Adolescent Disconnection from Brain Health and Impact on Brain Health Behaviour Decision-Making

by

Adam Agate

A thesis submitted in conformity with the requirements for the degree of Masters of Science

Institute of Medical Sciences
University of Toronto

© Copyright by Adam Agate 2015
Adolescent Disconnection from Brain Health and Impact on Brain Health Behaviour Decision-Making

Adam Agate
Masters of Science
Institute of Medical Sciences
University of Toronto
2015
Abstract

This qualitative content analysis study was performed to understand the views about brain health held by high school students in grades 9 and 10, and how this impacts their adoption of brain healthy behaviours. Three semi-structured focus groups interviews were held with 23 high school adolescents in the Greater Toronto Area. Three themes regarding participants’ views on brain health emerged from the data analysis: (1) Ambiguous Definition, (2) Lack of Understanding and (3) a Struggle for Relevance. These themes contributed to adolescents feeling disconnected from the topic of brain health and its impact on their present and future lives. This emerged as a barrier to the adoption of healthy brain health behaviours. There is a need to address the divide between the youth of our generation and the topic of brain health through the creation and implementation of more meaningful learning experiences about the brain.
Acknowledgments

It is not the mountains we conquer but ourselves.
- Edmund Hillary

I owe my sincerest gratitude to the people responsible for supporting me on this journey. First to my parents Cheli and Bill who have shown me what true unconditional love and support is. From a young age, you have done everything in your power to provide the best that life has to offer. Thank you for never doubting me even when I doubted myself. I hope you are proud of the man that you have helped me become.

To my little brother Jesse, thank you for the much needed laughs throughout this trying process. When you were born I told myself that I would try to be the best role model I could for you. Little did I know that you would become mine.

I would not have made it this far without the support of my closest friends and loved ones. I would especially like to thank Naomi and Kyle who have always been by my side to help me stand when I have fallen. The lessons you have taught me in generosity, support and love will stay with me forever. I am blessed to have had you in my life.

I also want to acknowledge my Baycrest colleagues who have been a part of my life as long as I can remember. Some of you have watched me grow up from a young boy while others have come into my life more recently. All the same, you have been a pillar of strength in my life and I would not be where I am today without you. Thank you to Lily, Maria, Iris, Emily, Daphna Grossman, Anna Grinberg, and all the wonderful staff and clients at the Samuel Lunenfeld Mountainview Club.

I want to recognize and thank the study’s 23 participants and the Moir family for making this work a possibility. It has been a privilege to hear your stories and I am humbled by your contributions to this work.

I would like to thank those that have been supporting me directly on this endeavour. Peter Whitehouse, Shelley Craig, and Victoria Calleja-Lorenzo, you have provided incredible insight and your presence has enriched both this project and my experience. An especially heartfelt gratitude is extended to my thesis committee members Pia Kontos and Joel Sadavoy. Thank you for mentoring me and challenging me. This project would not have been completed without you and I am forever grateful for your patience and confidence in me.

Finally, I must thank my supervisor Dr. Tiffany Chow. You have been my companion on this long trek. Through the hills and the valleys we have traveled together, and there is no guide I would rather have had to share this experience with me. I have grown so much in the past five years because of you. Thank you for all the hard lessons and reality checks. Thank you for all the encouragement and confidence. You have been my mentor throughout this process and will always be my role model in life. This accomplishment is not mine – it is ours. It has been a long road, and an incredible journey. We made it.
# Table of Contents

## Contents

Abstract ............................................................................................................................................... iii

Acknowledgments ............................................................................................................................... iv

Table of Contents ............................................................................................................................... v

List of Tables ...................................................................................................................................... x

List of Figures ................................................................................................................................... xi

List of Appendices ............................................................................................................................ xii

Chapter 1 ........................................................................................................................................ xi

Introduction ......................................................................................................................................... 1

  - Background and Context for the Study ......................................................................................... 2
  - Problem Statement ....................................................................................................................... 4
  - Purpose Statement ....................................................................................................................... 5

Chapter 2 ........................................................................................................................................ 6

Literature Review: Methods ............................................................................................................. 6

  - Literature Search #1 .................................................................................................................... 7
  - Literature Search #2 .................................................................................................................... 9
  - Literature Search #3 .................................................................................................................. 11

Data Collection and Analysis ........................................................................................................... 13

Literature Review: Discussion ......................................................................................................... 13

  - Use of Focus Groups with Adolescents .................................................................................... 13
  - Habit Formation and Behaviour Modification in Early Teens ................................................... 15
  - The Role of Peers and Friends in Health Behaviour Modification .......................................... 17
  - The Role of Parents in Behaviour Modification ....................................................................... 21
  - Learning from Teachers ............................................................................................................ 22
<table>
<thead>
<tr>
<th>Chapter/Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barriers formed by Current Health Beliefs of Students</td>
<td>23</td>
</tr>
<tr>
<td>Influence of Gender on Health Behaviour Modification</td>
<td>24</td>
</tr>
<tr>
<td>Boys</td>
<td>25</td>
</tr>
<tr>
<td>Girls</td>
<td>26</td>
</tr>
<tr>
<td>Strengths and Limitations of Current Health Education</td>
<td>28</td>
</tr>
<tr>
<td>Literature Review: Conclusion</td>
<td>31</td>
</tr>
<tr>
<td>Chapter 3</td>
<td>33</td>
</tr>
<tr>
<td>Introduction - Methodological Rationale</td>
<td>33</td>
</tr>
<tr>
<td>Defining and Discussing: Epistemology, Methodology, and Methods</td>
<td>33</td>
</tr>
<tr>
<td>Choice of qualitative methodology</td>
<td>37</td>
</tr>
<tr>
<td>Why use qualitative content analysis?</td>
<td>39</td>
</tr>
<tr>
<td>Historical context and development of qualitative content analysis</td>
<td>41</td>
</tr>
<tr>
<td>Choosing a qualitative content analysis approach</td>
<td>43</td>
</tr>
<tr>
<td>Why use focus groups?</td>
<td>44</td>
</tr>
<tr>
<td>Research Method and Process</td>
<td>46</td>
</tr>
<tr>
<td>Participant inclusion/exclusion criteria.</td>
<td>46</td>
</tr>
<tr>
<td>Focus group inclusion/exclusion criteria</td>
<td>47</td>
</tr>
<tr>
<td>Recruitment strategy</td>
<td>48</td>
</tr>
<tr>
<td>Data Collection: Focus Groups</td>
<td>52</td>
</tr>
<tr>
<td>Compensation</td>
<td>53</td>
</tr>
<tr>
<td>Sample size</td>
<td>54</td>
</tr>
<tr>
<td>Sampling and the focus group process</td>
<td>54</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>56</td>
</tr>
<tr>
<td>Field notes and memo writing</td>
<td>56</td>
</tr>
<tr>
<td>Data transcription and coding</td>
<td>57</td>
</tr>
<tr>
<td>Coding</td>
<td>57</td>
</tr>
<tr>
<td>Quality Criteria</td>
<td>59</td>
</tr>
<tr>
<td>------------------</td>
<td>----</td>
</tr>
<tr>
<td>Member checking</td>
<td>61</td>
</tr>
<tr>
<td>Multiple coding</td>
<td>62</td>
</tr>
<tr>
<td>Audit Trail</td>
<td>62</td>
</tr>
<tr>
<td>Prolonged Engagement</td>
<td>63</td>
</tr>
<tr>
<td>Reflexivity</td>
<td>63</td>
</tr>
<tr>
<td>Ethical Issues</td>
<td>64</td>
</tr>
<tr>
<td>Ethical treatment of participants</td>
<td>65</td>
</tr>
<tr>
<td>Potential risks and benefits</td>
<td>65</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>66</td>
</tr>
<tr>
<td>Chapter 4</td>
<td>67</td>
</tr>
<tr>
<td>Focus Group Summary and Descriptive Statistics</td>
<td>146</td>
</tr>
<tr>
<td>Focus Group #1 Summary</td>
<td>146</td>
</tr>
<tr>
<td>Focus Group #2 Summary</td>
<td>147</td>
</tr>
<tr>
<td>Focus Group #3 Summary</td>
<td>148</td>
</tr>
<tr>
<td>Qualitative Findings</td>
<td>68</td>
</tr>
<tr>
<td>Ambiguous Definition</td>
<td>69</td>
</tr>
<tr>
<td>(a) Mental health</td>
<td>70</td>
</tr>
<tr>
<td>(b) Functional health</td>
<td>74</td>
</tr>
<tr>
<td>(c) Identity</td>
<td>77</td>
</tr>
<tr>
<td>Lack of Understanding</td>
<td>80</td>
</tr>
<tr>
<td>(a) Flawed Education Model</td>
<td>81</td>
</tr>
<tr>
<td>(b) Skepticism about Educators</td>
<td>84</td>
</tr>
<tr>
<td>(c) Focus on Consequence</td>
<td>86</td>
</tr>
<tr>
<td>Struggle for Relevance</td>
<td>88</td>
</tr>
<tr>
<td>(a) Invisibility</td>
<td>89</td>
</tr>
</tbody>
</table>
(b) Peer Disinterest. ........................................................................................................93

(c) Emotional Detachment. ..............................................................................................96

Chapter Summary ........................................................................................................100

Chapter 5 .........................................................................................................................101

Discussion .........................................................................................................................101

The Analytic Narrative .....................................................................................................101

Confusion – What does “Brain Health” Mean? .................................................................101

Why should I care about brain health and how can I change it? .....................................104

Disconnection from Future Brain Health ......................................................................106

Beyond the Narrative: Brain Health Behaviours Are Not Adopted ...............................108

Defining Behaviour Adoption .........................................................................................108

Behaviour adoption is a conscious choice .....................................................................109

Behaviour adoption is an informed choice .....................................................................109

Missing Necessary Information for Brain Health Behaviour Adoption .......................111

Disconnection with Brain Health Raises a Barrier to Brain Health Behaviour Adoption ..........................................................................................................................112

Implications: Addressing Research Questions ................................................................114

Understanding Adolescents’ Relationship with the Topic of Brain Health ..................114

Difficulty Conceptualizing Brain Health .......................................................................115

Dissatisfaction with Health Education System ............................................................116

Relevance of Brain Health ..............................................................................................118

How Does Adolescents’ Relationship With Brain Health Impact Behaviour Adoption? ......122

What next? .........................................................................................................................123

Limitations .........................................................................................................................123

Conclusion .........................................................................................................................124

Future Directions ..............................................................................................................125
List of Tables

Table 3.1: .................................................................................................................. 58
Table 3.2: .................................................................................................................. 58
Table 4.1: .................................................................................................................. 147
Table 4.2: .................................................................................................................. 148
Table 4.3: .................................................................................................................. 150
List of Figures

Figure 1.1. ......................................................................................................................... 8
Figure 1.2. .......................................................................................................................... 10
Figure 1.3. .......................................................................................................................... 12
Figure 4.1. .......................................................................................................................... 69
Figure 4.2. .......................................................................................................................... 70
Figure 4.3. .......................................................................................................................... 80
Figure 4.4. .......................................................................................................................... 92
List of Appendices

Appendix A ........................................................................................................... 136
Appendix B............................................................................................................. 137
Appendix C............................................................................................................. 142
Appendix D............................................................................................................. 146
Chapter 1

Introduction

This qualitative study examines the relationship adolescents have with the topic of brain health. This research examines the perspectives of 23 adolescents in grades 9 and 10 in the Greater Toronto Area, utilizing a qualitative content analysis approach. Ultimately, the goal of this project is to build a better understanding of the relationship adolescents can have with the topic of brain health; otherwise, this relationship may act as a barrier to positive brain health behavior adoption. This information may be used to create future educational interventions aimed at promoting positive brain health behavior adoption amongst high school students.

Having both graduated from high school within the past decade and spent two summers doing behavioural research at the Samuel Lunenfeld Mountainview Club with those living with Frontotemporal Dementia, I have been fortunate to have witnessed the attitudes and perspectives on brain health from both ends of the life spectrum. Through this, it has become evident to me that adolescents may not be fully aware of the importance in their later years of maintaining positive brain health as early as possible, nor are they aware of the contribution of brain health to quality of life in the present or the future. This firsthand awareness has contributed to my interest in conducting this research.

This chapter outlines the background and the context for this study and it specifies the aims and objectives of this research. In addition, the organization of this thesis will be described through the content of each chapter. It is important to note that this project was initially motivated by my interest in dementia prevention and the background was written to reflect this. Over time, the scope of this study expanded to the promotion of positive brain health which encompasses a variety of interrelated aspects of health, such as concussion and mental health, while still including the prevention of dementia.
Background and Context for the Study

“Brain health” describes a wellness maintenance approach to optimizing cognitive and behavioural function throughout the lifespan. Brain health encompasses the prevention of dementia as well as the preservation of mobility and the stabilization of mood and emotion. This can be achieved by prevention of neurological disorders (e.g., stroke, traumatic brain injury) or investing in practices that enhance neuroplasticity or cognitive reserve (Barnes & Yaffe 2011, Feart et al 2009). Because a greater impact on modifiable dementia risk factors may result from early proactive prevention, more so than the reactive management of disorders like diabetes in mid-life (Scarmeas et al 2006), it behooves us to stoke brain health motivation among high school students. Studies regarding the implementation of brain health-promoting behaviours, such as the Mediterranean diet (Barnes & Yaffe 2011; Naqvi et al 2013; Scarmeas & Louis 2007) frequent rigorous exercise, (Anstey et al 2007, Hamer & Chida 2009) never smoking, (Akbaraly et al 2009, Karp et al 2006) leisure and socialization, (Wilson et al 2007) avoiding traumatic brain injury, (Roe et al 2008) and educational attainment (Meng & D'Arcy 2012, Sheffield & Peek 2011) imply a positive influence on health maintenance that would apply cumulatively throughout life to delay or even prevent dementia. There is only currently speculation that adoption of these behaviours in adolescence would provide even greater benefit, but our current understanding of diabetes, brain plasticity, and cognitive reserve support that speculation. Dementia has had slightly lower prevalence and incidence in a few recent population cohorts with high income status, and investigators speculate that in the absence of anti-dementia pharmacology for any of the observed cohorts, better nutrition and higher intellectual stimulation made the difference (Gerstorf et al 2011, Qiu et al 2013). Current late-life dementia prevalence is 6.5%, as opposed to the 8.3% projection based on elderly cohorts 20 years ago. In the comparison of nonagenarians between one decade and the next, there is
evidence for educational attainment and indirect evidence for physical activity to have made the
difference (Rocca et al 2011). The United States has shown a fluctuating pattern in reduction of
cardio- and therefore cerebrovascular disease prevention over time, which indicates that
adherence to brain health (the principles of which overlap considerably with cardiac health)
cannot be assumed to gain momentum from one generation to the next. We need to promote it
within educational environments so that it becomes engrained in individual habit, akin to non-
smoking (Burton et al 2009).

While there is no evidence that adolescents are spontaneously motivated to change their
health behaviours, existing programs show that high school students demonstrate an eagerness
for content about the brain. High school educators have recently observed youth motivated by
brain health and specifically AD, whether to pursue further education in neuroscience or as a
social concern. Evidence of this includes the rising number of Alzheimer’s clubs in high schools
around the Greater Toronto Area (GTA) as well as an increased number of students pursuing a
post-secondary education with a focus on the brain. Whereas 78 students wanted to specialize in
neuroscience in 2004, the University of Toronto Human Biology Program reports that 918
declared Neuroscience as major or specialty during the 2014-2015 school year. This increased
interest in content about brain health suggests that adolescents may be receptive to future
educational interventions promoting positive brain health. This focus on adolescents would also
support the Ontario Ministry of Education’s new curriculum objective to provide authentic
learning experiences of determinants of health for high school students (Ontario Ministry of
Education, 2015). Included in this objective was educating students about risk and resilience
against disorders that threaten normal cognitive health.

While the brain health content is known, the best opportunities for delivering this content
are not yet known. Adolescents are perceived as a challenging target group for behavioural
change (Stokes et al 2006). Before educational intervention trials may be designed, we must first gain a better understanding of the relationship adolescents currently have with brain health is, and how this relationship may impact the process of healthy brain health behaviour adoption. This richer understanding will provide the framework from which future educational interventions may be built upon.

**Problem Statement**

While brain health content is known, there is a dearth in the literature exploring adolescents’ current understanding and view of the topic of brain health. This information may be crucial in shaping educational tools aimed to reverse the rising prevalence of late-life neurological disorders such as dementia.
Purpose Statement

The purpose of this qualitative content analysis study was to explore the perceptions and lived experiences of adolescents in grades 9 and 10 and to better understand their relationship with the topic of brain health.
Chapter 2

Literature Review

This literature review was conducted to gain a knowledge foundation which may enrich and add context to the results of my analysis. It was initially intended to outline the current understanding of the process of brain health behaviour change in adolescents (aged 13-15), however there was an absence of such literature. Because of this, the review was expanded to create a general understanding of general health behaviour modification amongst adolescents. This literature review was particularly difficult, because the lack of literature focusing on brain health behaviour adoption led me to approximate and extrapolate a lot from the general literature in order to establish relevance to my thesis.

The review will begin with a brief overview of what is known about the importance of health behaviour decision-making and habit formation in early adolescents. Following this, factors such as peer, parental, and educator influences, health beliefs, and gender and their role in adolescent health behaviours will be explored. Finally, strengths and limitations of the current health education system will be explored. This is because school is a central fixture in young teenager’s lives and as such is an excellent platform from which they can become more engaged with the care of their own health (Koplan, Liverman et al. 2005).

Literature Review: Methods

Three literature searches were conducted in April 2014, May 2014, and August 2014 in the OvidSP database. The process was iterative, with common MESH terms in relevant articles being incorporated into the next search’s terms. Studies that met the eligibility criteria from the three searches were included in this review.
Literature Search #1

Search Terms: This search was conducted on April 19th 2014. Search terms are described below:

1. teen$ or adolesc$ or youth (3417478 articles)
2. behavio#r or adoption or change or modification or promotion or health (8691716 articles)
3. health behavio#r (10380 articles)
4. “and” (3550 articles)
5. brain
6. “and” (120 articles)
7. Remove Duplicates (120 articles)

The terms teen, adolescent, and youth are commonly used descriptors of our demographic of interest (high school students), so they were all included in the terms of our searches. However, we only retained articles where these terms referred to those of average high school age (13 – 18 years old). The term “brain” was added into the search in order to determine what existing literature might exist specifically regarding brain-related health behaviour modification among high school students. It was noted that this search term severely limited the number of resulting articles for review indicating that few studies have focused on behaviour modification in the context of brain health.

Inclusion Criteria: We included articles if they met the following criteria: (1) They were published in English, (2) were peer reviewed primary journal articles, (3) followed qualitative methodology (mixed methods studies were also included), (4) focus was on behaviour modification or perceptions of health behaviour, (5) and were looking at adolescents aged 13 – 18.

To reflect the contemporary attitudes and perceptions of youth today, we focused on studies published since the year 2000 to identify the most relevant information. This necessarily included articles from years 2005-2007, because there were so few articles that matched the
search criteria. Papers discussing behavioural or social theory, or methodology were excluded from the listed criterion as many were published before the year 2000 and were not qualitative in nature. The qualitative studies identified in the literature search had either used interviews or focus groups to elicit conversation that would later be transcribed and coded. Thirteen articles obtained from alternative sources were also included in the initial review.

![Flowchart showing the literature search process](chart.png)

**Figure 1.1** Literature search #1 on April 19, 2014 for research on health behaviour change in high school aged youth (13 – 18). Unique search term “brain” was included to bring forth any existing studies specifically examining brain health behaviour change in this population.
The majority of articles were excluded from the search due to titles indicating that they mis-match with the inclusion criteria (i.e. methodological approach not qualitative, examining health behaviour change in college students, review article). Furthermore, the articles chosen for inclusion were not related to brain health behaviour despite having the term “brain” included in the search. Articles accepted into the literature review were compared to find common mesh terms. The two common MESH terms identified were “Health Education” and “Health-risk Behaviours.”

**Literature Search #2**

**Search Terms:** This search was conducted on May 29\textsuperscript{th} 2014. Search terms are described below:

1. teen$ or adolesc$ or youth (3478892)
2. behavio#r or adoption or change or modification or promotion or health (8851670)
3. health behavio#r (10625)
4. “and” (3550)
5. Health Education (189057)
6. Health-risk behavio#rs (920)
7. “and” (22)
8. Remove Duplicates (19)

The search term “brain” was removed as it was found to be too restrictive. In its place, the new MESH terms “Health Education” and “Health-risk behaviours” were included in the search.

**Inclusion Criteria:** Inclusion criteria remained the same as the previous search.
Figure 1.2 Literature search #2 on May 29, 2014 for research on health behaviour change in high school aged youth (13 – 18). Unique search terms defined in applicable articles from literature search #1, “Health Education” and “Health-risk behaviours”, were included.

This literature search yielded four applicable articles. Examination of the search algorithm determined that the search term “Health-risk behaviours” heavily restricted the number of resulting articles. A broader third literature search was deemed necessary to increase the number of relevant articles for review.
Literature Search #3

Search Terms: This search was conducted on August 17\textsuperscript{th}, 2014. Search terms are described below:

1. teen$ or adolesc$ or youth (3478892)
2. behavio#r or adoption or change or modification or promotion or health (8851670)
3. health behavio#r (10625)
4. “and” (3550)
5. Health Education (189057)
6. “and” (494)
7. Remove Duplicates (423)

The search term “Health-risk behaviours” was removed in order to increase the amount of resulting articles.

Inclusion Criteria: The inclusion criteria were modified to be more expansive. Specifically, criterion (3) (were peer reviewed primary journal articles) was changed to include both peer reviewed primary journal articles as well as review articles. These review articles were used as a secondary source of relevant information and aided in the discovery of relevant studies that may have been missed in the initial search. The rest of the inclusion criteria remained the same as before.
Figure 1.2 Literature search #3 on August 17th, 2014 for research on health behaviour change in high school aged youth (13 – 18). The search term “Health-risk behaviours”, was removed and the inclusion criteria was expanded to include review articles.

In total, 63 articles in total were found during the three searches and included in the literature review.
**Data Collection and Analysis**

I analyzed and grouped articles included in the literature review according to the health behaviours analyzed (i.e. exercising, healthy eating, and substance abuse). I created subgroups for gender specific studies or studies that discussed the impact of gender on health behaviour change. From the analysis, I identified eight subthemes that were discussed: 1) Use of focus groups, 2) habit formation and behaviour modification in early teens, 3) the role of parents in behaviour modification, 4) learning from teachers, 5) strengths and limitations of current health education, 6) barriers formed by current health beliefs of students, and 7) influences of gender on health behaviour modification.

**Literature Review: Discussion**

**Use of Focus Groups to Study Adolescents**

In the literature review, focus groups were the most common means of data collection followed by one-on-one interviews. Of the two, the use of focus groups appeared to be most frequently used. I felt it important to briefly mention the justification for the use of focus groups proposed by other studies on adolescent health behaviour change.

Many studies note that unlike individual interviews, focus groups have the strength of facilitating knowledge development through interactive group discussions. This can be beneficial while studying a social phenomenon as these interactions may mimic those that take place in a real world, making the resulting data rich, while offering researchers an opportunity to tap into the multiple realities of people’s experiences in one session (Ashar & Lane 1993). As social factors likely influence adolescent perceptions of brain health and the process of brain health behaviour adoption, the interactive dynamic of a focus group may be best suited as a means of data collection in this study. Furthermore, power dynamics between adolescents and figures of authority have been found to play a role in participant responses in qualitative research.
groups may be particularly useful to shift perceived power dynamics in favor of participants and diminish any impact on response (Krueger 2006). As these unbalanced power dynamics may exist between myself and this study’s adolescent participants, the use of focus groups as a means of data collection may promote a more comfortable atmosphere and honest response. Other studies have also suggested that participants of all ages are empowered by focus groups, and that this sense of empowerment stems from interactive collaboration with the researcher and other participants, as well the feeling of being valued as an expert (Williams & Katz 2001). Participation in focus groups has also been described as educational and at times therapeutic (Marmoreo et al 1998), though it is important to note that these are not goals of focus groups.

In the past, focus groups have been used in health behaviour modification studies to inform the development of high school education programs while also evaluating students’ knowledge or attitudes about curriculum (Ashar & Lane 1993). These focus groups are essential in establishing a baseline of knowledge, beliefs, and attitudes regarding the health behaviour in question (Bindler et al 2012). This is an important consideration, as the results of this study may contribute to the creation of a high school educational program aimed at promoting positive brain health behaviour adoption.

It is interesting to note that in the literature, focus groups among adolescents commonly consisted of 5-9 students. It has been suggested that this range is ideal, as there are enough students present to make the experience more comfortable and less intimidating, while still being small enough in size to allow all members the opportunity to be heard (Allison et al 2005, Allison et al 1999, Hjelkrem et al 2013, Ng et al 2007, Stokes et al 2006). Focus groups were an effective form of data collection for the qualitative research articles included in this review, which in large part focused on the perspectives and experiences of adolescents in regards to
particular health behaviours. For this reason, I chose to recruit 5-9 participants in any focus groups conducted in this study.

**Habit Formation and Behaviour Modification in Early Teens**

Early adolescence is a period of development when individuals begin to gain independence and are heavily influenced by their peers. During this time, more health and lifestyle related decisions and opinions are formed (Bindler et al 2012). The opinions and habits formed in adolescence are often enduring, making it a challenge to alter them later on in adulthood (Lau et al 1990). Health behaviour choices such as the choice to be physically active are influenced by psychological, cognitive, emotional, social cultural and environmental factors (Sallis et al 2000). These factors may act as barriers or facilitators to health behaviour modification, and studies have shown that the way they are experienced varies from one demographic to another. Age, for example, may act as a barrier to positive health behaviour modification for adolescents as it signifies a stage of life where there is an increased drive to form interpersonal relationships, pressures to prepare for and make impactful future decisions, and the need to spend more time on academic pursuits. These considerations may often outweigh the risk of poor health behaviour repercussions (Allison et al 2005, Allison et al 1999). It is therefore imperative that efforts are made to understand the unique factors that influence the adolescent health behaviour decision-making process and the way that they are experienced. This understanding can then be used to inform future work for the creation of educational tools to guide youth into making healthy lifestyle choices. I believe that these factors likely influence not only health behaviour decision-making, but also the perception of any given aspect of health and the appraisal of its importance and value. As such, it would be beneficial for these factors to be explored when attempting to understand adolescents’ relationship with the topic of brain health.
The movement into new social situations, such as a transition from middle school to high school has been found to facilitate the adoption of new practices and behaviours. These new practices, however, often negatively impact health and include greater alcohol and tobacco consumption (Pavis et al 1998). Therefore, educational intervention programs focused on health behaviour change may be most effective for high school students. Studies have shown that there are inter-relationships between problem behaviours such as smoking, drinking and early sexual activity (Jessor & Jessor 1977). Similarly, health promoting behaviours such as a balanced diet, wearing seatbelts, and regular physical activity are also inter-related (Kandel et al 1978). This suggests that improving certain adolescent health behaviours may have a positive impact on other aspects of their health. As behaviours and practices that maintain positive brain health and to encompass a wide range of health behaviours including diet (Barnes & Yaffe 2011, Scarmeas et al 2006), exercise (Middleton et al 2010, Naqvi et al 2013), and smoking avoidance and cessation (Barnes & Yaffe 2011, Cataldo et al 2010), it is reasonable to deduce that improving awareness and education about brain health may have a holistic impact on overall health.

Creating impactful, long-term health habits in high school students may be especially challenging. High school students may have ego-centric views of themselves in that they acknowledge the expectations of their peers and apply these judgments on to others, yet exclude themselves from these standards (Stokes et al 2006). This can make it difficult for students to hold themselves accountable for their own health decisions. Furthermore, studies suggest that adolescents have a difficult time “colonizing” the future and conceptualizing future benefits and repercussions of their health behaviours (Lawton 2002). The ability to conceptualize future states and make decisions based of risk assessment develops during puberty (Steinberger et al 2005). In this way, adolescents are a particularly difficult group for which to promote health change, as they struggle to associate their current actions with future health (Wills et al 2008). This
disconnect from their future health status has promoted the attitude that “it will never happen to me” which appears to be common among youth, and has been identified as an intrapersonal barrier to information access and skill development to improve health (Emmons & Rollnick 2001). Because issues with brain health are often associated with the process of aging, it is possible that adolescents’ difficulty in conceptualizing their future health may be particularly impactful on the assessment of the importance of brain health in their own lives.

The Role of Peers and Friends in Health Behaviour Modification

The role of peers in adolescent decision-making has been explored in various health contexts. It has been established that peers and especially close friends seem to exert a large influence on health-relevant behaviours (Wills et al 2005). These influences often contribute to poor lifestyle choices. Studies that explore reasons for drinking or smoking have found that adolescents commonly cited social facilitation and peer influence as important contributors (Pavis et al 1998). Students were also found to form their view of fast food outlets as the most desirable option for food based off of short or fast-moving queues, in large part, due to wanting to spend more time socializing with friends and peers (Wills et al 2005).

At other times, peer influence can promote positive health behaviour change. A study of adolescent Norwegian girls described the largest draw of physical activity as a chance to socialize with their peers as opposed to the thought of future health benefits (Hjelkrem et al 2013). Furthermore, fun has been described as a motivator for physical activity, and the presence of friends during physical activity made it fun. Friends also have been described as positive guides to decision-making about physical activity (Allison et al 2005, Casey et al 2009, Jago et al 2009).
The transition to high school often results in dispersing of former friendship groups, which creates uncertainty, fear and the urgent need to quickly gain social support through the development of new friendships (Bonell et al 2012). During this time, students adopt the behaviours that they perceive as “normal” within their new social circle and this is what contributes to the rapid change in health behaviour practices observed among new high school students (Marcoux & Shope 1997). These include changes to eating behaviours in high school, where decisions about purchasing and eating food are often made as a group. Commensality (the practice of eating together) poses a challenge for those attempting to alter their unhealthy eating behaviours as youth may be unwilling to make healthier decisions if it goes against what their peers choose to eat (Wills et al 2005). High school students in areas with a lower socioeconomic demographic describe their educational environment as feeling “unsafe”, fearing social isolation and physical confrontation. Many reported the need to develop self-protective identities for the purpose of bonding with other students with similar identities. These “safe” identities were based on engaging in ironically risky health behaviours, such as recreational drug use (Bonell et al 2012).

Similar pressures have been described by adolescent boys who have attempted smoking cessation. There was a strong pressure amongst them to meet the status quo of their social circles lest they be punished with ridicule or rejection (Ng et al 2007). A review about the influence of peers on adolescent smoking (Kobus 2003), found that the pressure to smoke cigarettes described in many studies is overwhelmingly normative, and not coercive in nature (Kniskern et al 1983, Nichter et al 1997). Pressure from peers therefore was not experienced as a direct pressure, but internal pressure adolescents experienced to conform to what those around them were doing in an attempt to avoid exclusion, gain social approval, maintain autonomy and promote socialization. Interpersonal barriers among peers and friends have also been identified as a major
factor in youth attitudes on sexual activity. Adolescents described pressure from peers to be sexually active as negatively influencing their decision-making by disposing them to have sex earlier (Emmons & Rollnick 2001). Indeed it seems as if the fear of not conforming is a concern that guides adolescent health decision-making. This has been the basis of many substance abuse prevention programs that emphasize social influences and encourage youth to resist the pressure to conform to their peers (Lantz et al 2000).

The desire to fit in with the perceived norm is not the only concern that influences adolescent behaviour change. The fear of stigmatization or being a social outcast has been suggested as a strong motivator for youth to change their health behaviours. Stigmatization often takes the role of social rejection or bullying from peers because of noticeable and uncontrollable characteristics such as weight, sexuality, fitness level, or unhealthy teeth, or a willingness or unwillingness to partake in certain behaviours that are normative in the group (Stokes et al 2006). In this way, stigmatization may play a part in health behaviour decision-making and can motivate both positive and negative health behaviour change.

While attempting to blend in with peers plays an important role in the behaviour of adolescents, studies have also suggested that there is a desire to stand out among classmates in a positive fashion. Unhealthy behaviours such as smoking among adolescent boys can increase social standing among peers. Heavy importance is placed on appearing “mature” and “rich” to other classmates, especially if smoking popular cigarette brands (Ng et al 2007). Adolescent males have reported participating in sports in order to stand out from their friends (Allison et al 2005), while adolescent girls commented that they perceived being physically fit as synonymous with appearing thin (Gillison et al 2012). This finding indicates that both genders were at least partly motivated by the external pressures of appearances among their peers as opposed to intrinsic motivations. Adolescents often value health goals based on their contribution to image
and overall self-impression. The driving motivator for many students is therefore to improve their outward appearance in order to impress those in their social circles and subsequently improve their confidence (Stokes et al 2006).

It is known that high school students commonly form friendships and social circles with those that share common traits such as “gender, ethnicity, socioeconomic status, attitudes, normative beliefs, school performance, cigarette smoking, alcohol and drug use, engagement in deviant behavior and sexual behavior” (Kobus 2003), a concept referred to as friendship homophily. In a mixed-method study of adolescent behavioural change, there was a statistically significant relationship between those that heavily smoked or drank and having friends who exhibited the same behavioural tendencies (Pavis et al 1998). This phenomenon was also described by self-identified adolescent smokers, who viewed smoking as a “socializing factor” and expressed that most of their friends were also smokers (Ng et al 2007). This presents another peer-mediated barrier to positive health behaviour change, as it has been established that youth have difficulty making health decisions that differ from what is normative within their social circles. Compounding this issue, adolescents who display certain negative health behaviours may avoid or feel wary of those attempting to change these behaviours in themselves. For example, overweight adolescents described a desire to avoid peers attempting to lose weight and at times were alarmed by their friend’s desire to lose weight as they perceived them at risk for developing an eating disorder (Wills et al 2006).

In summary, the literature suggests that peers and friends are particularly influential on the adoption of behaviours that impact health. In many of these studies it appears as though potential health repercussions for adopting certain behaviours are not weighed as heavily in the decision-making process as the desire to socialize with peers and ‘fit in’ with social circles by exhibiting behaviours perceived as normative within the group. Therefore, adolescents appear to
value certain health behaviours based on the perceived desirability of the outcome in their friend circles. While no studies to my knowledge have explored brain health behaviour adoption amongst adolescents, it is plausible that peer influences are equally influential. This research may contribute to this gap in the current understanding of brain health behaviour adoption by exploring how adolescents’ relationship with the topic of brain health is influenced by their peers, and how this impacts the process of brain health behaviour adoption.

The Role of Parents in Behaviour Modification

A longitudinal study on health behaviour changes among adolescents found that while both peer and parental influence are significant regarding the magnitude of change that occurs, it is the parents that play the most important role in the changes of beliefs and behaviours (Lau et al 1990). While this claim has been disputed, it is clear that parents can critically influence the health behaviours of their children. One such example was described by youth attempting to increase the amount of physical activity they undergo each week. When parents were unable to provide transportation, it decreased the number of appealing opportunities for physical exercise. This issue was exacerbated in single-parent families and families with lower socioeconomic standing, as there was not a second person with whom to split household and child care duties (Quarmby et al 2011). Another study found that fear of punishment from parents for staying out too late kept adolescents from participating in organized sports activities and contributed to a sedentary lifestyle (Allison et al 2005). In this way, parents concern for their children’s safety deterred them from making healthy lifestyle choices. Adolescents have also defined maturity as emulating their parents’ behaviour, with little regard as to the health implications of said behaviours. Furthermore, adult role models such as teachers and parents that are observed participating in unhealthy behaviours such as smoking may viewed as hypocritical, resulting in their health advice often being disregarded (Ng et al 2007, Pakpour et al 2012).
Power dynamics complicate the ability for parents to effectively support positive health decision-making in their children. Adolescents acknowledge that these dynamics play an important role in their decision to seek support or advice on behaviour modification from their parents. It has been reported that youth often attempt to resist parental control and refuse to seek advice for behaviour modification from them, preferring to make decisions about their own health without adult intervention. This is thought to reflect a growing desire for independence that is commonly felt upon entering adolescents (Emmons & Rollnick 2001). In addition, many adolescents are not comfortable discussing certain health behaviours (such as sexual activity) with their parents out of concern of embarrassment or punishment, and therefore are unable to seek advice or support to facilitate unwanted behaviour change (Emmons & Rollnick 2001).

**Learning from Teachers**

Teachers are essential participants of the education system and therefore in guiding adolescents to make healthy behaviour choices. It is important to delineate what perceptions adolescents have of their teachers to determine how to more effectively deliver educational content. Review of existing studies has found that the level of trust felt towards educators influences the acceptance of new information and attitudes towards health behaviour adoption. Adolescents have expressed that a personal connection between their educator and the subject matter plays an important role in perceived trustworthiness. For example, a dentist teaching about dental health is regarded as a trustworthy source of information and their opinions would be viewed as more important (Stokes et al 2006). Causes for feeling skeptical of teachers include perception of the teacher’s lack of confidence, lack of preparedness to teach, negative attitudes towards course content, and inability to connect with their students. Trust in educators was associated with trust in the material that was taught, an essential requirement for behaviour modification (Emmons & Rollnick 2001).
Balance, moderation and variation were found to be implicit in the understanding of healthiness among adolescents and needs to be incorporated into lesson plans (Croll et al 2001, Hjelkrem et al 2013). As a result, the abstinence-only approach many teachers have taken towards negative health behaviours was strongly admonished by students. Often they felt as if more focus was spent on teaching abstinence from certain behaviours such as unprotected sex, than on explaining reasons why these behaviours were to be avoided. Furthermore, they took issues with what they perceived as infringement on their own independence (Emmons & Rollnick 2001).

Currently it is unclear who educates adolescents about brain health, or if any education occurs at all. If brain health education does occur, it is unknown if adolescents’ feel that their brain health educators are trustworthy sources of information. Because the literature suggests that teachers and the valuable information they impart play a crucial role in the development of positive health behaviours, it is important that adolescent perceptions of their brain health educators be captured in the data collected for this study.

**Barriers formed by Current Health Beliefs of Students**

Students in high school may have trouble understanding how specific health behaviours might impact them. Studies have suggested that adolescents conceptualize certain health behaviours as not playing an integral role in “overall general health” and therefore place less importance on changing attitudes and actions in regards to these behaviours. In a study on the attitudes of adolescents in Liverpool towards oral health for example, students felt that overall health is more important than the health of your teeth, and failed to see the connection between the two (Stokes et al 2006). Furthermore, during interviews and focus groups, adolescents have demonstrated misconceptions about the negative side effects and benefits of certain health behaviours such as smoking. In one study, false beliefs about the health benefits of smoking was
cited as reason to keep smoking, and that a negative impact on their health would only be seen with “heavy usage”, a term that varied from one student to another (Ng et al 2007). This highlights how misconceptions about health behaviours may contribute to continuation of these behaviours or failure to attempt cessation.

These findings are particularly interesting when applied to the topic of brain health. It may be most adolescents do not consider that brain health plays an important role in overall health, or that the concept of brain health is so unclear that its value to overall health and quality of life is intangible. This highlights the importance of first learning how adolescents’ understand the topic of brain health, as it likely to be influential on their brain health behaviour decision-making. Also, while not the primary goal of this study, there is a lack of literature that explores common misconceptions adolescents hold about the brain or brain health. This study may provide the opportunity to explore if any such misconceptions exist, and how these misconceptions may impact the choice to adopt brain health behaviours.

**Influence of Gender on Health Behaviour Modification**

Some of the articles from the literature review describe gender differences in the way health behaviour adoption is experienced. These are often in the form of unique barriers or societal pressures that are tied to gender identity and influence the motivations and challenges of health behaviour adoption. While the majority of articles discovered in the literature review were specifically focused on the influence of gender on health behaviour adoption, some articles used terms referring to gender and sex interchangeably. Sex and gender are often confused as synonymous and yet hold very different meaning.

Sex is a biological classification that is controlled by genetics and can be phenotypically identified. The terms often used to describe sex are male or female. In contrast, gender is a personal identification and refers to a chosen social role. While these social roles are based on
the sex of a person, someone may identify as being of a gender that is not stereotypically assigned to their sex. For example, someone who is genetically male may identify as being a girl. I will be discussing gender, not sex. This is because gender describes a social role, which I believe is a better fit for this study as I am exploring the social dynamics that influence perceptions of brain health and the process of brain health behaviour adoption. The terms male and female will only be used if they are representative of the terminology in a cited article.

**Boys**

I identified common themes of boy-specific barriers to positive health behavior modification in the literature. Studies have found that boys reported facing more barriers to positive behaviour change than girls (Rhee et al 2009). This phenomenon may be due in part to adolescent boy views on masculinity and the integral role it plays in their behaviours and social interactions with others.

The construct of normative masculine identities is often tied to risk taking, dominance, and acceptance of pain or health issues (Allison et al 2005). This may lead boys to adopt behaviours that negatively impact health such as smoking as it is portrayed as mature and makes them feel more “macho” and “self-confident.” One study of adolescent boys’ attitudes toward smoking found that they described their sense of masculinity being tied to their ability to smoke with friends, and there was fear that this masculinity would be challenged should they choose not to smoke. Smoking therefore reaffirmed their identity as boys (Ng et al 2007). This construct of masculinity that drives boys to participate in unhealthy behaviours may also facilitate positive health behaviour change however, as the experience of risk taking and dominance have also been cited as a reason for adolescent boys more pronounced participation in organized sports in comparison to their girl counterparts (Allison et al 2005, Gard & Meyenn 2000, Light & Kirk 2000). This theory is supported by findings that boys were more likely to participate in vigorous
activity during their school breaks than girls (Wills et al 2005). A study by Allison et al., which looked at male adolescents’ reasons behind participating in physical activity and barriers to participation found that extrinsic factors referenced included the opportunity to socialize, ‘fit in’, maintain an attractive appearance, and to prove themselves amongst their peers. Intrinsic factors mentioned were engaging in physical activity for enjoyment or to build skills (Allison et al 2005).

Peer interaction between boys appears to be markedly different from interactions between girls. Boys have reported having more difficulty entering new social circles than girls, which often lead to feelings of isolation and poorer well-being (Wills et al 2005). If teenage boys fail to meet the status quo of their social circles, they are punished with ridicule or rejection from those groups. (Ng et al 2007). Boys reported being actively discouraged by their peers to access sexual health information in order to maintain their “popularity.” This pressure was not found to be as large among girls who were more supportive about communicating health concerns within the group (Emmons & Rollnick 2001). Failure to conform may result in exclusion from social groups and a disconnect from any support system. In the absence of a social network, boys reported having little support when attempting to change negative health behaviours (Wills et al 2005).

**Girls**

While it has been suggested that boys are faced with more social barriers to positive health behaviour adoption than girls, there is evidence that girls contend with their own unique challenges while attempting to achieve a healthy lifestyle. Chief among these challenges is the added pressure of maintaining a certain “body image” through weight management and diet (Gillison et al 2012, Hjelkrem et al 2013). Social aspects of eating in a crowd cause anxiety among girls. Girls are particularly concerned about their weight and find themselves skipping
meals to fit in with the popular crowd – often leading to further negative feelings about self (Wills et al 2005). It has also been suggested that girls perceive lack of time as a barrier to exercise more frequently (Kimm et al 2006). While it is unknown why this phenomenon occurs, it has been suggested that motivational interviewing to improve self-efficacy may be effective in girls who have not yet developed an interest to be physically active (Emmons & Rollnick 2001).

Girls may actually have an easier time than boys internalizing motivation towards health behaviours such as exercise. This may be in part due to earlier development of maturity which has been described as giving them a better understanding of the connection between exercising and their own health. Girls consider exercise as a consistent and long term commitment rather than a short-term one (Gillison et al 2012). Furthermore, girls seem to place emphasis on healthy living for intrinsic purposes such as “feeling good about yourself” or a general feeling of content with oneself (Hjelkrem et al 2013). This focus on intrinsic motivation was not as present among boys. Interestingly, girls are still consistently reported as being less involved with physical exercise and sport in comparison to boys. This may be because their construction of female identity is not as heavily tied to participation in organized sport and physical activity as it is amongst male constructs of their identity (Light & Kirk 2000).

Cultural definitions of gender roles also seem to play a large part in how certain health behaviours are perceived, valued, or admonished by both boys and girls. In a study by Emmons et al., some girls reported a much higher comfort level in communicating health needs such as revealing sexual history and confusion about safe sex practices and issues to peers and friends than some boys do (Emmons & Rollnick 2001). The authors hypothesize that this is due to girls having more accepting and social circles that facilitate open communication and strengthen support. Furthermore, certain negative health behaviours are related by adolescents to masculinity. Smoking for example, may hold positive social connotations for boys, yet when a
girl smokes they may be perceived as impolite or ill-mannered (Ng et al 2007). It is possible that perceived gender roles might actually protect girls from participating in or adopting certain risky health behaviours.

While none of these studies focused on brain health, it is apparent that gender and adherence to perceived gender roles influences perceptions of health behaviours as well as motivations to participate in various healthy or unhealthy behaviours. Furthermore, the level of support for concerns about health issues and the ease of access to these support networks may vary between adolescents of different genders. It is therefore important to consider the impact of gender influences on adolescent perceptions of the topic of brain health and positive brain health in this study. This could be done through the use of semi-structured interview questions that prompt discussion of gender differences in the way brain health perceptions, education, and adoption are experienced.

Strengths and Limitations of Current Health Education

Our review of the literature identified that adolescents take issue with some aspects of the current state of health education and promotion in high schools. Students reported having health classes that they felt were too rushed or not held soon enough in the year (Emmons & Rollnick 2001). Furthermore, because of competition with academic classes, gym classes that focus on physical activity and health promotion have been described as increasingly shortened or cut (Bonell et al 2012, Koplan et al 2005). Consequently, students spoke of turning to media campaigns and community programs for supplementary information about risky behaviours and as guidance (Institute 2008).

The desire to achieve independence from adult control and thereby make autonomous decisions for themselves was a common theme among the studies of adolescent motivations for health adoption. An exploratory study of adult agendas and young people’s strategies to resist
this control reported that adolescent girls disliked rigid rules over the types of physical activity they could take part in and dress codes, which make them unwilling to participate in physical activity while in school. To resist these rules, girls described strategies to avoid class by “forgetting” to bring gym clothes to school or by faking illness (Brooks & Magnusson 2007).

Health messages from adults or the media that were perceived as controlling also negatively impacted student’s ability to take ownership over their own health. High school students spoke of how they exercised more often because they felt that they “should,” or because teachers and the media “wanted them to be healthy.” This indicates that they still view their health as a value that is not fully their own (Gillison et al 2012). This is important to note, as a lack of literature on adolescents and brain health education makes it difficult to ascertain if adolescents feel that current education model is too overbearing or controlling. If this is the case, any brain health education that may occur may be ineffective and could theoretically prevent adolescents from valuing and investing in their own brain health.

When students perceive increased control in their learning experiences and curriculum development, they describe a shift from feeling as if they are performing to adult-set standards to a general feeling of inclusiveness which is more friendly and rewarding (Brooks & Magnusson 2007). Communicating information and rationales for health behaviour change in a way that allows self-determination is more effective for engaging youth in their own health behaviour change (Gillison et al 2012). Adolescents desire educational material delivered in a way that is relatable to their own experiences. Current health education has been described as too “repetitive, too basic, and irrelevant.” Information presented in what is perceived as a “politically correct” way, such as using outdated or overly polite language, makes it hard to relate to for the adolescents in the class (Emmons & Rollnick 2001). Youth also expressed that they would be much more receptive to information coming from peers than from “older people” during health
classes. Classes that promoted interpersonal interaction such as working in groups, practicing communication skills, and peer role models were much more successful in sexual health education among youth.

Peer role models are particularly important as this made the content seem more real and relevant to students’ experiences (Emmons & Rollnick 2001). Another study of adolescents found that they were highly motivated to continue their positive health behaviour by seeking and overcoming challenges. A sense of achievement and competency was gained by working towards self-appointed goals. Monitoring their own progress encouraged students to continue their new health behaviours (Gillison et al 2012). It is unknown if adolescents feel that they are able to set goals for their own brain health. If they feel that unable to monitor their own brain health, this could potentially result in difficulty feeling motivated to care about and improve their own brain health.

Adolescents often describe the use of fear in current health education as a tool to motivate behaviour change. While reflecting on educational campaigns, adolescents have cited the focus on negative health effects of health behaviours such as smoking and drinking as being particularly impactful, especially when accompanied by graphic visuals including images and video (Emmons & Rollnick 2001). An additional cohort study found educational campaigns aimed at eliciting negative emotions such as fear and sadness are effective in promoting cessation rates of negative health behaviours such as smoking among adolescents (Institute 2008). Interestingly, these types of campaigns were especially effective among adolescents from lower socioeconomic populations (Durkin et al 2009). While fear may be a powerful motivational tool for behaviour change, to our knowledge, reports have not yet discussed if students support its use in educational interventions.
Literature Review: Conclusion

The studies reviewed all dealt with adolescent perceptions and experiences of health behaviour change. It was difficult to compare findings as they focused on different health behaviours and employed various recruitment and data collection methodologies. While the studies included in this literature review may have not been directly comparable, they do provide insight as to the current state of knowledge on adolescent health behaviours. Overall the studies suggest that the use of focus group methodologies in qualitative studies with adolescents is appropriate as it allows researchers to not only observe responses and interactions, but empowers participants so that they may have more frank and honest discussions.

Adolescents appear to be particularly susceptible to health behaviour changes during the start of high school due to a combination of entering a new social environment and a desire to create and maintain connections to their peers. While both parents and teachers have been found to influence the health decision-making process of adolescents, it seems that desire to be accepted and approved by peers is the strongest determinant. The way internal and external pressures and motivations that influence health behaviour decisions seem to be experienced differently, with girls demonstrating a higher capability of using intrinsic motivation to guide health behaviour choices and boys basing their health decisions heavily on peer influences as well as their perceived social constructs of masculinity.

These findings will provide insight into the data collected for this thesis. The literature has provided justification for the use of focus groups in this particular study to address potential power imbalances and capture the social dynamics that may influence perceptions of brain health through group discussion. Furthermore, this review has made me aware of the many factors that contribute to the process of health decision-making amongst adolescents. Chief amongst these factors are peers, parents, teachers and gender. This provides valuable insight during data
collection, as I can integrate questions and discussion prompts into my semi-structured interview script that may facilitate discussion of the role these factors play in perceptions of brain health and brain health behaviour adoption. My hope is that by providing me with a knowledge foundation, I will be better equipped to draw deep and meaningful conclusions from my work.
Chapter 3
Research Design and Methodology

Introduction - Methodological Rationale

My research question is to understand the adolescent experience of positive brain health behaviour adoption and identify what perceived barriers and facilitators regarding this adoption exist. I chose a qualitative methodological approach as the most suitable to answer this question because it is best suited for exploring a social phenomenon. This is because qualitative research holds the epistemological premise that reality is subjective and multiple. As such, qualitative research can be used to gain an understanding of the many different attitudes and beliefs within a social context. This is explained in greater detail further along in the methodologies section.

It is difficult to justify methods without first discussing the whole framework of research and knowledge generation. Therefore I will first start by briefly defining the interrelated concepts of epistemology, methodology, and methods. Then I will explain why a qualitative methodological approach was chosen, and more specifically why focus groups and a qualitative content analysis approach was used for data collection and analysis. I will also detail the origin of qualitative content analysis and the relevance and application of its approach to my research question and design.

Defining and Discussing: Epistemology, Methodology, and Methods

Epistemology is the theory of knowledge. It is a branch of philosophy concerned with the nature, components, sources and limits of knowledge. Researchers either actively or implicitly adopt theories of knowledge and the assumptions that these theories hold (Carter & Little 2007, Mauthner & Doucet 2003). These epistemological assumptions directly shape the process of knowledge inquiry, also known as research, by influencing methodology and the
implementation of methods. For example, one researcher may believe that the researcher is an active participant in the knowledge generation process, and that his bias, relationships and influence are all contributors to the knowledge gained. This researcher would argue that researcher influence is therefore an important aspect of the knowledge generated and should be transparently described. Another researcher may oppose this line of thinking and believe that those conducting research should set aside personal beliefs and knowledge so as not to introduce any bias. That researcher would likely believe that generalizability of the results is the primary goal. These two different epistemic assumptions would heavily influence the types of research questions asked, how the research is conducted and reported, and the way in which the quality of other articles is assessed. As such, epistemology can be thought of as the justification of knowledge (Carter & Little 2007).

In its most general of terms, “qualitative” research can be broadly defined as social research with the goal of understanding the meaning of human behaviour and action (Schwandt 2001), by asking “open questions about phenomena as they occur in context rather than setting out to test predetermined hypotheses” (Carter & Little 2007) (p.1316). This is achieved through the gathering of data in textual or artistic format (such as pictures, drawing, or dance) rather than numerical, and the analysis of these data in textual form as opposed to deriving and analyzing numbers (Schwandt 2001). Generally this approach relies on the narratives of the participants themselves to construct an interpretation of the meaning of their experience within their own social context (Kuckelman Cobb & Forbes 2001).

The epistemological assumptions of qualitative research differ significantly from those of the positivist paradigm. In positivism, reality is held to be an objective and measurable truth which is knowable and falls within the limits of probability. The approach to quantitative research focuses on determining causal relationships, through random sampling, researcher
objectivity, large sample sizes, and standardized questions with emphasis placed on establishing generalizability (Beck 2013, Patton 2002).

In contrast, interpretism holds that reality is subjective and fluid, and that there are multiple realities and perspectives that can be discovered. The qualitative research framework therefore is less constrictive with multiple paradigms, realities, and truths (Beck 2013, Denzin & Lincoln 2011). Another epistemological premise of qualitative research is that the researcher must participate subjectively with those who experience the phenomenon studied and that this results in participants and researchers simultaneously influencing one another (Charmaz 2004, Kuckelman Cobb & Forbes 2001). While this involvement is deemed a limitation by positivists because of the introduction of researcher bias, it is strength in qualitative research as it allows for purposeful sampling of information rich subjects. In qualitative research, transferability rather than generalizability becomes the goal (Beck 2013). Qualitative research is ultimately not about defining the objective world, but understanding how it is experienced and understood by individuals. Thus, the goal of qualitative research is to meaningfully conceptualize and report how people perceive the world. This rigorous description of people’s viewpoints and attitudes can act as the base for future explanatory research.

If epistemology can be thought of as the justification of knowledge, then methodology may be thought of as the rationale for methods. Methods in turn produce knowledge, so methodologies have epistemic content (Carter & Little 2007). Methodology is a term that is used loosely in the literature, with authors referring to formal theories such as symbolic interactionism, disciplines such as sociology, or specific methods such as focus groups. I prefer the definition that refers to methodologies as the study, description, explanation, and justification of methods (Carter & Little 2007, Kaplan 1998, Schwandt 2001). Methodology is therefore separate from the methods themselves, and focuses on gaining a broad understanding of the
process of scientific inquiry instead of the resulting products (Kaplan 1998). Methodologies can influence choice of methods and theories and can be suited to specific academic disciplines. Methodology shapes and is shaped by research design, questions, and objectives (Carter & Little 2007). As an example of methodology driving research design and objectives, a researcher interested in using ethnography to study drug use amongst a homeless population would focus his/her work on drug use in or as a culture unto itself. In contrast, a researcher attempting to understand and define why homeless people are more likely to use drugs may choose grounded theory as the best suited methodology for their research question, as it would provide his/her an opportunity to develop theory or a nuanced understanding of the lived experience that may be more transferable.

Carter and Little (2007) describe methods as research action, or the practical aspects of research which are constrained by and reflective of epistemic and methodological beliefs and choices. These include: process of sampling, data collection, data modification, and data analysis. The methods directly dictate the product of research. Different methods of data collection will produce different data, and the way these data are analyzed will produce different understandings of the phenomena. It is therefore important that methods are chosen carefully so that the research question is addressed in a way that is in congruence with the researchers’ chosen methodological and epistemological stance.

Epistemology, methodology, and methods together form the framework of knowledge inquiry. Good qualitative research can only be achieved with internal consistency between these three elements. This highlights the importance of providing an in-depth description of a one’s epistemological and methodological stance and justification for choice of methods, as this will provide the reader an understanding of why the research was conducted the way it was and the
process with which the results were obtained. This will give necessary contextualization for the reader to assess the interpretation of the results provided.

**Choice of qualitative methodology**

My research goal specifically looks to explore the experiences of students with brain health behaviour modification and how their attitudes, beliefs, and perceptions of themselves in relation to the world may act as a barrier regarding healthy brain behaviour adoption. Fundamentally, my goal is to understand human behaviour and action within a specific social context, with the assumption that rather than one reality, the experiences of this phenomena are subjective and multiple across contexts. These assumptions and goals reflect the epistemological assumptions and goals of qualitative research described in the section above, making the use of qualitative methodologies an appropriate choice.

Another factor that influenced the choice of qualitative methodology was that many of the articles regarding health modification discovered in the initial literature review were quantitative in nature, and expressed concerns about the limited applicability of their results. These studies suggest that while quantitative work can provide relevant information regarding health trends in adolescents, qualitative studies are needed to provide a more in-depth understanding as to why these trends exist (Pavis et al 1998). Furthermore, others have addressed the complexity of social models for health behaviour change amongst adolescents and beyond numerical representation; qualitative research is advocated as providing a good alternative or supplement to quantitative research in understanding health behaviour change, specifically grounded theory, qualitative content analysis, and ethnography to provide a richer understanding the varying contexts in which health behaviour change amongst adolescents occurs (Gard & Meyenn 2000, Middleton et al 2010, Ng et al 2007).
Another reason why qualitative methodology is appropriate for this study is that it appears that the topic of brain health behaviour modification amongst adolescents is insufficiently understood for educators who wish to influence future brain health outcomes in this population. The literature search I conducted found no articles that described adolescents’ views and perspectives about brain health, nor did it reveal any existing research that seeks to understand the process by which adolescents make health decisions that affect their own brain health. It is therefore imperative that preliminary work such as this project be conducted in order to provide a better understanding of adolescent brain health behaviour adoption, which in turn can be used to inform future research. Qualitative research is well suited for preliminary research as it provides an in-depth and rich description of the phenomena that can be built upon in future work (Kuckelman Cobb & Forbes 2001). Often the appropriate entry point for quantitative research is identified through qualitative research, as quantitative work may be difficult to conduct when lacking the necessary empirical foundation in the literature as is the case with adolescent brain health behaviour. In conclusion, the flexible and analytic inductive process of qualitative research, as well as the epistemic assumptions of qualitative methodologies, is a good fit for the nature of my initial inquiry into high school attitudes about brain health.

To remain transparent about myself and my role and experience throughout this study, I will identify the epistemological tensions that I faced throughout this project. Prior to this, all my research endeavors and knowledge had centered on quantitative research and the positivistic paradigm. I had previously been trained to believe that there was always one generalizable truth to be learned about any given phenomenon, and that to do so one must produce numerical data to be analyzed. This I believed had to be achieved through the use of studies designed to control any bias or variables through randomization and removal of the researcher and their perspectives from their own work. It was therefore jarring for me to understand and accept a new and
opposing way of thinking of research, but also to be self-aware of the impact of my own beliefs and values on the research process. This generated a degree of discomfort and anxiety for me, as acknowledgement of my role in the research process was something that I had previously avoided. The use of memoing described later in this section was particularly helpful as it allowed me to document and follow my train of thought as I began the to adopt a new and more appropriate set of epistemic assumptions to achieve my research goals. While difficult, I found the entire process rewarding and have now developed the ability to view other avenues of research and the world around me in a different light. I now recognize that viewpoints are not universally shared and this has allowed me to be open minded while conversing with others. Furthermore, I am more capable of critical analysis of research articles as I now consider the underpinning assumptions in published studies so as not to take knowledge claims for granted.

**Why use qualitative content analysis?**

The styles and approaches to doing qualitative research often have overlapping elements and procedures, however there are distinctions with regards to their individual history, strategy, epistemology, and ontology (Holloway & Todres 2003). Careful consideration of these differences must be used when selecting an appropriate methodology for a research project.

Qualitative content analysis is a qualitative research technique that in recent years has come into widespread use in health studies, and describes a range of approaches from interpretive to textual analysis (Hsieh & Shannon 2005, Rosengren 1981). It is a flexible methodology, and researchers may freely choose their approach based on their substantive interests (Weber 1990). Research utilizing qualitative content analysis focuses on the content and contextual meaning of the text, which may be derived from open ended survey questions, narrations, interviews, focus groups, or printed media (Kondracki & Wellman 2002, Tesch 1990). The process of data collection is inductive, with codes and themes or patterns identified.
directly from the textual data as opposed to being imposed prior to data collection and analysis. These themes can represent what is either explicit or implicitly communicated. There may be deductive elements to qualitative content analysis if choosing to do an interpretive analysis, as the resultant themes or categories are constructed by the analyst and therefore subjective and influenced by personal beliefs (Rosengren 1981). Content analysis is ideally used for concept building as opposed to theory development, and coupled with its innate flexibility is often thought of as one of the best suited methodologies for primary research in an underexplored field (Hsieh & Shannon 2005). In broader terms, the goal of content analysis is “to provide knowledge and understanding of the phenomenon under study” (Downe-Wamboldt 1992, p.314).

There are four main reasons that I felt qualitative content analysis was the most appropriate approach for my study. As revealed in the literature and previously described, there has been very little research regarding adolescents’ understanding of, and perception about brain health, and their approach to brain health behaviour decision-making. It is logical then to use content analysis to develop a complete understanding of this context before conducting studies using other commonly used qualitative methodologies such as grounded theory which go a step beyond to develop a nuanced understanding of the lived experience or develop theory. Second, a core principle of qualitative content analysis is that the interpreted results must always be established with the data (Graneheim & Lundman 2004). Quality and transferability of the study results are therefore directly tied to the depth and richness of the collected data. The thorough and extensive focus groups used in this study provide a sound empirical foundation from which an understanding of the process of brain health behaviour decision-making can be drawn. Thirdly, qualitative content analysis offers a level of flexibility with regards to a researcher’s chosen approach to data collection, and depth of analysis. For example, a researcher might choose to attempt a more descriptive approach and focus on the manifest content, the most
visible or obvious content. Another analyst may choose to instead interpret underlying meaning of the text, or the latent content (Downe-Wamboldt 1992, Kondracki & Wellman 2002). This offers an advantage over other similar methodologies, as the researcher may adapt his/her analysis approach to best suit the emerging data and contextual understanding of the phenomenon in question. As a new qualitative researcher who is studying an underexplored topic, the inherent flexibility of qualitative content analysis appealed to me as it both was more forgiving of minor alterations in methodological approach, and provided opportunity to freely explore the phenomenon without being constrained by existing theories of health behaviour modification. Finally, qualitative content analysis has a history of extensive use in both health and education research (Graneheim & Lundman 2004). My study explores a phenomenon that intersects with these two fields, and it was beneficial to choose a methodology that has been effectively used in both areas of research.

_Historical context and development of qualitative content analysis._

Content analysis has been used in research as early as the 18th century (Rosengren 1981), though it only began to gain momentum as an independent analytic technique in the 1950’s (Graneheim & Lundman 2004). It was initially used by researchers as a quantitative research method that would statistically describe textual data, and was often regarded as a quantitative analysis of qualitative information. Content analysis was viewed as an objective and systematic way to quantitatively describe the manifest content of communication (Berelson 1971). Eventually, a second use of content analysis that took a qualitative analysis approach was formed. This approach expanded to also include interpretation of latent content, and began to be used by researchers from various backgrounds (Graneheim & Lundman 2004). Due to the recognition of its potential as an approach to qualitative analysis, the application and popularity of qualitative content analysis by health researchers has increased in recent years (Nandy &
Sarvela 1997). In large part due to its evolving identity, researchers hold differing perspectives regarding what qualitative content analysis is and how procedures and interpretation processes should be carried out (Graneheim & Lundman 2004). In an attempt to maintain a level of order, qualitative content analysis was further broken down into three distinct approaches: conventional, directed, and summative (Hsieh & Shannon 2005). Of these three approaches discussed in the following passage, I chose a conventional content analysis approach.

The role of directed content analysis is to validate or extend a theoretical framework or theory, and therefore is used when there is already existing research and prior theory regarding the phenomenon. The research question is shaped by these existing theories, which also serve as predictors of variables. A predetermined coding schema is created based on identified key concepts in the literature, and then applied to collected data. Results are presented as supporting or not supporting a particular theory. The direct approach to content analysis is limited in that the researcher approaches the data with an informed bias, and may be more susceptible to finding data that is in support of a particular theory. Furthermore, the use of codes created prior to data analysis could result in the researcher missing contextual aspects of the phenomenon (Hsieh & Shannon 2005).

Summative content analysis takes an approach that is reminiscent of quantitative methodologies. Certain key words identified by the analyst are counted to explore its usage in the text. The aim is to discover the underlying meaning of the key word within the varying contexts that it is used. It is considered to be an effective approach to gain insight into the meaning of words and how they are used. The findings from summative content analysis are limited in their application however, as less focus is put on the broader meaning of the data (Hsieh & Shannon 2005).
Conventional content analysis is well suited to describing a phenomenon in which there is little existing theory or literature (Hsieh & Shannon 2005). Researchers immerse themselves in the data set, which they use to derive codes, categories and themes. The results are therefore grounded in the data, and this inductive category development is shared in the first steps of many qualitative methodologies (Kondracki & Wellman 2002). In conventional content analysis, a researcher may choose to focus on latent content, manifest content, or both. When taking a conventional approach to content analysis, a researcher will only discuss theories or research findings in the discussion. This is seen as a strength, as the researcher can gain information directly from the participants without the risk of intentionally or unintentionally imposing theory or expectations. The ability to approach the data collection and analysis process without these preconceptions is also what separates qualitative content analysis from other similar methods of analysis such as grounded theory or phenomenology. This does limit conventional content analysis’ applicability to theory generation and description of the lived experience, as the method of sampling and analyzing the data make it difficult to infer theoretical relationships between concepts. This methodology is thus best suited to concept development or model building (Hsieh & Shannon 2005).

Choosing a qualitative content analysis approach

Although all three approaches share similar data collection processes and ways to ensure rigour, conventional content analysis is best suited for my project, since it functions to provide a conceptual description of a phenomenon that is not well understood. In addition, my limited background in the field of health education put me in an enviable position where my data analysis may be less influenced by personal experience or theoretical perspectives. A conventional approach allowed me to use this to my advantage, as it takes strength from unbiased collection and representation of the results. A directed content analysis would not have
been a good fit for my study, as there have been no theories that relate specifically to the process of adolescent brain health behaviour decision-making. Furthermore, a study of this magnitude would not be effective in extending or altering more robust general theories regarding health behaviours. Finally, while a summative content analysis may have been effective in determining the meaning the words “brain health” hold for adolescents, it would prevent the study from painting a broader description of the way in which adolescents make their decisions about brain health behaviour.

**Why use focus groups?**

The use of focus groups as a means for data collection was appropriate to both the research question and the epistemological stance that I took regarding this research. As highlighted in the literature review, the purpose of focus groups is to draw upon participants’ attitudes, beliefs and experiences about a certain phenomenon (Kitzinger 1995). They are distinct from individual interviews in that they are assessing the multiplicity of views in a group context instead of individual views (Williams & Katz 2001). They are also independent from group interviews which emphasize the questions and responses between researcher and participant. Focus groups rely more on the interaction and insights produced by the group based on topics introduced by the researcher (Kitzinger 1995).

Because of the unique contribution of group dynamic and interaction, I felt that focus groups would best capture the context of the phenomenon. By specifying my subjects of interest as high school students, I purposively selected adolescents within the environment of a high school as many of adolescents’ decisions about health behaviours occur while in the social context of high school while with peers (Bonell et al 2012, Marcoux & Shope 1997). It was essential that my data collection method reflect this group context. This choice was further supported by findings in the literature review, which describe health behaviour choices and
beliefs as being affected by peers, parents, and societal expectations (Bonell et al 2012, Marcoux & Shope 1997). Social dynamics therefore are an integral part of the process in which health decisions are made, and thus provide further argument for choosing a data collection strategy that would capture these interactions.

The final consideration that led to the selection of focus groups for data collection was the inherent power differences between the participants and both myself and the health education professionals. By nature, students hold unequal power in relation to both their parents and teachers. The use of focus groups is particularly important when dealing with disparities in power such as this, as it empowers participants to discuss their feelings and views with less influence of my presence (Morgan & Kreugar 1993).

In summary, the epistemological assumptions deemed to be most suitable to my research question were those held in qualitative research. After further exploration, a qualitative content analysis – more specifically a conventional qualitative analysis approach – was the chosen methodology as it is best utilized as preliminary research in underexplored phenomenon such as brain health behaviour modification amongst high school students. Finally, focus groups were chosen as the method of data collection as it addresses the power imbalance between the younger participants and older researchers, and because the social interaction that is an intrinsic aspect of focus groups is central to the social influences and dynamics involved in youth health behaviour decisions.
Research Method and Process

Participant inclusion/exclusion criteria.

Participants in this study were adolescents in grades 9 or 10 of high school and were 14 – 16 years of age. Age and grade were self-reported and verified by schoolteachers and community leaders, as I did not have access to school or community centre records to confirm for myself.

The reason to include grades 9 and 10 students was two-fold. The preliminary reason was for the convenience of the participants. This project was initially conceived as a knowledge translation study involving participation in day-long workshops that would require prior preparation from the students. When discussing this project with the community gatekeepers consisting of community leaders, principals, teachers, and youth group coordinators, they suggested that students in grades 9 or 10 would be ideal subjects for the study on the basis that they had a lower school workload and would be more likely to have time to participate than students in grades 11 and 12. The study was then designed to reflect this. This aspect of the study design was carried over when the project was re-imagined as the current iteration.

The second reason younger students were chosen for participation was because health behaviours and beliefs are formed in early adolescence (Bindler et al 2012). Furthermore, the start of high school has been described as tumultuous, with rapidly changing social dynamics that may encourage students to adopt or discard health beliefs and behaviours in order to integrate themselves within new peer groups and gain their approval (Bonell et al 2012, Marcoux & Shope 1997). For these reasons, I believe it would be best to include students in grades 9 or 10 so that their experiences are captured during this crucial time. The choice was made to include students aged 14 – 16 as most grades 9 and 10 students in Ontario fall within this age range. Furthermore, I hoped that the inclusion of students with a broader variation of age in the focus groups could introduce a further layer of complexity in the power dynamics of the group.
In addition to age and grade requirements, in order to be eligible for the study, participants had to have a good enough command of English so as to be able to participate fully in the focus group discussions. Also, students were required to be attending high school in the Greater Toronto Area (GTA) so that their experiences would better represent those of youth in Toronto.

Focus group inclusion/exclusion criteria

The data generated by focus groups is unique as it is derived not only from the collection of individual opinions but also by group interaction\(^1\). With this in mind, the formation and execution of focus groups should be done with care and purposeful intent to create an ideal environment for the facilitation of meaningful discussion that is naturalistic and is comfortable for the participants.

For this reason, when organizing the focus groups, I chose to ensure an even ratio of the participants’ high school grade. I was concerned that there might be differences in the experiences of brain health behaviour adoption amongst students in grades 9 versus 10, which might inhibit the younger grade participants. I reasoned that this was plausible because students in grade 9 may still be navigating their new social environment and defining their role within their school, while students in grade 10 could be more mature and may have already comfortably established themselves within the high school environment. In my literature review, many articles discussed how there appear to be gender differences in the way health beliefs are formed and health behaviour decisions are made (Allison et al 2005, Gillison et al 2012, Ng et al 2007). While none of the articles pertained to brain health, I believed that it was plausible that gender could also influence the process of brain health behaviour change and thus chose to keep the

\(^1\) See “Why use Focus Groups” subsection for goals and strengths of focus groups.
gender ratio of those invited to participate in the study equal as well. By keeping the gender ratio within the focus groups the same, I hoped that there would be equal opportunity for both genders to share their perspectives and that any gender related differences would emerge during group discussion. Some have argued that single-gender focus groups work best with adolescents, as they tend to associate more with members of their own gender and teenagers may show a high level of interest in the opposite sex that may detract from discussion flow (Cannon et al 1996, Reith et al 1996). These arguments however may be out-dated, as mixed gender social groups are now more common amongst adolescents (Cassidy et al 1996), and the utilization of mixed-gender focus groups in past health belief studies have yielded successful discussion and data (Cohen et al 1996).

Another consideration that influenced participant selection was the planned size of the focus groups. In the literature there is a lack of consensus regarding the ideal size of a focus group, with some authors claiming 6 – 8 participants as ideal while others argue that 8-12 participants generates more engaging discussion (Hsieh & Shannon 2005, Tuckett 2004). Among adolescents however, the typical recommendation is to keep focus groups between 5-8 participants, as groups smaller than this may result in the focus group degenerating into parallel interviews, while it may be harder to maintain the focus of larger groups(Cannon et al 1996). One of the most common challenges for researchers running focus groups is participant turnout. Thus, choice to design the focus groups for 8 people was additionally made so that if selected participants did not attend the focus group, there would still be a good chance of the focus group size remaining in the recommended 5-8 participant range.

**Recruitment strategy**

Schools and community centres were recruited by my supervisor prior to my involvement in the project’s development. The use of schools and community centers for recruitment was
convenient as they were able to connect us to many students who fit the inclusion criteria for the project. Recruitment was initiated by contacting gatekeepers including community centre workers, teachers, and principals who had agreed to lend their assistance. Representatives from three institutions responded when contacted expressing continued interest in recruitment. These institutions were: i) ‘The Hub’ community centre located in Scarborough, ii) University of Toronto Schools (UTS) located in the downtown core, and iii) the Black Creek Community Health Centre located in North York. Unfortunately, despite several attempts, no focus groups from Black Creek could be convened because of scheduling difficulties.

Participants at the Hub were from the Priority Neighborhood Scarborough were attending David and Mary Thomson Collegiate Institute. With a demographic different from the affluent UTS student body, Priority Neighborhoods are at highest risk for substance abuse, violence, and academic failure (United Way, 2012). Students from Priority Neighborhoods typically do not refer to written materials for health information (Mensah, 2005), and it is unknown whether they scan the Web for health information. According to the 2011 Statistics Canada census, Canadians of South East Asian descent make up the largest proportion of new immigrants to Canada (Statistics Canada, 2011). Many of the students at The Hub are of South East Asian descent and come from recently immigrated families. We expected the experiences and attitudes from the focus group held at The Hub to differ from those of students recruited from UTS who are more likely to come from families with a higher income and from East Asian or Caucasian descent. In this way, I was able to include a wider range of experiences that may make the results more transferable.

Recruitment for the first focus group at The Hub was initiated through contact with their representative, who was given REB approved flyers describing the purpose of the study for distribution (Appendix A). This representative was also given the inclusion criteria and asked to
approach interested students who were part of various community groups at the Hub and who matched the criteria to collect contact information. Once this information was provided to me, I contacted the students by phone and provided a brief description of the study as well the date and time of the focus group. Because the participants were not of legal age to provide written consent, I also spoke with a parent or guardian over the phone to inform them about the study and asked for verbal consent for the student’s participation. Of all contacted students, only two were unable to attend the focus group and both cases were due to scheduling conflicts. If intent to attend the focus group was confirmed, an email was sent to the student that included an overview of the study and an informed consent form to have signed by their parent/guardian (Appendix B). All participants were required to bring this form to their focus group in order for them to participate. Recruitment continued until there were 8 confirmed participants with an even distribution of both sex and grade in the focus group. Students were contacted from the provided list which was ordered by a first-come-first-serve basis of expressed interest until all subgroups had been filled.

Participant recruitment methods used for the second focus group at UTS deviated from those used at The Hub. Initially recruitment was initiated the same way, with the Director of Science at the school acting as a gatekeeper and distributing the REB approved fliers to teachers of grades 9 and 10 students. The teachers then made class announcements and encouraged interested students to contact me directly via my provided email on the flier. In contrast to focus group at The Hub, interested students contacted me directly. The recruitment method then

---

2 See “Focus group inclusion/exclusion” subsection for reasoning behind gender/age distribution and target number of focus group participants.

3 For example, when four girls had already confirmed intent to participate, no more girls were contacted for that focus group.
followed the same procedure as that of the Hub, with verbal consent from a parent/guardian being obtained and informed consent forms being distributed for return at the focus group. As before, students were contacted on a first-come-first-serve basis until 8 students had confirmed and all subgroups were filled. Unfortunately this meant that some interested students were unable to participate in the focus group, however these students were encouraged to send me an email in the future should they want to follow up on the results of the study. While the recruitment strategy did differ between locations, I believe that this can be viewed as a strength of the study, as similar conclusions being obtained from varying methods and methodologies are thought to be stronger and more transferable (Patton 2002).

The final focus group was held again at The Hub, as our contact there had indicated that there were more students who were interested in participating. Recruitment strategy remained the same as that used previously at the Hub, with interested students being collected from various groups within the community centre. None of the selected students had participated in or heard of the previous focus group, and therefore were free of any a priori knowledge or expectations. While students were only contacted until 8 had confirmed their attendance, 3 friends who had not been screened unexpectedly arrived at the focus group. This presented an interesting dilemma, as we had not obtained informed consent form the parents/guardians of these students and their participation would skew the gender and age distribution. Also, their participation could hinder the social dynamics of the focus group by introducing established relationships. On the other hand, by turning away the friends we risked losing the participation of their counterparts. Eventually it was decided that variation in focus group makeup would be acceptable as uneven age and gender distributions and pre-existing relationships are representative of social context of adolescents in a high school environment. Thus the information obtained from this group would enhance the richness and depth of the study and arguably make my conclusions more
transferable (Charmaz 2004, Patton 2002). Parents or guardians of the students were contacted on the spot and verbal consent was obtained from each of them. These new participants were then allowed to participate in the focus group.

**Data Collection: Focus Groups**

A total of 23 students participated in one of three focus groups. Times and locations were assigned as convenient for the participants, taking place after school at the recruitment location. The focus groups were individually recorded and transcribed by myself verbatim. All three focus groups were moderated by both myself and a second moderator whose role was to keep track of time and make notes (e.g. key points of the discussion).

When arranging the location and setting of the focus groups, care was taken to keep the setting as familiar as possible so that the participants were comfortable. This was achieved by holding the focus groups at the site of participant recruitment. Furthermore, tables were put together in a way in which all participants and both moderators were sitting in the approximation of a circle and could easily establish eye contact with one another. Consideration was also given to seating arrangements. While ideally the more dominant speakers should be identified prior to the start of the focus group and placed beside the moderators, while those that appear shy should be placed across from the moderators to facilitate more eye contact, I decided to allow the adolescents the freedom to choose their own seat (Muller et al 1996). This naturalistic approach to seating was done so that the participants could sit beside those with whom they felt most comfortable. Furthermore, I wanted to distinguish the focus group environment from the typical authoritarian adult-child relationship of a classroom setting that I believed would be reinforced if I dictated the seating arrangement (Forbes et al 1996).

Each focus group began with the collection of all signed informed consent forms. Participants also signed in so that we could keep track of everyone in attendance. After this, a
scripted introduction was used that was designed to briefly outline the purpose of the study while empowering participants by situating them as the experts and the moderators as the students (Appendix C). During this time, participants were again informed that they would be recorded and assured of their confidentiality.

An in-depth interview guide with open ended questions was used (Appendix D) to guide the focus group discussion. This guide was created with input from Dr. Shelley Craig and was designed to allow a flexible approach to explore the phenomena in depth while allowing for new avenues of inquiry that were not anticipated (Patton 2002). In many cases, questions from the script were not asked as they were addressed in the flow of discussion generated by previous questions. After all questions on the interview script were addressed, participants were given the opportunity to add any additional comments to the discussion. The participants were then thanked and provided the opportunity to sign up for future contact in order to give input on the emerging results. They were also welcomed to contact me at any time if they had any questions or thought of something they would have liked to have brought up in the discussion.

After the focus groups were held, the gatekeepers used during the recruitment phase of the study were contacted to collect demographic information from the participants. This information included self-identified ethnicity and status of household (single parent or two parent household). The collection of this information was approved by the Baycrest Research Ethics Board.

Compensation

Participants were compensated for their time at a rate of $10 per hour, which is the rate set by the Baycrest Ethics Review Board. The incidental cost of transportation using public transit was also covered. Participants did not incur any other expenses by participating in this study. In total, all participants were given $26 in cash.
Sample size

The in-depth nature of qualitative research necessitates that the sample size be small. The cessation of data collection typically occurs when the researcher determines that saturation has been reached (Guthrie J. et al 2004). Saturation by definition is when no new information is emerging and there is replication of current categories, which ensures comprehension and completeness (Morse J. M. et al 2002). In this study, 23 students took part in three focus groups; this is the point in which saturation was determined to be reached. In these focus groups, I was able to listen to discussions of both girls and boys grades 9 and 10 students with varying ethnicities, upbringings and geographical locations. By the time the last focus group was conducted and analyzed, I had recorded repetition in the categories and themes that signified that no novel data was being brought forth. As the point of saturation cannot be predicted, there is no required number of focus groups that must be held before the claim of saturation may be made. Our saturation point of three focus groups falls within the recommendations of 3-5 focus groups made by Kreuger (2006).

Sampling and the focus group process

The use of purposive sampling is a hallmark of qualitative studies such as qualitative content analysis. By definition, purposive sampling is the non-random selection of participants based on desirable traits (Patton 2002). In the case of this study, participants were selected on the basis of their geographic location, age, gender, and grade. These criteria were chosen prior to the start of recruitment. It is important to note that this method of sampling is distinct from theoretical sampling which is commonly used in grounded theory, as there is much confusion about the differences between these two sampling methods (Coyne 1997). The main difference between the two is that purposeful sampling is done a-priori with the criteria being driven by the research question (Schatzman & Strauss 1973). Theoretical sampling also begins with a
purposive initial sample; however subsequent recruitment criteria may be altered in response to emerging data. This is beneficial to researchers attempting to inductively form a theoretical framework, or who wish to expand upon or test an existing one (Strauss & Corbin 1991). When describing a certain context or phenomenon, as is the case with qualitative content analysis, it is unnecessary to make iterative changes to the recruitment strategy.

The recruitment strategy used for this study was purposive in that it was non-random, though it utilized both opportunistic and systematic sampling. It was opportunistic in that areas rich in participants that matched our inclusion/exclusion criteria were identified and gatekeepers were utilized to facilitate recruitment. It was also systematic in the case of recruitment at The Hub, where a list of interested participants provided by a community centre acted as a sampling frame from which participants were purposively drawn from (Luborsky & Rubinstein 1995, Patton 2002).

The focus groups were conducted in a manner to achieve saturation, so the focus group script (Appendix D) was not followed directly and instead was used as a reference (though all included questions that were touched upon in each focus group). The questions were all open-ended, and discussion was mostly guided by the participants. The focus group script was checked periodically to ensure all major points of interest had been discussed, and to re-direct conversations where there was significant deviation. In the first focus group, the discussion was more structured and followed the interview script closely. As the transcripts from the initial focus group were analyzed, the structure of the focus groups changed to address emerging points of interest. While the script itself was not changed, the conscious effort to adapt the focus group discussion to the emerging data was necessary to maintain reflexivity and develop an adequate contextual description of the phenomenon. For example, students in the initial focus groups frequently deviated from discussions about brain health to discussions about general health.
Aware of this, I was careful in subsequent focus groups to guide participants back to the topic of brain health. Before the focus groups finished, any areas that the participants seemed interested in were further explored, and everyone was asked to contribute anything they felt was relevant to the discussion that they felt had not yet been covered. This gave the opportunity for participants to bring up any salient points that I may have not noticed or that were not covered by the semi-structured focus group script.

After the focus group, together with the other focus group moderator we spent time with the participants to explore any feelings that may have arisen from the discussion. All participants were then offered a chance to sign up for future contact so that they could see the results of the study and provide further input. Everyone was also encouraged to contact me at my provided email and cellphone should they have any questions or wish to discuss the topic of brain health further. None of the participants chose to do this, however all but four students agreed to being contacted for input on the results of the study.

**Data Analysis**

This section discusses the analytic strategies used to examine the data based on a qualitative content analysis approach.

**Field notes and memo writing**

While I led the focus group discussions, the other moderator would take observational notes including key points of the discussion, non-verbal communication, and descriptions of the focus group environment. Although voice recordings of all focus groups were captured, these written observations were useful in providing context that may have been missed during subsequent analysis of the recording and text (e.g. the recording captured one student’s statement of how emotional impact in health education is one of the most important influences on
behaviour adoption, yet without field notes I would not have been aware that the entire group nodded in agreement). Within 24 hours from the interview I created memos which I used to capture my rudimentary thoughts about the focus group and preliminary ideas about the content and possible codes. The memos served as a record of my initial impression of the data, as they facilitated self-reflexivity during the process of data collection and analysis (Hsieh & Shannon 2005). After re-listening to the focus group recordings and reviewing my notes, I made revisions to the memos, noted the significant issues discussed, and noted my own views about the participant’s described experiences.

Data transcription and coding

After each focus group was completed, I transcribed the discussion verbatim before the initiation of the subsequent focus group. There were 115 pages of transcription in total. Analysis proceeded in 3 distinct stages: (1) coding by labelling meaning units, and creating sub-categories and categories that are grouped by content and share a commonality, (2) narrowing and collapsing categories and subcategories: and (3) comparing the data sets, codes, and categories with one another and creating themes that link the underlying meanings to give structure to the described experience (Graneheim & Lundman 2004).

Coding

After transcription is completed, coding is the preliminary analytical step to examining the data. Codes are the labels given to meaning units, and can be assigned to objects, discrete events, or other phenomenon (Graneheim & Lundman 2004). They are described in the literature as “tools to think with” and should allow for the data to be thought about in different ways (Coffey & Atkinson 1996p.32)). Coding is not descriptive; during analysis codes are constantly compared with one another to reveal common concepts. For example, codes such as
‘refusing help’, and ‘rebelling against authority’ were contextually compared and grouped together to form the concept ‘gaining independence’. These concepts are then collapsed hierarchically into subcategories, categories and themes. This iterative and comparative process is an integral step in developing a rich and accurate contextual description of the phenomenon (Graneheim & Lundman 2004). Coding was conducted line-by-line, and both in-vivo codes (codes formed from words participants spoke directly in the text), and my own interpretive codes were used.

After completing line-by-line coding of the transcripts from each focus group, the codes were reviewed for their relevance to the study and emerging concepts. The codes were then grouped and formulated into categories.

<table>
<thead>
<tr>
<th>Transcript</th>
<th>Meaning unit</th>
<th>Code</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Right now, they say don’t do it. Instead, you really need to educate people on... not necessarily why you shouldn’t do it but this is what happens if you do do it, here are the benefits and here are the downsides. Right now it’s all about the negatives.”</td>
<td>- Only teaching the negatives in class&lt;br&gt;- Want to weigh pros and cons&lt;br&gt;- Being told what to do instead of making independent decision</td>
<td>- Missing information&lt;br&gt;- Discussion of negative outcomes&lt;br&gt;- Authoritative teaching</td>
<td>Focus on consequences</td>
</tr>
</tbody>
</table>

Below, table 2 provides further illustration of how codes and categories from different focus groups are brought together and lead the emergence of a theme.
Table 3.2: Theme development from codes and categories

<table>
<thead>
<tr>
<th>Theme</th>
<th>Struggle for Relevance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
<td></td>
</tr>
<tr>
<td>Invisibility</td>
<td>Emotion Detachment</td>
</tr>
<tr>
<td>Codes</td>
<td>Inability to track outcomes; perceived societal disinterest</td>
</tr>
</tbody>
</table>

Each category was named to accurately describe the meanings and ideas the participants conveyed. When possible, statements made by the participants were used to name the categories. After this process was completed I classified the categories into themes. This involved the grouping and comparison of data in such a way that it flowed into a cohesive story about the participant’s description of the phenomenon.

In summary, data analysis was conducted inductively in a bottom-up fashion. It began with the coding of raw data, followed by grouping of related codes and concepts into categories and subcategories. Through constant comparison and refinement, categories were collapsed and core themes emerged to characterize the participants’ relationship with brain health decision-making.

Quality Criteria

Trustworthiness is one of the cornerstones for qualitative research, though its definition varies depending on one’s assumed epistemological stance. As the name suggest, trustworthiness is a measure of the accurateness of the representation offered by a study’s findings, and is obtained through evaluation of the study and the process in which the results were generated. The terms trustworthiness and validity are often used interchangeably to describe the same measure by qualitative researchers, though I believe trustworthiness is a more appropriate descriptor as validity is a concept that is related to quantitative epistemologies.
There are many standards to achieving trustworthiness, which have been proposed as general approaches to evaluating qualitative work and share interchangeable and overlapping meaning (Corbin & Strauss 2008). While there are many purported methods of establishing trustworthiness (i.e. member checking, researcher triangulation, peer review, thorough and rich description, audit trails, and concrete examples of reflexive thought), the process in which a researcher should select one of these methods over another remains obscure and controversial (Creswell & Miller 2000). Despite this, it is clear that establishing trustworthiness is imperative should a researcher hope for their work to be of value to the academic community.

In the context of qualitative work, the components of trustworthiness include credibility, dependability, and transferability (Graneheim & Lundman 2004).

Credibility concerns itself with the focus of research, and how well the data, collection process, and analytical procedures address the intended research goal (Polit & Hungler 1999). One mark of credibility is choosing a diverse set of participants with various ages, backgrounds, and experiences. This increases the chance of creating more accurate picture of the phenomenon drawn from varying aspects and perspectives (Patton 2002). Another function of credibility is the selection of the most appropriate method of data collection and meaning units, as well as determining the appropriate amount of data that must be collected to sufficiently address the research aims. To facilitate evaluation of credibility in this regard, it is imperative that researchers provide a detailed description and justification regarding data collection and analysis procedures. Credibility also deals with how well the study’s themes and categories capture the full depth of the data, and this may be evaluated by the inclusion of quotations and by reaching a consensus amongst co-researchers, experts, and participants (Graneheim & Lundman 2004).

Dependability is another aspect of trustworthiness, and it involves taking into account the changes to the data over time and changes in a researcher’s decisions throughout the analysis
process (Lincoln & Guba 1985). While changes in analytical procedures and data collection are an important aspect of the iterative process that is qualitative research, the changes must be made in response to emerging content in the data. If this was not the case, there is a risk that inconsistencies throughout the research process would interfere with the credibility of the results. Dependability is most easily evaluated when the researcher makes clear his/her thought processes, and demonstrates reflexivity through the use of memoing and audit trails (Graneheim & Lundman 2004).

Transferability refers to the extent in which findings can be transferred to other settings or populations (Polit & Hungler 1999). In order to facilitate transferability, researchers should be very descriptive of the context in which their research takes place, and the selection process and inclusion criteria of participants. A rich, credible, and intelligible presentation of the results with liberal use of quotations would also enhance transferability. Ultimately however, while the author can make suggestions or claims to transferability, it is the reader’s decision whether or not they feel the findings are transferable to another context (Graneheim & Lundman 2004).

I have chosen to incorporate measures of trustworthiness that are suggested by Lincoln & Guba (1985), who proposed a framework for choosing measures based on a researcher’s epistemology. The five techniques I incorporated included member checking, multiple coding, audit trails, prolonged engagement, and reflexivity.

**Member checking**

Essentially, member checking refers to sharing emerging findings with the study participants, and using their reactions and input as a way to check the accuracy of the data analysis and interpretation (Sorin-Peters 2004). I achieved conformability in two ways. First, I would encourage further conversation with participants during the focus group when there was a need for more clarity. I also would end each focus group with a de-brief and summary of the
discussion, which gave participants the opportunity to provide insight regarding any misinterpretations. Second, I contacted participants that had indicated that they would be interested in a second member check and asked for their thoughts on the themes emerging from the data analysis. The contacted participants felt that the emerging themes resonated with them.

I also extended member checking to youth educators and Alzheimer club founders so that I could have their input on the emerging themes. I received six responses, and all respondents felt that the results were in line with their own perspectives and experiences.

**Multiple coding**

Another way I established trustworthiness was through multiple coding. Multiple coding refers to the process in which multiple researchers with varying backgrounds and experiences independently analyze and code the data. After this, the researches convene to discuss and compare their interpretations. This is particularly important; researcher influence on results and the concept of multiple realities is an integral component of qualitative research. While this means that it may be impossible to fully capture or describe a phenomenon in its entirety, having multiple people come to a similar description lends credibility to the accuracy of the results (Barbour 2000). In this study, a professor of neuroscience, a professor of social work, and an MSw all independently coded the three focus group transcripts. Overall, there was congruence among the emerging themes and categories. This was especially helpful to me, as I received valuable input from health professionals with varying backgrounds that helped shape my data analysis.

**Audit Trail**

An audit trail is a detailed collection of field notes that are created throughout the entire research project to enhance dependability and reproducibility (Patton 2002). My audit trail began
during my first read-through of the transcribed data, where I wrote my thoughts and impressions in the margins. I kept these notes along with my field notes in file folders, separated by focus group. These audit trails were used during thematic development to help facilitate the comparative process.

**Prolonged Engagement**

A researcher’s credibility is strengthened by duration of time he or she spends in both the topic of study and data collection field (Lincoln & Guba 1985). Prior to this research program, I was involved for two years with the Brain Day program where I traveled to middle schools in the city of Guelph to teach about brain health. This experience was very relevant to the phenomenon in this study, and helped guide my research. Furthermore, I spent a long period of time immersing myself within the data, reading and rereading it over the course of four months. This allowed me to become very familiar with the text, and facilitated a deeper and richer analysis.

**Reflexivity**

Reflexivity entails actively engaging in the process of self-reflection. This encompasses both awareness of one’s experiences and how they may affect the interpretation of data, and the emotions elicited during the entire research process (Charmaz 2004). By being transparent of one’s own values, judgments, experiences, background, and bias, a researcher is able to accomplish two things: increase awareness of one’s own assumptions that may impact data collection and analysis; and facilitate evaluation of the credibility and dependability of the findings (Gearing 2004). I engaged in reflexivity through the use of memoing and audit trails that tracked my activities, thoughts, and emotional response to the data collected during the focus groups.
All five of these components acted together to satisfy the three criteria of trustworthiness. Member checking allowed for research participants to confirm that the results captured the full breadth of the phenomenon that was described in the focus groups. Furthermore, input from community members experienced in adolescent education and health behaviour modification gave insight into other aspects of the phenomenon that may have been unintentionally looked over. This, along with the process of multiple coding conducted by three independent researchers and a prolonged engagement with the textual data adds strength to the claim of credibility of my findings. Dependability of the research process was supported by clear description of the research process including any changes that may have occurred in the methodology. Furthermore, by maintaining an audit trail and providing relevant information regarding my past research experiences, I have demonstrated that I have been reflexive throughout this endeavour and have been conscientious of how my thought processes will impact my interpretation of the results. While transferability of results may only be interpreted on an individual basis, I believe that my methods have allowed me to establish the credibility and dependability of the results. This, along with a thick description of the results and liberal use of quotations should facilitate assessment of the transferability of the conclusions drawn in this study to other youth.

**Ethical Issues**

Throughout this study, I was conscientious that ethics of proper treatment of participants, collection of data and its analysis, and responsibility to society were properly followed (Richards & Schwartz 2001). Participants were protected against deception and harm, and strict confidentiality and privacy was maintained. I also attempted to be as transparent as possible about my data collection and analysis process, and was careful to diligently report all my research activities in their entirety. To uphold my social responsibility, I will use this study to
advocate for and inform more effective brain health behaviour promotion aimed towards adolescents.

**Ethical treatment of participants**

The rights of participants were upheld through the use of several steps. The ethics protocol used in this study were presented to and approved by Baycrest’s research ethics board. Secondly, the study was presented very clearly to participants prior to their participation, both verbally and in written form (Appendix A). Consent forms (Appendix B) which described the study, its objectives, potential risks and benefits, and the methods by which confidentiality of information would be maintained were also signed by parents following my verbal explanation of what participation would entail. Participants and their parents were also informed that they could withdraw from the study at any time.

**Potential risks and benefits**

The only potential risk for participating in the study that was considered was that some students may find it uncomfortable to discuss their own health and experiences. This was managed by an introduction meant to empower students and place them as the leaders of the discussion, and by the involvement of experienced focus group moderators that could identify and respond to participant distress. Participants were encouraged to express themselves and provide one another a supportive environment. Had a participant become visibly upset, I would have asked them whether or not they would like to excuse themselves from the group. This situation did not occur in any of the focus groups.

Benefits of the study to the participants was the sense of accomplishment for contributing to the development of knowledge that could directly impact and benefit students such as themselves.
Confidentiality

Maintaining the confidentiality of the participants was of the utmost importance, and every effort was made to do so. Any personal information was kept secured in a locked room and cabinet, and no identifying characteristics were included in the thesis. Digital recordings are stored on my work computer that is password protected and locked in my office. After the studies’ completion, all digital data will be deleted and hard copies of the transcripts will be shredded. Also, participants used super hero code names that they assigned to themselves throughout the focus group process so that they would not be identifiable through audio recording.
Chapter 4

Findings - Participants’ Relationship with Brain Health

Initially, the main purpose of this research was to understand what barriers and facilitators to brain health behaviour adoption existed amongst the participating adolescents. After analyzing the data, it became evident that this question had two parts. The first element was understanding the participants’ relationship with brain health, and the second component was about how this relationship in and of itself acted as a barrier to brain health behaviour adoption. Therefore, as the project evolved, the purpose became not to simply describe barriers to brain health behaviour adoption amongst the participating adolescents, but also to understand what brain health means to them and how this understanding effects their ability to adopt brain health behaviours.

The results of the qualitative analysis of the focus group discussions will be explored in the following section. For referral, a brief summary of the proceedings from each focus groups as well as descriptive statistics (i.e. grade, ethnicity, gender, and household status) is provided in Appendix D. The purpose of this is to give insight into the demographic makeup of the three focus groups which will provide a better context from which conclusions may be drawn.
Qualitative Findings

Themes – Adolescents’ View of Brain Health and How this Impacts Brain Health Behaviour Adoption

This section is dedicated to presenting the qualitative data in a cohesive manner via graphical representation and rich supporting description of the main categories and themes that emerged. These themes will act to strengthen the limited understanding of what adolescents’ concept of brain health is, and how this impacts brain health behaviour decision-making. A liberal use of quotations from the focus groups that clearly illustrated a particular theme was interwoven into the results to add a rich context of the findings. While the students in each focus group had unique outlooks and personal experiences to share, there were striking commonalities in their views of brain health and the factors that influence their health behaviours. These shared experiences are represented in the themes discussed in this section.

Early analysis of the data revealed that participants’ concept of brain health was heavily intertwined with the process of brain health behaviour decision-making. These findings were resolved into three themes illustrated in Figure 4.1. While the themes are shown as discrete from one another, this was largely done for visual clarity. In truth, the themes overlapped to form a cohesive story as the participants shared their experiences.
There were three central themes that explored the participants’ concept of brain health. These three themes are discussed in detail and include: (1) an ambiguous definition of brain health, (2) a lack of understanding of factors that can influence brain health, (3) the struggle for relevance adolescents experience when considering brain health in relation to their own lives.

**Ambiguous Definition**

Brain health is a broad topic. It impacts - and is impacted by - many aspects of life. Participants demonstrated confusion over the definition of brain health throughout the focus groups, and would share opposing interpretations of brain health with one another. The inability to clearly define brain health was further made apparent as participants frequently changed their definition of the term throughout the discussion. Categories subsumed under the theme of ambiguous definition include: (a) mental health, (b) functional health, and (c) self-identity, and are depicted in Figure 4.2. These categories best describe the various meanings that participants attributed to ‘brain health’. While they are presented as discrete groupings, in reality there was a degree of overlap.
Equating mental health to brain health was a prevalent pattern throughout all three focus group discussions. Many participants commonly switched back and forth between brain health and mental health mid-thought, suggesting that the two terms were perceived as synonymous.

Brain health isn’t…it’s not something a lot of us think about. And people need to know because our brains are developing so young. People don't know about that and we need to tell them more about mental health... In health class [teachers] don’t really talk about brain health, so nobody thinks about mental health like it’s important (Green Lantern----- boy in grade 9, focus group #1).

In some cases, participants explicitly expressed their belief that brain health and mental health were interchangeable terms. When asked to describe issues that they believed someone with a brain injury would face in everyday life, a commonality amongst many of the responses was a focus on mental health issues. The following quotation illustrates one such response and
also conveys a view of mental health that many of the students shared; that it is fundamentally tied to emotional well-being and mood disorders:

Um…brain injury is like depression right? I have heard if you get hit on the head it can affect you, like with mood swings and stuff like that. Which can make things more difficult. And obviously when you have depression … then social interactions can become tricky. So I guess brain health is how you feel. Anxious, depressed, angry... really [Brain health is] mental health (Hawk Eye ----- girl in grade 9, focus group #2).

Interestingly, some participants who initially expressed their view that mental health and brain health were identical in definition would later on refer to them as separate entities. Here, the speaker of the prior quote appears to contradict herself during a discussion of how educational efforts in high school have focused on mental health but not brain health:

They teach us to be more healthy with our minds. But they never really talk about the brain, they just say that you as a person should be more healthy, exercise, eat healthy, to avoid depression. They teach us stuff like that. But they never really talk about the brain or brain health so it's not really specified (Hawk Eye ----- girl in grade 9, focus group #2).

These contradictions were frequent in all three focus groups and seem to indicate a sense of confusion surrounding the terms mental health and brain health. It was clear that participants felt that brain health and mental health were in some way related. Without a structured definition of brain health to refer to however, participants struggled to determine the magnitude of overlap between the two terms.

For participants, the ambiguity as to what mental health encompasses further complicated matters. Direct questions about their definitions of brain health and mental health were met with silence and looks of confusion that suggested uncertainty. This necessitated analyzing dialogue that had taken place within the context of mental health to gain an implicit
understanding of what participants associated with the term. As touched upon earlier, the majority of conversations surrounding mental health focused on mood disorders and emotional well-being. These discussions most often centered on depression and anxiety, and the impact they could have on one’s life. In particular, participants felt that these mental health issues were tied to academics and social interaction.

Sometimes [mental health] can affect us. For example I have problems with anxiety. Maybe because the courses I choose to take and the program I am put in at my school... I have tons of homework to finish at home and I get so anxious that I have trouble doing it all, and it usually means I'm not sleeping until 4 [am]. Because of [anxiety] I'm going to school without sleep and sleeping in class which is pretty bad (laughs). That's why I can't maintain things and do well in school... It makes it impossible to keep up and I get more behind. ...And then I feel even more anxious (Superman ----- girl in grade 10, focus group #1).

Also with mental health, no one wants to hang out with someone that's depressed right? So if you... I mean if you're sad all the time no one wants to hang out with you and then you'll feel like no one wants to be your friend and you get sad again. It’s like a cycle...you can’t get out of (Iron Man ----- boy in grade 10, focus group #2).

As this study was not originally focused specifically on mental health, the direction that the participants took this discussion were unexpected. These results indicate that the struggle with mental health are a point of concern amongst adolescents and one that adolescents feel is not being addressed or discussed within their high school environment.

As the quotes above illustrate, participants in this study also felt that the social and academic repercussions of poor mental health would often exacerbate the underlying issues. This resulted in a cycle that they believed was difficult to escape.

While most students appeared to associate mental health with the mood disorders and emotional well-being, some participants argued that these terms should fall under a separate
category of emotional health. Here, a participant shares this opposing view with other members in their focus group during a discussion about depression:

... I think that maybe that’s more emotional than mental health... it’s all part of brain health, but [depression] and the way you feel is more emotions than mental health. Mental health is more like psychological like addiction or learning disorders... (Wolverine ---- boy in grade 9, focus group #1).

Interestingly, the groups would often nod in agreement when these opposing statements were made, but would again refer to mood disorders while discussing mental health at later points in the discussion. This suggests that participants were unsure of what the term mental health meant to them.

The participants in the focus group often used mental health interchangeably with brain health. Throughout the discussions however, it became clear that students were unsure of what the term mental health encompassed, and if it was identical to brain health, a component of brain health, or an entirely separate entity. Mental health issues were an unexpected focus of the group discussions, and the findings suggest that struggles with depression and anxiety are often silent in a high school environment. The enigmatic connection to brain health contributed to participants’ ambiguous definition and understanding of brain health.
(b) Functional health.

A major point of discussion about health behaviours and their impact on the brain’s ability to carry out necessary functions indicated a sense of brain health without participants calling it such. Participants felt that these behaviours (e.g., alcoholism) would affect their ability to “function day-to-day,” and would prevent them from “doing what we want to do.” As such, functions of the brain - and behaviours that were perceived to affect these functions - were linked as an intrinsic component of participants’ definition of brain health. It is important to note that the material included in this category was discussed in the context of brain health but not mental health, which is why functional health and mental health are presented as discrete categories. The following quote demonstrates how functional health and mental health were viewed as two separate aspects of brain health:

And you also... [poor brain health] can lead to things like depression, but also depending on how severe it is and if it was an actual trauma to your brain then it could affect the function of your brain (Iron Man ---- girl in grade 9, focus group #2).

One of the most commonly cited functions of the brain during group discussion was memory. Participants felt that brain health maintenance was essential in maintaining memory integrity and recall, and that the loss of memory was one of the most feared consequences of poor brain health.

Memory... Your brain keeps memories and that’s how you decide about things and how you remember who is important to you... one of the things that [high school students] need to be taught about is how if you don’t take care of your brain you could lose your memories... which is really scary....No one really thinks about it but it’s scary [Superman ---- girl in grade 10, focus group #1].

Dialogue about brain health and memory were often centered on the topic of amnesia. Participants described amnesia as “short term or long term memory loss” that was an acute repercussion of a specific event. As a result, when participants spoke of maintaining brain health
within the context of memory the conversations were focused primarily on avoiding negative health behaviours that could cause brain injury and subsequent memory impairment. Interestingly, participants did not appear to relate memory to brain disease such as dementia.

A commonly cited health behaviour that participants felt would affect memory and cause amnesia was excessive alcohol consumption. Below is a personal anecdote that one of the participants shared about his experience drinking while discussing brain health and amnesia. After a night of heavy drinking, the participant awoke with impaired memory, which he described as frightening.

So when I drink a bottle of [alcohol]...So like... All I remember was just saying hi to random people and after my head started spinning a lot. I wake up the next day and my head was hurting a lot and I don’t remember where I was or what I did. I don't want that to happen again

[Asked if the headache or memory loss was worse]

Yeah. Not remembering last night is scarier. It would be worse... because you wouldn't know if something happened. So it was kind of scary (Terry Fox ---- boy in grade 10, focus group #3).

Participants also spoke of how memory loss could result from a traumatic brain injury. In particular, concussions caused by sports-related accidents or riding a bicycle without a helmet were thought to be implicated in amnesia onset.

I think the biggest reason [for amnesia caused by brain injury] for teenagers is riding bicycles without helmets... That’s one of the reason most teens... most of them don't think before doing it, they just go have fun. By wearing a helmet there is a lower chance of brain injury, but most teenagers don’t know about it even though it’s obvious... If some guy gets hit by a car on his bike he gets a concussion and then he forgets everything. And you just think oh snap ... you start thinking of the consequences of [not] wearing a helmet. Even if you don't like wearing one you probably should (Robin ---- boy in grade 9, focus group #3).
Well I think [some brain injuries] are harder to heal because a lot of the time it's not directly keeping you from doing things, but I guess brain injuries... like if you are playing hockey and get a concussion, it's harder to focus. Like headaches and I guess if it is really bad then... even memory loss. (Superman ---- girl in grade 10, focus group #1).

This kind of memory impairment was described as “more of a long term amnesia.”

Participants felt that this form of amnesia would also impair concentration which could have detrimental effects on both school performance and on the ability to communicate and interact with their peers.

Oh man. Um well I had a concussion playing hockey and I was out for three months. And then I was... it was very strange because I was away for the first two weeks of school after I got it and when I came back people noticed I was really confused all the time and I couldn't concentrate so... some things that some people did... not everyone but a couple people started to mess with me. So they would be like... I walked up to someone and I would say hi to them and they would say "who are you"? And I would believe them because I was really out of it and got really freaked out. But after that, the worst part was the teachers. They didn't really understand that I couldn't actually do things to my full ability so that was probably the most frustrating part of it because they weren't giving me enough time to recover. Thank you for your question (Captain America ---- girl in grade 10, focus group #2).

The connection between brain health and social interaction was explored in discussions of both mental health and functional health, and appeared to be a topic of overlap. This is further explored in the following category identity.

Another significant point of discussion during this study was that participants felt that brain health function was necessary for “everything”, and that “you need to be safe and keep your brain healthy so that you can do the stuff you care about. Like playing basketball, studying reading or hanging with your friends.” They sensed that maintaining brain function was
essential in preserving components of lifestyle including profession, mobility and communication.

I think the worst part about injuring your brain... it’s knowing you can’t do stuff you enjoy doing again. For some people what they do is their profession. If you’re a basketball player or professional athlete and something happens to [your brain], you basically are sitting and can’t do what you want. If you mess up your head, you can’t play sports, can’t hang out with your friends... you might not even move (Iron Man, boy in unknown grade, focus group #3).

While it was clear that focus group members felt functional health of the brain was a key component of brain health, the group discussions also highlighted how ambiguous the concept of brain health was. Since functional health of the brain impacted so many other lifestyle behaviours, participants had difficulty attributing specific aspects of health specifically to brain health. As a result, brain health was considered a branching general term with poor clarity and delineation.

Investigator: So why do you feel students don’t “get” brain health?

Because it’s hard to decide what brain health is... your brain is huge and related to everything, so it’s not really a stand-alone thing I guess? Without it you don’t... can’t function. It’s just health, so people don’t think of it as the brain, just the body in general. (Green Lantern ---- boy participant in grade 9, focus group #1).

(c) Identity

A fascinating finding of this study was the concept that brain health is related to one’s identity. As touched upon earlier, there is a great degree of overlap between the other two categories subsumed under the term ambiguous definition and this category. However, the way in which brain health was a part of one’s identity was a frequent enough point of discussion that I felt it was justified to receive its own category.
Participants felt that brain health was directly linked to self-identity. It was expressed frequently that in comparison to other forms of health that may impact the body and its ability to perform functions, brain health was also an intrinsic part of who you are. This unique aspect of brain health was also thought to be less visible from the perspective of others, which made issues surrounding one’s own brain health much harder for others to understand.

When people see you have a broken arm it's not really you just your body and ability to do stuff. But when it is a brain injury it is you that is affected... it's harder to understand. Some people don't get it and might think you're faking. It’s hard because it is invisible so people are quicker to judge and less quick to help (Hawk Eye ---- girl in grade 9, focus group #2).

I also think with arms and casts and stuff it's a lot easier to function with that. Obviously it will still be difficult but it's not... you can still do things like schoolwork and interact with people and if you have a broken arm it will be painful but it doesn't directly impact you as a person your ability to talk to people. Brain injuries can...which is really important (Black Widow ---- boy in grade 10, focus group #2).

Brain health status not only contributes to one’s self-identity, but also can alter how one is identified by others. At times, this could lead to students being treated differently by their peers because of brain health issues. Here, one participant speaks of how some students in her school were treated differently due to communication issues arising from their learning disorders:

… in my school there are people who are like disabled and all that stuff like mentally and like you don't understand what they say and all that. So it's going to be hard for them to communicate with other kids. People just feel… they’re different from us, so people judge and we don’t really mix (Batman ---- boy in grade 10, focus group #3).

Yeah, they may be judged by society as well. Like, people may think that they may be stupid or wonder why they don't get something. And then no one really want’s to be with them…talk with them or spend time with them. They are put down a lot (Black Widow ---- boy in grade 10, focus group #2).
Some participants expressed that many aspects of brain health – particularly mental health- were misunderstood by friends, family and society. Attempting to discuss concerns about one’s own mental health, they feared, would lead to empty platitudes and stigmatization.

People either ignore the issue or misunderstand it completely or flip it around. You hear a lot of people with... I don’t know, drug problems or depression talking about how their family is just saying be happy, or it's all in your head you just need to stop being so down about everything. So that's obviously a pretty negative attitude. I have a cousin who had problems with stuff like that and her family was like that. They recognized it as an issue... and we don't hang out much but when we do we talk. So she was saying that it was like... her family was just like this isn’t happening, just ignore it, it will all be better soon. I'm sure that it's fine. So either ignoring it or making the problem worse can make it harder. For her it was difficult (Cat Woman -- -- girl in grade 9, focus group #1).

The process of maintaining brain health was also thought to be a part of one’s identity. For example, some participants spoke of how the choice to drink or try drugs was heavily influenced by how they wished to self-identify. Some participants did not do drugs because they did not want to become an “addict.” Others spoke of avoiding these negative behaviors in an effort to avoid change peer and familial perceptions of themselves.

[In regards to drinking alcohol], mine is kind of the same thing. I don’t like my parents yelling at me. When I come home [drunk]. I have bad experiences and I don't want them to lose trust... I don’t want them to think I’m a bad kid. So ever since that one time I made them really upset I don't want to (Terry Fox ---- boy in grade 10, focus group #3).

In summary, participants felt that mental health, brain function, and brain health maintenance were all influenced – and influenced by – social interaction. In this way, social determinant was included in their definition of brain health.
Lack of Understanding

Another main theme in this study was the participant’s lack of understanding of brain health. While the previous main theme ambiguous definition highlighted participants’ confusion about the definition of brain health, this theme focuses on how the current delivery of brain health education has resulted in limited information about how brain health may be modified or optimized. This lack of understanding heavily contributed to participant’s disconnection from the topic of brain health, as it left participants feeling unequipped to attempt to make positive choices for their brain. It was felt that this lack of understanding was a result of both a misguided education system and unqualified educators that left participants feeling both frustrated with their schooling experience and ambivalent towards the topic of brain health. This feeling of ambivalence was enhanced by the sense that their education was limited to shallow discussions of risks to brain health, rather than a more meaningful analysis of how risky and beneficial behaviours directly impact the brain. The categories subsumed under this theme include: (a) flawed education model, (b) skepticism about educators, and (c) focus on consequences.
Figure 4.3 Categories related to ‘lack of understanding’

(a) Flawed Education Model.

Participants strongly felt that their schools offered a flawed education model. The students mentioned frequently that there were very few lessons focused specifically on the brain, which they believed to project an apathetic attitude of educators towards brain health. When lessons focused on the brain did occur, it was generally in health class. These lessons were not “taken seriously” by the students.

…I think the attitude during health classes where they have brain health discussions... people aren't serious about it. They’re just like whatever. No one really listens or pays attention. Everyone just rolls their eyes and sits through it, but no one is paying close attention or taking it seriously (Superman ---- boy in grade 9, focus group #2).

I was initially curious as to whether or not it was specifically brain health lessons that were taken seriously, or if it was health classes in general. When asked about this, the participants explained that it was the health lessons on the whole that were not often taken seriously. This was a point that was brought up in all three focus groups.

Investigator: Do you think people take it less seriously then health classes about other subjects? … [Unanimous No] (Focus Group #3)

…No… It’s not just brain health. I think health classes in general aren't taken seriously. It’s not taught well… it’s like the class and teacher and school…they are just going through the motions and whatnot (Green Lantern ---- boy in grade 9, focus group #1).

… But again most people don't take those seriously. Well a lot of people don't take the entire course seriously (Iron Man ---- girl in grade 10, focus group #2).

When asked why health classes were not taken seriously, the participants quoted various reasons. One such reason was that health class was not usually marked, and if it was, these marks
were thought to rarely matter. This was because health class was usually a small component of the physical education course compared to the main focus on sports and physical activity. Participants perceived physical education class unimportant because they were “not really teaching anything of value”, and therefore felt that the grades associated with these classes were also of lesser value. Without the pressure to receive good grades, participants felt that students did not feel as motivated to pay attention in class and commit the lessons to memory.

... they don't have tests for health class either. Like they sometimes just have an opinion essay and people bullshit that. But there's not a real test so people don't take it seriously. ...when there is a quiz they just memorize [information regarding brain health] long enough to do well on the tests but they don't take it seriously.

Investigator: Why is that?

... At our school it's not taken seriously because that grade doesn't matter (Hulk ---- boy in grade 10, focus group #2).

According to the participants, another reason that health classes were not taken seriously was that it was perceived that the lessons generally covered information in a shallow manner. Often the classes would teach things that the participants felt they already knew, leading to boredom and the sense that the class itself was ‘silly’ and ‘useless’.

... I don't feel that the health classes were too hard-core in my school, but I don’t know, it was kind of irrelevant to me...so it feels useless. It wasn't hard-core... They didn’t tell us anything cool that we didn’t know. People only take hard-core classes seriously. [Health class] was a joke (Hulk ---- boy in unknown grade, focus group #3).

Another discussed issue was the amount of time spent teaching health lessons. Participants mentioned that the classes were only taught over the course of a very short period – often only for a few days. Because of this, there was not very much time to learn the information
or get a detailed understanding of brain health, or even general health. The following discussion demonstrates this sentiment:

I feel that [brain health education] has to be long term. It has to be taught for a while. It can't be something short term like a unit. It needs to be held throughout a year, like a year of school. It can be something small but done every day so it's in our heads and we know what you're saying (Superman ---- girl in grade 10, focus group #1).

The health lessons usually fall into one unit of physical education. Which is only one semester long. That's only two weeks of learning health. And then we all just move on (Green Lantern ---- boy in grade 9, focus group #1).

Yeah exactly (Batman, girl in grade 9, focus group #1)

Investigator: So you think that having something taught for a shorter period of time sometimes makes it hard for that stuff to stick?

[Group all says Yes]…Yeah for sure (Superman ---- girl in grade 10, focus group #1).

Another issue with the current education model was that health classes – especially about the brain – depended on readings more so than interactions and were therefore very text heavy. This was perceived as boring to the participants and they surmised their educators were also un-invested in the content. This failure to make the learning experience engaging spurred lack of interest and poor understanding of brain health.

At our school, the [mental health unit] I was telling you about. It's so boring. They give you booklets. Thick booklets. And you take them out during homeroom and you read them and answer questions with our homeroom teacher. It’s supposed to create a bond but our teacher doesn't like it either. So it's one of those things where our teacher is like "Ok class... so... what do you think hurt her feelings?" And we will all just look at her and make something up because it's nothing... it's not really caring. And it’s from a booklet and its reading (Batman --- girl in grade 9, focus group #1).

Participants spoke about how brain health lessons would be more effectively taught in a class such as biology rather than in health. Interestingly, this sentiment was shared across all three focus groups. Participants felt that the lessons in biology were taken more seriously since
the marks “mattered” more. The participants also felt that since biology was a year-long course, it would allow for a more in depth and engaging teaching experience about brain health.

…I think it would be more useful if they taught about mental health in biology or science and actually explained the reasoning behind it because… people take that more seriously (Wolverine ---- boy in grade 10, focus group #3)

Yeah [the sciences] are courses that most people do take seriously. And also I think that a lot of the time when people are presented with just facts and told what is happening it's not that good for retaining the information. But if it's taught in biology this is what's happening inside of your brain and this is how it is affecting the rest of you and different parts of your brain and emotions and stuff. It would be much better (Hawk Eye ---- girl in grade 9, focus group #2).

(b) Skepticism about Educators.

Another factor that contributed to participants’ lack of understanding about brain health was skepticism about their educators. The majority of health lessons occurred at school and were not often discussed in extracurricular activities or at home. As a result, they considered high school teachers as among the most prominent health educators in their lives. All the same, they felt that these teachers lacked the knowledge and expertise to teach them about brain health.

They are not experts on that subject so it makes it hard for them to tell the class about brain health or whatever...They just Wikipedia it and then read the page to us... but they don’t really know what they are teaching... Teachers have to know what they are talking about instead of just reading a paper (Batman --- girl in grade 9, focus group #1).

This was important because when asked how they would want to learn brain health (or any health lessons), the most frequent answer was from someone who was perceived as an expert.

[We need] people who are really well educated about [brain health]. Because a lot of the health classes it's just… you can tell they don't know that much which makes it a lot less easy to learn. You care a lot less and you learn a lot less (Black Widow --- boy in grade 10, focus group #2).
I think definitely health class should be taught by someone who is educated and whatnot… People that majored in neuroscience I guess… That way they could actually answer our questions…I would trust someone who has already spent a lot of time learning about it... an expert (Green Lantern --- boy in grade 9, focus group #1).

Yet other participants also defined an expert as someone who could share a personal experience of illness. Here one student talks about how the involvement of a cancer survivor in one of their health classes had made the lesson powerful and memorable. They went on to suggest how this experience could be replicated in the context of a brain health lesson.

… I think definitely people who have had experience. In class last year when we were learning about cancer and treatment processes, they had teacher who had firsthand experience with cancer come in and talk to us and explain how they got through it and I think that would be really helpful [for a brain health lesson]. Someone who had a mental illness and recovered or was still coping with it even came in and said this is what I'm doing to keep myself healthy and how I changed my lifestyle and all that (Batman ---- boy in grade 9, focus group #2).

Participants felt educators had limited health knowledge themselves and no personal experiences with the material to share. Because of this, participants sensed that the material they were teaching was unreliable. This resulted in their peer groups feeling as if there was ‘no point’ in paying attention to the lessons. Ultimately, this contributed to their lack of knowledge about both brain health, and general health.

Nobody really knows... No one cares [about brain health] ‘cause no one listens to [the health educators]. They aren’t hardcore, you know? No idea what they are even teaching. So why should we even pay attention? ... If you want to know something just google it…. Like they never drink so how can they try to school us about drinking? (Terry Fox---- boy in grade 10, focus group #3).

Participants also quoted educator enthusiasm as an important factor in knowledge retention. They believed that a teacher’s enthusiasm and passion can and should ‘rub off’ on the
students, making the lessons more engaging and memorable. While there were no good examples of enthusiastic educators, participants cited such enthusiastic teachers in other fields of study. Here, one participant describes how a passionate librarian enriched his English class.

…but yeah he [the librarian] was very passionate. When you looked around and found him in the school he was always in the library because that is the stuff he does and loves. If you need help in English then people go to him because he can incorporate it into everything he does. People know him at school for that. I think he was one of those kinds of teachers, someone who you can tell is genuinely passionate and into the topic. If there was one of those teaching health chances are more likely [people will] listen and have an interest (Wolverine ---- boy in grade 9, focus group #1).

Unfortunately, participants felt that the few health lessons about the brain they had were taught by instructors who appeared uninterested in the material. There was a sense that they just wanted to get through the material as fast as possible and had put no time and effort into creating a meaningful learning experience. One student explained how this made her skeptical of her teacher and disregard both the class and the information taught.

In our mental health unit this year, our teacher started off from the mental health unit saying “I was on the way to work today and there was this guy with no pants on. And the guy beside me said wow you're retarded. Do you think this was the appropriate way to respond? And she had nothing else planned for the rest of the period. She just showed us an antiquated video. And it didn't appeal. The question was boring and dry and no one wanted to discuss morals of their actions. It was clear that she had no incentive to teach anything well. She didn't really care at all about the lesson and that's bad. I don’t trust her to teach me anything right. It’s probably why we don’t know much about mental health now (Black Widow ---- boy in grade 10, focus group #2).

(c) Focus on Consequence.

The third category subsumed under the theme lack of understanding is focus on the consequence of poor brain health management. This theme encompasses what participants felt
most hindered their learning about brain health in high school. Current health education highlights the consequences of negative health behaviours in an effort to scare students into a healthier lifestyle. While this approach was effective at times, it left participants unsure of the mechanism behind the undesirable outcome. Furthermore, little time was spent on how to improve one’s health, which left lacking key pieces of information that they felt was necessary to make healthier decisions for themselves.

There was frustration around a narrow focus on repercussions of certain negative health behaviours. They felt that these lessons only provided a partial picture of how to maintain their own health, by only focusing on what behaviours to avoid rather than explain how these behaviours actually affected them, which behaviours should be adopted and why. Without all the information, participants felt that they were unable to fully understand how their behaviour could positively influence their health.

… I think health education in its current state is way too much about preventing things and not enough about teaching kids about why these things could have an effect… … Like "don't smoke weed because it will make your processing abilities lower" and stuff but it's not about brain injuries and here's how you fix it, here's how you prevent it… so instead of saying don't do it, you really need to educate people on... not necessarily why you should do it but this is what happens if you do it, here are the benefits and here are the downsides…. That would give us a better idea of what we are getting ourselves into. Because right now it feels like we are just being told what to do and what not to do. (Captain America ---- girl in grade 10, focus group #2).

The feeling that current health education was paternalistic was shared amongst many of the participants. They perceived the lessons as taking an abstinence approach by telling them what they should and should not do, rather than empowering them to make their own health decisions. This authoritative approach was perceived as both unhelpful and difficult to apply in
real life. Here, a participant shares how the limited abstinence-based approach to health lessons left the student feeling unable to manage inevitably risky behaviours.

Like if you tell kids not to smoke weed or drink alcohol or do drugs or have sex, they will probably do it anyways because it's the nature of society I guess. You have to teach them to be safe with it. Contraception, using birth control and not doing hard drugs. Making sure to get your drugs from safe places and not the sketchier places I suppose… Because the reality is that they are going to have sex and try drugs, and they don’t know how to protect themselves (Batman --- girl in grade 10, focus group #1).

I'm just saying it should really be about keeping it more safe then preventing it. Because if you can't prevent it, it will happen anyways. You want to make sure it happens in the best way possible… like [health teacher] who taught us how to identify which types of weed were laced with something. So if we ever did try to do anything we would be safe (Iron man, girl in grade 10, focus group #2).

Participants in this study clearly expressed a desire to learn more about how to improve their health, rather than just learning about what could damage it. This was a particularly salient point in the context of brain health, as participants felt that they only knew how to damage their brain, but not how to improve it. The participants described this learning experience as only covering “one side of the coin.”

They always talk about what we should avoid but we don’t know how to improve our brain. Like how exactly does this cause an issue and how can we reverse it. We know a lot about what to avoid, but they don’t… they don’t really tell us about what we can do to make our brain better so it’s only half the story. So if we don’t understand how to make it better then what can we do? (Superman ---- girl in grade 10, focus group #1).

**Struggle for Relevance**

The third major theme that described participant’s experience with brain health was a *struggle for relevance*. This theme encompasses the struggle participants experienced trying to find the relevance of brain health in their day-to-day lives. This theme became more complex
then I initially expected. While the discussions quickly revealed that brain health was not perceived as a pertinent topic to adolescents, it also became clear that the participants strongly felt that brain health was important. They struggled to find relevance in a topic that was both foreign but valuable. This struggle for relevance contributed to the lack of clarity participants experienced regarding how maintaining brain health would benefit them. Participant’s felt that major factors that contributed to brain health’s irrelevance in their lives were (a) the relative invisibility of brain health, (b) peer disinterest, and (c) emotional detachment from the topic of brain health. These categories are summarized in figure 4.4.

**Figure 4.4 Categories related to ‘struggle for relevance’**

(a) *Invisibility.*

For something to be visible means that it is observable and noticeable. Because of these traits, more consideration and value is placed on topics, phenomena, or issues that are visible
because they are more difficult to ignore. The invisibility of the topic of brain health therefore led to the perception of it being less relevant in the participant’s lives. Participants felt that many aspects of brain health were invisible. Participants described two forms of invisibility that they felt were associated with brain health: The inability to track brain health wellness and what they perceived as society turning a “blind eye” toward the topic of brain health.

The importance of being able to track health outcomes was something that participants in all three focus groups stressed was tied to the relevance of different forms of health. By being able to monitor health progression or deterioration, participants felt that they had the opportunity to receive continuous feedback that would motivate their future health decisions. For example, one participant found that her ability to run longer periods of time without ‘losing her breath’ made her feel that she had made meaningful improvements in both her athletic capabilities and heart health:

I don’t think your health is normally the focus of many people when they go out to run... Most of it is just... about making small improvements. Maybe they are competing and they are running or they just want to look better or get skinnier... you do it for the short term goals... like when I was running I noticed I could go longer without losing my breath, so I knew I was getting stronger. It keeps you going (Hawkeye ---- girl in grade 10, focus group #2).

Conversely, another participant spoke of how the loss of muscle mass after a long period of absence from the gym motivated him to begin working out again.

…when I stopped going to the gym I noticed that I was heavier and all my [muscle] gains were going away. When I looked in the mirror and noticed it, it made me want to start working out again (Hulk ---- boy in grade 10, focus group #2).
Both these examples demonstrate how easily visible, physical changes allow for monitoring health progression, and how this monitoring is often a motivator to adopt health and health behaviours. In the case of the brain however, participants felt that there were no ways to track any progression or deterioration. Because of this, participants felt like they were only able to take a passive role in managing their own brain health which made the topic itself feel less relevant.

The participants’ all-or-nothing perception of brain health was another factor that contributed to the theme of invisibility. When describing issues or injuries of the brain, participants did not describe progressive disease but rather critical and easily observable events such as concussions, intoxication, nervous breakdowns, or being born with a mental disorder. The image of brain health painted by these discussions was one in black and white. Either one was “fine” and acted “normally,” or they were “injured,” “sick,” or “different” in some noticeable way. This perception led to the concept of brain health as something that was invisible until there was a problem. This led to participants feeling that “you don’t worry about it until it happens… because you never think about it until you see it happen to yourself” (Wolverine ---- boy in grade 10, focus group #3). This made brain health seem less relevant to participants, as it was something to be managed when a major crisis occurred, rather than something that could be gradually improved upon.

Despite the lack of evidence that brain health management could be relevant in their lives, participants still sensed that brain health was in some way important. This led them to wanting more educational experiences about brain health. Even though it doesn’t seem important now…it's like drugs. Not everyone does them but everyone has the potential to do them. It’s like brain health. Not everyone will get a brain health problem but everyone could get one. It's good to learn about (Black Widow --- boy in focus group #2).
Another type of invisibility related to brain health was its invisibility to society. This category overlapped with a great number of other themes and categories in this study. Participants indicated throughout the group discussions that their personal value systems were influenced heavily by what they perceived as the values of their family, peers, teachers, school and community. As brain health was a topic that received little attention from society, participants found it difficult to value it themselves. “It’s hard to care when nobody else does (Hulk ---- boy in unknown grade, focus group #3).”

As discussed in the category ‘skepticism about educators’, participants felt that their teachers and their school as a whole did not appear to care about brain health. Other health initiatives promoting healthier eating habits and a more active lifestyle were much more prominent in the high school environment. Participants felt that this made brain health seem unimportant when compared to other health issues that garnered more exposure.

In school you hear a lot about exercising, eating health and whatnot, they are always telling us about the dangers of being overweight or out of shape…so people pay a lot more attention to that…but brain health isn’t really talked about…it should be talked about more I think (Green Lantern ---- boy in grade 9, focus group #1).

Participants also felt that brain health was not “on the radar” of society. None of the participants recalled discussing brain health with a family member, even though conversations about other health related habits such as drug use and sexual health were frequent. In addition, the participants cited the contrast between the abundant health-related awareness campaigns focusing on cancer, and drinking and driving and the lack of similar campaigns about brain health.
Yah. I see don't drink and drive on TV advertisements. I don't see any ads for wearing helmets or taking care of your brain. I’ve never seen them…I don’t think anyone thinks it’s really an issue (Terry Fox ---- boy in grade 10, focus group #1).

(b) Peer Disinterest.

This category explores how participants felt that their peers were disinterested in brain health. There is some overlap between this and the category of ‘disease invisibility’, as this peer disinterest contributed to the concept of brain health’s invisibility to society. Participants in all three focus groups indicated that their peers were the most impactful in shaping their own opinions and perceptions about the importance of various health behaviours and outcomes. As such, I felt that peer disinterest should be represented as a separate category in order to both provide a richer description of this concept and establish the important contribution of peers to the participant’s perceptions of the relevance of brain health in their own lives.

Throughout the focus group discussions, participants repeatedly spoke about how the relevance of certain health behaviours or outcomes in their lives was often tied to its perceived value to their peers. Because of this, many students would adopt similar views, goals, and health behaviours in an effort for acceptance by their circle of friends. At times, this would result in the adoption of unhealthy behaviours or views.

…I think that no matter how many times you say don't do this don't do that, if you live in a society where something is very prevalent, you are going to get involved. If you have one person in a group of friends where everybody has smoked weed before, chances are that one person who hasn't is going to try it (Superman ---- girl in grade 10, focus group #1).

Sometimes participants felt that peer interest in healthy behaviours could positively impact them. For example, they described exercising more rigorously or eating healthier because they felt that weight management was something that their peers valued and admired.
Maybe you get bullied for being overweight or whatnot so you might want to change it… you want to look good so you eat better and exercise more. Everyone in high school cares about looks so you have to care too (Green Lantern ---- boy in grade 9, focus group #1).

Well the guys at our school all work out together… We encourage each other at the gym. Everyone’s all about being fit and looking [strong]. So that’s why probably I care about exercising so much…Everyone knows it’s good for you… your heart and appearance (Hulk ---- boy grade 10, focus group #1).

Others would avoid certain harmful health behaviours they felt were taboo among their friends. Here, a participant talks about how a pact with his group of friends made him stop drinking:

My friends would get angry I was doing drugs…. because when I started to drink a long time ago… me and my friends made a promise to never do drugs. So when I done that I never drank for a while now. Because I don't want to break that promise… not doing it is important to me (Wolverine ---- boy in grade 9, focus group #3).

Because peers influenced the importance participants placed on certain health behaviours and outcomes, it was clear that peer views on brain health was also interrelated with the topic’s relevance in the participant’s lives. Unfortunately participants felt that their peers were ambivalent to the topic of brain health.

The issue of peer disinterest in brain health was brought up in all three focus groups. It was commonly felt that most high school students ‘don’t think about their own brain health’, and that among the participant’s peers, ‘no one really cares’ to learn more about it. These feelings contributed to the participant’s perception of their peers as being disinterested in brain health.
The following is the response of several participants when asked if they felt that their peers cared about brain health:

Investigator: … Do you think a lot of people care about brain health in high school as it is right now?  
(Group unanimously says no. 5 Second pause then everyone laughs)  
Not many people are aware of it (Batman ---- girl in grade 9, focus group #1).  
We talk a lot about our bodies instead of our brains… (Green Lantern ---- boy in grade 10, focus group #1).  
Everyone is thinking about other things that seem more important... people worry about their appearance and how they look, so no one is really thinking about their brain. It just doesn’t seem important to most people (Superman ---- girl in grade 10, focus group #1).  

Participants also felt that they were unable to broach the topic of brain health with their peers. Because peers were disinterested in the topic, participants felt discussions about brain health would sound forced or authoritative.  

…Between my friends and me none of us are too serious. So if you try to be too serious with your friends they start to look at you and wonder are you an authority figure? That’s how it is with my friends. Of course they know I care about their well-being. But for me to just randomly come up to them and start talking about brain health, they would be like "What’s wrong with you? What are you?" (Superman ---- girl in grade 10, focus group #1).  

This peer disinterest made it difficult for participant’s to remain interested in brain health themselves. As one participant put it, “most people don’t really care about [brain health] and that makes it feel so… unimportant I guess. It’s hard to care about something if your friends don’t (Iron Man ---- girl in grade 10, focus group #2).”  

Peer disinterest not only made the topic of brain health seem less relevant to the participants, but also made some participants feel that their own struggles with brain health were unimportant to their friends.
You can’t just bring up brain health to your friends. They will be all like ‘who do you think you are? Stop trying to teach me stuff’... once I mentioned how I should maybe start wearing a helmet because I was scared of getting hurt and they looked at me like… you’re crazy. So I dropped it.” (Batman ---- girl in grade 9, focus group #2).

Participants felt that this lack of interest in brain health made them feel unsupported with their own perceived brain health issues. This gave them the sense that their own brain health was irrelevant. The following is a discussion that highlights the difference in support from peers when comparing brain health issues to other ‘general health’ issues.

It’s hard to talk about mental health because it’s… there’s a stigma about mental health… so you can’t really talk to your friends. Like I thought I was depressed for a while and I couldn’t really talk to anyone. When I did, they just seemed…disinterested. It made it hard (Hawk Eye ---- girl in grade 10, focus group #2).

Yeah it’s hard because no one treats [brain health] like it is an actual relevant issue… but they do for other things… everybody [would be] very encouraging no matter who it is because quitting smoking is pretty common, so it feels like it matters. But when you are depressed it feels like everyone thinks you’re crazy and makes you feel like maybe it doesn’t really matter (Captain America ---- girl in grade 10, focus group #2).

(c) Emotional Detachment.

The final category that contributed to brain health’s lack of relevance in participant’s lives was emotional detachment. When describing issues important in their lives, there was a common thread among participants of having an emotional investment in the material. This emotional investment made engaging with the issue an experience that would often elicit feelings such as sadness, excitement, anger or happiness. These feelings would make the participants feel more connected and engaged with the issue which made it seem more relevant in their lives.
Emotional attachment was often attained through the use of videos. In all three focus groups, participants expressed how Mothers Against Drunk Driving awareness videos shown at school elicited feelings of sadness and fear which in turn made them feel more connected to the issue of drinking and driving:

There were mothers from drinking and driving I think it was? That video was really eye opening... really sad. If I was ever to see my mom hold a glass of something and then drive it would affect me. I would tell her not to because I watched that and it kind of scared me… I started to really care about not ever drinking and driving myself (Superman ---- girl in grade 10, focus group #1).

Effective use of videos could cause emotional attachment to even the most seemingly irrelevant of issues in participants’ lives. One focus group discussed how the film ‘Blackfish’ had made their entire student body very aware and passionate about aquatic animal welfare and rights:

… there is another documentary called Blackfish and it is about killer whales kept in captivity and that was the most powerful film I had ever seen. Just because of the way they presented all the information. And it appealed a lot to the younger demographic, especially in Canada…They showed the real life repercussions of putting orcas in captivity…The family of the killer whale was crying out for it. They put down a big net and then they got a bunch of them in the net. And when they took out the baby they wanted they let the net down so that they could all swim away but none of them swam away. They stayed for hours and cried for their baby. It was so heartbreaking... It was very powerful. Everyone at school felt so sad after watching it and soon everyone was wearing buttons and promising to never go to Sea World (Black Widow ---- boy in grade 10, focus group #2).

While they had many examples of different issues in which they had become emotionally invested, none of the participants could recall similar emotionally powerful experiences regarding brain health. Participants felt that this contributed to a lack of emotional attachment to
the subject of brain health, and recommended more use of ‘emotional messages’ to make the subject of brain health seem more relevant to adolescents.

… I can’t think of any videos with powerful messages about mental health or brain health. It’s not like it is for drinking and driving, they don’t really have anything that makes you feel connected. So I don’t think a lot of us really feel anything when we think of brain health… So the messages are kind of lost because the whole thing doesn’t seem to matter… I was making [a brain health education program], I would use a lot more of those powerful videos (Captain America --- girl in grade 10, focus group #2).

… I think the issue with mental health is people not being aware of things happening. So if you're looking to start solving the problem by making people aware, having a powerful movie would be a great way to do it. Because as we know, it does make people aware of the issue you're trying to fix…. people aren’t aware, and they don’t feel that connection to it… (Black Widow ---- boy in grade 10, focus group #2).

Another factor that contributed to participant’s emotional detachment was a lack of exposure to people who had experienced issues surrounding brain health. By interacting with people suffering from various health issues, participants felt that they gained a new perspective about how these health issues could one day impact themselves or their loved ones. These exposures acted as emotional anchors that tied the health issues to the participants.

Yeah. My grandfather died of lung cancer because he smoked. And no one else in my family ever smoked again and I don't think I will ever smoke. Or I might smoke once but I'm not going to get addicted to it. So when you see someone in your family or among your friends who suffered from something you are less likely to do it because you know the consequences first hand. It’s more emotional and…realer I guess (Superman ---- boy in grade 9, focus group #2).

While one student spoke of an interaction with a cousin suffering from depression, most participants felt that they did not have any exposure or interaction with people suffering from brain health related issues. This left participants feeling like they had no emotional anchor to the issue of brain health, making the topic seem less relevant in their lives: “… you don’t really see
people who have lived with brain health problems so it doesn’t feel… real… people don’t feel strongly about [brain health] because of that (Cat Woman ---- girl in grade 9, focus group #1)

Participants also felt that they were not emotionally anchored to their future brain health. Some participants thought of their future selves as a separate and unfamiliar person. One participant shared a study she had recently read that had resounded with this experience:

I read this one study saying that people, when you measure their brainwaves, they don’t actually think of their future selves as themselves, they think of them as a stranger. I thought that was cool! I definitely believe that students just don’t really think of their future selves as themselves in general (Hawk Eye ---- girl in grade 10, focus group #2).

Without an understanding of how brain health could be modified, and what role it played in their lives, participants felt that the topic was far removed from themselves. Even though they had a sense that brain health was important, many participants seemed to feel that they were powerless to change it. Because of this, some participants viewed brain health as a distant statistic that they were not a part of.

I think that's very difficult because most people don't really... They hear you have this percent of chance of something bad happening if you don’t take care of your brain... But people still don’t... And I think it is because especially as teenagers we detach ourselves from the statistics. We don't think it will happen to us, we think of ourselves as exceptions. And that is a problem because you don't actually see the harm you just think you are immune to it (Captain America ---- girl in grade 10, focus group #2).

Yeah. Thinking I'll be the other 20%. I also think that it really helps to see it. So if you wanted people to consider dementia… they would want to know how you could stop it… and if you see someone close to you that has dementia that's... it seems a lot more real than people just telling you that you could get dementia an here are your chances. Then you're like ok... that seems far away (Iron Man ---- girl in grade 10, focus group #2).
Emotional detachment from aspects of age-related brain health was also made clear by what was not spoken about. During all three focus groups, none of the participants independently brought up the topic of dementia, aging, or personal experiences with family members or loved ones that suffered from neurodegenerative disorders.

**Chapter Summary**

The first section of the results provided descriptive statistics relating to the grade, gender, ethnicity, and household status of the participants in each focus group. Following this, the qualitative results of the study were presented that described the participants’ relationship with the topic of brain health. These themes were examined and liberal use of quotations were used to provide depth, richness, and context to the findings. The themes that emerged included the *ambiguous definition* of brain health, participants’ *lack of understanding* of brain health and how it may be influenced, and the participants’ *struggle for relevance* when attempting to reconcile their assumption of brain health’s importance with their limited understanding and exposure of the topic and its role in their own lives. These three themes together contributed to an analytic narrative that tells the story of a *disconnection*. The related story described participants’ disconnection from the topic of brain health both in their current lives and in the future. This will be discussed in the following chapter.
Chapter 5

Discussion

This section is dedicated to discussing the results of the qualitative content analysis. In this chapter, I will begin with an analytic narrative on how the three previously discussed themes come together to tell the story of adolescent disconnection from the topic of brain health in both the present and future. I will also discuss how this disconnection contributes to adolescents’ inability to adopt brain health behaviours into their everyday lives.

The Analytic Narrative

The analysis of the three main themes revealed that the participants were telling a story of disconnection from the topic of brain health. This story integrates the themes that were explored, because the participants’ disconnection from the topic of brain health was a result of their ambiguous definition of brain health, a lack of understanding about how brain health may be managed, and the struggle to find the relevance of brain health in their own lives. This section is based on how the participants tell their stories and how I interpret their experiences. This story is organized as follows:

1. Confusion - What does brain health mean?
2. Why should I care about brain health and how can I change it?
3. Disconnection from Future Brain Health

Confusion – What does “Brain Health” Mean?

Students have a hard time conceptualizing brain health because it is a topic that overlaps with many aspects of life and health. Educators, parents, and peers also appear to struggle with
the topic of brain health which contributes to the sense that brain health is not something that can be discretely defined, but rather something that is intricately related to everything. While many adolescents struggle to define brain health, when asked directly, discussion around the topic revealed that participants create categories which represent what brain health means to them: *mental health, functional health, and identity*. These categories are created after reflection of personal experiences with the brain and are therefore representative of brain health issues that are contemporary and more pertinent to those in adolescence, as opposed to late-life–related brain health issues. For example, despite the rising prevalence of dementia being a significant motivation in the creation of this project, dementia and aging were not discussed in any of the focus groups without prompting. The categories that were discussed appeared to be ambiguously defined, as participants struggled to determine whether each category was interchangeable with the term brain health, was a component of brain health, or was something else entirely. The ambiguity of the topic of brain health led to participants feeling unable to connect to the topic of brain health.

One of the most enthusiastically discussed categories under the topic of brain health was mental health. In all three focus groups, discussion of brain health would transition to discussion about mental health. The majority of participants agreed that mental health issues themselves encompass both emotional and psychological wellbeing. During these discussions, many participants would share personal experiences with anxiety and depression. Mental health issues are at the forefront of the minds of many adolescents, and some participants expressed that these issues were not being adequately supported – both at home and in a high school environment. Should brain health education be further incorporated into the high school curriculum, many participants hope that more awareness and understanding about mental health issues will increase the emotional support provided by peers, educators, and parents.
While mental health appeared to be connected in some way to the topic of brain health from the perspective of the participants, many of them disagreed about whether or not mental health itself was a part of brain health, or something else entirely. Some participants felt that mental health and brain health are interchangeable terms. This belief led to many participants feeling that brain health education efforts should focus on emotional and psychological well-being. Conversely, other participants felt that mental health was a separate topic entirely, and that brain health in fact referred to functional health.

When participants discussed functional health, they referred to what they felt were the most important functions of the brain – particularly memory, the ability to communicate, being able to perform physical actions such as walking, running, and the ability to participate in sports. While they felt confident that the brain was involved in the execution of these functions, participants also shared a sense of confusion over how the brain was involved and the importance of its role. Furthermore, some participants felt that since the brain is involved in the function of everything, the functional health aspect of brain health is a diffuse and broad subject. In this way, functional health of the brain was also considered ambiguous and contributed to the ambiguity surrounding the definition of brain health.

Another category assigned to participants’ definition of brain health is identity. Unlike other forms of health discussed in the focus groups such as lung health and heart health, participants feel that brain health is intertwined with sense of self. This is because participants believe that brain health is tied to mood, emotion, memory, and the ability function in day-to-day activities – aspects that together is felt to contribute to both personal and social identity. In this way, brain health takes on a different meaning than other aspects of health. In fact, some participants expressed confusion, as they felt that the term brain health did not refer to a health aspect at all, but rather encompassed a state of being. This confusion underpins the ambiguous
relationship participants currently have with the topic of brain health. Ultimately, this ambiguity contributed to the feeling of disconnection from the topic of brain health.

Why should I care about brain health and how can I change it?

Other than the ambiguity surrounding the definition of brain health, there existed a more absolute disconnect from brain health expressed by the participants. This disconnection was expressed as a lack of control over brain health outcomes and a lack of motivation to engage with the topic of brain health. A large contributor to this disconnection was considered to be high schools’ approach to brain health education.

Brain health was described as hardly ever discussed at school or at home. When education or discussion regarding brain health does occur, it is most often in health class. This introduces a multitude of issues. Health class by in large is taught for only a few weeks a year, and represents a small portion of the physical education curriculum. Because of this, health education is crammed into only a few weeks of class, and these lessons are more often spent on other aspects of health such as lung health, heart health, sexual health, and drug avoidance rather than specifically being focused on the brain. This leaves some adolescents questioning the importance of brain health, as it appears to be unimportant in their curriculum. In addition, the participants expressed that their health classes appeared to be very authoritative in nature, with teachers giving them instructions of certain behaviours to avoid and the consequences that could follow should their advice not be taken. This left the participants with little knowledge on what behaviours could positively influence their brain, and only a vague understanding of how some activities may potentially harm their brain. As the role of the brain in daily life and the definition of brain health were already ambiguous concepts to begin with, participants were left disconnected from repercussions of negative brain health behaviours as they struggled to
conceptualize how it could impact their lives. Furthermore, without an understanding of how to improve their brain health and track these improvements, the participants felt that the ability to improve their brain health was largely out of their control. Participants expressed a keen interest on introducing brain health and other health lessons in science classes, where it is felt more time would be spent on explaining what kinds of interactions the brain is responsible for, and how the brain can be both physically and functionally altered by the adoption of various behaviours.

Another frustration surrounding brain health education in high schools was the perceived disinterest in brain health amongst educators and peers. Educators in particular were viewed as disinterested in brain health and health class in general, speeding through lessons to return to the physical activities they preferred to teach in class. This perceived disinterest in turn left the adolescents in the class feeling that the topic was unimportant. In addition, even the more enthusiastic educators were often viewed as lacking the expertise and knowledge to provide accurate and meaningful information about the brain as they were “only gym teachers.” This mentality made it difficult for the adolescents to take what few brain health classes offered in their high school seriously.

Adolescents struggled with the relevance of brain health in their own lives in a large part due to its invisibility. One contributing factor was the persisting concept that brain health was an “all or nothing” health factor. By this, participants meant that brain health seemed to only be evaluated when there was a crisis—such as when suffering a concussion. Otherwise, there was no readily apparent spectrum from which brain health could exist. Without being able to monitor small improvements or deficits in brain functionality, participants were left with the sense that they should only be concerned with brain health when an issue occurred. In this way, brain health was an often invisible health factor, making it seem only situationally relevant at best.
One of the most heavily discussed reasons for feeling disconnected with the topic of brain health was a lack of emotional connection. Participants discussed how either personal experiences or touching videos often made them feel more connected to an issue or cause such as drinking and driving, heart health and cancer. In the case of brain health, many of the participants felt that they did not have similar experiences to draw upon. This left the topic of brain health feeling emotionally distant, contributing to participants disconnection with the topic.

Disconnection from Future Brain Health

Brain health is an ambiguous concept that is difficult to conceptualize. Even educators and parents appear to be unfamiliar or uncertain about the meaning of brain health. The ambiguity of brain health as a concept, coupled with a lack of understanding and unclear relevance made it feel that brain health was not meaningful to either the participants or their peers. Ultimately this failure to establish a meaningful link between brain health and their own life made it difficult to feel connected to the topic of brain health.

Participants not only felt that they were disconnected from brain health in their present lives, but were also disconnected from brain health and its role in their future. This disconnection from the future had two main components: a general disconnection from their future selves, which contributed to a disconnection from their future brain health.

The feeling of being disconnected from their future selves was discussed in all the focus groups. Participants thought of their future selves as a separate and unfamiliar person. This disconnection from their future selves became even more apparent when participants were asked how they imagined themselves at 70. They openly struggled with imagining themselves far into the future, and were not sure as to what they considered a ‘healthy’ 70 year old should be capable of. Some participants hoped that at 70 they would still “be able to walk”, while others
felt that they should still be able to “play basketball.” All participants felt that they had not ever considered themselves that far into the future.

Disconnection was thus not limited to just brain health, but also a more general disconnection from the future. Participants described this as a “focus on the short term instead of the long term.” This focus on ‘short term’ was particularly impactful on consideration of future brain health. Many brain health diseases such as dementia are ‘long term’ issues in that they develop later in life. Because of their disassociation from the future, participants had difficulty connecting these more progressive late-stage brain health issues to their own lives. In fact, to my surprise, participants did not even connect these long term issues with the topic of brain health. In all three focus groups, none of the participants brought up dementia or aging in their definition of brain health. Even after being asked directly about dementia, participants were left with very little to say.

In this way, many aspects that are commonly considered to be a part of brain health were not considered in the participants’ definition of brain health. This ties into the theme of ambiguous definition, and highlights how participant’s uncertainty as to what constitutes as brain health directly contributed to their disconnection with the topic.

Disconnection was also intertwined with the themes lack of understanding and struggle for relevance. Without an understanding of how brain health could be modified, and what role it played in their lives, participants felt that the topic was far removed from themselves. Even though they had a sense that brain health was important, many participants seemed to feel that they were powerless to change it. Because of this, some participants viewed brain health as a distant statistic separate from themselves.
Beyond the Narrative: Brain Health Behaviours Are Not Adopted

An overarching conclusion from this study was that brain health behaviours are not adopted. Initially, this study set out to determine barriers to positive brain health behaviour adoption amongst adolescent high school students. This purpose was chosen with the underlying assumption that adolescents did adopt brain health behaviours. Through my analysis it became clear to me that there was another part of the adolescents’ story that I had not considered – their relationship to the topic of brain health. This relationship played a key role in participants’ ability to adopt brain health behaviours, and so it was crucial to explore this relationship before discussing the barriers and facilitators to brain health behaviour adoption. The result was the three themes that had previously been discussed: (1) the ambiguous definition of brain health; (2) a lack of understanding of brain health; and (3) a struggle to find the relevance of brain health in everyday life. This culminated as a disconnection from the topic of brain health.

Participants were so disconnected from the topic of brain health that they could not actively adopt brain health behaviours. In this way, the disconnection participants felt towards the topic of brain health itself was the biggest barrier to adoption of brain healthy behaviours. In this section, I will discuss the nuances of this powerful finding.

Defining Behaviour Adoption

It is important to first define ‘behaviour adoption’ as used in the context of this study. I chose to accept the participants’ implicitly and explicitly expressed health behaviour adoption. To participants, there were two criteria for behaviour adoption to occur: the adoption had to be a conscious choice, and it had to be an informed choice.
**Behaviour adoption is a conscious choice**

By conscious choice, participants meant that the health behaviour was adopted after a consideration of the consequential health implications. Participants described this consideration as “weighing the pros and cons” before “making a decision for yourself.” It became clear that participants viewed health behaviour adoption as an active decision.

This is an important distinction to make. While behaviours and actions affecting health occur regularly in participant’s lives, these actions are rarely considered health repercussions and are therefore made passively. For example, one participant described the choice to eat fast food as being driven by taste rather than health considerations: I don’t think [about health repercussions] when I decide to eat burgers and fries… most of us just eat it because it tastes good (Green Lantern ---- boy in grade , focus group #1).

The notion that health behaviour adoption is an active process of consideration raises an important issue. To adopt a health behaviour, one must have the necessary knowledge of how the decisions will impact their health, and by extension, their own lives. Without this information, there can be no “weighing of pros and cons”, and behaviour decisions will instead be made solely based off factors unrelated to health. Therefore, when participants’ spoke of health behaviour adoption as a conscious choice, they were also referring to it as an informed choice.

**Behaviour adoption is an informed choice**

Participants also felt that health behaviour adoption was an informed choice. In the focus group discussions, participants repeatedly referred to three key pieces of information that informed their health decisions. These were: What aspect of health was being affected, how the health behaviour would impact this aspect of health, and why this impact was important in the participants’ lives.
Unsurprisingly, participants felt that an important aspect of health behaviour adoption was having a clear understanding of the health aspect that would be impacted. In all the examples of health behaviour adoption that the participants discussed, they felt confident in their understanding of the health issue being impacted. For example, many of the participants were comfortable discussing lung cancer, as it appeared to be a topic of familiarity. What participants associated with ‘lung cancer’ appeared to be generally the same in all three focus group; a disease that impacted the lungs that could cause breathing issues, discomfort, and death. While not a thorough understanding, this clarity of concept appeared to provide the framework that was necessary to make an informed health behaviour decision. You have to know what it is first before you can fix it.”

The next key piece of information needed for informed choice was knowing how a behaviour would affect one’s health. Continuing with the previous example, participants often discussed how smoking would increase the chances of themselves and their loved ones of developing lung cancer. While participants again did not go into great deal about the science behind how smoking and lung cancer were related, there was a clear understanding of this link in all the discussions. This was important, as some participants felt that this connection was a major factor in their personal decision not to smoke.

The final piece of information that was necessary to make an informed decision was why the impact on the participants’ health was important to them. As discussed in the theme ‘struggle for relevance’, the value participant’s placed on certain health outcomes was affected by a variety of factors including personal beliefs, emotional attachment, and relevance to peers (and to a larger extent society). Preventing lung cancer was important to many participants because they had friends or relatives who had suffered from it. This made the disease seem more relevant and also emotionally anchored the participants to it. Furthermore, health practices that could
increase risk of lung cancer, such as smoking, were considered taboo in many of the participants’ social circles. In combination, these factors made the behaviour of smoking avoidance and the prevention of lung cancer important to the participants. By understanding how the choice to smoke could impact their health and their lives, participants described feeling better able to make health decisions for themselves.

**Missing Necessary Information for Brain Health Behaviour Adoption**

Having established the requirements for the adoption of health behaviours as defined by the participants, I can now discuss their experience regarding brain health behaviour adoption. While reviewing the themes that emerged from exploration of the relationship participants had with brain health, it became clear to me that participants experienced a disconnection from the topic. This disconnection prevented them from adopting brain health behaviours. This is not to say that participants did not engage in activities that could impact brain health, but rather that these behaviours were not influenced by consideration of their health impact. Each of the three themes that contributed to this disconnection are directly related to the three components identified as necessary for health behaviour adoption.

The theme ‘ambiguous definition’ describes how brain health is an abstract concept to participants. There was uncertainty as to what exactly brain health encompassed, and it was often described as being “general” and “related to everything.” As discussed, a clear understanding of a health aspect was crucial for participants to make informed decisions about health behaviour adoption. It was therefore difficult for participants to make informed brain health decisions as their very understanding of brain health was ambiguous.

In the theme ‘lack of understanding,’ I discussed how a flawed education model left participants feeling unsure as to how their actions could impact brain health. For example, some participants described learning how to identify mental health issues, yet they were unsure as to
what they could do to prevent such issues from occurring in the future. This left them unclear as to what behaviours or lifestyle choices could protect or harm their brain health. As health behaviour adoption was described as an informed decision that considered how behaviour could impact health, this lack of understanding left participants unable to truly adopt brain health behaviours.

The final component participants felt was necessary in order to make an informed decision to adopt health behaviours was understanding how the particular aspect of health could influence their lives. In the theme struggle for relevance, it was discussed how participants had difficulty identifying reasons that brain health should matter to them. While there was an underlying assumption held in all three groups that brain health was important and should be taught more, participants also spoke of how brain health seemed at times to be irrelevant. This stemmed from various issues including a lack of interest from peers, invisibility of brain health both symptomatically and in society, and a lack of emotional attachment to the subject. Furthermore, the concept of brain health itself was already ambiguous which added another layer of complexity for participants when trying to determine the importance of brain health management in their own lives. Without the information and experiences necessary for brain health to appear meaningful and relevant, the participants lacked the means to make purposeful and informed decisions regarding their own brain health.

*Disconnection from Brain Health Raises a Barrier to Brain Health Behaviour Adoption*

Ultimately, this study has found that the current relationship participants have with brain health acts as the largest barrier to brain health behaviour adoption. As discussed, in order to adopt a health behaviour, participants felt that the decision must be both conscientious and informed. In the case of brain health however, the emerging themes suggested that such a
decision cannot take place. This finding is supported by the discussions in all three focus groups, where participants failed to discuss a single health behaviour that they themselves had adopted with consideration of their own brain health.

Of course, participants did discuss making various health decisions that I knew could impact brain health, including decisions regarding smoking, drinking, helmet use, diet, and cardiovascular activity. In all these discussions however, it was revealed that the motivations for these decisions – while plentiful and complex – were often based on social repercussions, personal enjoyment, or health concerns for oneself or loved ones. None of these motivators were clearly identified by the participants as being consideration for brain health. Because brain health was not considered in the decision-making process, participants never adopted it in such a way that satisfied their own definition of health behaviour adoption.

Disconnection was used to describe the way participants experienced their own relationship with brain health, and this sense of disconnection was contributed to by the previously discussed themes. As these three themes all have been shown to play a role in participants’ inability to adopt brain health behaviours, this disconnection best represents the largest barrier to brain health behaviour adoption faced by participants. Participants described connection to an issue or topic as engagement driven by both self-motivation and motivation driven by others. Conversely, a disconnection would describe a lack of motivation to engage with a given issue. This fits well into the overall story described in this study, as a lack of motivation to engage with brain health was a clear contributor to participants’ inability to pursue the adoption of brain health behaviour.
Implications: Addressing Research Questions

I will now summarize how this study addressed my initial research questions discussed in the introduction. In addition, I will draw upon the work discovered in the literature review and discuss how these findings contribute to or support the existing body of knowledge on brain health and health behaviour adoption. The main objectives of this study were:

1. To better understand the relationship between adolescents and the topic of brain health
2. To determine how this relationship impacts the adoption of positive brain health behaviours

Understanding Adolescents’ Relationship with the Topic of Brain Health

The literature review conducted for this study revealed that adolescent brain health behaviour adoption is an underexplored topic. While there are many studies describing other forms of health adoption amongst adolescents, none looked specifically at brain health, nor analyzed the relationship adolescents shared with the concept of brain health. Thus, many of the results of this study are novel and add to the limited knowledge about the relationship adolescents have with the topic of brain health. Through my analysis I have gained a far better idea of how adolescents classify brain health, what their current understanding of how brain health may be modified is, and their perceived value and importance of brain health in their own lives.

As previously discussed, the relationship adolescents have with the topic of brain health is best summarized as disconnected. This disconnected relationship with brain health is a novel finding and encompasses adolescents feeling unsure as to the meaning of brain health and its importance in their own lives. As this appears to act as a barrier to positive brain health behaviour adoption, it is essential that educators wishing to improve brain health behaviour education look first to rectify the issues contributing to adolescents’ disconnection with brain
health. The following section is dedicated to discussing these contributing factors in the context of the greater body of literature.

**Difficulty Conceptualizing Brain Health**

One of largest contributors to adolescents’ disconnection with brain health was their difficulty defining brain health. This finding was unexpected, as literature captured in the review did not emphasize the importance of a conceptual foundation. However upon further analysis of the studies included in the literature review, it is clear that conceptualization of health provides the framework from which understanding and health goals may be built. One such example was a study by Brooks & Magnusson (2007) who found that adolescents define heart health as ‘fitness’, which is measured through physical endurance and BMI. This facilitated positive heart health behaviour adoption through the setting of goals such as exercising more to improve endurance and eating healthier to lose weight. In contrast, adolescents struggled to conceptualize brain health which made it difficult for them to set similar goals. To address adolescent disconnection with the topic of brain health, it may be beneficial for educational efforts to focus on providing a more structured framework from which adolescents can build their definition of brain health. In deciding what should be included in this framework, educators should look to what adolescents currently associate with brain health.

The most discussed aspect of brain health in this study was mental health. In particular, adolescents spoke about their own struggles with anxiety and depression. As the number of adolescents suffering from mental health issues is thought to be on the rise (Collishaw, 2004), it follows that mental health would be an important issue to the participants. Adolescents are interested in mental health, and therefore it may be beneficial to include it as a part of future brain health educational frameworks. Also of importance was that many of the participants felt that there was not adequate support systems in place both in and out of school for those suffering
from mental health issues. This lack of support for adolescents with mental health issues has already been identified (Geoff, 2003), and attempts to redress this issue have been initiated. These include recommendations for further education and increased employment of guidance counsellors, the introduction of mindfulness and wellness workshops throughout many community centres, and anonymous call centers that provide advice and emotional support (Berner et al., 2011; Sacks 2007; Hoiton 2010). The results of this study add further evidence of the need for the implementation of these support services.

**Dissatisfaction with Health Education System**

Another poignant finding of this study was that adolescents are dissatisfied with the current health education system. The amount of content focused on the brain was considered severely inadequate, and some students reported not having had any lesson focused on brain health while at school. This deficit in the education system has left participants frustrated with their lack of knowledge and understanding about brain health which in turn contributes to the sense of being disconnected from the topic.

Throughout the discussion, participants revealed some of their own misconceptions about brain health, such as: the belief that the brain stops developing in adolescence, that concussions can only have short-term health repercussions, and the belief that dementia was reversible. This lack of knowledge about brain health may potentially have detrimental effects on adolescents’ ability to make healthy choices for their brain. Studies have shown that many adolescents who are given inadequate health education hold misconceptions about dangerous lifestyle choices such as smoking or eating take out, and that this can lead to poor health choices and negative health outcomes (Ng et al., 2007; Koplan et al., 2005). In comparison to other types of health, failure to educate high school students about brain health may be even more detrimental as adolescents feel that the brain is not discussed outside of the classroom.
It is known that having positive role models from whom to seek information and guidance is an essential component of positive health behaviour adoption. Apart from teachers, these role models may include parents and other family members. By observing their role models words and actions, adolescents’ behaviour is influenced (Metzger, 2007; Sacks, 2009). Participants’ parents engaged with them about the importance of heart health, lung health, and drug avoidance, but did not discuss brain health. As this study has found that there are fewer platforms from which adolescents can be reached about the importance of brain health, it is imperative that brain health education be prioritized in high schools and in the home.

Participant dissatisfaction was centered not only on brain health education, but the entire health education system as a whole. This finding is consistent with other studies in which adolescents describe health education as irrelevant, basic, and repetitive. Participants also found health classes to be poorly planned and rushed to make time for physical activity, another established complaint in the literature (Emmons & Rollnick 2001; Allison et al 2005).

Another factor that contributed to participant dissatisfaction with their health education was skepticism about their educators. Participants in this study agreed that their health teachers are not perceived as experts on their subject matter, and many participants in this study felt this meant that the information that was being taught was unreliable. This is of importance, as perceived expertise and reliability of knowledge brokers for information retention and behaviour modification is well established in the literature (Emmons & Rollnick 2001; Heath, 2005). Adolescents from this study also view current health and brain health education as didactic in approach, which elicits feelings of frustration. As described in the literature, paternalistic educating approaches often limit adolescents’ sense of freedom and control, making them feel as if adults are telling them what to do. This challenges adolescents’ desire for autonomy and can result in rejection of the educational material (Heath, 2005; Metzger, 2007). Furthermore, this
didactic form of teaching may decrease adolescents’ sense of self-efficacy. Self-efficacy was described by Bandura (1997) as a belief in one’s capabilities, and it is directly influenced by one’s sense of autonomy. Perceived self-efficacy is a determining force in successful behaviour adoption as it plays a role in what one feels capable of taking on.

The current health education appears to be lacking on many fronts. Adolescents feel that an inadequate amount of time is spent educating students on brain health. Furthermore, the entire health education system is viewed as rushed and irrelevant, and often takes an authoritative teaching approach that inhibits the development of autonomy and information retention. Furthermore, health educators are perceived as being unknowledgeable in their teaching subject, which causes adolescents to dismiss any information presented in class. To improve this situation, future adaptations to high school health education programs should look to increase student participation and engagement throughout the learning process. In addition, it may be beneficial to add brain health as a component of the curriculum.

Relevance of Brain Health

An interesting finding from this study is that adolescents struggle when trying to find the relevance of brain health in their own lives. Adolescents appear to feel that brain health is important in some way, however they lack the clear definition and understanding needed to know why it is important. Adolescents in this study also felt that brain health was “off the radar of society” in comparison to other forms of health that receive more attention such as heart health or lung health. As adolescents’ individual values are known to be heavily influenced by the perceived values of their social circles (Stokes et al, 2006), this likely contributed to the sense that brain health is not as valuable or important as other forms of health. In particular, participants in this study described how their peers were the most significant influencers on the adoption of health behaviours. Exercising, alcohol and drug use, and food choices were all
described as being motivated by the desire to be perceived as “normal” within various social circles. This desire for adolescents to adhere to normative behaviours in an effort to fit in has been well established in the literature (Gillison et al 2012).

Another issue that participants in this study expressed was that brain health was perceived as “all or nothing”, whereas other forms of health were thought to exist on a scale. For example, participants felt that heart health could steadily improve or dissipate based on diet and exercise, and this fluctuation could be observed through weight changes or physical endurance. On the other hand, brain health was visualized as remaining more or less at a consistent baseline unless a catastrophic issue such as a concussion or a mental health disorder caused an observable change in behaviour or function. Without quantitative indicators such as blood pressure or weight that could be used for ongoing appraisal of brain health status, participants were left feeling that their actions were disconnected from their brain health outcomes. It is known that adolescents are often motivated to continue positive health behaviours by creating and overcoming personal health goals (Gillison et al 2012). Monitoring and overcoming these goals creates a sense of accomplishment and not only reinforces the healthy behaviour, but also improves confidence and sense of autonomy (Stokes et al 2006). The results of this study suggest that the promotion of positive brain health may come with a unique set of challenges, as the majority of healthy behaviours for the brain are preventative in nature with the effects not always being easily observable.

One major finding of this study was that participants appear to be disconnected from their future brain health. While it has been suggested that adolescents experience difficulty when attempting to “colonize” the future and conceptualize future health benefits (Lawton 2002), what was surprising was that the disconnection adolescents appeared to have with the topic of brain health was in part a product of a disconnection from the older generation. None of the
participants in any of the focus groups considered aging related issues during their discussions about brain health, and even when prompted had difficulty thinking of any personal experiences involving grandparents or other elderly loved ones. It was felt that there were few opportunities to interact with those from the older generation, and that this made the concept of aging particularly hard to grasp. It may be that these experiences are representative of a growing disassociation between our youth and the elderly. This is an especially important consideration in the context of brain health, as youth engagement with the elderly may provide a new perspective of the importance of brain health not only in their present lives but in their future.

**Gender Differences – Stigmatization**

The literature review conducted for this study identified differences in the way different genders experience the process of health behaviour adoption. These differences were often in the form of gender-specific societal pressures that motivated health behaviour change and at times acted as a barrier to positive brain health behaviour adoption. Amongst boys for example, higher risk activities such as smoking or not wearing a helmet while biking or playing sports was considered to be tied to masculine identity. Because of this, boys described feeling pressured to participate in activities that could negatively impact their health (Ng, 2007). Likewise, girls felt that there was more pressure directed at them to maintain a specific body image and weight in comparison to boys. While this did motivate them to exercise more frequently, girls felt that their focus was shifted to meeting unhealthy body weight goals rather than improving overall health (Brooks, 2007). In recognition of these findings, the semi-structured interview script used in this study was designed to promote discussion about gender differences that may exist in the relationship adolescents have with the topic of brain health. Through these discussions, participants shared how they felt that unlike other forms of health (i.e. cardiac health, lung
health, sexual health), adolescents’ relationship with brain health was relatively uniform across genders. The exception to this was the sense that certain social stigmas around issues involving brain health that were influenced by gender identity.

According to the Canadian Mental Health Association, stigma is defined as a negative stereotype that leads to judgement and can act as a barrier to a complete and satisfying life. In this study it was found that adolescents described brain related stigmas as being experienced differently by each gender. Boys expressed that the normative constructs of masculinity did not allow for sharing feelings or seeking support, a feeling that has been described in other studies exploring masculinity and gender roles (Kniskern J. et al., 1983). This was particularly impactful when it came to mental health issues. While girls felt more comfortable sharing personal struggles with mental health issues and seeking support, boys felt that this would be construed as showing weakness which would be both emasculating and lead to social rejection by peers. This left boys feeling like they had to deal with mental health issues in isolation and without access to support. In this way, boys felt that they faced two forms of stigma: the stigma associated with having mental health issues, and the stigma associated with being a boy who has mental health issues.

Girls felt that they faced gender-specific challenges and stigma in the context of traumatic brain injury. They described education focusing on concussion prevention as lacking in comparison to their boy counterparts. It was felt that this was the result of an archaic view that girls are at a lower risk of concussion or injury as they are less physical while playing sports. Furthermore, girls in particular felt that their peers and teachers were not empathetic or accommodating during their recovery period from the concussion. They believed that this stemmed from a stereotype that as girls their injuries may be not as serious or exaggerated.
While the participants in this study felt that they had experienced stigmatization around brain health related issues, they did not appear to face any from their peers while participating in the focus group. Many students felt comfortable enough to openly share personal stories of their own struggles with mental health issues and concussion recovery (e.g. Captain America) during the group discussions. Their peers listened respectfully and appeared to be understanding and empathetic to these struggles. It may be that the comments or actions that contribute to the stigmatization adolescents feared about brain health issues are only being made by a small subgroup of students. Alternatively, it may be that the focus group environment itself fostered more respectful interactions between participants, as maintaining a sense of comfort, inclusiveness and respect throughout the discussions was a paramount goal in this study.

**How Does Lack of Relationship with Brain Health Impact Adolescents?**

The experiences shared by the participants in this study suggest that brain health behaviours are not adopted by adolescents. This is a powerful finding given so little is known about how adolescents approach brain health behaviour adoption. As discussed earlier, it should be noted that the definition of behaviour adoption used in this study was that of the participants. Participants felt that behaviour adoption was an active process involving a conscientious and informed choice. It is interesting to note that this definition is different than those offered in much of the literature which classifies health behaviour adoption as either passive or active (Marcoux, 1997; Jessor, 1977; Hjelkrem 2013). As adolescents are disconnected from the topic of brain health and lack a thorough understanding of how it can be impacted, they are left unable to make an informed choice to adopt a brain healthy behaviour. Future educational interventions must focus on establishing a clearer definition of brain health while also raising awareness of the importance of positive brain health maintenance so that adolescents will feel more connected to
the topic. After this disconnection is resolved, efforts to promote positive brain health behaviour adoption may be more successful.

**What next?**

There are several things that I would like to do on completion of this thesis. The first is to discuss the findings with the gatekeepers at participating schools and community centres. They have expressed interest in the findings, which they believe will provide valuable insight for the implementation of future brain health directed curricula, as well as the identification of areas to be improved upon in the current approach to health education. In particular, there are many researchers at Baycrest involved in intergenerational research about brain health maintenance and dementia prevention. For this reason, youth attitudes towards brain health may be pertinent to them. I would also like to share this information with the study participants so that they can benefit from the knowledge that they helped generate.

**Limitations**

This study used a recruitment method that selected participants that were either part of existing community groups or science classes in high school. Therefore, this group of participants may already have had some pre-existing relationships prior to participation that may have affected their interactions in the focus group and thus the data that was collected and analyzed. Moreover, those that may be completely disinterested in brain health would not have contacted me or agreed to participate in this study since the topic would have held little interest for them. Data from participants that may be completely uninterested with the topic of brain health may have added dimension and richness to the developing categories and the understanding of how adolescents with no interest in brain health view the topic. In addition, purposeful sampling of adolescents from various ethnic, cultural, and religious backgrounds could have added more depth to the discussion, since these
factors could influence the way participants understood brain health and its importance in their own lives.

The other type of limitation has to do with the focus group sizes. Although I strived to maintain 5-8 participants per group, there were unexpected additions to focus group #3. The number of 5-8 participants was selected as it had been demonstrated to be an effective number for adolescent focus groups (a small enough number of participants so everyone would have the opportunity to speak, but enough to overcome any power differentials between participants and researcher). Focus group #3 had more participants, and also was the focus group that I had the most difficulty eliciting discussion from. I found that there were some participants that needed constant encouragement throughout to remain active in the discussion, while others tended to dominate. While both myself and the other focus group moderator did our best to promote equal participation, I believe that the larger number of participants likely influenced the data collection process. During analysis, focus group #3 appeared to have the shortest quotes and the most pauses which may be due to the large number of participants. Should a similar study be conducted in the future, a contingency plan for both over and under representation at the focus groups should be created in advance.

**Conclusion**

This study applied a qualitative content analysis approach to explore the relationship adolescents share with the topic of brain health. It became clear from the narratives that adolescents struggle with the topic of brain health, and feel disconnected from it. This disconnection encompasses a disconnection from the meaning of brain health, how it can be altered or changed, and why it is important in both the present and future.

This disconnection itself acted as one of the biggest barriers to brain health behaviour adoption. Without the feeling of being connected to the material, adolescents felt unable to consider
brain health outcomes while making behavioural decisions. In this way, adolescents found themselves making decisions that ultimately did impact their brain without fully understanding what this impact was or how it could affect their own lives. This research provides the framework from which future brain health educational intervention trials may be built upon.

**Future Directions**

Since this is the first study to analyze the relationship between adolescents and the topic of brain health, there is still much to be explored and expanded upon in future studies. In this section, I will discuss both the short term and long term future directions of this work.

While this project expanded our knowledge and understanding of adolescent views of brain health, the results also raise questions that further research can address. One of the major findings of this study is the disconnection that adolescents experience regarding the issue of brain health. This disconnection was linked in large part to the perception of health educators as unqualified and uninterested. It may be that this perception of educators is itself a product of their own disconnection with the topic of brain health. Future focus groups should be held with teachers, community leaders, and other types of educators to gain a better understanding of what their perceptions and relationship with the topic of brain health is. Teachers appear to be central to delivery of information about brain health, and therefore are central to generating apathy and excitement about the brain amongst students. Interviewing teachers may add conceptual and substantive knowledge about the contributors to adolescent disconnection with brain health. This may also identify where gaps in educators’ knowledge about brain health exists, so that improvements in their training could be made.

I also believe more focus groups should be held with adolescents and educators from both public state schools and private schools, because they may each employ a different health
curriculum or contrasting pedagogies. If so, this difference may impact adolescents’ relationship and understanding with the topic of brain health. Furthermore there are likely significant differences in the socio-cultural characteristics of parents, teachers, and students within varying school settings (ethnicity, geography, class, etc). This study did not take into account the different cultural backgrounds and values of participants during selection. Varying cultural worldviews may alter the way the topic of brain health is understood and perceived. For example, some ethnic groups may be more prone to living in multi-generational households, which could allow individuals to have more contact with older generations and decrease difficulty in inhabiting their own futures. By expanding future studies to include a more diverse selection of schools and community centres, more knowledge may be gained regarding potential influences on how adolescents perceive brain health and how they experience brain health education in the classroom.

In the long term, it may be advisable to develop a survey tool from which quantitative data may be drawn. After creating a more in-depth understanding of how adolescents classify brain health and the barriers that exist to brain health behaviour adoption, a survey representing these findings could be created and sent to a large volume of students in grades 9 and 10. This survey would identify what aspects of brain health interest them, what they believe fits under the definition of brain health, and how they would like to be taught about brain health. The use of this tool would allow for a more quantifiable data set that, while more rigid, would provide grounds for generalizability. This could provide more information from which to base future educational intervention trials.

An educational intervention trial would be needed to test developing brain health education programs. These educational programs could be developed with the participation of community leaders, educators, health advocates, and adolescents and would be informed by the
knowledge generated by both this study and future projects. Should these educational intervention trials be successful, it would provide further support for the implementation of brain health education in the high school curriculum.
References


Barbour RS. 2000. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 1115-17


Beck CT. 2013. Routledge international handbook of qualitative nursing research. pp. 1 online resource (p.). Abingdon: Routledge


Charmaz K. 2004. Premises, principles, and practices in qualitative research: revisiting the foundations. *Qual Health Res* 14: 976-93


Institute NC. 2008. The role of the media in promoting and reducing tobacco use. *Tobacco Control Monograph* 19


Morgan DL, Kreugar RA. 1993. When to use a focus group and why In *Successful Focus Groups*: London:sage


Nandy BR, Sarvela PD. 1997. Content analysis reexamined: Arelevant research method for health

education. *American Journal of Health Behavior* 21: 222-34


Ng N, Weinheall L, Ohman A. 2007. 'If I don't smoke, I'm not a real man'--Indonesian teenage boys' views about smoking. *Health Educ Res* 22: 794-804


Appendices

Appendix A

FOCUS GROUP SURVEY

We are looking for 9th and 10th grade students to assist in the design of health education modules!

There will be a two-hour meeting during which we will ask you questions about how you feel important health issues would best be taught in a classroom setting.

Participants will receive monetary compensation for their time and TTC tokens for transportation.

To sign up or for more information, email Adam Agate
aagate@research.baycrest.org
or phone 647-828-2730.

Study conducted by Tiffany Chow, MD (Baycrest Health Sciences, University of Toronto), Shelley Craig, PhD, MSW (University of Toronto), and Peter Whitehouse, MD, PhD (Case Western Reserve University)

Date of Preparation: 1/02/2014
Appendix B

Intergenerational Design for Knowledge Translation to Improve Students' Brain Health Behaviours

Principle Investigator: Tiffany Chow, MD 416-785-2500 x3459

Co-Investigators: Shelley Craig, PhD, MSW 416 978 8847

Heather Fraser, BBA 416 962 8852

Peter Whitehouse, MD, PhD 216 464 6449

Your child aged 13-18 is being asked to participate in this research study conducted by Dr. Tiffany Chow from the Division of Neurology at the University of Toronto, Dr. Shelly Craig from the Faculty of Social Work at the University of Toronto, Heather Fraser from the Rotman School of Management at the University of Toronto, and Dr. Peter Whitehouse from the Division of Neurology at Case Western Reserve University. We are recruiting 9th and 10th graders to advise us on how to best educate on brain health. Up to 8 students will be included in each focus group meeting. We expect to conduct no more than 4 focus groups, though students will only be asked to participate in one. Participation in this study is voluntary. You should read the information below, and ask questions about anything you do not understand before giving permission to participate.

PURPOSE OF THE STUDY

We are holding focus groups to determine how to best design health education programs aimed towards high school students. We hope to address a new mandate from the province of Ontario to create more authentic learning experiences during the school day.
PROCEDURES

Each focus group meeting will last no longer than two hours, during which the leader will ask approximately 7 questions for each student to answer. Because we want to make sure we record everyone’s opinions, we will be tape-recording each meeting and the co-leader may write notes.

POTENTIAL RISKS AND DISCOMFORTS

The only risk of participating in this meeting is discomfort if participants feel uncomfortable talking about their own health.

ANTICIPATED BENEFITS TO SUBJECTS AND SOCIETY

From this study, we hope to learn what forms of education would be most effective for high school students, so that we can better design learning modules.

ALTERNATIVES TO PARTICIPATION

You may choose not to allow your child to participate in this study.

STATEMENT OF CONFIDENTIALITY

Signing this paper allows us to record each participant’s voice and report his/her opinions, but we will not reveal names or identifiers in the report.

STATEMENT OF RESEARCH REVIEW, VOLUNTARY PARTICIPATION, AND OFFER TO ANSWER QUESTIONS

A committee (Institutional Review Board or Research Committee) of medical and non-medical people periodically reviews and approves this research for scientific and ethical merit. You will be told of any new information, which may affect your willingness to continue in this research. Your refusal to participate will in no way involve penalty or loss of benefits to which you are otherwise entitled. Your participation is strictly voluntary. If you have any questions now or
later, please ask us. You will be given a copy of this form to keep. If at any time you feel any infringement of your rights, you may contact the Baycrest Research Ethics Board Chair, Dr. Ron Heslegrave, at 416-785-2500 x2440 for answers to any questions about the research and your rights.

PAYMENT FOR PARTICIPATION

Participants will be paid $20 each for their time, as well as receiving two TTC tokens to cover travel costs.

OFFER TO ANSWER QUESTIONS:

Participation will be supervised by Dr. Tiffany Chow at 416-785-2500 x3459 or pager number 416-381-8482, whom you may contact with any questions or concerns regarding the study.

If you wish to contact someone not connected with the project about your rights as a research participant, feel free to call the Baycrest Research Ethics Board Chair, Dr. Ron Heslegrave, at 416-785-2500 x2440. Dr. Heslegrave has no connection to the study and is not involved in conducting this study in any way. You will be given a copy of this form to keep.

Healthy Control Subject/Legal Guardian Consent

CONSENT – My signature below indicates:

- I have read the information provided above.
- The information has explained the study procedures, purpose, risks and benefits.
- I have been assured that confidentiality will be maintained.
- I have a right to withdraw from the study.
• I understand that unexpected abnormal findings arising from my participation in the study will be communicated to my treating physician with my permission.

• I have been given the opportunity to ask questions and all of my questions have been answered to my satisfaction.

• I have been given a copy of this form.

• By signing this form, I grant consent to participate in the research as described.

BY SIGNING THIS FORM, I WILLINGLY AGREE OR GIVE PERMISSION TO PARTICIPATE IN THE RESEARCH IT DESCRIBES

______________________________________
Name of Legal Guardian

______________________________________  _________________
Signature of Legal Guardian              Date

SIGNATURE OF INVESTIGATOR OR QUALIFIED STUDY PERSONNEL

I have explained the research to the subject or his/her legal representative, and answered all of his/her questions. I believe that s/he understands the information described in this document and freely consents to participate.
______________________________
Investigator or Qualified Study Personnel’s Printed Name

______________________________   _____________________
Signature of Investigator           Date (must be same as Legal
or Qualified Study Personnel       Guardian’s)

This consent form will not be used by non-English speaking subjects.
Appendix C

Focus Group Semi-Structured Interview Introduction Script

“Thank you for attending today’s meeting. My name is Adam, and I am a graduate student at the University of Toronto. Also here today to help me with the group discussion is [name of co-moderator]. [Brief background of moderator]...and will be taking notes throughout the discussion. Recently the government of Ontario has wanted to create new learning experiences about the brain for high school students. I am part of a team that is trying to create new and innovative brain health education programs for the classroom.

I have asked all of you to come here today so that I can speak with you and get a better idea of how you feel about brain health. By “brain health”, I mean habits or practices that you can integrate into your life to help prevent sports-related concussion or even Alzheimer’s disease. You’ve been in school for years now, so you may have already had classes or discussions about health habits, like smoking or drinking and driving. We would like to know what those lessons have been like for you. What did you find really stuck with you from those lessons? Did you find some methods of teaching about these health habits ineffective? What might help or stop you from putting what you learn into practice? You are our experts in what works for your age group and so we look forward to hearing your thoughts and opinions.

Over the next two hours, I will ask a few questions that I would like each of you to answer. Our team will be happy to try to answer any questions that you have. My goal is to get all of you talking instead of listening to me, so do interrupt when you want to say something. Remember, we are here to learn from you today, and we will do our best to capture your opinions. Opinions are neither right nor wrong. I will be tape-recording this discussion and the team may occasionally write notes. You will be paid $20 for your time at the end of the day. If you cannot stay for the entire meeting or you do not feel comfortable being recorded on tape, you may leave at this time. If you would still like to participate in this meeting, we will begin in five minutes.”

Ground rules:

1. Listen to others when they are speaking
2. Do not judge others or tell others how they should behave, think or act
3. Only one person speaks at a time
4. Please respect the confidentiality of others in the group… What is said in this group should stay in this group

**Opening:** Let’s start by introducing ourselves - please tell me a name (it can be a fake one), then state one healthy choice that you have considered in the past week. You don’t have to have done the “right” thing. It can be anything, like taking the stairs instead of the escalator, or choosing your meal. (5 minutes)

**Introductory (Introduce topic and generate discussion – 10 minutes):**

If you had an arm injury, you could imagine how that could cause some problems opening doors, eating, going to the bathroom. With that in mind, what problems do you think someone might have if they have an injured brain?

**Transition Questions (Move conversation to Key Questions):**

1. Think back to lessons you remember from health classes you have had in the past. Did it change the way you acted or thought in any way?

**Key Questions:**

2. We define lifestyle as the choices that you make on a regular basis. These choices depend on what is important to you and can include what you eat, wear, and do in your spare time. A great example of a lifestyle change is deciding to quit smoking, or to go to the gym every other day. What or whom do you think can be particularly motivating when trying to make a lifestyle change?

3. What kinds of lifestyle changes that could affect your brain health have you considered in the past?
4. Do you think that the experience of making decisions to improve your brain health can be easier or harder for different genders?

5. Is it important to learn and care about your brain health in high school?

6. Are there certain people you would rather learn about brain health from?

7. Are there certain people you would rather not have to learn about brain health from?

**Ending Questions:**

8. If you wanted to get your classmates to start caring more about their brain health, how would you do it?

9. If you were in charge of creating a brain health education program for high school students, what kinds of activities or take home messages would you make sure to include or avoid?

10. Before we end this discussion, I am going to summarize what I learned from you today. Please stop me and correct me if I missed something or got it wrong (Summarize what we took away from focus group).

All right that concludes the meeting. Thanks to everyone for all you great input. We all learned a great deal from you over the past couple of hours. I will give you all my email and phone number so that you can get a hold of me if you think of something that you forgot to mention during our group discussion. If you are interested in receiving a report on what we learned from today’s discussion in a few months time, please sign your name and put down an email address where we can send you that information.
As you leave, please collect your $20 and money for the TTC from (Tiffany or Shelley) where you can also sign your name on the follow-up sheet. Signing the follow up sheet means that you would be willing to be contacted one more time in a few months to do a review of our findings. It would be a great help and would be really appreciated.
Appendix D

Focus Group Summary and Descriptive Statistics

Focus Group #1

The first focus group was held on March 27, 2014 at The Hub community centre in Scarborough. I moderated the focus group with the assistance of a Baycrest employee with previous experience running focus groups. There were no noticeable existing friendships among the participants, and the atmosphere was relaxed and friendly. Two participants were absent, so the focus group proceeded with only 6 participants. The discussion lasted 74 minutes, and all participants were very engaged.

*Table 4.1 Participant Characteristics of Focus Group #1*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participant Frequency n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Grade</strong></td>
<td></td>
</tr>
<tr>
<td>Grade 9</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Grade 10</td>
<td>3 (50)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Boy</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Girl</td>
<td>3 (50)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2 (33)</td>
</tr>
<tr>
<td>South-East Asian</td>
<td>3 (50)</td>
</tr>
<tr>
<td>African American</td>
<td>1 (17)</td>
</tr>
</tbody>
</table>
Family Status

Single Parent 2 (33)
Two Parent 4 (67)

Focus Group #2 Summary

The second focus group was held on April 24, 2014 at UTS with 7 participants. The focus group was moderated with the assistance of my supervisor. The participants seemed familiar with one another, however there were no clearly observable friendship groups. One participant was absent. The discussion lasted 97 minutes, and all participants were very engaged.

Table 4.2 Participant Characteristics of Focus Group #2

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participant Frequency n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Grade</strong></td>
<td></td>
</tr>
<tr>
<td>Grade 9</td>
<td>4 (57)</td>
</tr>
<tr>
<td>Grade 10</td>
<td>3 (43)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Boy</td>
<td>3 (43)</td>
</tr>
<tr>
<td>Girl</td>
<td>4 (57)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>3 (43)</td>
</tr>
<tr>
<td>South-East Asian</td>
<td>1 (14)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>3 (43)</td>
</tr>
<tr>
<td><strong>Family Status</strong></td>
<td></td>
</tr>
</tbody>
</table>
Focus Group #3 Summary

The third focus group was held on July 3rd 2014 at The Hub community centre in Scarborough. The focus group was moderated with the assistance of my supervisor. One student was absent from the focus group, however three students who had not been invited to participate arrived due to being invited by friends. It was decided that they would be allowed to participate in the focus group, bringing the total number of participants to 10. This focus group was more difficult to run due to the high volume of participants, and discussion was difficult to direct in comparison to the previous focus groups. The discussion lasted 115 minutes.

Table 4.3 Participant Characteristics of Focus Group #3

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participant Frequency n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade*</td>
<td></td>
</tr>
<tr>
<td>Grade 9</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Grade 10</td>
<td>4 (40)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Boy</td>
<td>6 (60)</td>
</tr>
<tr>
<td>Girl</td>
<td>4 (40)</td>
</tr>
</tbody>
</table>

4 See Methods section, “Recruitment Strategy” subsection for more information.
### Ethnicity*

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian</td>
<td>3 (30)</td>
</tr>
<tr>
<td>South-East Asian</td>
<td>4 (40)</td>
</tr>
</tbody>
</table>

### Family Status*

<table>
<thead>
<tr>
<th>Status</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single Parent</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Two Parent</td>
<td>4 (40)</td>
</tr>
</tbody>
</table>

* We were unable to locate and collect demographic information from participants that had not initially been invited to participate in the focus group.