Nutr**I**tion-related health of **C**hildren with Trisomy 21 and their lived experience receiving nutrition **K**nowledge and care (**NICK**): A mixed methods study in Manitoba

By

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Declaration

In 2021, when I began my PhD Interdisciplinary Studies program, I had been a dietitian for 15 years. I had also been a mom for 11 years, and Nick's mom for 6 years. I have three sons and Nick is my youngest. He was diagnosed with Trisomy 21, which is characterized by others as an intellectual and developmental disability, when he was 3 days old. I too had recently joined the ranks of those classified as having a disability, based on the diagnosis I received in 2020 of an incurable and progressive neurological condition. Although, it has been my experience, and is likely unsurprising to any parent reading this, that my diagnosis has always been overshadowed (by my own choice) by that of my child's.

I did not know for sure that Nick would be born with Trisomy 21. I received a meeting with an experienced geneticist during my pregnancy due to unexpected findings from ultrasound images. I declined the offer to undergo an amniocentesis during my pregnancy because the geneticist I met with told me that he could not guarantee the test results would be 100% accurate, and that there was a (small) chance of risk to the baby. When Nick was born, another experienced geneticist came to my bedside and told me, based on his observation of Nick and years of experience, that he did not believe my baby was born with Down syndrome. However, to be comprehensive, he ordered tests to confirm his visual assessment.

Three days later, I was informed by a nurse that the geneticist who came to my bedside was coming back to the hospital to speak with me. Nick was still a patient at the NICU, due to experiencing distress during labour. Of course, I immediately knew why the geneticist was coming to meet with me, even though the nurse was not allowed to tell me. Obviously, he was not coming to the hospital to visit the parent of a patient for no reason. When we met, he apologized for being wrong about his initial assessment and handed me a package of Down

syndrome-related resources; the kind of resources that are intended to comfort parents after receiving the diagnosis. Eventually, I scanned through the books, but I have yet to read them in their entirety and at that time, I barely touched them. I was not interested in reading about other parents' perceived feelings of loss, sadness, anger, or mourning; nor was I willing to share the children's book that contained outdated language with my older boys.

My initial response to the geneticist was to say, "So what?" and reassure him that he had nothing to apologize for; he disagreed, believing he had misled me or given me false hope. Thankfully, I had perspective, even then. While Trisomy 21 may not be on a list of attributes a parent expects to learn about their new baby, it is far from making the top 10 list of things I would not want you to tell me about any of my children. I only asked 2 questions: 1) What does it mean? and, 2) What do I need to do as a mom? His answers were exactly what I needed to hear. He told me that Down syndrome is different for different people and that my greatest teacher would be Nick himself, with time. He only confirmed that Nick would need help with some things sometimes. I knew instantly in that moment, and was relieved to know it, that Nick's greatest gift in life would be having two older brothers. The geneticist told me that my job was to love him as I loved my other children. And that was the greatest gift *I* received when Nick was born, hearing that, then, from him. I told him that was easy.

Six weeks later, at a follow-up appointment, Nick and I met with a (different) resident geneticist, who told me that Nick would likely be diagnosed with Alzheimer's disease around the age of 50 and die by the time he was 60 years old. As much as I could, I suppressed that new knowledge. As a person of faith, I doubted any human's certainty about my son's lifespan and cause of death although, as a scientist, I knew better than to completely dismiss statistics of that degree.

Eventually, I searched for research about Trisomy 21 and nutrition. I quickly found out that there is very little research conducted on the topic, particularly in Canada. It struck me as inadequate to read about statistics suggesting persons with Trisomy 21 were more likely to experience nutrition-related conditions and diseases, and then learn about the lack of research or intervention involving the same. For example, as a dietitian I knew there was a large body of evidence linking specific dietary patterns with a reduced risk of developing dementia, including Alzheimer's disease, but noted that these studies did not include persons with Trisomy 21. Again, I was struck by the discrepancy of knowing, on the one hand, about a person's apparently extremely high risk of developing Alzheimer's disease but then, on the other hand, their complete exclusion from research or intervention efforts to prevent the same. Even though as a long-time dietitian, I was fully aware that nutrition is never valued as it should be, I was appalled and disappointed that in circumstances where intervention may have great impact, nutrition did not appear to be meaningfully considered. When Nick received his diagnosis, he was automatically referred to multiple healthcare providers and allied healthcare professionals who followed him for years, except for nutrition, and I doubted it was because I was a dietitian.

Around the same time, I began a research position in a related research area that included adults with intellectual and developmental disabilities, who had been previously institutionalized. I began learning, and realizing, how great were the health inequities among these people compared to the rest of the population and even worse, their treatment by society at large throughout human history. Of course, this became personal for me very quickly. Anytime I read about a person with a condition characterized by others as a disability, notably always by others who did not have the same condition, I felt as though I was reading about my son.

Also, around this time, Nick was entering the school system as a kindergarten student, and for the first time since his birth, cared for by others in my absence for longer periods of time. I was receiving an education of my own about how society at large labels and categorizes and perceives my child. This was a particularly fascinating experience because that was also around the same time when I too was now labelled and categorized and perceived differently by some people, based on having received a medical diagnosis characterized as disabling. I was learning about this word disability, and all the other words used to mean the same thing. I was also learning about myself, and what I thought about these labels, and how it felt to have them applied to me and my son. I was learning about inclusive education, and what it means on paper compared to what it means in practice. I was learning about who held positions of power and influence (and who did not); who were the decision-makers for policies related to how health, education, and family services are provided to individuals and families. I was learning about the word advocacy, and what it means to be an advocate and in particular, a parent advocate. I was interested to read about how us parent advocates are discussed and described in literature. I reflected about which 'type' I was, and which 'type' I wanted to become. I understood the teachings of social role valorization, I absorbed whatever I could find about the history of disability, and I pondered about all these things.

From my participation in online parent support groups, I was disheartened to learn about other parents' experiences parenting a child with disability. From my participation on boards of non-profit organizations as a parent representative, I was inspired by many (parents, researchers, and others) who have tirelessly worked on behalf of those with disabilities for decades. I was grateful Nick was born in 2015, even though there is still so much room for improvement. I was humbled by my vulnerable position and feelings of powerlessness in environments outside of my

home. As one example, to say the least of my experience with the school system over the past 5 years, it has been challenging and relentless; there are no days off.

So, by the time I was registering for grad school (again!), my brain was on fire. I needed to determine what first step, what first project, I could feasibly undertake to highlight the gap in literature and practice I observed, and now lived, to start fulfilling what became so obviously clear, my calling. I went back to my roots, to the field of nutrition, and added education and disability and community health, to create an interdisciplinary doctoral program of study. I was thoughtful about working with a kind supervisor, who is an expert in the field of disability and also, someone I trusted sincerely believed, and actually cared, that being a student was one of several other lesser roles I embraced, next to mom. It was a privilege to be in familiar advisement of a past and formidable supervisor, a kind human, and a respected researcher in the field of nutrition. And it was an honour to get to know a new advisor, another kind human, with lived experience and expertise in the field of disability, who encouraged and inspired me to be more courageous and confident than I felt.

Since no data existed about the nutrition-related health of Canadian children with Trisomy 21, creating baseline data became the goal. I knew that my experience was only mine, and that I needed to capture the lived experiences of other parents and families in my research project too. It was a pleasure and a privilege to get to know them. With my findings, I hope to advocate for greater attention to be paid in research and in practice to children with Trisomy 21 and their families. The completion of this thesis is just the beginning -

Abstract

Background: Children and adults with Trisomy 21 are more likely than those without Trisomy 21 to develop nutrition-related conditions and diseases. The nutrition-related health of Canadians with Trisomy 21 is unknown. This study aimed to determine the nutrient intake of children with Trisomy 21 living in Manitoba and to identify factors that may influence their nutrition-related health. It also explored the perspectives of parents and caregivers about their child's nutrition-related health and their lived experience receiving nutrition knowledge and care.

Methods: Mothers of 14 school-aged children (n=7 female, average age 9 years old) with Trisomy 21 completed a 24-hour dietary recall and a survey. Nutrient intake was calculated using FoodFocus Version 4.2, and data were analyzed descriptively. Fisher's exact test was conducted to test for significant associations between nutrient intake adequacy and factors influencing nutrition-related health. A deductive and inductive thematic analysis approach was used to describe qualitative data. An index (NICK index) to determine nutrition-related health was created as a derived variable computed based on several measures. **Results:** Intake of sodium, added sugars, and saturated fat was greater than dietary reference intakes. Intake of vitamin D, calcium, and fibre was less than recommended amounts. Intake of iron, protein, and carbohydrate was within recommended amounts. Most children consumed a dietary supplement and engaged in moderate intensity physical activity for over 60 minutes daily. No significant associations were observed between nutrient intake adequacy and factors considered as influencing nutrition-related health. Parents discussed positive and negative experiences receiving nutrition knowledge and care. Nutrition-related health among the children was determined to be less than optimal using the NICK index. **Conclusions:** The study findings offer a snapshot of nutrition-related health of children with Trisomy 21 living in Manitoba, and their

experience receiving nutrition knowledge and care. Together the findings discover a need to improve the nutrition-related health of children with T21 living in Manitoba. Optimizing nutrition-related health of children with T21 may decrease their risk of developing nutrition-related conditions and diseases as they age.

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To those who discouraged me and dismissed me, thank you – I am stronger because of you. *To those who encouraged me and supported me*, thank you – I pray that you receive in multitude what you have so generously given to me. *To Jack, Luke, and Nick* – each of you, in your own way, becoming a man among men – thank you for sharing me with my own ambition and dreams. Thank you, *God*, for letting me be their mom.

Dedication

To my boys - *Jack, Luke, and Nick.*

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Chapter 1

Introduction

Down syndrome (DS), is a naturally occurring chromosomal arrangement associated with chromosome 21. DS is present in 1 in every 750 live births in Canada (Public Health Agency of Canada, 2017). As of 2020, there are approximately 22, 367 people with DS in Canada, which is an increase from an estimated 5138 people in 1950 (de Graaf et al., 2025), representing 0.6% of the Canadian population (Statistics Canada, 2021). Trisomy 21 is the most common form of Down syndrome (Canadian Down Syndrome Society, n.d.). In this form of DS (Trisomy 21), there is an extra copy of chromosome 21. The other forms of DS are translocation and mosaicism. In the former (translocation), occurring in 2-3% of those with DS, an extra part of or whole copy of chromosome 21 is attached to a different chromosome. In the latter (mosaicism), occurring in 1% of those with DS, an extra copy of chromosome 21 is present in only some body cells. Throughout this proposal, T21 and DS will be used interchangeably.

Manitoba is one of the 10 Canadian provinces and has great resources for research on child health. Much is known about the health status of children in Manitoba through regular reports based on Manitoba administrative data (Brownell et al., 2008; 2012) although, even the last report was published 10 years ago. Based on administrative databases, DS prevalence among Manitoba children was reported to be 1.59 per 1000 infants under the age of 1 year between 2001-2006. However, other than prevalence, we know little about the health and well-being of children with T21. Despite data availability, no study has examined the health and wellbeing of Manitoba children with T21 in Manitoba. At the national level, none of the health, or disability surveys collect health data in conjunction with a T21 diagnosis, resulting is a significant knowledge gap. For example, while trend analysis of available data show that obesity

rates among all Canadian children have nearly tripled in the last 30 years (Public Health Agency of Canada, 2019), there is currently no information available about the weight status of Canadian children with T21. As another example, the Canadian Health Survey on Children and Youth collects nutrition-related data for Canadians 1 year and older, and collects data on some (e.g., Autism, Fetal Alcohol Spectrum Disorder), but not all types of developmental disabilities (Statistics Canada, 2023).The same is true for Canadians over 18 years of age, as the Canadian Community Health Survey collects information about health and well-being including nutrition but does not include questions on types of disabilities (Government of Canada, 2022). Furthermore, the Canadian Survey on Disability that collects information about different types of disability among Canadians 15 years of age and older, contains very limited health-related questions and nothing on nutrition (Statistics Canada, 2022).

Research from other jurisdictions report that children with T21 have a higher risk of experiencing overweight or obesity compared to children without T21 (O'Shea et al., 2018; Basil et al., 2016). Obesity is a known risk factor for diabetes and cardiovascular disease across the lifespan (American Diabetes Association, n.d.; Barnes, 2011). In the UK, Aslam and colleagues (2022) reported that diabetes diagnosis was four times more common among children and young adults (5-34 years) with T21 compared to those without T21 of the same age. A higher prevalence of sarcopenia was reported among adults with T21 compared to controls (Villani et al., 2024). Sarcopenia may be characterized as age-related loss of lean muscle mass, which may be prevented through interventions that include a nutrition-related component earlier in life (Villani et al., 2024). Alzheimer's disease has also been reported to be more prevalent in people with T21 (Patel et al., 2025; Landes et al., 2020; Salehi et al., 2016) due to the extra genetic material on the 21st chromosome, which may increase the production of plaques in the brain, and

present decades earlier than in those without T21 (Fortea et al., 2021; Salehi et al., 2016). While several dietary patterns across the lifespan have been associated with a reduced risk of cognitive impairment (Bhave et al., 2024) and Alzheimer's disease in people without T21 (van den Brink et. al, 2019), this same association has not been studied in people with T21. This is unsurprising given that people with intellectual and developmental disabilities (IDD), a term that is commonly used to categorize T21, have not been historically included and accurately represented in health and nutrition research (Johnston et al., 2022).

Researchers in the UK recently reported their findings about the research landscape for three genetic syndromes, of which T21 was one, and found that less than 1% of research funding was spent on them (Cristescu et al., 2024). Furthermore, their recommendations included that more research relevant to everyday life is needed, as is ensuring that research is informed by people with lived experience. This recommendation was echoed again recently by another team of researchers based in the UK and USA, who advocated for the involvement of people with complex needs, such as those with IDD, in research and policy (Flint et al., 2025). They stress that the voices of those who are neurodiverse and obese are particularly important given that this subgroup within our population is marginalized and experiences multiple forms of stigma. Others have also reasoned that optimal nutrition is indeed essential to those who live with disability (Groce et al., 2013).

The current exclusion of people with T21 in research that is meaningful and relevant may be a reflection of ableism within the study of population health and within society at large. Ableism may be characterized as believing that people with disabilities are less valued, and able to contribute or participate in society, than others (Peters et al., 2024). The consequences of ableism are prevalent within all systems levels, as evidenced by the limited opportunities and

inclusion of people with disabilities, such as within research settings (Cristescu et al., 2024). Further, entrenched ableism in medicine and other health care disciplines, results in people with disabilities being made vulnerable, as activities that are considered typical parts of their daily living are perceived as indicators of a low quality of life by others (Janz, 2019). This type of (aversive) ableism is particularly dangerous in that it is not easily identified, as it presents as others meaning well (demonstrating low explicit/conscious disability prejudice) but possessing implicit (unconscious) disability prejudice (Janz, 2019; Friedman, 2018).

Diet, or dietary intake, refers to the foods and beverages an individual consumes whereas a dietary pattern refers to established trends of food and beverage consumption *over time*. Foods and beverages contain nutrients that the body needs for growth, development, and maintenance. The study and process of using nutrients from food and beverage consumption for growth, development and maintenance, and their role in chronic disease prevention and management, may be referred to as nutrition (World Health Organization, 2025). Individual nutrient requirements change over time and depend on life stage and other factors. For example, requirements for some nutrients are increased during periods of growth. If there is an excess or inadequate amount of nutrients made available to the body, then an individual's health may be impacted in the short- or long-term. Nutrient excess or inadequacy may reflect food and beverage consumption, nutrient metabolism in the body, or both. There are several factors that may impact the amount of nutrients made available in the body by directly or indirectly influencing food and beverage consumption and/or the way nutrients are used in the body. For example, food insecurity may reduce the access or ability to obtain adequate amounts of food to consume; medication use may change the way nutrients are used in the body.

Nutrition-related health may be assessed by considering nutrient intake and diagnosis of nutrition-related conditions and diseases. Nutrition is one factor associated with body weight management (American Diabetes Association, n.d.; Barnes, 2011), diabetes and cardiovascular disease (American Diabetes Association, n.d.; Barnes, 2011), and Alzheimer's disease (van den Brink et. al, 2019). Awareness of the factors that impact food and beverage consumption and the way nutrients are used in the body is essential to fully understanding what influences nutrition-related health at the individual level. In the context of children with T21, determining their food and beverage consumption, and assessing factors that may influence their food and beverage intake is a *first* step to understanding how to prevent the development of nutrition-related conditions and diseases throughout their lifespan (Aslam et al., 2022; O'Neill et al., 2005).

There are currently no *specific* nutrition recommendations or guidance for Canadians with T21. However, the Canadian Paediatric Society (CPS) does include DS among a list of other diagnoses, in their practice point for the nutritional evaluation of the neurologically impaired child (Casey et al., 2020). It is important to highlight the problematic nature of this categorization system as it is another example of ableist attitudes, and exemplifies how diverse diagnoses, that are characterized as intellectual and developmental disabilities by those without these diagnoses, are grouped together without recognition or acknowledgement of their unique differences. As an example, other medical diagnoses, such as diabetes and cardiovascular disease, are classified by several categories, with separate and specific recommendations for care.

The CPS recommends clinicians to 1) monitor growth, 2) monitor feeding problems, 3) customize energy requirements according to individual needs, and 4) monitor vitamin and mineral intake in children with low energy intakes and provide supplementation, as necessary

(Casey et al., 2020). Suggested tools to determine nutrition-related health include collecting diet history, conducting nutrient analysis, and evaluating nutritional biochemistry. There is no clear directive in the CPS practice point to provide a referral to professional nutrition services rather, clinicians are advised to exercise clinical judgement when determining nutrient needs, considering that only limited, and possible inaccurate, nutrition data are available. Notably, it is questionable whether clinicians are adequately trained to conduct comprehensive nutritional assessments or provide person- or family-centred nutrition counseling (Essel, 2022). Indeed, improving the nutrition education within medical curriculum, and building partnerships between physicians and dietitians to facilitate the referral process, has been previously recommended (Pojednic et al., 2023). Currently, there are no Canadian nutrition resources or clinical practice guidelines, available from Dietitians of Canada, the national association of registered dietitians and nutritionists in Canada, that are specific to T21, or any other condition that is similarly characterized as an intellectual and developmental disability. Furthermore, in a recent study designed to investigate the knowledge, attitudes, practices, and perceptions of Canadian dietitians who support people with IDD, most were interested in learning more, did not feel they had access to appropriate resources, and denied having received training to work with this population (Harriman et al., 2025).

In the US, the American Academy of Pediatrics (AAP) highlights nutrition and activity as two areas requiring ongoing and annual assessment throughout childhood in their guidelines regarding pediatric care for children with T21 to maintain appropriate weight (Bull et al., 2022). The AAP guidelines include to 1) monitor growth patterns using DS specific charts and 2) monitor any feeding problems, 3) encourage families to establish optimal dietary and physical exercise patterns to prevent obesity, then 4) emphasize healthy diet and lifestyle for preventing

obesity, and later 5) counsel for a healthy diet and activity, if needed. These general dietary and lifestyle guidelines do not differ, and are even less specific, than guidance offered for the general population in both Canada and the US (Government of Canada, 2019; U.S. Department of Agriculture and U.S. Department of Health and Human Services, 2020; Canadian Society for Exercise Physiology, 2021; U.S. Department of Health and Human Services, 2018). Furthermore, similar to the CPS practice point for the nutritional evaluation of the neurologically impaired child (Casey et al., 2020), the AAP guidelines do not appear to consider the level of nutrition education or training of the clinicians themselves to conduct a comprehensive nutritional assessment or to provide appropriate and meaningful family-centred nutrition counseling or education to parents and caregivers (Bull et al., 2022). Notably, there are no specific strategies about *what* constitutes a healthy diet, or *how* to implement diet and lifestyle changes. This may be considered problematic given that some caregivers of young children (2-6 years old) with T21 have reportedly expressed greater stress related to feeding (Brantley et al., 2023) and may appreciate further guidance.

The latest update of the AAP guidelines does include an additional recommendation to discuss dietary supplements with parents and caregivers of children with T21 (Bull et al., 2022). This recommendation was based on findings from a study that found nearly half of parents (n=1,167) of a child with DS aged less than 18 years provided dietary supplements to their child, yet almost one-fifth of these parents shared that they did not inform their child's doctor about dietary supplement usage because they were not asked (Lewanda et al., 2018). While questions about dietary supplement usage is a standard component of comprehensive nutrition assessment conducted by dietitians, the current AAP guidelines do not include a recommendation to provide a referral for professional nutrition services to parents and caregivers of a child with T21 (Bull et

al., 2022), despite advocacy efforts by the Academy of Nutrition and Dietetics, a national association representing food and nutrition professionals in the United States, for dietitians to provide these services (Ptomey & Wittenbrook, 2015; Conway et al., 2020). More recently, Ptomey and colleagues (2023) published weight management recommendations for youth with DS, based on the efforts of a group of clinicians and researchers. Notably, caregivers were provided with an opportunity to provide feedback on the clarity and feasibility of the recommendations. Impressively, there is repeated mention within these recommendations to work within a multidisciplinary team, that includes dietitians, and several resources for monitoring healthy lifestyle behaviours including specific strategies to share with families. While the strategies themselves are not unique to children with T21 and their families, and several barriers are identified that may impact the adoption of these recommendations (for example: increased reliance on parents and caregivers, increased stress among parents and caregivers, feeding difficulties), adequate screening of nutrition-related health and intervention among children with T21 is advocated to promote health. Common healthy lifestyle behaviours for children include consuming a healthy diet, being active, getting enough sleep, and reducing screen time.

Currently, there is a lack of basic knowledge regarding the nutrition-related health of Canadians with T21 and their lived experience receiving nutrition knowledge and care. There is no monitoring system to evaluate the same, nor specific clinical practice guidelines to prevent nutrition-related conditions and diseases across the lifespan in this population. The proposed research study aims to address the gap in nutrition and health literature by including parents and caregivers of school-aged (6-12years) children with T21 living in Manitoba, Canada, to determine the nutrition-related health of their child and to learn about their lived experience

receiving nutrition knowledge and care. The proposed research findings have the potential to inform meaningful and relevant future *preventative* nutrition and healthcare practice in Manitoba and throughout Canada, that positively impacts the health of Canadians with T21 and works towards their attainment of health and nutrition equity.

Study Objectives

The specific objectives of this research study are:

1) To determine the nutrient intake and factors that may influence nutrition-related health of children with T21 living in Manitoba;
2) To explore the perspectives of parents and caregivers of children with T21 about their child's nutrition-related health, and their lived experience receiving nutrition knowledge and care in Manitoba.

Research Questions Related to Objective 1:

1) What foods and beverages do school-aged children (6-12 years) with T21 living in Manitoba consume?
2) Do nutrient intakes from food of school-aged children (6-12 years) with T21 living in Manitoba meet dietary reference intakes?
3) What factors influence the nutrition-related health of school-aged children (6-12 years) with T21 living in Manitoba?

Research Questions Related to Research Objective 2

1) Do parents and caregivers of school-aged children (6-12 years) with T21 have concerns about their child's nutrition-related health?

2) Do school-aged children (6-12 years) with T21 and their parents and caregivers living in Manitoba receive nutrition knowledge and care?
3) What has been the lived experience of, and preferences for, receiving nutrition knowledge and care of parents and caregivers of school-aged children (6-12 years) with T21 living in Manitoba (if applicable)?

Research Hypotheses

Regarding the first research objective, I hypothesize that:

1) School-aged children (6-12 years) with T21 living in Manitoba will consume a *limited* variety of foods and beverages.
2) The nutrient intake of children with T21 living in Manitoba will *not* meet national dietary guidelines.
3) There will be multiple factors that influence the nutrition-related health of school-aged children (6-12 years) with T21 living in Manitoba.

Regarding the second research objective, I hypothesize that:

1) Parents and caregivers of school-aged children (6-12 years) with T21 living in Manitoba will have concerns related to their child's nutrition-related health.
2) School-aged (6-12 years) children with T21 and their parents and caregivers living in Manitoba do *not* currently receive nutrition knowledge and care.
3) Parents and caregivers of school-aged children (6-12 years) with T21 living in Manitoba will have preferences regarding the way they and their child receive nutrition knowledge and care.

Chapter 2

Literature Review

This chapter is organized into several sub-sections: 1) Epidemiology of T21, 2) Nutrition-related health of children with T21, 3) Factors influencing nutrition-related health of children with T21, 4) Existing knowledge gaps, and 7) Conceptual frameworks used in this research study.

Epidemiology of Trisomy 21

In 1866, Dr. J. Langdon H. Down was the first to classify what is commonly known as Down syndrome today (Down, 1866). Advanced maternal age is considered the most significant risk factor associated with DS; a lifelong condition that may impact morbidity and mortality and may cause intellectual disability (Public Health Agency of Canada, 2017), ranging from mild to severe (Bull, 2020). Advancements in prenatal screening have led to early detection of DS in Canada (Public Health Agency of Canada, 2017). Notably, researchers have observed an association between the introduction of prenatal screening and increased population-level reduction rates of DS worldwide (de Graaf et al., 2021; de Graaf et al., 2015). For example, de Graaf and colleagues estimate a population reduction rate of 27% due to DS-related elective terminations in Europe (2021) and a reduction rate of 30% in the United States (2015). Recently, the same researchers published population level estimates in Canada, estimating 54% fewer children with DS in Canada due to DS-related elective terminations (de Graaf et al., 2025).

Postnatally, primary care providers may suspect a diagnosis of DS based on the infant's appearance and decreased muscle tone; their suspicions may be confirmed by conducting a genetic test to look at the complete set of chromosomes (Bull, 2020). Identification and management of health risks decrease morbidity and improve quality of life among those

diagnosed with DS (Public Health Agency of Canada, 2017) although, unequal access to health care and services exist (Bull, 2020). The current estimated life expectancy for someone with T21 living in Canada is approximately 60 years old, reflecting a 25-year increase since the 1980s due to improved medical care (Weijerman & de Winter, 2010). However, there is limited knowledge of nutrition-related health status of children with T21 globally, and in Canada. The following section provides a summary of what is known about nutrition-related health of children with T21.

Nutrition-Related Health of Children with T21

The nutrition-related health of Canadian children with T21 has not been determined, nor has their access to nutrition knowledge and care. Nutrition-related health may be assessed by considering nutrient intake and diagnosis of nutrition-related conditions and diseases and may be measured by evaluating food and beverage consumption and considering factors known to impact nutrition-related health such as medical history, food insecurity, or food preferences and aversions. Limited published data from the international research community has produced inconsistent findings on the nutrient intake and weight classification of children with T21 (Kahraman et al., 2024; Bialek-Dratwa et al., 2023; Roccatello et al., 2021; Oulmane et al., 2021; Lewanda et al., 2018; Magenis, et al., 2018; O'Shea et al., 2018; Samarkandy et al., 2012; Basil et al., 2016; AbdAllah, A.M. et al., 2013; Grammatikopoulou et al., 2009; Luke et al., 1996), and are summarized in this section, as are findings related to physical activity and child feeding practices. However, no international data were discovered related to lived experience accessing nutrition knowledge and care.

Classification of Body Weight and Composition

Using self-reported data, a research study conducted in Turkey found that among 90 children with T21 living in Istanbul, between the ages of 9-13 years old, 26.6% were overweight and 44.4% were obese (Kahraman et al., 2024). In a retrospective cohort study, Basil and colleagues (2016) obtained data on body mass index (BMI) for 303 children and youth aged 12-18 years with T21 based on their electronic medical records from a local hospital in the US and compared prevalence of overweight and obesity between this group of children and children without DS as the control group. They found that the prevalence of overweight and obesity was significantly higher among children with T21 compared to those in the control group [(Overweight: 22.4% vs 15.1%); (Obesity: 47.8% vs 12.1%)]. Similarly, among 34 children with DS between the ages of 6 and 18 years, and their siblings without DS (n=23), living with their parents in Turkey, Kaya and colleagues (2024) observed significantly higher prevalence of both overweight and obesity among those with DS (35% versus 13%).

In 2018, O'Shea and colleagues conducted a study to determine the prevalence of overweight and obesity among 61 children and youth between the ages of 4 and 16 years with T21 living in Ireland by calculating BMI and measuring percentage body fat using bio-electrical impendence analysis (BIA). Study participants were recruited through a national T21 organization and physical activity centre. According to BMI calculations, the prevalence of overweight among male and female study participants with T21 was 35.5% and 30%, respectively. The prevalence of obesity among male and female study participants with T21 was 16.1% and 10%, respectively. Perhaps unsurprising, O'Shea and colleagues (2018) found lower levels of overweight and obesity when BIA was used to measure adiposity compared to BMI. BMI is well-known as an imperfect and insensitive measure of body composition; however, it is

commonly used in epidemiological studies to track changes over time. According to percentage body fat measurements, the prevalence of overweight among male and female study participants with T21 was 20% and 11%, respectively, and the prevalence of obesity among male and female study participants with T21 was 12% and 3.7%, respectively (O'Shea et al., 2018). The findings by O'Shea and colleagues support expert opinion to employ more than one approach, when feasible, to accurately measure and assess body weight and composition. Bialek-Dratwa and colleagues (2023) also reported lower prevalence rates of overweight and obesity among their study population of 195 people with T21 between infancy to 30 years old living in Poland although, their assessment of body weight status was calculated by BMI, and their study did not include a control group. Among their study population of 211 people, they report 15.3% (n=30) and 5.6% (n=11) were overweight and obese, respectively (Bialek-Dratwa et al., 2023).

In contrast, while AbdAllah et al. (2013) observed a higher prevalence of overweight and obesity (53%) in 30 children with T21 between the ages of 6-18 years living in Saudi Arabia, compared to 30 age-matched control (43.3%). However, the observed difference was not statistically significant. Children with T21 included in this study were recruited from the Help Center in Jeddah; the control group were students from a local primary school, and relatives from clinical nutrition department students in king Abdul-Aziz university. On their website, the Help Center in Jeddah is described as a non-profit organization that operates as an institution currently serving over 350 children with intellectual disabilities, whose needs were not being met in hospital or regular school settings, by using specialized programs and activities (2022). Whether children enrolled at this institution are representative of children with T21 living in the community and attending community schools is unknown. In 2012, Samarkandy and colleagues measured body weights, to calculate BMI, and triceps skinfold thickness, a measure of

subcutaneous fat, among 108 children with DS living in Saudi Arabia between the ages of 5 and 12 years old and their siblings (n=113) closest in age. They observed significantly greater excess subcutaneous fat (9.3% versus 2.7%) among the children with DS and greater prevalence of overweight and obesity (43.5% versus 12.4%) compared to their siblings. In their study, Samarkandy and colleagues recruited study participants from 2 schools reportedly for students with DS in Saudi Arabia and notably, who lived with their families in a home environment. Given the discrepancy between the findings of these researchers studying body weight status and composition of children with DS living in Saudi Arabia, it may be reasonable to suggest there are differences in an institutional-like setting compared to a home-like setting that may influence nutrition-related health.

Previously in 1996, Luke et al. (1996) designed a study to examine body composition in children with T21 between the ages of 5-11 years living in the US. They included 10 children with T21 in their study recruited from local hospitals and a DS advocacy organization, and 10 children without T21 as a control group recruited from a local hospital. Luke et al. (1996) measured body composition in three different ways: deuterium dilution, BIA, and four-site skinfold thickness measurements, and did not observe a significant difference in body composition between the two study groups. However, a larger sample size may have been needed to detect differences between groups.

Grammatikopoulou et al. (2009) also performed multiple measurements of body composition (skinfold measurements and waist and hip circumference) in their cross-sectional study of 34 children with T21 between the ages of 2 and 18 years living with their families in Greece. Children in the study group were recruited through schools that provided education to children living with disability. According to growth charts for children with T21, the prevalence

of normal weight, overweight, and obesity were estimated at 67.7%, 20.6%, and 11.8%, respectively, among all study participants (Grammatikopoulou et al., 2009). Significant differences between younger and older children were observed. For example, according to growth charts for children with T21, the prevalence of normal weight among younger children (2-9 years) and adolescents (10-18 years) was 90.9% and 56.5%, respectively. Furthermore, according to growth charts for the children in the general child population, the prevalence of normal weight, overweight, and obesity among all the study population were estimated at 23.5%, 52.9%, and 14.7%, respectively (Grammatikopoulou et al., 2009). Again, significant differences between younger and older children were observed. For example, according to growth charts for the children in the general population, the prevalence of overweight among younger children (2-9 years) and adolescents (10-18 years) was 36.4% and 60.9%, respectively (Grammatikopoulou et al., 2009). The differences observed in the prevalence of normal weight and overweight/obesity between younger and older children may reflect changes to food selection and independent decision-making about food consumption as children age (Grammatikopoulou et al., 2009). It is possible that as children get older, their parents and caregivers have less influence and control over their child's food and beverage choices whereas, media, marketing and peers may exert a greater influence (Potvin Kent et al., 2024; Prowse, 2017; Salvy et al., 2011). Oulmane and colleagues (2021) also report age-related differences in the prevalence of overweight and obesity among children with DS living in Morocco. They report *the same* prevalence of overweight and obesity, based on BMI, among children with DS between the ages of 2 and 10 years old, but differences in prevalence among older ages.

In sum, despite the absence of literature published about the body weight status of Canadians with T21, there are some estimates based on studies conducted elsewhere. The

reported estimates are summarized in Table 1. In studies that measured body weight status based on BMI and included a control group, children with T21 had greater prevalence of overweight and obesity compared to those without T21 (O'Shea et al., 2018; Basil et al., 2016; AbdAllah et al., 2013). Notably, in most studies reporting prevalence of overweight and obesity based on BMI among children with T21 (Kahraman et al., 2024; O'Shea et al., 2018; Basil et al., 2016; AbdAllah et al., 2013; Grammatikopoulou et al., 2009) prevalence rates were greater than those reported among Canadian children between the ages of 5-17 years old without T21 (Rao et al., 2016). An exception was observed in Poland, where prevalence rates of overweight and obesity among 195 people with T21 under the age of 30 years old that were *less than* prevalence rates of overweight and obesity among Canadian children aged 6-17 years old without T21 (Rao et al., 2016).

Table 1

Prevalence of obesity and overweight in children with DS

Authors	Country	Children with DS				Children without DS			
		n	Age	% over weight	% obese	n	Age	% over weight	% obese
Kahraman et al., 2024	Turkey	90	9-13 years	26.6	44.4	-	-	-	-
Bialek-Dratwa et al., 2023	Poland	195	0-30 years	15.3	5.6	-	-	-	-
O'Shea et al., 2018	Ireland	61	4-16 years	35.5 (male) 30 (female)	16.1 (male) 10 (female)	-	-	-	-
Rao et al., 2016	Canada	-	-	-	-	*	6-17 years	18.3	13.1
Basil et al., 2016	United States	303	2-18 years	22.4	47.8	1020	3-18 years	15.1	12.1
AbdAllah et al., 2013	Saudi Arabia	30	6-18 years	53	53	30	6-18 years	43.3	43.3
Grammati-kopoulou et al., 2009	Greece	24	2-18 years	52.9	14.7	-	-	-	-

*Based on data from the Canadian Community Health Survey 2024 and Canadian Health Measures Survey 2007/09, 2009/11, and 2012/13.

Finally, Andrew and colleagues (2023) examined correlates of children's nutritional status based on data for 30 children with an average age 9 years old with T21 living in Indonesia. They used a nutritional assessment tool from Indonesia's Ministry of Health based on four categories of body weight. They found a significant positive correlation between children's nutritional status and energy intake; and a significant negative correlation between children's nutritional status and paternal education, and children's diet quality, which was measured using the Diet Quality Index International tool. Given that nutritional status was determined solely

based on body weight, it is unsurprising that energy intake and diet quality were positively and negatively correlated with nutritional status, respectively. While it may be likely that children with higher body weight may consume more total energy from food, children with higher body weight are not necessarily likely to consume higher quality diets (nutrient-rich food and beverages) from which the total energy from food is derived.

Nutrient Intake

International research studies that have examined nutrient composition of diets of children with T21 yielded mixed findings. For example, a recent review summarized food intake among persons with T21 (Gruszka & Wlodarek, 2024). Findings from this review suggest low intake of fruits, vegetables, whole grains and dairy products, and excessive intakes of meat products and sugar-containing foods and beverages among children and adults with T21.

AbdAllah and colleagues (2013) collected daily food and beverage consumption using 24-hour dietary recalls from 30 children with T21 (14 males and 16 females) between the ages of 6-18 years living in Saudi Arabia to assess their nutrient intake. While it was specified that parents provided consent for their child to participate in this study, it was not reported who completed the 24-hour dietary recalls. Energy and nutrient content were analyzed using the Arabiam Program for Food Analysis and compared to the Recommended Dietary Allowance (RDA). Researchers reported a significantly higher daily energy, macronutrient (fat, protein, carbohydrate), and fibre intake in children and youth with T21 compared to the control group. Both groups were reported to consume less than the RDA for fibre and micronutrients (AbdAllah et al., 2013).

Kaya and colleagues report adequate intakes of protein, fat, and vitamin D among 34 children with DS living in Turkey, and no significant differences between their intake of these

nutrients and their sibling's intake of the same nutrients. Conversely, energy, carbohydrate, fibre, calcium, and iron intakes were less DRI recommendations among children with DS, and only significantly different than their siblings for calcium and iron (Kaya et al., 2024). Notably, the intakes of calcium and iron were significantly *higher* among children with DS compared to their siblings. Finally, intakes of sodium were in excessive of DRI recommendations among children with DS and not significantly different than their sibling's intake of the same mineral.

Luke et al. (1996) also reported inadequate intake of several micronutrients and dietary fibre among both children with T21 (n=10), and the controls (n=10) living in the US . However, Luke and colleagues reported no significant differences between the two study groups in terms of the average daily energy and macronutrient intakes, calculated based on 3-day diet records completed by parents. Diet records in this study were analyzed using the Food Processor II program and compared to the RDA.

Roccatello and colleagues (2021) reported mixed findings regarding nutrient intake of children with T21 living in Italy (n=29). For example, they found caloric intake surpassed recommendations among preschool children, but met recommendations among younger children, and were below the recommended levels for adolescents. Furthermore, they noted that excess intakes of protein and saturated fat consumed by children with T21 also reflected protein and saturated fat intakes of children without T21 living in Italy. Their findings are based on data collected on food and beverage consumption using a 3-day food record completed by parents and then compared to Italian population-level recommendations.

Grammatikopoulou et al. (2009) also collected 3-day dietary records completed by parents, analyzed intake using Food Processor 7.40 for Windows, and compared output to the RDA. They reported several differences in food and beverage consumption between younger and

older children with T21 such as higher daily energy and macronutrient intake in the latter group. The percentages of energy from protein, carbohydrate and fat were within Acceptable Macronutrient Distribution Range (AMDR) for all study participants. Interestingly, younger children met the RDA for more micronutrients than older children, which may reflect a more nutrient-dense dietary pattern in the former group.

In a cross-sectional study, Magenis and colleagues (2016) assessed food and beverage consumption of a convenience sample of 19 children with T21 between the ages of 5-18 years who attend the Association of Parents and Friends of the Exceptional in Brazil. They compared the intake of the study group with DS with the intake for a control group (n = 19 children without T21) recruited from a school in the community. Researchers collected dietary intake using a 3-day food record completed by parents, analyzed by NutriBase software, and compared to the Dietary Reference Intake (DRI). Despite several micronutrient deficiencies in both study groups, Magenis and colleagues (2016) observed greater micronutrient adequacy among children with T21 compared to controls. They also reported significantly higher energy, protein, and carbohydrate intake among children with T21 compared to the control group. Finally, following current trends in the general population, inadequate fibre intake and excessive sodium intake were observed for all study participants (Magenis et al., 2016). In contrast, Kahraman and colleagues (2024) reported more *insufficient* energy intake (51.2%), compared to *excessive* energy intake (5.6%), among 90 children aged 9-13 years old with T21 living in Istanbul, based on 3-day food records. There was no control group included in this study.

Finally, in their study that included 195 children with T21 living in Poland between 0-30 years of age, Bialek-Dratwa and colleagues (2023) invited parents to complete a survey questionnaire to assess the dietary habits of their children based on the frequency of consumption

of specific food groups. Bialek-Dratwa and colleagues (2023) found that: 1) vegetables were consumed mostly once a day by approximately 42.6% of their study population, and several times a day by 31.8%. Likewise, fruit consumption was reported mostly once a day by 44.6% of their study population, and several times a day by 37.4% of their study population. Dairy products were consumed everyday by 36.9% of the study population and meat was consumed several times a week by 54.9% of the study population. About one third of the study population (31.3%) consumed meat once a day, and 10.3%consumed meat several times a day. While serving sizes and nutrient intakes were not determined in this study, the frequency of consumption of specific food groups reported indicates that these children may not be obtaining adequate amounts of nutrient-rich foods from these food groups.

There are multiple factors that may impact the quantity of foods and beverages that a child typically consumes as well as how nutrients are metabolized in the body. It is not clearly understood if or how significantly a diagnosis of T21 impacts food and beverage consumption or nutrient metabolism. Interestingly, Ross and colleagues have studied the influence of food sensory properties on preferred foods consumed by children with T21 (2019; 2022; 2024) and report specific textures that are desirable in snack foods: crispy, dissolvable, and savoury. Offering nutrient-rich foods that possess these food sensory properties may be an important strategy to improve nutrient intake from food consumption among children with T21.

Limitations to the aforementioned studies are several and include the following: 1) there are not many studies overall and some may be outdated, 2) sample sizes tend to be small, 3) different food and beverage consumption data collection and analytical methods are employed, 4) different recruitment strategies and sample sources were used, and 5) there appear to be no inclusive longitudinal nutrition research studies of children with T21.

Dietary Supplement Usage

As already reported in this proposal, the most recent AAP guidelines for clinicians supervising the health of children and adolescents with T21 include a recommendation to discuss dietary supplementation with parents and caregivers (Bull et al., 2022). This recommendation is based on the study conducted by Lewanda and colleagues in 2018 that aimed to determine characteristics of dietary supplement use among children with T21 and their parents and caregivers. They created an anonymous survey, and made it available on a tablet in a health clinic in the United States and online by sharing links on multiple national advocacy websites for parents to complete (Lewanda et al., 2018). In total, 1,167 parents and caregivers completed the survey, with many of the respondents from the US, but there were some who lived elsewhere. Lewanda and colleagues (2018) report that 37.9% of survey respondents shared that they currently provide dietary supplements to their child with DS, and that 11.6% had done so in the past. While a variety of dietary supplements were reported, the average number provided to children was 3, and the most popular types were antioxidants (Lewanda et al., 2018). The majority of survey respondents who reported providing dietary supplements at any time to their child with DS reported doing so by the time the child was 4 years old.

Of the parents who reported currently providing their child with DS a dietary supplement, the majority believed they observed improvement in the areas of speech, immune function, attention, and cognitive ability (Lewanda et al. 2018). However, lack of observed improvement by parents and cost of supplementation, which reportedly averaged between $15 and $400 a month, were cited as the most common reasons for discontinuing dietary supplementation. Sources of information for dietary supplement use were usually not credible nor was information about supplement use shared with the pediatrician by 19% of those who reported providing a

dietary supplement to their child with DS (Lewanda et al., 2018). Of those parents who did not share information about dietary supplement usage with pediatricians, 32.6% reported that they were not asked, and 25% reported that they anticipated disapproval from their child's pediatrician. Data about the characteristics of dietary supplement use among potential siblings without T21 by the same survey respondents were not collected in this study.

Factors Influencing Nutrition-Related Health of Children With T21

There are several known factors that may influence nutrition-related health. In published research studies that have included children with T21, child-feeding practices (of the parent) and physical activity (of the child) have been most commonly measured.

Child-Feeding Practices

A closer look at parent and caregiver child-feeding practices among children with T21 and their siblings was conducted in a cross-sectional study designed to assess the relationship of child-feeding practices with weight status by O'Neill and colleagues. (2005). A total of 36 families with one child with DS and one child without DS, between the ages of 3 and 10 years of age, were recruited through physicians and local advocacy organizations in Philadelphia, US. Parents, mostly mothers, completed the previously validated Child Feeding Questionnaire (CFQ) that measures aspects of a parent's use of controlling feeding practices. Anthropometric data were also collected to calculate BMI. After adjustment for demographic variables (age, sex, physical activity, race, ethnicity, income, and maternal education), there was a significant difference for feelings of responsibility for feeding and concern about weight status by parents for children with DS compared to their siblings (O'Neill et al., 2005). Children with DS included in this study also had significantly higher BMI compared to their siblings after accounting for differences in their age and sex. After adjusting for demographic factors listed above, there was a

significant positive association between the parent's concern about their child's weight status and the child's BMI among all children included in this study (n=72), suggesting a potential area of further exploration for obesity prevention.

In their review about obesity prevention in children with T21 via diet and physical activity intervention, Pelleri and colleagues (2024) concluded that parents' education is necessary to improve the nutrition-related health of children with T21. Likewise, based on the findings from their scoping review about early eating experience among children with DS, Hielscher and colleagues (2023) report greater parental caution and control regarding feeding practices, and concern about their child's weight. They also suggested providing assistance and support to parents during early feeding experiences to facilitate skill development and improve eating ability among children with DS.

Physical Activity

Recommendations for physical activity among children with T21 are not different than those for children without T21 (Ptomey et al., 2023). Canadian physical activity guidelines, developed by the Canadian Society for Exercise Physiology, recommend that children aged 5-17 years old engage in at least 60 minutes of moderate to vigorous physical activity per day (Canadian Society for Exercise Physiology, 2021). In a sample of 29 children with T21 between 2-16 years of age living in Italy, researchers determined that the majority (79%) spent a minimum of 2 hours per week practicing a sport outside of their school environment, and that average daily screen time was less than 1 hour (Roccatello et al., 2021). Conversely, results from The National Survey of Children's Health In the United States indicated that children with T21 were less likely to engage in physical activity and had increased screen time compared to children without T21 (Diaz, 2020).

Researchers in Japan (Yamanaka et al., 2020) found nearly half of the children with T21 aged 7-12 years (n=93) engaged in 60 minutes of moderate to vigorous physical activity per day, although there were some differences between weekdays and weekend days and age ranges. Finally, based on the findings from their review of interventions implemented to improve body composition among people with T21, Martinez-Espinosa and colleagues (2020) recommend prescribing structured physical exercise. Notably, as with dietary habits, developing physical activity habits earlier in life may increase the likelihood that they are maintained throughout the lifespan and therefore, physical activity may be an important modifiable factor to improve nutrition-related health among children with T21.

Existing Knowledge Gaps

Despite its importance to health, and their increased risk of developing nutrition-related conditions and diseases across the lifespan, nutrition, and children with T21, respectively, are not extensively studied. Current evidence reveals mixed data about the nutrient intake, body weight status, and factors influencing nutrition-related health among children with T21 living elsewhere. There is limited data about the body composition (versus body mass index) of children with T21 and no data regarding their lived experience receiving nutrition knowledge and care. Currently, there is no baseline data published within a Canadian context.

Conceptual Frameworks

Two main conceptual frameworks or perspectives were considered in this study and are briefly described in this section: 1) the sociological model of health, and 2) patient engagement in research.

Sociological Model of Health

In this study, consideration of the sociological model of health is essential to gaining an accurate understanding of the nutrition-related health of children with T21, as it is well-established that several socioeconomic factors affect diet quality and food choices at the individual level (Jiao, 2024). While individual level factors such as food preferences and aversions, energy needs, medical history, and ability to feed oneself, may influence the quantity or type of food a child consumes, there are several other external factors that may influence the foods and beverages a parent or caregiver chooses to purchase and serve to their child. Data about social determinants of health collected in this study included parent and caregiver values and beliefs about nutrition, household income, geographic location, ethnicity, and newcomer status. Consideration of these data will help to identify potential external factors that may influence the foods and beverages consumed by children with T21 living in Manitoba, and better understand their nutrition-related health.

Patient Engagement in Research

The Canadian Institutes of Health Research (CIHR) characterizes patient engagement in research as the meaningful involvement and active collaboration of individuals with personal lived experience of a particular research interest, in a variety of roles across the research continuum (CIHR, 2019). Within this context, the term ‘patients’ refers to individuals with personal lived experience of a particular research interest, and they are considered *research*

partners or *patient engagement researchers.* By becoming more active in the research process as patient engagement researchers, those with personal lived experience of a particular research interest establish themselves as more powerful agents and challenge the typical system of knowledge control (Baum et al., 2006; Kousholt & Juhl, 2021). Furthermore, Muhammad and colleagues (2015) emphasize the need to equalize power distribution by identifying and addressing the inherent unequal power relations that typically exist between researchers and their research partners. They offer that this reflexive relationship means being aware of how one's identity/ies and power may influence who is being researched (within a specific community), who is making the decisions, and whose voice is heard when research findings are disseminated. They also suggest that researchers who share similar identity background with those that are researched on may be considered *insiders* and able to gain insight and access that is otherwise unavailable to others.

The overall goal of patient engagement in research is to focus on priorities that are important to patients, and to produce meaningful findings that are *actually used* to inform policies and improve healthcare practices thereby, improving their relevance and impact on individual health (CIHR, 2019). Guiding principles proposed by CIHR to accomplish this goal include: 1) inclusiveness (diverse patient perspectives are represented in the research), 2) support (patient engagement researchers are adequately and appropriately supported to contribute to the research process, 3) mutual respect (all involved in the research respect each other's expertise and experiential knowledge), and 4) co-build (all involved work cooperatively together throughout the research process).

Patient engagement in research promotes the inclusion, collaboration, and respect of diverse voices and communities (Aldridge, 2015), which is evocative of recommendations to

consider and incorporate the constructs of inclusion, diversity, equity, and access in health research and practice (Baranowski et al., 2024; Government of Canada, 2022). Before beginning my research project, and throughout the research continuum, I met with patient engagement researchers, as research partners, in a consultative nature to plan and design some aspects of my project. My goal was to learn from their collective lived experiences parenting and caregiving a child with T21, particularly in relation to their child's nutrition-related health. I aimed to build trust with this community of parents and caregivers, and to ensure that my research project, and its findings, would be meaningful to them. I used feedback received from parent and caregiver research partners to make decisions about several aspects of my research project including finalizing study objectives and research questions, creating a survey instrument, planning recruitment and knowledge translation strategies, and reviewing preliminary findings and data interpretation.

Patient Engagement Activities

Three patient engagement activities were conducted with parents and caregivers of children with T21, *also referred to as parent engagement researchers or parent engagement research partners*, and are described in detail in Appendix A. Briefly, the objective of the first patient engagement activity was to build relationships with parents and caregivers of children with T21 living in Manitoba, and to discuss nutrition-related topics important to them. The objective of the second patient engagement activity was to request feedback from parent and caregivers of children with T21 living in Manitoba about different food and beverage consumption data collection tools, and to brainstorm recruitment strategies. The objective of the third patient engagement activity was to request study participants to review preliminary findings and data interpretation, and to share their ideas for knowledge dissemination.

The first patient engagement activity informed the research plan by creating a comprehensive list of potential nutrition-related factors that may impact the nutrition-related health of children with T21, which were included in the survey instrument data collection tool. The second patient engagement activity informed the research plan by guiding the selection of the proposed data collection tools and format, and expanding the scope of the recruitment strategy. The third and final patient engagement activity occurred after data analysis was complete. Notably, study participants were invited to participate in this online activity, as their feedback regarding data interpretation was requested. In addition, parents were asked to share their ideas to disseminate the study findings widely. Their feedback was used to guide the planning of knowledge translation and mobilization and, to meaningfully enhance the interpretation and discussion of several study findings.

Ethical Considerations in Research Concerning Pediatric Populations

Parents and caregivers of school-aged (6-12 years) children with T21 who consented to participate in the research study as either parent engagement researchers or as study participants were asked to participate on behalf of their child. *In their role as a parent engagement researcher,* parents and caregivers were asked to: 1) share their perspective about what they consider to be most important nutrition-related research topics and considerations related to their child's health, 2) offer suggestions about how to recruit a diverse and large sample that is representative of the Manitoba population, 3) provide feedback about different food and beverage consumption assessment tools to use for quantitative data collection, 4) review data interpretation to ensure its accuracy of their lived experience, and 5) share ideas about how to disseminate findings widely to diverse knowledge users using a variety of knowledge translation

tools. *In their role as a study participant,* parents and caregivers were asked to: 1) share information about their child's food and beverage consumption and other factors that influence their child's nutrition-related health and, 2) share their lived experience receiving nutrition knowledge and care and other nutrition knowledge translation tools, which may be considered a shared experience with their child. Due to the young age (6-12 years) of children with T21 represented in this research study, and the variable degree of ability among children with T21, the personal information and shared lived experiences provided by parents and caregivers, as either parent engagement researchers *or* study participants, may occur without their child's permission or awareness.

As there is no current clear standardized process for parents and caregivers of children with T21 to follow as they participate in research as parent engagement researchers or study participants on behalf of their child, Flinders' (1992) framework of *ethical literacy* was considered as a guide in the research study. Briefly, Flinders (1992) recommends that researchers adopt a broader ethical paradigm that includes deontological, relational, and ecological perspectives, in addition to the more common utilitarian ethical framework (which seeks to appraise moral reasoning based on positive and negative consequences), to protect human subjects in research.

Deontological ethics consider whether research procedures follow ethical standards such as honesty and justice (Flinders, 1992). This perspective ensures that parents representing their child in research maintain their children's rights, privacy, and safety. Relational ethical goals prioritize having a caring attitude towards others that is, an ethic of caring. As family and friends are the most common models for a caring relationship, this perspective may be relevant when parents and caregivers act as parent engagement researchers or study participants on their child's

behalf, as they may be the most likely to embody a caring attitude towards the research subject of interest that is, their child. Relational ethics proposes that researchers should perceive their work as *collaborative* and be engaged in dialogue with those they research. For example, when parents and caregivers are acting as parent engagement researchers on behalf of their child, they have an obligation to ensure that there is open communication with the child and that their adult interests or perspectives do not overshadow those of the child. Finally, ecological ethics emphasize the interdependent nature of relationships and recognizes that an individual (child, parent, researcher) is part of a larger system. Understanding the overlapping systems of influence on individuals and their relationships with others is critical to understanding their lived experiences (Bronfenbrenner, 1976; 1986).

Together, this ethical guidance may be used to inform parenting and research practice with pediatric populations (regardless of disability status) that is, an obligation to: 1) avoid wrong, 2) demonstrate a caring attitude toward the child, 3) acknowledge their unique circumstances, and 4) work in good faith and collaboratively with them. This ethical framework was used to guide decisions throughout the research continuum for this research project in several ways including: 1) only data that specifically addresses the goals of the research study was collected from study participants, 2) non-invasive data collection tools were used and, 3) all data were kept confidential and analyzed at the aggregate level so that individual privacy was maintained.

Chapter 3

Methods

Study Design

A cross-sectional mixed methods research study was conducted using an exploratory descriptive approach following a concurrent triangulation design, also known as a convergent parallel approach (Edmonds & Kennedy, 2017). Both quantitative and qualitative data were collected independently at the same time and analyzed separately. Afterwards, the different but complementary data were compared and related in the interpretation stage.

Study Setting

The study was conducted in the prairie province of Manitoba, Canada. Approximately, 1.3 million people live in Manitoba and just over 250, 000 are children between the ages of 0 and 14 years old (Statistics Canada, 2021). The median age of the population is 38 years old. Approximately 36% of Manitobans between the ages of 35 and 64 years old reside in a rural setting and approximately 38% reside in an urban setting (Statistics Canada, 2021). English is the first official language spoken for approximately 1.2 million Manitobans (Statistics Canada, 2021). Approximately, 18.5% Manitobans self-identify as Indigenous, 90% are Canadian citizens, and 20% are immigrants (mostly from Asia). The Manitoba population is culturally diverse.

Study Population

The study population in this research study consisted of school-aged children with T21 between the ages of 6 and 12 years old, with or without any sibling, living in Manitoba. Their parents or caregivers consented to be study participants in the research study and to share

information on behalf of their child. A total of 14 children and 14 parents or caregivers were included in this study.

Recruitment

Recruitment was planned to attain a convenience sample of a maximum of 20 study participants, who were parents and caregivers of children with T21. The children with T21 are referred to as the study population and their parents or caregivers are referred to as the study participants. Given the novelty of determining baseline data about the nutrition-related health of Canadians with T21 and, considering the feasibility to complete a mixed methods research study within the timeline of a doctoral degree, a maximum sample size of 20 was proposed and approved by the advisory committee before beginning data collection. Furthermore, a sample size between 9 and 17 interviews in qualitative research has been determined adequate to reach saturation (Hennick & Kaiser, 2022). Due to the exploratory descriptive nature of this research study design, no exclusion criteria was applied to the sample in an effort to recruit a diverse study sample. Recruitment strategies were informed by parent engagement research partners, as described in detail in Appendix A.

In September 2024, an email was sent to request assistance with recruitment to multiple local and provincial advocacy organizations including: Inclusion Winnipeg (IW), Manitoba Down Syndrome Society (MDSS), StAmant, Specialized Services Children and Youth (SSCY), Family Advocacy Network (FAN) of Manitoba, Excellence in Neurodevelopment and Rehabilitation Research in Child Health (ENRRICH), three provincial government departments (Education, Health, and Families), social assistance programs (Immigrant Centre Manitoba (ICM), Winnipeg Introduction for Newcomers (WIN), Manitoba Association of Newcomer Serving Organizations (MANSO), Supporting Employment & Economic Development (SEED)

Winnipeg, and Special Olympics (SO). The emailed request was to share an invitation to participate in the research study, along with a one-page summary, with each organization's respective networks. Email recipients who did not respond to the first email request received a follow-up email request 2 weeks after the first email request was sent. All email recipients responded to the email request except for ICM, WIN, and SO. The provincial Education and Health government departments and SEED declined the request to share information about the research study for the purposes of recruitment.

The Department of Education recommended requesting assistance from individual school divisions. Based on this recommendation, an email request was sent to 6 randomly selected school divisions throughout Manitoba: Louis Riel (Winnipeg), Mountainview (Parkland), Frontier (Northern), Southwest Horizon (Parkland), Prairie Rose (Central), and Sunrise (Southeast/Interlake). Three of the six school divisions (Frontier, Louis Riel, and Southwest Horizon) responded to the email request, and agreed to review the one-page summary of the research project and consider the request. Louis Riel school division also requested completion of a brief online research form. St.Amant and SSCY requested completion of their respective organizations' research access/ethics application packages. These additional research access/ethics application packages were both completed and submitted before the end of September 2024. Ethics approval was granted from SSCY on October 03, 2024, and from St.Amant on November 22, 2024. Active recruitment of study participants began immediately after approval was granted from these organizations, at the end of November 2024.

All organizations who agreed to facilitate recruitment received a one-page electronic research summary for their use to share with their networks, which included email and phone contact information of the principal investigator. St.Amant created two social media posts and

requested permission to use in conjunction with the one-page research summary on December 11, 2024. An amendment to include these two social media posts as part of the recruitment strategy from St.Amant was submitted to the Research Ethics Board on December 12, 2024.

Positionality

Before beginning data collection, I shared my positionality as the researcher and interviewer, a woman, a parent of three children (including one with T21), a rural Manitoba resident, a parent advocate for inclusion, a dietitian, and a graduate student, with all study participants before beginning data collection in an attempt to establish feelings of mutual trust and comfort. Acknowledgement that all individuals have multiple identities, and considering the intersection of those identities, aligns with the framework of intersectionality. This approach may be considered good practice in helping researchers better understand themselves and those they aim to learn more about. It was important to acknowledge the potential barrier I presented in my role as a researcher and registered dietitian seeking information from parents and caregivers about the foods and beverages they provided to their child. It was equally important to acknowledge the potential benefit I gained from being an insider researcher, in the disclosure of my role as a mother to a child with T21. Notably, welcoming and respecting lived experiences of parenting a child with T21 that were different than my own, and remaining nonjudgmental about information shared about child and family food and beverage consumption, were essential components to facilitating an open conversation throughout the data collection process.

As an insider researcher who shared some lived experiences with my study population, disclosure of my identities, and demonstrable sincere interest in the identities of my study participants, was intended to build a trusting relationship and create a comfortable space for study participants to share their experiences so that I may better understand them. For example,

shared membership in non-profit organizations, shared experiences mothering children, shared experiences advocating for inclusive education, and shared experiences based on geographic location of residency, were examples of discussion topics that facilitated feelings of connectedness between me (as the researcher) and the study participants. Indeed, the preamble before data collection tended to centre around issues related to common life events rooted in our shared human experiences rather than about the research study, nutrition, or T21.

I endeavoured to become aware of my biases through personal reflection and self-awareness throughout the entire research process. Initially, engaging in patient engagement initiatives with parents and caregivers as research partners on a consultative basis was a first step in acknowledging my limited understanding about diverse lived experiences parenting a child with T21 and also, my limited training and understanding about nutrition-related health for these children. Furthermore, my training as a registered dietitian, or my own experience as a mother to a child with T21 living in a rural community in Manitoba, may have influenced the way in which I received information shared with me about topics related to T21, nutrition, healthcare services, and parenting. So then, as part of my own personal reflection, I wrote a reflexive memo to facilitate awareness and identification of my personal biases after each data collection meeting with parent and caregiver study participants. As they were an exercise in personal reflection, the reflexive memos were kept confidential and stored securely and will not be published.

Finally, personal reflection occurred throughout the research continuum continuously as I planned to collect, analyze, interpret, discuss, and share data. In particular, the lens through which I viewed the data as a dietitian, a mother, a researcher, a rural Manitoba resident, and a parent advocate, created different feelings regarding what the findings reflected about the nutrition-related health of children with T21 and more importantly, what may be the next steps to

improve the nutrition-related health of these children. For example, ideas about how to meaningfully improve dietetic practice, support for parents, healthcare service delivery across the province of Manitoba, future inclusive research studies, and advocacy initiatives were inspired by acknowledging my own personal biases through reflection, and the overall goal of presenting the data with as much objectivity as possible.

Data Collection

Data collection began in December 2024 and was extended until the end of February 2025 to recruit as many study participants as possible. Parents and caregivers of children with T21 indicated their interest to participate in the research study as study participants by directly texting or emailing me, the principal investigator. At this time, an electronic consent form was provided to interested parents and caregivers for their review and signature, and a request was made for their availability to meet virtually for a data collection meeting. Parents and caregivers were encouraged to ask questions at any time throughout the data collection process. Consenting study participants were assigned a nonidentifying participant number to maintain their anonymity and confidentiality. The master list containing the participants' numbers, their names and contact information was stored securely in a password-protected file on a password-protected computer accessible only to the principal investigator.

Virtual data collection meetings using Zoom or Microsoft Teams were scheduled according to each study participant’s preferences and availability. A link for the virtual data collection meeting was provided to each study participant beforehand. All data collection meetings were scheduled for 2 hours. The consent form was reviewed with each study participant at the beginning of each virtual data collection meeting, before data collection began. Verbal consent to conduct and record a virtual data collection meeting was also requested before

beginning data collection. Finally, study participants provided a signed and initialed consent form to the principal investigator, which was stored in a secure multi-factor authenticated university account to maintain study participant anonymity and confidentiality.

Quantitative and qualitative data were collected using a 24-hour dietary recall (Appendix B) and survey instrument (Appendix C). The survey was administered orally by the principal investigator during the recorded virtual data collection meeting. A 24-hour dietary recall was completed with study participants to gather information about their child's food and beverage consumption. Notably, the 24-hour dietary recall was administered by me, a trained registered dietitian with extensive experience using tools to collect data about food and beverage consumption. As previously noted, the format and content of data collection tools were informed by parent engagement researchers (Appendix A). The survey instrument was designed to collect information other than food and beverage consumption that are known to be important to nutritional health. For example, questions about demographic and socio-economic characteristics, and other factors related to nutrition-related health such as dietary supplement usage, breastfeeding history, ability to feed oneself, medical history, and physical activity were included. A complete list of the factors considered, and the corresponding survey questions, is presented in Appendix D.

24-Hour Dietary Recall

The 24-hour dietary recall was conducted with study participants to assess their child's food and beverage consumption. Data collected from a 24-hour dietary recall may be used to estimate both nutrient deficiencies and excessive nutrient intakes in a population (Health Canada, 2006). The process used to conduct the 24-hour dietary recall in the Canadian Community Health Survey (Health Canada, 2006) was followed in this research study and is described in

Appendix B. Consideration was given when scheduling data collection meeting times with study participants to ensure that the 24-hour dietary recall was reflective of the child's intake on a previous Canadian school weekday, and not during regularly scheduled spring or winter breaks, on a statutory or national holiday, or during the summer months. To avoid some of the limitations of using a self-reported dietary data collection method, and to ensure that reported food and beverage consumption reflected typical intake, study participants were informed in advance that they would be asked to share information about the food and beverages their child consumes during the data collection meeting. However, they were not told what type of dietary data collection tool would be used. Furthermore, the 24-hour dietary recall was conducted at the beginning of the data collection meeting, so some data collected using this tool was able to be reviewed and validated by responses provided to questions in the survey instrument administered afterwards. For example, information about food allergies, preferences, intolerances, and dietary supplement usage may have been shared using both the 24-hour dietary recall tool and the survey instrument.

Probing questions were used to ensure accuracy and completeness of data. It took on average 30 minutes to complete the 24-hour dietary recall with each study participant during the data collection meeting.

Survey Instrument

Currently, there are no dietary or nutritional questionnaires in published literature that have been validated for use with parents or caregivers of children with Trisomy 21. The survey instrument used in this study (Appendix C) was developed based on expert nutrition knowledge on factors that influence food and beverage consumption and nutrition-related health (Appendix D), known potential nutrition-related concerns among children with T21, lived experience as a

parent to a child with T21, as well as knowledge and expertise from other professionals working in the areas of nutrition, community health sciences, and disability studies.

The survey instrument was designed to collect quantitative and qualitative data that includes, but is not limited to: 1) demographics (age, sex, household income, ethnicity), 2) relevant medical and family history, 3) access to health and nutrition knowledge and care, 4) self-reported anthropometric measurements, 4) parent and caregiver concerns about child's nutrition-related health, 5) history of breastfeeding, 6) presence of allergies, 7) swallowing or choking concerns, 8) dietary supplement usage, 9) breakfast consumption, 10) food cravings and aversions, 11) food security, 12) meal support requirements, 13) parent and caregiver perceptions about nutrition in general, and 14) preferred ways of receiving nutrition knowledge and care. In its entirety, the survey instrument was designed to collect data about many factors, at the individual and systems level, that may impact individuals' food and beverage consumption and nutrition-related health.

Importantly, questions on the survey instrument were informed by parent engagement researchers to ensure its use would produce a relevant and comprehensive assessment of the child's nutrition-related health. For example, some parents and caregivers shared that the COVID-19 pandemic impacted their child's eating habits and ability to engage in physical activity, so a question about the impact of COVID-19 pandemic was included in the survey questionnaire. In another example, parent engagement research partners identified that the onset of puberty was a potential factor influencing their child's nutrition-related health and so, a question about whether the child has experienced puberty was included in the survey questionnaire.

Consultation with others also informed some of the questions included in the survey instrument. For example, the inclusion of a question about who is the child's primary care provider (family physician, pediatrician, nurse practitioner) was informed by discussion with other healthcare professionals who shared that there may be significant differences based on where the child and their family reside in the province. This is also an important consideration because training, and perceived value, of nutrition as a contributing factor to health may differ among primary care providers and as such, may influence whether the child's nutrition-related needs are adequately addressed. The survey questionnaire was not pilot tested before use in the research study. However, I completed the survey in its entirety to test the survey for clarity and consistency, as a mom to child with T21.

Questions in the survey questionnaire were either close- or open-ended to facilitate collection of quantitative and qualitative data, respectively. There was a total of 43 questions; 41 were close-ended and 2 were open-ended. Of the 41 questions that were close-ended, 18 questions had follow-up open-ended questions to request study participants to elaborate and provide more information. For example, if a study participant expressed that they had concerns about their child's food intake, then they were asked to describe what those concerns were in detail. Study participants were asked to elaborate on some open-ended questions to validate some, but not all, quantitative data collected, and also, to provide a greater understanding of their lived experience. Therefore, the total number of questions asked of each study participant was unique and based on their individual responses and personal lived experience. Trustworthiness of the qualitative data was ensured by allowing study participants to express themselves freely in a confidential and comfortable environment. Throughout the data collection process, I encouraged study participants to elaborate and provide more detail, as they were able and willing, so that

their responses about their lived experiences were accurately depicted and documented. It took approximately 60 minutes to complete the survey instrument with each study participant during the data collection meeting.

After data collection was completed, recording of the meeting was stopped, and the study participants were again thanked for their time and contribution to the research study. Study participants agreed to provide their mailing address at the conclusion of the data collection meeting, and an honorarium of $50 was mailed to each study participant afterwards.

Data Management

All data were collected, protected, processed, coded, and managed by myself to ensure confidentiality, consistency, and quality of data. Direct identifiers were removed from the research data collection tools (for example: 24-hour dietary recall, survey instrument, interview transcripts) and replaced with a nonidentifying participant number assigned to each study participant. A coding manual and Excel database file were developed before beginning data collection to facilitate data entry (Appendix D). Transcripts of each data collection meeting were automatically transcribed using Zoom or Microsoft Teams and saved in a multi-factor authenticated online university account accessible only to me. In addition, names and locations, and any other potentially identifying characteristics in the transcripts themselves, were altered to protect the anonymity of the study participants.

The non-identifying participant number assigned to each study participant was used in all electronic documentation and analysis to protect the confidentiality of parents and children. A master list containing non-identifying participant numbers assigned to each study participant, and their identifiable information (for example: name, contact information), was stored in a separate and password-protected computer file on a password-protected computer, accessible only to me.

Any physical copies of data collected from each study participant were stored in a secure location and accessible only to me.

Study Measures

Several variables were included in the survey questionnaire used in this research study to describe the parents, their concerns about their child's nutrition-related health, and their experience receiving nutrition knowledge and care for their child; and to describe the children, their nutrition-related health, and factors influencing the same. Intakes of selected nutrients of interest, based on food and beverage consumption data collected using a 24-hour dietary recall, were compared to recommended dietary guidelines using FoodFocus Version 4.2. Other variables were entered into a spreadsheet using a coding manual (Appendix D) that was generated after creating the survey instrument but before data entry.

Nutrition-related health in this research study was characterized by considering nutrient adequacy, presence of nutrition-related conditions and diseases, and other factors known to influence nutrition-related health. A 24-hour dietary recall and survey instrument were used to collect mixed data about these variables. Afterwards, mixed data were compared and related, and an index measuring nutrition-related health was created (NICK index). Parents were asked to share nutrition-related health information on behalf of their child, and information about themselves to contextualize the child's home environment and consider external factors that may impact the child's nutrition-related health. For example, questions asked of the parents about their household income or geographic location within the province also applies to their children, as they lived together in the same home.

Parent Measures

The survey questionnaire included optional questions about the survey respondent (ie. the parent of the child with T21). Variables included their age, self-identified gender and ethnicity, relationship to the child, location (ie. urban versus rural) and duration of residency within Manitoba, whether they moved to Canada within the past year, household income, and their perceived value of nutrition to their child's overall health.

Furthermore, parents were asked to share theirs and primary care provider's concerns about the child's food and beverage intake, growth patterns, and overall health. Parents also discussed their experience receiving nutrition knowledge and care for their child and what their preferences were for receiving such services.

Child Measures

Demographic data was collected to describe the children with DS using a survey questionnaire. Parents who consented to participate in the study provided answers to survey questions on their child's behalf about their child's birthdate, age, sex, body weight and height, and primary care provider. Parent study participants also shared their child's food and beverage intake using a 24-hour dietary recall template. Food lists extracted from the 24-hour dietary recall were further categorized based on food and beverage type (ie. meat products, meat alternatives, dairy products, etc).

The survey instrument included several questions about individual- and external-level factors that may influence a child's nutrition-related health. For example, parent study participants shared information about their child's dietary supplement use, food preferences and aversion, and allergies. Other variables of interest related to nutrition-related health included information about the child's age, sex, medical history, family history, onset of puberty,

breastfeeding history, swallowing or choking concerns, physical activity levels and intensity, screen time usage, breakfast consumption, and eating ability. Finally, external-level factors such as the child's participation in a food or nutrition program at school, impact of the COVID-19 pandemic on food intake or physical activity, access to their primary care provider, religious and cultural beliefs, and child-feeding practices were considered. In this latter case, as an example, whether the child with T21 was served the same food at home as their siblings without T21 (if they had any siblings), and whether food was used a reward by parents, was assessed as potential child feeding practices that may impact the child's food and beverage consumption and thereby, their nutrition-related health.

Data Analysis

Analysis of quantitative and qualitative data collected using the survey instrument was conducted separately using descriptive statistics, and deductive and inductive thematic analysis, respectively. Descriptive analysis of the survey data was conducted using Microsoft Office Excel Version 16.77.1. Means, standard deviation, and range were calculated for the following variables: age, body weight and height, and selected daily nutrient intake levels. Proportions were calculated for the following variables: sex, gender, type of and access to a primary care provider, relationship between study participant and child with T21, newcomer status, location and duration of residency in Manitoba, ethnicity, annual household income, dietary supplement usage, medical and family history of nutrition-related disease or condition, food allergy or intolerance, breastfeeding history, onset of puberty, enrolment in school breakfast or lunch program, ability to eat alone or unsupervised, using food as a reward, cultural or religious impact on food intake, physical activity levels, screen time usage, impact of the COVID-19 pandemic, and provision of the same food provided to siblings.

For qualitative data, inductive and deductive thematic analysis was an iterative process that involved reviewing the transcripts repeatedly by two researchers, who worked independently, to generate codes based on the text. Once identified, codes were grouped into themes. Qualitative variables included: parent's perceived impact of the COVID-19 pandemic on their child's food intake or physical activity levels, meal support at school and home, parent and primary care provider concerns about their child's overall health, food and beverage consumption, body weight or height; and their lived experiences and preferences receiving nutrition knowledge and care.

Analysis of nutrient intake using the 24-hour dietary recall was conducted using FoodFocus Version 4.2, a nutrition analysis software program. FoodFocus calculated intake of selected nutrients for each individual child based on their food and beverage consumption and compared their intakes to dietary guidelines. The reference value for some nutrients was different for each child, as age, sex, body size, and/or activity level were entered into the program and influenced the recommended amount. For example, the recommendation intake of energy for each child was dependent on their age, sex, height, weight, and reported physical activity amount and intensity. Also, dietary reference intakes (DRIs) are grouped by age. The ages of the study population (6-12 years) overlapped two DRI age groups: 4-8 years old, and 9-13 years old. As such, as an example, the recommended intake of calcium for a child between the ages of 4-8 years old is 800 mg/day whereas the recommended intake of calcium for a child between the ages of 9-13 years old is 1300 mg/day.

Afterwards, the average intake for each nutrient for the entire group of children was calculated, as well as the proportion of the study population who consumed intakes that were more than, within, or less than the DRIs. Food lists from the 24-hour dietary recall data

collection tool were also reviewed and categorized according to food group or type. Then the average number of servings of different food groups/types was calculated at the aggregate level. A summary of how the collected data were organized and analyzed to answer the research questions and meet the study objectives is presented in Table 2 and Table 3.

Finally, bi-variate analysis was conducted to examine the relationship between nutrient intake adequacy (variable 1) and other factors known to influence nutrition-related health (variable 2). The list of other factors considered (variable 2) included: child's diagnosis or family history of nutrition-related condition or disease, attainment of physical activity and screen time recommendations, breastfeeding history, onset of puberty, food preferences, requirement for assistance or supervision during eating times, influence of religion or culture, impact of the COVID-19 pandemic, reception of nutrition knowledge and care, Indigenous identity, rural residency, female sex; and parent's use of food as reward, parent or primary care provider concerns about child's overall health or food intake or growth patterns, duration of parent's residency in Manitoba, and annual household income.

Table 2

Organization of data to meet the 1st study objective

Objective	Research Question	Data Source	Data Analysis
To determine the nutrient intake and factors that may influence nutrition-related health of children with T21 living in Manitoba	1) What foods and beverages do school-aged children (6-12 years) with T21 living in Manitoba consume?	24-hour dietary recall	Descriptive statistics to organize food lists collected from the 24-hour dietary recall based on food type serving sizes and beverage choice frequencies
	2) Do nutrient intakes from food of school-aged children (6-12 years) with T21 living in Manitoba meet dietary reference intakes?	24-hour dietary recall	Descriptive statistics using FoodFocus which calculated nutrient intakes based on food and beverage consumption collected from the 24-hour dietary recall and compared to dietary guidelines
	3) What factors influence the nutrition-related health of school-aged children (6-12 years) with T21 living in Manitoba?	24-hour dietary recall and survey instrument questions about medical history, family history, impact of the COVID-19 pandemic, onset of puberty, breastfeeding history, food allergies/cravings/aversions, swallowing difficulties, breakfast consumption, enrolment in school nutrition program, requiring assistance during eating time, food used as a reward, religious or cultural impact, physical activity level and intensity, screen time usage, and being served the same foods as siblings (if applicable)	Descriptive statistics using Microsoft Excel to describe factors that impact nutrition-related health based on quantitative data (collected from the survey instrument) and bivariate analysis to determine association between nutrient intake adequacy and factors influencing nutrition-related health

Table 3

Organization of data to meet the 2nd study objective

Objective	Research Question	Data source	Data analysis
To explore the perspectives of parents and caregivers of children with T21 about their child's nutrition-related health, and their lived experience receiving nutrition knowledge and care in Manitoba	1) Do parents and caregivers of school-aged children (6-12 years) with T21 have concerns about their child's nutrition-related health?	Survey instrument questions about parent or primary care provider concerns about child's overall health, food intake and growth patterns	Deductive and inductive thematic analysis based on qualitative data collected from the survey instrument
	1) Do school-aged children (6-12 years) with T21 and their parents and caregivers living in Manitoba receive nutrition knowledge and care?	Survey instrument questions about previous reception of nutrition knowledge and care and desire to receive the same in the future	Descriptive statistics using Microsoft Excel to describe access to nutrition knowledge and care based on quantitative data collected from the survey instrument
	2) What has been the lived experience receiving nutrition knowledge and care of parents and caregivers of school-aged children (6-12 years) with T21 living in Manitoba?	Survey instrument questions about parent and child's experience receiving nutrition knowledge and care (if applicable) and preferences for the same in the future (if applicable)	Deductive and inductive thematic analysis based on qualitative data collected from the survey instrument

Data collected from the survey instrument that was not used to answer the research questions were used to describe the parents and the children. For example, data collected about gender, age, relationship to the child with T21, household income, location and duration of Manitoba residency, ethnicity, and their understanding about the value of nutrition in relation to overall health, were used to describe the parents. Data collected about age and sex were used to describe the children. Given the young age of children in this study, and because all children represented in this research study resided with the parent who consented to be a study participant, data about household income, location of residency in Manitoba, and ethnicity were shared between the parent and their child.

Afterwards, a comparison and review of all mixed data was completed to provide a more accurate and comprehensive understanding of individual nutrition-related health in the data interpretation stage. Consideration of nutrient intake adequacy and quality, based on comparison to national dietary guidelines using the FoodFocus software, in combination with consideration of other factors that may influence food and beverage consumption, facilitated greater understanding of individual nutrition-related health compared to if only one type of data was considered and/or separately from another type of data. For example, considering personal health information about medical diagnoses, allergies, food aversions, or dietary supplement usage may provide context regarding the selection of food and beverage items the parent or caregiver provides to their child, and/or the amount of food and beverages that is consumed by the child. Furthermore, exploration of parent and caregiver concerns about their child's nutrition-related health may offer insight, clarification, and more detail about their lived experience receiving nutrition knowledge and care for their child. For example, if a parent expressed that they value nutrition as an important factor of their child's health, but do not wish to receive nutrition

knowledge and care for their child, exploration of their past experiences receiving the same may reveal additional context to enhance understanding. It is possible that past negative experiences with health care providers were not perceived as meaningful or impactful by parents. Together, in comparing and relating qualitative and quantitively data with one another, an overview of nutrient-related health and experiences receiving nutrition knowledge and care may be described, at least for the children accounted for within this research study. Notably, recommendations to improve nutrition-related health may be more focussed and meaningful given a more insightful analysis.

In addition to describing mixed data separately, and together, to better understand nutrition-related health of children with T21, an index (NICK index) to characterize nutrition-related health based on collected data was created by considering: 1) nutrient adequacy of selected nutrients from food and beverage consumption based on comparisons to dietary guidelines, 2) absence of diagnosed nutrition-related conditions and diseases, and 3) several other selected factors that may influence food and beverage consumption or nutrition-related health (for example: relevant family medical history, physical activity levels, dietary supplement usage). Together these data were used to assess nutrition-related health and estimate whether a child experienced *optimal* nutrition-related health. For example, a child with adequate intake of selected nutrients, absence of diagnosed nutrition-related conditions and diseases, and presence of other factors known to enhance nutrition-related health, would receive a higher score. Importantly, nutrition-related health was not characterized as either ‘good’ or ‘bad’ but rather, on a continuum towards *optimal* nutrition-related health.

Research Objective 1

The first research objective was to determine the nutrient intake and factors that may influence nutrition-related health of children with T21 living in Manitoba. To achieve this objective, food and beverage consumption data collected from the 24-hour dietary recall were analyzed using FoodFocus Version 4.2 (FoodFocus, 2021). FoodFocus is a nutrition analysis software that contains nutrient data for nearly 6000 foods, incorporated from the 2015 Canadian Nutrient File (published by Health Canada), and compares food and beverage consumption to age-specific national nutrient recommendations such as the Dietary Reference Intakes (DRIs) and Acceptable Macronutrient Distribution Ranges (AMDR; Public Health Agency of Canada, 2006; Institute of Medicine, 2000). Additionally, descriptive statistics were used to analyze all quantitative data collected through the survey instrument on factors influencing nutrition-related health (Appendix E) using Microsoft Office Excel.

Research Objective 2

The second research objective was to explore the perspectives of parents and caregivers of children with T21 about their child's nutrition-related health, and their lived experience receiving nutrition knowledge and care. To achieve this research objective, qualitative data collected from applicable open-ended questions included in the survey instrument were analyzed using deductive and inductive thematic analysis. Data were reviewed and coded by two researchers independently and involved generating themes based on an iterative process of reviewing and coding the qualitative data. We used both a deductive and inductive thematic analysis approach for the analysis. For the deductive approach, tentative codes were generated from research questions. Data which did not align with research questions were analyzed using an inductive approach wherein codes were generated based on the content of the transcript text

itself. Following this, codes were grouped into themes by two researchers, who analyzed the data separately. A third researcher with extensive experience in qualitative research was involved when consensus was not reached on themes, and to review the findings based on qualitative data.

Preliminary findings were shared with the advisory committee. In addition, study participants were invited to review preliminary study findings and provide feedback, as part of one patient engagement initiative (Appendix A).

Nutrition-Related Health Index

An iterative process of creating a tool to assess nutrition-related health (NICK index), based on mixed data collected in this research study, occurred after data analysis and is an example of how data triangulation was used in this study. Different methods to collect quantitative and qualitative data in this research study provided a fuller and more balanced understanding of nutrition-related health among children with T21 and guided the creation of the NICK index. For example, the selection of variables to include in different versions of the NICK index included review of both quantitative and qualitative findings. For some variables, such as concerns about child's health or food intake, qualitative data provided more information to better understand a quantitative finding. Together, by reviewing mixed data for a single variable, determination of its relevance was estimated with greater credibility. The same was true for variables *not* selected to be included in the NICK index. For example, qualitative data provided a greater understanding as to why some variables such as religion, culture, or using food as reward, may not be relevant to determine the nutrition-related health of this study population.

The NICK index aimed to *estimate* the study population's nutrition-related health. Nutrition-related health in this research study was characterized by considering nutrient adequacy, presence of nutrition-related conditions and diseases, and other factors known to

influence nutrition-related health. A total of six versions of the NICK index were created, based on different variables, ranging between 11 variables (in version 1) to 25 variables (in version 6). The list of variables considered in all versions of the NICK index are presented in Table 4. Version 1 includes variables 1-11, version 2 includes variables 1-13, version 3 includes variables 1-15, version 4 includes variables 1-18, version 5 includes variables 1-22, and version 6 includes variables 1-25.

Individual scores were calculated by considering all variables included in each version of the NICK index, with each variable weighted equally (1 point). Children who attained a score of 75% were classified as having 'optimal' nutrition-related health. Children who attained a score of 50% were classified as having 'adequate' nutrition-related health. The use and validity of the NICK index may be tested in future nutrition research studies with this population.

Table 4

Variables included in the nutrition-health index (NICK index)

1	Protein intake within recommended ranges
2	Carbohydrate intake within recommended ranges
3	Total fat intake within recommended ranges
4	Saturated fat intake within recommended ranges
5	Fibre intake within recommended ranges
6	Added sugar intake within recommended ranges
7	Sodium intake within recommended ranges
8	Calcium intake within recommended ranges
9	Vitamin D intake within recommended ranges
10	Iron intake within recommended ranges
11	Daily multivitamin supplement usage
12	Breakfast consumed 5 or more times per week
13	Child was breastfed
14	60 minutes of daily physical activity
15	Less than 2 hours of daily screen time
16	Absence of nutrition-related condition or disease
17	Absence of family history of nutrition-related condition or disease
18	Parent/caregiver valued nutrition as important part of child's overall health
19	Parent/caregiver did not have concerns about child's overall health
20	Parent/caregiver did not have concerns about child's food intake
21	Child's primary care provider did not have concerns about child's overall health, food intake, or growth patterns
22	Parent/caregiver was a long-term resident of Manitoba
23	Household income greater than $100 000 annually

At a *minimum*, nutrient intake adequacy may be characterized by considering 1) whether a child's daily food and beverage consumption met the recommended daily intake of 10 selected nutrients (protein, fat, carbohydrate, saturated fat, dietary fibre, added sugars, calcium, iron, vitamin D, and sodium) and 2) if they were provided with a daily multivitamin. Attaining a score of at least 50% (6/11) was considered 'adequate' for the purposes of this research study. Subsequent iterations of the scoring tool included other factors known to influence nutrition-related health to assess what is the minimum amount of information needed to accurately reflect the nutrition-related health of a child and to determine whether adding more information impacts the score. In practice, the smallest set of information required to determine nutrition-related health of a child with T21 will make the scoring tool more practical and feasible for implementation.

Contingency Tables

Further analysis was conducted using 2x2 tables to describe in more detail the association between dependent variables measured in this research study. The use of 2x2 tables is appropriate for dichotomous categorical variables (for example: data that can be categorized into 2 categories only). For each 2x2 contingency table, the rows represented the child's nutrient intake adequacy, and the columns indicated the presence of absence of one selected factor that may potentially impact the child's nutrition-related health.

Fisher's exact test and odds ratios were calculated to determine if there was an association, and potentially the degree of association, between the child's nutrient intake adequacy and factors known to potentially impact the child's nutrition-related health. A p-value < 0.05 was considered statistically significant.

Ethical Considerations

Ethical approval was granted from the University of Manitoba Health Research Board on August 19, 2024, #HS26565 (H2024:227). Consent was requested and received from parent and caregiver study participants, respectively, before data collection. Following the *Basic Elements of Consent Disclosure Statements for Survey Research*, available on the University of Manitoba's Office of Research Ethics and Compliance webpage, informed consent included sharing information with participants about the study purpose and procedures, and any potential risks, discomforts, benefits, or costs associated with study participation. Participants were also assured of confidentiality and reminded of their right to withdraw from the study and ask questions at any time. There was no conflict of interest to declare.

Chapter 4

Results

Fourteen school-aged children between the ages of 7 and 12 years old with T21 were included in the study, and their parents (n=14). The average age of participating children was 9 years, and 50% were female (n=7). Information about the average weight and height of children included in the study, who is their primary care provider, and whether they were seen by the same within the past year, is summarized in Table 5. Data on child's birthdate was used to validate their reported age.

Table 5

Characteristics of the children with T21 who participated in the study

	n (%)	Average mean ± SD (range)
Age	14 (100%)	9 ± 2 years (7-12)
Sex		
Female	7 (50%)	
Male	7 (50%)	
Weight[ab]		37 ± 21 kg (20-99)
Height[ab]		123 ± 13 cm (104-145)
Seen by a pediatrician	14 (100%)	
Within the past year		
Yes	13 (93%)	
No	1 (7%)	

[a]self-reported data

[b]missing data on weight (n=1) and height (n=2)

All participating parents were moms (n=14), and all believed that food and nutrition are an important part of their child's overall health. Most of the moms (n=13) were between 31-50 years old. None of the moms had moved to Canada within the past year, and just over half (n=8)

resided in an urban setting within Manitoba. The majority of participating moms (n=12) had lived in Manitoba for over 31 years at the time of data collection. Slightly over two thirds of moms (79%) described themselves as Caucasian and only three (21%) self-identified themselves as Indigenous. Almost two thirds (77%) of mom reported an annual household income greater than $100,000. Characteristics of the moms are summarized in Table 6.

Table 6

Characteristics of the participating parents

	Total N (%)	Proportion n (%)
Relationship to the child	14 (100%)	
Mother		14 (100%)
Father		0 (-)
Valued nutrition to child's overall health	14 (100%)	
Yes		14 (100%)
No		0 (-)
Age	14 (100%)	
Between 31-50 years old		13* (93%)
Moved to Canada within the past year	14 (100%)	
Yes		0 (-)
No		14 (100%)
Residence in Manitoba	14 (100%)	
Urban		8 (57%)
Rural		6 (43%)
Ethnicity**	14 (100%)	
Caucasian		11 (79%)
Indigenous		3 (21%)
Other		2 (14%)
Annual household income***	13 (93%)	
Less than $50, 000		0 (-)
Between $50, 000 and $100, 000		3 (21%)
Greater than $100, 000		10 (71%)

*age of remaining study participant not presented to protect their anonymity
**multiple self-reported responses permitted
***n=1 preferred not to answer

Research Objective 1

The first research objective was to determine the nutrient intake and factors that may influence nutrition-related health of children with T21 living in Manitoba. Three research questions were posed to achieve this objective: 1) What foods and beverages do school-aged children (6-12 years) with T21 living in Manitoba consume?, 2) Do nutrient intakes from food of school-aged children (6-12 years) with T21 living in Manitoba meet dietary reference intakes?, and 3) What factors influence the nutrition-related health of school-aged children (6-12 years) with T21 living in Manitoba? Data collected from the 24-hour dietary recall was analyzed to answer the first two research questions. Data collected from the survey was analyzed to answer the third research question related to this research objective.

Food and Beverage Consumption

Food and beverage consumption lists were provided by each participating mother on behalf of their child were descriptively analyzed and categorized by type. Meat alternatives consumed by children with DS in this study included mostly peanut butter and eggs and rarely, beans, lentils, or seeds. Also, dairy products consumed tended to be mostly cheese and flavoured yogurt choices followed by milk. Remaining food items were organized into additional categories such as whole grains, snacks foods, restaurant meals, and other foods. Whole grains consumed by children with T21 in this study were oatmeal and popcorn. Snack foods included crackers, applesauce, granola bars, and pretzels. Other foods included condiments, chocolate, chips, juice, and dessert.

Canada's Food Guide

When applicable, serving sizes from the 2011 version of Eating Well With Canada's Food Guide (Appendix G) were used to estimate the number of servings from specific food

groups such as grain products, meat products and alternatives, dairy products, and fruits and vegetables. When serving sizes were not applicable, for example, for snack foods or restaurant meals, frequency of consumption was tracked. A summary of the types of food consumed daily by children with DS in this study is presented in Table 7.

Among the children with DS, the average number of servings of whole grains (0.79 ± 1.25) was low. The average number of servings of grain products was the highest (3.54 ± 1.76) followed by fruits and vegetables (3.21 ± 2.80), dairy products (2.46 ± 1.70), and meat products (1.29 ± 0.83). Notably, the average number of servings of meat alternatives (peanut butter, eggs, lentils, beans, seeds) was nearly as high as the average number of servings of meat products (1.21 ± 1.42), which aligns with the current version of Canada's Food Guide (Government of Canada, 2019), which recommends greater consumption of plant-based sources of protein foods. Among the children with T21, frequency of consumption of 'other' foods (condiments, chocolate, chips, juice, dessert) was relatively high (4.18 ± 2.38), of snack foods (crackers, applesauce, granola bar, pretzels) was relatively moderate (1.71 ± 1.54), and of restaurant meals was low (0.21 ± 0.43).

Table 7

Summary of daily food types consumed by children with T21

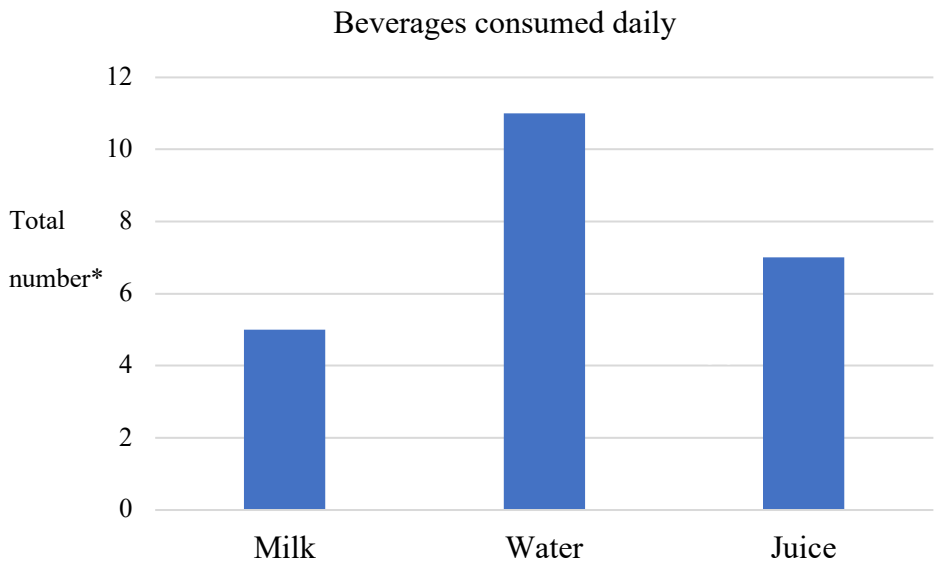
Food type	Average number of servings consumed per day* mean ± SD (range)
Whole grains**	0.79 ± 1.25 (0, 4)
Grain products	3.54 ± 1.76 (0, 5)
Meat products	1.29 ± 0.83 (0, 3)
Meat alternatives***	1.21 ± 1.42 (0, 5)
Dairy products[+]	2.46 ± 1.70 (0, 5)
Fruits and vegetables	3.21 ± 2.80 (0, 8)
Snack foods[++]	1.71 ± 1.54 (0, 4)
Other foods[+++]	4.18 ± 2.38 (0, 8)
Restaurant meals	0.21 ± 0.43 (0, 1)

*according to Eating Well With Canada's Food Guide servings (2011 version; Health Canada, 2011; Appendix G), if applicable (not all food types have recommended servings)
**oatmeal and popcorn
***mostly peanut butter and eggs; beans and lentils (n=2); seeds (n=1)
[+]cheese, yogurt, and milk
[++] crackers, applesauce, granola bars, pretzels
[+++] condiments, chocolate, chips, juice, dessert

Beverages consumed by children with DS in the study, based on data collected from the 24-hour dietary recall, included water, juice, and milk (Figure 1). Nearly all children with DS (n=11) reported drinking water daily. Half of the children with DS (n=7) consumed juice daily, and less than half (n=5) consumed milk daily. Notably, no soft drink consumption was reported for children with T21 in the study population.

Figure 1

Summary of frequency of beverage consumption by type among children with T21



*total number of times beverages were reported by study population. Quantity of each reported beverage choice was variable, sometimes immeasurable ('sips'), and sometimes unknown (when beverages were consumed outside of home environment).

Dietary Reference Intakes

Dietary references intakes (DRIs) were used to assess food intake variety based on the adequacy of selected nutrient intakes. Among the children with T21 in this study, 86% (n=12) consumed a daily protein intake within the Acceptable Macronutrient Distribution Range (AMDR); 71% (n=10) consumed a daily carbohydrate intake within the AMDR; and 50% (n=7) consumed a daily fat intake within the AMDR (Table 8). Notably, daily fat intake was *below* the AMDR for 29% (n=4) among children with T21 included in this study. Additionally, as an indicator of whole grain and fruit and vegetable consumption, 21% (n=3) of children with DS consumed an Adequate Intake (AI) of total dietary fibre (Table 9). Notably, daily dietary fibre intake was *below* the AI for 79% (n=11) of children with DS included in this study (Table 9).

Table 8

Daily macronutrient intake of children with T21 compared to dietary reference intakes (DRIs)

Macronutrient	Average % energy (range)	AMDR* % energy	More than DRI n (%)	Meets DRI n (%)	Less than DRI n (%)
Protein	14 (6, 20)	10-30	0 (-)	12 (86%)	2 (14%)
Carbohydrate	54 (36, 68)	45-65	2 (14%)	10 (71%)	2 (14%)
Fat	32 (22, 57)	25-35	3 (21%)	7 (50%)	4 (29%)

*DRI Acceptable Macronutrient Distribution Range (AMDR)

Nutrient Intake

Nutrient analysis based on food and beverage consumption from the 24-hour dietary recall was compared to applicable age- and sex- specific recommended dietary reference intake values using FoodFocus. A summary of selected daily average nutrient intake levels and their comparison to dietary reference intakes is presented in Table 9. Among the micronutrients, iron was consumed in adequate amounts by 93% (n=13) of the children with DS in this study. However, no children with DS consumed the recommended amount of vitamin D, less than half (n=6) consumed the recommended amount of total energy, and 71% (n=10) did not consume the recommended amount of calcium or fibre, respectively. Conversely, over half (n=8) the children with T21 consumed more than the recommended amount of total energy, 71% (n=10) consumed more saturated fat than what is recommended, 71% (n=10) consumed more added sugars than what is recommended, and all (n=14) children with T21 consumed more sodium than what is recommended.

Table 9

Daily nutrient intake of children with T21 compared to dietary reference intakes (DRIs)

Nutrient	Average per day mean ± SD (range)	DRI	More than DRI n (%)	Meets DRI n (%)	Less than DRI n (%)	Total N (100%)
Total energy	2119 ± 606 kcal (1193, 2961)	1300-2400 kcal/day*	8 (57%)	0 (-)	6 (43%)	14 (100%)
Protein	73 ± 29 g (27, 135)	30-222 g/day*	0 (-)	12 (86%)	2 (14%)	14 (100%)
Fat	81 ± 41 g (30, 167)	33-115 g/day*	2 (14%)	7 (50%)	5 (36%)	14 (100%)
Saturated fat[+]	*10 ± 3% (4, 16)*	-	*10 (71%)*	*4 (29%)*	*0 (-)*	*14 (100%)*
Trans fat[++]	*1 ± 1 g (0, 5.7)*	-	*-*	*-*	*-*	*14 (100%)*
Carbohydrate	283 ± 67 g (174, 398)	134-481 g/day*	2 (14%)	10 (71%)	2 (14%)	14 (100%)
Added sugars[+]	*8 ± 4% (1, 13)*	-	*10 (71%)*	*4 (29%)*	*0 (-)*	*14 (100%)*
Fibre	*19 ± 7 g (6, 29)*	*18-34 g/day***	*0 (-)*	*3 (21%)*	*11 (79%)*	*14 (100%)*
Sodium	2852 ± 935 mg (1305, 4396)	1200-1500 mg/day**	14 (100%)	0 (-)	0 (-)	14 (100%)
Calcium	899 ± 423 mg (302, 1541)	1000-1300 mg/day*	0 (-)[^]	4 (29%)	10 (71%)	14 (100%)
Iron	15 ± 7 mg (6, 33)	8-10 mg/day*	0 (-)[^]	13 (93%)	1 (7%)	14 (100%)
Vitamin D**	115 ± 76 IU (10, 244)	600 IU/day*	0 (-)	0 (-)	14 (100%)	14 (100%)

*daily intake compared to DRI Recommended Dietary Allowance (RDA)
**daily intake compared to DRI Adequate Intake (AI)
[+]daily intake presented as % total energy (kcal) and compared to American Heart Association (AHA) 'above ideal' guideline
[++]no recommended daily intake level established (Health Canada, 2018)
[^]no daily intake exceeded the Tolerable Upper Limit (2500 mg/day for calcium and 40 mg/day for iron for female and male children 4-13 years)

Comparison of Findings Between Food Type and Nutrient Analysis

The following observations about the food and nutrient intake of children with T21 included in this study was validated by comparing the food type summary, assessed based on comparison to Canada's Food Guide (Health Canada, 2011; Government of Canada, 2019), and the nutrient analysis of food and beverages consumed, based on comparison to the DRIs, respectively:

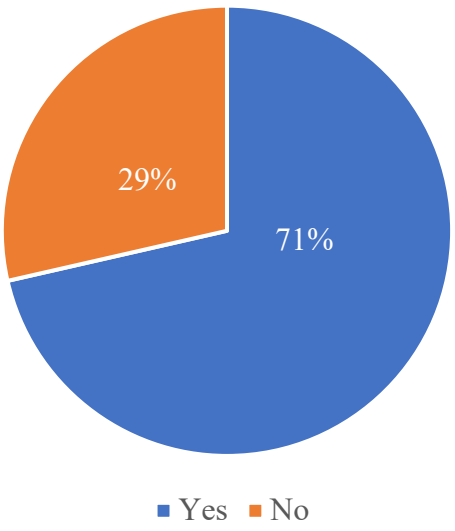
1) An adequate average number of daily food servings of meat products and meat alternatives and grain products align with an adequate average intake of daily protein, carbohydrate, and iron;
2) A low average number of daily food servings of fruits and vegetables aligns with an inadequate average intake of daily dietary fibre;
3) Less daily servings of vitamin-D fortified milk compared to more daily servings of yogurt and cheese, and low consumption (n=1) of other dietary sources of vitamin D, such as fish, align with an inadequate average intake of daily vitamin D;
4) Fewer daily servings of vitamin-D fortified milk compared to more daily servings of yogurt and cheese aligns with an inadequate average intake of calcium, as yogurt and cheese contain less calcium than milk.
5) On average, among the total number of children with T21 included in this study, snacks or 'other' foods were consumed approximately 83 times in one day, which aligns with their excessive average intake of daily added sugars, saturated fat, and sodium, as these types of foods typically contain higher amounts of these ingredients.

Dietary Supplement Usage

Daily dietary supplements were provided by parents to 71% (n=10) of children with T21 included in this study (Figure 2). The most commonly consumed daily dietary supplement was a multivitamin, which was reported for 8 out of 10 study participants. Other dietary supplements were provided to a fewer number of children with DS. However, these data are not presented as it may contain identifying information for the child with DS (for example: a dietary supplement may be recommended to treat a medical diagnosis other than Down syndrome).

Figure 2

Daily supplement usage among children with T21



Factors Influencing Nutrition-Related Health

There are several factors that may influence a person's nutrition-related health at the individual level such as medical history, ability to eat, and food preferences. However, when applying a socio-ecological lens, these individual-level factors are shaped by external forces that interact at various levels, affecting individuals' behaviour including those related to food and beverage consumption. Some examples of external factors relevant to a child's food and

beverage choices may include religion, household income, and enrollment in a school nutrition breakfast program. Findings from data collected in this study about potential factors related to the nutrition-related health of children with DS are summarized in Table 10.

Table 10

Individual and external factors related to nutrition-related health among children with T21

Factor influencing nutrition-related health	Yes n (%)
Medical history of nutrition-related condition or disease	9 (64%)
Family history of nutrition-related condition or disease	10 (71%)
Food allergy or intolerance	4 (29%)
Breastfed	12 (86%)
Onset of puberty	1 (7%)
Swallowing or choking concerns	0 (-)
Consumes breakfast 5 times per week	14 (100%)
Food preferences or cravings	13 (93%)
Food aversions or dislikes	12 (86%)
Enrolment in school breakfast or lunch program	2 (14%)
Requires help or supervision to eat at home	11 (79%)
Requires help or supervision to eat at school	11 (79%)
Food is used as a reward	8 (57%)
Religion impacts food and beverage choices	2 (14%)
Culture impacts food and beverage choices	5 (36%)
COVID-19 pandemic impacted food and beverage choices or physical activity levels	8 (57%)
Physically active more than 60 minutes per day	12 (86%)
Screen time more than 2 hours per day	11 (79%)
Served same foods as siblings	8 (75%)

Medical History

Among the children with DS included in this study, 64% (n=9) received a diagnosis of a medical condition that may affect food intake or nutrition-related health. Among those with a diagnosis of nutrition-related condition or disease (n=9), the most common diagnosis was hypothyroidism (n=4), followed by heart conditions and constipation.

Family History

Among children with DS included in this study, 71% (n=10) had a family history of a nutrition-related condition or disease. Among those with a family history of a nutrition-related condition or disease (n = 11), the most common condition was diabetes (n=6). Other reported family histories of nutrition-related conditions or diseases included heart conditions, hypertension, and hypothyroidism.

Food Allergy or Intolerance

Among the children with DS included in this study, 29% were diagnosed with food allergy or intolerance. Among those diagnosed with food allergy or intolerance, the most common type was lactose intolerance (n=2).

Breastfeeding History

Most children with T21 included in this study (86%) were breastfed.

Onset of Puberty

The majority of children with T21 included in this study (93%) had not yet experienced puberty.

Swallowing or Choking Concerns and Assistance During Eating

None of the moms reported that their child with T21 experienced swallowing difficulties or that they had concerns about their child choking while eating. Notably, 79% (n=11) of

children with T21 included in this study reportedly required assistance or supervision during eating times at home, and at school. Two moms expressed concern about their child's ability to chew some types of food such as meat.

Moms were asked to elaborate about their child's required meal support at home. They (moms) reported they provided three types of eating support to their child with DS at home: 1) Reminders and prompts to facilitate safe and efficient eating, 2) Assistance opening packages, and 3) Assistance with feeding. Moms shared that their child with DS needed reminders to chew their food, eat slowly, or to continue eating.

Moms were also asked to elaborate about their child's required meal support at school. Five types of meal support were reported: 1) Reminders and prompts to facilitate safe and efficient eating, 2) Group or individual supervision, 3) Assistance opening packages, 4) Self-feeding practice, and 5) Assistance with feeding. Notably, one mom did not know if their child with DS received assistance or supervision during eating times at school.

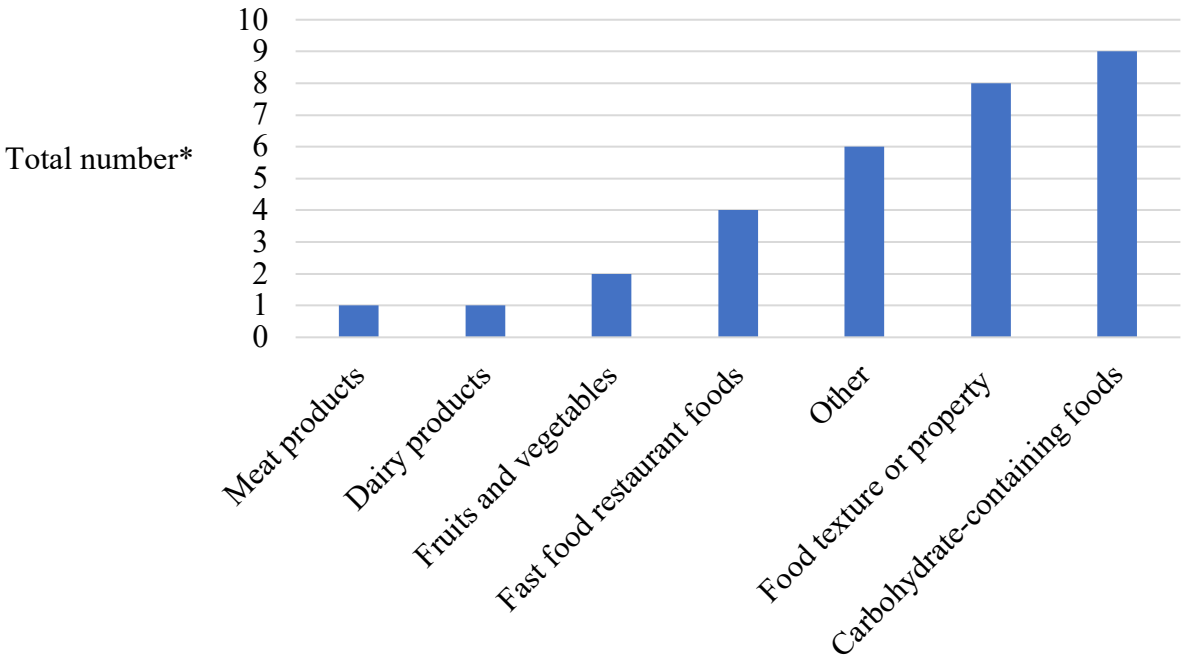
Finally, among the children with T21 included in this study, 79% (n=11) were not enrolled in a breakfast or lunch program at school.

Breakfast Consumption, Food Preferences and Aversions

All children with DS included in this study reportedly consumed breakfast at least 5 times per week. Among the children with DS included in this study, 93% (n=13) had food preferences or cravings. Food preferences or cravings were varied (Figure 3). Carbohydrate-containing foods (bread, rice, buns, pasta, rice, crackers) were listed most often (n=9) followed by foods with specific properties (n=8) such as soft, crunchy, pureed, plain or familiar; and 'other' foods (n=6). 'Other' foods included jam, chocolate, snack foods, popcorn, pizza, and ice cream.

Figure 3

Types of food preferences or cravings among children with T21

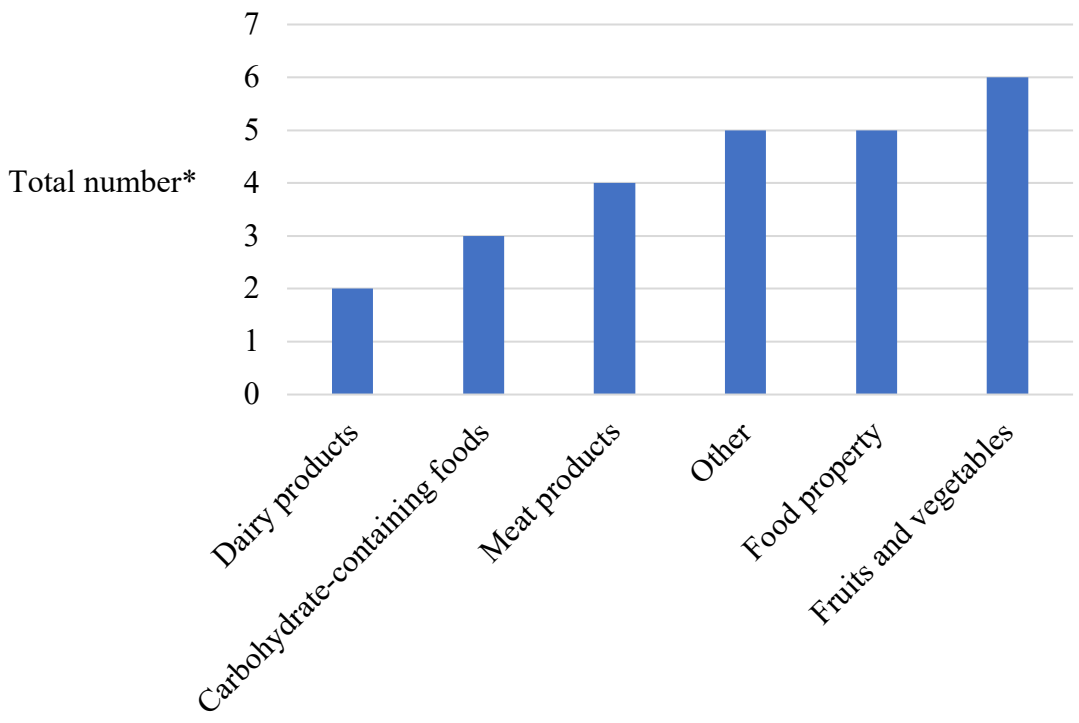


*total number of types of food preferences or cravings is greater than the number of children with DS included in this study because more than one response per child was permitted

Among the children with T21 included in this study, 86% (n=12) had food aversions or dislikes. Food aversions or dislikes were varied (Figure 4). Fruits and vegetables (n=6) were listed most often (n=9) followed by foods with specific properties (n=5) such as soft, chunky, spicy, sour or dry; and 'other' foods (n=5). 'Other' foods included cake, sauce, carbonated beverages, and cultural foods.

Figure 4

Types of food aversions or dislikes among children with T21



*total number of types of food aversions or dislikes is greater than the number of children with DS included in this study because more than one response per child was permitted

Religion and Culture

Among the moms who participated in this study, 86% (n=12) shared that they did not believe that religious beliefs impacted their child's food and beverage choices. Similarly, 64% (n=9) of mom did not believe that culture impacted their child's food and beverage choices.

Family Dynamics

Among the children with T21 included in this study, 86% (n=12) had siblings. Of these, 75% (8 out of 12) of children with T21 were served the same foods as their siblings without T21. Notably, in the cases where there was differentiation, some moms reported that different foods

were served sometimes (not always) and some moms shared that all members of their family were served different foods, not only their child with T21.

Just over half (57%; n=8) of moms reported using food as a reward for their children with DS. However, a very low proportion of moms who reported using food as a reward did so regularly (n=2).

Physical Activity, Screen Time, and the COVID-19 Pandemic

Among the children with DS included in this study, 86% (n=12) engaged in more than 60 minutes of physical activity per day, and for 71% (n=10) of children with DS, their physical activity was reportedly of moderate intensity (versus low or high). Notably, no moms reported that their child with DS engaged in high intensity physical activity.

Among the children with DS included in this study, 14% (n=2) engaged in less than 2 hours of screen time per day. Notably, 21% (n=3) of children with DS engaged in more than 4 hours of screen time per day.

Among the moms who participated in this study, 57% (n=8) shared that the food intake or physical activity of their child with T21 was impacted by the COVID-19 pandemic. Moms who reported an impact of the COVID-19 pandemic on their child's food intake or physical activity were asked to elaborate about the impact. They reported that the COVID-19 pandemic: 1) influenced the foods and beverages their child with DS consumed, 2) influenced the physical activity of their child with DS, 3) caused them to have concerns about their child's future, and 4) reduced the frequency of healthcare services provided to their child with DS. For some children with DS included in this study, the COVID-19 pandemic disrupted or limited the supply of their preferred foods.

Bivariate Analysis

A series of bivariate analyses were conducted to determine individual-level characteristics and external factors that were significantly associated with children's daily nutrient intake adequacy. Contingency tables for each analysis are shown in Appendix F. Daily nutrient intake adequacy was defined as meeting at least 50% of the recommended intake of 10 selected nutrients (Table 9), and receiving a daily multivitamin; those who met less than 50% of the recommended intake of 10 selected nutrients and did not receive a daily multivitamin were classified as not receiving adequate daily nutrient intake. Results of statistical tests to determine whether there was an association, and/or to what degree there was an association, are summarized in Table 11. Statistical significance was not observed between daily nutrient adequacy and any factor that may influence nutrition-related health measured in this study. Variables that were excluded included whether the parent moved to Canada within the past year, parent gender, parent values about nutrition, child breakfast consumption, and child swallowing or chewing concerns, because there was no variation observed among data collected. Child diagnosis of food allergy, child enrolment in school nutrition program, and child requiring assistance during eating times at school, were also excluded because more than 2 responses were received to these questions (for example: yes, no, I don't know). Furthermore, whether the child with DS was served the same foods as their siblings was excluded because not all children with DS included in the study had siblings. Finally, parent age was excluded to protect the identity of the moms who participated in this study.

Table 11

Factors associated with daily nutrient intake adequacy of children with T21

	Factor	Odds Ratio (OR)	OR 95% Confidence interval (lower limit, upper limit)	Fisher's exact test* (p value)
1	Child has diagnosis of nutrition-related condition or disease	5.00	(0.38, 64.39)	0.2378
2	Child has family history of nutrition-related condition or disease	3.00	(0.22, 39.61)	0.4056
3	Child meets physical activity recommendations**	5.00	(0.20, 125.79)	0.6000
4	Child meets screen recommendation	3.50	(0.24, 51.90)	0.3846
5	Child was breastfed**	0.11	(0.00, 2.72)	0.4000
6	Child has experienced puberty**	0.38	(0.01, 11.17)	0.8250
7	Child has food aversions**	0.11	(0.00, 2.72)	0.4000
8	Child has food preferences	0.29	(0.02, 4.24)	0.3846
9	Child requires assistance or supervision during eating times at home	1.67	(0.11, 24.26)	0.6154
10	Religion influences child's food choices	1.40	(0.07, 28.12)	0.6923

	Factor	Odds Ratio (OR)	OR 95% Confidence interval (lower limit, upper limit)	Fisher's exact test* (p value)
11	Culture influences child's food choices	3.00	(0.31, 28.84)	0.3427
12	COVID-19 pandemic impacted child's food intake or physical activity	2.00	(0.22, 17.89)	0.4709
13	Child has received nutrition knowledge and care	0.67	(0.06, 6.87)	0.5944
14	Child is Indigenous	0.60	(0.04, 8.73)	0.6154
15	Child lives in a rural location in Manitoba	6.00	(0.58, 61.84)	0.1562
16	Child is female	0.30	(0.03, 2.76)	0.2960
17	Parent uses food is used as a reward	0.17	(0.02, 1.72)	0.1562
18	Parent has concerns about child's overall health	2.00	(0.22, 17.89)	0.4709
19	Parent has concerns about child's food intake	0.60	(0.07, 5.14)	0.5291
20	Parent has concerns about child's body weight or height	6.00	(0.58, 61.84)	0.1561
21	Primary care provider has concerns about child's health	0.60	(0.41, 8.73)	0.6154
22	Parent has lived in Manitoba for over 30 years**	0.11	(0.00, 2.72)	0.4000
23	Greater than median annual household income in Manitoba	3.00	(0.23, 39.61)	0.4056

*One-tailed Fisher test where $p<0.05$ is considered statistically significant
**Corrected for sampling zero

Research Objective 2

The second research objective was to explore the perspectives of parents and caregivers of children with T21 about their child's nutrition-related health, and their lived experience receiving nutrition knowledge and care in Manitoba. Three research questions were posed to achieve this objective: 1) Do parents and caregivers of school-aged children (6-12 years) with T21 have concerns about their child's nutrition-related health?, 2) Do school-aged children (6-12 years) with T21 and their parents and caregivers living in Manitoba receive nutrition knowledge and care?, and 3) What has been the lived experience of, and preferences for, receiving nutrition knowledge and care of parents and caregivers of school-aged children (6-12 years) with T21 living in Manitoba (if applicable)?. Data collected from the survey were analyzed to answer these research questions.

Parent Concerns About Child's Overall Health

Of the participating mom, 57% (n=8) reported that they had concerns about the overall health of their child with T21. Three types of concerns were identified using inductive and deductive coding: 1) Concerns about the child's food and beverage consumption, 2) Concerns about factors influencing the child's nutrition-related health, and 3) Concerns about the child's health in the future.

Food and Beverage Consumption of Children with T21

Concerns reported by moms about the food and beverage consumption of their child with T21 related to the adequacy of the child's nutrient and fluid intake. For example, P1 shared "XX doesn't drink enough and XX's very active . . . I know your nutrition and your energy are very related."

Factors Influencing Nutrition-Related Health of Children with T21

Other factors were discussed by moms about the nutrition-related health of their child with DS including: sleep health, physical health and body weight. Sleep health was identified by some moms as being an important factor influencing their child's health. For example, P9 shared that "XX wakes up every single night. XX's awake for about 2 hours . . something's happening at night in XX sleep . . . something is keeping XX awake, whether it's pain . . . or if it's reflux, which is what I think is probably more of a reflux thing." P10 explained "XX's waiting for surgery for sleep apnea because XX wakes up all night long and can't breathe, and hopefully, that will make a difference."

A collection of other individual physical health factors (for example: dry skin, reflux, heart condition) were discussed by moms as influencing the overall health and well-being of their child with DS. For example, P7 described "XX skin is very dry, and XX always complains that it's itchy and XX's got like a lot of redness . . . I don't know if it's like eczema psoriasis, but like very rashy face, rashy skin."

Many moms shared their concerns about their child's body weight, and recent changes to the same. For example, P3 worried that "X's still very underweight and XX's struggling to gain weight" while other parents expressed concern with weight gain. For example, P6 shared "I don't know if it's because of the muscle tone with Down syndrome, but XX is overweight for XX age . . . that is kind of like a concern, just that XX is overweight." Likewise, P7 noted "XX definitely has gained a lot of weight in, I would say in the last 2-3years. And although the doctor seems to not be too concerned, it is concerning to me." P10 elaborated to clarify "I want XX to be able to move XX body and use it . . . I don't think it's just stigma, I'm actually worried about XX ability to get up and do things and move around."

Future Health of Children with T21

In addition to sharing their concerns about their child's food and beverage consumption, and other factors related to their child's nutrition-related health, some mom shared their worries about their child's health in the future (near and far). For example, P1 expressed "XX energy has been really, really low and XX sleep has not been good for the last couple months . . . sometimes I wonder about things like that." P3 reported that "The pediatrician ordered blood work because XX has been looking quite pale lately. We've all kind of noticed, but I haven't heard back yet from that." P10 also shared that "XX also has a life limiting heart condition so XX's unlikely to live a normal life or to live a full life, so I worry about that a lot."

Parent Concerns about the Body Weight of Height of Their Child with T21

When asked specifically whether they had any concerns about the height or weight of their child with T21, 47% (n=6) of moms answered in the affirmative. Of those who stated they were concerned about their child's body weight or height, they were asked to elaborate and describe their concern. While a few moms offered statements about their child's under- or over-weight body status, despite regularly monitoring of the same, overall, inductive coding of their responses revealed a new main theme of moms experiencing emotional stress related to their feelings of responsibility about the food choices and body weight of their child with T21.

> P3: It feels like it's such a struggle to get them to gain weight and then we go there and they're like, you have to try harder. I'm like trying pretty hard. So as a mother, it's a little hard to go through that to know that even your best effort is still not quite good enough.
>
> P10: I think I put a lot of pressure on myself that XX should eat something different, and XX doesn't want to . . . XX's literally eating the same thing all the time."

Parent Concerns about the Food Intake of Their Child with T21

Among the moms who participated in this study, 57% (n=8) shared that they were concerned about the food intake of their child with DS. Of those who shared their concerns, saturation was reached regarding the type of information generated from the transcripts. Inductive and deductive coding identified 2 main themes: 1) Concerns about the child's food and beverage consumption, and 2) Concerns about the child's health in the future.

Food and Beverage Consumption of Children with T21

Subcodes highlighted by moms regarding the food and beverage consumption of their child with T21 included: 1) Limited variety and nutrient intake, 2) Restrictive food texture preferences, 3) Insatiable appetite, and 4) Negative experiences related to eating.

Limited food choice impacted overall variety and consequently, nutrient intake. For example, P8 shared "So XX likes these 3 things. Sometimes XX will have XX, it depends on XX energy level and mood. But XX has very limited food." Similarly, P14 reflected "I wish XX was a bit more adventurous and tried new foods."

For some children with T21, their preferences for specific food textures reportedly impacted what foods they consumed. For example, P1 shared that "There's things I think XX likes . . . XX likes the taste but XX doesn't eat them because of a texture and XX''ll get upset" and P9 agreed that ". . . it's always kind of been texture . . . I'd puree stuff myself, but I can never get it like ground fine enough for XX."

Other moms spoke about what they perceived to be an insatiable appetite of their child with DS. P8 shared that "XX seems to always be hungry, and so like there's not really like a shut off valve for XX. Especially if XX likes something . . . . XX will go to town until you tell XX to stop, and even then XX'll want more . . . we usually do have to cut XX off." Likewise, P10

observed “I think when XX's tired, I think XX actually thinks XX's hungry. So the messages are crossed. So XX doesn’t stop (eating).”

Finally, a couple of moms described the emotional and negative (past and present) experiences related to eating of their child with T21. P9 shared that “XX’s so aversive to trying new things. Like it's almost like every single day at, you know, whenever we sit down to eat, XX doesn't want to sit down to eat, and XX’s pushing XX plate . . . there's no enjoyment, I think, in food.”

> P1: And then finally, our doctor referred us to the food clinic and they put us back on purees. And I remember when they told me that whoever told me that I needed to pressure XX to eat solid foods was wrong. I literally cried because nobody had said that to me and I think that whole time in XX’s life was so hard and . . . XX little body remembers how stressful that was so now when we try to get XX to try new foods, there's like a gut reaction where XX just automatically starts gagging or gets heightened emotions around it.

Future Health of Children with T21

Some moms shared their concerns about the future health of their child with T21, as it related to their nutrition-related health in the present. For example, P2 explained “We just don't want to go down the wrong road because we know our kids can become obese, right? So we're, monitoring things and we're always checking ourselves and what XX's getting, So we don't set XX up for failure.” P9 detailed “If we can't get XX constipation under control that's going to affect the nerves in XX bowels and then we're going to start having accidents . . . and then we're going to regress back to, you know, diapers or something like that.”

Primary Care Provider Concerns about Health of Child with T21

All of the children with T21 included in this study were followed by a pediatrician as their primary care provider. When moms were asked if their child's pediatrician ever shared concerns about their child's growth, food intake, or physical activity, 21% (n=3) answered yes. Moms were asked to describe in detail what concerns their child's pediatrician shared with them. Inductive and deductive coding revealed 2 main themes: 1) Child's food and beverage consumption and 2) Factors influencing nutrition-related health.

Food and Beverage Consumption of Children with T21

One mom shared that their child's pediatrician discussed inadequate nutrient intake, related to their child's food choices. P9 stated "About XX iron being low . . . you just need to try to get XX to eat some meat and try to get XX to eat maybe some shellfish."

Factors Influencing the Nutrition-Related Health of Children with T21

Another mom described their child's experience receiving a diagnosis for hypothyroidism, which was associated with changes to their child's body weight. P11 explained "Well, because of the thyroid . . . that was completely undiagnosed, and that was pretty severe when we realized what was going on with XX. And then when we got XX on XX meds and that all normalized, XX definitely shot up and lost a bunch of weight . . . so XX wants to see XX in 3 months . . ."

Provision of Nutrition Knowledge and Care in Manitoba to Children with T21

Among the moms who participated in this study, 71% (n=10) reported that they had received in the past, or were currently receiving, nutrition knowledge and care for their child with T21. The same proportion of moms (71%; n=10) reported that they would like to receive nutrition knowledge and care for their child with DS in the future.

Parent Experiences and Preferences Receiving Nutrition Knowledge and Care for their Child with T21

Among the moms who shared they had received nutrition knowledge and care for their child with T21 (71%; n=10), moms were asked to describe their experiences with these services and identify the services or methods they found most helpful. From deductive coding of responses several themes emerged including the following: 1) Positive experiences receiving nutrition knowledge and care, 2) Negatives experiences receiving nutrition knowledge and care, 3) Nutrition knowledge and care provision from multiple healthcare service providers, and 4) Information sharing approaches that were perceived as helpful by parents.

Positive Parent Experiences Receiving Nutrition Knowledge and Care for their Child with T21

Some moms spoke positively about the nutrition knowledge and care they received for their child with T21. For example, receiving services from an occupational therapist about how to improve their child's food and beverage consumption.

> P1: We had an occupational therapist through XX last school and XX was so wonderful and amazing. XX used to give us like different mouth sensory exercises to help the with the goal of helping XX get more comfortable with different sensations so that XX could eat more foods.
>
> P3: XX's been seeing the feeding clinics since XX was two years old. XX's been seen at least once a year, I would say, although with the pandemic in there, it's hard to remember what was going on then. I think we had a few phone appointments and it's been helpful. There's a pediatrician and an OT there. The OT will give suggestions . . .used to give suggestions on getting XX on solid food, but now that his weight has kind of slowed down lately they're more focused on what XX's actually eating . . . So yeah, they gave me

some things about how to add that to XX diet and the vitamins and it's been good overall, I would say . . . I feel supported by them.

Positive experiences occurred receiving services from other health professionals as well.

P4: The SSCY center was amazing, because that helped me so much . . . I didn't know how much XX should be taking when XX was on the feeding tube . . . so that was really helpful. They told me exactly how many milliliters of formula XX needed, and then if XX ate this, then XX could have less, and there was a whole big formula for that.

P11: It was good . . . We were concerned with the amount of foods that XX was eating. It was like a list of the 5 things that XX would just cycle through and wanting to get those nutrients in. XX was a lot more picky when XX was younger, and it was a good experience. She (the dietitian) basically just said, to keep providing and give one thing that we know XX does like. So then eventually it kind of caught on and just took a lot of time . . . it was a good experience, and we got in fairly quickly as well with like the referral.

Negative Parent Experiences Receiving Nutrition Knowledge and Care for their Child with T21

Unfortunately, for some study participants, receiving nutrition knowledge and care for their child was not always a positive experience. P1 shared "There was a public health nurse when XX was really little . . . The public health nurse was awful." P4 added "With the dietician. I feel like I didn't get enough information from her. So a lot of what we've been doing is self research. I wish that the dietician would have followed up more after getting the XX (not T21) diagnosis." P9 also shared her disappointment, "Basically the help that we were given was basically just to keep introducing it (the food) . . . the lip and tongue tie was something that I discovered with my friend . . . That was a big disappointment because we struggled for so long

with trying to get her to breastfeed . . . and nobody even investigated whether it was an issue inside of XX mouth, why XX couldn't latch so. That was frustrating."

Parents Receive Nutrition Knowledge and Care for their Child with T21 from Multiple Healthcare Providers

Some moms spoke about receiving nutrition knowledge and care for their child with T21 from multiple healthcare professionals.

> P1: Public health when XX was really little, and then the food clinic, they had a dietitian and then there was two people we saw there. I think the other one might have been an occupational therapist, but I can't totally remember . . . and then XX's pediatrician . . . we (also) had an occupational therapist through XX last school . . .
>
> P7: I just recently took XX to a naturopath on my own accord. I mean, of course, we get some advice from our doctor like XX's primary caregiver, the pediatrician . . .
>
> P9: We've been to feeding clinic . . . And then we've seen 3 different dietitians as well throughout our journey . . . OT at SSCY . . . I was seeing lactation consultants . . . The dentist that did XX lip and tongue snip, she gave me probably the most help . . . I also took XX to an osteopath who specializes in breastfeeding . . .

Approaches Perceived as Helpful by Parents when Receiving Nutrition Knowledge and Care for their Child with T21

Moms who participated in this study were asked about the types of nutrition-related healthcare services they would like their child with T21 to receive and how often and, how they would prefer to receive nutrition knowledge and care. Based on responses to these questions, moms are reportedly interested in learning about a variety of nutrition-related topics (fibre, metabolism, constipation, mouth anatomy, sleep) and, regarding the sensory components of food

and our sensory relationship with it. Moms also expressed interest in more research about the topics important to children with DS.

> P1: . . . even research like this can be really helpful because our kiddos have different sensory needs . . . their mouth anatomy is literally different than other kids and so that impacts them . . . there needs to be more understanding of kiddos with Down syndrome specifically, and how we can better support them on that journey, because now I have a XX that's basically traumatized from XX childhood food experiences, and that's not OK, and it limits XX experiences.

Some moms discussed the type and format of nutrition-related services they would prefer to receive for their child with T21. Frequent and individual meetings with a healthcare professional were perceived as more personalized and meaningful, but both in-person or virtual options were considered acceptable.

> P3: It would be nice if they were closer, but that's the same for every single doctor because we're XX hours away. So it's hard to go down for all the appointments all the time . . . a Teams meeting here would be nice to be able to do every two months with a nutritionist or a pediatrician . . .”
>
> P7:I like virtual or in person, the best, I would say, because I just feel like that's the most informative usually. And then you can actually ask questions and things like that. But I also do enjoy webinars. I find when I get emails that just kind of gets lost in the shuffle of all the other emails. Same with handouts. They just end up floating around my house.
>
> P8: I think, a meeting, probably because that's a little bit more personalized part . . . it doesn't matter how which way in person or virtual, but meeting would be better.

Non-judgmental and supportive approaches were cited by moms as helpful when receiving nutrition information and care for their child with T21 from healthcare professionals. P1 shared "And then the doctor, the pediatrician, XX was really wonderful in the sense that it was really basic information, but XX was supportive so it was nonjudgmental." P10 concurred "I think it's been really important that I've received care through people who are questioning fatphobia."

Triangulation of Quantitative and Qualitative Data

Nutrition-Related Health Status of Children with T21

As previously described in the Methods section, the NICK index was created to determine nutrition-related health of children with T21 included in this study based on triangulation of quantitative and qualitative data collection in this research study. A summary of the several iterations of the NICK index is presented in Table 12. In total, 6 versions of the NICK index were created with a variable number of factors considered, ranging from 11 to 25. Notably, the proportion of children with T21 attaining a score greater than 50% (determined to be considered 'adequate' on the continuum of nutrition-related health) was highest in versions 4-6 (71%; n=10) when 18-25 factors were considered (Table 12). Notably, in no versions of the NICK index did any child with T21 attain a score of 75%, the minimum value determined to be considered 'optimal' on the continuum of nutrition-related health.

Table 12

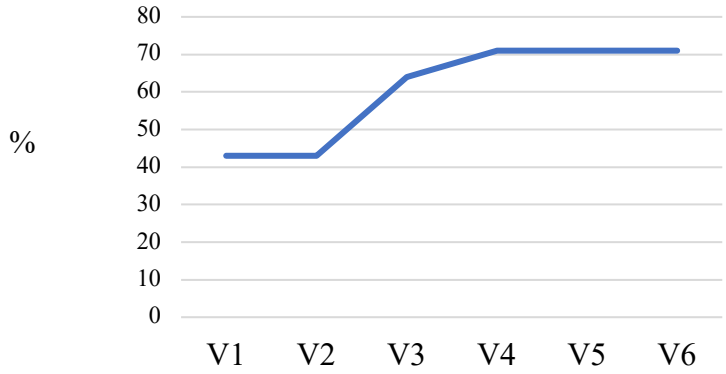
Nutrition-related health of children with T21

Version number (V#)	Factors considered	Total number of factors n	N Total (%)	Average score mean±SD (range)	Proportion scoring greater than 50% n (%)
1	Child's daily intake of 10 selected nutrients* and daily multivitamin usage (V1)	11	14 (100%)	5 ± 1 (2, 6)	6 (43%)
2	V1 plus child's daily physical activity and screen time levels (V2)	13	14 (100%)	6 ± 2 (2, 8)	6 (43%)
3	V2 plus child's breastfeeding history and breakfast consumption (V3)	15	14 (100%)	8 ± 2 (4, 10)	9 (64%)
4	V3 plus medical and family history of nutrition-related conditions and diseases, and diagnosis of food allergy or intolerance (V4)	18	14 (100%)	9 ± 2 (6, 12)	10 (71%)
5	V4 plus parent/caregiver and primary care provider concerns about child's health, growth, or food intake (V5)	22	14 (100%)	11 ± 2 (7, 14)	10 (71%)
6	V5 plus selected social determinants of health** (V6)	25	14 (100%)	14 ± 2 (10, 17)	10 (71%)

*protein, fat, carbohydrate, saturated fat, dietary fibre, added sugars, calcium, iron, sodium, and vitamin D
**Manitoba residency within the past year, parent value about nutrition, parent household income

Figure 5

Proportion of children with T21 attaining a score greater than 50% using different versions (V1-V6) of the NICK index



Summary of Findings

In sum, among the children with T21 included in this study, greater than the recommended intakes of sodium, added sugars, and saturated fat were observed. Conversely, daily intakes of vitamin D, calcium, and fibre were less than recommended amounts. However, daily intakes of iron, protein, and carbohydrate were within recommended amounts. Most children in the study population consumed a dietary supplement and engaged in daily moderate intensity physical activity for over 60 minutes. Overall, the nutrition-related health of children with T21 included in this study was adequate but not optimal, based on scores using the NICK index, which was designed to consider nutrition-related mixed data collected in this study to determine nutrition-related health of children with T21. Furthermore, there were no statistically significant associations observed between daily nutrient intake adequacy and any individual or external level factors influencing nutrition-related health measured in this research study. Moms shared their concerns about the nutrition-related health of their child with T21, particularly about

their child's body weight status, limited food/nutrient intake, and impact to future nutrition-related health. They also revealed positive and negative experiences receiving nutrition knowledge and care for their child with T21 from multiple care providers. Positive experiences included receiving meaningful care and follow-up and observing positive changes to their child's food intake and overall health. Negative experiences included feeling as though the care they received was not individualized, relevant, or impactful, and lacking follow-up and continuity of care. Moms also provided feedback about how they prefer to receive nutrition knowledge and care for their child with T21. Notably, individualized, supportive, non-judgmental, and online or in-person interactions were preferred.

Chapter 5

Discussion

The goal of this research study was to address the existing knowledge gap in Canadian literature about nutrition-related health and Trisomy 21. As a *first* step, this research study aimed to: 1) determine the nutrient intake and factors that may influence nutrition-related health of a sample of school-aged children between the ages of 6 and 12 years old with T21 living in Manitoba, and 2) learn more about their lived experience receiving nutrition knowledge and care.

To achieve the research objectives, a mixed methods research study was designed to collect both qualitative and quantitative data about the nutrition-related health of children with T21 living in Manitoba and their experiences receiving nutrition knowledge and care. A 24-hour dietary recall and a survey instrument were used to collect mixed data. Utilizing mixed methods is a notable strength of this research study. The addition of qualitative data allowed for greater understanding of quantitative findings and lived experiences. Further, utilizing different data collection tools within one data collection meeting with study participants provided an opportunity to validate some data as it was being collected, and to seek more information from study participants to clarify understanding and context. Also, patient engagement initiatives with parent engagement research partners prior to data collection for this research study is highlighted as a strength. Feedback from parent engagement research partners was valuable to improving recruitment, data collection and interpretation, and knowledge translation strategies. Hopefully, incorporation of their feedback throughout the research continuum also increased the relevance and meaning of the study findings to this key group of knowledge users.

Evidently, a small sample size lacking diversity in key areas (gender, ethnicity, duration of Canadian/Manitoban residency) is a limiting factor to generalizing the findings from this

study. A more expansive research project that included a more representative sample within Manitoba, or Canada, is recommended for future research to confidently advocate for and inform changes to health- and nutrition-related practice and care of all Canadians with T21.

The study participants were all female mothers, mostly Caucasian (79%; n=11), and between the ages of 31-50 years old (93%; n=13). Among them, 21% (n=3) self-identified themselves as Indigenous, which is a greater proportion than the 5% prevalence rate across Canada (Statistics Canada, 2021). Most of the study participants reported that their annual household income was greater than $100 000, which is more than the median household income of private households in Manitoba (approximately between $60 000-$70 000; Statistics Canada, 2021). Notably, the study population did not include families reporting less than the annual median household income in Manitoba. Most of the study participants were recruited through their membership with the MDSS. While this is a province-wide non-profit advocacy organization, not all Manitoban parents of caregivers of children with T21 may have membership with MDSS, so the study sample may not be considered a representative sample of children with T21 living in Manitoba. Data about marital status, or total number of occupants in a household, was not collected in this research study. This may have been an important factor to consider, to better understand the income earning potential, and barriers to the same, of families with children with T21.

This study aimed to recruit parents and caregivers of school-aged children with T21. While their relationship to their child with T21 was asked of study participants during data collection meetings (for example: mother, father, grandparent, etc), data to differentiate between birth, foster, or adopted parents or caregivers was not collected. Among a larger study sample, it may be reasonable to consider this type of data about parentage, as it is possible that birthplace

and other circumstances at the time of birth may potentially influence the (nutrition-related) health of a child. However, in a small study sample drawn from a small provincial population, such as the one in this research study, this type of information may be considered identifying and non-publishable.

Research Objective 1

The first research objective was to determine the nutrient intake and factors that may influence nutrition-related health of children with T21 living in Manitoba. Research questions related to the first research objective included: 1) What foods and beverages do school-aged children (6-12 years) with T21 living in Manitoba consume?, 2) Do nutrient intakes from food of school-aged children (6-12 years) with T21 living in Manitoba meet dietary reference intakes?, and 3) What factors influence the nutrition-related health of school-aged children (6-12 years) with T21 living in Manitoba?. Discussion of the study findings associated with the first research objective and related research questions are presented next.

Food and Beverage Consumption and Nutrient Intake of Children with T21

Based on descriptive analysis of food and beverage consumption data, the types and amounts of foods and beverages consumed by children with T21 included in this study revealed adequate intakes of grain (approximately 5 when considering grain and whole grain servings), dairy (2.46 +/- 1.70), and meat and alternatives products (approximately 2), which was also reflected in adequate nutrient levels of carbohydrates and protein when food intake was analyzed for nutrient content. In contrast, the study population consumed a low average number of servings of fruits and vegetables (3.21 +/- 2.80) and whole grain products (0.79 +/- 1.25), reflected in inadequate intakes of fibre. Notably, the number of servings children with T21

included in this study consumed foods from these food groups was comparable to that observed of Canadian children of similar ages without T21 (Hack, 2021).

Frequency of snack and 'other' food consumption was high among the children with T21 included in this study and corresponded with excessive intakes of added sugars and sodium. Notably, children with T21 included in this study consumed a variety of different types of foods, even if not always in adequate amounts, which corresponds with the varied food types consumed by children with DS reported by other researchers (Bialek-Dratwa et al., 2023).

A recent review that summarized food intake among persons with T21 (Gruszka & Wlodarek, 2024) reported low intake of fruits, vegetables, whole grains and dairy products, and excessive intakes of meat products and sugar-containing foods and beverages among children and adults with T21. These findings are like those observed in this study regarding low fibre, fruit and vegetable, and whole grain intake. However, the findings reported by Gruszka & Wlodarek (2024) differ than those observed in this study regarding dairy and meat products.

Among the children with T21 included in this study, the daily average energy intake was approximately 2100 kcal, which was higher than energy intakes reported among children with DS living in Turkey (approximately 1800 kcal/day; Kaya et al., 2024), Brazil (approximately 1800 kcal/day; Magenis et al., 2018), and Saudi Arabia (approximately 1700 kcal/day; Samarkandy et al., 2012). Notably, daily average energy intake in the study population was higher than Canadian female children without DS, but lower than Canadian male children without DS, between the ages of 9-13 years old (Ng et al., 2021). The estimated average total energy intake among Canadian girls between the ages of 9 and 13 years old was approximately 1700 kcal/day and 2200 kcal/day for boys (Ng et al., 2021).

Despite these differences, total energy intake from food and beverage consumption was greater than the Adequate Intake (AI) for 57% (n=8) of the study population and less than the AI for 43% (n=6) of the study population. Given that AI is intended to meet or exceed the needs of most individuals, it is concerning that nearly half the children with T21 included in this study did not consume adequate energy, especially given the period of growth and energy needs expected during this life stage. Indeed, if consistent, overall inadequate energy intake likely leads to inadequate nutrient intake, and unfavourable consequences to nutrition-related health over time.

The children with T21 included in this study consumed an average daily intake 283 grams of carbohydrate, which was higher than intakes reported among children with DS living in Brazil (280 grams; Magenis et al., 2018), Saudi Arabia (247 grams; Samarkandy et al., 2012), and Turkey (208 grams; Kaya et al., 2024), but comparable to findings about carbohydrate intake (as a percentage of total energy) of American children with DS (Luke et al., 1996). Compared to larger sample sizes (n=1842) of Canadian children without T21 between the ages of 9-13 years old, the children with T21 included in this study consumed comparable amount of protein, fat, and carbohydrate and within the AMDR (Ng et al., 2021). An average of 16.2% of energy from protein was observed among Canadian children without T21 and 13.5% among the children with T21 included in this study; both were within the AMDR. An average of 33.4% of energy from fat was observed among Canadian children without T21 and 29.5% among the children with T21 included in this study; both were within the AMDR. An average of 49.3% of energy from carbohydrate was observed among Canadian children without T21 and 54.3% among the children with T21 included in this study; both were within the AMDR.

Dietary fibre intake among the children with T21 included in this study did not meet DRI recommendations for 79% (n=11), whereas added sugar intake exceeded amounts determined as

‘ideal’ by the American Heart Association (AHA; no more than 6% of total energy per day) for 79% (n=11). Adequate fibre intake is a well-known protective and preventative factor against several chronic diseases such as some types of cancer and cardiovascular disease (Veronese et al., 2025). Further, among children, low dietary fibre intakes may be associated with greater prevalence of constipation and obesity (Boctor, 2020).

While the impact of added sugar on human health has at times produced mixed results, depending on the health condition studied, the overall effect appears to be negative when consumed in excess (Gillespie et al., 2023). The daily average intake of added sugars among the children with T21 included in this study was 41 grams, and while this amount is higher than the ‘ideal’ amount suggested by the AHA, which is 36 grams/day for men and 25 grams/day for women (American Heart Association, 2024); it is *less than* the daily limit recommended by Diabetes Canada (50 grams; Diabetes Canada, n.d.). Notably, added sugar intake of children with T21 has not been reported elsewhere.

Inadequate fibre intake among children with DS have also been reported in Brazil (Magenis et al., 2018), Turkey (Kaya et al., 2024), Saudi Arabia (AbdAllah et al., 2013), and the United States (Luke et al., 1996). The daily average dietary fibre intake among the children with T21 included in this study was 19 grams, which is the same as what has been observed among children with DS living in Turkey (19 grams; Kaya et al., 2024); less than what has been observed among children with DS in Brazil (23 grams; Magenis et al, 2018); and greater than what has been observed among children with DS in Greece (9 grams; Grammatikopoulou et al., 2009), Saudi Arabia (12 grams; Samarkandy et al., 2012), and among Canadian children without DS (17 grams and 15 grams for boys and girls, respectively, between the ages of 9-13 years; Ng et al., 2021).

Adequate protein intake observed among the children with T21 included in this study align with findings reported by other researchers in Greece (Grammatikopoulou et al., 2009) and the United States (Luke et al., 1996). Children with T21 included in this study consumed on average approximately 73 grams of protein a day, which was higher than average amounts reported among children with DS living in Brazil (68 grams; Magenis et al., 2018), Turkey (71 grams; Kaya et al., 2024), and Saudi Arabia (55 grams; Samarkandy et al., 2012). Notably, children with T21 included in this study consumed on the average the same number of servings of meat alternatives as meat products (1 serving per day of each); adequate amounts of meat alternatives were also observed among children with DS living in Italy (Roccatello et al., 2021). Emphasis on consuming plant-based sources of protein is noted in the most recent versions of both Canada's and Italy's dietary guidelines (Government of Canada, 2019; Rossi et al., 2022).

Furthermore, iron intake levels were within recommended ranges for most of the children with T21 included in this study (93%; n=13). This is important, given that supplementation of this mineral may be recommended in some children with DS, who experience sleep problems and have low ferritin concentrations, which is an indicator of iron storage in the blood (Bull et al., 2022). Likewise, Grammatikopoulou and colleagues (2008) reported 75% of their study sample, consisting of children with DS between the ages of 6 to 9 years old living in Greece, met the daily dietary reference intake for iron. The daily average intake of iron among the study population was 15 mg, which was higher than intakes reported for children with DS living in Turkey (10 mg; Kaya et al., 2024), Brazil (14 mg; Magenis et al., 2018), and the United States (10 mg; Luke et al., 1996); but lower than that for children with DS living in Saudi Arabia (25 mg; Samarkandy et al., 2012). Children with T21 included in this study consumed a higher daily

average of iron than Canadian children without T21 (approximately 14 grams and 12 grams for boys and girls, respectively, between the ages of 9-13 years; Ng et al., 2021).

Children with T21 included in this study consumed on average approximately 81 grams of fat per day, which is more than the average amount consumed by children with DS living in Turkey (73 grams; Kaya et al., 2024), Brazil (53 grams; Magenis et al., 2018) and Saudi Arabia (53 grams; Samarkandy et al., 2012). Interestingly, among the children with T21 included in this study, daily total fat intake as a percentage of total energy was within recommended ranges for only half (n=7) of the children, despite a high number of times 'other' and snack foods were consumed, which tend to contain higher amounts of fat. It may be of concern that among the children with T21 included in this study, approximately one-third (n=4) did not meet the recommended intake for fat, an important macronutrient required for optimal growth and development during childhood. Compared to Canadian children between the ages of 9-13 years old without T21 (Ng et al., 2021), who consumed approximately 33.4% of total energy from fat, the children with T21 included in this study consumed less total fat as a percentage of total energy intake per day (32.1%), but both were still within the AMDR.

Children with T21 included in this study consumed an average of 2.5 servings of dairy products per day, which is within the recommended number of servings suggested by older versions of Canada's food guide for children between the ages of 5 and 13 years old (Health Canada, 2011). However, despite the apparent adequate daily intake of dairy products, daily nutrient levels of calcium were less than DRIs for 71% (n=10), likely due to more common reported consumption of cheese and yogurt dairy products instead of milk, which contains greater amounts of calcium per serving size. The daily average intake of calcium among the children with T21 included in this study was 899 mg, which is higher than amounts reported

among children with DS in Brazil (688 mg; Magenis et al, 2018), Turkey (840 mg; Kaya et al., 2024), Saudi Arabia (515 mg; Samarkandy et al., 2012), and the United States (897 mg; Luke et al., 1996). The children with T21 included in this study consumed a comparable daily average intake of calcium compared to Canadian children without T21 (approximately 1100 milligrams and 900 milligrams for boys and girls, respectively, between the ages of 9-13 years; Ng et al., 2021).

Another important finding was related to Vitamin D intake. Levels of vitamin D intake from food and beverage consumption were below recommended intakes for all the children with DS included in this study (n=14). This is not surprising given that vitamin D-fortified milk and fatty fish are among the few food sources of dietary vitamin D (Government of Canada, 2022), and neither of these were consumed in notable amounts by the children with DS included in this study. The average daily intake of vitamin D among children with DS included in this study was 115 IU, which was lower than average daily intake levels of vitamin D observed among children with T21 living in Turkey (approximately 222 IU; Kaya et al., 2024), and those of Canadian children *without* T21 (228 IU and 188 IU for boys and girls aged 9-13 years old, respectively); but higher than intakes reported among children with T21 living in Brazil (94 IU; Magenis et al., 2018).

Among the children with T21 included in this study, snack foods (crackers, applesauce, granola bars, pretzels) were consumed on average 1.7 times per day, and 'other' foods (condiments, chocolate, chips, juice, dessert) were consumed on average 4.2 times per day. Snack and 'other' foods usually contain higher amounts of nutrients that are typically recommended *to limit* such as, added sugar and sodium; which is reflected in the observed

excessive intake of both these nutrients among the children with DS included in this study. Similar findings were observed among Canadian children without T21 (Hack, 2021).

The daily average intake of sodium among the children with DS included in this study was 2852 mg, which was lower than intakes reported among children with T21 living in Turkey (3164 mg; Kaya et al., 2024), in Brazil (3209 mg; Magenis et al., 2018); but higher than intakes reported among Canadian children without T21 (2740 mg and 2410 mg for boys and girls aged 9-13 years old, respectively; Gowrishankar et al., 2020). Notably, higher than recommended intakes for sodium have been observed among *apparently healthy* children globally (Rios-Leyvraz et al., 2025).

Among the children with DS included in this study, water, juice, and then milk, were the most frequently consumed beverage choices. Notably, none of the children with DS included in this study consumed carbonated sugar-sweetened soft drinks. Fluid intake of children with T21 has not been described in detail in existing literature although, Magenis and colleagues reported low water intake among children with T21 living in Brazil (2018), and greater variety of sugar-containing beverages was reported among Canadian children without T21 (Warren et al., 2022).

Among the children with DS included in this study, daily dietary supplementation was common (71%; n=10). This finding is consistent with findings of previous studies of children with T21 (e.g.,(Lewanda et al., 2018). However, the rate of supplementation among the children with DS included in this study (71%) was much higher than the reported rate for children with T21 living in the United States (approximately 38%; Lewanda et al., 2018) and in Turkey (approximately 15%; Kaya et al., 2024). For the majority (80%) of dietary supplement users among the children with DS included in this study, the dietary supplement provided was a daily

multivitamin, which may have helped to address inadequate dietary intakes of some nutrients such as calcium and vitamin D (Bayer Incorporated, 2021).

Factors Influencing Nutrition-Related Health of Children with T21

Among the 14 children with T21 included in this study, there were no statistically significant associations found between their daily nutrient intake adequacy and medical or family history of nutrition-related condition or disease, physical activity levels, screen time usage, breastfeeding history, onset of puberty, food aversions or preferences, requirement for assistance or supervision during eating times, religion, culture, the COVID-19 pandemic, reception of nutrition knowledge and care, ethnicity, geographic location or duration of residency in Manitoba, sex, food used as a reward, parent or primary care provider concerns about child's health, or household income. This could potentially be due to the small size included in this study. A study with a larger sample size reported significant associations between nutrition-related health status of children with T21 and several factors that were considered in our study. For example, in their study of 30 children with T21 between the ages of 7-12 years old living in Indonesia, Andrews and colleagues (2023) reported a significant negative association between children's nutritional status and paternal education, and between children's nutritional status and children's diet quality; and a significant positive correlation between children's nutritional status and children's energy intake. These researchers did not observe a significant correlation between children's nutritional status and maternal education, parents' total income, children's physical activity, and maternal knowledge score. Notably, in their study, nutritional status reflected body weight status alone (Andrews et al., 2023) and they considered different factors than those included in this research study as well.

Body weight status was not considered as an independent or dependent variable in this research study for the following reasons: 1) data about body weight and height was self-reported from parent's recollection of their child's most recent body weight and height measurement, which may or may not have been completed by themselves, 2) body weight status was not the focus of this research study, as it is only one of several factors that are important and influential to nutrition-related health, and 3) the target study population age range for this research study is during a time of constant growth and development, wherein the consistency (or lack thereof) and pattern of growth may be considered a more important indicator of a child's nutrition-related health than a single measure of their body height and weight. Therefore, nutrient adequacy based on food and beverage consumption as an indicator of diet quality, was chosen as the dependent variable in this research study. Furthermore, data about parent or primary care provider concerns about the child's growth pattern was collected, to account for the potential impact of body weight status on nutrition-related health of children, and these concerns were considered in some iterations (versions 5 and 6) of the NICK index (Table 12) as important variables to include in the assessment of a child's nutrition-related health.

Despite the absence of an observed statistically significant association between the daily nutrient adequacy of children with T21 included in this study and factors influencing their nutrition-related health, discussion of some factors may be considered insightful for future research opportunities and improvements to nutrition knowledge and care practice. For example, among our study population, carbohydrate-containing foods and those possessing specific food properties were listed most often as preferred foods. Similar findings have been observed by others (Roccatello et al., 2021; Kaya et al., 2024; Ross et al., 2019, 2022, 2024), suggesting there may be an opportunity to improve the variety and nutrient density of consumed foods by these

children by appealing to their preferences. Importantly, it seems pertinent to emphasize that the reportedly consumed and preferred food properties of any group of children with T21included in a research study may vary according to a variety of factors such as culture, age, and season. Indeed, the takeaway from research findings such as these may be that there is individual choice and variation among food and beverages choices that need to be considered to implement meaningful and effective dietary interventions that aim to improve a child's nutrition-related health.

Even though nutrition-related medical and family history was not determined to be significantly associated with nutrient adequacy among the study population, this type of information may be important to monitor over time throughout the lifespan, as diagnoses of several nutrition-related conditions and diseases are likely to occur after childhood. The same may be said about monitoring for the presence/absence of food allergy, which potentially impacts food and beverage consumption to a lesser or greater degree, depending on the allergy, and may also change over time.

It is notable to highlight that all the children with T21 included in this study were seen regularly by a pediatrician, regardless of urban or rural residency in Manitoba, suggesting that infants diagnosed with T21 at the time of their birth receive a referral to a pediatrician (versus a general practitioner) in Manitoba. However, as no one in the study population resided in remote or isolated locations within the province, it is unknown whether the same access to pediatrician care is available to all Manitoban children with T21. Furthermore, it is unknown whether the same referral process occurs in other Canadian provinces. Among the moms who participated in this study, 93% (n=13) confirmed that their child was seen by their pediatrician at least once within the past 12 months. In 2008, it was reported in the Manitoba Child Health Atlas that

Manitoban children aged 0-19 years old received approximately 3 annual visits per year with their physician, which included visits with pediatricians and some other specialists (Brownell et al., 2008). Compared to these findings, the school-aged children between the ages of 7-12 years old with DS included in this study received one-third the number of visits with their primary care providers annually. Notably, the age range of the children with T21 included in this study was narrower than that reported about in the Manitoba Child Health Atlas and did not include early years (0-5 years), when children may attend physician visits more often to monitor growth and development, and to receive immunizations.

Assistance and/or supervision during eating times is another factor that may warrant closer investigation, particularly among children who are not assigned 1:1 care at school, given that 79% (n=11) of the children with T21 included in this study required these supports. For example, if assistance or greater time to eat is required but not allocated to a child, then they may not have the opportunity to consume an adequate intake that supports their nutrient needs. Kaya and colleagues (2024) also reported children with T21 included in their study needed help with eating, but only among approximately 38% of their study population. Of concern, it may be noted that one of the moms included in this research study did not know if their child received assistance or supervision during eating periods at school. While true for only one parent among those who participated in this study, it is a reminder about the need for effective communication between home and school to ensure that there are no unnecessary barriers to a child consuming adequate food safely to support their learning needs, particularly since some children may spend a significant part of their day at school and consume a significant portion of their total energy intake there.

It is important to note that there were no swallowing and choking concerns reported by moms about their child with T21 included in this study. This finding was surprising as most of the moms reported that their child with T21 required assistance or supervision during eating times. It is possible that because in all cases where assistance or supervision during eating times was required, it was provided; therefore, moms may not have had reason to report concerns about swallowing or choking issues. However, some moms expressed concerns about their child with T21 not being able to chew some types of foods such as meat (n=2) and experiencing discomfort while eating due to past negative experiences associated with eating (n=1). In this latter regard, the cause of discomfort was perceived to be related to having a negative experience receiving nutrition knowledge and care in the past, which highlights the need to advocate for the provision of informed and compassionate child- and family- centred healthcare services. Furthermore, greater examination of swallowing and choking concerns among a larger sample of children with T21 may yield greater insight, since feeding problems such as these have been identified among children with T21 by other researchers although, with variation in prevalence (Kaya et al., 2024; Bull et al., 2022).

Although there was no observed significant association between daily nutrient adequacy of the children with DS included in this study and the impact of culture or religion, these factors may have greater influence in a larger and more nationally- or culturally- diverse study sample. Notably, 79% (n=11) of the moms who participated in this study identified as Caucasian and 86% (n=12) had resided in Manitoba for over 30 years.

In this study, the COVID-19 pandemic did not have a statistically significant effect on daily nutrient adequacy of children with T21 included in this study. However, through qualitative interviews with moms, 57% (n=8) reported that the COVID-19 pandemic had an

impact on their child's food intake, physical activity, or nutrition-related health monitoring during that time. Notably, some children with T21 included in this study would have been 4 years old or younger during the COVID-19 pandemic. Given this, if they were cared for within a home environment during those early years, they may have been less impacted by closures and restrictions limiting physical activity opportunities outside of home environments during the COVID-19 pandemic. Finally, for some parents, their experience during the COVID-19 pandemic highlighted their concerns about their child's health in the future in a similar circumstance, where food supply may be disrupted again. There is no other published studies on the impact of the COVID-19 pandemic on children with T21 living in Canada or elsewhere.

Despite disruptions during the COVID-19 pandemic, 71% (n=10) of the children with DS included in this study reportedly met the recommended physical activity level of at least 60 minutes per day at the time of the study (Canadian Society for Exercise Physiology, 2025). Their activity level was described as low or moderate intensity by their moms. Similar findings were published by researchers in Japan (Yamanaka et al., 2020), while researchers in Italy reported higher levels of daily physical activity among children with T21 (minimum 2 hours per day; Roccatello et al., 2021). Conversely, among Canadian children in the general population between the ages of 5 and 17 years old, only 40% met the physical activity guidelines (Statistics Canada, 2019). While a greater proportion of the children with DS included in this study engaged in physical activity compared to what has been observed among the child population in Canada at large, the intensity of their physical activity may be improved from low-moderate to high. Furthermore, increasing the number of opportunities for children with T21 to engage in physical activity, or prescribing structured physical activity (Martinez-Espinosa et al., 2020) may help children with DS and their parents meet and maintain an active lifestyle.

Among the children with DS included in this study, only 14% (n=2) engaged in less than 2 hours of screen time per day, which meets the recommendation for recreational screen time (Canadian Society for Exercise Physiology, 2025). Notably, 21% (n=3) of children with DS included in this study engaged in more than 4 hours of screen time per day. Approximately 57% (n=8) of the children with DS included in this study reported between 2-4 hours of screen time a day, which is comparable to findings among children with T21 living in Saudi Arabia (Samarkandy et al., 2012). In comparison, among Canadian children between the ages of 5 and 17 years old without T21, approximately 53% met the recommended screen limit, and the average amount of screen time was 3 hours per day (Statistics Canada, 2019). Indeed, all Canadian parents of children with and without T21 may benefit from support, programming, and strategies that facilitate behaviour choices that are associated with positive health outcomes. In this way, applying a social ecological lens to examine more closely what factors may be improved to positively impact individual and family choices to engage in behaviours associated with positive health outcomes (for example: nutrient-rich food and beverage consumption and moderate-high intensity physical activity) may be helpful to determine what supports and services are most meaningful to children and parents. For example, exploring opportunities for children with T21 within school and community settings to engage in team-based sport and activity where their participation is welcome, and their needs are meaningfully supported.

Review of Research Hypotheses Related to the 1st Research Objective

The research hypotheses were informed by knowledge of the nutrition-related health of pediatric populations in general, and review of relevant literature specific to populations with T21. Regarding the first research objective, I hypothesized that school-aged children between the ages of 6-12 years with T21 living in Manitoba would consume a limited variety of foods and

beverages and inadequate nutrient intake levels compared to dietary guidelines. This hypothesis was based on knowledge about the suboptimal nutrition-related health among the general Canadian population, and review of published data about the nutrition-related health of persons with T21 living outside of Canada. I also hypothesized that there would be several factors, at the individual and other systems level, that influence the nutrition-related health of children with T21 living in Manitoba. This hypothesis was based on knowledge about the sociological model of health and personal experience working as a dietitian with individuals and families to improve nutrition-related health. The first two hypotheses were correct, in that the average number of daily servings of some food groups were low, which was reflected in overall inadequate intake levels of some nutrients compared to national dietary guidelines. Furthermore, some moms discussed their own concerns about their child's limited variety and/or unwillingness to try new foods. However, based on statistical tests conducted to determine if there was an association between daily nutrient intake adequacy (based on the daily intake of 10 selected nutrients and multivitamin supplement) and factors that may influence nutrition-related health, no significance was detected among this study sample size although, some observations based on descriptive analysis support future research in this area and improvements to nutrition knowledge and care practice.

Research Objective 2

The second research objective was to explore the perspectives of parents and caregivers of children with T21 about their child's nutrition-related health, and their lived experience receiving nutrition knowledge and care in Manitoba. Research questions related to the second research objective included: 1) Do parents and caregivers of school-aged children (6-12 years) with T21 have concerns about their child's nutrition-related health?, 2) Do school-aged children

(6-12 years) with T21 and their parents and caregivers living in Manitoba receive nutrition knowledge and care?, and 3) What has been the lived experience of, and preferences for, receiving nutrition knowledge and care of parents and caregivers of school-aged children (6-12 years) with T21 living in Manitoba (if applicable)? Discussion of the study findings associated with the second research objective and related research questions are presented next.

Concerns About Child's Nutrition-Related Health

Of those who had siblings among the study population (n=12), 75% of parents reported that they served their children with T21 the same foods as their other children. This observation contrasts findings from O'Neill and colleagues (2015), who found a significant difference for feelings of responsibility for feeding children with T21 compared to their siblings. However, like O'Neill and colleagues (2015), parents in this research study also shared concerns about their child's weight status. Notably, when parents were asked if they had concerns about their child's body weight or height, one parent spoke of emotional stress related to their feeling of responsibility about their child's food choices and, their child's body weight.

Additionally, when parents were asked if they or their child's primary care provider had concerns about their child's overall health or food intake, parents shared several examples. Notably, concerns from their child's primary care provider were less common than concerns from the parents themselves (n=3 versus n=8). Concerns about the child's food and beverage consumption included limited variety and inadequate amounts of nutrients, restrictive food preferences, insatiable appetite, and negative emotions associated with eating. Concerns about other factors that may influence nutrition-related health include an assortment of physical health indicators especially, body weight status, particularly if unexplained changes to weight were recently observed. Parents also spoke about their concerns about their child's health in the future,

related to current co-existing medical diagnoses other than T21, and the potential of experiencing additional diagnoses in the future.

Parent Lived Experience and Preferences Receiving Nutrition Knowledge and Care

Among children with T21 included in this study and their moms, reception of nutrition knowledge and care was relatively common (71%; n=10) and provided by multiple healthcare service providers. Additionally, 71% (n=10) of moms shared that they would like to receive nutrition knowledge and care in the future for their child with T21. However, not all experiences receiving nutrition knowledge and care were perceived as positive by moms. Notably, location of residence did not appear to be a barrier to receiving nutrition knowledge and care among the children with DS included in this study and their moms, who resided equally between urban and rural settings within Manitoba, as apparently most had access to professional nutrition knowledge and care. Interestingly, approximately one-third of moms (n=4) stated they did not wish to receive nutrition knowledge and care for their child with DS in the future, even though all moms claimed to value nutrition as an important part of their child's overall health. It is unknown if the disinterest to receive future nutrition knowledge and care for their child with DS was exclusively a consequence of having negative experiences receiving the same in the past, or because moms felt they were adequately educated or resourceful to become well-informed about nutrition-related topics as necessary by themselves, or a combination of these or other factors. Finally, of those who were interested in receiving nutrition knowledge and care for their child with DS in the future, moms supported future research initiatives about T21 and nutrition, and shared that they would like to receive more information about a variety of nutrition-related topics including, but not limited to, metabolism, sleep, and the sensory components of food. Individualized virtual or in-person meetings were regarded as the preferred format to receive

nutrition knowledge and care from healthcare professionals by moms, and non-judgemental and supportive approaches when discussing nutrition-related topics about their child with DS (including concerns) were preferred.

Review of Research Hypotheses Related to the 2nd Research Objective

Regarding the second research objective, I hypothesized that parents and caregivers of children with DS living in Manitoba would have concerns related to their child's nutrition-related health and preferences regarding how they receive nutrition knowledge and care for their child. These hypotheses proved to be true, as moms shared several concerns related to the overall health, food intake, and body weight status of their child with DS. They also shared ideas about the type and format of how they preferred to receive nutrition knowledge and care, and what approaches were perceived to be most helpful when communicating with healthcare providers. I had not expected that the children with DS included in this study and their moms would be current or past recipients of nutrition knowledge and care, as most (71%; n=10) had in fact, previously received the same, and from multiple healthcare providers.

Nutrition-Related Health of Children with T21 Using the NICK Index

Nutrient intake adequacy and selected factors known to influence nutrition-related health, based on mixed data collected in this research study, were compiled in several iterations of the NICK index to determine the nutrition-related health of the children with DS included in this study. Based on the quantitative and qualitative data collected in this research study about children with T21 living in Manitoba, regardless of the combination of nutrition-related health factors considered, no child with DS included in this study attained a score determined to be 'optimal' nutrition-related health (75%). At best, 50% was accepted as a score indicating 'adequate' nutrition-related health and even then, not all children with T21 included in this study

achieved this score although, there was some variation among different versions of the NICK index (Table 12). Given these findings, after carefully comparing and relating both quantitative and qualitative data, there is reason to advocate for the provision of improved nutrition knowledge and care to children with T21 living in Manitoba to improve their nutrient intake and nutrition-related health. Additionally, use of the NICK index in future research studies including children with T21, and in practice among health care providers who provide care to children with T21, may be a useful resource to determine their nutrition-related health. For example, in practice, primary care providers may refer children with T21 to nutrition professionals for nutrition assessment using the NICK index to determine their nutrition-related health.

Strengths and Limitations of the Research Study

This research study had several strengths. First, it is the first Canadian research study to include children with T21 and determine their nutrition-related health, so the findings are novel. Second, patient engagement initiatives were conducted prior to data collection to inform several aspects of the research study as an attempt to design a research study that would reflect the values and lived experiences of families and caregivers and produce findings that may be perceived as meaningful. Third, the mixed method design provided an opportunity to collect richer data that more accurately depicts the nutrition-related health of Manitoban children with T21 and enhances the understanding of their lived experience receiving nutrition knowledge and care. Fourth, more than one data collection tool was used in a single data collection meeting to collect information about food and beverage consumption, which may increase the likelihood that the information shared was accurate, as there was an opportunity to validate responses.

There are several types of information bias likely to occur in health studies from either how study participants are selected, or how data is collected or measured (Althubaiti, 2016). An

unavoidable limitation in nutrition studies that aim to collect data about food and beverage consumption from individuals living in uncontrolled environments are the imperfect data collection tools available and in particular, their reliance on accurate and comprehensive self-reporting. To mitigate the potential impact of self-reporting bias, simultaneous collection of mixed data during one data collection meeting with individual study participants in this research study provided an opportunity to valid different types of data. For example, responses to some questions included in the survey instrument about food and beverage preferences or aversions were compared to data collected using the 24-hour dietary recall tool. Likewise, semi-structured interview questions designed to explore greater context about factors impacting nutrition-related health and lived experience receiving nutrition knowledge and care validated close-ended questions within the survey instrument. Furthermore, a shorter recall period (24 hours) may be preferable when asking study participants about routine or frequent events such as typical food and beverage consumption (Althubaiti, 2016). Although, on the other hand, a shorter recall period and single timepoint measurements may not reflect long-term health. Further, the 24-dietary recall does rely on memory and self-reported data, which may not always be accurate (therefore susceptible to recall bias). As parents were sharing food and beverage consumption data for their school-aged child on a school weekday, it is also possible that they were unaware of some foods or beverages their child consumed at school, or if their child was cared for outside of the family home or by another caregiver before or after school.

Another limitation of using a 24-hour dietary recall to collect information about food and beverage consumption is that it only reflects the dietary intake of one particular day, which may or may not reflect a person's usual intake. For example, data collected using a 24-dietary recall may not reflect the intake of foods and beverages that are consumed regularly but not daily, such

as restaurant foods. Among the children with T21 included in this study, there was only one child who happened to consume restaurant (fast) food on the day their food and beverage consumption was recorded. This may be an example of a potentially incomplete or inaccurate reflection of the typical intake of restaurant (fast) food consumed by the children with DS included in this study. The same may be true of the children's consumption of soft drinks, which happened not to be consumed by any child with DS included in this study on the day the food and beverage consumption was recorded. While it may be possible that water, juice, and milk are the only beverages consumed by these children with DS, it is also likely that some children with DS included in this study consume other beverages such as soft drinks sometimes.

Self-reported data about physical activity may also be considered a limitation. However, the purpose of collecting data about the daily duration of physical activity of children with T21 included in this study was to assess whether the child engaged in a sedentary lifestyle, and not to evaluate their physical activity with precision. Further, requesting information about the duration of physical activity greater or less than 60 minutes aligns with gathering data to compare the amount of daily physical activity to the Canadian daily physical activity recommendations for young children. Admittedly, and notably, the intensity of physical activity is also an important consideration. Definitions of low, moderate, and high intensity activity were provided to moms to help them answer this question about their child with DS with accuracy. Self-reported data about the duration and intensity of physical activity were a valuable input to more accurately assess the nutrient intake of foods and beverages consumed using the nutrition software program. For example, for each child's individual profile in FoodFocus, their age, self-reported height, weight, physical activity duration, and physical activity intensity, were entered to determine their

daily energy needs. Subsequently, the recommended intake of some nutrients was based on calculated daily energy needs.

It is possible that as a fellow mom to a similarly-aged child born with T21, as a practicing dietitian, or as a rural and long-term resident of Manitoba, my interpretation of the data may be biased. To mitigate any potential bias I inadvertently introduced, a multitude of factors were included and considered when assessing nutrition-related health in this research study, and data analysis was reviewed by others. Further, parent engagement research partners informed the list of factors that were included and considered as important to nutrition-related health. After each data collection meeting, I wrote reflexive memos to help identify person biases. Triangulation of mixed data and different data collection tools was further intended to reduce bias and increase validity. Finally, after data analysis was completed, I met with parent engagement research partners to share preliminary findings and to ask for their review of my data interpretation.

A small study sample size is a limitation to generalize the findings produced from this research study, and because it lacked diversity in parent gender, household income, and ethnicity, it may not be considered representative of parents or caregivers of children with T21 living in Manitoba. As nutrition-related health data for the siblings of the study population was not collected in this research study, there was no comparison between the absence of presence of a T21 diagnosis within a similar home environment. However, among the study population, 14% (n=2) did not have any siblings and also, among those who did have siblings, they may have been outside the target age range of our study population (6-12 years old). Indeed, a larger study sample overall would have been preferable to draw comparisons between children with T21 and a control group, whether the control group was derived from sibling data or from the general population. Additionally, the study population did not include parents or caregivers who had

moved to Canada within the last year, Manitobans living in isolated locations, dads, younger or older parents, or lower-income households. Given these absences and lack of diversity, the children with T21 included in this study and their moms may not be considered representative of Manitoban children with T21 and their parents or caregivers.

Finally, in reviewing quantitative and qualitative data together to create the NICK index and determine overall nutrition-related health of children with DS included in this study, 'adequate' nutrition-related health was determined to be attainment of 50% of nutrient adequacy of selected nutrients and consideration of selected factors influencing nutrition-related health. While 50% may be considered a 'passing' grade, it is a modest indicator for health and arguably less than one may consider acceptable. Indeed, optimal nutrition-related health is likely to be considered far greater than even 75%, a score which no child included in this study attained, indicating that there is much room to improve nutrition-related health among children with T21 living in Manitoba based on the study findings.

Chapter 6

Conclusions

There is much to learn about the nutrition-related health of Canadian children with T21 and what may be done to improve their nutrition-related health throughout their lives. This research study offers some foundational knowledge about the current nutrition-related health of children with T21 living in Manitoba, and their nutrition-related health needs. Increased attention to Canadian children with T21 is required to support research initiatives including the same, and to improve the current provision of nutrition knowledge and care offered to these children and their families.

Recommendations for Future Research, Policy and Practice

Based on the findings generated from this research study, several suggestions may be made for future research studies to continue building the knowledge base about the nutrition-related health of Canadian children with T21. Collecting data from a larger, and more diverse, study population may be more representative of Canadian children with T21. Further, a larger and more diverse study population may provide stronger evidence regarding whether there is, and to what degree, an association between their nutrient intake adequacy and selected factors influencing their nutrition-related health. The NICK index may be used in future research studies to test its validity to measure the nutrition-related health of a larger and more representative study population. Finally, future research studies may include measurements of body composition among children with T21; and quantity and quality of sleep, as sleep is an important indicator of good health (American Heart Association, 2025), and obstructive sleep apnea has been identified as a common problem among some children with T21 (Bull et al., 2022).

Based on the findings generated from this study, several suggestions may also be made to improve the current provision of nutrition knowledge and care to Canadian children with T21. Given the low score of nutrition-related health among the children with T21 included in this study using the NICK index in this study, attention to the nutrition-related health of children with T21 by multiple healthcare professionals is warranted immediately. Indeed, it may be pertinent for all children with T21 to receive referrals for professional nutrition-related supervision and monitoring upon receipt of their T21 diagnosis. Importantly, these services need to be person- and family- centred and meaningful, and provided by competent and compassionate healthcare providers. Advocacy to generate attention and investment in the health of Canadian children with T21 is necessary to secure commitment and funding to support inclusive research studies, appropriate programming, and relevant nutrition knowledge and care.

Knowledge Translation

Knowledge mobilization of the study findings is extensive, as the aim is to increase knowledge and to inform behaviour, attitudes, practice, policy, and future research. Part of the goal of collecting qualitative data in this research study was to learn more about how parents and caregivers of children with T21 prefer to receive nutrition knowledge and care. This feedback was used to inform both the type and format of knowledge translation products created to share research findings with study participants. Research findings will be disseminated widely in accessible formats to accommodate diverse knowledge users. At the time of publishing this dissertation, a 1-page written summary of findings has been shared with study participants, parent engagement research partners, and organizations who facilitated recruitment.

Future distribution of findings includes to others who serve children with T21 and their families such as educators, childcare providers, healthcare service providers, relevant government departments, and local political leaders. For example, the 1-page summary of findings may be shared widely, submitted to traditional and online news outlets, and also be used for advocacy initiatives. Finally, manuscripts will be submitted for publication in academic journals (for example: *Canadian Journal of Dietetic Research and Practice*, *Pediatric Research*, *Nutrients*, *Journal of Intellectual and Developmental Disabilities*), and abstracts for conference presentations or workshops (for example: Manitoba Nutrition and Dietetics Research Day, Manitoba Down Syndrome Society Annual Conference, Dietitians of Canada Annual Conference, Beyond Limits Conference, Health and Wellbeing in Developmental Disabilities Conference, International Association for the Scientific Study of Intellectual and Developmental Disabilities Conference, Canadian Paediatric Society Conference Canadian Nutrition Society Conference, American Academic of Pediatrics Conference).

References

AbdAllah, A.M., Raffa, S., Alaidaroos, T., Obaid, & R. Abuznada, J. (2013). Nutrition-related health of some children and adolescents with Down syndrome in Jeddah. *Life Science Journal, 10*(3), 1310-1318.

Althubaiti, A. (2016). Information bias in health research: definition, pitfalls, and adjustment methods. *Journal of Multidisciplinary Healthcare, 9*, 211-217. https://doi.org/10.2147/JMDH.S104807

Aldridge, J. (2015). *Participatory research: Working with vulnerable groups in research and practice.* Policy Press.

American Diabetes Association. (n.d.). *Weight management: Extra weight, extra risk.* Retrieved May 1, 2025, from https://diabetes.org/health-wellness/weight-management/extra-weight-extra-risk

American Heart Association (2025). *Life's Essential 8*. Retrieved May 1, 2025, from https://www.heart.org/en/healthy-living/healthy-lifestyle/lifes-essential-8

American Heart Association. (2024). *Added sugars.* Retrieved May 1, 2025, from https://www.heart.org/en/healthy-living/healthy-eating/eat-smart/sugar/added-sugars

Andrew, R., Lubis, N.D.A., Nasution, F., & Paramita, D.A. (2023). Factors affecting nutritional status of children with Down syndrome of 7 to 12 year-old in Medan. *Journal of Epidemiology and Public Health, 8*(2), 255-264. https://doi.org/10.26911/jepublichealth.2023.08.02.10

Aslam, A.A., Baksh, A., Pape, S.E., Strydom, A., Gulliford, M.C., Chan, L.F., for the GO-DS21

Consortium. (2022). Diabetes and obesity in Down syndrome across the lifespan: A retrospective cohort study using U.K. electronic health records. *Diabetes Care, 45*(12), 2892-2899. https://doi.org/10.2337/dc22-0482

Baranowski, M.S., Webb, N., & Slater, J. (2024). What's the big IDEA? An exploration of inclusion, diversity, equity, and access (IDEA) in population health nutrition research and practice. *Applied Physiology, Nutrition, and Metabolism.* https://doi.org/10.1139/apnm-2023-0215

Barnes, A.S. (2011). The epidemic of obesity and diabetes: trends and treatments. *Texas Heart Institute Journal, 38*(2), 142-4.

Basil, J.S., Santoro, S.L., Martin, L.J., Wusik Healy, K., Chini, B.A., & Saal, H.M. (2016). Retrospective study of obesity in children with Down syndrome. *The Journal of Pediatrics, 173*, 143-8. https://doi.org/10.1016/j.jpeds.2016.02.046

Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health, 60*, 854-857. https://doi.org/10.1136%2Fjech.2004.028662

Bayer Incorporated. (2021). *Flintstones vitamins.* Retrieved May 1 2025, from https://www.flintstonesvitamins.ca/en/

Bhave, V.M., Oladele, C.R., Ament, Z., Kijpaisalratana, N., Jones, A.C., Couch, C.A., Patki, A., Guarniz, A.L.G., Bennett, A., Crowe, M., Irvin, M.R., & Kimberly, W.T. (2024). Associations between ultra-processed food consumption and adverse brain health outcomes. *Neurology, 102*(11). https://doi.org/10.1212/WNL.0000000000209432

Bialek-Dratwa, A., Zur, S., Wilemska-Kucharzewska, K., Szczepanska, E., & Kowalski, O. Nutrition as prevention of diet-related diseases: A cross-sectional study among children

and young adults with Down syndrome. *Children, 10*(36). https://doi.org/10.3390/children10010036

Birch, L.L., Fisher, J.O., Grimm-Thomas, K., Markey, C.N., Sawyer, R., & Johnson, S.L. (2001). Confirmatory factor analysis of the Child Feeding Questionnaire: a measure of parental attitudes, beliefs and practices about child feeding and obesity proneness. *Appetite, 36*, 201-10. https://doi.org/10.1006/appe.2001.0398

Boctor, D. (2020). The role of dietary fibre and prebiotics in the paediatric diet. *Paeditrics and Child Health, 25*(4), 263. https://doi.org/10.1093/pch/pxaa032

Brantley, C., Knol, L.L., Douglas, J.W., Hernandez-Rief, M., Lawrence, J.C., & Wind, S.A. (2023). Feeding stressors and resources used by caregivers of children with Down syndrome: A qualitative analysis. *Journal of the Academy of Nutrition and Dietetics, 123*(12): 1713-1728. https://doi.org/10.1016/j.jand.2023.07.002

Bronfenbrenner, U. (1976). *The ecology of human development: Experiments by nature and design.* Harvard University Press.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology, 22*(6), 723-742. https://psycnet.apa.org/doi/10.1037/0012-1649.22.6.723

Brownell M., De Coster C., Penfold R., Derksen S., Au W., Schultz J., & Dahl M. (2008). *Manitoba Child Health Atlas Update.* Winnipeg, MB: Manitoba Centre for Health Policy, November 2008. Retrieved from http://mchp-appserv.cpe.umanitoba.ca/deliverable.php?referencePaperID=76180

Bull, M.J., Trotter, T., Santoro, S.L., Christensen, C., Grout, R.W., & The Council on Genetics.

(2022). Health Supervision for Children and Adolescents with Down Syndrome. *Pediatrics, 149*(5): e2022057010. https://doi.org/10.1542/peds.2022-057010

Bull, M.J. (2020). Down syndrome. *New England Journal of Medicine, 382*(24), 2344-2352. https://doi.org/10.1056/NEJMra1706537

Canadian Down Syndrome Society. (n.d.). *Healthy aging.* Retrieved June 1, 2025, from https://cdss.ca/resources/healthy-aging/

Canadian Down Syndrome Society. (n.d.). *Down syndrome facts and frequently asked questions.* Retrieved June 1, 2025, from https://cdss.ca/resources/general-information/faq/

Canadian Institutes of Health Research (2020). *Ethics Guidance for Developing Partnerships with Patients and Researchers.* Government of Canada, Canadian Institutes of Health Research. https://cihr-irsc.gc.ca/e/documents/ethics_guidance_partnerships-en.pdf

Canadian Institutes of Health Research. (2019). *Strategy for Patient-Oriented Research: Putting Patients First Patient Engagement Framework.* Government of Canada, Canadian Institutes of Health Research. https://cihr-irsc.gc.ca/e/48413.html

Canada Research Coordinating Committee. (2024). *Best practices in equity, diversity and inclusion in research practice and design.* Government of Canada, Canada Research Coordinating Committee. https://www.sshrc-crsh.gc.ca/funding-financement/nfrf-fnfr/edi-eng.aspx#6

Canadian Society for Exercise Physiology. (2025). *24-hour movement guidelines.* Retrieved May 1, 2025, from https://csepguidelines.ca

Cardenas, D., Correia, M.I.T.D., Hardy, G., Gramlich, L., Cederholm, T., Van Ginkel-Res, A., Remijnse, W., Barrocas, A., Ochoa Gautier, J.B., Ljungqvist, O., Ungpinitpong, W., & Barazzoni, R. (2023). The international declaration on the human right to nutritional care:

A global commitment to recognize nutritional care as a human right. *Clinical Nutrition, 42*(6), 909-918. https://doi.org/10.1016/j.clnu.2023.04.009

Casey, L.M.,and the Canadian Paediatric Society Nutrition and Gastroenterology Committee. (2020). *Nutritional evaluation of the neurologically impaired child.* Canadian Paediatric Society. Retrieved from https://cps.ca/en/documents/position/nutritional-evaluation-of-the-neurologically-impaired-child

Conway, C., Lemons, S., & Terrazas, L. (2020). Academy of Nutrition and Dietetics: Revised 2020 standards of practice and standards of professional performance for registered dietitian nutritionists (competent, proficient, and expert) in intellectual and developmental disabilities. *Journal of the Academy of Nutrition and Dietetics, 120*(12), 2061-2075. https://doi.org/10.1016/j.jand.2020.08.094

Costanzo, P.R. & Woody, E.Z. (1985). Domain-specific parenting styles and their impact on the child's development of particular deviance: the example of obesity proneness. *Journal of Social and Clinical Psychology, 3*(4), 425-445.

Cristescu, L., Scerif, G., Pellicano, L., Van Herwegen, J., & Farran, E. (2024). *Shape Research, Change Lives: Setting priorities in genetic syndrome research.* Retrieved from https://doi.org/10.31234/osf.io/whbfp

de Graaf, G., LaChance, L., Buckley, F., Skotko, B.G. (2025). Estimation of the number of people with Down syndrome living in Canada. (2025). *Genetics in Medicine, 27*(7). https://doi.org/10.1016/j.gim.2025.101422

de Graaf, G., Buckley, F., & Skotko, B. (2021). Estimation of the number of people with Down syndrome in Europe. *European Journal of Human Genetics, 29*(3), 402-410. https://doi.org/10.1038/s41431-020-00748-y

de Graaf, G., Buckley, F., & Skotko, B.G. (2015). Estimates of the live births, natural losses, and elective terminations with Down syndrome in the United States. *American Journal of Medical Genetics, 167*(4), 756-767. https://doi.org/10.1002/ajmg.a.37001

Diaz, K. M. (2020). Physical activity and sedentary behaviour among U.S. children with and without Down syndrome: The National Survey of Children's Health. *American Journal on Intellectual and Developmental Disabilities, 125*(3): 230-242. https://doi.org/10.1352/1944-7558-125.3.230

Diabetes Canada. (n.d.). *Sugar & diabetes: Position statement.* Retrieved July 1, 2025, from https://www.diabetes.ca/advocacy---policies/our-policy-positions/sugar---diabetes

Down, J.L.H. (1866). Observations on an ethnic classification of idiots. *London Hospital Report, 3*, 259-262.

Edmonds, W.A., & Kennedy, T.D. (2017). *An applied guide to research designs: Quantitative, qualitative, and mixed methods.* (2nd ed.). SAGE Publications, Inc. https://doi.org/10.4135/9781071802779

Essel, K. (2022). The first 1000 days – a missed opportunity for pediatricians. *American Journal of Public Health, 112*(8), S757-759. https://doi.org/10.2105%2FAJPH.2022.306999

Flinders, D. (1992). In search of ethical guidance: constructing a basis for dialogue. *Qualitative Studies in Education, 5*(2), 101-115. https://doi.org/10.1080/0951839920050202

Flint, S.W., Naglowski, J., Murray, K., & Simonetti, J. (2025). A call for increased involvement of people with obesity and neurodiversity in policy, research, and practice. *The Lancet Diabetes & Endocrinology, 13*(5), 371-372. https://doi.org/10.1016/S2213-8587(25)00088-9

FoodFocus. (n.d.). Retrieved March 1, 2025, from http://www.foodfocus.com

Fortea, J., Zaman, S.H., Hartley, S., Rafii, M.S., Head, E., Carmona-Iragui, M. (2021). Alzheimer's disease associated with Down syndrome: a genetic form of dementia. *The Lancet Neurology, 20*, 930-942. https://doi.org/10.1016/S1474-4422(21)00245-3

Friedman, C. (2018). Aversive ableism: Modern prejudice towards disabled people. *Review of Disability Studies, 15*(4).

Gillespie, K.M., Kemps, E., White, M.J., Bartlett, S. E. (2023). The impact of free sugar on human health – a narrative review. *Nutrient, 15*(4), 889. https://doi.org/10.3390/nu15040889

Gowrishankar, M., Blair, B., & Rieder, M.J. (2020). Dietary intake of sodium by children: Why it matters. *Paediatrics Child Health, 25*(1), 47-53. https://doi.org/10.1093/pch/pxz153

Government of Canada. (2022). *Canadian Community Health Survey.* https://www.canada.ca/en/health-canada/services/food-nutrition/food-nutrition-surveillance/health-nutrition-surveys/canadian-community-health-survey-cchs.html

Government of Canada. (2022). *Social Sciences and Humanities Research Council: Guide to including diversity considerations in research design for doctoral and postdoctoral award applicants.* https://www.sshrc-crsh.gc.ca/funding-financement/apply-demande/guides/doctoral_postdoctoral_edi_guide-doctorat_postdoctorales_guide_edi-eng.aspx

Government of Canada. (2022). *Vitamin D.* https://www.canada.ca/en/health-canada/services/nutrients/vitamin-d.html

Government of Canada. (2019). *Canada's food guide.* https://food-guide.canada.ca/en/

Grammatikopoulou, M.G., Manai, A., Tsigga, M., Tsiligiroglou-Fachantidou, A., Galli-

Tsinopoulou, A., & Zakas, A. (2009). Nutrient intake and anthropometry in children and adolescents with Down syndromes – a preliminary study. *Developmental Neurorehabilitation, 11*(4), 260-7. https://doi.org/10.1080/17518420802525526

Groce, N.E., Kerac, M., Farkas, A., Schultink, W., Bieler, R.B. (2013). Inclusive nutrition for children and adults with disabilities. *The Lancet Global Health, 1*(4), e180-e181. https://doi.org/10.1016/S2214-109X(13)70056-1

Gruszka, J., & Wlodarek, D. (2024). General dietary recommendations for people with Down syndrome. *Nutrients, 16*, 2656. https://doi.org/10.3390/nu16162656

Hack, S., Jessri, M., & L'Abbe, M.R. Nutritional quality of the food choices of Canadian children. *BMC Nutrition, 7*(16). https://doi.org/10.1186/s40795-021-00422-6

Harriman, E., Kerr, E., O'Bertos, T., Fotheringham, M., Richmond, M., & Lieffers, J.R.L. (2025). Knowledge, attitudes, and practices of Canadian dietitians regarding supporting individuals with intellectual and developmental disabilities. *Canadian Journal of Dietetic Practice and Research.* https://doi.org/10.3148/cjdpr-2025-003

Health Canada. (2018, September 17). *Canadian ban on trans fats comes into force today*. [Press release]. https://www.canada.ca/en/health-canada/news/2018/09/canadian-ban-on-trans-fats-comes-into-force-today.html

Health Canada (2011). *Eating Well With Canada's Food Guide.* (HC Pub.: 4651). https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/fn-an/alt_formats/hpfb-dgpsa/pdf/view_eatwell_vue_bienmang-eng.pdf

Health Canada (2006). *Canadian Community Health Survey, Cycle 2.2, (2004)— A guide to accessing and interpreting the data.* https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/fn-an/alt_formats/hpfb-dgpsa/pdf/surveill/cchs-guide-escc-eng.pdf

Help Center (n.d.). Retrieved May 1, 2025, from https://www.helpcenter.med.sa

Hennick, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine, 292.* https://doi.org/10.1016/j.socscimed.2021.114523

Hielscher, L., Irvine, K., Ludlow, A.K., Rogers, S., & Mengoni, S.E. (2023). A scoping review of the complementary feeding practices and early eating experiences of children with Down syndrome. *Journal of Pediatric Psychology, 48*, 914-930. https://doi.org/10.1093/jpepsy/jsad060

Institute of Medicine. (2000). *Dietary Reference Intakes: Applications in Dietary Assessment.* The National Academies Press. https://doi.org/10.17226/9956

Janz, H. (2019). Ableism: The undiagnosed malady afflicting medicine. *Canadian Medical Association Journal, 191*(17), E478–E479. https://doi.org/10.1503/cmaj.180903

Jiao, L. (2024). Social determinants of health, diet, and health outcome. *Nutrients, 16*, 3642. https://doi.org/10.3390/nu16213642

Johnston, K.J., Chin, M.H., & Pollack, H.A. (2022). Health equity for individuals with intellectual and developmental disabilities. *Journal of the American Medical Association, 328*(16), 1587-1588. https://doi:10.1001/jama.2022.18500

Kahraman, S., Karsli, E., & Ihlamur, M. (2024). Evaluation of nutritional status of young adolescents diagnosed with Down syndrome: a descriptive study. *Nutrire, 49*(30). https://doi.org/10.1186/s41110-024-00272-9

Kaya, N., Basmisirli, E., Inanc, N., Kip, M., & Kendirli, G. (2024). Nutritional status and

Mediterranean diet adherence of children with Down syndrome and their siblings. *International Journal of Developmental Disabilities.* https://doi-org.uml.idm.oclc.org/10.1080/20473869.2024.2345959

Kousholt, D. & Juhl, P. (2023). Addressing ethical dilemmas in research with young children and families. Situated ethics in collaborative research. *Human Arenas, 6*(3), 560-579. https://doi.org/10.1007/s42087-021-00236-9

Landes, S.D., Stevens, J.D., & Turk, M.A. (2020). Cause of death in adults with Down syndrome in the United States. *Disability and Health Journal, 13,* 1-9. https://doi.org/10.1016/j.dhjo.2020.100947

Lewanda A.F., Gallegos, M.F., & Summar, M. (2018). Patterns of dietary supplement use in children with Down syndrome. *The Journal of Pediatrics, 201*, 100-5. https://doi.org/10.1016/j.jpeds.2018.05.022

Luke, A., Sutton, M., Schoeller, D.A., & Roizen, N.J.M. (1996). Nutrient intake and obesity in prepubescent children with Down syndrome. *Journal of the American Dietetic Association, 96*(12), 1262-1267. https://doi.org/10.1016/S0002-8223(96)00330-6

Magenis, M.L., Machado, A. G., Bongiolo, A.M., da Silva, M.A., Castro, K., & Perry, I.D.S. (2018). Dietary practices of children and adolescents with Down syndrome. *Journal of Intellectual Disabilities, 22*(2), 125-134. https://doi.org/10.1177/1744629516686571

Martinez-Espinosa, R.M., Molina Vila, M.D., & Garcia-Galbis, M.R. (2020). Evidences from clinical trials in Down syndrome: Diet, exercise, and body composition. *International Journal of Environmental Research and Public Health, 17*(12), 4294. https://doi.org/10.3390/ijerph17124294

Muhammad, M., Wallerstein, N., Sussman, A.L., Avila, M., Belone, L., & Duran, B. (2015).

Reflections on researcher identity and power: The impact of positionality on community based participatory research (CBPR) processes and outcomes. *Critical Sociology, 41*(7-8), 1045-1063. https://doi.org/10.1177/0896920513516025

Ng, A., Ahmed, M., & L'Abbe, M. (2021). Nutrient intakes of Canadian children and adolescents: Results from the Canadian Community Health Survey (CCHS) 2015 – Nutrition Public Use Microdata Files. *American Journal of Clinical Nutrition, 114*(3): 1131-1140. https://doi.org/10.1093/ajcn/nqab143

O'Neill, K.L., Shults, J., Stallings, V.A., & Stettler, N. (2005). Child-feeding practices in children with down syndrome and their siblings. *The Journal of Pediatrics, 146,* 234-8. https://doi.org/10.1016/j.jpeds.2004.10.045

Oulmane, Z., Hilali, M.K., & Cherkaoui, M. (2021). Obesity and overweight in youth and adults with Down syndrome in Morocco: Prevalence and determinants. *Nutrition Clinique et metabolisme, 35*(3), 200-206. https://doi.org/10.1016/j.nupar.2021.03.005

O'Shea, M., Gibson, L., Leo, J., & Carty, C. (2018).The prevalence of obesity in children and young people with Down syndrome. *Journal of Applied Research in Intellectual Disabilities, 31*, 1225-1229. https://doi.org/10.1111/jar.12465

Patel., P., Sun, W., Mataruga, A., Fung, K., & Balogh, R. (2025). The incidence and prevalence of dementia among Ontario adults with and without intellectual and developmental disabilities. *International Journal of Geriatric Psychiatry.* https://doi.org/10.1002/gps.70050

Pelleri, P., Mazzuca, G., Pietrobelli, A., Zampieri, N., Piacentini, G., Zaffanello, M., & Pecoraro, L. (2024). The role of diet and physical activity in obesity and overweight in children

with Down syndrome in developed countries. *Children, 11*(9), 1056. https://doi.org/10.3390/children11091056

Peters, A., Honisch, S.S., Arentsen, M., Bruce, C., Catala, A., Fichten, C., Lindsay, S., Lord, P., Martino, A.S., McGuire-Adams, T., Mendez de la Brena, D., Nolan J., Peers, D. (2024). *Analysis of barriers and recommendations developed in consultation with the Advisory Committee on Accessibility and Systemic Ableism (ACASA).* Retrieved from https://www.sshrc-crsh.gc.ca/about-au_sujet/governance-gouvernance/committees-comites/accessibility/reports-rapports/acasa-ccacs-eng.aspx#_85

Pojednic, R., Phillips, E., Shehadeh, A., Muller, A., Metallinos-Katsaras, E. (2023). Physician nutrition advice and referrals to registered dietitians. *American Journal of Lifestyle Medicine,17*(6), 847-854. https://doi.org/10.1177/15598276221092304

Potvin Kent, M., Bagnato, M., Remedios, L., Soares Giumaraes, J., Gillis, G., Soto, C., Hatoum, F., & Pritchard, M. (2024). Child and adolescent exposure to unhealthy food marketing across digital platforms in Canada. *BMC Public Health,* 24, 1740. https://doi.org/10.1186/s12889-024-19094-5

Prowse, R. (2017). Food marketing to children in Canada: a settings-based scoping review on exposure, power and impact. *Health Promotion and Chronic Disease Prevention in Canada, 37*(9), 274-292. https://doi.org/10.24095/hpcdp.37.9.03

Ptomey, L.T., & Wittenbrook, W. (2015). Position of the Academy of Nutrition and Dietetics: Nutrition knowledge and care for individuals with intellectual and developmental disabilities and special health care needs. *Journal of the Academy of Nutrition and Dietetics, 115*(4), 593-608. https://doi.org/10.1016/j.jand.2015.02.002

Public Health Agency of Canada. (2019). *Childhood obesity.* Government of Canada, Public

Health Agency of Canada. https://www.canada.ca/en/public-health/services/childhood-obesity/childhood-obesity.html

Public Health Agency of Canada. (2023). *Dietary reference intakes tables: Overview.* Government of Canada, Public Health Agency of Canada. https://www.canada.ca/en/health-canada/services/food-nutrition/healthy-eating/dietary-reference-intakes/tables.html

Public Health Agency of Canada. (2017). *Down Syndrome Surveillance in Canada, 2005-2013.* Government of Canada, Public Health Agency of Canada. https://www.canada.ca/en/public-health/services/publications/healthy-living/down-syndrome-surveillance-2005-2013.html

Rao, D.P., Kropac, D., Do, M.T., Roberts, K.C., & Jayaraman, G.C. (2016). *Health Promotion and Chronic Disease Prevention in Canada, 36*(9), 194-198. https://doi.org/10.24095/hpcdp.36.9.03

Rios-Leyvraz, M., Jendly, M., Ortega, N., da Costa, B.R., % Chiolero, A. (2025). Worldwide and time trends in sodium and potassium intakes in children and adolescents: A systematic review and meta-analysis. *BMJ Nutrition, Prevention & Health.* https://doi.org/10.1136/bmjnph-2024-001016

Roccatello, G., Cocchi, G., Dimastromatteo, R. T., Cavallo, A., Biserni, G. B., Selicati, M., & Forchielli, M. L. (2021). Eating and lifestyle habits in youth with Down syndrome attending a care program: An exploratory lesson for future improvements. *Frontiers in nutrition*, *8*, 641112. https://doi.org/10.3389/fnut.2021.641112

Ross, C.F., Bernhard, C.B., Surette, V., Hasted, A., Wakeling, I., Smith-Simpson, S. (2024). The

influence of food sensory properties on eating behaviours in children with Down syndrome. *Food Research International, 175*. https://doi.org/10.1016/j.foodres.2023.113749

Ross, C.F., Bernhard, C.B., Surette, V., Hasted, A., Wakeling, I., Smith-Simpson, S. (2022). Eating behaviours in children with Down syndrome: Results of a home-use test. *Journal of Texture Studies, 53*(5), 629-646. https://doi.org/10.1111/jtxs.12703

Ross, C.F., Bernhard, C.B., & Smith-Simpson, S. (2019). Parent-reported ease of eating foods of different textures in young children with Down syndrome. *Journal of Texture Studies, 50*(5), 426-433. https://doi.org/10.1111/jtxs.12410

Rossi, L., Canani, S.B., Censi, L., Gennaro, L., Leclercq, C., Scognamiglio, U., Sette, S., Ghiselli, A. (2022). The 2018 revision of Italian dietary guidelines: Development process, novelties, main recommendations, and policy implications. *Frontiers in Nutrition, 9.* https://doi.org/10.3389/fnut.2022.861526

Salehi, A., Ashford, J.W., & Mufson, E.J. (2016). The link between Alzheimer's Disease and Down Syndrome. A Historical Perspective. *Current Alzheimer Research, 13*(1), 2-6. https://doi.org/10.2174%2F1567205012999151021102914

Salvy, S-J., Elmo, A., Nitecki, L. A., Kluczynski, M.A., & Roemmich, J.N. (2011). Influence of parents and friends on children's and adolescents' food intake and food selection. *The American Journal of Clinical Nutrition, 93*(1), 87-92. https://doi.org/10.3945/ajcn.110.002097

Samarkandy, M. M., Mohamed, B.A., Al-Hamdan, A.A. (2012). Nutritional assessment and obesity in Down syndrome children and their siblings in Saudi Arabia. *Saudi medical journal, 33*(11), 1216-1221.

Sohail, S-S. & Mitchell, W.B. (2024). Nutrition for brain health: Keeping adolescents in MIND. *Pediatric Research, 96*, 19-20. https://doi.org/10.1038/s41390-024-03095-6

Statistics Canada. (2023). *Canadian Health Survey on Children and Youth.* Government of Canada, Statistics Canada. https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5233

Statistics Canada. (2022). *Canadian Survey on Disability.* Government of Canada, Statistics Canada. https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3251

Statistics Canada. (2021). *Census of Population.* Government of Canada, Statistics Canada. https://www12.statcan.gc.ca

Statistics Canada. (2019). *Health Fact Sheets: Physical activity and screen time among Canadian children and youth, 2016 and 2017.* [Fact sheet]. Government of Canada, Statistics Canada. https://www150.statcan.gc.ca/n1/pub/82-625-x/2019001/article/00003-eng.htm

U.S. Department of Health and Human Services. (2018). *Physical activity guidelines for Americans. 2nd edition.* health.gov

U.S. Department of Agriculture and U.S. Department of Health and Human Services. (2020). *Dietary guidelines for Americans, 2020-2025. 9th Edition.* DietaryGuidelines.gov

van den Brink, A.C., Brouwer-Brolsma, E.M., Berendsen, A.A.M., van de Rest, O. (2019). The Mediterranean, Dietary Approaches to Stop Hypertension (DASH), and Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diets are associated with less cognitive decline and a lower risk of Alzheimer's disease: A review. *Adv Nutr, 10*(6), 1040-1065. https://doi.org/10.1093/advances/nmz054

Veronese, N., Gianfredi, V., Solmi, M., Barbagallo, M., Dominguez, L.J., Mandala, C., Di

Palermo, C., Carruba, L., Solimando, L., Stubbs, B., Castagna, A., Maggi, S., Zanetti, M., Al-Daghri, N., Sabicio, S., Nucci, D., Goslin, C., & Fontana, L. The impact of dietary fiber consumption on human health: an umbrella review of evidence from 17,155,277 individuals. (2025). *Clinical Nutrition, 51*, 325-333. https://doi.org/10.1016/j.clnu.2025.06.021

Villani, E.R., Onder, G., Marzetti, E., Coelho-Junior, H., Calvani, R., Di Paola, A., & Carfi, A. (2024). Body composition parameters and sarcopenia in adults with Down syndrome: a case-control study. *Aging Clinical and Experimental Research, 36*, 81. https://doi.org/10.1007/s40520-023-02680-9

Warren, C., Hobin, E., Manuel, D.G., Anderson, L.N., Hammond, D., Jessri, M., Arcand, J., L'Abbe, M., Li, Y., Rosella, L.C., Manson, H., & Smith, B.T. (2022). Socioeconomic position and consumption of sugary drinks, sugar-sweetened beverages and 100% juice among Canadians: A cross-sectional analysis of the 2015 Canadian Community Health Survey-Nutrition. *Canada Journal of Public Health, 113*(3), 314-362. https://doi.org/10.17269/s41997-021-00602-8

Weijerman, M.E. & de Winter, J.P. (2010). Clinical practice: The care of children with Down syndrome. *European Journal of Pediatrics, 169*, 1445-1452. https://doi.org/10.1007/s00431-010-1253-0

White, A.N., Chevette, M., Hillerstrom, H., & Esbensen, A. (2022). Parental perspectives on research for Down syndrome. *Journal of Applied Research in Intellectual Disabilities, 35*(1), 179-187. https://doi.org/10.1111/jar.12937

World Health Organization. (2025). *Nutrition*. https://www.emro.who.int/healthtopics/nutrition/introduction.html

Yamanaka, E., Inayama, T., Ohkawara, K., Okazaki, K., & Kita, I. The association between obesity and sedentary behaviour or daily physical activity among children with Down's syndrome aged 7-12 years in Japan: A cross-sectional study. *Heliyon, 6*(9), e04861. https://doi.org/10.1016/j.heliyon.2020.e04861

Appendix A: Patient Engagement in Research Initiatives

Background

Patient engagement initiatives for this research study were supported by a George and Fay Yee Centre for Healthcare Innovation Preparing for Research by Engaging Public and Patient Partners award, granted in the spring of 2023. Parents and caregivers of children with T21 of any age living in Manitoba were invited to participate as *parent engagement researcher partners* through direct email invitation via their membership with the Manitoba Down Syndrome Society (MDSS). The email invitation included a positionality statement that described myself as a graduate student, dietitian, and parent of a child with DS. The email invitation also stated the intended goals of engaging with other parents and caregivers of children with DS living in Manitoba, to: 1) learn more about nutrition in children with DS, 2) ensure research objectives and questions reflect diverse perspectives, and 3) design a research project that generates interest in study participation. Notably, in a recent survey that included 228 parents of children with T21 less than 18 years old, the majority of parents reported that they were willing to participate in research yet only 36% previously had participated in research (White et al., 2021). Parents and caregivers were asked to join a virtual group discussion about nutrition and DS to help achieve these goals. Direct contact information (email address and phone number) for myself was provided in the email invitation. Parents and caregivers interested in participating in a virtual group meeting were asked to share their interest with me via phone call, text, or email, as per their communication preference.

When patient engagement researchers are included in the planning and design stages of research, ethics approval is not required (CIHR, 2020). Notably, data is not collected about the patients, nor about the engagement process itself, and patients will not be quoted. Rather,

patients are asked to use their lived experience to inform decisions about research. Researchers working with patients are able to record high-level notes and use the results of the engagement initiative to inform research decision-making. Importantly, results are not a source of qualitative research data.

First Patient Engagement in Research Activity

Twelve parents and caregivers expressed interest in attending the first virtual patient engagement meeting, which occurred in the summer of 2023. Parents and caregivers were asked to share their preference and availability to meet virtually, and whether they required support (internet access, childcare) to participate in the virtual meeting. A date and time for a 90-minute virtual meeting was selected to reflect the group's collective availability, and each parent and caregiver was provided a link to connect to the virtual meeting.

Four parents and caregivers attended the first virtual patient engagement meeting in July 2023. The purpose of the first meeting was to build relationships and discuss nutrition-related topics important to children with DS. Parents were informed that their feedback was intended to inform the objectives, questions, and direction of the proposed research study. During introductions, parents shared some information about their personal lived experience as a parent to a child with DS. Then, as a group, and based on their own lived experience, parents collectively identified several important nutrition-related topics among children with DS including, but not limited to: puberty, digestive health, food preferences/cravings/aversions, dietary supplements, fluid intake, impact of the COVID-19 pandemic, use of food reward, culture, religious beliefs, and breastfeeding. Finally, as a group, there was discussion about why diversity among the patient engagement researcher partners and future study participants was important to accurately represent lived experience of parenting and caregiving a child with DS in

Manitoba. The group acknowledged the lack of diversity among the parents who participated in the first virtual patient engagement meeting. At the conclusion of the meeting, parents were thanked for their time and requested to participate in another virtual meeting in 4-6 weeks. All parents received a $25 gift card in the mail as an honorarium afterwards.

Second Patient Engagement in Research Activity

Parents and caregivers of children with T21 of any age living in Manitoba, who originally expressed interest in participating in a virtual meeting to discuss nutrition and DS (n=12), received a follow-up invitation (email or text, as per their preferred communication method) to participate in a second virtual meeting. The invitation included the goals of the second meeting, to: 1) receive feedback about different food and beverage consumption data collection tools, and 2) share ideas about recruitment strategies. Parents and caregivers who expressed interest in participating in a second virtual group meeting received a link to connect to the virtual meeting, which was scheduled for 90-minutes and based on the group's collective availability. Parents and caregivers were asked whether they required support (internet access, childcare) to participate in the virtual meeting.

Two parents and caregivers attended the second virtual patient engagement meeting in August 2023, approximately 5 weeks after the first virtual patient engagement meeting. These two parents and caregivers were new to the group and had not attended the first virtual meeting. A third parent, who had attended the first virtual meeting, experienced technical difficulties connecting to the second virtual patient engagement meeting. Therefore, they requested meeting virtually at a later date to share their feedback individually. This request was granted and the virtual meeting with the third parent occurred in September 2023. In total, there were 3 parents

and caregivers who participated in the second virtual meeting and their feedback is presented collectively.

After introductions, I shared information about different food and beverage consumption data collection tools that may be used to assess dietary patterns and nutritional health in nutrition research: 1) 24-hour dietary recall, 2) 3-day food record, and 3) food frequency questionnaire. Parent engagement researcher partners shared that they preferred to use the 3-day food record or the 24-hour dietary recall for data collection about foods and beverages their child consumed. Food frequency questionnaires were perceived to be overwhelming, as was being asked to weigh foods their child consumed (completing a weighed food record). Parent engagement researcher partners shared that data collection over the phone or virtually suited their needs and preferences. It was suggested that data collection in the study participant's home may prompt recall about food and beverage consumption. It was also noted that research study participation or data collection activities were not overwhelming or burdensome for parents and caregivers of children with T21, as they have extensive lived experience answering questions about their child's health.

Parent engagement researcher partners shared many ideas about how to recruit a diverse sample that would be representative of the Manitoba population of parents and caregivers of a child with T21 and included: advocacy organizations (MDSS, Family Advocacy Network (FAN) of Manitoba), social assistance programs (for newcomers, immigrants, and refugees; for those living in poverty), government departments, recreational organizations, healthcare service providers, social media, and school divisions. At the conclusion of the meeting, parents were thanked for their time. A $25 gift card honorarium was sent to parents in the mail afterwards.

Third Patient Engagement in Research Activity

Moms who participated in this study (n=14) received a follow-up invitation (email or text, as per their preferred communication method) to participate in a third and final virtual patient engagement meeting. The invitation included the goals of the third meeting, to: 1) review preliminary findings and data interpretation, and 2) share ideas about dissemination of study findings. Moms received a link to connect to the virtual meeting, which was scheduled for 90-minutes.

Two moms attended the second virtual patient engagement meeting in April 2025, approximately 2 months after data collection was completed. Introductions were conducted first to build trust and connection among the group. Afterwards, preliminary findings were presented to the moms, with an invitation to ask questions and discuss the findings at any time. Moms shared meaningful insight about the interpretation of several study findings, which were incorporated into the discussion of study findings. For example, moms contributed insights as to why the COVID-19 pandemic may not have influenced the food intake or physical activity of some children. Importantly, moms did not find any inaccuracies in the data interpretation. Parents also shared their ideas for widely distributing study findings to diverse knowledge users, which closely resembled the list previously created to recruit a diverse study sample. Notably, conversation about sharing the study findings with primary care providers who care for children with T21 in Manitoba was emphasized. They also recommended sharing dietary guidelines for some nutrients with parents and caregivers, particularly for nutrients found to be consumed in inadequate amounts among the children with DS included in this study. Finally, there was discussion about how the study findings may be used to advocate for improved and consistent nutrition-related care among children with T21 living in Manitoba. At the conclusion of the

meeting, moms were thanked for their time. Parents received a $25 gift card in the mail as an honorarium afterwards.

Appendix B: 24-Hour Dietary Recall Template

(adapted from the Canadian Community Health Survey, 2015)

1) Quick List: Ask study participant to list all foods and beverages their child consumed in a 24-hour period during the day before the data collection meeting in any order they wish (without being interrupted by the interviewer).

2) Forgotten Foods: Ask study participant a series of question probing for forgotten foods from various categories that are commonly consumed by children such as sugar-sweetened beverages (juice, flavoured dairy and non-dairy beverages, slushies, sports drinks, soft drinks), dessert and 'other foods' (chips, cookies, doughnuts, candies, pudding, jello, cake, chocolate bars, ice cream), cheese, crackers, baked goods (muffins, cinnamon buns), yogurt (containers, tubes, drinks), fast food/restaurant foods.

3) Time and Occasion: Ask study participant to share the time their child began eating/drinking each of the reported foods and they would call that eating time (for example: breakfast, lunch).

4) Detail Cycle: Ask the study participant for more detailed food descriptions including amounts consumed, additions to the foods, preparation methods, and where the food was consumed. Use hand tools to help study participant approximate quantity (for example: 1 fist/1 baseball reflects 1 c grain, 1 softball reflects 2 c grain, 1 tennis ball reflects ½ c grain, 2 thumbs reflects 1 ounce cheese, palm of hand/deck of cards reflects 3 ounce protein, golf ball reflects 2 tbsp)

5) Final probe for any missing foods or beverages consumed by child.

Appendix C: Survey Instrument

Hello parents and caregivers,

Thank you for agreeing to participate in our research study about nutrition and Down syndrome. Nutrition refers to many things: 1) the food and beverages we consume, 2) the nutrients found in the foods and beverages we consume, 3) how nutrients are used in the body, and 4) the role of nutrients to prevent or manage disease.

The amount of nutrients our body needs from food and beverages changes over time. There are many factors that influence the food and beverages we consume and how nutrients are used in our body. We can control some of those factors but not all of them.

There is some research that suggest people with Down syndrome are at risk of developing nutrition-related conditions and diseases as they get older (for example: diabetes, Alzheimer's disease). However, right now in Manitoba, there is no data about nutrition among people with Down syndrome.

The goal of this research study is to learn more about nutrition and Down syndrome among young children (6-12 years old) living Manitoba. We are interested in learning about: 1) the food and beverages they consume, 2) the factors that influence what food and beverages they consume, and 3) their experience receiving nutrition-related information and healthcare services.

We will follow an *ethic of caring* as we conduct this study and collect nutrition-related information about children with Down syndrome. Only data that specifically addresses the goals of the research study will be collected from parents and caregivers.

Your feedback is valuable. The information you share will help us understand nutrition and Down syndrome among children living in Manitoba. The overall goal of our research study is to learn how to best provide nutrition-related information and healthcare services to children with Down syndrome and their families. We hope to help prevent the risk of nutrition-related conditions and diseases among Manitobans with Down syndrome.

Are there any risks to participate in this study? As parents and caregivers we are responsible for providing food and beverages to our children and this is not always an easy task. It is possible that participating in this study will create some emotional distress among individuals when sharing information about their child's food and beverage consumption, medical history, eating ability, and other factors. *Please know that you do not have to answer any questions that may cause distress. We can also take a break whenever you need one.*

Will my personal information be kept private? All personal information you share will remain confidential. All findings from our research study will be presented at the group level so that individual children, parents, and caregivers will not be identified. All records will be kept in a locked secure area and only those persons identified will have access to these records. No information revealing any personal information such

as your name, address or telephone number will leave the University of Manitoba.

What do I do if I have questions? If you have any questions about your participation in this study as a research participant, then please contact the Principal Investigator, Maria Baranowski, by phone at (204) 898-0172, or by e-mail at baranowm@myumanitoba.ca. For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Thank you very much for your time and contribution!

The questions asked are presented in 3 sets.
There are 43 questions in total.
The time expected to answer all of the questions is approximately 1 1/2 hours.

PARTICIPANT ID NUMBER__ __ __
SURVEY DATE __ __/__ __/__ __
(MM/DD/YY)

The first set of questions are about your child and their overall health. *Please answer all the questions.*

1) When was your child born?

   Please write the **DATE OF YOUR CHILD'S BIRTH** *in the space below:*

   __ __/__ __/__ __(MM/DD/YY)

2) What is your child's age today?

   Please write your **CHILD'S AGE** *in the space below:*

   __ __

3) What sex was your child assigned at birth?

   Please place an **X** *beside your response. Please select one answer only.*

   F ___
   M ___
   Intersex __
   Prefer not to answer ___

4) What is your relation to your child?

   Please place an **X** *beside your response. Please select one answer only.*

   Mother ___
   Father ___
   Guardian ___
   Grandparent ___
   Sibling ___
   Other __

5) Has your child received a **diagnosis** of any medical condition(s) other than Down syndrome that may affect their food intake or nutrition (for example: hypothyroidism)?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #5, please place an* **X** *beside your child's diagnosis(es). Please select as many conditions that apply.*

___ diabetes ___ high blood pressure ___ metabolic

___ heart condition ___ hypothyroidism ___ allergy

___ obesity ___ vitamin/mineral deficiency

___ other:_____

6) Does your child have a **family history** of any medical condition(s) that may affect their food intake OR nutrition (for example: diabetes)?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

No ___

I don't know ___

a. *If you answered YES to question #6, please place an* **X** *beside your child's family history. Please select as many conditions that apply.*

___ diabetes ___ hypertension ___ metabolic

___ heart condition ___ hypothyroidism ___ allergy

___ obesity ___ vitamin/mineral deficiency

___ other:_____

7) Do you have any concerns about your child's **overall health**?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

IF RESPONSE IS **YES** TO Q7, THEN ASK Q7a BELOW:

7a) Can you tell me more about your specific concerns?

8) Do you have any concerns about your child's **food intake**?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

IF RESPONSE IS **YES** TO Q8, THEN ASK Q8a BELOW:

8a) Can you tell me more about your specific concerns?

9) Did the COVID-19 pandemic have an impact on your child's food intake or physical activity?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

IF RESPONSE IS **YES** TO Q9 THEN ASK Q9a BELOW:

9a) Can you tell me more about **how the COVID-19 pandemic impacted your child's food intake or physical activity**?

10) What is your child's current weight approximately?

Please write your **CHILD'S CURRENT WEIGHT** *in the space below:*

___ pounds OR ___ kilograms

___ I don't know

11) What is your child's current height approximately?

Please write your **CHILD'S CURRENT HEIGHT** *in the space below:*

__ feet __ inches OR ___ centimetres

___ I don't know

12) Children are in a stage of growth and development and their heights and weights are constantly changing. Do you have any concerns about your child's **height or weight**?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

IF RESPONSE IS **YES** TO Q12, THEN ASK Q12a BELOW:

12a) Can you tell me more about your specific concerns?

13) Has your child experienced puberty?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know __

14) Who is your child's primary care provider? (for example: nurse practitioner, family doctor, pediatrician)

Please write your response in the space below:

15) Has your child seen their primary care provider in the past 12 months?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

16) Has your child's primary care provider ever shared any concerns with you about your child's **growth, nutrition, food intake, or physical activity?**

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

IF RESPONSE IS **YES** TO Q16, THEN ASK Q16a BELOW:

16a) Can you tell me more about what were those specific concerns?

The second set of questions are about your child's food intake and food environment. *Please answer all the questions.*

17) Was your child breastfed?

Please place an **X** *beside your response. Please select one answer only.*

Y ___
N ___
I don't know ___

18) Does your child have any food allergies or food intolerances (for example: lactose intolerance, sensitivity to gluten)?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #18, please write your* **CHILD'S ALLERGY(IES)** *in the space below:*

19) Does your child have any food cravings or food preferences (for example: sweet foods, sugar-sweetened beverages, soft foods)?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #19, please write your* **CHILD'S FOOD CRAVING(S)** *in the space below:*

20) Are there any foods your child does not like to eat?

Please place an **X** *beside your response. <u>Please select one answer only.</u>*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #20, please write your* **CHILD'S FOOD AVERSION(S)** *in the space below:*

21) Does your child have any **swallowing OR choking concerns** that may impact their food intake?

Please place an **X** *beside your response. <u>Please select one answer only.</u>*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #*21, *please write your* **CHILD'S SWALLOWING OR CHOKING CONCERNS** *in the space below:*

22) Does your child eat breakfast **most** of the time (5 times a week or more)?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

23) Does your child currently take a multivitamin or supplement of any type?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #23, please write your* **CHILD'S MULTIVITAMIN OR SUPPLEMENTS** *in the space below:*

24) Does your child participate in a breakfast or lunch program **at school**?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

25) Does your child need help or supervision to eat **at home**? (for example: helping opening wrappers or containers, reminders to chew slowly)

Please place an **X** *beside your response. <u>Please select one answer only.</u>*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #25 please write your* **CHILD'S REQUIRED MEAL SUPPORT AT HOME** *in the space below:*

26) Does your child need help or supervision to eat **at school**? (for example: helping opening wrappers or containers, reminders to chew slowly)

Please place an **X** *beside your response. <u>Please select one answer only.</u>*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #26, please write your* **CHILD'S REQUIRED MEAL SUPPORT AT SCHOOL** *in the space below:*

27) Is food used as a reward for your child in any setting? (for example: toilet training, good behaviour)

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #27, may you please describe* ***how food is used a reward f****or your child in the space below:*

28) Do religious beliefs impact the types of food and beverages your child consumes? (for example: faith-based fasting)

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #28, may you please describe* ***how religious beliefs impact the types of food and beverages your child consumes*** *in the space below:*

29) Does culture impact the types of food and beverages your child consumes?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

a. *If you answered YES to question #29, may you please describe* ***how culture impacts the food and beverages your child consumes*** *in the space below:*

30) Approximately how many minutes of physical activity does your child engage in on a daily basis?

Please place an **X** *beside your response. Please select one answer only.*

Less than 60 minutes ___

More than 60 minutes ___

I don't know ___

31) *In your opinion*, does your child engage in **low, moderate, or high** intensity when they are physically active? (Describe different intensities based on definitions provided by the Canadian Society for Exercise Physiology 2024, included below).

Please place an **X** *beside your response. Please select one answer only.*

Low intensity ___

Moderate intensity ___

High intensity ___

I don't know ____

Vigorous intensity is typically 7x the intensity of rest; 7-9/10 self-perceived capacity; heart rate increases; body temperature increases; cannot say more than a few words before pausing for breath; examples are active games that include running and chasing, fast bicycling, martial arts, jumping rope, aerobics, sports, vigorous dancing, and cross-country skiing.

Moderate intensity is typically 4-7x the intensity of rest; 5-6/10 self-perceived capacity; heart rate increases; can talk but not sing; examples are rollerblading, cycling, household chores, games that include catching and throwing.

32) *On average,* how much screen time (TV, computer, tablet, cell phone) does your child have per day?

Please place an **X** *beside your response. Please select one answer only.*

Less than 1 hour ___

Between 1-2 hours ___

Between 2-4 hours ___

Over 4 hours ___

I don't know ___

IF CHILD DOES **NOT** LIVE WITH SIBLINGS, THEN PLEASE SKIP Q33 BELOW

33) Is your child given the same foods as their siblings?

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

IF RESPONSE IS **NO** TO Q33 THEN ASK Q33a BELOW:

33a) Can you tell me more about what are the differences?

The third set of questions are about nutrition-related information and healthcare services. *Please answer all the questions.*

34) Has your child **ever** received nutrition-related information and healthcare services? (for example: referral to a dietitian, nutrition information, nutrition counselling)

Please place an **X** *beside your response. Please select one answer only.*

Y ___

N ___

I don't know ___

IF RESPONSE IS **YES** TO Q34, THEN ASK Q34a BELOW:

34a) Can you tell me more about those services? For example: what kind of nutrition services has your child received? How often? *Did you think it was helpful? What was the experience like?*

35) Would you like your child to receive nutrition-related information and healthcare services **in the future**?

Please place an **X** *beside your response. <u>Please select one answer only.</u>*

Y ___

N ___

I don't know ___

IF RESPONSE IS **YES** TO Q35, THEN ASK Q35a, BELOW:

35a) Can you tell me more about the types of services you would like your child to receive, and how often? Can you tell me about how you prefer to receive information or services from healthcare professionals?

36) In your opinion, is food intake and nutrition an important part of your child's overall health?

Please place an **X** *beside your response. <u>Please select one answer only.</u>*

Y ___

N ___

I don't know ___

This is the end of our survey about

nutrition and children with Down syndrome living in Manitoba.

Thank you very much for your participation in our research study!

The remaining questions are about you, the survey respondent.

37) What is your age today?

Please place an **X** *beside your response. Please select one answer only.*

18 years and under ___

19-30 years ___

31-50 years ___

51-64 years ___

65 years and older ___

Prefer not to answer ___

38) What is your gender?

Please place an **X** *beside your response. Please select one answer only.*

F ___

M ___

Non-binary ___

Prefer not to answer ___

39) Have you moved to Canada in the past 12 months?

Please place an **X** *beside your response. Please select one answer only.*

Yes ___

No ___

Prefer not to answer ___

40) Please select the amount that describes your **annual household income**.

Please place an **X** *beside your response. <u>Please select one answer only.</u>*

Less than $20 000/year ___

$20 000 - $50 000/year ____

$50 000 - $100 000/year ___

More than $100 000/year ___

____

Prefer not to answer ___

41) What is your **ethnicity*?***

Please write **YOUR ETHNICITY** *in the space below:*

Prefer not to answer ___

____

42) Where do you live in Manitoba?

Please place an **X** *beside your response. <u>Please select one answer only.</u>*

Rural ___

____

Urban ___

Prefer not to answer ___

43) How long have you lived in Manitoba?

Please place an **X** *beside your response. <u>Please select one answer only.</u>*

5 years or less ___

6-10 years ___

11-30 years ____

31 years or more ____

Prefer not to answer ____

Appendix D: Factors Influencing Nutrition-Related Health

Table 13

Factors that may impact nutrition-related health

Factor	Question(s) from survey instrument
Age	What is your child's age today?
Sex	What is your child's sex?
Medical history	Has your child received a diagnosis of any medical condition(s) other than Down syndrome that may affect their food intake OR nutritional health? (for example: hypothyroidism)
Family history	Does your child have a family history of any medical condition(s) that may affect their food intake or nutritional health? (for example: diabetes)
COVID-19 pandemic	Did the COVID-19 pandemic have an impact on your child's nutritional health? (for example: their food intake or physical activity level)
Body weight	What is your child's current weight approximately?
Body height	What is your child's current height approximately?
Hormonal changes	Has your child experienced puberty?
Access to healthcare services	Who is your child's primary care provider? (for example: nurse practitioner, family doctor, pediatrician) Has your child seen their primary care provider in the past 12 months?

Access to healthcare services continued	Has your child ever received professional nutrition services? (for example: referral to a dietitian, nutrition education, nutrition counselling) Where do you live in Manitoba?
Breastfeeding history	Was your child breastfed?
Allergies	Does your child have any allergies?
Food preferences	Does your child have any food cravings? Does your child have any food aversions?
Eating ability	Does your child have any swallowing or choking concerns that may impact their food intake? Does your child require meal support at home? Does your child require meal support at school?
Breakfast consumption	Does your child eat breakfast most of the time?
Dietary supplement usage	Does your child take a multivitamin or supplement?
Food security	Does your child participate in a nutrition program at school? Please select the amount that describes your annual household income.
Food used as an incentive	Is food used as a reward for your child in any setting?
Religious dietary restrictions	Do religious beliefs impact the types of food and beverages your child consumes?

Cultural influences	Does culture impact the types of food and beverages your child consumes?
Physical activity	Approximately how many minutes of physical activity does your child engage in on a weekly basis? In your opinion, does your child engage in low, moderate, or high intensity when they are physically active? On average, how much screen time does your child have per day?
Parent/caregiver age	What is your age today?
Relationship to child	What is your relation to your child?
Parent/caregiver ethnicity	What is your ethnicity?
Parent/caregiver citizenship	Have you recently moved to Canada?
Parent/caregiver residency	Where do you live in Manitoba? How long have you lived in Manitoba?

Appendix E: Coding Manual

Variable name	Concept/ value label	Source	Numeric or character response	Variable width	Variable location	Type of variable	Question text	Code	Responses
STUDY_ID	Study participant identification number	Survey page 1	Numeric	3	1-3	Nominal		XXX	3-digit number assigned to each study participant (001, 002, 003)
SURV_DAT	Date survey is completed	Survey page 1	Numeric	8	4-11	Interval		MM/ DD/ YY	Date survey is completed
CHILD_BD	Birth date of child	Survey Q1	Numeric	8	12-19	Interval	When was your child born?	MM/ DD/ YY	Date of child's birth
CHILDAGE	Age of child	Survey Q2	Numeric	2	20-21	Interval	What is your child's age today?	XX	2-digit number that corresponds to the age of each study participant
CHILDSEX	Sex of child	Survey Q3	Numeric	1	22	Nominal	What is your child's sex?	1 2 3 99	Female Male Intersex Prefer not to answer
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
RELATION	Respondent's relation to child	Survey Q4	Numeric	1	23	Nominal	What is your relation to your child?	1 2 3 4 5 6	Mother Father Guardian Grandparent Sibling Other
MED_HIST	Medical history of child	Survey Q5	Numeric	1	24	Nominal	Has your child received a diagnosis of any medical condition(s) that may affect their food intake OR nutritional status?	1 2 3	Yes No I don't know
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
MED_COND	Medical diagnoses of child	Survey Q5A	Numeric	1-2	25-26	Nominal	If YES to Q5, write the name of medical condition(s)	1 2 3 4 5 6 7 8 9 97	Diabetes Heart condition Obesity Hypertension Hypothyroidism Vit/min deficiency Metabolic disorder Allergy Other N/A (NO to Q5)
FAM_HIST	Family history of child	Survey Q6	Numeric	1	27	Nominal	Does your child have a family history of any medical condition(s) that may affect their food intake OR nutritional status?	1 2 3	Yes No I don't know
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
FAM_COND	Family history of medical conditions of child	Survey Q6A	Numeric	1-2	28-29	Nominal	If YES to Q6, write the name of family history medical condition(s)	1 2 3 4 5 6 7 8 9 97	Diabetes Heart condition Obesity Hypertension Hypothyroidism Vit/min deficiency Metabolic disorder Allergy Other N/A (NO to Q6)
HEALCONC	Survey respondent's concerns about child's overall health	Survey Q7	Numeric	1	30	Nominal	Do you have any concerns about your child's overall health?	1 2	Yes No
FOODINTK	Survey respondent's concerns about child's food intake	Survey Q8	Numeric	1	31	Nominal	Do you have any concerns about your child's food intake?	1 2	Yes No
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
COVID19	Impact of COVID	Survey Q9	Numeric	1	32	Nominal	Did the COVID-19 pandemic have an impact on your child's food intake or physical activity?	1 2	Yes No
CHILD_WT	Weight of child	Survey Q10	Numeric	2	32-33	Interval	What is your child's current weight?	XX	Weight in kilograms (2.2 pound = 1 kilogram)
CHILD_HT	Height of child	Survey Q11	Numeric	2-3	34-36	Interval	What is your child's current height?	XXX	Height in centimetres (1 inch = 2.54 centimetres; 1 foot = 12 inches)
GROWCONC	Survey respondent's concerns about child's growth	Survey Q12	Numeric	1	37	Nominal	Do you have any concerns about your child's growth patterns?	1 2	Yes No
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
PUBERTY	Child experienced puberty	Survey Q13	Numeric	1	38	Nominal	Has your child experienced puberty?	1 2 3	Yes No I don't know
CHILDHCP	Child's healthcare provider	Survey Q14	Numeric	1	39	Nominal	Who is your child's primary care provider?	1 2 3 4 5	Pediatrician Family doctor Nurse practitioner I don't know Other
DOC_DATE	Date of last doctor's appointment	Survey Q15	Numeric	1	40	Nominal	Has your child seen their healthcare provider in the past 12 months?	1 2 3	Yes No I don't know
DOC_CONC	Doctor concerns about child's overall health, nutritional health, or growth patterns	Survey Q16	Numeric	1	49	Nominal	Has your child's doctor ever shared any concerns with you about your child's overall health, nutritional health, or growth patterns?	1 2 3	Yes No I don't know
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
BREASTFD	Child's breastfeeding history	Survey Q17	Numeric	1	48	Nominal	Was your child breastfed?	1 2 3	Yes No I don't know
ALLERGYA	Child allergies	Survey Q18A	Numeric	1	49	Nominal	Does your child have any allergies?	1 2 3	Yes No I don't know
ALLERGYB	Child allergies	Survey Q18B	Character	2-100	50-149	Nominal	If YES to Q18A, then write allergies	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q18)
FOODPREF	Child food preferences or cravings	Survey Q19A	Numeric	1	150	Nominal	Does your child have any food cravings or preferences?	1 2 3	Yes No I don't know
PREFLIST	Child food preferences or cravings	Survey Q19B	Character	2-100	152-249	Nominal	If YES to Q19A, then write food preferences and cravings	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q19A)
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
DISLIKES	Child food aversions	Q20A	Numeric	1	250	Nominal	Are there any foods your child does not like to eat?	1 2 3	Yes No I don't know
DISLIST	Child food aversions	Q20B	Character	2-100	252-349	Nominal	Please list the foods your child does not like to eat	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q20A)
SWALCHOK	Swallowing or choking concerns of child	Survey Q21A	Numeric	1	350	Nominal	Does your child have any swallowing or choking concerns?	1 2 3	Yes No I don't know
SWALCONC	Swallowing or choking concerns of child	Survey Q21B	Character	2-100	352-449	Nominal	Please list your child's swallowing or choking concerns	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q20A)
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
BREAKFST	Breakfast consumption of child	Survey Q22	Numeric	1	450	Nominal	Does your child eat breakfast most of the time?	1 2 3	Yes No I don't know
SUPPLEMT	Multivitamin or supplement intake of child	Survey Q23A	Numeric	1	451	Nominal	Does your child take a multivitamin or supplement?	1 2 3	Yes No I don't know
SUPPTYPE	Name of multivitamin or supplement	Survey Q23B	Character	2-100	453-550	Nominal	List the name of multivitamin or supplement	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q23A)
NUT_PROG	Child enrolment in nutrition program	Survey Q24	Numeric	1	551	Nominal	Does your child participate in a nutrition program at school?	1 2 3	Yes No I don't know
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
MEALSUPH	Child need for meal support at home	Survey Q25A	Numeric	1	552	Nominal	Does your child require meal support at home?	1 2 3	Yes No I don't know
HOMESUPP	Child meal support at home	Survey Q25B	Character	2-100	554-651	Nominal	Describe meal support at home	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q25A)
MEALSUPS	Child need for meal support at school	Survey Q26A	Numeric	1	652	Nominal	Does your child require meal support at school?	1 2 3	Yes No I don't know
SCHOSUPP	Child meal support at school	Survey Q26B	Character	2-100	654-751	Nominal	Describe meal support at school		Text to be converted into numerical codes after data collection* N/A (NO to Q26A)
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
FOOD_REW	Food used as a reward	Survey Q27A	Numeric	1	752	Nominal	Is food used as a reward in any setting?	1 2 3	Yes No I don't know
REW_DESC	Food used as a reward	Survey Q27B	Character	2-100	754-851	Nominal	Describe how food is used as a reward	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q27A)
RELIGION	Impact of religion on child intake	Survey Q28A	Numeric	1	852	Nominal	Do religious beliefs impact child's intake?	1 2 3	Yes No I don't know
REL_DESC	Impact of religion on child intake	Survey Q28B	Character	2-100	854-951	Nominal	Describe how religious beliefs impact intake		Text to be converted into numerical codes after data collection* N/A (NO to Q28A)
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
CULTURE	Impact of culture on child intake	Survey Q29A	Numeric	1	952	Nominal	Does culture impact child's intake?	1 2 3	Yes No I don't know
CUL_DESC	Impact of culture on child intake	Survey Q29B	Character	2-100	954-1051	Nominal	Describe impact of culture on child's food intake		Text to be converted into numerical codes after data collection* N/A (NO to Q29A)
ACTIVITY	Amount of child's daily physical activity	Survey Q30	Numeric	1	1052	Interval	Approximately how many minutes of physical activity does your child engage in on a daily basis?	1 2 3	Less than 60 min More than 60 min I don't know
ACTI_INT	Intensity of child's daily physical activity	Survey Q31	Numeric	1	1053	Ordinal	In your opinion, does your child engage in low, moderate, or vigorous intensity when they are physically active?	1 2 3 4	Low Moderate High I don't know
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
SCREENTM	Amount of child's daily screen time	Survey Q32	Numeric	1	1054	Ordinal	On average, how much screen time does your child have per day?	1 2 3 4 5	Less than 1 hour 1-2 hours 2-4 hours More than 4 hours I don't know
SIBLINGS	Child eats like siblings	Survey Q33A	Numeric	1	1055	Nominal	Does your child usually eat the same foods as their siblings?	1 2 3	Yes No I don't know
SIB_DIFF	Difference between child's intake compared to siblings	Survey Q33B	Character	2-100	1057-1164	Nominal	Describe differences between child's intake and their siblings	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q33A)
NUT_SERV	Nutrition services received by child	Survey Q34A	Numeric	1	1165	Nominal	Has your child ever received nutrition services?	1 2 3	Yes No I don't know
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
SERVDESC	Description of nutrition services received by child	Q34B	Character	2-100	1167-1174	Nominal	Describe nutrition services received by child	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q34A)
FUT_SERV	Future nutrition services received by child	Survey Q35A	Numeric	1	1175	Nominal	Would you like your child to receive nutrition services in the future?	1 2 3	Yes No I don't know
FUT_DESC	Description of future nutrition services received by child	Survey Q35B	Character	2-100	1177-1184	Nominal	Describe future nutrition services received by child	 97	Text to be converted into numerical codes after data collection* N/A (NO to Q35A)
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
NUTRI_NB	Importance of nutrition to survey respondent	Survey Q36	Numeric	1	1185	Nominal	Is nutrition an important part of your child's overall health?	1 2 3	Yes No I don't know
OPTIONAL supplementary demographic questions									
ADULTAGE	Age of survey respondent	Survey QS1	Numeric	1-2	1186-1187	Ordinal	Please select your age range	1 2 3 4 5 99	Under 18 y 19-30 y 31-50 y 51-64 y 65 y and older Prefer not to answer
ADULTGEN	Gender of survey respondent	Survey QS2	Numeric	1-2	1188-1189	Nominal	What is your gender?	1 2 3 99	Female Male Non-binary Prefer not to answer
CANADIAN	Canadian citizenship of survey respondent	Survey QS3	Numeric	1-2	1190-1191	Nominal	Have you recently moved to Canada?	1 2 99	Yes No Prefer not to answer
Variable name	**Concept/ value label**	**Source**	**Numeric or**	**Variable width**	**Variable location**	**Type of variable**	**Question text**	**Code**	**Responses**

			character response						
YRINCOME	Annual household income of survey respondent	Survey QS4	Numeric	1-2	1192-1193	Ordinal	Please select an amount that describes your annual household income	1 2 3 4 99	< $20 000 $20-50 000 $50 - 100 000 >$100 000 Prefer not to answer
ETHNICTY	Ethnicity of survey respondent	Survey QS5	Character	4-100	1197-1292	Nominal	What is your ethnicity?	 99	Text to be converted into numerical codes after data collection* Prefer not to answer
LOCATION	Geographic location of survey respondent	Survey QS6	Numeric	1-2	1293-1294	Ordinal	Where do you live?	1 2 99	Rural Urban Prefer not to answer
MANITOBA	Length of residence in Manitoba	Survey QS7	Numeric	1-2	1295-1296	Ordinal	How long have you lived in Manitoba?	1 2 3 4 99	5 or less 6-10 11-30 31+ Prefer not to answer

Appendix F: 2x2 Contingency Tables

Table 14

Daily nutrient intake adequacy and presence of nutrition-related condition or disease among children with T21

		Diagnosis of nutrition-related condition or disease n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	5	1	6
	No	4	4	8
	Totals	9	5	14

Fisher's exact test revealed no significant association between having a diagnosis of a nutrition-related condition and the daily nutrient intake adequacy ($p = 0.2960$). The odds ratio was 5, 95% CI [0.39, 64.39].

Table 15

Daily nutrient intake adequacy and presence of family history of nutrition-related condition or disease among children with T21

		Known family history of nutrition-related condition or disease n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	5	1	6
	No	5	3	8
	Totals	10	4	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and a diagnosis of a nutrition-related condition ($p = 0.4056$). The odds ratio was 3, 95% CI [0.23, 39.61].

Table 16

Daily nutrient intake adequacy and daily physical activity adequacy among children with T21

		Daily physical activity adequacy n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	6	0	6
	No	6	2	8
	Totals	12	2	14

Corrected for a sampling zero by adding 0.5 to each cell in the contingency table, Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and meeting daily physical activity guidelines ($p = 0.6000$. The odds ratio was 5, 95% CI [0.20, 125.79].

Table 17

Daily nutrient intake adequacy and screen time guideline adherence among children with T21

		Screen time guideline adherence n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	2	4	6
	No	1	7	8
	Totals	3	11	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and meeting daily screen time guidelines ($p = 0.6000$). The odds ratio was 5, 95% CI [0.20, 125.79].

Table 18

Daily nutrient intake adequacy and breastfeeding history among children with T21

		Child was breastfed n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	4	2	6
	No	8	0	8
	Totals	12	2	14

Corrected for a sampling zero by adding 0.5 to each cell in the contingency table, Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and breastfeeding history ($p = 0.4000$). The odds ratio was 0.11, 95% CI [0.00, 2.72].

Table 19

Daily nutrient intake adequacy and onset of puberty among children with T21

		Child has experienced puberty n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	0	6	6
	No	1	7	8
	Totals	1	12	14

Corrected for a sampling zero by adding 0.5 to each cell in the contingency table, Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and onset of puberty (p = 0.8250). The odds ratio was 0.38, 95% CI [0.01, 11.17].

Table 20

Daily nutrient intake adequacy and food aversions among children with T21

		Child has food aversions n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	4	2	6
	No	8	0	8
	Totals	12	2	14

Corrected for a sampling zero by adding 0.5 to each cell in the contingency table, Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and the child having food aversions ($p = 0.4000$). The odds ratio was 0.11, 95% CI [0.00, 2.72].

Table 21

Daily nutrient intake adequacy and food preferences among children with T21

		Child has food preferences n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	4	2	6
	No	7	1	8
	Totals	11	3	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and the child having food preferences (p = 0.3846). The odds ratio was 0.29, 95% CI [0.02, 4.24].

Table 22

Daily nutrient intake adequacy and requiring assistance during eating times at home among children with T21

		Child requires assistance during eating times at home n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	5	1	6
	No	6	2	8
	Totals	11	3	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and the child requiring assistance during eating times at home ($p = 0.6154$). The odds ratio was 1.7, 95% CI [0.11, 24.26].

Table 23

Daily nutrient intake adequacy and impact of religion on food and beverage consumption among children with T21

		Religious beliefs influence the child's food and beverage consumption n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	1	5	6
	No	1	7	8
	Totals	2	12	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and religious beliefs influencing the child's food and beverage choices (p = 0.6923). The odds ratio was 1.4, 95% CI [0.07, 28.12].

Table 24

Daily nutrient intake adequacy and impact of culture on food and beverage consumption among children with T21

		Culture influences the child's food and beverage consumption n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	3	3	6
	No	2	6	8
	Totals	5	9	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and culture influencing the child's food and beverage choices ($p = 0.3427$). The odds ratio was 3, 95% CI [0.31, 28.84].

Table 25

Daily nutrient intake adequacy and impact of the COVID-19 pandemic among children with T21

		COVID-19 pandemic impacted child's intake or physical activity levels n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	4	2	6
	No	4	4	8
	Totals	8	6	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and the influence of the COVID-19 pandemic on the child's food and beverage consumption or physical activity levels ($p = 0.4709$). The odds ratio was 2, 95% CI [0.22, 17.89].

Table 26

Daily nutrient intake adequacy of children with T21 and the provision of nutrition knowledge and care

		Child/parent received nutrition knowledge and care n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	4	2	6
	No	6	2	8
	Totals	10	4	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and having received nutrition knowledge and care ($p = 0.5944$). The odds ratio was 0.67, 95% CI [0.06, 6.87].

Table 27

Daily nutrient intake adequacy and Indigeneity among children with T21

		Parent self-identifies as Indigenous n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	1	5	6
	No	2	6	8
	Totals	3	11	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and Indigeneity (p = 0.6154. The odds ratio was 0.6, 95% CI [0.04, 8.7].

Table 28

Daily nutrient intake adequacy and setting of residence in Manitoba among children with T21

		Child resides in a rural location in Manitoba n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	4	2	6
	No	2	6	8
	Totals	6	8	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and setting of residence in Manitoba ($p = 0.1562$). The odds ratio was 6, 95% CI [0.58, 61.8].

Table 29

Daily nutrient intake adequacy and sex of children with T21

		Child is female n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	2	4	6
	No	5	3	8
	Totals	7	7	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and sex of child (p = 0.2960). The odds ratio was 0.3, 95% CI [0.03, 2.76].

Table 30

Daily nutrient intake adequacy of children with T21 and food used as a reward by parents

		Parent uses food as a reward n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	2	4	6
	No	6	2	8
	Totals	8	6	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and parent using food as a reward ($p = 0.1562$). The odds ratio was 0.17, 95% CI [0.02, 1.72].

Table 31

Daily nutrient intake adequacy of children with T21 and parent concerns about their health

		Parent has concerns about child's health n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	4	2	6
	No	4	4	8
	Totals	8	6	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and parent having concerns about their child's health ($p = 0.4709$). The odds ratio was 2, 95% CI [0.22, 17.89].

Table 32

Daily nutrient intake adequacy of children with T21 and parent concerns about their food intake

		Parent has concerns about child's food intake n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	3	3	6
	No	5	3	8
	Totals	8	6	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and parent having concerns about their child's food intake ($p = 0.5291$). The odds ratio was 0.6, 95% CI [0.07, 5.14].

Table 33

Daily nutrient intake adequacy of children with T21 and parent concerns about their body size

		Parent has concerns about child's body height or weight n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	4	2	6
	No	2	6	8
	Totals	6	8	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and parent having concerns about their child's body height or weight (p = 0.1561). The odds ratio was 6, 95% CI [0.58, 61.84].

Table 34

Daily nutrient intake adequacy of children with T21 and primary care provider concerns about their health

		Primary care provider has concerns about child's health n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	1	5	6
	No	2	6	8
	Totals	3	11	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and primary care provider having concerns about the child's health ($p = 0.6154$). The odds ratio was 0.6, 95% CI [0.04, 8.73].

Table 35

Daily nutrient intake adequacy of children with T21 and parent length of residency in Manitoba

		Parent's length of residency in Manitoba greater than 30 years n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	4	2	6
	No	8	0	8
	Totals	12	2	14

Corrected for a sampling zero by adding 0.5 to each cell in the contingency table, Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and the parent's length of residency in Manitoba ($p = 0.4000$). The odds ratio was 011, 95% CI [0.00, 2.72].

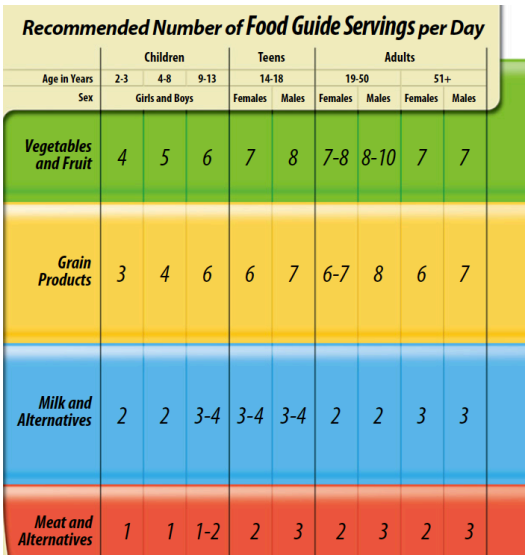
Table 36

Daily nutrient intake adequacy and household income among children with T21

		Household income greater than median household income in Manitoba n		
		Yes	No	Totals
Daily nutrient intake adequate n	Yes	5	1	6
	No	5	3	8
	Totals	10	4	14

Fisher's exact test revealed no significant association between having daily nutrient intake adequacy and having greater than the median household income in Manitoba ($p = 0.4056$). The odds ratio was 3, 95% CI [0.23, 39.61].

Appendix G: Canada's Food Guide Serving Sizes (2011 Version)



Recommended Number of Food Guide Servings per Day

	Children			Teens		Adults			
Age in Years	2-3	4-8	9-13	14-18		19-50		51+	
Sex	Girls and Boys			Females	Males	Females	Males	Females	Males
Vegetables and Fruit	4	5	6	7	8	7-8	8-10	7	7
Grain Products	3	4	6	6	7	6-7	8	6	7
Milk and Alternatives	2	2	3-4	3-4	3-4	2	2	3	3
Meat and Alternatives	1	1	1-2	2	3	2	3	2	3