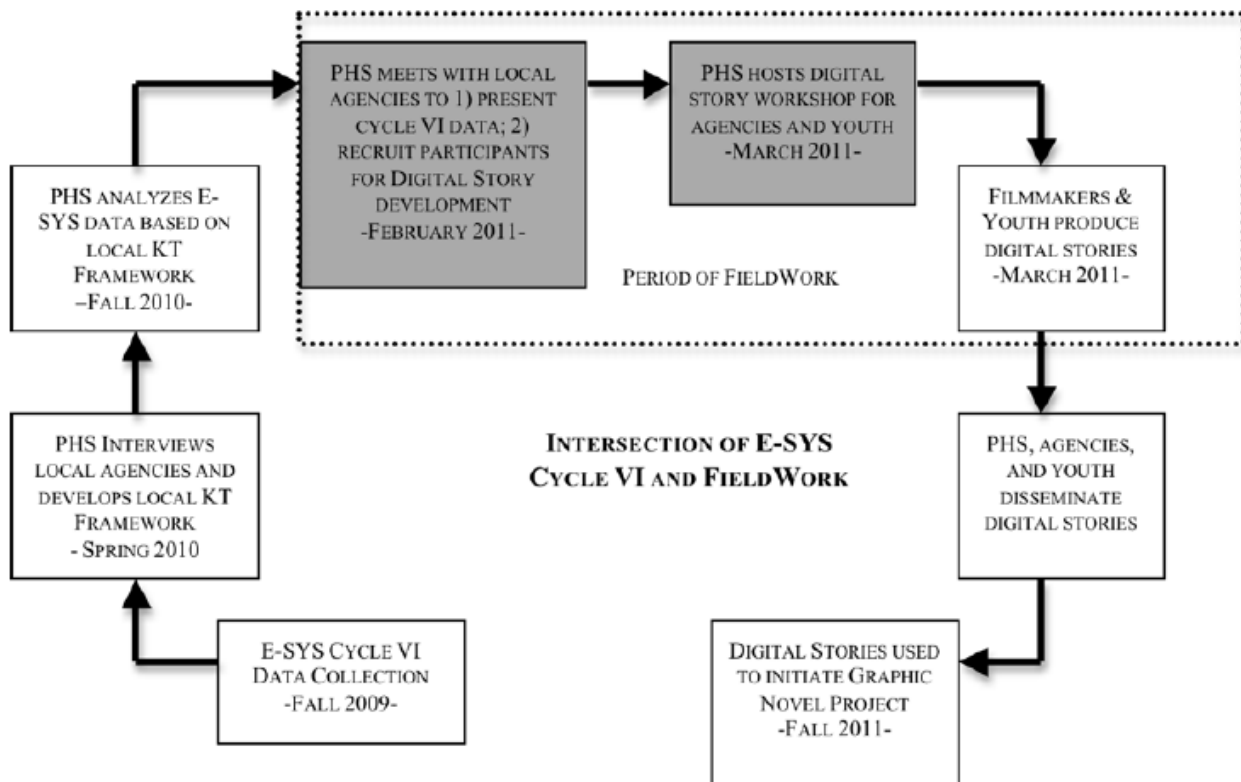


Figure 3.2: Intersection of E-SYS Cycle VI and Fieldwork

### 3.3.1 Key Stakeholder Interviews

In an effort to value each participant’s unique perspective and expertise, interviews were conducted in a semi-structured format. According to Sterk and Elifson (133) “the assumption underlying semi-structured and unstructured interviewing is that the study participants are knowledgeable, have a meaningful perspective to offer, and are able to make this explicit in their own words” (p. 137). With this in mind, semi-structured interviews served as an ideal approach due to the value they place on participant opinion and perspective.

The original interview guide was informed by Jacobsen et al.'s framework (112) (see Appendix I), the research questions (see Section 1.1), and further informed by the documents described below. Prior to each interview, the interview guide was amended, with significant differences in some questions based on the organizational level corresponding to each participant. The process of amending or refining the questionnaire is not uncommon within qualitative research, and it is an acceptable strategy in order for each action to build successively on the previous one (134).

I conducted fourteen interviews between January and May 2011. With the exception of those participants who did not work in Saskatoon, interviews occurred in person at a location selected by the informant. For those participants not based in Saskatoon, the interviews occurred over the phone. The majority of the interviews were audio-recorded, however four participants expressed their desire not to be recorded. As such, their perspectives were captured through the notes taken during the interview and field notes written immediately following the interviews.

As illustrated in Figure 3.1, E-SYS is composed of representatives from PHAC, PHS, local agencies, and street-involved youth. As such, informants were chosen to represent these four levels of stakeholders. Table 3.1 provides a breakdown of informants by organizational level, gender and age.

<b>Organization</b>	<b>Number of Interviews</b>	<b>Gender (Female: Male)</b>	<b>Age Representation (Under 24: Over 24)<sup>10</sup></b>
Public Health Agency of Canada	3	2:1	0:3
Public Health Services	5	4:1	0:5
Local Agencies	3	2:1	0:3
Youth	3	1:2	3:0

Table 3.1: Interview informants by organizational affiliation, gender and age.

<sup>10</sup> The age of 24 is used as the point of separation as it is the upper limit of E-SYS' definition of youth as discussed in Section 2.3.1.

Informants were selected based on their knowledge and/or involvement with E-SYS and the KTE activities, as well as their willingness to participate in this research project. Potential PHAC informants were identified based on their past and/or present involvement with E-SYS, and the invitation to participate in the study was extended by a PHS representative. Due to my familiarity with PHS and the local agencies at the time of fieldwork, the invitations to participate were extended directly by me. Invitation to the youth to participate in this study was extended at the digital story workshop, and facilitated by the local agency that had invited the youth to the workshop. Interviews began in January with those informants with a more contextual perspective, focusing on PHAC and PHS. Once the March 4<sup>th</sup> and 5<sup>th</sup> Workshop took place, interviews were conducted with local agencies, youth and some PHS representatives.

### **3.3.2 Observation of Youth Engagement Activities**

As efforts were made throughout the fieldwork to engage street-involved youth in the KTE activities, participant observation of the KTE activities proved essential. As suggested by Flick (135), “observation...enables the researcher to find out how something factually works or occurs” (p. 215). In this way, observing the youth engagement activities allowed me to document the actual process and activities. I utilized an *observer as participant* approach as defined by Polgar and Thomes (136) allowing me to interact with participants and “ask questions and search for answers” (p. 739)(137). Along with seeking the opinions and reactions of the street-involved youth, I also documented in detail the manner in which the activities were carried out in an effort to provide a “thick” description of the KTE activities.

The actual observations of the KTE activities were carried out in two specific instances: (1) the February 14<sup>th</sup> event at the Broadway Theatre, and (2) the March 4<sup>th</sup> workshop at the West Winds Community Clinic in Saskatoon. Notes were taken throughout the observation process with additional field notes written immediately following the events. No identifiers were made or kept of the participants at these events.

### **3.3.3 Document Review**

The intent behind document review as a data collection strategy is well articulated by Sterk and Elifson (133): “documents not only provide valuable data, but the investigation of documents also is likely to generate new areas of inquiry that may not have emerged if data collection has been limited to interviews” (p. 144). The types of documents I was able to access

for analysis include PHAC and PHS authored documents that reported on previous E-SYS phases, as well as documents that outlined guidelines and responsibilities for community sites to conduct E-SYS.

Prior to entering the field, I was able to access a number of documents that served to inform and provide context to this thesis study, and specifically the interview questions. Not only did this allow to me ground the interviews, but it allowed me to more fully engage in the interviews due to my familiarity with E-SYS and some of the surrounding issues. In a number of the interviews I also sought recommendations for further documents that could inform this study. A number of participants facilitated access to these documents if they were not publicly available. Throughout the analysis process, the documents served to complement the data that was gathered through interviews and observation. In particular, the documents proved to be useful in tracing the history of ideas and evolution of the E-SYS and KTE discussions.

### **3.4 Data Analysis**

Within qualitative research, analysis often occurs concurrently with data collection (138,139), and “in the process of analysis, data are consolidated, reduced, and to some extent interpreted” (p. 130)(131). The following will provide an overview of the analysis process and decisions made throughout. The analysis process in this study followed both inductive and deductive paths at varying times in a complementary manner. Prior to beginning fieldwork the process of analysis began with reviewing documents to inform the approach to the study and the interview guide. As the interviews were conducted, what was immediately learned from the interviews influenced the future interviews, providing clarity and new avenues of inquiry to explore.

As each interview was completed, I began the process of transcription and this continued throughout the fieldwork process. Upon completing transcription following data collection, I re-listened to the audio recordings, checking the interviews for accuracy, and organized all the data in preparation for analysis (139). Analysis involved re-reading the transcripts repeatedly, noting preliminary themes that emerged. I also highlighted and coded those sections of the interviews that spoke plainly and coherently, as well as ensuring as diverse a representation of voices as possible within the preliminary themes. Coding, as described by Creswell, is the process of “organizing the material into chunks or segments of text before bringing meaning to information” (p. 186)(139). After reviewing and coding the transcripts, I organized the codes into themes

based primarily on Jacobsen et al.'s conceptual framework (112), with other themes emerging directly from the data. I continued the analysis process, re-coding, questioning the initially identified themes, and exploring alternate ways to organize the data.

The final step in qualitative analysis is, “making an interpretation or meaning of the data” (p. 189)(139). As issues of representation are raised by both postmodernism (126, 140) and postcolonialism (129,141), I sought to gain participants’ interpretation of the events to present alongside my own. While my overall interpretation of the data will be presented in the Chapter 5, I will present interpretations offered by the research participants in Chapter 4.

### **3.5 Issues of Trustworthiness**

Given the explicitly social nature of qualitative research, Schwandt (142) discusses the challenge of a “valid” interpretation by any researcher: “interpretations are always made in a context or background of shared (social) beliefs and practices... [interpretations are] infused with political and ethical implications related to matters of power and authority” (p. 12). Researchers have argued that within naturalistic inquiry, and specifically within critical research trustworthiness is a more appropriate term (125,143). In an effort to further clarify these issues, Lincoln and Guba (143) present trustworthiness as being comprised of a number of central concepts including credibility and dependability. In addition to the criteria proposed by Lincoln and Guba, I will also address the issue of reflexivity given its prominence within standards to assess qualitative inquiry, and its grounding in critical theory (144-146).

**Credibility.** Lincoln and Guba’s (143) description of credibility includes a number of processes including prolonged engagement, persistent observation, triangulation, and negative case analysis. In an effort to meet the criteria of prolonged engagement, I have engaged with PHAC, PHS and local agencies to varying extents since late spring 2010. This has not only served to provide me with a deeper understanding of the issues facing the stakeholders upon entering the field, but it has informed my analysis and KT related to this study. I sought to triangulate data through the various data collection strategies (interviews, observation, documents) and the various informants (PHAC, PHS, CBOs, and street-involved youth). Lastly, negative case analysis outlines a search for statements and understanding contrary to the initial understanding, and incorporating those contrary understandings into the final report and interpretation. Through repeated reviews of the data, and specifically the transcripts, I have



strived to stay true to the data particularly when the data challenges my own perspective or interpretation.

**Dependability.** Lincoln and Guba (143) describe the researcher's ability to achieve dependability through the presence of a clear audit trail that could be followed by another researcher. To this end, I have provided a detailed account of my own analysis and fieldwork, documenting the judgments and decisions I made as a researcher, and providing a clear description of the context for those judgments. Although some of the decisions and judgments may not be the ones made by the reader, I have strived to present these judgments in a spirit of transparency and dependability.

**Reflexivity.** Reflexivity, an essential concept within qualitative research is, "an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process" (p. 484)(147). As described by Merriam (131), "all observations and analyses are filtered through one's worldview, one's values, one's perspectives" (p. 39). Due to these realities, understanding not just the theoretical perspective of the researcher, but the researcher being aware of and making known, how their personal background and epistemology influence their approach and participation within the research is essential (134,144,145,147).

Merriam (131) suggests that one's view of the world and thinking is significantly influenced by their academic discipline. Furthermore she suggests that, "this perspective affects the nature of the question raised, which in turn determines the research design, which in turn influences the conclusions drawn" (p. 54). To this end it is important that I acknowledge not only the influence of my present department of study, Community Health and Epidemiology, but also the influence of the discipline of social work on my approach and thinking in regard to research.

Miley, O'Melia and DuBois (148) trace the influence of social constructionism<sup>11</sup> and feminism within the field of social work. Within social work, social constructionism places individuals within the social and cultural environment, emphasizing "the social elements of meaning generated through language, cultural beliefs and social interaction" (p. 31)(148). Feminism brings a political element to social work practice and challenges practitioners to

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<sup>11</sup> As defined by Miley, O'Melia and DuBois (148), social constructionism focuses on how people construct meaning in their lives, emphasizing "the social elements of meaning generated through language, cultural beliefs, and social interaction" (p. 31).

address gender bias and oppression in their practice; “feminism forces workers from a stance of neutrality into a position of advocacy” (p. 32)(148). These two theoretical perspectives capture the essence of my approach to research as influenced by social work, recognizing the social, political, and economic influence on the research and the research problem, while overtly intending my research to contribute to challenging the oppressive structures that presently exist.

As much as one’s discipline and studies shape their approach to research, it is also essential to identify that one’s personal background influences their approach to their study. To this end I must acknowledge the privilege and power I experience as a white male of western-European descent living in Western Canada, and as a Master’s student. To borrow a phrase, I am overprivileged (149). My reality, both historically and day-to-day, is significantly different than that of street-involved youth. I have worked closely with street-involved youth and adults in the past, both within the context of community-based organizations and as a government employee. These experiences have challenged me to continually explore my role within these systems of empowerment and oppression, and provide me with a window into a world I have only witnessed from the outside. This exploration has left me grounded in a commitment to social justice, and it is with a spirit of humility grounded in a commitment to social justice and equity that I carried out this study.

### **3.6 Ethics**

This study received ethical approval from the University of Saskatchewan Behavioural Research Ethics Board on January 6, 2011 with amendments on April 21, 2011. This study also received ethical approval from the Saskatoon Health Region on January 20, 2011. I obtained oral consent for the interviews conducted over the phone and written consent for the in-person interviews. The only exception to this was with the youth informants. In an effort to accommodate varying levels of literacy, I sought verbal consent with the youth, and the consent form was read and reviewed with them prior to beginning the interview. In the case of observation, I presented an explanation of the research project and the consent to any observed participants, and they were provided an opportunity to withdraw their consent at any point throughout the observed activities, as well as following their completion.

### **3.7 Limits and Delimitations**

As with any study, there are a number of limitations and delimitations that were present throughout the study design and process. A significant limitation of this study was that I

approached the participants and the project through a collaboration with PHS. This partnership strengthened the thesis project, but it also aligned me with PHS as I engaged with participants. There were experiences in the fieldwork where I feel participants hesitated or held back in fully sharing their perspective due to my relationship with PHS. Although this hesitation could be due to any number of factors, my relationship with PHS inevitably shaped these interactions. Another factor that shaped interactions with participants was the fact that Saskatoon is a relatively small community, particularly the community of professionals associated with E-SYS and street-involved youth. Although no names or positions are used in the presentation of the results, certain participants were very conscious of how they framed their perspectives, and were particularly sensitive in how their perspectives may be interpreted by others.

Another noteworthy limitation I faced was that a number of local agencies that have been involved with E-SYS did not participate in the study. The majority of agencies that were willing to participate in this study described themselves as having a fairly positive relationship with PHS in particular. However, it was very clear from interactions with PHS and local agencies, that there are other experiences and perspectives within the Saskatoon community.

The majority of the key delimitations faced in this study are related to the limits of a Master's level research project and the decision to utilize a case study design. As identified earlier, fieldwork took place between January and May 2011, but the KT work related to E-SYS continues at the time of writing. Time also impacted the fact that certain participants were not provided the opportunity to comment on the completion of the KTE activities undertaken by PHS. Although interviews were designed strategically to capture the greatest diversity of perspectives, certain interviews occurred earlier in the process than was ideal for commentary on the actual KTE activities. Furthermore, there are a limited number of participants, and therefore a limited number of perspectives.

Lastly, it must be stated that this project was not designed as an evaluation of the KTE activities of PHS or E-SYS in general. This study was designed to capture the context in which KT has emerged as a priority, and how the organizational context of E-SYS has influenced the efforts of PHS to engage local stakeholders. The engagement and participation of the KT targets is essential to any KT related activity and without engagement of those populations, the effectiveness of KT is greatly compromised.

### **3.8 Relevance & Knowledge Translation**

As outlined earlier, this study arose out of real pressures and questions that PHS and E-SYS were facing. Due to the partnerships that existed prior to my involvement, I was able to engage in meaningful discussions with PHS about their areas of interest related to E-SYS. It was out of these discussions that KT emerged as a priority, along with the broader issues of accountability in research.

This research project has explored a topic of interest to PHS, and a priority area for PHS and PHAC. Postcolonial theory explicitly emphasizes the importance of praxis-oriented inquiry and a commitment to “redressing inequities” (129). Furthermore, Kvale (150) and others (146) have suggested that qualitative research should be evaluated based on the capacity of the developed knowledge to be understood and implemented.

Given these considerations, and in the spirit of reciprocity, I have been able to offer support to a number of PHS activities related to E-SYS. Specifically related to this research project, I am producing a companion report to the thesis that I will share with PHS and other interested participants. This report is intended to share the more pragmatic findings of the study regarding KT and the local efforts to engage agencies and youth. I have also had the opportunity to support a local community-based organization in their application for funding to continue to build off of the digital stories, providing employment opportunities for young artists and further opportunity for street-involved youth to share their experiences. Lastly, I have participated in some preliminary meetings with PHAC and other E-SYS community sites to develop a comprehensive national KTE strategy.

## CHAPTER 4 RESULTS

The primary research question guiding this thesis study is: *What do Public Health Services' efforts to engage local agencies and street-involved youth in knowledge transfer and exchange activities reveal about the influence of the E-SYS organizational context on youth and agency engagement?* In order to answer that question, the context of E-SYS as a study composed of multiple players must first be explored, along with an account of how KT emerged as a priority for the organizations involved in E-SYS. Second, a description of the specific activities that PHS' undertook to engage local agencies and street-involved youth in Phase VI KTE will be provided. The final component of this chapter will examine the influence of the E-SYS organizational context on engaging street-involved youth and local agencies in the KTE activities.

The various components of the research question will be addressed through use of the assorted forms of data. Individual interviews form the primary set of data to answer these questions, however the participant observation specifically informs the description of the KTE activities that PHS undertook. Additional data are provided by documents that were collected from both PHAC and PHS. The sources of the data are noted throughout the presentation of the results.

The presentation of the results relies heavily on the use of select quotes from the interviews. The intention behind this reliance on the direct quotations is two fold. First off, how I integrate postcolonial and postmodern perspectives highlights issues of representation, and direct quotes limits my interferences with representation. Secondly, the extensive use of quotations allows me to ensure as many different voices as possible are represented.

Given the nature of the organizational levels involved in E-SYS, certain informants are better positioned to comment on particular aspects of the research question. Certain PHAC and PHS participants, for example provide insight into the historical context of E-SYS and the emergence of KT as a priority. Within the historical sections, there is limited commentary from the local agencies and youth. The voices of the local agencies and youth are most prominent in descriptions of the actual KTE activities.

### **4.1 The Historical Context of the Enhanced Street Youth Study**

This section offers an overview of the emergence of E-SYS as a national study. Following a brief historical account of E-SYS, I will provide a breakdown of the actual process

of conducting E-SYS in Saskatoon along with a brief explanation of the roles of the various organizational partners.

#### **4.1.1 E-SYS Inception**

The inception of E-SYS is well documented within a number of PHAC reports including *Street Youth in Canada* (15). Based on interviews with PHAC and PHS representatives, the accounts of this history are uncomplicated. As shared by one PHAC participant:

The rationale for beginning the enhanced youth surveillance is something that was discussed back in 1997, when a group of STI [sexually transmitted infection] clinic directors met, as they typically did in those days...They were reviewing the notifiable STI stats and not surprisingly, noted the alarming burden that, at least based on reported rates, that the youth have when it comes to Chlamydia and gonorrhoea. So the thinking was at that time, 'you know we really need to find out more about what's happening within the youth population.' Keep in mind those directors were from, you know across jurisdiction...The feds and their various counterparts were meeting just to talk about the STI stats. It was also a time when they were discussing whether there ought to be any national goals around STIs. Something to shoot for...and so it was back in 1997 that this group, STD [sexually transmitted disease] group, federal, provincial, territorial group, decided that it would be really important to look at more of what's happening among the youth, and in particular, among street-involved youth. 'Cause in the youth spectrum, they may be the most vulnerable of the youth.

As articulated by the informant, there was general agreement among the federal, provincial, and territorial partners involved. What was unique about the follow-through from the partners was the decision to develop a national surveillance system. Although some preliminary research on the health of street-involved youth was taking place in Canada at the time, a surveillance system focused on street-involved youth was a novel idea in the Canadian landscape.

I mean there were certain research studies. Say for example in Montreal, Dr. Elise Roy was doing a research study on street youth, but not a surveillance study. The difference between...surveillance and research is research tends to be a very time limited thing...whereas surveillance you know, systematically, ongoing collection of information.

In late 1998, the pilot phase of E-SYS initiated by the Division of STD Control & Prevention in Health Canada, took place in Vancouver, Ottawa, and Halifax (15). Following what was determined to be a successful pilot phase, E-SYS was expanded. From Phase II until the present, E-SYS community sites have included: Vancouver, Edmonton, Saskatoon, Winnipeg, Toronto, Ottawa, and Halifax (15). E-SYS has collected data approximately bi-

annually, with Phase II occurring in 1999, Phase III in 2001, Phase IV in 2003, Phase V in 2005, and Phase VI still ongoing in some sites in 2011.

#### **4.1.2 E-SYS Objectives**

Since Phase I of E-SYS, the objectives have been clearly articulated and as one can expect from a surveillance system, have changed very little. In fact the infections that have been monitored (chlamydia, gonorrhoea, syphilis, HIV, herpes simplex virus, hepatitis B, hepatitis C) have not changed with the exception of the addition of Human T-lymphotropic virus (HTLV) to the list monitored infections. What appears to have changed is the expansion of the objectives to explicitly include studying “risk behaviours” related to the infections. As articulated by one informant, the determinants around transmission of infections and the reported rates of infections are inseparable:

Via the reported rates we know that the burden is higher among the younger populations. And so it’s really important to find out what are the factors? What are the determinants? What are the trends and why does this happen? And so, the whole questionnaire of street-involved youth was built to address the broader issues around transmission of STIs. Yeah, that was the driving force. But you can’t be talking about STIs in isolation without talking about the determinants of health. Without looking at not just HIV, but all the relevant sexually transmitted infections which we do....I mean that piece hasn’t changed at all, and it’s informed and influence by the environments that the youth find themselves in. So that’s been the main goal, and that goal, really remains unchanged.

Although arguably the objectives of the surveillance system have not changed significantly over its existence, there had been a shift in how the results are framed and how intentionally those results are shared. A few informants who have a historic familiarity with E-SYS attributed this shift to increased knowledge of the infections within street-involved youth.

Well, just from what I’ve read and heard, I think the study has certainly gotten better over time. Gotten better in certain things. I think, and I have to be fair to the study. I think initially when they were doing more of the baseline, trying to get some baseline data and information across Canada that was sort of a different stage. But it seems like now the study has moved to a point where they’re very concerned about transferring the knowledge and the information they get out of doing this work. And putting this information back into the hands of people who can use this.

This notion that the initial phases of E-SYS were to capture a “whole picture” of the health of street-youth related to STBBIs was echoed by a number of the informants from PHAC and PHS who have had involvement in E-SYS from early on. These same informants expressed a

noticeable shift in the E-SYS efforts in more recent years to more intentionally share the E-SYS results in an easily applicable form. This priority of sharing the E-SYS results and the emergence of KT will be further explored in Section 4.2.

#### **4.1.3 E-SYS Study Design**

As discussed in Chapter 2, the design and process of a research study or a surveillance system influences the effectiveness of KT efforts related to that study. To this end, it is important to outline the design and processes involved in carrying out E-SYS. Although slight differences are inevitable from phase to phase, what is presented below is a general overview of the design and process and a description of the roles of each of the organizational levels involved in E-SYS.

The *Procedural Guidelines* (117) state, “surveillance was designed as a cyclic, multi-centre cross-sectional survey.” As multiple sites across multiple jurisdictions are involved in each E-SYS phase, PHAC has taken on the role of coordinating and initiating the E-SYS phases.

So basically PHAC’s role is initiating data collection, and helping to organize and implement across all the sites. But it really is the sites that make E-SYS successful because they’re responsible for the actual data collection and they do their own site-specific analysis. Whereas at PHAC we would do more national and aggregate analysis, or trying to look at the differences between sites.

One of the challenges of coordinating a multi-site surveillance system is ensuring consistency across sites and over time, to maintain the integrity of the surveillance system. In regards to maintaining site participation over time, E-SYS has been relatively successful.

I think the fact that our partners, the sites are just...they’re definitely motivated. I mean we’ve had partnerships going for like 10, 12 years now. That’s a lifetime in any other kind of context. And the fact that there’s been that continued involvement is I think a testament to the importance of not losing out on what the data and information can tell us as it informs other contexts.

This informant identifies continued access to E-SYS data as one of the important motivators for successful partnerships, but equally as important is the financial support provided by PHAC to carry out E-SYS.

So the role of the feds has been in providing the technical and the content support, the funding to allow for a national roll up, and in essence the stewardship in working with various sites that are interested in participating to move this forward. And that role in a sense continues to date.

In addition to the financial and technical support the sites receive, one PHS informant spoke of an underlying motivation for their continued participation.



I think it may have been because it's a Public Health Agency of Canada project, and [PHS] like[s] to be seen as participating in national research. So there's a certain amount of, I don't know, prestige or something there. But it may also be because [PHS] have so little focus on youth, that it felt like something that they should be paying attention to.

No matter what specifically motivates the local sites' participation, both PHAC and the local sites recognize the integral role that the local sites play in continuing the surveillance system. The importance of the community sites to the success of E-SYS was poignantly described by one PHS informant:

They [PHAC] recognize that they're too far away from the ground to see really what's relevant or what's the language or whatever. And they say, and they've said this more than once, 'we're depending on you to provide the context. We don't have the context. You have the context.'

#### **4.1.3.1 Questionnaire**

One of the first steps in each E-SYS phase is refining the questionnaire that is utilized to collect information from street-involved youth. As described in *Street Youth in Canada* (15), "the questionnaire was modified at the start of each data collection phase to respond to new information obtained during the previous phase. Core questions, however, remained unchanged, allowing for time trend analyses of disease prevalence as well as key risk factors" (p. 41). This process was further described by one of the PHAC informants:

So I believe as far as Cycle 1, it was fairly comprehensive. We haven't necessarily taken away, or added to the infections that we look at...The general flow and the content of the questionnaire has been fairly stable and it needs to be because this is a repeat cross-sectional surveillance system, and if you mess with the questionnaires too much you're going to lose out on trend analysis. But what has happened over time, because the epidemic might change, might shift, we need to be modifying the questions as appropriate to be in line with what are the latest with respect to the epidemiology.

The process of revising the questionnaire throughout the history of E-SYS has involved PHAC consulting the sites as well as "experts in the field and other stakeholders" (p. 6)(117). As identified in the quote above, the design of a surveillance system limits the extent that the questionnaire can change from phase to phase, and PHAC has been responsible to balance the changes needed to ensure E-SYS is relevant, while trying to maintain the integrity of the surveillance system. Despite the limited changes PHAC can make, a number of the local informants described PHAC's approach as responsive to the site needs and requests.

...I think [PHAC] are fairly responsive. I think [PHAC] made some changes to the questionnaire, but again they were trying to based on the feedback from the sites who thought it just sucked big time.

This statement also highlights one of the on-going tensions with the E-SYS questionnaire that was frequently identified by a number of the local PHS and agency informants, and will be further discussed in section 4.4.2.1.

#### **4.1.3.2 Recruitment**

Once the questionnaire has been revised, the next step in the surveillance system is recruiting the street-involved youth participants. The general recruitment method is laid out within the *Procedural Guidelines* (117):

Recruitment methods are tailored to each centre's conditions and requirements as well as capacity to process potentially large numbers of candidates interested in participating in the survey. Recruitment strategies may involve staff in drop-in centres promoting the survey to their clients prior to the survey implementation period. Staff at participating community-based agencies that serve street-involved youth may also be asked to promote the survey, prior to and throughout the recruitment period, although this is site-dependent (p. 7).

Each community site undertakes the recruitment process as best fits the work of the community site and the identification of street-involved youth. The general recruitment strategy is described as snowball sampling (15), but each site adapts this strategy to suit their specific site. This flexibility in recruitment was further described by one of the PHAC informants:

So the idea has always been around outreach. So whether you're a street nurse being on the streets (which is the case in Vancouver), or whether you are actually recruiting in youth drop-in centres, it's ultimately about identifying where the youth are. And then the word of mouth gets friends and other people coming into the recruiting phase. So it's built on outreach.

Within Saskatoon, partnering with local agencies has always been an integral part of the recruitment process. One PHS informant who has been actively involved with E-SYS in Saskatoon since it began describes the recruitment strategy as follows:

For the most part our clientele in Street Health that are high risk, tend to be the 30 to 45 year olds. So we don't have a lot of really young people. For the most part a lot of them haven't engaged in injection drug use to the same degree, to warrant coming to the service in that way. So we don't connect with them on a regular basis. So we need other agencies to access them.

The need for local partnerships in Saskatoon appears in part to be driven by the incongruence between the population targeted by E-SYS and the populations PHS, and specifically the Street Health Program, regularly provide services to.

In the first phase of E-SYS undertaken in Saskatoon in 1999 over 50% of the youth in E-SYS were recruited from local agencies outside of PHS, and this pattern has continued to more recent E-SYS recruitment (130). How actively agencies involve themselves in recruitment varies from agency to agency.

Well, [local agencies] have been primarily contributors by recruiting youth for us, so we would either get their permission to put posters up on their premises or talk to their clientele about an opportunity to make 10 or 20 bucks.

One of the strategies E-SYS uses to recruit youth is the provision of a stipend as funded and outlined by PHAC (117). Even with the valuable partnerships with local agencies and the stipend for youth who participate, street-involved youth are a challenging population to engage and informants at all levels readily acknowledged this challenge and the resulting impact on the E-SYS results.

Recruitment is not easy and that I think we all acknowledge that it isn't an easy to reach population. And yes, we do depend on the [community-based organizations] that have programs that specifically cater for this group. And then we actually only reach those who actually show up for those programs. So the youth don't even bother to show up, you know - those are a lot more vulnerable. All I can say is this is just a challenging aspect of doing this type of community based research.

#### **4.1.3.3 Data Collection**

Data collection takes place concurrently with recruitment and is comprised of a research nurse administering a 60-90 minute questionnaire, and taking a urine and blood sample from the street-involved youth (15). The eligibility criteria is laid out in the PHAC *Procedural Guidelines* (117):

- In order to be considered eligible to participate in the survey a person must be
1. 15-24 years of age, inclusive (In provinces where youth aged 14 years are eligible to be involved in research studies, the minimum age to participate in this study will be 14 years) AND
  2. able to understand spoken French and English AND
  3. able to provide informed consent AND
  4. Not have already participated in the current survey round
- In addition, in the last six months,
5. Have run away from home or other place of residence for three consecutive days or more OR
  6. Been thrown out of home or other place of residence for three consecutive days or more OR
  7. Been without a fixed address for three consecutive days or more.

Youth who meet the age criteria, but who have not been out of home other place of residence for three consecutive days or more, will not be included in the study. (p. 15).

Although the eligibility criteria for participants are laid out by PHAC, the actual screening for eligibility occurs at a local level, and ensuring participants meet these criteria has been a challenge for PHS. One local informant described the challenge associated with meeting the criteria and acknowledged the importance of the local research team understanding and valuing the eligibility criteria as it is designed:

I think when [the previous PHS E-SYS coordinator] took over she said, ‘ok absolutely we’re sticking with the criteria [for recruitment]’ (laughs). Whereas prior to that we needed 225 participants, and that was our goal. And again, if you don’t have the background around research, and don’t see the value in trying to maintain the standard for who should participate, it falls off the wheels pretty quickly...We were interviewing kids [in past cycles] that maybe ran away from home overnight...So I think that’s maybe the other reason why you really do want somebody with a research background, because they value the importance of trying to be consistent and recruit the appropriate clients for the study itself.

#### **4.1.3.4 Analysis**

Once the interviews are completed and the body fluid samples processed the data go to PHAC for entry and cleaning. PHAC then returns the site-specific data in disaggregated format. Once the data are returned to the community sites, how the data are analyzed, disseminated and applied is unique to each site.

In the earlier phases of E-SYS, there were a number of issues regarding the return of data to the community sites and a number of informants identified this historic challenge.

At one point in the study, I can’t remember what year or even years, there was some issue around the data. So [PHAC] were not providing [PHS] the data back. We were waiting for them to do the analysis, it wasn’t part of the contract. So once we did all the data we sent to them, and then we waited for them analyze it and send it back. And so we evolved through that process to saying, ‘well we’re waiting too long for the data. You’re sending it back 2 or 3 years later, so it’s not relevant for us anymore.’ So that’s when we switched to them agreeing to send data back, but then we needed to have the in-house epidemiological perspective to do something with it.

The focus of the analysis conducted by PHAC is to track national trends, leaving any local analysis as the responsibility of the sites. Whereas some sites, such as Saskatoon, have made it a priority to take on this responsibility, other sites still lack the local capacity, limiting their ability

to utilize the data locally. As described by a PHAC informant, this has resulted in PHAC assisting sites with local analysis in some limited cases.

At PHAC level, we do the national, or the aggregated, the combined analysis of all the sites and share the preliminary findings back with all the sites. However over time some of the sites had come up with some problems, with a lack of human resources or expertise to actually do the analysis themselves. So over the years, some of the sites have asked PHAC to do the actual, some of the data content analysis for them.

As stable as a multi-year surveillance system such as E-SYS would appear to be, upon taking a closer look one becomes aware of the challenges of a multi-site, multi-year surveillance system. The natural next step of a surveillance system upon completion of analysis in one surveillance cycle, is to utilize or disseminate the data. As will be explored below, the process of E-SYS sharing the surveillance data has not followed as simple of a path as the literature on surveillance systems suggests it might.

## **4.2 The Emergence of Knowledge Transfer & Exchange**

Knowledge transfer and exchange (KTE) as a priority for E-SYS is a relatively recent development. However, there are a number of activities that PHAC and PHS have pursued in the past in an effort to disseminate the E-SYS results. This discussion will give a brief account of these historical activities before exploring how KTE emerged as a priority for E-SYS.

### **4.2.1 History of E-SYS Knowledge Transfer & Exchange: PHAC**

At a federal level, the historical efforts that went into disseminating the E-SYS results have largely taken the form of publicly available national reports and conference presentations. Although reports and conference presentations are traditional forms of KT within the academic and epidemiological communities, all informants within PHAC agree that these passive approaches to KT have not been sufficient to see the E-SYS study have an impact.

And reports being written arguably is a form of knowledge translation because if you don't have the information pulled together then it makes it harder to share, right?...At the national level, we've put out reports. That's pretty much it...We've put out reports, we've shared via presentations and so on with our federal counterparts from the RCMP on out, around the results in the hopes that the information can be used in their programming or can be shared with their stakeholders, et cetera. But I think we can do much better.

In addition to producing reports, PHAC informants spoke of the informal dissemination of the findings through how E-SYS informs the work of those involved and their interactions with

colleagues at the national level. One federal informant argued that the E-SYS results influence work at the federal level through her knowledge of the study results.

It's always iterative. You go back and forth, and back and forth, and together you build capacities in both directions. And the stories become shared stories and then getting a sense of again what's real, what's important, informs me in terms of where my priorities need to be as I talk with senior management at PHAC, right?

Although this informal dissemination represents an additional avenue for the E-SYS results to have an impact, it is opportunistic, more challenge to trace and not a focused implementation strategy as articulated in the KT literature.

#### **4.2.2 History of E-SYS Knowledge Transfer & Exchange: PHS**

As mentioned above, each E-SYS site is responsible for its own site specific KT. As articulated by one federal informant, the intensity of KT at the local sites varies significantly.

Not everyone agrees [KT is] a priority, just because there are multiple priorities. It's not saying one jurisdiction is right or wrong. It's just where it fits within the priority, and it's been mixed. So in certain jurisdictions where this is a key to the biz, I think there's been much more enhanced communication with various organizations in the thinking through and the knowledge translation.

Saskatoon as an E-SYS site has largely mirrored the KT experience at the federal level. The majority of effort in reporting E-SYS results has been passing on the federal reports to local agencies working with street-involved youth, or including some E-SYS results in local health region reports.

I think the documents that [PHAC] have produced over the years on the Street Youth Study, when we received those, because they would send us copies, then we would distribute those to all organizations that participated. So we'd send them to the School Boards, EGADZ, Teen Wellness, whoever had sent clients. But again, that's about as much as we did from my perspective.

Also similar to the PHAC experience, informants within PHS spoke about informal or intuitive use of the E-SYS data.

So I would say intuitively you take the information. Because we were conducting the interviews, and there was only one or two nurses doing that. So those two nurses would compare and contrast, 'while this is what is what I'm hearing.' 'This is what I'm hearing.' And based on that intuitive knowledge, that's how we would implement a program. It wasn't from the data analysis sent to us.

One PHS informant who has maintained involvement with E-SYS over its phases did share a story of an attempt to utilize the E-SYS data to inform the programming provided by PHS after Phase III was completed.

One year we used the data...so we used some of the data where we implemented a healthy sexuality program [at a local agency], whereby, because food was an issue, we would offer a meal prep. And then we did some work around sexual health. So we did implement some programming based on a year of data. That wasn't sustainable. I mean we had some money to do some things, and we ran out of the money...So, yes I would say we used it at least once, but in 10 years. That's probably not the best.

Throughout the interviews with PHS informants it became clear that there were some significant barriers to engaging in more active KT. As identified in the example of the healthy sexuality program, limited resources have created some barriers to engaging in more assertive KT. The timing of the analysis, as discussed above, was also cited as a limiting factor in the early E-SYS phases. Lastly, the E-SYS questionnaire was identified as a barrier. The influence of each of these barriers will be discussed in more detail in Section 4.4.

#### **4.2.3 Knowledge Transfer & Exchange Emerges as a Priority**

As articulated by all the informants interviewed, there is an open acknowledgement that E-SYS has not been disseminated or applied to its full potential. There are two key factors that seem to have led to this realization: (1) the limits of traditional KT efforts, and (2) the emergence of KT as a growing field within the field of public health.

The first documented mention of KT in the E-SYS documents is in a 2008 draft document entitled *Enhanced Canadian Street Youth Surveillance (E-SYS): Report on the Results from the National Knowledge Transfer and Exchange Needs Assessment and Environmental Scan*. This report begins with a brief background on the emergence of KT as a priority area for the E-SYS partners.

Knowledge transfer and exchange activities, identified as priority areas during the National Meeting held early February, 2007, require focused attention to realize the full potential of the surveillance system and the wealth of data collected. In late 2007 and early 2008, a National Knowledge Transfer and Exchange Needs Assessment and Environmental Scan for E-SYS was conducted as a means of engaging stakeholders in the planning and development of national knowledge transfer and exchange activities...These elements will then be combined into a set of recommended action items for knowledge transfer and exchange for 2008-2010 for the E-SYS surveillance system (p. 1)(151).

When speaking with informants about why KT emerged as a priority at the 2007 National E-SYS Meeting, many informants felt it was a result of KT gaining momentum within the public health and epidemiology field in general.

[KT as a priority] would have come from the wider field...So for sure, this has been around for a long time, and I think E-SYS has adopted it as probably most national studies have. It is now part of their accountability, is how they're moving these results into the arena so things get done.

What materializes from the 2008 report is the prioritization of a more active dissemination strategy. This interest in more active dissemination was further echoed by nearly all the informants:

So we always have some sort of report or something that summarizes the data. But what I would like to see is actually developing something that is a little more user-friendly. Cause the reports are a good reference document, but I don't think that they're good for certain stakeholders or reaching out to certain populations.

This expressed interest in KT moves beyond just wanting to see the E-SYS results more widely disseminated, but as expressed by one PHAC informant, to see KT result in public health action.

You know both PHAC, working with the rest of the team, really like to use more of the information because to us, just accumulating information cycle after cycle, publishing reports and sharing within the same group, I mean by the same group, I'm talking the team, the E-SYS team, it's not sufficient. It needs to be translated into action, public health action.

According to many of the informants, what further contributed to the KT priority was how the study and resulting data had progressed over the years. Those informants that had a lengthy history of involvement with E-SYS spoke of the early years as providing a sense of the landscape of health and street-involved youth in Canada. While more recent cycles have allowed the sites and PHAC to realize the potential for sharing the wealth of information in E-SYS.

You know, I think it was gradual, but I think we've been on this path of the knowledge translation now I would say for at least 5 years. This is our second cycle...where there's knowledge translation included in the budget, and I think over time as we realized what we had in terms of information, it was like...what are we going to do with all of this, right?

#### **4.2.4 Targeting Youth for KTE:**

The current targeting of youth for KTE emerged from the *Enhanced Canadian Street Youth Surveillance (E-SYS): Report on the Results from the National Knowledge Transfer and Exchange Needs Assessment and Environmental Scan*. The report suggests that targeting youth



became a priority for the 2008-2010 recommended actions. Other identified targets, such as policy makers, were to be prioritized in “subsequent fiscal years.”<sup>12</sup> The targeting of youth for KTE was then written into the *Procedural Guidelines*, and subsequent *Cycle VI Protocol*.

Within the E-SYS *Procedural Guidelines* (117) and the *Cycle VI Protocol* (16) there are a number of identified potential KTE targets for E-SYS.

Sites will have the freedom to develop appropriate local KT&E strategies. Site-specific KT&E strategies include dissemination to policymakers, researchers, and at-risk youth...Nonetheless, it is imperative that the data be returned to the youth (p. 48).

This notion that the participants of E-SYS, street-involved youth, are the prioritized targets for KTE is a rather unique notion within KT literature. If, as articulated by one informant, the purpose of KTE is “concrete action,” then the question becomes what sort of concrete action is aspired to by targeting street-involved youth for KTE. When this question was asked of one informant, the response was:

I think that again, it’s mostly an accountability issue. That it suddenly has become unacceptable to study populations and not give them the results of the study. I don’t think the expectation ever was that youth having seen this information for the first time were all about to change their behaviour. Certainly that was not the case. It’s almost like a formality that it should go back to the population.

Interestingly, one of the consequences of targeting street-involved youth for KTE within E-SYS Phase VI is that the process appears to have shaped some of the informants’ understandings of KT. As per below, one of the underlying rationale for KTE has become to report the study findings back to the study population.

I mean I think that the knowledge translation is so basic, ‘cause it isn’t always about getting it back to the population that’s being studied. It’s the really, you know we’ve got a policy analyst that’s come in and I think that everybody is getting on that page of moving information into the hands of people that can use it, whether it’s practitioners or program managers or what...If we don’t do that, then all the surveillance and all the analysis is not worth anything.

Although reporting back to the study population is an important process, KT as defined in the literature, emerged out of a desire to ensure study findings are applied. These two objectives are not necessarily analogous as will be discussed in more detail in Chapter 5.

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<sup>12</sup> It is worth noting that at the time of writing PHAC and the community sites are working to develop a national KTE strategy for E-SYS. Policy makers are one of the groups that are being prioritized for potential KTE efforts at the national level.

### **4.3 The Knowledge Transfer & Exchange Activities of Public Health Services**

In Phase VI of E-SYS each community site was provided with a KT budget from PHAC and the following instruction as per the *Procedural Guidelines* (117):

Sites will have the freedom to develop appropriate local KT&E strategies. Site-specific KT&E strategies include dissemination to policymakers, researchers, and at-risk youth. In the past, possible routes of dissemination have included presenting data at major national or international STI and HIV/AIDS conferences and in peer-reviewed journals...In order to influence changes in programming, data have been presented to administrators and staff of youth services organizations. Nonetheless, it is imperative that the data be returned to the youth (p. 47-48).

Although, as outlined above, each site has the freedom to design their own KTE activities, there is a clear priority placed on targeting street-involved youth. Within Saskatoon, PHS targeted their activities at engaging street-involved youth, as well as the local agencies that have been crucial to E-SYS recruitment and connecting to street-involved youth in general. This section will provide an account of the activities that PHS undertook in an effort to engage local agencies and street-involved youth.

#### **4.3.1 Pre-Phase VI Activities**

The set of activities described in Sections 4.3.1 and 4.3.2 occurred in advance of this research project. Interestingly, the pre-Phase VI activities and the actual Phase VI E-SYS process are not explicitly described as KTE activities by PHAC. Nonetheless, these activities merit a brief description based on the KT literature's description of study design and process influencing KT efforts.

Prior to undertaking Phase VI of E-SYS, the Saskatoon site E-SYS coordinator met with a number of local agencies that have had historic involvement with E-SYS in Saskatoon. These consultations were intended to inform local agencies of the upcoming Phase VI of E-SYS, as well as to gauge their interest in the study.

When I was talking to agencies before we began Phase VI, it wasn't my sense that they'd ever actually looked all the way through a questionnaire. I did go around with questionnaires and talked to them about the study and about study findings from the previous phase, although we didn't have a published report. We did a one-pager for them and I did talk to them one-on-one.

#### **4.3.2 Conducting E-SYS Phase VI**

Following the consultation process, the actual Phase VI process began in Saskatoon with recruitment in the summer of 2009. As per the Phase VI protocol, recruitment was largely

conducted through local agencies, some having more actively recruited youth participants than others. Local agencies involved in Phase VI recruitment include AIDS Saskatoon, the Core Neighbourhood Youth Coop, the Indian and Metis Friendship Centre, and the John Howard Society. In addition, the programs and services offered by PHS (i.e. Sexual Health and Street Outreach) recruited youth participants (65).

It is worth noting that a number of agencies that had been involved with recruitment for the past E-SYS phases were not actively involved in Phase VI. These agencies include EGADZ, CRU Youth Wellness Centre, and the White Buffalo Youth Lodge. One local agency representative that did not recruit for Phase VI, but had been an active agency partner for E-SYS in past phases, briefly described one of the challenges they identified with the recruitment process.

You know, it would be great [to assist with recruitment] and what I said to the person that wanted to do the interview, was to come hang out first. Not do the interview, just come hang out first, you know? But just the time frame, it just wasn't realistic for them. And that's sort of fair enough, but you know, it's definitely a challenge.

The actual data collection (interviews and fluid samples) took place from June to October, 2009. The majority of the 131 participants were interviewed by two research nurses employed by the Saskatoon Health Region, and the participants received up to \$20 for their time and contribution. Of the 131 participants, 92% (120) identified as Aboriginal, and 68% (90) identified as male (65). As KTE was on the minds of the E-SYS coordinator at this stage, youth participants were invited to leave their contact information for any future activities related to E-SYS. Of the 131 youth participants, 2 left their contact information for this purpose. Although the focus of this research project is not on the experience of youth being interviewed for E-SYS, multiple local informants discussed the youth experience of being interviewed for E-SYS, and one informant discussed the experience of conducting the interviews:

That is just, how is anybody going to use that information? And you're feeling in a position where I had to ask those questions because it's part of the national data set. You know, it made me mad. Because I know that nobody is going to use that information, and to have that repeated. And then to have some youth, you know we got comments like, 'I just feel like...I sold my soul for \$10,' or something much dirtier than selling your soul. I heard that expressed in notes from feedback from nurses, and we forwarded those notes on to PHAC...we really need to know why we want to ask questions. We should have a rationale that is validated every single year to see why we are asking that question, and have everybody on board, or you know try to work for consensus on that.

### **4.3.3 The KTE Activities**

Following the data collection in 2009, PHS undertook its first explicit KTE activity. This involved consulting with local agencies that have involvement with street-involved youth to gauge their interest in E-SYS results. Agency feedback was used to inform the local analysis and dissemination strategies PHS undertook.

Over May and June 2010, ten agencies were interviewed. They were “chosen on the basis of service orientation, their recruitment of E-SYS study participants and ability to meet with the researchers within the two month period” (152). From these interviews topics of interest for the local analysis were determined (i.e. home violence, education, justice, homelessness, injection drug use and addictions, etc.). In past E-SYS phases, local analysis topics were chosen based on their relevance to the work of PHS. Regarding knowledge dissemination, “all agencies indicated an interest in creative media, both for youth audience and policy-level audiences” (152). Another significant finding from these agency consultations was the lack of use of local data by local agencies. Furthermore, local agencies felt they were knowledgeable of the E-SYS topics based on their daily interactions with street-involved youth. In the fall of 2010, PHS carried out data analysis based on the identified topics of interest, and began planning knowledge dissemination activities that would make use of creative media, specifically digital stories.

In January 2011, I began fieldwork for this thesis project, and it coincided with sharing the data analysis with local agencies (see Appendix II for a timeline of the 2011 KTE activities). In addition to sharing the analysis results, agencies were requested to assist in recruiting youth for upcoming KTE activities. Through interactions with PHS upon beginning my fieldwork, my understanding was that the KTE activities were planned to engage youth by providing them an opportunity to create digital stories. PHS would then use the completed digital stories as an entryway to share the E-SYS results with policy-makers and other youth. As the KTE activities were refined it became apparent that the digital story activities were being designed to build capacity among local agencies to create and utilize digital stories. Although youth would be creating digital stories, this was somewhat of a complementary goal, as the E-SYS focus was partnered with a digital story workshop. One of the PHS informants described their interest as follows:

So that’s really why we were really interested in this, is to translate the information for street youth, but to use the technology to do other work.

Beginning in late January 2011 and continuing to early February, 3 PHS representatives attempted to connect with local agencies to deliver the completed data analysis that had been condensed into 2-page reports (see Appendix III for a sample 2-page report). In addition to the 10 agencies that were consulted in the summer 2010, a few select agencies with an explicit interest in street-involved youth were also contacted. Efforts were made to meet face-to-face with a representative of each local agency to discuss the E-SYS results and the upcoming KTE activity planned for February 14<sup>th</sup>. The process of securing meetings with the local agencies was not without its challenges as is briefly described by one of the PHS representatives involved in the process:

So I wasn't in on the initial interviews, so that lack of continuity was an issue and I felt like I was trying to reach out and make new relationships with people who may have an awareness [of E-SYS], or may not. So, in the end it was difficult because not everybody wanted to, ah, there might have been a turnover of staff at some of the agencies, so that lack of continuity on either end was a hindrance...I think it was interesting because we got to reach out and try and engage agencies that we hadn't really spoken with before. So that was interesting as far as they probably have some potential to work with Street Health anyhow.

On February 6<sup>th</sup> 2011, PHS sent out a poster advertising the February 14<sup>th</sup>, 2011 event to the agencies that had been targeted. The initial commitment of agencies to attend the February 14<sup>th</sup> event was mixed, with those agencies that participated in the spring of 2011 consultations being more open to the idea. The advertising for the event made clear that attendees would be provided with pizza, and youth provided with an opportunity to enter a draw to win a digital camera. Agencies were asked to bring "2-3 young people who would benefit learning how to share their stories through technology." The rationale behind the limited number of youth was two-fold. First, PHS was interested in youth who were in a position to focus on telling their story and not experiencing crisis. Secondly, only a limited number of youth would actually be able to complete the full digital story process with the filmmakers in March 2011 due to limited time. Therefore, if a large number of youth attended, only certain youth would be selected based on the quality and relevance of their stories to continue with the digital story process.

#### **4.3.3.1 Introducing Digital Stories**

The digital story workshop organized by PHS to engage street-involved youth was a new area for PHS to explore in working with youth. The idea of utilizing digital stories as a strategy to engage youth in KTE was based on the success of this strategy in the Vancouver E-SYS site. At

the 2010 Annual E-SYS meeting in Ottawa, a handful of example digital stories were presented to participants, and two Vancouver-based filmmakers presented their experience developing the digital stories with street-involved youth in Vancouver. This successful example of engaging youth, along with the interest of local agencies in creative media, led PHS to explore conducting a digital story workshop in Saskatoon as a KTE strategy.

The February 14<sup>th</sup> event was held at the Broadway Theatre in Saskatoon and was scheduled for 11:15am-12:45pm. Although a set time was established and communicated to potential agency participants, one agency and a number of youth arrived prior to 11am. The core of the event was a presentation facilitated by two PHS representatives and consisted of introducing the idea of digital stories, as well as sharing some of the findings of E-SYS Phase VI. The presentation was intended to gain the interest of youth and agencies to attend the March 4<sup>th</sup> & 5<sup>th</sup> workshops with the filmmakers from Vancouver. As an introduction to the presentation, the PHS facilitators introduced all the PHS representatives who were present and involved in organizing the event. Approximately 20 of the attendees were youth and agency representatives.

In an effort to make the presentation more engaging for the audience, electronic clickers were handed out and the presentation was interspersed with examples of digital stories and questions about the E-SYS results for the audience to respond to using the clickers. The presenters would pose questions about E-SYS statistics to the audience, and once responses were received via the electronic clickers, the E-SYS results would be revealed alongside the audiences' responses. Also scattered throughout the presentation were examples of digital stories that street-involved youth in Vancouver had put together related to E-SYS. The presenters mentioned numerous times throughout the presentation about the need for youth to be involved with E-SYS and make the study findings interesting.

Based on observations and interviews with 2 of the youth who attended the session, the digital stories and clickers were successful in engaging them, as was the "joking" rapport between the presenters. Both youth also mentioned that the free pizza lunch helped them show up on the actual day, and one of the youth really liked the comfortable seats in the Broadway Theatre as well as the discussion about the actual technology involved in creating the digital stories.

After the presentation there was an opportunity for questions, and although the youth did not ask questions, one of the attending agency representatives was concerned about where the digital

stories would end up and asked a number of questions about the future use of the digital stories. The response to the concerns was not definitive as the intention was for the dissemination plan to be a collaborative process between PHS, agencies, and youth going forward.

Following the event on February 14<sup>th</sup>, efforts shifted to recruiting youth and agency participants for the March 4<sup>th</sup> & 5<sup>th</sup> workshop where the digital stories were to be produced. This involved 2 PHS representatives again contacting the core agencies to request they attend and bring a few youth they felt would be interested in creating digital stories.

On February 28<sup>th</sup>, 2011 a number of PHS representatives met to explore outstanding issues and review the agenda for the March 4<sup>th</sup> & 5<sup>th</sup> event. One of the challenges that arose in this discussion was real concern that no youth were going to be present at the March 4<sup>th</sup> & 5<sup>th</sup> event. Despite the numerous agency contacts that had been made, as of February 28<sup>th</sup> there were no confirmed youth attendees and a limited number of committed agencies.

As one of the identified objectives for the March 4<sup>th</sup> & 5<sup>th</sup> event was to introduce local agencies to the idea of using digital stories in their own work, a strategy on how to attract broader agency appeal was discussed at the February 28<sup>th</sup> meeting due to the lack of commitment to attend. One PHS informant involved in this process shared her thoughts:

And just to reflect on that, if you flip around you know, as much as we tried to engage agencies, [only one agency] was just on us. They were like, 'can we get involved? How can we do? What more can we do?' Out of the other 12 or however many agencies there really wasn't anybody pursuing this with us. We were the ones instigating all of this, trying to get people back to us. Whether that was indication of distaste, like they didn't want to play with us, or whether other agencies aren't up for this, or people are too busy or people weren't around. I don't know....

Another PHS informant shared her thoughts on the challenges the team faced in recruiting agencies and youth:

I think the challenges from my perspective was the tight time frames. So I was a bit concerned that we did our event at Broadway...it seemed to me that we were sending out an invitation for the following Friday. Like to me there just wasn't enough lead time, promotion time, to really ensure that we had a large enough audience there to benefit [the filmmakers] being there...So to me it was a bit tight, and that would be, might be the challenge, just getting the word out.

In an effort to address the concerns around lack of agency participation it was decided that a broader email invite should be sent. On March 1<sup>st</sup>, an email invite was sent to over 200 partners that PHS works with, some of whom work with street involved populations, and focused on the

idea of creating digital stories with the tagline, “Looking for a new way to reach your audience? “Project” your message with a new type of media!”

#### **4.3.3.2 Digital Stories & Local Agencies**

The morning presentation of March 4<sup>th</sup> had been advertised as an opportunity for agencies to be introduced to, and learn the basics of digital story telling. Two filmmakers from Vancouver with experience in digital story telling and working with street-involved youth were brought in to run the workshop. In addition to the local agencies that were originally targeted, 3 young artists from a local arts-based youth-focused agency were in attendance and trained over the two days to create digital stories. The intention behind their presence was to provide agencies interested in creating digital stories an introduction to local artists who would be prepared to facilitate digital story making in the future.

The presentation for agencies was scheduled to run from 8:30am to 12:00pm, and was held at the West Winds Primary Health Care Centre. In attendance at 8:15am were 15-20 agency participants and 3 artists from the local arts-based agency. The presentation began with a brief introduction regarding how the workshop arose, including a brief overview of E-SYS. The rest of the morning presentation was facilitated by the Vancouver-based filmmakers, and focused on storytelling and making digital stories.

The majority of the morning presentation focused on how to take a story, and trim it down its core so that it can be told in 60 to 90 seconds at most. As described by one of the event organizers:

We didn't talk lots about E-SYS. So in terms of knowledge translation in that sense, we didn't talk lots about E-SYS or what this means...we didn't actually talk about the technology very much, and how you actually use this, you know? Lots of it was on, the emphasis was just on how you get a story.

One of the participants in the morning session, who also had some involvement in planning the event spoke about one of the strengths of the focus on story in the morning workshop:

And [the workshop] reassured me that [digital story making] wasn't as complex as what I thought it might be...and even getting the story out, it doesn't have to be a story that's deep and dark and all these things happening. It's just, it's a story. And as long as you have a beginning and a middle and an end, that's all you need. And I think that was a good message, to not get intimidated by looking for the best story.

Partway through the morning presentation 3 representatives of a local community agency arrived with 4 youth who were interested in participating in the digital story process over the next



day and a half. One of the event participants shared her thoughts on the arrival of the agency and youth:

I always find it interesting, the dichotomy between ourselves as professionals and youth. We're all there at 8:30, ready to go...(laughs) and [the youth] wander in at 10:00. It's just, it's different. And it just demonstrates how important it is, to create knowledge experiences for them that are meaningful. You know, none of them were there at 8:30, so we probably didn't necessarily plan the best for their agenda's, right?

Although the presence of these youth was not anticipated by the Vancouver filmmakers, one informant commented on the benefit of their arrival and participation:

It got me excited when I saw [the youth] come into the room. It added some energy to the room...it became real because these kids were there for a purpose.

Despite the potential benefit to the process of the youth's morning arrival, one of the agency informants who brought 2 of the youth did not feel that the morning presentation was very engaging for the youth. The informant described the morning presentation as too long, and shared that she felt like she was trying to keep the youth in-line.

Despite the fact that the fears of no agencies or youth arriving were not realized, there was still some dissatisfaction with the level of participation at the event. One PHS informant who was involved in organizing the event expressed this disappointment:

We wanted people who would actually be able to come and use this tool right away. So I was disappointed that we didn't have enough, get enough people there. And not for lack of trying, because I'm sure that first distribution list had 60 people on it. There was a lot of people who, you know, there wasn't much interest or participation from the University. There was a little bit, but...it was people we'd already been in contact with, so that was unfortunate.

The morning presentation ended as scheduled at 12:00pm, and the youth were provided with lunch in another room in West Wind to allow the filmmakers and organizers to set up for the afternoon workshop, and for the agency representatives to leave.

#### **4.3.3.3 Creating Digital Stories with Youth**

The afternoon workshop was scheduled to run from 12:00pm to 3:00pm on March 4<sup>th</sup>, and was designed for the youth to share and shape their stories into 60 to 90 second stories. The March 5<sup>th</sup> Workshop was designed to take the refined stories and actually create the digital stories. In order to respect the privacy and intimacy of the youth sharing and telling their stories, I did not engage in participant observation at these events. However, I did attend in an effort to

support the process and describe the general process based on my observations and interviews with informants following the workshop.

The March 4<sup>th</sup> afternoon session was held in the same space as the morning session, with 3 SHR representatives, the 2 filmmakers and 4 youth. The 4 youth who were present were all known to each other and were recruited by one local agency. The agency staff were not invited to attend the afternoon session. One of the agency staff, when later interviewed, stated that she had wanted to stay for the afternoon, and the youth wanted her to stay, but that was not how the process was designed.

The March 5<sup>th</sup> workshop was held at a local arts-based organization and ran from 1:00pm to 6:00pm. Of the 4 youth that had participated in the March 4<sup>th</sup> session, 3 were able to attend on March 5<sup>th</sup>. The one youth who did not attend had a prior commitment on March 5<sup>th</sup>. Also present were 4 SHR representatives (2 left early into the afternoon), 2 artists from the arts-based organization, and one of the Vancouver filmmakers. The focus of the day was to create the digital stories.

The youth were provided with a stipend of \$100 for their participation on both workshop days, and although this was a motivator for youth participation, all of the youth interviewed stated that it was not the only motivator. The youth also mentioned the desire for their stories to be shared in an effort to inform government representatives and hopefully make a difference in the lives of other youth. Two of the youth spoke about their interest in learning the technology that was used to create the digital stories, and one youth spoke about the workshop providing him with something positive to do with his time.

At the end of the March 5<sup>th</sup> workshop, one digital story was complete, with the other two stories in various states of completeness. Youth and PHS informants both mentioned the lack of time to complete the digital stories on March 5<sup>th</sup> as an issue.

[March 5<sup>th</sup>] worked out. But again I think the logistics of having more people so we could have gotten, so we could have got her done...a little faster with more convenience to the kids, because we lost them [early in the afternoon]. And I don't know if that was the kids, or if it was how we set it up.

Based on the interviews with the youth informants, they all spoke positively about the workshop overall. But the limited time and support to complete the stories was cited as the most significant critique. One of the youth informants spoke about going to finish his story at a later date but the challenges of making arrangements to do so prevented this from happening. These challenges

were family issues that had arisen for that youth since the actual workshop, as well as struggles for PHS to coordinate arrangements with the arts-based organization.

#### **4.4 Interpreting the KTE Process**

The core of the research question is interpreting what the KTE activities reveal about the influence of the organizational context on engaging both street-involved youth and local agencies. The following reflections of the informants on their experience in the KTE activities are from the interviews. This section is organized into the two most significant themes the organizational context: (1) the E-SYS history and (2) relationships.

##### **4.4.1 The Influence of E-SYS on Engagement**

As argued within the KT literature, study history and process shape engagement in KT. Specifically, the actual process of data collection for E-SYS as well as the limited historic KT, have hindered engagement in the Phase VI KTE activities.

One of the very first limits to engagement was that E-SYS had little to no name recognition outside of PHS in Saskatoon. Even among the community agencies that actively recruited youth for E-SYS and participated in the KTE activities, many of them were not certain about the purpose of E-SYS. As shared by one agency informant:

We were aware that studies were going on, but not necessarily this one...So it's very similar to, whether it's a detox study with Saskatoon Tribal Council, or you know, or a paper on intravenous drug use, it's all basically to gain knowledge of why we're here, where we're at, and how we can, in three letters, how we can fix it.

Youth informants were also unfamiliar with E-SYS. The one exception was one youth informant who had also been a participant in Phase VI data collection. Part of this lack of familiarity may have to do with the number of studies that target street-involved youth and agencies providing services to youth.

I think there's, well for me I see a number of things. In particular Aboriginal populations have been studied to death. And there's a lot of animosity towards that. People are like, 'K, eff off. You're coming here, you're doing this.' And usually people have done that for their own individual momentum or their organizations' momentum, and it's like there's nothing to keep it back. So people get fed up with that.

It is also important to note that just because agencies and youth are not familiar with E-SYS, this does not mean they do not have an opinion or perspective on research. This is evident in the quote above, and further discussed by the local E-SYS coordinator.

I do get the sense that CBOs are becoming more aware of the problem of studies and the accountabilities of studies. They're very busy, they're very focused on what they're doing, they love what they do, they're passionate. They don't have a lot of respect for, I would say they don't necessarily have a lot of respect for national studies. It just doesn't have the cred with them that it would with Public Health Services for example. So they would want to see what's in it for our clients, is kind of the way they filter things.

One local agency informant shared her perspective on the usefulness of national or large studies as follows:

And I think for front line workers it's the opposite. We can't get the mass numbers, but we see it every day with these guys. With you know, 'oh I can't find a place to live,' or, 'oh, I'm doing this or doing that.' And so we see it, we know it, we're totally aware of it, we can articulate that, but yet, we don't have the ability to find out what it is in the large scale.

#### **4.4.1.1: The E-SYS Process**

As initially presented within the review of KT literature, the actual process of a study (i.e. design, recruitment, etc.) influences engagement in KT. The significance of this more active involvement of the KT targets in the study process was echoed by all of the community agency informants.

So I guess the biggest role that we always think of, which is horrible for government but is the process, is more important than the outcome. And so if there was young people involved in helping work on questions of the study, if there was young people involved in the planning of the study, or going, what organizations would they go to, you know. All of those things are really valid. And making them a part of the process rather than just what the outcome is.

The E-SYS questionnaire was identified by all the agency informants, as well as a number of the PHS informants, as a particularly vivid barrier to engagement. One PHS informant who was also involved in administering some of the E-SYS questions in Phase VI shared her experience administering the E-SYS questionnaire:

My sense was I was very uncomfortable when I had to pinch hit to do the questionnaire because I totally believed that some of these questions were not only irrelevant to the youth but they were offensive and invasive.

This concern was further expanded upon by one local agency that identified that it was not just the wording of the questionnaire that was a barrier for youth, but the intimacy of the questions that are being asked.

I think that the questions that are being asked, is a lot. Especially if they're not prepared for it. Especially if abuse issues come out, or things like that. I think that our organization is really, really great, and we have a lot of mental health

support people, and that come from the health region...But I know a lot of organizations that might not do that. That might, 'K, you got twenty bucks, let's go.' And maybe don't have the actual supports, or the tools to do that right? So that's where I get worried, because it's re-traumatizing for some people, and we can get re-victimizing them. And so I think, how much do we want to go for data?

Given the intimate nature of the questions being asked, the same agency informant speculated about the integrity of the study given the lack of relationship between the youth and the interviewers.

I've often wondered when I see the questions, whether if myself had asked them, or if someone who knows [the youth] had asked them, what the, or does that sway the whole, you know, I'm not sure. But it's definitely, it makes you really cautious.

#### **4.4.1.2 The Absence of KT**

Along with questioning the study process, and in particular the questionnaire, it became very clear that the lack of local KT in the past also hindered engagement with local agencies and youth:

So [street-involved youth] tell their story, but at the same time they say, I've told this story to 20 people, or 10 people, or 5 people, and you know what, I'm still in the same boat. I still don't have a place to live.

This is not to say that had KT been conducted at a local level street-involved youth would have a place to live, but the lack of action as a result of the E-SYS findings has created barriers to engagement as further identified by one PHS informant:

When you shared what [a local agency representative] had mentioned about, 'how many years has this study been going on and now you're getting around to making a digital story about what life is really like?' That's pretty damn embarrassing...when you think about the millions of dollars that you've poured into doing this and now you're getting around to the real story.

As discussed earlier, this lack of KT in the past was partially a result of the delay in data being returned to community sites once it was sent to PHAC/Health Canada. This connection was not lost on the PHS informants:

And I also think that because the timeliness of the data it was, really got crazy for a while, and it would be like 2 years later. While that data is old by then, and you don't feel very comfortable going back to your agencies two years later and saying, 'well we finally have the data analyzed and this is what it told us.'

Although the lack of a timely return of data clearly hindered the potential of KTE activities, a few PHS informants suggested that this lack of historical KT may be partially a consequence of the

evolution that studies go through over time. One PHS informant shared her own experience as she became more familiar with the E-SYS results:

In terms of information, it was like, while what are we going to do with all of this right? It's one thing to say that in a national report that the surveillance of street youth across the country demonstrates that they have higher risk factors that lead to STIs. But what about, how does that impact you at a local level? What should you glean from that information to look at? What are the programs and services in your community? Who's providing them? How are they providing them? And what did we learn from doing this research to actually take a serious look at? Are we flying by the seat of our pants?

Once the data was being returned to the community sites in a timely manner, the next issue faced by those sites was how to apply and share the data in a meaningful and appropriate way. As has been discussed, one of the challenges within any surveillance system is balancing consistency from cycle to cycle, while maintaining relevance. E-SYS is not exempt from this challenge, and one of the issues PHS faced when looking for trends in the longitudinal the data was the changes that had been made to E-SYS over the years. As shared by one PHS informant:

I tried to trend a couple of things and the questions had changed sufficiently, that many of the, I was only able to grab a kind of the handful of the ones that we had reported in 2007 from the 2005 phase that were asked the same way.

Even in the areas where determining trends was possible, challenges emerged when trying to link the E-SYS results to local programming:

To be fair, the questions don't exactly lend themselves to program improvement. This year is the first time we would asking something like, what are the main reasons you share?...there needs to be more qualitative research questions in order to hone anything to a particular intervention. I don't think this study as it stands lends itself to any kind of intervention. And really Public Health can only use the information to change its programming or to do some advocacy, but they aren't particularly involved in advocacy for youth. They are fairly major players in advocacy for harm reduction.

Later on in our interview, this same informant raised the issue again:

The basic flaw, the fatal flaw with this questionnaire is they ask about the risks, so the risk is kind of a yes or no, and it's there. But they don't go into why the risk is there. There are no questions that are pointed towards the 'why' of the behavior and so you can't really even address an intervention, because you've got the what, but you don't have the why.

In addition to the challenge of applying the data, agencies expressed a cautious approach to utilizing statistical data. This lack of utilization of local statistical data was revealed in the spring

2010 community consultations, but further insight was provided in one of the interviews with an agency informant:

I was having this conversation with my partner about being a statistic, and how when they say, ‘that Aboriginal such and such,’ or ‘this much more likely to get this,’ it’s like people can misrepresent that. And it’s not Aboriginal kids are this much likely. It’s kids in poverty are this much more likely to get diabetes...My kids are Aboriginal, they’re not at risk of diabetes...but we don’t live in poverty. So I guess it’s how you see those things, and [study findings] really shape [youth] identities, and I think that’s where I don’t know if I’d want to show them all those things. It would just depend on the scope, especially if you’re living in these areas and you’re seeing these things. So it’s how you give back that information and that I think’s really important, and I’m working on that, but it’s tricky.

#### **4.4.1.3: Undertaking KT**

Throughout the process of interviewing participants and observing the KTE activities, it was evident that the KTE activities, for both PHS and the agencies, were occurring in addition to their day-to-day responsibilities. As stated by a PHS representative:

So theoretically I’ve been excited about this whole idea that we’re going to get out from behind our boxes, and we’re going to figure out what people want to know and we’re going to do everything we can to move it into where it can be used. But man, there aren’t enough hours in a day. There are skills that I simply don’t have. There’s time that I don’t have. And the project management part of this knowledge translation has been really challenging for me. I’ve needed [another staff] to do all that stuff that I don’t have time, because nothing else in my job has changed...it’s all still there.

Working with partners such as community-based agencies and street-involved youth requires a certain degree of flexibility and consideration of their schedules and demands on their times.

Both youth and local agency representatives identified the timing and organization of the KTE activities as potential barriers to their participation.

The issue of expertise was also identified as a limitation from another PHS participant and is important to note:

And you know, you’re limited by budget, you’re limited by staff and man-hours and youth engagement. There’s lots of things that just wasn’t our expertise, but it fell on us to do it. So I think we did pretty good considering. But you know, some challenges were there, definitely.

Although KT is understandably seen as an extension of any research project, the PHS informants directly involved in the planning for the KTE activities readily acknowledge the need for KT-specific expertise throughout planning the KTE activities.

In addition to expertise, informants also spoke to the fact that KT requires a conscious and committed effort. As is evident throughout the E-SYS history, dynamic KT does not take place unless it is made a priority, and this is not lost on community partners. As stated by one community informant in reference to research in general:

Because I mean everybody wants their results shared, but there's not necessarily a concerted effort on that part. Because the idea is just to do the study. And we have the study, but often there's not funding in there, or there's not the energy to actually, now what do we do with it?...So that's a, I think, an added piece. Which is good. Which is really good and that's where, to us from a community-level, I think that's the biggest, that's the most tangible positive that we can see.

Based on this comment, it is clear that intentional KT not only improves knowledge translation, but also improves relationships with the community-level agencies, thereby improving the success of future projects and KT efforts.

#### **4.4.2: Relationships**

The actual process of engaging local agencies in both E-SYS and the KTE activities related to E-SYS rests primarily with PHS in Saskatoon. What became very evident, both from the comments of informants and my own observations, is that PHS has limited relationships with local agencies working with street-involved youth in Saskatoon and these limited relationships shaped the KTE process.

##### **4.4.2.1: Limited Relationships**

One of the seemingly obvious reasons for this limited relationship is that PHS has limited services that are accessed or targeted at street-involved youth, or youth in general. This lack of a direct, frequent connection with street-involved youth was echoed by all the PHS informants.

I think that there's lots of places where Public Health could expand on our youth services. Out of our Disease Control Department, we don't strictly have like Youth Outreach Services, or you know, it's just whoever comes to us under that high risk umbrella. So [the KTE process] was a good eye-opener in terms of seeing kind of where we need to redirect our focus.

The lack of a relationship between PHS and local agencies working with youth was particularly poignant for one PHS informant when she read the report that came out of the spring 2010 consultations with local agencies:

It was kind of eye-opening to me, that where [E-SYS] was new information to us to some extent because we don't primarily work with youth, to hear lots of the agencies say that, 'oh we already know that,' or you know, they weren't surprised by that information. I think that pretty much drew attention to a



disconnect between Public Health and the people doing work primarily with youth.

From discussions with some of the informants, it became evident that not only did PHS not have strong relationships with many youth-serving agencies, in some cases the relationships were quite bad.

I think that's my biggest frustration right now, is trying to work with some of the agencies and realizing that we actually have a rather bad history (chuckle), that we got to somehow put right.

This sentiment was echoed by one of the agency informants who shared a story of collecting information for a different PHS-led project. While contacting other local agencies to collect information for this PHS-led project, the informant ran into staff within a number of local agencies who would not contribute to the project when it was revealed that the project was run by PHS. In fact the informant also stated that she has not yet seen any product or outcome of that project, or heard anything about a timeline for the project outcome to be made available.

One PHS informant felt that part of what has strained relationships with local agencies is related to the strong emphasis on accountability that exists within government agencies.

I think the whole accountability thing has really gone a little far in...in every way that Public Health sometimes asks questions because they think they need to be accountable and that creates a distrust.

Another informant attributed part of the limited relationship between PHS and community partners to a structural tension that exists between community and government agencies:

Well, this is my personal opinion and shared by a few of my colleagues. I think there's always a struggle between the non-governmental agencies and the service providers like health, because we're seen as the "haves" and they see themselves as the "have nots." And so there is that tension sometimes around, 'how come you get that kind of funding to do that kind of work? We could do that work, and we wouldn't, it wouldn't cost as much.' So I don't think that's ever going to go away. Unless at some point we had, unless we had more equity. And this is what it's about. I mean, not only does that happen between [government] and the agencies, but it happens between the agencies. There is so much competition for the resources to do the work they want to do. I think that is something that we will always have to be mindful of. That we will always have to work on.

The direct relationship between PHS and street-involved youth appears to be even further removed than the relationship between PHS and community agencies. This is most evident in PHS' reliance on local agencies to recruit E-SYS participants. This distance between PHS and street-involved youth was readily acknowledged by all PHS informants.

For the most part our clientele in Street Health that are high risk tend to be the 30 to 45 year olds. So we don't have a lot of really young people. For the most part a lot of [young people] haven't engaged in injection drug use to the same degree to warrant coming to the service in that way. So we don't connect with them on a regular basis. So we need other agencies to access them.

Of the services that PHS offers that may be of interest to youth, one PHS informant felt that youth were accessing other service providers.

Although to be honest, I do get the sense that the younger clients actually don't access the Street Outreach because EGADZ is running a parallel service. Or SHARP, or whoever they prefer to get their supplies from.

Another PHS informant speculated that, similar to PHS' relationship with local agencies, this limited relationship may have more to it than just PHS not providing services that target youth specifically.

'Cause what I've found sometimes is, young people want to be helped, but they don't want it in a sort of patronizing way. They want it in a way that also shows their dignity and worth. And I think that's where [PHS] sometimes miss the boat.

One local agency who described themselves as having a good relationship with the Saskatoon Health Region, discussed some of the challenges facing SHR in engaging youth.

I think [SHR] haven't, and I know as the umbrella organization as a whole they've done some things to improve that. Like there's adult ally training in how to meaningfully work with young people...I mean look at the median age of the people that work at the Health Region, right? Like I'm not sure what the statistics are, but often times they're a lot older women, right? So I think, until we start addressing the employment things as well, and have more diverse people that can represent different things, I think that is going to be definitely one way to get to work with youth. As well as, I don't know what they, what it is about the Health Region, but it's not youth friendly. It hasn't been youth friendly. I know they're working on it.

A suggestion from one PHS informant to address this lack of relationships was to strategically develop relationships, and acknowledge the limitations facing PHS.

Well it's a little bit like going into developing countries, or you're going in with some big aid thing. You don't set up your own shop and say, 'ok, let me start here.' You make use of the agencies that are on the ground, that have the relationships, cause you can't be all things to all people.

The importance of PHS having some kind of relationship with agency and youth was acknowledged by informants at all organizational levels. One agency informant shared the idea that youth are not coming to their agency workers with their health questions or concerns, and

she felt that they would be more open to discussing any issues with a nurse or a PHS representative.<sup>13</sup>

Although informants shared their perspectives on why PHS does not have strong relationships with youth and local agencies, one also has to consider the circumstances facing agencies and youth that may limit their interest or ability to engage with PHS. For example, even those agencies that have strong relationships with youth shared that they struggle to understand why there are times youth do not come out to certain events.

Like some days we'll have this really great presenter, we'll have the food ready, and we won't have anyone show up. And from what I know, from a lot of the other community agencies that I talk to, it's very similar you know. There's a lot of opportunities out there for young people. Which is great, really great, but sometimes they either don't access it, or they don't, you know. So because we are a drop in centre, I face that all the time...One day, we'll have like 25 kids, and the next day we have nobody. And you're like, what the heck, you know?

#### **4.4.2.2: Limited Success**

Despite the limited relationships and barriers in forging new relationships, the KTE activities initiated by PHS did result in some level of successful engagement with local agencies and youth. Based on the informant interviews and observations, this success can largely be attributed to two things: (1) the positive relationship that PHS has with certain agencies, and (2) the creative approach to KTE taken by PHS.

Most of the agency informants who were involved with the KTE activities spoke openly about the positive relationship they have with PHS or the Saskatoon Health Region in general, and projects that the agency and SHR have collaborated on in the past.

We have a long-standing relationship with the Health Region. You know, we've been involved in a number of different projects, including being a community mentor for a number of graduated students going into the medical profession.

One agency informant who did not speak of a strong existing relationship with PHS was nonetheless attracted to E-SYS due to her underlying belief in partnerships and the need for agencies to work together. Regarding the KTE activities specifically, she identified the opportunity for the youth to have their voice heard and using creative media as her primary motivation for her involvement. This was echoed by all the local agencies that became involved

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<sup>13</sup> In the past, PHS has had nurses visit community agencies to meet with youth clientele. At present, this practice is not as common, and happening on a more limited basis.

in the KTE activities and by the youth informants. One PHAC informant who was familiar with digital stories spoke about the potential of creative media from her perspective.

Another issue is just making the data interesting, because no one wants to sit through, well I shouldn't say no one, but the majority of the youth probably wouldn't want to sit through a power point presentation if numbers are just being listed. So it's a matter of presenting the data in a way that's interesting and also relevant to them. But not only just presenting the data, you have to frame it in such a way that you're getting their feedback, because you're describing their lives.

It is also important to note that from PHS' perspective, creative media is a new approach that is being explored for sharing health information and broader health promotion activities.

Public Health is getting a bit clued in on the social marketing thing. They realize that that's where they need to go. They realize that writing reports and making up little pamphlets and stuff is not where it's at anymore. So they are moving into that.

Although the creative media approach experienced some success in engaging youth and agencies, there were still components of the actual KTE process that could have been improved if youth and youth-focused organizations were involved in planning the KTE events. One issue that came up repeatedly with agencies and youth was the timing of the March 4<sup>th</sup> morning workshop. Although youth arrived at 10am, the presentation was not designed for youth engagement, and the youth struggled to pay attention. The agency representatives that came with the youth shared that it was a struggle to keep the youth interested and focused. Although this may seem like a minor issue regarding the actual event, one agency informant poignantly articulated the broader message that poor timing can send to youth.

Respondent: A program that's conducive to [street-involved youth's] interests, their ideas and lifestyles.

Justin: Yeah. And it's interesting you say that you're designing the program around [street-involved youth], as opposed to designing a program and hoping that they'll come.

Respondent: Exactly. Which is the exact opposite than the way that the government and a lot of agencies have been doing all along for a number of years. We know what's right, we will set this up, and you will come. And if you don't come, then you're a fuck-up. You weren't here at 9 in the morning, you weren't here at 8... You're a loser, we're not going to help you. You screwed up.

Another challenge identified by the informants was that the process was designed to select certain youth to continue over the digital story process, while other youth would not be invited to

continue. Although the logistics of making the digital stories dictated that a limited number of youth could be involved in the March 4<sup>th</sup> & 5<sup>th</sup> workshop, agencies felt they needed to limit the youth they brought so as to prevent any youth from experiencing a feeling of rejection.

Lastly, one suggestion offered by an agency informant was to partner with more local agencies involved with the arts, and local filmmakers. As already described, PHS brought in Vancouver-based filmmakers for their expertise in digital story making and familiarity with E-SYS. However, one agency informant spoke about the potential for accessing local experts.

I guess for me there's an organization that's doing [digital stories] right now in the community, so it would have been nice to build upon that, or work within that that's happening because they've already done the legwork, right? So it's really had to be an external force coming in to do something you know.

#### **4.5 Conclusion**

The history of E-SYS is clearly alive today in the way it explicitly and implicitly shapes the KTE activities and efforts to engage youth and agencies in Saskatoon. The emergence of KT as a written priority related to E-SYS has ensured that community sites are striving to engage youth and stakeholders in discussions regarding the E-SYS results. The actual KTE activities undertaken by PHS to engage street-involved youth and local agencies benefitted from the consultations undertaken with local agencies, and their use of digital media.

The KTE activities also faced many barriers related to the actual E-SYS process, historical lack of KT and the limited relationships PHS presently has. Ultimately, the E-SYS process and KTE activities speak to the challenges facing many public health departments. These challenges, as well as possible future directions for E-SYS KT will be discussed in detail in Chapter 5.

## CHAPTER 5 DISCUSSION

This study's purpose is to understand the influence of the organizational context of E-SYS on the KTE activities PHS engages in. As identified throughout, the context in which E-SYS takes place is essential to understanding the KT efforts. Of the partners involved in E-SYS, the primary focus of the Discussion is on PHS' role and the relationship between PHS and local agencies and youth.

While undertaking the study I strove to understand the context in which E-SYS is operating and to listen to the multiple voices that make up E-SYS. Listening and reflecting throughout the process has left me with many more questions than I had upon entering the study, but it has also provided me with some insight into KT processes, and the realities of public health environments.

I will discuss three main ideas that arose from this process. First, I will discuss how partnerships were manifest throughout the KT process, and the importance of partnership to the KT process. Second, I will discuss some of the challenges and realities that exist within the public health field, and how they influence KT and ultimately action on the SDOH. Finally, I will conclude with recommendations for future KT efforts related to E-SYS, and some key areas for future research.

### **5.1 Partnership**

Partnerships are essential to research and KT. Furthermore the importance of engaging the end-user population in KT activities, as well as the study process, is well established in the KT literature. In an effort to qualify the nature of the participatory processes and partnerships that took place within the KTE activities, I will apply Arnstein's ladder of participation to the participatory processes. I will also discuss a number of themes that came to light including issues around the study relevance, power, and epistemology.

#### **5.1.1 The Participatory Process**

Prior to exploring the KTE activities in terms of participatory frameworks, it is important to recognize that the participatory processes were initiated by PHS, and did not emerge from the community. PHS consulted local agencies about the possibility of engaging local youth and agencies in KTE activities so a certain level of input informed the KTE activities. PHS also sought to engage street-involved youth to develop their stories of experiences with street culture

in Saskatoon into digital stories. The fact that PHS initiated the process limits the potential for the participatory processes of the KTE activities to be empowering (54).

As discussed in Chapter 2, numerous frameworks exist that aim to qualify participatory processes. For this thesis study, Arnstein’s framework is particularly relevant due to its explicit consideration of power. Within Arnstein’s framework, the degree of participation is framed based on the participants’ power or autonomy to make decisions (51,57).

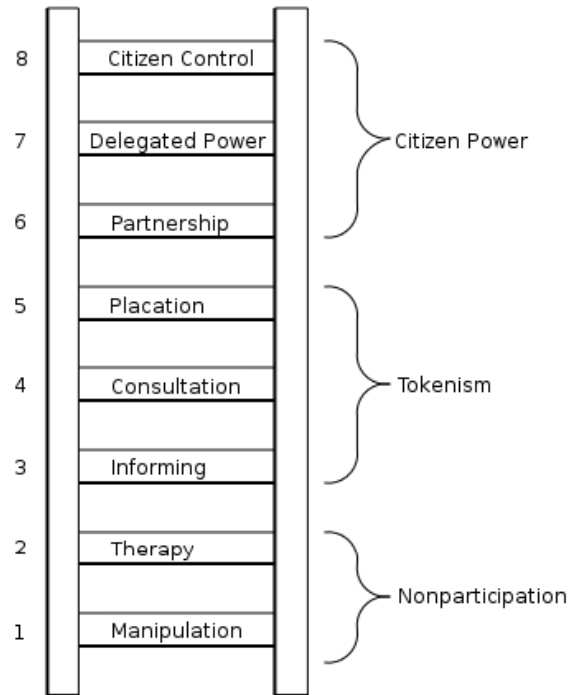


Figure 5.1: Arnstein’s ladder of citizen participation (57)

When reviewing the form of participation the youth were invited to engage in, at worst it can be seen as “therapy,” and at best “placation.” Involving youth in sharing their stories to create the basis for a broader public health campaign could go a number of different ways. For example, if PHS were to utilize the digital stories as a health intervention to educate other youth, street-involved or otherwise, it is difficult not to characterize this approach as therapy. Arnstein describes participation as therapy as a strategy to have participants, “adjust their values and attitudes to those of larger society” (p. 221)(57). In this way, therapy as participation does not build participant power. On the other hand, if the stories shared by the youth are conceptualized as a tool to help engage and inform policy-makers of life involved in street-culture, placation may be a more accurate description. Placation, as described by Arnstein, allows “citizens to advise or plan ad infinitum but retain for powerholders the right to judge the legitimacy or feasibility of the

advice” (p. 223)(57). Throughout the digital story process PHS retained the power to determine the effectiveness or legitimacy of the stories shared by the youth. Furthermore PHS still retains the power on how the digital stories are used in the future.

Regarding the involvement of agencies in the KTE process, Arnstein’s conceptualization of “consultation” is the most apt description. “Inviting citizens’ opinion, like informing them, can be a legitimate step toward their full participation. But if consulting them is not combined with other modes of participation, this rung of the ladder is still a sham since it offers no assurance that citizen concerns and ideas will be taken into account” (p. 222)(57). To PHS’ credit, the input offered by local agencies was taken into account when analyzing local Cycle VI data and developing the KTE activities targeting youth. The role of local agencies beyond consultation was limited to recruiting youth participants and providing agencies with the Cycle VI results. The exception to this is the ongoing work PHS is engaged in with a local agency to support a project that emerged out of the KTE activities.

From the outset, neither PHAC nor PHS claimed that the KTE process was designed to build citizen power. In this way Arnstein’s ladder may be not be viewed as the best framework to conceptualize the participation process of the KTE process. However, KT processes without real consideration of power and building citizen power are limited at best in addressing issues of health equity (115).

### **5.1.2 Issues of Power & Knowledge**

Given the application of Arnstein’s ladder to the participatory processes, it is clear that partnership building and participatory processes should have played a much larger role within the KTE activities and E-SYS as whole. In fact, the limited roles for partners in the KTE activities are evocative of the role of community agencies and street-involved youth within E-SYS as a whole. These limited roles bring with them a number of significant issues including a limited ability for E-SYS to address power and epistemological gaps that exist between partners.

We would argue that multiple cultures, not simply two or three, are involved in community-based research projects, and that differences among these multiple cultures must be addressed in order to transfer and exchange knowledge successfully (p. 35)(115).

Although E-SYS is not community-based in terms of being initiated or driven by the community, it does involve community partners and represents a number of different organizational cultures.



Given the number and types of groups involved, the need to address the epistemological and power differences that exist between them is paramount.

The digital story process did bridge some of the gaps that exist between the E-SYS partners. For example, the health professionals framed the process by seeking specific stories about experiences of life involved in street culture. The digital stories shared by street-involved youth received limited editing<sup>14</sup> by the professionals involved. Additionally, the integration of the E-SYS statistics into the digital stories then presented two differing epistemological approaches beside each other. It would be naïve to suggest that the stories of the youth are given the same merit as the E-SYS statistics within the public health world merely as a result of their joint presentation. However the joint presentation is an example of how the KTE process provides an opportunity for multiple epistemological perspectives to be heard. Furthermore, the youth explicitly discussed their interest in having their stories shared with other youth and government representatives as a key motivation for participating in the KTE activities. The joint presentation increases the likelihood that PHS will utilize the digital stories and the youths voices will be heard by a larger audience.

The integration of the experiences of street-involved youth into the KTE process is also important as it recognizes the youth as “epistemologically active” (109). One common critique of traditional knowledge dissemination activities is that they are often based on the assumption that the new “knowledge” presented will be adopted and integrated as it is presented (109). This assumption ignores that fact that end-users, whether street-involved youth or policy-makers, have their own unique approach to adopting and integrating new information.

Within E-SYS in general, one of the most obvious influences of the limited participatory role of youth and agencies is the actual relevance of E-SYS. Although E-SYS gathers a significant amount of information, informants struggled with knowing how the E-SYS results could be applied. This is a particularly poignant concern given that KT is about the *application* of study findings, and not just the sharing or dissemination of results.

Although issues of power between PHS and the community were apparent throughout the KTE activities, issues of power that exist within the multiple organizational partners must also be

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<sup>14</sup> The editing that took place was primary based on the requirements of the digital story format (e.g. length was kept under 2 minutes). Additional editing was driven by the filmmaker whose primary role was to capture an engaging and succinct story. Editing around some language took place, but in collaboration with the youth.

acknowledged. For example, the PHS representatives responsible for organizing and facilitating the KTE activities are not responsible for deciding whether PHS should continue with E-SYS. Nor are they responsible for resource allocation related to KT activities in general or the services PHS provides, limiting their ability to shape some of the organizational influences on KT.

## **5.2 Knowledge Translation within the Field of Public Health**

As this thesis study was grounded in the day-to-day realities of a public health department, it provides a window into the challenges of conducting KT within the field of public health. This reality places KT within a world of competing priorities. Furthermore, the limited mandates of public health departments shape how KT takes place and who is targeted for KT.

### **5.2.1 Competing Priorities**

One of the most obvious tensions that emerged throughout the fieldwork was the tension PHS and local agencies faced in planning and conducting the KTE activities. More often than not, the KTE activities were not given designated resources, but expected to be undertaken in addition to the day-to-day responsibilities facing informants. As presented in the Results, this tension highlights the need for a concerted focus and specific resources for KT.

Throughout the KTE planning process it became evident that the competing priorities that exist within public health departments shaped the KTE activities. In the early planning stages of the digital story workshop the intention was to design a process that would engage street-involved youth and involve them in a plan for wider dissemination of the digital stories and E-SYS results. As the planning progressed, the objective seemed to shift so that the primary objective became teaching the process of developing digital stories to local agencies: a capacity building exercise. Part of the motivation for this shift in objectives appeared to be the need for PHS to justify the cost of bringing in the two filmmakers from Vancouver through ensuring a larger audience to work with them. *In my 3 months of fieldwork, the objectives of the KTE shifted at least two times.*

This example highlights another tension within public health departments across Canada. Government departments are increasingly required to be scrupulously conscious of any resource expenditures. This “accountability”<sup>15</sup> for resource expenditures can also impede efforts to build relationships in day-to-day public health practice. One PHS informant shared the following

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<sup>15</sup> Although accountability is not the most accurate term to describe the relationship between the various levels of bureaucrats, it is used in this case to reflect the words of a participant as presented in Section 4.4.2.1.

story, which highlights one example of how these tensions can shape relationship-building efforts.

[The PHS manager] said, ‘well why don’t you find out if [PHS] might be able to help them get more condoms for cheap or something like that?’ So I asked [the agency director] ‘is there anything we can do for you? Can we try and help you out with your supply of condoms?’ And [the agency director] was interested in that. So I went back [to the PHS manager] and said, ‘yeah, [the agency] is interested.’ And then [the PHS manager] said, ‘ok, ask [the agency director] how many [they] need and what’s the price [they’re] paying now.’ And you know, at the time I didn’t really twig. The ‘how much does he need,’ but ‘how much are you paying?’ That’s the under, like how we undercut...It’s almost like you offer with one hand, but you hold back a little bit.

### **5.2.2 Limiting Mandates**

In addition to the competing priorities shaping the KTE activities, E-SYS and its KT efforts are further influenced by the mandates of the partners involved. For example, while interviewing one PHAC participant and discussing greater participation of street-involved youth in defining the E-SYS study problem, she stated:

The struggle though Justin, is that what might be a priority for a street-involved youth might not necessarily fit within our mandate, right? In terms of what we get funding to do...And so, let’s take an example...one gets infected with a sexually transmitted infection and the risk behaviours one engages in to increase the risk for that infection, in all likelihood is not as high a priority for someone as, ‘where am I going to get my next meal? Or where am I going to spend the night?’ But that’s where the kind of coming together of the determinants of health approach and the broader lens comes in.

Each E-SYS organizational partner has their own mandate and must contend with the limitations of those mandates. One approach to overcoming these limitations is to partner with other organizations that are better positioned to take action on the areas that appear off limits. In many ways, E-SYS appears particularly well designed to overcome any one organizational limitation through the involvement of various partners across jurisdiction and geographic area. However E-SYS has yet to take full advantage of this strategic partnership arrangement, despite the value of a joint “bottom-up” and “top-down” approach to addressing health inequity (153,154).

### **5.2.3 Research & Knowledge Translation**

Evident throughout the interviews with Saskatoon-based agency informants was the sentiment that certain populations, including street-involved youth, are over-researched. Part of the frustration with research may also be attributed to the lack of real improvements to the daily

conditions facing the study populations. Ultimately this lack of action on the most immediate needs facing street-involved youth speaks to the lack of effective KT related to E-SYS.

One of the possible explanations for this shortcoming that emerged from the interviews was a misunderstanding of KT. As presented in Section 4.2.4, one of the conceptualizations of KT by a few PHS informants was that KT is about sharing the results of a study with the study population. I would argue that this understanding of KT is misguided, and undermines the intention of KT because it erroneously equates returning results with reciprocity. Reciprocity does not consist of reporting back to a study population what that population has told the researcher in the study process. Rather, reciprocity is about addressing the issues and concerns the study population has shared with the researcher, and *applying* the research findings in such a way to address the research problem (115). If the organizational partners that form E-SYS are to adopt this conceptualization of KT as reciprocity, KT will shift to action on health inequity as experienced by street-involved youth.

#### **5.2.4 Knowledge Translation & Action on the Social Determinants of Health**

As presented earlier, the field of public health is immersed in literature focusing on health promotion, health equity, and the SDOH. The limited application of these concepts in public health practice creates its own set of challenges for E-SYS. At this stage PHAC and PHS have not applied the E-SYS results to address the SDOH. Unfortunately engaging in more active KT does not innately resolve this tension as there are a number of factors that influence how KT takes place. For example, the majority of health KT literature emerges from the clinical setting and further emphasizes an individual focus. Secondly, and perhaps more significantly, the field of public health exists within a global and national political context in which neoliberal policies are increasingly common, and PHAC and PHS are not exempt from this reality. Numerous scholars have documented the influence of neoliberal policies and the resulting increased focus on downstream and individual-level health interventions (28,29,33), ignoring or sidelining a SDOH approach.

Hofrichter suggests there is an opportunity within the history of public health to realign public health practice; “the history of public health has also always been closely associated with themes of social justice and movements designed to achieve social equality and democracy, as well as self-determination and liberation from oppression” (p. 7)(155). If public health practice, and E-SYS, can ground themselves in social justice, the resulting KT activities will shift focus

and more directly act on the SDOH, and ultimately result in a healthier population. As put by Labonte (156), “these cautions do not mean that public health should give up on promoting healthier lifestyles, but they do imply that we have to be much more wary of its limited impacts on creating a healthier public” (p. 48).

### **5.3 Future Action & Research**

Given the guidance of critical theory and post-colonialism, and the desire for this thesis study to offer some reciprocity to the participants, I feel it is essential to offer some recommendations, as well as avenues for future research. The recommendations are intended for both PHAC and PHS, given that they largely drive the E-SYS processes. The avenues for future research are based on broader reflections, and present a select few of the numerous questions I am left with upon completing this thesis study.

#### **5.3.1 Recommendations:**

The research process involved of this thesis study offered numerous insights into E-SYS and KT, and it would be remiss not to provide some core recommendations for the organizational partners involved in E-SYS.

1. **Increased Partnership:** Increased meaningful partnership within E-SYS is essential for improved KT. In an effort to develop these partnerships, PHAC and PHS need to make partnership with local agencies a greater priority throughout their day-to-day practice. There is no question that this type of shift will require increased time and resources. However, increased partnership will also assist with many of the barriers PHS encountered throughout the KTE activities. In particular, strengthened partnerships with local community-based agencies will assist with PHS to understand how to apply and make meaning of the E-SYS results.
2. **A Critical Review of E-SYS:** One of the limitations of how E-SYS has embraced KT is the notion that KT occurs after knowledge creation. It is evident throughout the KT literature that the success of KT is heavily influenced by both the study problem and the study design. As stated by Lee and Garvin (111) “problem definition is particularly powerful because the very act of defining a problem helps to drive preferred solutions” (p. 455). Acknowledging some of the limitations facing surveillance systems, engaging with community agencies and the youth they support to re-visit the current E-SYS design and problem definition could

radically reinvigorate E-SYS. In this regard, engaged scholarship and its emphasis on collaborative inquiry appears particularly relevant.

At the very least future E-SYS KT processes need to seek far more meaningful opportunities for local agencies to engage in knowledge exchange processes. A more collaborative exchange process could serve to increase the relevance of E-SYS, more effectively bridge power and epistemological gaps, and overcome some of the limitations inherent in any one system. Furthermore, more intense exchange processes are particularly important when dealing with complex issues such as the health of street-involved youth (115).

3. **Action on the Social Determinants of Health:** Action on the SDOH is required to effectively address health inequities such as those facing street-involved youth. E-SYS provides an excellent example of a public health surveillance system that has incorporated some of the underlying notions of the SDOH within it. However, the KT activities that have emerged have been limited in acting on the SDOH. Although I have offered some possible explanations for this lack of action above, one KT strategy that is essential to address the SDOH is to target and engage policy-makers in KT processes. Partnerships with local agencies remain essential through their expertise of the day-to-day barriers and realities facing street-involved youth. In addition, policy-makers represent another important partnership that needs to be formed due to their ability to shape the policy making process and address some of the structural barriers facing street-involved youth.

### **5.3.2 Future Research Directions**

The reality of conducting one study means that many more avenues of inquiry are not explored. Throughout the study process many new questions and queries emerged that I was unable to explore. Three of the most significant areas of potential exploration include the role of power and relationships in E-SYS, the role of gender in E-SYS and KT, and developing meaningful indicators or markers in which to evaluate KT efforts.

**Power and Relationships.** This thesis study provides a window into some of the relationships and power dynamics that exist within E-SYS, specifically the dynamics that exist in Saskatoon between PHS and local agencies and youth. However, there are also significant power dynamics within the relationship between PHAC and PHS, as well as between PHS, the Saskatoon Health Region and the Saskatchewan Ministry of Health. Power permeates every

facet of bureaucracy (28), and although I strove to reveal the role power plays within KT and the Saskatoon-based KTE activities specifically, there is a need for further understanding of how power shapes national studies and KT. A complementary study exploring the historical relationship between PHAC (and previously Health Canada) and the community sites would provide poignant insight into the way power and relationships shape another facet of E-SYS. Furthermore, exploring how local health regions and public health departments are influenced by the politics and agendas of the provincial Ministries of Health across Canada would also provide depth to many of the issues raised within this thesis study.

**Gender Based Analysis.** When addressing any issue, and particularly an issue such as health equity, the role of gender is critical. As put forward by Sen and Ostlin (157), “taking action to improve gender equity in health, and to address women’s rights to health, is one of the most direct and potent ways to reduce health inequities overall, and to ensure effective use of health resources” (p. 226). It is unfortunate that I was unable to more fully explore the role that gender played within E-SYS and the KT efforts. One of the first E-SYS results that struck me as particularly relevant to a gender-based analysis is the finding that the majority of street-involved youth are male (15). Given the increased marginalization that women experience, including female street-involved youth (85) I can only assume that this finding is not accurately capturing the experiences of female youth and their involvement with street culture.

Furthermore, and as stated throughout this thesis, power and epistemology shape KT. Both power and epistemology also influence how gender is experienced, and therefore there are many avenues of exploration surrounding the interaction of gender and KT processes that merit further study.

**Evaluating Knowledge Translation.** Efforts to evaluate KT process are still in their preliminary phases. There are obvious challenges to developing indicators to evaluate KT, but in public health environments where evaluation has gained increasing attention, it will not be long before evaluation of any KT activities is made a priority. One of the evaluation markers that appeared to guide PHS’ decision making throughout the KTE process is the number of attendees at the March 4<sup>th</sup> workshop. Although number of attendees is a commonly used marker to measure the success of events, it is not particularly meaningful and says nothing about how the knowledge presented is received. Benoit et al. (158) suggest a more relationship-focused evaluation framework related to KT.

In the absence of highly reliable and valid indicators of the KT, we acknowledge that our strongest indicators of KT success are inter-organizational longevity in the context of major cutbacks to [community-based non-profit organization] funding as well as co-involvement in a variety of products, including workshops, conferences, and scholarly publications. Yet, it is also significant that engagement in these partnerships has changed all partners' previously held views of the target populations, the research endeavour, and the policy and practice implementation process (p. 20).

If KT efforts within public health are to focus on addressing health inequities, indicators of success need to consider such crucial components of the KT process as forming and maintaining partnerships, diversity of partnerships, and the formation of power. This is a complex and dynamic area of study, but absolutely critical if public health is to embrace KT in a manner that takes action on health inequity.

#### **5.4 Conclusion**

The influence of partnership within E-SYS is a powerful theme throughout the thesis, whether it relates to participation or issues of power and knowledge. KT is also clearly an important trend within the field of public health, but requires serious consideration in how it is conceptualized and carried out within public health practice. Public health, as a practice, has faced significant barriers over the last number of years with increasing priority being placed on downstream health services. Within Saskatoon, KT is becoming a priority within public health practice but in the midst of numerous priorities. Furthermore, if KT is to address the SDOH, partnerships with agencies must become a greater priority, and be more fully integrated into the research process.

E-SYS represents an excellent opportunity for PHS and PHAC to implement more active partnerships. However, for E-SYS to be as effective as it has the potential to be requires reviewing its present format with the expertise and insight of community-based agencies and street-involved youth.



## CHAPTER 6 CONCLUSION

The emergence of KT as a priority for E-SYS provides an excellent opportunity to observe how public health agencies struggle to embrace and undertake KT. Although KT has a lot in common with the principles that underlie health promotion, principles that are not new to the field of public health, the placement of many public health organizations within government creates unique challenges. E-SYS is uniquely positioned to take advantage of the many partners that are involved in the study process, and leverage those partnerships to support KT. However, as evident in PHS' experience, embracing these partnerships is not without challenges.

Upon entering this study my hope was to explore the gap that exists between researchers and community. The KT experience related to E-SYS provides one example of the barriers and challenges that exist, and highlights the importance of partnership in every aspect of a research project. From problem definition to the study process to KT, it is clear that researchers need to be conscious of how the processes they engage in shape the relationships they need. It also becomes very evident that in a surveillance study such as E-SYS, this is not without its challenges.

Reflecting back on the study experience and what is written in this thesis, the one driving revelation is the importance of relationship. Each partner involved in E-SYS brings their strengths and expertise, as well as their limitations. If any of the E-SYS partners hope to truly address the health inequities facing street-involved youth, those partners need to strengthen the existing partnerships, and seek new ones. Although E-SYS provides a lot of information, the expertise that exists within community-based agencies is just as important. Taking action on the SDOH will also mean developing new partnerships with policy-makers, and gaining a greater understanding of how policy is made. This entire process requires each E-SYS partner to be aware of their own limitations and rely on the strengths of the other partners.

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APPENDIX I  
Jacobsen et al.'s framework

Select questions from Jacobsen et al.'s (112) framework:

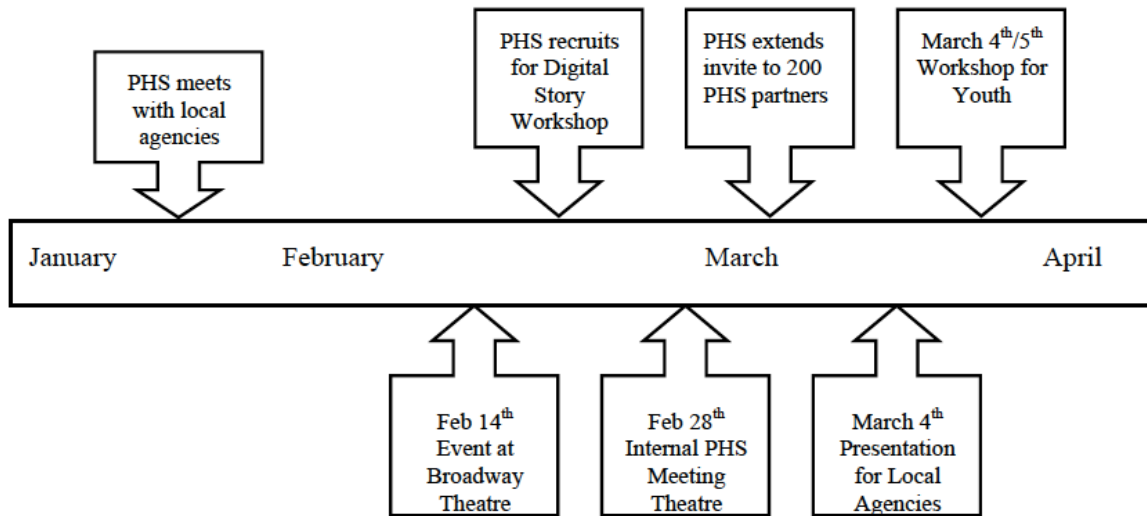
1. The User Group
  - What is the political climate surrounding the user group?
  - How big is the user group?
  - What is the user group's attitude toward decision-making
  - What criteria do the user group used to make decisions?
  - What actions are available to the user group?
  - What sources of information does the user group access or use?
  - For what purposes does the user group use information?
  - Has the user group demonstrated an ability to learn?
  - What incentives exist for the user group to use research?
  - Is the user group cynical about research and researchers?
  - How sophisticated is the user group's knowledge of research methods and terminology?
  - Does the user group have a history of being involved in knowledge translation?
  - What are the user group's expectations of the researcher? Of the knowledge translation process?
  - How many user group members will be involved in the knowledge translation process? Who are they?
  
2. The Issue
  - To which policy sector(s) does the issue relate?
  - For which other groups is the issue salient?
  - How does the user group currently deal with this issue?
  - Are things changing with the issue? How quickly are those changes taking place?
  - How much uncertainty surrounds the issue?
  - How much conflict surrounds the issue?
  - What risks are associated with the issue?
  - Is it necessary to possess a particular expertise in order to understand the issue?
  
3. The Research
  - What research is available?
  - Is the research unambiguous?
  - Is the research consistent?
  - What is the quality of the research?
  - What is the source of the research?
  - Is the research very focused and fragmented or quite broad and synthetic in focus?
  - Does the research suggest an immediate application? Is it action-oriented?
  
4. The Researcher-User Relationship
  - How much trust and rapport exist between the researcher and the user group?

- Do the researcher and the user group have a history of working together?
- Is the user group stable or is it likely to undergo changes that will affect knowledge translation?
- Will the research be interacting with a designated representative of the user group? Will that representative remain the same throughout the life of the project?
- How frequently will the researcher have contact with the user group?
- Have the research and the user group agreed about the desired outcomes of knowledge translation?
- Have the research and the user group agreed about the responsibilities each will have during knowledge translation?

#### 5. Dissemination Strategies

- Should the audience come to the researcher or should the researcher go to the audience?
- What is the most appropriate mode of interaction: written or oral, formal or informal?
- If using written or oral mode, what format is most appropriated to the user group? What are the group's preferences vis-à-vis length/time commitment?
- What level of detail will the user group want to see?
- To what extent, and in what ways, should the researcher continue to be available to the user group after the conclusion of translating the knowledge?

APPENDIX II  
Timeline of 2011 KTE Activities





## **Drug use Fact Sheet**

### **Preliminary Results from Enhanced Street Youth Study (eSYS) 2009**

#### **The majority of street youth used non-injection drugs (pot, ecstasy, speed)**

- 86% (103) used marijuana in the past three months; 35% (46) cocaine; 30% (39) ecstasy; 29% (38) hallucinogens
- 44% (58) binged on alcohol more than once a month in the past 3 months; 15% (19) binged on alcohol 2 or 3 times a week in the past 3 months; 17% (23) never binged on alcohol
- 25% (3) cocaine/crack users (who never injected drugs) tested hepatitis C positive

#### **One in three youth have used injection drugs at least once; one in four have used injection drugs more than once**

- The average age of injection drug initiation was 18 yrs for males, 15 yrs for females
- 51% (22) of all persons who used injection drugs were female
- 33% (14) cited "curiosity" as the main motivation to try injection drugs, 14% (6) cited "family using" and 14% (6) "friend using" 12% (5) answered "to help cope"
- 63% (27) of injection drug users<sup>1</sup> reported using cocaine in the past 3 months; 44% (19) dilaudid; 42% (18) morphine; 25% (11) ritalin 21% (9) methamphetamine
- 35% (15) reported using crack as the drug taken most often in the past 3 months
- 29% (11) have shared needles; the majority (23) inject themselves but 35% (14) are injected by others, usually a friend (6), partner (3) or family member (3)

#### **Self-reported health status among persons who used injection drugs<sup>16</sup> was mixed**

- Only 12% (5) rated their physical health as poor but 47% (17) either self-reported or tested hepatitis C positive; 14% (6) either self-reported or tested HIV positive
- 47% (20) rated their mental health as "very good or excellent;" but 21% (9) rate "poor"
- 47% (20) knew where to go to talk about physical or mental health

#### **Persons who inject drugs faced risks in their sexual behaviour**

- 40% (17) rated their risk of getting an STI, HIV or HCV as "low or no risk"
- 44% (19) self-reported testing positive for chlamydia in the past
- 34% (13) did not use a condom at last intercourse
- 42% (16) used non injection drugs before or after sex and 34% (13) used injection drugs One quarter (10) had sex with partners who used injection drugs before or after sex
- 37% (14) have been involved in the sex trade; 21% (8) in the last three months; an additional 25% have used sex to obtain drugs, alcohol, cigarettes, shelter, food and clothing or other items
- The average age of sex trade initiation was 14 years; the majority (13) were female

#### **Homelessness and injection drug use were significantly associated**

- Injection drug users<sup>1</sup> were 3 times more likely to have slept in a public place in the last three months (park, bridge, doorway) than other youth (OR=3.3 p = 0.04)<sup>17</sup>

#### **Abuse is significantly associated with injection drug use**

- Youth who were physically abused were 4 times more likely to be injection drug users compared to other youth (OR= 4.2 p= 0.002)<sup>2</sup> youth who are sexually abused are 3 times more likely to be injection drug users than other youth (OR =3.3 p=0.007)<sup>2</sup>

#### **One in five youth who used injection drugs were currently in school**

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<sup>16</sup> 43 youth reported injecting drugs once or more (referred to as "persons who injected drugs"); 38 youth injected drugs more than once (referred to here as "injection drug users")

<sup>17</sup> OR (odds ratio) is a statistical test of association between characteristics. A p value of/under 0.05 expresses "statistical significance."

- Injection drug users were 8 times more likely to have been expelled or dropped out of school (OR = 8.76 p= > 0.001)<sup>2</sup> than youth who did not use injection drugs

**Less than half of injection drug users received government support in the past 3 months**

- As main income 18% (7) had regular work; 16% (5) sold drugs or stole goods; 10% (4) sex work, 5% (2) recycled bottles

**Addiction Services**

**Of 45 youth who thought of seeing an addictions counsellor over half started a program**

- 57% (15) had finished a program but relapsed (10)
- Suggestions by youth of program supports needed included “talking to people after the program,” “more beds,” and “more doctors for methadone clinics”

**The main barrier cited for accessing Addiction Services was waiting “lists too long”**

- 20% (9) cited that waiting lists were too long; other barriers included “can’t find” (2) “not enough social supports,” (2); “programs don’t support cultural needs” (2)